Behind closed doors: access to district nursing exploring multiple perspectives

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Psalm 54 verse 4

Surely God is my help,
the Lord is the one who sustains me

Abstract

The aim of this study was to explore factors that promote or hinder access to district nursing from different perspectives. It was an exploratory, sequential, mixed methods study, carried out in three phases to address the main research question, How do patients, carers, district nurses and health and social care professionals experience access to district nursing in London? Methods included focus groups with patients and district nurses, semi-structured interviews with carers, surveys of district nurses and health and social care professionals and appraisal of service information on provider websites. Levesque *et al's* (2013) model of access informed data analysis to consider opportunities for access and accessibility, as well as supply and demand aspects of access. Thematic, descriptive statistical and content analyses were used for the respective findings, revealing hidden worlds in the ways access was experienced. Issues of equity, transparency and power were highlighted as the service is brought to patients at home. The findings suggest: i) the district nurse's role was not well understood and the service was invisible ii) service information on websites was often absent, limited and variable, and oriented to professionals making referrals, with a lack of information targeted at patients and carers iii) district nurses exerted control of access through overt and covert means, for example, determining who met the housebound criterion iv) self-referral was not widely known or practised and v) patients and carers experienced access as a series of disruptions over which they had little control, and where district nurses appeared to be overwhelmed by demand and workforce shortages. Decisions about access appeared to be influenced by contextual and resource factors, particularly capacity and commissioning. In conclusion, continuity of holistic care emerged as important for accessing district nursing fully, and patients and carers described transformational experiences when access to the service worked well. The study's findings have informed a model of access indicating access as a continuum, that is not based on utilisation alone, and is a better fit with the unique context and characteristics of district nursing. The study does not claim generalisability but draws on participants' experiences from a range of perspectives to present new insights to reveal enablers and barriers to access, thereby contributing to knowledge that can inform future research, theory development, access policy and district nursing practice.

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Abbreviations

A&E	Accident and emergency departments of acute hospitals
APPG	All Party Parliamentary Groups
BAME	Black and Minority Ethnic groups
BOS	Bristol online surveys
CCG	Clinical Commissioning Groups
CTT	Community Treatment Team
CQC	Care Quality Commission
DCLG	Department for Communities and Local Government
DH	Department of Health
DHSC	Department of Health and Social Care
FYF	Five Year Forward View (NHS, 2014)
GDSS	Government Digital Service Standard
GP	General Practitioners
GLA	Greater London Authority
HCA	Health care assistant
HSCIC	Health and Social Care Information Centre
HEE	Health Education England
HEI	Higher Education Institution
HCHC	House of Commons Health Committee
LHC	London Health Commission
LTC	Long-term Conditions
LTP	Long Term Plan

ICO	Integrated Care Organisation
ICS	Integrated care systems or service
IDAOPI	Income deprivation affecting older people index
LSOA	Lower layer super output area
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
n.d.	No date of publication supplied
NMC	The Nursing and Midwifery Council
NPCN	National Primary Care Network
NQB	National Quality Board
ONS	Office of National Statistics
PCN	Primary Care Network
QNI	The Queen's Nursing Institute
URL	Uniform resource locator i.e. a web address
RCN	The Royal College of Nursing
RNIB	Royal National Institute for the Blind
SPA	Single point of access
SPQ	Specialist Practitioner Qualification
STP	Service and Transformation plans
SCC	Survey Coordination Centre
WHO	World Health Organisation

Glossary

Access	'the "fit" between characteristics of providers and health services and characteristics and expectations of clients' (Penchansky and Thomas 1981 p.139)
BSA	British Social Attitudes - survey of members of the public in England, Scotland and Wales about their views on the NHS and health and care issues by random sampling and interviews
Carers	Carers provide unpaid care by looking after an ill, older or disabled family member, friend or partner. It could be a few hours a week or round the clock, in one's own home or down the motorway (Carers UK, 2015a)
Care recipient	Person who is being looked after by a carer
Caseload	Patients who are being seen by a district nurse; the allocation is usually based on geographical area and/or aligned to GP populations and comprised of mainly older people
Community nurse	A registered nurse working in the community, usually in a district nursing team
Datix	An online serious incident report form (Datix Ltd, London, UK).
District nurse	'A qualified nurse with a graduate level education and specialist practitioner qualification recordable with the Nursing and Midwifery Council' (DH 2013 p.10)
First assessment	A holistic needs assessment is carried out by the district nurse following referral. The initial assessment forms the basis of care planning and coordination, and should be conducted in partnership with patients and carers (McGarry, 2003; Burke, 2017; Gough, 2018).
Holistic assessment	Assessment encompasses physical, emotional, psychological, spiritual, social, environmental and sexual health needs and support care needs

	of patients and family carers (McHugh *et al,* 2003; Dickson, 2018).
Long-term condition	is one that 'cannot be cured but can be managed through medication and/or therapy' (Panagioti *et al*, 2014)
iCAT	An electronic catalogue on Kingston University's library site, with a search facility for all subscribed electronic sources including journals and databases
PEG feeding	Percutaneous endoscopic gastrostomy
PICC line	Peripherally inserted central catheter. A PICC line is a thin, soft, long catheter that is inserted into a vein in arm, leg or neck. The tip of the catheter is positioned in a large vein that carries blood into the heart. The PICC line is used for long-term intravenous (IV) antibiotics, nutrition or medication, and for drawing blood.
Referral	'Referral to treatment, waiting time is the length of time from the date that a referral is received by the service until the date that the first definitive treatment is provided' (DH, 2011)
Self management support	Self-management support is primarily designed to develop the abilities of patients to undertake management of health conditions through education, training and support to develop knowledge, skills or psychological and social resources (Panagioti *et al*, 2014)
Single point of access	A central place, site or phone number (e.g. 999, NHS Direct, GP out-of-hours, NHS 111) which provides a gateway to a range of health and social services including referrals (Medical dictionary, n.d.)
Triage	is the process of determining the priority of patients' treatments by the severity of their condition or likelihood of recovery with and without treatment (Wikipedia)

Chapter one: Introduction

Introduction

The district nursing service has been providing nursing care to those living in the community for over 160 years. From its inception, district nursing has been rooted in local communities and provided direct access to patients. When district nursing was incorporated into the NHS, the principle of universal access to healthcare, free at the point of delivery, was enshrined. Even though it is the largest of the community health services, little is known about access to district nursing.

This study aims to explore access to district nursing from the perspective of patients, carers, professionals and district nurses, as well as the factors that promote or hinder access. The chapter provides an overview of the study, its aim, objectives and main research question and finally, the organisation of the thesis is set out.

My interest in district nursing arose from my professional background, having worked in London as a district nurse and taught previously on the district nursing specialist practice course. As the number of training places fell between 2008-2019, it was evident that investment in district nursing was in decline. This was puzzling given the sustained policy emphasis on community-based care.

My particular interest in access was sparked by an evaluation, undertaken with colleagues, of a community nursing service specification for a Primary Care Trust (PCT). We found the quality of the district nursing service was being questioned; there was a lack of access, with poor response times for referrals and erosion of the district nurse's role (Skinner *et al,* 2009). The scope of the evaluation precluded any exploration of patients' and carers' views.

Recognising this gap in the evidence, combined with the vulnerability of district nursing patients and carers, my initial idea was to explore access and quality solely from their perspectives. This also related to my interest in service users' and carers' involvement, having taught this on an interprofessional module on the specialist practice course, and having completed an evaluation of service user and carer involvement in health and social care education at another HEI (Brechin *et al,* 2000*;* Ross *et al,* 2014; Skinner, 2011).

However, the further I explored the topic, I recognised increasingly the policy complexity, as well as the contradictions and tensions in health and social care and the absence of patient and carer perspectives. It seemed important to explore all these views in order to understand the meaning of access within the district nursing context, and establish evidence that can inform a better public narrative.

Overview of the study

District nurses work with patients, carers and health and social care professionals providing access to the service. The way in which the service is accessed, the eligibility criteria, referral practices and differences between the supply and demand sides of access are less well understood. Comparatively, there is little research on access to district nursing. This study focuses on a discrete area of district nursing practice and hopes to make a contribution to what is already known. Access to district nursing will be explored from multiple perspectives to gain in-depth understanding from those making and receiving referrals, and those receiving the service to address the following research question: How do patients, carers, district nurses and health and social care professionals experience access to district nursing in London?

Aim and objectives

Aim

To explore access to the district nursing service from different perspectives and the factors that promote or hinder access to district nursing

Objectives

1. Explore patients', carers', district nurses' and health and social care professionals' experiences and preferences of access to district nursing, through focus groups and semi-structured interviews with patients, carers and district nurses and surveys of district nursing staff and health and social care professionals.

2. Identify factors that may promote or hinder access to district nursing, including service information, referral criteria and pathways and organisational factors, through focus groups and semi-structured interviews, surveys and web information.

3. Appraise information about district nursing on provider websites through content analysis for accessibility, clarity of the referral criteria and referral process.

Organisation of the thesis

Chapter one Introduction

This chapter explains my interest in access to district nursing and provides an overview of the study, its aims, objectives and main research question and how the thesis is organised.

Chapter two District nursing and the policy context

This chapter explores district nursing and the policy context by consideration of the origins of district nursing, the district nurse's role, service demand and capacity in relation to access and policy. The underpinning paradox is introduced: on the one hand, district nursing is championed as central to the policy directive of delivering care closer to home, while on the other, experiencing long-term trends of declining workforce numbers. Questions are signaled in relation to access, and inform the study's scope and main research question.

Chapter three Access and district nursing

This chapter critically reviews the literature to understand what research has been undertaken on access in relation to district nursing, and identifies research questions that remain unanswered. A systematic approach was taken to search for and review the literature to inform the study's methodology. Twelve studies were identified and two overarching themes emerged: barriers to access and partnership working. Inequity of access was highlighted in the studies' findings, with structural inequalities, and methodological considerations raised. Penchansky and Thomas' (1981) definition of access was adopted to inform the review and study. A summary of critical issues and areas for further research are presented, which contribute to the study's rationale and research design.

Chapter four Access - concepts, definitions and theoretical frameworks

This chapter explores theoretical concepts and approaches to access health care and district nursing. Definitions and frameworks are discussed in relation to the supply and demand sides of access, drawing on theory and research. In particular, the work of McIntyre *et al* (2009) and Levesque *et al* (2013) are analysed, with insights applied to district nursing. Levesque *et al's* (2013)

model was particularly relevant and adopted to inform the analysis of the findings from the range of perspectives, drawn from the entire dataset.

Chapter five Methods

This chapter explains the research design as an exploratory, sequential, mixed methods study, to address the main research question, *How do patients, carers, district nurses and health and social care professionals experience access to district nursing in London?* The research design and decisions taken are explained, to meet the study's aims and objectives, drawing on the critical review of the research literature, and set out how the theoretical frameworks informed the study. A description of the research process and ethics approval is given, alongside potential ethical issues and steps taken to mitigate them, and my role as a researcher.

Chapter six Patients' and carers' views of access to the service - findings from focus groups and interviews

This chapter presents the findings from the thematic analysis of two focus groups conducted with patients and interviews with ten carers to explore their different perspectives of access to district nursing. There were similarities and differences between carers' and patients' experiences, and two common themes were defined in relation to access: expectations and control. Patients and carers expectations of the service did not wholly match the service provided. They experienced the service as invisible and a number of barriers getting access.

Chapter seven District nurses' views of access to the service - findings from focus groups

This chapter presents the findings, following thematic analysis, of four focus groups conducted with district nurses working in three provider organisations in London**.** Two main themes were identified, the use of control and the appropriateness of referrals to the service. District nurses did not feel their role or service was understood, contributing to their sense of invisibility. In permitting access, overt and covert control was exercised by district nurses. Being housebound was an important eligibility criterion, but also problematic, in deciding who was housebound.

Chapter eight Results of surveys - district nurses and health and social care professionals

This chapter presents the results of two surveys, for district nursing staff and health and social care professionals. Both surveys were conducted in two provider organisations in London. The results indicated that health and social

care staff have a different understanding of the service to district nurses. This was borne out in their understanding of the eligibility criteria and whether patients could self-refer. Access to service information seemed to be dependent on what colleagues told them, principally GPs and hospitals.

Chapter nine Findings from the analysis of providers' websites

This chapter presents an analysis of web-based information about district nursing held on seven provider websites in London. Data were captured from websites as they appeared in the public domain. Paper-based documentation, such as district nursing leaflets and referral forms, where provided or referred to on the webpages, were included. The focus of the analysis was on the accessibility of the web-based information and clarity of information about accessing the service. Though website pages, on the face of it, seemed accessible, information about the services and access was variable and professionally oriented, with an emphasis on referral.

Chapter ten Discussion

The main integrated findings are discussed, drawing on the literature and selected theoretical aspects of access to district nursing. Levesque *et al's* (2013) framework was used to analyse the data drawing on key dimensions and abilities that represent both supply and demand aspects of access. Two cross cutting themes, equity and transparency, that emerged from the analysis of the findings are discussed. A key finding was that access was problematic and inequitable and reinforced the invisibility of district nursing. Patients and carers experienced it as a series of disruptions. Consideration is given to whether the main research question is answered.

Chapter eleven Implications and conclusions

This chapter presents the implications of the findings in regards to theory, practice and policy. Based on the findings, a model of access is proposed that better fits the unique context of district nursing, drawing on Levesque *et al's* framework, together with a proposed information strategy and approaches to address capacity. It identifies the contribution of the study in relation to current research literature. In particular, self-referral and the housebound criterion contribute to knowledge of access to district nursing. Limitations of the study are raised and suggestions for further research made. A reflection on my positionality and the PhD journey is included, including lessons learned and what could have been done differently.

Chapter two: District nursing and the policy context

Introduction

The chapter provides the background to district nursing and the policy context for the study. It sets out what I argue is an underpinning paradox. On the one hand, district nursing is championed as central to the policy directive of delivering care closer to home, while on the other, there has been a long-term decline in investment in the workforce (NHS, 2019a; Ball *et al*, 2014; Drennan, 2019). This paradox is explored through a review of the origins of district nursing, the district nurse's role, service demand and capacity in relation to current policy. The invisibility of district nursing is highlighted in each area, raising questions about the implications for access to the service.

Care closer to home

District nursing sits within an expanded adult community nursing service, under the broad umbrella of community health services, and is the largest group (Drennan and Davis, 2008; Carter, 2018). District nurses provide holistic care, principally to older and vulnerable people in their homes (QNI, 2015; QNI 2019b).

The principle of holistic care is espoused in district nursing and reflects the WHO 1948 definition of health, encompassing complete physical, mental and social wellbeing and not just the absence of disease or infirmity (Baguley, 2018). While this definition has been viewed as idealistic, and perhaps self-congratulatory, it has stood the test of time in that it prioritises health as multi-dimensional, and provides a focus by which to address social inequalities and assess shortcomings in care delivery (Ibid).

Over time, care provided by district nurses has arguably been influenced by commissioning priorities for example, the management of acute and long-term conditions and end of life care (QNI, 2009; QNI, 2019a; DH, 2013). In the literature there is some challenge to the notion of holism in district nursing, notably in studies of end of life patients where psychological support was less evident (Wilson *et al,* 2002; Nagington *et al,* 2016). Nonetheless, the role of the district nurse and the service offered today remains rooted in the community and can be recognised from its nineteenth century origins, which are explained later in this chapter. However, it is less clear how access is conceptualised in contemporary practice, how it is experienced by patients

and carers, and how altered direct access which was the norm at the inception of the service has evolved (QNI, 2009).

Bringing care closer to home has been a consistent policy imperative over a number of administrations and restated most recently in the NHS Long Term Plan (LTP) for England (NHS, 2019a). This is driven by spiraling health care costs arising from demographic change and increases in long-term conditions (DH, 2012a). By 2024, 10% of the population will be over 75 years and it is estimated that by 2051 one in 15 people in England will be 85 years or older (DH, 2014a; HSCIC, 2014). Fifteen million people in England have long-term conditions, and 30% of those aged 75 years or more, have more than one long-term condition (DH, 2012a; DH, 2014a; DH, 2014d). Despite parallel policy drivers to improve public health and prevent ill health, most of the NHS budget is spent on treatment (NHS, 2014; NHS, 2019a). District nursing caseloads reflect these demographic trends and health priorities.

In the face of overwhelming, open-ended demand and costs, more skilled home care is needed (QNI, 2013a). Hospital care is the most costly and older people are high users of hospital services (HSCIC, 2014). One in five people aged 85 years and over used the accident and emergency, inpatient and outpatient services, and two thirds of emergency admissions were from this group (HSCIC, 2014). Nonetheless, older people prefer to stay at home and want access to flexible personalised services (Robert *et al,* 2011; DH, 2014a; NHS, 2019a; NHS, 2019b).

District nurses have been identified as having a crucial role in avoiding hospital admissions and facilitating early discharge, and form part of the new integrated community-based health care arrangements (DH, 2014a; NHS, 2019a; NHS, 2019b).

It is argued they are well placed in providing skilled care to meet these preferences, policy directives and demand (DH, 2013; QNI, 2019a; QNI, 2019b). Since its origin, district nursing has provided a model of care that is person-centred, personalised and a 24/7 service, an aspiration in current policy directives (NHS, 2019a). The assumption that district nursing practice is holistic continues to be asserted, being restated in the most recent QNI standards (2015) but it is largely unchallenged by the profession. However, delivering holistic care depends on sufficient resources and capacity to support people at home safely (QNI, 2019a). While the NHS Constitution guarantees access to NHS services, based on clinical need and free of charge, in reality there is a widening gap between demand and capacity in district

nursing that has yet to be addressed (NHS, 2015a; Maybin *et al,* 2016; NHS, 2019a).

At the same time, community health services have been re-shaped and new community nursing services and roles introduced, the number of district nurses has fallen dramatically, notably over the past 20 years, fewer district nurses are being trained (QNI, 2019a; NHS Providers, 2018; Drennan, 2019; QNI, 2017a).

Finally, district nurses are barely mentioned in policy documents and rarely have leadership roles (NHS, 2014; NHS, 2019a; NHS, 2019b; DH, 2013). These deficits have been highlighted for many years along with a tacit assumption that district nursing capacity is limitless (Haycock-Stuart *et al*, 2008; QNI, 2009; RCN, 2014; QNI, 2015a, QNI, 2016; Carter, 2018). This therefore highlights is a likely disconnect between the lack of capacity and its impact on the patient experience of access to the service (QNI, 2019b). District nurses appear to be invisible from policy and workforce perspectives, and their role and work are also said to be invisible among NHS services, as care takes place behind closed doors (QNI, 2019a; Goodman, 2000).

Origins of district nursing

District nursing predates the NHS and welfare state. It was founded in 1859 when William Rathbone, a wealthy Liverpool merchant and philanthropist, employed Mary Robinson to nurse his wife at home (Baly, 1981). He extended this service to Liverpool's poor, and with advice from Florence Nightingale funded and set up a training school attached to the Royal Infirmary (QNI, 2009).

The nurses were organised by 'districts' i.e. aligned to parishes and overseen by a Lady superintendent; the success of these district nursing associations spread across the country (QNI, 2017a). A range of nursing and public health duties were provided to all age groups, with day and night cover, which included what would now be considered social care needs, such as bathing and dressing patients. They provided care for the whole family, which arguably is rooted in the notion of a holistic approach to care, which as noted above, remains strongly associated with district nursing to date (QNI, 2019b). District nurses were well known and visible to their communities, wearing a distinctive uniform and living in locally provided accommodation (Baly, 1981; QNI, 2017a).

Access was based on an annual subscription, which paid district nurses' salaries although the poor and vulnerable did not have to pay. The district nurse could be accessed directly, anyone could send for the district nurse, or a doctor may advise referral (QNI, 2017b). National training for district nurses was provided by the QNI when it was established in 1887, continuing until 1968 (QNI, 2017a; Baly, 1981).

In 1948, district nursing became part of NHS provision and free at the point of access. Since the 1960s, training took place in tertiary education institutes (Baly, 1981). Local authorities employed district nurses until the 1970s, though they were considered members of the primary health care team and worked closely with GPs (Baly, 1981). Today, district nurses continue to provide care at home to poor, vulnerable and mainly older people, within a defined geographical area and aligned to GPs. The service operates 365 days a year, with most having 24 hours cover (Ball *et al,* 2014). The extent to which district nurses are visible and accessible to the communities they serve, or to those wishing to make referrals, is unknown.

The role of the district nurse

The district nurse's generalist role and skills have become more complex in response to rising needs and challenges in health and social care. By 2006, the QNI reported a crisis in role identity and poor articulation of the district nurse's expertise (QNI, 2006; Drew, 2011). In recognition of this, the QNI published their voluntary standards, endorsing district nurses as community experts, providing a wide range of patient-centred nursing care in home and community-based settings, for those with acute, long-term and multiple health challenges and end of life care (QNI, 2015a). This affirmed the district nurse's autonomous generalist role associated with a holistic approach that included: needs assessment; flexible and responsive management; coordination of planned and unplanned care with patients and their families and partnership working with colleagues across health and social care (QNI, 2015a).

Even so, the district nurse's role remains contested; it seems elastic on the one hand, stretching to meet different policy agendas, often to reduce costs. For example, during the 1990s some health care needs were re-defined as social care, resulting in greater medicalization of the role (NHS and Community Care Act, 1990). On the other hand, prevention and aspects of the role, though essential for better health outcomes and delivery of holistic care, are compromised due to task driven workloads (QNI, 2019a; Maybin *et al,*

2016). As complex care happens 'behind closed doors', it is perhaps difficult for managers to appraise the scope and nature of the role and its activities, which has contributed to a reductive understanding of their role, characterized as a set of tasks and transactions that feeds into commissioning.

Leadership and qualifications

Decisions to permit access to the service involve a first assessment, where the district nurse determines eligibility and the care required. District nurses have a longstanding norm of visiting within 24 hours of referral. Health and social care professionals, mainly GPs, make referrals, though it is less clear whether patients or carers can also make referrals. Housebound patients and carers are isolated, and perhaps less knowledgeable about the role and service with implications for access. District nurses report receiving inappropriate referrals, though factors that influence access across the service have not been researched (McHugh *et al,* 2003; Clover, 2010).

Traditionally, district nurses work autonomously and lead small teams of qualified nurses and unqualified support staff, comprising 14% qualified district nurses and 75% registered nurses, and on average they visit 9-12 patients daily, spending longer with patients compared to unqualified nurses (Ball *et al* 2014). Carter's (2018) review found variations in the average time community nurses spent delivering care to patients, ranging from 33%-80% among twelve providers, indicating reducing variations could improve access significantly. The size of district nursing caseloads also varies widely (QNI, 2019b).

As the key decision makers, district nurses undertake a lengthy training to prepare for their role,

> 'By district nurses, we mean: Qualified nurses with a graduate level education and specialist practitioner qualification recordable with the Nursing and Midwifery Council' [NMC] (DH 2013 p.10)

The NMC standards guiding specialist practitioner training are twenty years old and currently being reviewed by the NMC: it is expected the QNI voluntary standards will be adopted (NMC, 2001; QNI, 2015a; NMC, 2020). As graduate nurses with prescribing rights since 1999, district nurses were found to be more highly qualified than hospital nurses, with 62% holding a nursing degree compared to 37% of hospital nurses (QNI, 2017a; Ball *et al*, 2014). Though a QNI (2015a) survey found over half of respondents' employers did not require district nursing team leaders to have the specialist practitioner qualification.

While there is an increasing demand for skilled and high-quality nursing care outside of hospital, specialist practitioner programmes are under pressure (QNI, 2017a). A number of factors influence this: the expansion of new and specialist roles, greater skill mix and substitution, ambivalence about the necessity of training, and changes to pre-registration nursing (Edwards and Dyson, 2003; QNI, 2009; Williams and Sibbald, 2001; QNI, 2019b; Drennan, 2019).

Newly qualified nurses are expected to have the skills to nurse in the community, without having to train as district nurses. Although, preparing pre-registration nurses to work seamlessly between hospital and community settings has not been as expected, with concerns raised about patient safety (Willis, 2012; Willis, 2015; Elliot, 2010; Ball *et al,* 2014; QNI, 2019a). A common assumption is that nursing skills for acute care in hospital settings are neatly transferable, but the skill set for nursing in the community is quite different (Drennan *et al,* 2005; QNI, 2017b). Drennan (2019) makes the point that the specific knowledge base of community nursing is invisible to professionals and managers who have never worked in primary care.

Generalist and specialist roles

There has been a tension between the generalist role of the district nurse and the development of new specialist community roles, which tend to be disease or condition specific. Many of these new and specialist roles, for example, palliative or continence care are integral to the district nurse's generalist role and rewarding aspects that district nurses do not wish to give up (Ball *et al,* 2014). This contributes to concerns about the loss of district nurses' skills and holistic care (QNI, 2013b; QNI, 2015b).

The expansion of community health services and outreach specialisms from hospitals, such as diabetes, though intended to improve care and reduce hospital admission, has led to confusion about titles, roles, skills and qualifications (QNI, 2019b). Until comparatively recently, the generic term community nurse seemed to supplant that of district nurse, which perhaps masked further not only the presence of district nurses, but also their distinctive community specialist qualification and skills (QNI, 2019a).

On the one hand, attempts to down grade and 'drown out' what district nurses have to offer risks losing a unique service to the most vulnerable and which already delivers on key policy ambitions, including person-centred and personalised care, support for carers and caseload and resource management (QNI 2009; NHS, 2019a; Coulter, 2005). On the other hand, it may be that district nurses have outgrown their usefulness and that claims to patient-

centred holistic care are no longer deemed appropriate or offered.

A person-centred approach

From patients', carers' and voluntary sector groups' perspectives there is evidence they want: good information, confidence in health professionals, awareness and understanding of specific health conditions; the right treatment from the right staff at the right time; continuity of care; being treated as a person; being given time and partnership with professionals (Robert *et al,* 2011; DH, 2012c; QNI, 2013b). Relational aspects are very important to patients, whereby the ability to trust health staff may supersede having a choice of service (Gainsbury, 2009; Coulter, 2005; Fotaki *et al,* 2005; Robert *et al,* 2011).

From the research and grey literature, three unique values encapsulate district nursing: i) knowing the patient and care context by building trusting relationships, ii) providing individualised, holistic care that promotes independence and iii) care continuity (Luker *et al*, 2009; Kennedy, 2002a; Gerrish, 2000; McGarry, 2003; McGarry, 2004; QNI, 2015; QNI, 2019b; Maybin *et al,* 2016). These critical aspects of the district nurse's role are difficult to capture and measure and may contribute to their marginalization (QNI, 2019a, Ball *et al,* 2014; Proctor, 2013).

Measuring district nursing

Measuring what district nurses do presents challenges and so the emphasis has been recording tasks completed, rather than holistic care or patient outcomes (QNI, 2009: Carter, 2018). The complexity and unpredictability of care means that neither nurses nor managers considered data recordings meaningful, and not all activities were recorded (QNI 2014b; QNI, 2019b). They may be a poor proxy of the service accessed. Nonetheless, the need to capture what district nurses do has become increasingly important, particularly to demonstrate to commissioners value for money and that contracts are being fulfilled. However, in England there are no national or standardised data on district nursing that can inform its development, which perpetuates a reductionist view of the role and service, where essential work remains invisible (QNI, 2019a; NHS Providers, 2018; Carter, 2018).

The challenge for policy makers is to develop indicators based on relational aspects of patients' experience rather than relying on quantitative survey metrics (Robert *et al,* 2011). Although NHS Improvement (2017) developed a scorecard of performance indicators for community trusts, including the Community Friends and Family test, most did not seem relatable to district nursing. The access indicators were oriented to hospital admissions avoidance

and reducing treatment times (NHS Providers, 2018). Relational aspects also have the benefit of capturing,

> 'patient stories across organisational and service boundaries and highlight issues of accessing services, transition and continuity of care…' (Robert *et al* 2011, p.5)

Given district nurses operate at the interface of different services this also makes it difficult to disaggregate their singular contribution to outcomes, limiting understanding of their role (Griffiths *et al,* 2008; Maybin *et al,* 2016; Ball *et al,* 2014). In this way it can be argued that claims of patient-centredness and holistic care are open to challenge (McGarry, 2003).

Provision of district nursing

Until 2013, district nursing was an NHS service initially provided by PCTs and later commissioned by them (DH, 2008; McKinsey, 2009; DH, 2012a). Following the 2012 health reforms, clinical commissioning groups (CCG) replaced PCTs and community health services were contracted out to 'any qualified provider organisation', with public health transferred to local authorities (DH, 2012a; QNI, 2014a; QNI, 2019a). Access continued on the basis of need, but improvements in quality and efficiency were to be achieved by reforming commissioning arrangements (DH, 2012a).

This policy change was augmented further by the Five Year Forward (FYF) view in England which advocated, 'one size does not fit all' and gave CCGs more control over the services they commission, reinforcing cost containment and unnecessary hospitalization (NHS, 2014; QNI 2019a). The FYF view supported the development of new models of care to address the divide and barriers between primary, community and acute services.

By 2017, there were 35 stand-alone community providers in England, of which 11 were NHS Trusts, 6 were Foundation Trusts, 17 were social enterprises and one was a limited company (QNI, 2019a). Carter's (2018) review of community and mental services found, in addition to 18 community health trusts in England, a further 190 Trusts provided some community health services. In some cases, there was vertical integration with secondary care (Smith and Jack, 2012). Since its inception district nursing had become a local rather than a national service, with variations in performance among providers (Carter, 2018; NHS Providers, 2018).

In the same year, NHS organisations were required to form sustainability and transformation partnerships (STP) that comprised CCGs, NHS providers and Local authorities to promote population health and integrated care systems

(ICS) (NHS, 2017). Increasingly, social care was recognised as essential to achieve these policy goals, notwithstanding the crisis in social care (Coulter *et al,* 2013; NHS, 2014; NHS 2019a; Carter, 2018).

Commissioning district nursing

These reforms have introduced a level of complexity affecting monitoring, accountability, and overly bureaucratic commissioning (Carter, 2018; NHS Providers, 2018). Compared with coterminous PCTs, CCGs cover smaller areas where a community health provider may relate to five or more CCGs with different block contract specifications, one trust had to report on 6,000 (DH, 2012a; Carter, 2018; QNI, 2019a). The contracting and retendering processes left no time for providers to concentrate on the core business (NHS Providers, 2018). Carter (2018) found that NHS Improvement lacked detailed knowledge of what services the community trusts provided or when they moved in or out of the independent sector (Carter, 2018).

New models of provision were trialled in fifty vanguard sites to develop better integration between primary, secondary and community services, some of which included social services (NHS, 2014; NHS, 2016a). Primary care networks (PCNs) have also been created and community health services are expected to align to them, but as Murray (2019) asserts, what works for GPs may not work for community health services. Community providers view the model of STPs as acute focused, rather than strengthening and expanding community services (NHS Providers, 2018).

Although the QNI (2019a, p.35) asserts that, 'The role of the qualified District Nurse is absolutely central to this vision of the NHS', the focus on integrated care ought to have ensured a clear role for district nurses but they are invisible in these policies. However, it is important to recognise that the QNI has a vested interest in promoting district nursing in policy debates. Even so, having always operated at the interface of acute, primary and social care services, their skills and expertise in managing and coordinating care are widely recognised and viewed as essential for integrated care (Ball *et al,* 2014; Thomas *et al*, 2006).

If the district nurse's role, skills and title have become less visible than they once were perhaps their presence in the community is no longer obvious: despite being considered 'the glue that holds the wider health and care system together' (NHS Providers 2018, p. 3). At the same time, demand for this service is rising, though it is unclear if all those in need of the service can access it.

Equity and access

The assumption behind universal health care coverage is it makes equitable care possible (Culyer and Wagstaff, 1993). Access to NHS health care is a right in the UK and often re-stated in health policies (DH, 2012a; NHS, 2015a; NHS, 2019a). However, there is evidence that the NHS does not provide equitable care: poorer or older people do not receive the same access or quality of care compared to those who are richer and younger (Coote, 2009). Little is known about patients' or others' experiences of access to district nursing, and whether such access is equitable. Access to health care is essential not only to combat health inequalities but also acts as a key quality indicator (Maybin *et al,* 2016; Penchansky and Thomas, 1981).

If, as argued above, district nurses are invisible in the NHS, how does this affect service demand, accessibility to the communities they serve, and those making referrals?

The following section explores demand and capacity through the access lens, and considers what is known and understood in terms of policy and available research for district nursing.

Demand for district nursing

The evidence for care closer to home is overwhelming as demand and the need for district nursing rises. The fastest increase in the UK's population has been for those aged 85 years and over, reaching 1.6 million in 2016 and expected to double to 3.2 million by 2041, i.e. 4% of the population (ONS, 2018). There were over half a million people aged 90 years and over in 2013 (ONS, 2013). A person aged over 85 years is 14 times more likely to be admitted to hospital than someone aged between 15-39 (DH, 2008). In 2012, half of hospital beds were for people aged 65 years or over and by 2017 accident and emergency admissions had risen by 9% (HSCIC, 2014; CQC, 2019).

Seventy per cent of NHS expenditure is on long-term conditions (NHS Providers, 2018). The cost of diabetes services alone was estimated as at least £3.9 billion, representing 4% of the NHS budget in 2010 (HC, 2014). Of the fifteen million people in England with long-term conditions, 58% are over 60 years, and 70% of the population aged 45 years or over is overweight or obese (DH, 2012a; HSCIC, 2014). Dementia in the UK is expected to increase to over a million people by 2025, and doubling by 2051 (Prince *et al,* 2014; DH, 2009). The projected increase in people with multiple long-term conditions rose by a third in the last ten years to 2.9 million, and the prevalence for multiple long-

term conditions increases with age, currently 25% of those with long-term conditions (DH, 2012a; DH 2014d). Thirty per cent of the population accounts for 70% of the NHS expenditure, c£100B, and the rate of increase in long-term conditions is unsustainable (DH, 2012a).

One in four people over the age of 75 needs a nurse's care at home, rising to one in two people over 85 years and district nurses visit more than 2.6 million people a year (QNI, 2013a). Of the 5.5 million carers in England, 40% report that caring affects their physical or mental health and had difficulty accessing services (DH, 2014c; Arksey and Hirst, 2005; Dixon-Woods *et al,* 2003; Greenwood *et al,* 2015; Greenwood *et al,* 2016). There is considerable evidence to indicate deficits in supporting those with long-term conditions in the community (HC 2014 p 34; NHS Providers, 2018). There seems to be an increasing need for holistic care for those with multiple long-term conditions (NHS, 2014).

Forecasting demand

Forecasting demand based solely on trend analyses has limitations. For example, though the average number of GP visits increased markedly in older people, with fifty per cent of all GP visits for long-term conditions, but increased rates of service use alone are poor measures of access. They do not indicate the quality of service accessed, nor do they show the impact on related services (Polisson, 2011; DH, 2012c; Campbell and Salisbury, 2015; Robert *et al,* 2011).

Chalk and Legg's (2017) study challenges this by adopting a qualitative systems approach, identifying seven factors driving demand for district nursing, including complex needs, early hospital discharge and reduced GP capacity. By exploring causal loops and reinforcing loops, they found causal relationships between these areas that created 'vicious cycles' of demand. For instance, where a GP review was delayed, this caused A&E attendance and a district nursing referral. NHS Providers (2018) concur, stating the top three reasons driving demand were: the complexity of needs, unplanned capacity constraints in social care and likewise for the acute sector. An underpinning lack of capacity remained a prominent factor in the district nursing study, which exacerbated demand, thus inhibiting policy and practice goals from being achieved (Chalk, and Legg, 2017; NHS Providers, 2018).

Capacity

Despite the increasing demand for high-quality home-based services, there is a major gap in capacity, as supply has not kept pace with demand (Maybin *et al,* 2016; NHS Providers, 2018). There are 44% fewer district nurses than ten years ago: the number of qualified district nurses has decreased from 7,716 in January 2010 to 4,441 in April 2020 (NHS Providers, 2018; NHS Digital, 2020). A number of inter-related factors contribute to this decline: recruitment and retention, presumptions about capacity, staff morale, deficits in workforce planning and foremost, a lack of investment (Drennan, 2019; Maybin *et al,* 2016; QNI 2019b). Not only is district nursing invisible in policy terms but also as a workforce (QNI, 2019a).

District nurses form part of a skilled but ageing workforce, the average length of community experience is eleven years and 35% of qualified district nurses are 50 years and over (QNI 2006; QNI, 2009; Ball *et al*, 2014). Training numbers have plummeted dramatically, with only five district nurses trained in London for the year 2010, though this rose to 74 by 2016 (QNI, 2017a). Despite the recent increase in training places, there is concern this number has plateaued and is insufficient to replace staff retiring, or meet rising demand (QNI 2014a; QNI, 2017a; Ball *et al,* 2014).

It is no longer sustainable for many HEIs to offer the specialist practitioner programme and they have come under pressure to reduce the course length (QNI, 2017a). Alternative education models, online courses and apprenticeships, are being trialled to improve recruitment, with the possible development of a community nursing branch in pre-registration nursing programmes (Willis, 2015; QNI, 2017a). Although, more community-based teaching will be required, and community placements are already in short supply (QNI, 2019a).

Despite the policy assumption that capacity can be increased to meet future demand, the community nursing workforce has not grown, quite the opposite and providers are concerned that they cannot meet current let alone future demand (Carter, 2018; NHS, 2014; NHS Providers, 2018). The district nursing workforce fell by almost 9% between September 2009 and July 2020, from 32, 699 to 29,283 (NHS Digital, 2020). The hoped-for transfer of nurses from the acute sector to the community has not happened, and there are no quick fixes (NHS, 2014; Carter, 2018; NHS, 2019a).

Globally, there is a crisis in nursing supply, and in England there is a shortfall of 41,722 nurses, with a fifth more NMC registrants leaving the profession

than joining (Drennan and Ross, 2019; QNI, 2019a). This affects the supply chain to district nursing, and coupled with a high turnover of community nursing staff, a 9.5% vacancy rate in community services and concerns about team resilience, they present serious challenges for ensuring access to quality services and meeting access targets (Drennan, 2019; NHS Providers, 2019; Carter 2018; Chalk and Legg, 2017).

Recruitment and retention

Recruitment and retention remain the biggest challenge facing district nursing (QNI 2019b; NHS Providers, 2018). International recruitment cannot be relied on to meet these shortfalls, as in the past, so policy makers need to adopt a more sophisticated and evidence-based model to plan for future demand (Drennan and Ross, 2019).

This extends to more nuanced recruitment and retention approaches, necessitating a thorough understanding of district nursing and staff profile, in order to promote and present a positive image of the service (Drennan and Ross, 2019). However, outwith of recruitment, community services have not been promoted or well understood by other NHS sectors and policy makers, and being attributed to the diversity, organisational complexity and lack visibility of community services (NHS Providers, 2018; Charles, 2019; QNI, 2019a). Support and funding for training, offering professional development and career pathways, are other ways to attract and keep staff (Drennan and Ross, 2019; Drennan, 2019; QNI 2019b). Without any national plan or impetus to develop district nursing, ad hoc local arrangements abound and limit career progression opportunities (Elliot, 2010). There is no national leadership for community services as for other areas (NHS Providers, 2018).

While district nurses have taken up senior management and specialist roles, this has further depleted district nursing teams (Smith and Jack, 2012; Drennan, 2019). Community matron and nurse consultant posts are more attractive, offering reduced caseloads and higher status and pay (DH, 2006). Although, the numbers in these posts have also fallen in the past decade: by 45% for community matrons and 50% for nurse consultants, while nurse managers increased by 19% (NHS Digital, 2020).

Specialist posts and initiatives, such as Buurtzorg, are also vulnerable to cost pressures, particularly if they are not embedded in the wider service (Drennan and Goodman, 2011; QNI, 2019a; NHS Providers, 2018; Drennan *et al,* 2018). The trend towards a more specialist workforce was raised in the Five Year Forward view, whilst acknowledging that a holistic approach was preferred by patients with multiple long-term conditions (NHS, 2014). District nurses'

generalist skill set is valued by commissioners, noting expertise in holistic assessment, leadership, managing risk and complexity, resilience and cost effectiveness, among others (QNI, 2019a; Carter, 2018).

Capacity viewed as unlimited

There is a pervasive presumption that district nursing capacity is unlimited. Haycock-Stuart *et al's* (2008) seminal research characterised this as a 'ward without walls'. The QNI's (2019b) survey found that although commissioners were aware of staff shortages, they did not permit district nurses to close their caseloads. This reflects the structural inequity of block contracts for community service providers compared to hospital providers, due to the way competition and procurement disproportionately affect community service providers who,

> '…are forced to absorb demand increases and cost pressures by increasing caseload size, reducing the number of staff, changing the skill mix of staff or raising the eligibility criteria for access to services' (NHS Providers, 2018 p. 27)

Block contacts require delivery of the service irrespective of cost or other pressures, such as skills shortages without the opportunity to re-negotiate contracts (NHS providers, 2019).

The impact of unlimited capacity directly affects access, but it is not clear what the eligibility criteria are for district nursing, how they are being raised or by whom. While the relationship between staffing, skill mix and quality are well known, this has not been explored for access (Carr-Hill, 1992; Audit Commission, 1999; Thomas *et al,* 2006; Drennan and Davis, 2008; Kirkup, 2018). District nurses have sought to define their referral criteria as a means to explain the service, and manage demand and capacity (RCN, 2003; Bowers and Cook, 2012). Drennan (2019) found some district nurses used their lack of clinical competence for rare conditions as a way to control their caseloads. These approaches appear to be reactive, and more about rationing scarce resources, rather than offering equitable access.

The impact of caseload demands is critical for community staff, as they face the pressure of clinical priorities and patients waiting to be seen, leading to stress and sickness, and exacerbating capacity problems (NHS Providers, 2018; Chalk and Legg, 2017). A pilot of the adapted Buurtzorg model proved to be very effective in achieving both staff and patient satisfaction, and the benefit of a manageable caseload size seemed instrumental to this, particularly in comparison to the experience of the wider district nursing service (Drennan *et al,* 2018).

There is evidence that district nurses provide care at detriment to themselves, preferring to complete work and regularly working unpaid overtime (Maybin *et al,* 2016; QNI, 2019a; Ball *et al,* 2014). Though policy makers acknowledge the capacity gap, meeting open-ended demand necessitates district nurses working in a task driven way, and for which they are criticised (QNI, 2019b). Carter (2018) acknowledged the strain on staff, tasking NHS Improvement to increase support to trusts to improve staff engagement, retention and wellbeing. The QNI (2019b) recommends analysis of workforce data to discover the reasons why district nurses leave before retirement age, barriers to career development, including pay cuts whilst taking the specialist practitioner course, and the impact of workload.

Guiding principles for safer staffing and caseloads have been produced by the RCN and QNI, but the NICE (2015a) review of district nursing caseloads was inconclusive, due to a lack of robust evidence (RCN, 2013; QNI, 2016). However, lessons from Kirkup's (2018) inquiry signal clearly where accountability lies when cost savings are prioritised above safe staffing and provision: work to determine safer caseloads remains unresolved (QNI, 2019b).

A further policy presumption is that district nurses, as well as supporting acute services, can relieve pressure on GPs (Carter, 2018; Campbell and Salisbury, 2015). This reflects well-known difficulties in accessing GPs, however, it is unclear how this will happen if district nurses do not have capacity to undertake their current work (Ware and Mawby, 2015). Without investment in the workforce, how will this be possible and meet access targets (QNI 2019a; Ball *et al,* 2014; NHS, 2014). Nonetheless, Carter's (2018) review identified efficiency savings of £1 billion to reduce national operational variations and increase productivity in community health and mental health services.

Savings and investment

For district nursing, these efficiencies are intended to release capacity for more and faster hospital discharge, better patient outcomes and potentially provide more support to GPs. Largely premised on expanding the use of mobile working, better technology and systems, and given that an estimated 29% of district nurses use paper-based processes (QNI, 2018). By reducing duplication and administration, time is made available to see more patients, accelerating access and weekend discharges. The single point of access (SPA) was seen as best practice to streamline referrals, though unspecified a range

of access routes was used by providers, resulting in poor communication and coordination (Carter, 2018). Without further detail it was not possible to discern how the existing systems affected access in district nursing.

The proposed costs savings for community health were intended to ensure support for the wider health system, although investment was advocated for mental health services (Carter, 2018). There was no indication of any investment to expand the community health workforce, though district nursing has suffered from a chronic lack of investment (RCN, 2013; Maybin *et al,* 2016).

Major investment has been promised in the Long Term Plan, with an additional £4.5 billion earmarked for primary and community care, to remove barriers to integrated services through joint funding (NHS, 2019a). It is unknown whether this investment will reach district nursing, though given the history it seems unlikely (NHS, 2019a; QNI, 2019a). From providers' perspectives, the STPs have not taken up the opportunity to expand or strengthen community services (NHS Providers, 2018).

The five-year STP/ICS plans are supposed to be based on realistic workforce assumptions and deliver all LTP commitments (NHS, 2019b). Achieving these policy ambitions will require more than efficiency savings in district nursing. National leadership and long-term investment in district nursing is required, as it needs to be reviewed as a national service, ensuring access to qualified district nurses (QNI 2019a; DH, 2014a; Maybin *et al,* 2016; QNI, 201b).

Therefore, the supply and demand sides of access are challenging for the NHS and district nursing. I have argued that the lack of visibility of district nursing in terms of its presence in the community and NHS may well have an impact on access, which may be exacerbated by different models of provision and variations in systems and practice.

Summary

This chapter sought to provide the background and policy context for this study. Access to district nursing was explored, drawing on its origins and current policy and practice. The key questions were raised as to why district nursing can be viewed as both central, but also at the same time, invisible in policy terms and secondly, the extent to which this may have an impact on accessing the service. This policy paradox is demonstrated by the sustained demand for skilled nursing care at home, commensurate with demographic

and health care needs, alongside the dramatic shrinkage of the district nursing workforce and numbers being trained.

Over time, and despite the policy rhetoric, and changes to the provision of district nursing, there has been no substantive or sustained investment to ensure demand can be met. This capacity gap, though acknowledged by policy makers, together with commissioning pressures, suggests how district nurses is seen as task-focused and rationed.

As discussed, district nursing's expertise is 'in a key arena for health care: the patient's own home' (QNI 2009, p.42), however, this very location has been seen as contributing to its invisibility (QNI, 2019a; Goodman, 2000). If district nurses are not only invisible in policy terms but behind closed doors with their patients, it begs the question, how does this affect service accessibility to the communities they serve and those making referrals?

District nursing also fulfills other key policy drivers such as, patient choice, personalisation and public health, offering the service patients and carers say they want (Addicott, and Dewar, 2008; Arnold *et al,* 2004). How then are older, vulnerable and housebound people, who arguably could benefit from district nursing, aware of the service or able to access it? The extent to which direct access still exists and factors affecting patients, carers and those seeking access to district nursing are poorly understood and this study seeks to explain.

The next chapter provides a review of the research literature to discover what is known about access to district nursing and key issues informing this study and its design.

Chapter three: Access and district nursing

Introduction

Access continues to be a goal of health care policy, and improving access is a step towards universal coverage. However, experts agree that defining and researching access is problematic (Evans *et al,* 2013; Gulliford *et al,* 2001; Goddard and Smith, 2001; Dixon-Woods *et al,* 2005). Access, as a field of enquiry, is relatively neglected in the district nursing literature. This chapter seeks to review the literature that does exist, with a focus on understanding what is known and what research questions are yet to be addressed. In this thesis the definition of access adopted is the degree of fit between the patient and the health care system (Penchansky and Thomas, 1981). The studies in this review identify concerns relating to access to district nursing that question whether the service offers such a fit. Conceptual and theoretical aspects of access are addressed in the next chapter.

An overview of the selected studies is presented, followed by a critical discussion of the context and quality of the research and the wider literature. The review is organised by two inter-related themes: barriers to access and power imbalances. A summary provides the synthesis of critical issues about access to district nursing, and identifies areas for further research and how they underpin the rationale for this study and the research questions posed. The search strategy and limitations for the review are explained first.

Search strategy

I adopted a search strategy that was dynamic and iterative rather than exhaustive (Bell, 2014; Greenhalgh, 2006; Dixon-Woods *et al*, 2005). A systematic approach was taken to guide the search (Ridley, 2008; Greenhalgh, 2006). Two search engines; three databases and citations were used with the following search terms: district nursing, district nurse, community nursing, access, accessibility, barriers and primary care. An overview of the strategy is provided in table 3.1, for the sake of clarity not all searches have been included.

Initial scoping searches were carried out using Google and Google Scholar. The Google search was abandoned, as the first 20 pages comprised NHS district nursing provider websites. The University's library catalogue search facility (iCAT) was used for more systematic searching of CINAHL, Medline/PubMed and Social Sciences databases. The grey literature and hand

searching were also used throughout the study. Depending on the search source used, the results varied from an overwhelming number of results to more manageable numbers, as shown in table 3.1. Search terms were adjusted and filters refined to increase sensitivity to relevant literature. The parameters set out below, informed by Bell's (2014) checklist, were used with Boolean operators and iCAT filters:

1. Language: Studies in English
2. Dates: 2005-2020
3. Where: Primary care
4. Discipline: District nursing and papers referring to access
5. Location: UK only
6. Excluded: Studies of access: in hospitals or secondary health services, community nursing roles unconnected to district nursing e.g. paediatric nursing.
   Not published in peer reviewed journals
7. Other terms: District nurse, community nursing, primary care, accessibility, barriers, referrals

Table 3.1 Overview of the search strategy

Search	Keywords used	Search source	Number of records listed
1	district nursing + access	Google	189,000
2	access to district nursing	Google Scholar	7,550
3	'district nursing' or community nursing AND access OR accessibility OR barrier OR opportunity AND referral - with filters	CINAHL Medline/PubMed Social Sciences Full text	146
4	'district nursing' or home nursing AND access OR accessibility OR barriers AND referral OR referrals - with filters	CINAHL Medline/PubMed Social Sciences Full text	227,093
5	'district nursing' AND access OR accessibility OR barriers AND referral OR referrals OR NHS - with filters	CINAHL Medline/PubMed Social Sciences Full text	1,014,678
6	'barriers to access' AND 'district nursing' - with filters	CINAHL Medline/PubMed Social Sciences Full text	945
7	'District nursing' AND access AND barriers AND NHS with filters	CINAHL Medline/PubMed Social Sciences Full text	79
8		Citations/hand searching	6

Studies were reviewed by title and rejected if they did not meet the parameters. The large volume of records retuned in various searches was daunting and abandoned if they could not be refined or where the filters were not sufficiently sensitive, for example, non-UK studies continued to be listed. In searches three and seven, abstracts of the remaining studies were read, and full text articles retrieved for those with potential for inclusion. Hand searching of references followed. Further and deeper searches were made of authors whose work focussed on district nursing and access namely, Gerrish, Goodman and Luker. No individuals were approached for recommendations of alternative literature, as the frequently cited authors' studies were revealed in hand searches. From this process, twelve studies were selected.

Limitations

While the table may give the impression of a straightforward process, keeping track was testing, even with electronic records of searches. Refining search terms and rejecting articles based on titles may have excluded relevant studies, perhaps reflecting some unconscious bias. There were no studies that sought to research access to district nursing, however studies were included because their findings signaled important issues about access and district nursing. Nonetheless, the search strategy seemed to be appropriate as a number of suitable studies featured in more than one search for example, Gerrish.

Overview of the studies

Twelve studies were incorporated into this review, of which nine were primary research and three reviews. Apart from one longitudinal analysis (Arksey and Hirst*,* 2005), all primary studies were qualitative (Bentley, 2003; Ford *et al*, 2018; Gerrish 1999; Gerrish, 2001; Goodman *et al*, 2005; McHugh *et al,* 2003; Nagington *et al,* 2016; O'Brien and Jack, 2010). Gerrish's two publications reported different aspects of data from a large ethnographic study and both were included in the total. All twelve studies were considered for their relevance to the study's research question, appraised for the quality of their evidence (explained below) and were therefore deemed suitable for inclusion in the review.

Five of the primary studies focussed on professional perspectives (Gerrish 1999; Gerrish, 2001; Goodman *et al* 2005; McHugh *et al,* 2003; O'Brien and Jack, 2010). One study focussed on patients and carers (Nagington *et al,* 2016) and another solely on carers (Arksey and Hirst, 2005). Only one empirical

study was designed to explore patients' and health professionals' perspectives of access to primary care (Ford *et al,* 2018). Reviews included quantitative and qualitative studies. Two areas of district nursing practice were researched, palliative care and care homes. Two studies about GP access were included, as district nurses and GPs share the same patient populations and GPs are a key conduit for referrals.

Table 3.2 provides an overview of the studies, presented alphabetically by the first author's surname with a brief critique of each in relation to the quality of the evidence provided.

A quality appraisal tool was used to consider the validity and relevance of each study (Critical Appraisal Skills Programme, 2018). The checklist included ten questions including: the clarity of the aims, the appropriateness of the methodology and the study design, the adequacy of the sampling and recruitment strategy, the robustness of data collection, a clear statement of findings and rigour of analysis, and the relationship between the researcher and participants. This tool was straightforward to use and facilitated appraisal of the trustworthiness, value and relevance of the study in context. Selected findings arising from data analysis are also provided in table 3.2, as germane findings and further critique of the studies are discussed later.

Table 3.2 **Overview of studies included in the review**

Author	Aims, Design, Methods, Sampling	Findings	Critique of the quality of the evidence
Arksey and Hirst (2005)	To investigate carers' use of and access to primary care and GP services A longitudinal review Secondary data analysis of two studies: a survey and a literature review (n=20 studies) with complementary consultation with policy makers (n=12) and practitioners (n=8)	- Male carers have increased contacts with GPs and female carers who live with care recipients have less contact - Five types of barriers identified: professional responses to carers' role; service organisation and delivery; language or culturally held beliefs and practices; carer or care recipient characteristics; and unmet information needs	Both studies reviewed evidence from related aspects of carers' experiences of health care access over a ten-year period, which were complementary and strengthened the findings. First, the British Household Panel Survey drew on a representative sample of adults (n=5000) and data were reviewed for transitions to caregiving. However, being a general-purpose survey, it was not designed specifically to elicit these transitions. A strength of the study was carers' data were organised to identify transitions from would-be carer stage to actual caregiving roles, with adults interviewed at annual intervals. Though the sample identified carers co-resident with care recipients, so those carers not living with care recipients may not have been included. The second study reviewed the literature to identify what promotes or hinders carers' access to health care and the measures in place to improve this. A quality appraisal tool for all the studies was used by one researcher, while 20% of the sample was cross-checked. No independent researcher was involved, therefore weakening the strength of inter-rater reliability with subsequent with potential for bias. It was less clear here what the inclusion and exclusion criteria were for the consultation or why a primary research study directly involving carers or primary care staff was not considered. The lead author had written other papers on this topic, some drawn from the same study and referred to them for methodological details. Other than calls for further research, there was no reflection on the methods used or limitations of the study. Nonetheless, the aim of the study appears to have been met, and important findings revealed barriers to access in relation to health care for carers.
Bentley (2003)	To identify the factors which influence elderly people's access to health care services within a village context and to explore prevalent beliefs regarding the seeking of health care A mini-ethnographic approach	- Cultural factors influenced coping in health and illness and in legitimising access to primary health care - Informants did not see the need to exercise their rights as consumers of health care -The hierarchical position of elderly people is unchanged in respect of	The design involved observation of participants in the village club and semi-structured interviews undertaken in their homes. The sample is small and excluded those who did not attend the village club, but included those who could access primary health care autonomously, enabling observation. The validity of the data was tested by interview transcripts being returned to participants, with their tape recordings, for comments. Though it was less clear if there were any changes as a result. A colleague from a different area reviewed the anonymised transcripts to check the categories and themes, and interpretation of the findings.

	Nine key informants were observed and interviewed by the researcher who was a district nurse practising in the village	the medical model of health care and is a significant barrier to access	The limitations of a mini-ethnographic study were acknowledged, including its short duration, necessitating a particular focus and narrow geographical reach. Any researcher bias was not explicitly acknowledged, given she was a district nurse working at the same practice where the participants were registered. However, a reflective diary was kept throughout to document specifically the researcher's part in the study, reflecting a strength of the ethnographic approach and use of different data sources. Although, she acknowledges her role as researcher was not separate from her nursing role, and the influence of her professional culture. She interprets this positively where participants were at ease sharing their ideas, and reported enjoying the experience. It is possible that participants held back information though the researcher was aware of this potential, as may be the case in any study. Although the study involves few participants in a rural location and all attended the same GP practice, nonetheless the strength of the study design was appropriate in being able to identify views and beliefs on access. These findings documented changes in access culture relative to the particular context, and the study's aim appears to have been met.
Coldrick and Crimmons (2019)	To analyse the evidence from families and carers of patients with life-limiting conditions to identify any inconsistencies in the provision of palliative care by district nurses A literature review Ten studies: three international studies and four qualitative studies. The research question was formulated after the searches: What are family members' and carers' perceptions of palliative care provided by district nurses in primary healthcare?	Two main themes emerged: access to palliative care services and the quality of palliative care services - suboptimal coordination and significant variations in access - perceptions of district nurses' care were positive but out of hours service regarded as inadequate - palliative care services were accessed primarily through district nurses and they are optimally placed to coordinate services.	The literature review's inclusion and exclusion criteria were set prior to any searches and applied rigorously: earlier searches rejected quantitative studies and 30 out of 40 studies were rejected because they focussed exclusively on district nursing. The final ten studies were critically analysed for emerging patterns from the findings to elicit two themes. However, a general comment was made acknowledging the individual limitations of these studies' methodologies, but there was no indication of how the quality of the studies was appraised. This could possibly have been included in the search criteria and verified by an independent party. The researchers recognised the limitations of the small number of studies included and justified this as they had limited time - though this is not mentioned in relation to the search strategy. They acknowledged too that while on the one hand, small-scale studies provide rich data about people's experiences, but on the other hand it is only a snapshot in time. They acknowledged that these studies might have missing data as the research methods required retrospective perceptions of family members. Only two themes were generated and the studies seem to have been explored in depth in relation to them, though details of how they were generated or verified were not given. There appears to be considerable agreement across the findings

			from the studies, with researchers identifying the first theme as the most discussed, suggesting this theme was based on frequency. The broader policy and practice discussion tended to be UK oriented, and the researchers recognised that findings from Norway, Sweden and Canada may not be transferable, due to different models of community based care, and ill defined nursing roles. Although, the review had a small sample, sufficient quality evidence was found to address the research question that was generated after the searches.
Dixon-Woods *et al* (2005)	To produce theory: a logical, plausible and useful explanation, grounded in a comprehensive but not exhaustive body of evidence, about access to health care A review of the literature A new methodology used critical interpretive synthesis, extensive literature search, strategic sampling, appraisal and critique using a similar process to primary qualitative research - grounded theory. Extensive literature searches: 262 studies were included in the general synthesis alone.	- Definitions of access and equity of access remain elusive and difficult to operationalise for research, thus methodological, conceptual and theoretical problems hinder investigating access and the extent to which access is inequitable - Access can be understood though the concept of candidacy which explains the way in which people negotiate access to health care - Services can be conceptualised in terms of how porous or permeable they are - Lack of capacity, variations in quality, differences in resource allocation and service configuration create access-disadvantaged groups -Adjudications are made in the context of operating conditions, including scarcity of resources.	An interpretive synthesis, using a meta-ethnographic approach, which intentionally interprets and incorporates evidence to inform an insightful and useful stance. The approach was intentionally inclusive, avoiding the constraints of a systematic review and recognising that meta-ethnography is usually used for a small number of qualitative studies. Consequently, the research question was imprecise at the start of the search process, but had a set of guided topics and a wide range of search strategies were used and not limited to particular types of study. The papers were screened for relevance, forming a theoretical sampling frame. The quality of all the studies was appraised using five key questions irrespective of the study type in order to maximise inclusion and eliminate papers that were 'fatally flawed'. Different teams used the quality criteria to review the studies placed on an Access database. The authors offer both a critique and a defence of their new methodology including reproducibility, potential inclusion of more studies and the use of different research paradigms to build theory. They do not claim reproducibility, but recognise the interpretive process, and use of different teams or lines of argument which can lead to different interpretations, as may arise in all qualitative research. They argue that other types of review would have excluded more studies, and different methodologies would not have been used to develop theory. Nonetheless, their analysis is rigorous and grounded in the evidence, achieving the aim of deriving new insights about access to health care towards theory development.

Ford *et al* (2018)	To explore barriers to accessing primary care for socio-economically disadvantaged older people in rural areas. A qualitative study Semi structured interviews of older people (n=15) over 65 years in receipt of financial support living in a rural location. Four focus groups with health professionals: GPs, practice managers, senior community nurses, district nurses, community nurses and community physiotherapists (n=16)	- Access to services understood by older people's own set of unwritten rules or social contract - Most found it difficult to access primary care - Health professionals reported how rising demands and coupled with service constraints necessitated service developments, including fewer home visits, telephone consultations, triaging calls and modifying appointment system.	This study explored strengths and limitations throughout, and a fairly robust approach was taken to the data collection and analysis. The study's sample of patients was relatively small with recruitment difficulties but they were overcome using a novel approach engaging community pharmacists. There was a further concern that two patients were not socio-economically disadvantaged though the researchers were cautious when interpreting those data. GPs and practice managers were recruited from research active practices but this was not acknowledged in regards to potential bias. Thematic analysis seems to have been handled systematically to ensure rigour and trust worthiness, using Braun and Clarke's (2006) checklist. Different members of the team undertook: coding and generation of the themes; checking transcripts for accuracy. The research team and patient representatives interrogated the final themes. While themes were derived from the findings, the claim that the social contract was generalizable may be an overstatement - even so this analysis was located in the wider literature. The study design seems appropriate to achieving the study's aim.
Gerrish (1999)	To examine how policy directives concerning the provision of individualised care were modified in their transformation into practice and the implications this carried for the care provided in patients' homes from minority ethnic backgrounds An ethnographic study Conducted in an English NHS community trust with an ethnically diverse population. Two stages i) an organisational profile and to understand the policy context regarding responses to ethnic diversity and in-depth	- Marked inequalities were found in the allocation of district nursing provision across GP practices which had an impact on the services provided to minority ethnic patients - Despite these differences all patients referred to district nurses received care, however covert processes seemed to limit district nursing teams' caseload size in practices with large populations.	The selected findings reported were part of a larger ethnographic study of the provision of district nursing to patients from different ethnic backgrounds. The aims, study design, sampling, data collection and analysis were clearly explained, although there was no discussion of the limitations of the study. However, the data methods identifying ethnicity may be questionable from a post Black Lives Matter perspective, where perceptions and constructions of race and ethnicity have been re-framed. Ethnicity data were not recorded by Trusts or GP practices at that time. Patients were deliberately not asked about their ethnicity as the researcher was interested in the district nurses' conceptualisation of patients' ethnicity. This limited further distinction between patients beyond being deemed Asian - when they were from Bangladesh, India and Pakistan. Though in the first stage, ethnicity data were analysed from the census, it was less clear how this related to the ethnicity categories district nurses used to describe their patients: white; Asian; European and Afro-Caribbean. Nonetheless, this did not appear to affect the analysis of the findings that showed an inverse distribution of district nursing resource to GPs with high numbers of Asian patients, and no evidence of discrimination in the provision of care.

	interviews with managers ii) participant observation study with six district nursing teams. The researcher was an academic and qualified district nurse.		
Gerrish (2001)	To examine the nature and effects of communication difficulties between district nurses and South Asian patients and their carers. An ethnographic study – this is the same as above, being part of a larger ethnographic study drawing from the same dataset generated.	- Over half South Asian patients had little or no understanding of spoken English - South Asian patients and their carers disadvantaged due to limited use of interpreters and reliance on family members to translate - Language barriers observed where advice on treatment compliance may not have been fully understood - Psychological support for patients and carers was severely restricted - Follow up visits were made where no interpreter was available and constrained on-going assessment of needs	While it was acknowledged that categorisation of the south Asian patients understanding of English was subjective - it was not clear if the researcher determined this solely based on her observations. Most were single visits which was the first and only time the researcher met the patients and or carers, this potentially limited the accuracy of assessing competence in English. The potential impact on communication by the possible inhibiting effect of the researcher's presence was not mentioned. Nonetheless, the findings appear to be robust in teasing out comparisons in access to psychological support and health promotion between white patients and those minority ethnic patients who had a good command of English and those Asian patients, particularly women, who had little or no English.
Goodman *et al* (2005)	To report on two studies to address the same three research questions. 1. What is the contribution of district nursing and other primary care services to care homes without on-site nursing provision? 2.What strategies promote participation and collaboration between residents; care home staff and NHS primary care nursing staff	- Nurses were the most frequent NHS professional visiting care homes - District nurses and care home managers believed they had good working relationships but had differing expectations of what the nursing contribution should be. - The range of services residents had access to was influence by: expectations about the nursing	Both studies reviewed had relatively small sample sizes, completed two years apart, and the response rate by care home managers was small. The authors' acknowledged that organisational change may have been a factor affecting relationships between the care home staff and district nurses and that the reason care home managers did not respond may reflect poor relationships with district nurses. Neither study sought to discover residents' perspectives, and their views were represented by what care home managers' views were of the district nursing service. This may have limited the scope for analysis of residents' perspectives in regard to district nurses' contribution to their care and discovering strategies that promoted their participation. However, both studies' findings appear to have been

	3. What are the current obstacles and aids to partnership working and learning? A review of two empirical qualitative studies conducted in inner London and a Shire county Two phases i) Exploratory phase 10 focus groups of 74 community nurses, care home managers and their staff ii) Survey phase: two surveys conducted by post and telephone: district nurse team leaders (n= 113) across eight Trusts and care home managers (n=142)	contribution; training and support care home staff received from district nurses and degree of partnership working	rigorously analysed using NUDIST for the qualitative data and SPSS used for descriptive analysis of the quantitative survey data.
McHugh *et al* (2003)	To explore district nurses' perceptions and experiences of referral of cancer patients and to gain insight into these referral processes. A qualitative study Interviews district nurses (n=20) in three primary care trusts.	- District nurses expressed concern about the completeness, accuracy and appropriateness of referrals. Five main themes were identified: referral process; priority of referrals; communication issues; differing expectations by patients of district nurses, and access in crisis situations	The study used an interpretive approach, carried out by researchers involved with community nursing education. The thematic analysis was conducted by two of the researchers using NViVo. However, it was unclear which of the researchers had conducted the interviews even though differences were discussed until consensus was reached. Although the study design did not include any other perspectives, the study's strengths included its clear scope and that the findings were located in other studies.
Nagington *et al* (2016)	To examine how knowledge (as an ethical concept) impinges on quality of care: a poststructural analysis of palliative and supportive district nursing care A qualitative study	- Patients and carers extant knowledge of district nursing was limited - Patients and carers current knowledge of district nursing was restricted to physical care provision	The design was compromised as the intention was to conduct two interviews with patients and carers but due to the high morbidity rate this was not possible. This did not seem to have a significant impact on the quality of the data collected. Data from interviews were analysed both iteratively and comparatively, generating codes, alongside the review of other theories and literature, informing the interview protocol. The researchers recognised the limitations of ever expanding areas of analysis and as a result focussed on knowledge as this had emerged as a

	Semi structured interviews patients (n=26) and their carers (n=13) receiving district nursing services	- Unable to conceptualise the district nurse's role developing as their disease progressed - Isolation of patients and carers prevents networking with others and are unable to develop knowledge of district nursing	constant theme. The study took 5 years, time may also have been a factor, though this was not addressed in relation to any impact on the findings. Although, the researchers acknowledged that due to the nature of poststructuralism claims to rigour and validity may not be made. However, they followed certain conventions to ensure this was demonstrated: by complying with NHS Research ethics requirements to recruit participants and ensuring data were not analysed by the researcher, a palliative care specialist, who had conducted the interviews, recognising potential bias. A strength of the study was the research advisory group which included service users.
O'Brien and Jack (2010)	To explore the views of community nurses, district nurses and specialist palliative care nurses of end of life care and the place of death for patients with cancer. A qualitative study Two focus groups of district nurses and specialist palliative care nurses (n=19) in two PCTs in northwest England	- Care packages may be hampered by service capacity - Relatives disappointed that assumed care did not materialise - Poor discharge planning and coordination - Unrealistic promises were made by hospital staff about extensive packages of community care - Difficulty establishing additional equipment - Inadequate out of hours service for medical provision and medication	The paper reports on one of two main themes, service provision, derived mainly from the district nurses' focus group. Conversely, the other theme, carer breakdown, is reported in an earlier publication and reflects specialist palliative care staff views. While this dichotomy is explained by differences in roles and in this case limited involvement of palliative care nurses with the service requirements, the findings from both focus groups are given as representing consensus. As no 'dissenting views' are presented, it is unclear if any important views have been omitted, or if more focus groups were needed. Despite claims otherwise, the topic guide seemed to have mainly closed and leading questions. While rigour of thematic analysis is attended to, different theoretical models are cited and both researchers independently undertook the analysis. However, the process for explaining how they reached consensus is less clear. A strength of this study is that it is a response to a perception by practitioners that hospital admissions were increasing for those at the end of life, although the findings reveal poor hospital discharge practice discharge. The analysis does identify a number of barriers to access to palliative care at home, and locates them in the wider literature.
Walshe and Luker (2010)	To examine how district nurses provide nursing care to patients in the palliative phase of their illness. A Realist review of the literature Forty six papers employing a range of research methods are	- District nurses value providing palliative care, the importance of relationship with patients and the emotional difficulties of providing such care - District nurses have key skills in providing physical care and	This review built on an earlier one and adopted a rigorous approach to include a wide range of studies, and drew out implicit assumptions about practice from the wider literature. These assumptions were translated into a set of nine statements and used to interrogate the literature. Although it claimed to be an international study, most of the sources were from the UK, which may have resulted in some UK bias. Adopting a realist approach meant that quality appraisal criteria were secondary to the contribution each study may make in developing the synthesis, though relevance and rigour must be assessed. Even so, while the researchers did

	incorporated into the review including international studies	coordinating the work of others, less so with psychological aspects - District nurses feel undervalued and express reluctance to work with other health and social care professionals in providing care	not use formal appraisal tools, they asked key questions to determine relevance and the quality of the evidence. However, they were generally critical of small-scale qualitative studies, where many used interviews and were oriented to district nurses' views. In terms of limitations, it was unclear precisely why studies were considered poor quality or how many papers this applied to, though they assert their collective value is a strength to support or refute the propositions about district nursing. This also relates to their wider view that more observational studies were needed, as well as those that would capture other views, particularly patients and carers, and practice outcomes. Importantly, despite considerable evidence to support the propositions, the synthesis failed to show how district nurses provide nursing care to patients, and as a result it was unable to indicate the outcomes of care or inform palliative care practice. Reporting negative findings is a strength and increasingly rare, and their advice for future research is well grounded and moves beyond 'more of the same' to focus on the impact of the service and outcomes of care.

Organisation of the review

The following section presents a critical discussion of the context and quality of the research and wider literature. Each study's findings has been analysed in relation to access and a synthesis presented under two main themes: barriers to access and power imbalances. Both themes are inter-related and relevant findings discussed under a set of subthemes.

Barriers to access

'Access is concerned with the availability of suitable opportunities to use health care' (Burt 2010, p.33). All studies included were concerned with opportunities to use health care and identified barriers to access for particular vulnerable groups that feature on district nursing caseloads. This section discusses cultural, ethnicity and gender barriers.

Cultural

Across the access literature, the importance of understanding and taking account of cultural barriers to improve access has been identified (Dixon-Woods *et al,* 2005*;* Gulliford, *et al,* 2001; Goddard and Smith, 2001). Understanding how patients and carers conceptualise health and illness is important as it influences help seeking behaviour. This is explored in two studies of older people's access to primary care in rural areas (Bentley, 2003; Ford *et al,* 2018).

Both studies showed similarities in the way older people viewed access. Bentley (2003) found access was influenced by how patients coped with health and illness and holding to an (arguably) outmoded medical model of health care. As a result, older people deferred to professionals, namely GPs. They believed that GPs were powerful, always busy and resources were limited. Consequently, they avoided bothering doctors unnecessarily and legitimised access by waiting until their symptoms were severe. This reflects Dixon-Woods *et al's* (2005) finding where those in more deprived communities manage their health as a series of minor or major crises, rather than preventing ill health or maintaining health.

These findings align with Ford *et al's* (2018) study of deprived older people, who perceived access as a social contract. A set of unwritten rules underpinned patients' understanding of access, whereby they believed they gained goodwill for future access by not bothering GPs with trivia. As a result,

GPs would be flexible in providing appointments and home visits. Bentley found that patients did not see themselves consumers of health care, rather over consultation would meet with doctors' disapproval. They believed they were helping the doctor by not using precious resources. However, Dixon-Woods *et al* (2005 p.7) state,

> 'The moral character that has been imposed on help-seeking as a result has made people highly sensitive to the demands on professional time'.

It is not known how patients perceive access to district nursing and whether this affects their use of the service, or if any such social contract extends to district nursing.

Nevertheless, disadvantaged groups were not aware of other services to improve access, such as NHS Direct, and older people were less likely to use this service, perhaps preferring to see their own GP (Goddard, 2009; Goddard, 2008). Patients in Bentley's study were prepared to accept a longer wait to see their GP of choice. However, this acceptance of their position in the hierarchy was seen as a significant barrier to their use of healthcare. Although, Bentley did not characterise this as their choice.

Ford *et al* also reported practical barriers to access, such as busy phone lines, the lack of appointments and triage, which older people viewed as a breach of the social contract. Whether patients receiving district nursing experience similar barriers is unknown. Although, Maybin *et al's* (2016) report on district nursing quality, found patients valued scheduled appointments and being able to contact district nurses between appointments. Interestingly, although district nurses knew scheduling was important to patients, it was not a shared priority. For older people in the primary care studies, it seemed necessary for them to fit the service, as they understood it (Penchansky and Thomas, 1981). However, Dixon-Woods *et al* (2005) study found that health care organisations often rely implicitly on an 'ideal user', who matches how the service is intended to be used.

Health professionals, in Ford *et al's* small qualitative study, recognised disadvantaged older people did not use the service as intended, for example by requesting home visits. Although not explicitly stated in either study, patients did not appear to conform to the ideal user. This begs the question whether district nursing providers rely on an ideal user, and if so, how is this perceived by patients, carers, district nurses and health and social care

professionals making referrals to the service?

A strength of the qualitative design, of both these small rural studies, was they uncovered beliefs and attitudes about access that otherwise would be difficult to discover. However, the findings are not generalisable especially to urban contexts and the participants did not reflect district nursing caseloads of mostly housebound patients. Both studies provide useful insights into service utilisation and older people's view of their role in access, which may resonate with older people seeking to access district nursing.

Ethnicity

District nurses work with diverse populations, and it is argued their caseloads should reflect the population served to ensure equity of access (Peckover and Chidlaw, 2007). However, unfortunately, there is some cumulative knowledge from studies of district nursing caseload profiles that suggests inequitable access for minority ethnic groups (Cameron *et al* 1989; Gerrish, 1999; Peckover and Chidlaw, 2007). Research findings indicate that minority ethnic groups are under-represented, largely due to structural and organisational factors.

A strength of Gerrish's (1999) ethnographic study was her analysis of resource allocation. She found historical inequitable distribution of district nurses to general practices, with the lowest allocation to those with a large ethnic minority population. Currently, CCGs have responsibility for commissioning equity of access and could influence resource allocation (Wenzyl *et al,* 2015). Although, caseload profiling is being advocated as a means to manage district nursing demand and complexity rather than address inequalities of provision or unmet need (Harper-McDonald and Baguley, 2018).

Gerrish (1999) did not find any evidence that district nurses did not provide the service to minority ethnic patients. However, in her related study, inequity in the quality of care provided to South Asian patients and carers was observed, due to language and communication barriers with district nurses (Gerrish, 2001). District nurses were less likely to use professional interpreters and relied on family members to translate. These language barriers appeared to restrict opportunities for relationship building and holistic care, like psychological support and patients' understanding of treatment compliance. The strength of both studies is in their use of ethnographic design, providing unique insights into district nursing practice that is normally hidden, to reveal inequitable access to district nursing for minority ethnic groups.

Health inequalities are well known for black, Asian and minority ethnic (BAME) groups, despite the absence of a narrative on racial and structural disadvantage (Marmot *et al*, 2020). However, the impact of two global phenomena in 2020, Black Lives Matter and the Covid-19 pandemic, has compelled debate and calls for change. The removal of the section on discrimination from Public Health England's (PHE) report of the relative risk of Covid-19 for BAME led understandably to an outcry (Moore, 2020). Consequently, the need to address racial inequalities has been acknowledged, and an NHS Race and Health Observatory established. However, it remains to be seen how wider structural inequalities will be addressed.

A qualitative study of district nurses' awareness of cultural diversity also found district nurses failed to meet language and communication needs of minority ethnic patients (Peckover and Chidlaw, 2007). As in Gerrish's study, district nurses were aware of a lack of provision to some minority ethnic patients, and the contributing factors, but district nurses did not question continuing inequities. Services that lack cultural sensitivity or stereotype patients may mean that services are not offered and ethnic minorities may become alienated from organisations (Dixon-Woods *et al,* 2005). 'Caring for their own' was a stereotypical assumption about minority ethnic communities found in a number of studies (Cameron *et al,* 1989; Arksey and Hirst, 2005; Gerrish, 1999; Peckover and Chidlaw, 2007).

Gerrish's (2001) research is one of the few empirical studies of ethnicity and district nursing, though not explicitly stated, she found professionals assumed family members would be willing to act as interpreters. While the study's design provides rich detail for reviewing practice, there are limitations to what can be observed and interpreted about the impact for patients' and carers, and particularly where the researcher does not speak the language.

Gender

Gender was a factor in the studies examined: two studies highlighted gender differences in how patients and carers, respectively, engaged with services (Bentley, 2003: Arksey and Hirst, 2005). Bentley's small qualitative study suggests patients considered GPs powerful and in control of all community health services but men appeared to feel more confident about expressing dissatisfaction about their care. On the other hand, when women had reason to complain they seemed less willing to do so, fearing repercussions like removal from the GP's list, and adopted a deferential approach.

The difficulty of drawing conclusions too far from this study is that was a small sample in a rural location and the paper does not make it clear if the men had made complaints and if they would complain to GPs about GPs.

There is a suggestion that attitudes towards general practice are changing; for example, the 2018 British Social Attitudes survey showed that satisfaction with the GP service is the lowest since the survey began (Phillips *et al,* 2018). The results from this national survey and in-depth interviews, based on random sampling, lend weight to Bentley's findings, where older people tended to be more satisfied with the NHS, and those over 75 years had even higher rates of satisfaction. The main source of dissatisfaction was the length of time to get a GP or hospital appointment. Unfortunately, it was not possible to discern satisfaction rates for district nursing, as it was not disaggregated in the BSA survey.

The majority of patients on district nursing caseloads are women, as are carers (Age UK, 2019a; Age UK, 2019b; Age UK, 2020; Carers UK, 2015a; DHSC, 2018). One in four women aged 50-64 has caring responsibilities, compared to one in six men (Carers UK, 2015a). On becoming carers, men had more contacts with GP services, while women who lived with the care recipient had the lowest number of contacts (Arksey and Hirst, 2005). It was not clear why this was the case, though other findings in the study showed carers had insufficient time for themselves, putting the needs of care recipients above their own, as well as inflexible appointment times.

Goddard (2009) acknowledged a lack of evidence of differential access to health care by older women, but emphasised their social disadvantage, experiencing poverty as three times greater than the general population. Patients on district nursing caseloads include mainly women who are very old, poor and housebound. It is not known whether their perceptions and experiences align with these studies or if other barriers operate affecting access to district nursing.

Power imbalances

Throughout the literature the concepts and experiences of access and quality are interwoven (Goddard and Smith, 2001; Goddard, 2008; Goddard, 2009; Maxwell, 1984; Donabedian, 2005). It seems there is a dominant strand of thinking supported by evidence that access to health care is essential to ensure health equity and 'that the quality of service is also an intrinsic element of access…' (Goddard and Smith, 2001 p.1151).

This section considers the relationship between perceptions of the balance of power regarding access and quality for: choice and control, partnership working, information and referrals.

Choice and control

Policy documents (DH, 2012a; DHSC, 2018) and the seminal Marmot (2020) review emphasise that health quality, equity and choice remain central to health care policy reforms and tackling widening health inequalities. While Marmot *et al* (2020) present an evidence-based strategy to address social determinants of health, governments encourage the public and patients to exercise greater choice and control over their health, and for services to be more responsive (NHS, 2015a; Goddard, 2009; Coulter *et al,* 2008; Cameron *et al,* 2012; DHSC, 2018). This includes attempts to make health care like other consumer experiences (Coulter *et al,* 2008).

It is notable that in the primary care studies referred to above, older people's preferences for service access seem to run counter to the policy and practice of patient engagement and choice. The research suggests other aspects of the service are valued, like care continuity. While in the following group of palliative care studies, access to quality care was prominent.

O'Brien and Jack (2010) found where patients had chosen to die at home this was impeded because of poor coordination between and across agencies. Palliative care was primarily accessed through district nurses as care coordinators, yet care quality may depend on others (Coldrick and Crimmons, 2019). For example, inadequate out of hours medical cover was highlighted in a number of studies, affecting access to pain relief, care continuity and unnecessary hospital admission (O'Brien and Jack 2010; Coldrick and Crimmons, 2019; Lee *et al*, 2017).

Wide variations in access to palliative care services were found across health and social care, with different perceptions and experiences of what services were available (Shipman *et al,* 2013; Coldrick and Crimmons, 2019). This is important given that most people who express a preference have stated their wish to die at home (Hoare *et al,* 2015). O'Brien and Jack's and Coldrick and Crimmons' studies captured professionals' and carers' views respectively, though neither design included patients.

Patients and carers were included in Nagington *et al's* (2016) qualitative study, which found a lack of knowledge about district nursing impeded care quality. This found patients' and carers' choices were limited by their inability

to envisage district nurses providing future care and support needs.

While patient and public involvement and patient choice policies have introduced a quasi-consumerist model of patient engagement within the NHS, the evidence suggests older people's access needs and preferences are different. Bentley (2003 p.10) makes the point that older people may be unable to adopt a consumerist approach as they cannot readily 'take their trade elsewhere'. As district nursing patients rely on care being brought to them, district nurses may hold considerable power in defining what, how and to whom the service is offered.

Partnership working

It is a widely understood principle that district nursing involves partnership with patients and carers (QNI, 2015a). This is based on a social model of health, enabling power to be balanced between professionals and patients (Skinner, 2018). Holistic assessment and individualised care, though largely uncontested in the research literature (as argued in chapter two), are intended to provide opportunities to agree needs and negotiate care with patients, taking into account the uniqueness of each context and home environment (Gerrish, 2000; Maybin *et al,* 2016).

However, Dixon-Woods *et al's* (2005) analysis of access for vulnerable groups, assert that professionals determine needs and the legitimacy of these needs to permit access to services. Their review adopted a novel methodological approach, a critical interpretive synthesis, that identified candidacy as patients' ability to negotiate access to health care (Dixon-Woods *et al,* 2005). Candidacy was premised on many factors, including patients having the necessary skills, resources and information.

Rather than a partnership or therapeutic relationship, candidacy seems more like a series of transactions, between professionals and/or organisations and patients. Candidacy is a useful means to review access critically from the perspective of vulnerable groups, as it also challenges the notion of partnership. Nonetheless, the extent to which vulnerable patients on district nursing caseloads would be able to exercise candidacy is uncertain.

Across the studies reviewed, the importance of the relationship between district nurses and patients was highlighted, in terms of its role in identifying needs and providing access to care, resources and support (Gerrish, 2001; Bentley, 2003; Goodman *et al*, 2005; Walshe and Luker, 2010). The context of district nursing is distinctive in that needs assessment and care are provided

in the patient's home (QNI, 2013b; McGarry 2004; McGarry, 2008). This home context can facilitate candidacy, power may be shifted in the patient's favour, because the district nurse is both nurse and guest, and patients may feel more empowered (Walshe and Luker, 2010; McGarry, 2003; McGarry, 2004; McGarry, 2008). However, McGarry (2008) found that despite district nurses encouraging participation, patients tended to comply with district nurses' wishes.

O' Brien and Jack's (2010) small qualitative study did not include patients' or carers' views, but found the quality of patient care was dependent on the quality of the relationship with nurses. These findings align with other studies (Kennedy, 2004; Luker *et al,* 2009; McGarry, 2008; Haycock-Stuart *et al*, 2008). However, this was not universal and seemed to depend on the care context, as Goodman *et al* (2005) found care home managers felt district nurses did not know residents as they would patients at home, and this limited holistic care. Though the study did not include residents' views, it seems likely they may be less able to exercise candidacy, and thus may face two sets of organisational barriers.

For carers, the research suggests that they are not getting access to the help and support they need, and experience some of the same barriers as patients, including culture and language (Arksey and Hirst, 2005; Gerrish, 2008). Partnership working should extend to carers to assess their needs and provide support, as an integral part of the district nurse's role (QNI, 2015a; QNI, 2019a). Knowles *et al's* (2015) study of carers' experiences of long-term conditions, found they were reluctant to identify themselves as carers but suggested that health professionals were ideally placed to validate carers and encourage support seeking.

This contrasts with findings from a longitudinal review of primary care, where health professionals did not recognise the role of carers, and as a result help and support were not offered (Arksey and Hirst, 2005). This aligns with other small qualitative studies where district nurses were reliant on GP and hospital referrals to identify carers, but those making referrals were unaware this was the district nurse's role (Gerrish, 2008; Simon and Kendrick, 2001). Arksey and Hirst concluded caregiving for carers is essentially reactive and transactional, and call for further research to understand barriers fully before genuine partnership can take place.

The literature suggests those who are most disadvantaged and vulnerable face the prospect of multiple barriers at every point of access (Goddard, 2008). Dixon-Woods *et al* (2005) considered the effort required by individuals to access services, where services that are highly permeable are easiest to use. While, less permeable services require much more work by patients in order to gain a point of entry and sustain engagement. The evidence suggests district nursing may be a less permeable service and as it involves working in partnership with health and social professionals across many boundaries and organisations, creating multiple points of discontinuity (Maybin *et al,* 2016; QNI, 2019a; QNI 2019b; Cameron *et al,* 2012).

Goodman *et al* (2005) reviewed two mixed methods studies of care homes that explored partnership working, and found organisational and operational barriers impeded access to district nursing (Gage *et al* 2012; Goodman *et al* 2016). Care home managers felt residents' and care homes' priorities were secondary to NHS priorities and service delivery methods. Differing definitions and expectations about district nurses' contribution influenced the services provided. Another review found similar concerns regarding integrated working in care homes and a lack of access to district nursing (Davies *et al,* 2011).

Goodman *et al* concluded that residents did not appear to receive the equivalent care as those living in their own homes, care was more task oriented. It was unclear if residents were aware of this disparity, although the second research question intended to review strategies to promote resident participation. It was unclear if this had been addressed.

Being a resident of a nursing or residential home is a barrier to accessing both mainstream and specialist NHS services (Dixon Woods *et al* 2005; Davies *et al,* 2011: NHS, 2019a). Even so, district nursing is the most frequent NHS service provided to care homes (Goodman *et al*, 2005; Gage *et al*, 2012). The evidence from these studies points to particular barriers for patients and carers accessing district nursing, and the complexity and challenge for integrated services.

Information

Access to service information is considered essential to raise awareness and empower patients and carers to use services (Gulliford, 2009). There is evidence that accessing knowledge and information requires considerable work and vulnerable patients may be more disadvantaged (Dixon-Woods *et al,* 2005).

From many studies, consistent evidence is emerging of a lack of service information and understanding of the district nurse's role (Arksey and Hirst, 2005; Bentley, 2003; Goodman *et al*, 2005; McHugh *et al* 2003; Nagington *et al,* 2016; O'Brien and Jack, 2010; Walshe and Luker, 2010). In O'Brien and Jack's study, district nurses indicated hospital staff gave inaccurate information; promising care packages to palliative care patients that could not be delivered, suggesting a lack of understanding of both the district nurse's role and also how services operate in the community. Though evidence points to a lack of information, it should be noted that it was not possible to detect how or if information about the service was imparted.

Nagington *et al's* (2016) innovative approach explored the role of knowledge, as an ethical concept, and its importance to the nurse-patient relationship and care quality. They found palliative care patients and carers had limited knowledge and understanding of district nursing and the district nurse's role. This impinged on care quality, as they were unaware that district nurses could offer psychological support. As patients and carers were isolated from others, they had no means to learn about the whole service and holistic care (Nagington *et al,* 2016). This study has relevance to district nursing as a whole, as district nursing patients are usually housebound and isolated, and may not have networks to share or find information about district nursing. None of the studies mentioned any written material or the Internet as a source of information about district nursing.

Arksey and Hirst's (2005) review found carers had unmet information needs. A survey found all GPs and district nurses reported giving ad hoc information to carers, when it was sought (Simon and Kendrick, 2001). Gerrish's (2008) research found district nurses provided support to carers at crisis points. For example, incontinence could present as a crisis, but carers found it difficult to access helpful information and resources (Drennan *et al,* 2011). Another GP survey, found only 5% provided leaflets or care packs for carers (Greenwood *et al,* 2010). Although Arksey and Hirst identified available resources, it was not clear what information was being given, and if it was tailored specifically for carers or included information about district nursing.

A lack of access to service information and knowledge of district nursing seems to reinforce power imbalances and undermine partnership working. The evidence suggests patients' and carers' engagement, choices and access are limited by what they are told and their subjective knowledge and experiences. Patients and carers need access to timely, accurate and relevant

information in user-friendly formats to be able to make informed decisions (Coulter *et al,* 2008; Nagington *et al,* 2016).

These studies show variations in access to district nursing and information about the service for care homes, palliative care and minority ethnic patients, and carers, and indicate vertical equity concerns. However, it is not known if any of these access barriers affect patients and carers across district nursing caseloads i.e. horizontal equity of access (Oliver and Mossialos, 2004). This raises questions about how patients, carers and health and social care professionals making referrals find out about district nursing and the district nurse's role.

Referrals

Access to district nursing follows a referral process and most referrals come from GPs and hospitals (McHugh *et al,* 2003). In the studies reviewed, where those making referrals did not understand the district nurse's role and information was unavailable, access appeared to be inequitable for carers and palliative care patients. Peckover and Chidlaw (2007) concluded under representation of minority ethnic patients on district nursing caseloads might be due to the lack of GP referrals, and a lack of awareness of district nursing among these communities.

District nurses were reliant on GPs and hospitals referring carers as well as care recipients (Gerrish, 2008; Arksey and Hirst, 2005). Those making referrals act as gatekeepers to district nursing, and as GPs make the most referrals they are the main gatekeeper (McHugh *et al,* 2003; Goldrick and Crimmons, 2019; Peckover and Chidlaw, 2007).

In McHugh *et al's* (2003) small qualitative study, district nurses did not receive all cancer referrals, which they attributed to a misunderstanding of their expertise. Most hospital referrals were for physical tasks. Although district nurses conduct holistic assessments, task-based referrals seemed usual which meant patient needs might be pre-determined or limited through the referral process (QNI, 2019a; McHugh *et al*, 2003). This approach may exclude patients who could benefit from district nursing, and the way the referral process operates shifts control to those making referrals (QNI, 2009). However, the perceptions and experiences of those making referrals to district nursing are unknown.

District nursing referrals have long been identified as problematic and often cited as inappropriate (RCN, 2006; QNI, 2009; Ball *et al,* 2014; QNI, 2019a). Such referrals are viewed as time wasting, as they had to be returned or redirected (QNI, 2009). McHugh *et al* also found some hospital referrals were of poor quality, being incomplete and inaccurate. Important information was missing, such as medication and whether patients knew their diagnosis. Experienced district nurses drew on contextual factors to make decisions about priorities and response times (McHugh *et al 2003;* QNI, 2019a). This study reveals little about the referral process, other than hospitals may have different systems and the common referral method was fax. It is not known if there are differences between those making referrals, in the way referrals are made, and accepted, and the systems and methods used.

Traditionally, district nurses have not refused referrals, especially due to capacity and resource issues (Audit Commission, 1999; Haycock-Stuart *et al,* 2008; QNI 2009; QNI, 2014b; QNI, 2019a). A QNI (2019a) online national survey of district nursing found 63% of respondents (n=2858) never refused referrals. However, for 48%, the frequency with which referrals were refused or deferred in relation to capacity and resource issues, increased with size of the caseload. Deferred work included ill-health prevention and health promotion.

This signals variations in service access across the country. It is not known what other factors influence the way access to district nursing is determined, including deferred access and local or national referral criteria. In McHugh's study, there was no mention of referral criteria; this may be because district nurses considered all cancer referrals appropriate. Although McGarry's (2008) study found district nurses had a clearly defined local referral criterion 'having a nursing need', though no other Trust criteria were mentioned. Having a nursing need appears to be a broad criterion and open to different interpretations by patients, carers, district nurses and health and social care professionals.

From the review of the literature, there are many points of failure in regard to access. These barriers and power imbalances raise questions not only about how patients, carers and health and social care professionals know about and understand district nursing, and the district nurse's role, but also how to access the service effectively.

Summary

This literature review signals there is limited research on access to district nursing. None of the studies had a primary focus on access to district nursing. Therefore, this review draws on relevant research on access that has a bearing on district nursing. Primary care studies threw light on to the way older people perceive access and their expectations of services. Inequitable access to district nursing emerged from the studies on palliative care, care homes, minority ethnic patients and their carers. Although these patient groups are important, they represent a small percentage of district nursing caseloads, so it is unknown if these findings can be generalised to the whole caseload. Most studies were small and qualitative, and mainly captured a single viewpoint, usually district nurses. Only one empirical study included patients. Nonetheless, they highlighted a number of areas where access to district nursing was impeded and warranted further investigation.

A number of questions remain unanswered from different perspectives, indicating further research is required. What do patients, carers, district nurses and those health and social care professionals know and understand about district nursing, the district nurse's role and referral process? It is unclear what barriers to access exist across the district nursing caseload, regarding horizontal equity. What are patients' and carers' access needs and preferences, including information needs and do they have candidacy? Do district nurses and health and social care professionals use referral criteria and what are their experiences of the referral process? Current research has not adequately answered these questions, but has raised issues about the fit between district nursing patients and the service.

Across the access literature, there are calls for further research, and particular research, which examines access from both supply and demand sides (Gulliford *et al,* 2001; Dixon-Woods *et al,* 2005; Levesque *et al,* 2013). There is a need to learn more about the experiences of access from patients, carers, district nurses and health and social professionals. Most of the studies in the review were qualitative and related to the supply side of access.

Further research adopting a mixed methods approach to explore access from different perspectives, could contribute to a more complete understanding of access to district nursing. This study intends to adopt this approach to address the following two research questions:

How do patients, carers, district nurses and health and social care professionals experience access to district nursing in London?

What factors promote or hinder access to district to nursing?

The next chapter presents conceptual and theoretical aspects of access and considers how they align with district nursing, and the extent to which they can be used to inform the design of this study.

Chapter four: Access – concepts, definitions and theoretical frameworks

Introduction

Access is a complex, multidimensional and elusive concept that continues to challenge researchers and health economists in conceptualising, defining and evaluating access (Goddard and Smith, 2001; Dixon-Woods *et al,* 2005; McIntyre *et al,* 2009; Saurman, 2016; McLaughlin and Wyszewlanski, 2002*;* Gulliford, 2009; Goddard, 2009). Even though there is little consensus about what access means, an important principle is that of equity of access (Oliver and Mossialos, 2004). This chapter focuses on conceptual and theoretical aspects of access drawing on the literature and is organised into two sections. Section A presents key concepts, definitions and an overview of selected frameworks. In section B, two frameworks of access are reviewed in more detail and considered in the context of district nursing. The chapter concludes with a critique of the frameworks and set out how they inform the conceptualisation of access for this study.

Section A Concepts, definitions and frameworks

The need for consensus and a conceptual framework of access has been identified as necessary to formulate, explain and evaluate access policy (McIntyre *et al*, 2009; Goddard and Smith, 2001). Much of this research has focused on the supply side of access, that is, services provided rather than demand side considerations, from the individual or population viewpoints (Goddard and Smith 2001). Prior to exploring definitions of access, three concepts are highlighted, equity of access, need and candidacy, as they have a bearing on how access may be conceptualized.

Equity of access

Equity of access is defined as equal access for equal need (Oliver and Mossialos, 2004). This is horizontal access, and a central tenet of the NHS, where everyone with same needs has the same opportunity to use the service, as opposed to vertical access, where there is unequal access for unequal need (Wenzl *et al*, 2015). Other equity principles include: equal use for equal need, equal quality for equal need and equal health outcomes for equal need (Oliver and Mossialos, 2004; Whitehead, 1988). Access and equity of access are considered in the literature as indicators of health inequalities, reflected in Braveman and Gruskin's (2003, p.254) definition of health equity,

> ‘the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage - that is, different positions in a social hierarchy.’

Oliver and Mossialos (2004) argue it is essential that those with equal need have equal opportunities to access health care, although even where equal opportunities exist, individuals may not make use of these opportunities Equity of access is a supply side consideration, as equal services are made available for equal need (Goddard and Smith, 2001).

Need

It is argued the concept of need is an important determinant of access. Given that access is always to a service, provider or institution, needs are defined as met or unmet, depending on the adequacy of the services provided (Levesque *et al* 2013; Victor, 1991). A need may be determined at individual, group or population level and may be defined as, ‘the ability to benefit from a health or social care service’ (Victor 1991, p. 166). The evidence of capacity to benefit from health services is usually derived from epidemiological and clinical studies, although this research begs the question whether benefit is equitable (McIntyre *et al,* 2009).

In empirical studies, assumptions were often made about levels of needs, and that this opens up ‘a whole host of issues relating to individual choice and inherent healthiness’ (Goddard and Smith 2001 p.1150). While need is an essential concept underpinning access, it is acknowledged it requires further development and consensus (Oliver and Mossialos, 2004; Goddard and Smith (2001).

Candidacy

A problem with some of the access literature discussed above suggests access is often seen as a static concept that makes assumptions that services are standard and human behaviour is predictable. Arising from their review of access for vulnerable groups, Dixon-Woods *et al* (2005) coined the term candidacy to better understand access as dynamic and relational,

> ‘Candidacy describes the ways in which people’s eligibility for medical attention and intervention is jointly negotiated between individuals and health services.’ (Dixon-Woods et al, 2005 p.6).

This important work argues candidacy is an ongoing active process where joint negotiation is influenced by many factors. These factors include interactions with individuals and professionals, staff attitudes, resources, operational and organisational conditions and policy drivers. A corresponding concept of permeability on the supply side was identified to signify the ease with which services can be accessed in relation to candidacy. Highly permeable services require less work for individuals to use the service and there is a lower threshold for candidacy. Conversely, less permeable services need much more work to gain entry and sustain engagement.

Candidacy is useful in identifying enablers and barriers to access from the individual's viewpoint, at each stage of the process. This includes how vulnerable people engage with the service initially and over time, how their needs and eligibility for the service are judged, taking into account the wider service context (Dixon-Woods *et al,* 2005). The concept of candidacy considers both supply and demand sides of access. However, for candidacy to operate effectively equal power relations need to exist between patients and service providers. This may not be possible for those who are vulnerable or marginalised and does not account for wider structural inequalities.

Defining access

From this brief overview, it is clear access has been conceptualized in many ways and the term is contested; with researchers and policy experts asserting access is multidimensional and not easy to define (Goddard and Smith 2001; Levesque *et al* 2013; Dixon-Woods, 2005; Saurman, 2016). Though there is no consensus on the meaning of access, most definitions share common elements. This includes consideration of supply and demand sides of access and the pre-conditions for access, where opportunities for access need to exist (Gulliford *et al,* 2001; Burt, 2010*;* Saurman, 2016).

Table 4.1 presents in chronological order, six frameworks expressed through their definitions of access and corresponding dimensions. With the exception of Penchansky and Thomas' framework, distinguishing features are highlighted in ***bold italics*** in table 4.1 and explored later.

Overview of access frameworks

This subsection provides an overview and critique of each framework presented in table 4.1. Six conceptual approaches are included in the table with four earlier models considered here as they relate more to the supply side of access. The other two frameworks, McIntyre *et al* and Levesque *et al*, are discussed in section B, having adopted significantly different approaches

to address supply and demand aspects. While all these different approaches reflect 'ideal' conditions for access, at the same time they highlight barriers to access. It is important to recognise the context within which these frameworks have been developed, as they may reflect particular health care systems (Goddard and Smith, 2001).

Penchansky and Thomas' (1981) seminal research continues to inform theoretical frameworks of access, through the use of, or adaptations to, their definition and dimensions of access. Typically, this is in the use of the availability and accessibility dimensions, though Saurman's (2016) view is that these are unnecessary distortions, as the dimensions are not being fully utilised.

Table 4.1 Frameworks of access: definitions and dimensions

Authors	Definition	Dimensions
1. Penchansky and Thomas (1981 p.139)	'the "fit" between characteristics of providers and health services and characteristics and expectations of clients`'.	Accessibility Availability Acceptability Affordability Adequacy
2. Gulliford *et al* (2002 p.188) Gulliford (2009 p. 223)	'Facilitating access is concerned with helping people ***command appropriate health care resources*** to preserve or improve health' 'is concerned with the processes of ***gaining entry*** to the health care system'	Availability Utilisation Effective services ***Equity***
3. Goddard and Smith (2001 p.1151)	' the ability to secure a ***specified*** set of healthcare services, at a ***specified*** level of quality, subject to a ***specified*** maximum level of personal inconvenience and cost, while in possession of a ***specified*** amount of information.'	Availability ***Quality*** Costs ***Information***
4. McIntyre *et al* (2009 p.179)	'the ***empowerment*** of the individual to use health care and as a multi-dimensional concept based on the interaction (or degree of fit) between health care systems and individuals, households, and communities'	Availability Affordability Acceptability
5. Levesque *et al* (2013 p.8)	'the opportunity to identify healthcare needs, to ***seek*** healthcare services, ***to reach, to obtain or use*** healthcare services and to actually have the need for the services fulfilled.'	***Approachability*** Acceptability Availability and accommodation Affordability ***Appropriateness***
6. Saurman (2016 p.236)	'The degree of fit between the user and the service, the better the fit the better the access'	***Awareness*** Accessibility Availability Acceptability

		Affordability Adequacy

Penchansky and Thomas

Their conceptualization of access was derived from research, using survey data on patient satisfaction in New York. The findings highlighted the inter-related nature of supply and demand and the multi-dimensional approach required to ensure the fit between providers and patients. The five 'As' dimensions identified as necessary for and integral to their definition of access are:

- Accessibility which is concerned with the location of the service and convenience in time and cost to the service user
- Availability means there are sufficient resources to meet demand for the service
- Acceptability is where the service responds to the social and cultural concerns and attitudes from the perspectives of service users and providers
- Affordability encompasses direct costs, including incidental costs, to service users and providers to make services affordable
- Adequacy refers to service organisation such that it is well placed to receive service users and that they can use the service e.g. referral and appointment systems and service hours, including out of hours provision.

The definition and dimensions seem to have stood the test of time. They offer an inclusive approach to achieve access, as all dimensions, though differentiated, need to be operating in the right way. This framework is not limited to entry and utilization of services (Gulliford *et al,* 2001). Setting out these conditions for access, conveys its complexity and fragility, since these dimensions also highlight where barriers may arise.

Many authors refer to, or have adapted, Penchansky and Thomas' framework, and their dimensions have been used to conduct research to evaluate access (Saurman, 2016). However, there have been some direct and indirect challenges to this conceptualization over time. For instance, it has been criticised as lacking engagement and the role of service users or communities somewhat passive within these dimensions (McIntyre *et al,* 2009; Levesque *et al,* 2013). It is important to reiterate the model was designed in the USA, where health coverage is primarily driven by variable insurance policies, and therefore has limited transferability to the NHS context.

Gulliford et al

Their conceptualisation of access was devised from a scoping study to inform commissioners about future areas of access research in the UK. (Gulliford *et al,* 2001). They posited access could be viewed as either opportunities to 'have access' or to 'gain access' to a service (Gulliford *et al,* 2002). Respectively, this represents supply and demand aspects of access. The distinction between *having access,* whereby the service exists and there is potential for access and *gaining access,* denoting entry to the service and the processes involved. This distinction highlights the conditions necessary for actual access, and where access occurs across a continuum, starting from contact with the service and up to utilisation, providing a means to measure access.

To gain access, the right conditions must be met including giving individuals' access to resources and removing barriers 'to preserve or improve their health' (Gulliford *et al,* 2001 p.6). They assert there are at least four dimensions that need to be considered as part of this definition:

- Availability refers to adequate supply of services so the population can have access
- Utilisation considers organisational, financial and socio-cultural factors which incorporate affordability, accessibility and acceptability of services to enable populations to gain access to services.
- Effective services means gaining access to satisfactory health outcomes through relevant and effective services
- Equity addresses both availability and barriers to access in recognition of different health need and cultural perspectives of population groups to command appropriate health resources.

Gulliford *et al* nest three of Penchansky and Thomas' dimensions under their dimension utilisation of services. This dimension is broad, countering the notion that having access is solely based on the presence of services. Even so their key conclusion is that equity is the most important dimension. This underpins all the dimensions, recognising that fair access should lead to improved health outcomes, evidenced by health inequalities and unequal access for vulnerable groups (Gulliford *et al, 2002)*.

However, they recognise the importance of health care resources in meeting the needs of different population groups, whether access is defined as service

availability, service utilisation or health outcomes. As their research sought to adopt a standardised approach to measure access, by focusing on a particular service, this may be less meaningful for a generalist service, such as district nursing. Their emphasis on utilisation results in a focus on supply side issues and its use as a proxy for access: this is a common criticism of the limitations of such frameworks (McIntyre *et al,* 2009; Goddard and Smith, 2001). In this study of district nursing it seemed important to consider conceptually both supply and demand sides of access.

Goddard and Smith

They devised a general theoretical framework to evaluate equity of access in the NHS, and tested their framework with existing studies. As health economists, they identified a theoretical gap in most empirical studies where equity was measured through variations of a single treatment, contact or a particular service. They acknowledge that access is a complex concept and difficult to operationalise: they also reviewed other equally under developed concepts including, need and demand when formulating their framework. Their definition of access emphasises specificity in what potential service users and providers need in key areas to access the service and would facilitate evaluation (table 3.1). This definition identifies a set of four measures of supply side variations of access:

- Availability of services may vary and there may be insufficient supply to certain groups, services need to be in place before utilization can occur
- Quality of services offered varies between population groups
- Costs may be imposed by health services on different groups
- Information about the availability of services is not equally made clearly known by health services to all population groups

Other frameworks acknowledge the interconnectedness of quality and access, for instance where high levels of utilisation may indicate poor quality service (Gulliford *et al,* 2002). However here, quality and information are essential dimensions only in relation to the supply side (McIntyre *et al*, 2009). They themselves acknowledge that studies of access tend to focus on the supply side through the availability of services. Although Goddard and Smith identify important variations that have potential to address demand aspects other than barriers. However, the framework is inherently focused on the supply side, and though information is an important dimension the accessibility dimension has been omitted (McIntyre *et al*, 2009).

Saurman

Saurman adopted Penchansky and Thomas' (1981) definition of access and five dimensions for her framework of access (table 3.1). From her research of a mental health service in rural communities in Australia, she argued that Penchansky and Thomas' theory is incomplete and identified awareness as a missing dimension. Her rationale for modifying Penchansky and Thomas' framework was that awareness was necessary for both individuals and providers as,

> 'it seems that awareness has become an assumed dimension of health care access. No health care service can be effective if it does not respond to context or if the intended population does not know it exists.'
>
> (Saurman 2016 p.37).

Awareness is more than knowing the service exists, but being able to understand and use this knowledge, and develop health literacy. From her findings, service users were unaware of when and how to use the service, who and what the service is for, and how to share this information. In that sense, Saurman challenges the notion that service use is a sufficient proxy for access and urges consideration of health literacy as essential to empower individuals and providers.

This modified framework builds on and upholds Penchansky and Thomas' definition of access regarding the degree of 'fit' between the patient and the provider. The dual facing aspect of awareness means providers need to be aware of their population and needs as much as patients need to be aware of the service. This dimension is both a supply and demand side consideration.

However, when reviewing other frameworks, Saurman is critical of others who do not use all Penchansky and Thomas' dimensions as intended, where they combine, omit or distort the original conceptualization. Although she accepts the inter-connectedness of the dimensions, it is not clear how this occurs with awareness and the assumed need to maintain awareness. Though she recognised that Levesque *et al* (2013) addressed awareness in their framework of access, she argues that, as awareness does not appear in any part of Penchansky and Thomas's theory it should be a permanent addition to their framework to improve access.

Summary of section A

The four frameworks reviewed above stand on their own and are distinctive, reflecting different contexts in which they were developed or reimagined. Even so there were commonly held features:

- Access is difficult to articulate and there is a need for consensus to develop a common framework to inform research and policy
- Access is a multidimensional concept and there is an inter-relationship between these dimensions
- Most frameworks made reference to Penchansky and Thomas' definition of access, as the fit between individuals and providers and used their five dimensions to develop their own framework
- Supply and demand aspects of access need to be considered, though these frameworks tended to address the supply side. Additional dimensions attempted to re-dress the balance between supply and demand sides
- A common critique of evaluation was utilisation being used as proxy for access
- Most frameworks were informed by research
- The context within which access took place influenced its conceptualisation, particularly regarding the health care system in operation.

Section B Frameworks of access and district nursing

This section reviews the two remaining frameworks of access and how they relate to district nursing: McIntyre *et al* and Levesque *et al*. Both frameworks are considered as they address the supply and demand sides of access, and adopt broad definitions of access. While the context and premise of each framework differs, certain features resonate with district nursing, such as holistic person centred care, which as noted earlier, is historically viewed as the gold standard, and has been incorporated into the professional standards (NMC 2001, QNI, 2015a; QNI, 2015b; QNI, 2019b). Consideration is given to which access frameworks best apply to district nursing and how they have been used in this study.

McIntyre et al (2009)

This framework adopts a more radical approach to access; it shifts towards a demand focus and incorporates consideration of socio-economic inequalities influencing access outcomes. The context for their framework is important, as South African health economists developing an evaluation framework for access in low and middle-income countries.

Their conceptualization of access is multidimensional and focuses on the empowerment of individuals and communities (table 4.1). Defining access as empowerment intentionally recognizes and addresses power imbalances between patients and providers,

> 'access to health care represents the empowerment of an individual to use health care and reflects an individual's capacity to benefit from services given the individual's circumstances and experiences in relation to the health care system.' (McIntyre *et al* 2009, p.181).

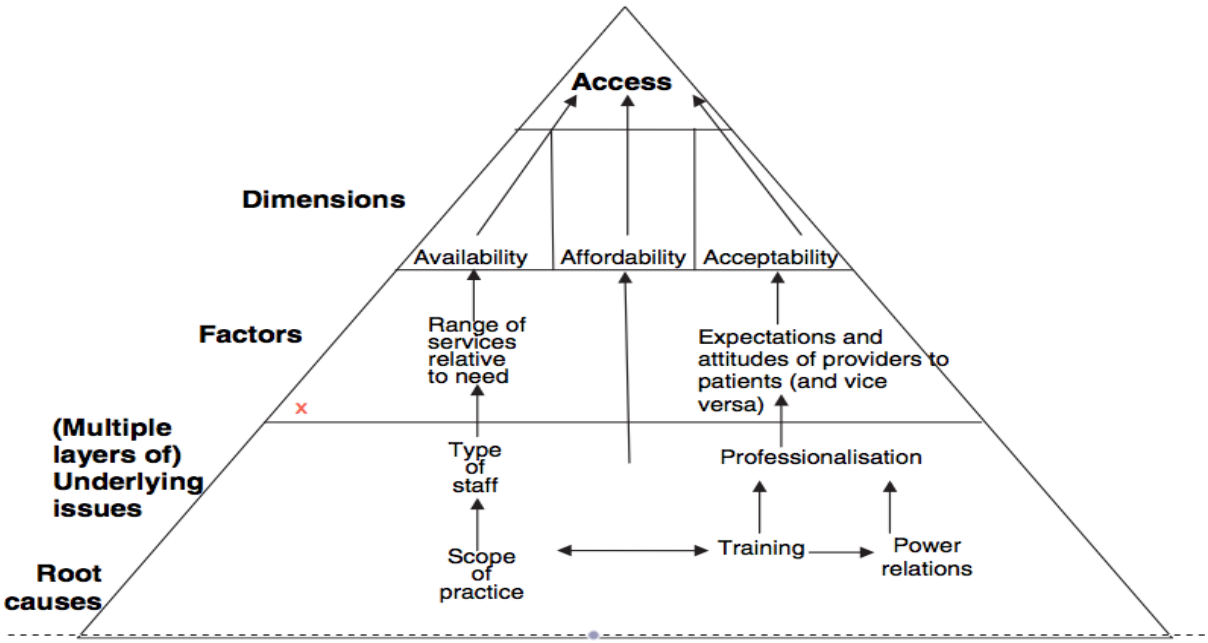
This counters what they view as 'the pervasiveness of the influence of information and power relations on access' in an attempt to balance supply and demand sides of access (McIntyre *et al*, 2009, p.188). Knowledge is an important element of empowerment, in redressing the balance of power between individuals and providers to support or improve access. Empowerment is viewed as a pre-requisite for access and three dimensions have been drawn from Penchansky and Thomas' framework. Each of these dimensions is distinct, but it is the interaction between them which determines the level of access:

- Availability goes beyond the usual definition of time and space to include providers' willingness to adapt services e.g. home visits; service hours; quality, quantity and range of services in relation to health needs to provide comprehensive care
- Affordability includes the full cost to the individual to use services and the individual's ability to pay, considering impact on household budgets, (reflecting demand in their health care system)
- Acceptability considers provider and patient attitudes and expectations, including the efficiency of processes of using the service, from first contact through to referral

Though they keep the spirit of Penchansky and Thomas' definition as the fit between patients and providers, they have adapted some dimensions: combining accommodation, accessibility and availability dimensions to provide a more inclusive availability dimension reflecting, 'the right health services being available in the right place and at the right time' (McIntyre *et al* 2009 p.189). Reducing the number of dimensions is intended to aid evaluation and to understand underlying factors and root causes impeding access. Two themes cut across all dimensions, information and power. The underpinning context of inequality in relation to these dimensions is emphasized as necessary to achieve access.

Figure 4.1 illustrates McIntyre *et al's* framework with the dimensions and underpinning factors and causes. The arrows show the relationship and interplay between causes, factors and dimensions.

Figure 4.1 **McIntyre *et al's* 'Access Evaluation Framework'**



Source: McIntyre *et al,* 2009 p.190 reproduced with permission from Cambridge University Press. Please note only one example has been offered here for availability and acceptability.

The advantage of this framework is that it seeks to address the prevailing focus on the supply side, where utilisation is used as a proxy for access. Further, structural inequalities are acknowledged as preventing empowerment and need to be addressed first. However, this may mean that access remains an aspiration. Though the context and the health care system of this framework differs from the NHS, nonetheless, health inequalities and the need to empower individuals and communities resonates with research and UK policy drivers (Dixon-Woods *et al*, 2005; Goddard, 2009; Marmot *et al*, 2010; Marmot *et al,* 2020).

Their conceptualisation of empowerment, though not defined explicitly, might include the concept of candidacy where individuals, have a degree of health literacy, and can negotiate care with service providers (Dixon-Woods *et al,* 2005). They acknowledge the need for a shift in power relations away from professionals, in defining needs and services, towards patients having a role in shaping services, in recognition of diverse needs and communities. While they acknowledge there is no consensus on the meaning of access, they argue, it is more than the opportunity to use health care services. The limitation of their approach is they do not define empowerment and the framework is untested. As Gulliford (2009) observes empowerment may have multiple meanings and may be as difficult to articulate as access.

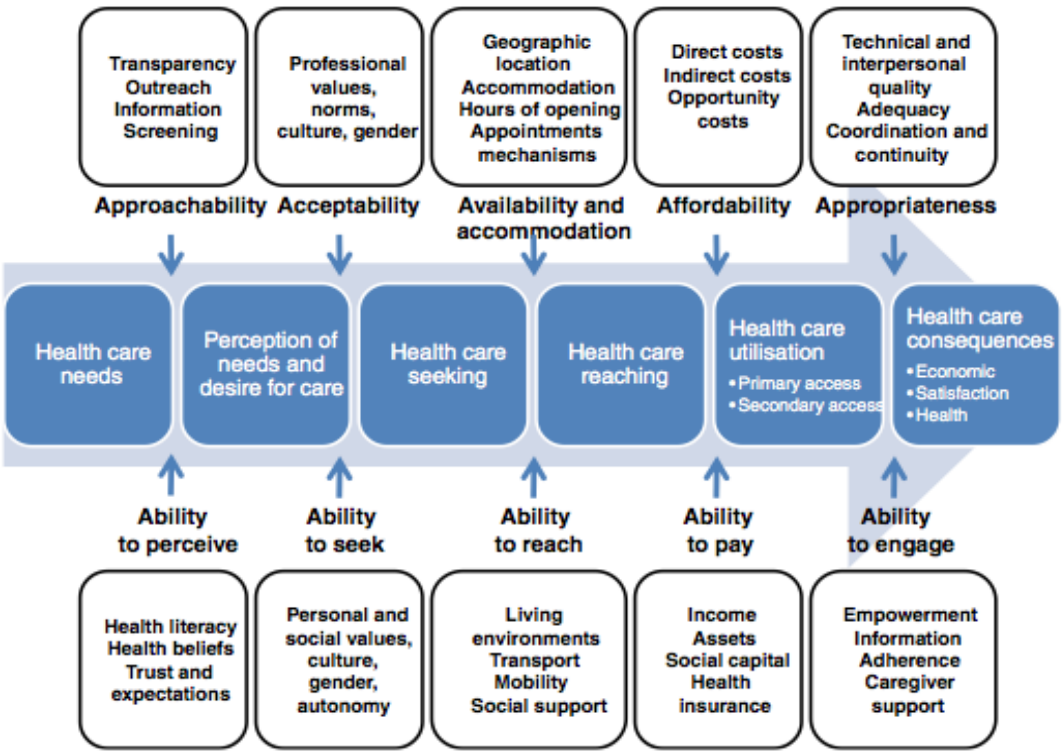
Levesque et al

Levesque *et al's* framework was developed following a synthesis of the research literature. They wanted to produce a conceptual framework that could be operationalized and address supply and demand sides of access. Their broad definition of access encompasses the whole process, from the opportunity to identify health care needs through to having this need fulfilled (table 4.1). The advantage of this definition is that it does not stop at utilization or initiation of care. It makes a distinction between having the opportunity for access and accessibility, which describes the services that provide the opportunity.

Though their framework is based on all of Penchansky and Thomas' dimensions, it has been radically developed under this overarching concept of accessibility, within which five supply side abilities sit. Some of Penchansky and Thomas's dimensions have been combined but the framework has two new dimensions, approachability and appropriateness, and five corresponding demand side abilities (figure 4.2). These dimensions and abilities represent barriers and facilitators to access, operating in a dynamic and potentially cumulative way at each stage in the process (Levesque *et al* 2013).

While their definition of access does not mention Penchansky and Thomas' reference to the fit between providers and patients, it is implicit in the potential for interaction and gaps between these dimensions and abilities.

Figure 4.2 Levesque *et al's* 'Conceptual framework of access to healthcare'



Source: Levesque *et al* (2013 p.5): unrestricted reproduction permitted in any medium as an Open Access article under the terms of the Creative Commons Attribution License.

Access may be seen as the interface between potential patients and providers, reflected in the approachability dimension e.g. providing service information, and the corresponding ability to perceive the service e.g. health literacy. Those supplying the service, as well as those using the service influence access. This may be reflected in the appropriateness dimension e.g. continuity of service and the ability to engage e.g. empowerment. The demand side population abilities reflect a patient-centred framework where patients participate and are involved in their care, reflected in the final ability the 'ability to engage' i.e. treatment decisions (figure 4.2).

Though this framework is untested, they acknowledge that measuring access is complex and that a variety of measures and methods should be used to capture different perspectives. The framework would present challenges for evaluation and seems to be less focused on equity of health.

District nursing context and access frameworks

The following subsection considers both frameworks in the context of district nursing. Features from each framework were mapped to four features of district nursing, and discussed in earlier chapters: 1. Patient-centred care 2. Holistic needs assessment 3. Location of care delivery 4. Partnership working (table 4.2). Consideration is given to which framework better aligns to district nursing.

These features are inter-related and longstanding in district nursing. They are professed to be central to district nursing and have been largely uncontested by the profession. However, to a limited extent, the research and policy literature suggests shortcomings associated with patient centred care and holistic assessment. For example, where psychological support for palliative care patients has not been demonstrated and where the service is seen as becoming task driven (Luker and Walshe, 2010; QNI 2019b). The third area where the literature suggests dissonance between the rhetoric and reality of practice is partnership working. This is a complex area of research across health and social care, but there is some research evidence highlighting district nurses' difficulties in engaging patients in partnership (Cameron *et al,* 2012; McGarry, 2003; McGarry 2008).

1. Patient-centred

As noted before, patient-centred care is viewed as a core tenet within district nursing and it is intentionally tailored to patients' and carers' needs (Maybin *et al*, 2016, QNI, 2015a). Both frameworks focus on what individuals and populations require to access services. McIntyre *et al* centre on empowerment, where individuals are given information and their knowledge of services underpins their ability to get access. This emphasis addresses power imbalances with professionals rather than tailoring needs for a patient-centred approach.

Levesque *et al's* framework declares itself to be patient-centred, and identifies the abilities that individuals and populations need at each stage of the process. Although empowerment is included within the ability to engage, this seems to relate more to negotiation of treatment than feature throughout the framework, although the role of health literacy and information is identified at the start. This framework is purposively mapped to the patient's care journey.

2. Holistic

Holistic needs assessments are understood to be carried out by district nurses, based on a social model of health, taking account of the unique context for patients and families, and revisited as circumstances change (Gough, 2018; QNI, 2019b). McIntyre *et al's* framework is underpinned by recognition of underlying socio economic root causes and factors impeding empowerment and thereby access. As a result, the framework's three dimensions present as supply side considerations and the need for equity. Empowerment as access seems to be limited, as it is framed in terms of patients' expectations of efficient processes, from initial contact with and referral to the service.

Table 4.2 Overview of district nursing and McIntyre *et al* and Levesque *et al* features

McIntyre *et al*	District nursing	Levesque *et al*
1. Patient empowerment - Knowledge -Information	**1. Patient centred** - Needs led - Vulnerable population	1. Patient centred - Population's abilities paired with access dimensions - Barriers and gaps identified - Umbrella of accessibility
2. Broad definition of access - Demand focus - Underlying factors and causes of inequity of access	**2. Holistic needs assessment** - Social model of health - Complex care - Long-term conditions - Maintaining health	2. Broad definition of access - Supply and demand balanced - Process and stages of access are extended - Acceptability: professional values and norms - Ability to seek: personal, social and cultural values; autonomy
3. Availability: range of services relative to need, service hours; home visits, type of staff,	**3. Location of care delivery** - At home - 24/7 service	3. Approachability: transparency; information - Ability to perceive: health literacy; expectations - Availability: service hours - Ability to reach: living environments; mobility; social support
4. Acceptability: expectations and attitudes of professionals and patients - Professionalisation - Power relations	**4. Partnership working** - Nurse-patient relationship - Care planning - Concordance - Carer support	4. Appropriateness: interpersonal quality; coordination and continuity - Ability to engage: empowerment; information; adherence

Comparatively, Levesque *et al's* framework offers a balance between the supply and demand sides, through paired dimensions and abilities. The process of access has a wider scope, represented as stages across the dimensions and abilities. The additional dimensions, approachability and appropriateness are 'bookends' to a holistic view of access, from potential patients recognising their health care needs through to coordination and continuity of the service received and having needs met.

3. Location of care

District nursing care takes place mainly in the home as a 24/7 service (Ball *et al,* 2014). Patients are housebound and vulnerable as the care accessed takes place behind closed doors (Maybin *et al,* 2016). Both frameworks align with district nursing, taking account of service availability in how and where services can be accessed, and service hours. McIntyre *et al* note providers need to be flexible in the location of service delivery, including at home. Levesque *et al's* 'ability to reach' dimension, takes account of diverse living environments, levels of mobility and social support and transport.

4. Partnership working

In district nursing, a partnership approach is expected, from the first contact and assessment, where the nurse-patient relationship may be built, care plans agreed, concordance achieved and support for carers offered (Kennedy, 2002a; Luker *et al* 2009; QNI, 2015). Both frameworks suggest partnership working is necessary for access, and even perhaps candidacy though neither mentions this. For McIntyre *et al,* patients would be involved in negotiating access to resources, reflecting a concern for equity. However, Levesque *et al* capture elements of this practice across their dimensions and abilities.

Both frameworks have unique and complementary features that align with district nursing. Nonetheless, Levesque *et al's* detailed and holistic framework aligns more closely, as their conceptualisation of access is intentionally patient-centred. It also addresses accessibility from supply and demand sides, identifying barriers and enablers and adopting a holistic view of access beyond service utilisation. In defining access as the opportunity to have health needs fulfilled, this aligns with patient care goals within district nursing and this is important where care may occur over a long period of time.

How the theories have been used in the study

The main critique of the frameworks discussed in this chapter is that there is an inherent bias towards supply side considerations of access, augmented by a focus on equity and service utilisation as a proxy for access. Most

frameworks overlook the role of service users as active participants in the decision making around access, which runs counter to the move in the NHS towards greater public engagement and patient participation. To that extent the frameworks appear to be professionally determined and represent the aims and contexts within which they were devised, across different health systems and the actual health services explored. However, each framework highlights particular aspects of access in the way its dimensions are conceptualised, including the power relations between service users and providers, and the important roles of information and health literacy in empowering service users.

No single theoretical framework applied neatly to the context of district nursing, however key aspects of three frameworks have been used to inform the conceptual design of the study and analysis of its findings. First, Penchansky and Thomas' (1981) definition considers the fit between the service user and the service and together with dimensions of access, they have been used further to inform the conceptualisation of access and also data collection. Secondly, Goddard and Smith's (2001) theory has informed the study's mixed methods design, with the need to investigate the supply and demand sides of access, including the role of information about services in providing access.

Lastly, Levesque *et al's* (2013) model, because it was published after data collection commenced, provided a comprehensive approach to analyse the study's findings. This model built on Penchansky and Thomas's definition and dimensions of access but also developed more comprehensively the supply and demand side considerations of access. In relation to the demand side, the development of service users' abilities not only addresses the notion of the 'fit' between the service user and the provider but also addresses deficits in other models regarding demand and where service users appear to be more passive in the process. As Levesque *et al's* model aligned best with the context of district nursing, it was also used to inform a proposed model of access for district nursing drawing on the findings of the study, as explained in chapter eleven.

Summary

Access is elusive and contested. It has been conceptualized in many ways (Goddard and Smith 2001; Levesque *et al* 2013; Dixon-Woods *et al*, 2005). Though Penchansky and Thomas' conceptualization of access remains influential, the lack of consensus and absence of an agreed definition

continue to pose methodological and theoretical challenges for research and policy development (Dixon-Woods *et al,* 2005; Goddard and Smith, 2002).

This chapter explored concepts, definitions and selected conceptual frameworks of access and considered their applicability to district nursing. While there is no single perfect framework, Levesque *et al's* framework emerged as the best fit with district nursing conceptually, and acts as a point of reference for analysis of the study's findings, informing conceptualisation of access to district nursing. The next chapter explains the exploratory, sequential, mixed methods design used in this study.

Chapter five: Methods

Introduction

The previous chapter outlined the conceptual influences informing the study design, which encompassed, a broad definition of access, consideration of supply and demand sides of access and a patient-centred approach (Levesque *et al,* 2013; Goddard and Smith, 2001). They are relevant to the study as they reflect district nursing practice and its claim to offer continuity of care that is patient-centred and holistic, discussed in chapters two and four (Boot *et al,* 2013*;* Chilton, 2018; QNI, 2015; QNI, 2019b).

This chapter explains the methods in three sections. Firstly, it sets out the research questions and context within which the study took place. The second section provides a justification for and explanation of the research design, methodological approaches supporting design decisions, consideration of researcher positionality, and the limitations of the approach taken. Finally, how the research was conducted is explained. Further reflections on the research process and limitations are explored in chapter eleven.

Research questions

i) How do patients, carers, district nurses and health and social care professionals experience access to district nursing in London?

ii) What factors promote or hinder access to district to nursing?

Sub questions

1. How do patients, carers, district nurses and health and social care professionals find out about the district nursing service?
2. What are patients, carers, district nurses and health and social care professionals' perceptions of accessing the service?
3. Who can access the district nursing service?
4. How is the district nursing service accessed?
5. What are the perceived enablers and/or barriers to access?

Context

The timeframe in which the study took place spanned the Coalition and Conservative administrations, with reforms and re-structuring of the NHS implemented in 2013 (Health and Social Care Act, 2012). Commissioning responsibilities for district nursing transferred from PCTs to CCGs. New service delivery models for district nursing emerged. This included mergers between

district nursing providers, with attendant organisational turbulence and staff changes, which had an impact on the study sites.

Overview of the study design

This PhD is an exploratory, sequential, mixed methods study conducted in Greater London, mainly in two providers. As discussed in chapter four, the design was influenced conceptually by two particular theoretical models of access: Penchansky and Thomas' (1981) definition and dimensions of access and Goddard and Smith's (2001) imperative to research both the supply and demand sides of access.

Data were collected in three phases. In phase one, focus groups were conducted with patients and district nurses and semi-structured interviews conducted with carers. In phase two, an on-line survey of district nursing staff and a postal survey of health and social care professionals were undertaken. In phase three, an analysis of web information held on provider websites about district nursing was carried out. The study was designed to permit initial data analysis from phases one and two, to inform data collection instruments in subsequent phases. Analytical tools for the respective methods were used, including thematic analysis, statistical review and content analysis to address the study's aim and objectives presented in chapter one, and the research questions above.

Research design and methodological issues

The drive for robust evidence to inform health and social care practice has been biased historically towards positivism, with special weight given to quantitative research, commonly randomised controlled trials, using large samples and statistical tests to support the reliability and validity of findings (Gomm *et al,* 2006; Avis, 2003; Greenhalgh, 2006; Brown *et al*, 2003). This hegemony is associated with objective testing of hypotheses, establishing cause and effect and generalising research findings that can be translated into formal guidance for clinicians e.g. NICE (Greenhalgh, 2006; Bryman, 2008). A quantitative research paradigm is presented as diametrically opposed to a qualitative paradigm in terms of philosophical underpinnings and methods used (Bryman, 2008).

In a qualitative paradigm, the ontological and epistemological origins assert there are multiple realities and truths, originating from subjective experiences (Bryman 2008, Flick, 2018). They are captured by methods encompassing talk,

text and interaction to produce equally reliable and valid data (Flick, 2018; Gomm *et al,* 2000). By its nature qualitative research, with smaller sample sizes, has been open to critique in terms of validity and generalisable findings.

However, this critique has been challenged, as its intention is not to produce a single generalisable truth, but rather understanding and insight. Validity in qualitative research is demonstrated by the trustworthiness and authenticity of data and data analysis (Braun and Clarke, 2008). Thematic analysis is commonly used to identify and analyse patterns in the data through coding (Braun and Clarke, 2008). Data are broken down and given names, codes, representing meaningful or relevant categories, from which to identify themes (Bryman, 2008; Mays and Pope, 2000). As Saldana (2008 p.4) asserts, 'Coding is not a precise science; it's primarily an interpretive act'.

Theoretical ideas informed the design and analysis of this study, whilst recognising their power to influence 'how evidence is collected, analysed, understood and used…' (Alderson 1998, p.1007). On the other hand, Avis (2003) challenges the need for methodological theory in qualitative research, arguing that it hinders critical reflection between methodological theory and empirical evidence. Nonetheless, these dichotomous ontological, epistemological and methodological traditions were considered when designing the study (Bryman, 2008).

Quantitative design

A quantitative research design was considered for this PhD but not deemed appropriate, as it does not seek to derive a single and definitive source of truth. Using a deductive numeric approach would not enable the first research question to be answered, as participants' experiences of access could not be meaningfully measured numerically (Bryman, 2008). The design would have had to rely on surveys and or experiments to compare participants' experiences (Greenhalgh, 2006). To do this, large samples of participants would have to be recruited to produce generalisable results, and would be costly and time consuming, and unlikely to generate meaningful findings.

A quasi experiment might was considered but rejected as it would have had to recruit patients in need of the service, those waiting to receive it and those receiving it (Gomm *et al,* 2000). This was not considered practicable or ethical (Ibid). However, a pre-coded quantitative survey could identify barriers and enablers to access district nursing, expressed in the second research question.

Therefore, a solely quantitative design was rejected as neither research question was premised on a hypothesis regarding access.

Qualitative design

A qualitative design is suited to the study's first research question to understand how participants' experience access to district nursing. Inductive enquiry underpins qualitative research and would enable the subjective meaning of participants' perceptions of access to be interpreted by the researcher, using a constructionist approach (Bryman, 2008; Flick, 2018).

Research methods, such as interviews, documentary analysis and ethnography, enable subjective data to be collected and interpreted to recognise multiple truths (Flick, 2018; Braun and Clarke, 2008; Bowen, 2009). As Flick (2018 p.317) observed, 'Not every method is appropriate to every research question'.

Alternative qualitative approaches to data collection were considered for this study in relation to the study's research questions. For example, participatory methods were not considered ideal as they require observing the referral process from multiple perspectives. As referrals are episodic and some elements are not capable of being observed, this would only have generated a partial picture. Secondly, as participatory methods are a snapshot in time and observe current practice in social settings, they offer limited understanding of past experiences of access and referral.

Consideration was given to the respective data analysis methods corresponding to the methods selected. For instance, thematic analysis or qualitative content analysis are employed to construct themes and produce meaningful statements (Flick, 2018). Thematic analysis has been criticised for its lack of transparency in generating themes, though themes are always derived from the data, 'Where themes come from in qualitative research is sometimes a mystery.' (Gomm *et al* 2000, p.253). However, using Braun and Clarke's (2008) staged process explains how themes have been generated. While a qualitative strategy was chosen, it was not wholly appropriate in addressing the second research question which seeks to discover factors promoting or hindering access to district nursing.

Mixed methods design

As neither quantitative nor pure qualitative methods were ideal to investigate the research questions, it was decided to combine the best of both through a mixed methods design (Greenhalgh, 2006; O'Cathain *et al,* 2007). Although both paradigms have distinct philosophies and methods, a mixed methods design draws on strengths (Mays and Pope, 2000; Bryman 2008; Crossan, 2003). In this study using an 'equal but contrasting partners' approach, where there is no hierarchy between these different methods, enables the sequential application of contrasting methods during different phases of a study (McDowell and MacLean1998, p.18).

The popularity of mixed methods designs may reflect a move away from purely deductive methods and a medical model of health towards the acknowledgement of the legitimacy of patients' experiences, as 'experts by experience' (Cameron *et al* 2012; Hogg, 1999; Skinner, 2018). In district nursing, such a social model of health takes account of the locus of care and incorporates individuals' perceptions of their health and wellbeing (Gough, 2018; Baguley, 2018; QNI, 2019a). Further, district nurses work in partnership with patients and carers and such interactions lend themselves to interpretive inquiry (QNI, 2019a; Goodman *et al,* 2005; Jaye, 2002).

Justification, rationale and features of mixed methods research design

For the reasons set out above, an exploratory, sequential, mixed methods study design was adopted. Contradictions and tensions arising from opposing ontological and epistemological positions and methods were acknowledged. However, this design drew on strengths from both traditions to address the study's aim, objectives and research questions (Bryman, 2008; Brown *et al,* 2003, Creswell, 2011). Incorporating multiple perspectives was an important driver for the design, and reported as a gap in previous studies (Walshe and Luker, 2010). The design enabled complementary methods to be used for data collection and analysis, providing a more complete picture and potential for triangulation (Bryman, 2008).

Three forms of data collection methods were employed. Firstly, focus groups and semi-structured interviews were used to gain rich detail, revealing any common and shared understandings about access and how this is understood and interpreted by patients, carers and district nurses (Bryman, 2008).

Secondly, surveys of district nursing and health and social care staff were designed to capture knowledge of the district nursing service, its referral criteria and methods. On-line surveys were planned because they offer faster,

cost effective and potentially easier access to sample populations (Toepoel, 2016). Lastly, documentary analysis of service information held on providers' websites, was conducted as 'data beyond talk' and recognising, 'Documents represent a specific version of realities constructed for a particular purpose.' (Flick 2008, p.380).

Sequential phased recruitment and data collection were important aspects. Initial analysis was designed to inform data collection tools and research instruments in later phases. Focus group and interview data contributed to the development of the survey instruments and questions for website appraisal. The surveys also informed website appraisal questions providing a means to review their content. This facilitated appraisal of the nomenclature and language used for key terms, for instance what the service was called, and concepts, such as self-referral or being housebound (Flick, 2018). Therefore, using both qualitative and quantitative methods was intended to offset some of their inherent limitations, and strengthen the overall design.

It follows that these methods required appropriate data analysis approaches (Bryman, 2008). Three approaches were used: thematic analysis for focus groups and semi-structured interviews, statistical analysis for the surveys and content analysis for websites. Thematic analysis is one of a number of qualitative approaches, though like qualitative data analysis in general, the process can be complex as there are large bodies of data and there are no accepted rules to guide implementation (Bryman, 2008).

Braun and Clarke's (2008) model of thematic analysis was adopted for three reasons. Firstly, it is a theoretically flexible analytic method, being independent of theoretical constraints that can be applied across a range of research questions and theoretical frameworks, including constructionism (Braun and Clarke 2013, p. 121). Secondly, rigour in generating themes can be demonstrated through a systematic and transparent approach using its six phases to guide the analysis. They acknowledge themes are defined, having been constructed by the researcher, rather than being discovered or emerging (ibid). Thirdly, they developed a set of criteria as a checklist to identify good thematic analysis.

The design constructed for this study has sought to demonstrate consistency between its aim, questions, methods and the researcher's social constructivist stance as this '…is the essential underpinning and rationale for any study' Proctor (1998, cited in Crossan, 2003 p.48).

Limitations of a mixed methods approach

Alternative qualitative approaches to data collection were rejected in favour of semi-structured interviews, focus groups and documentary analysis to answer the research questions. However, it is recognised these methods too have their limitations.

A comparative advantage of participatory approaches means more time is spent with participants and a greater understanding of the context and language can be gained. There is less reliance solely on what is being said as behaviours are observed. On the other hand, interviews and focus groups rely largely on verbal responses, although some body language and interaction in focus groups are noted. Even so, a wide range of issues do not lend themselves to observation and asking participants to describe and reflect is often a preferred way to find out individuals' experiences and explore perceptions of certain phenomena Bryman, 2008; Flick, 2018). For this reason, ethnographic studies frequently include interviews. A participatory approach to data collection would also require more time and resource, which was not feasible for this study.

Limitations of the focus groups and semi-structured interviews methods include: inadequate recruitment, poor engagement, researcher bias, through for example leading questions or ignoring 'unfavourable' responses, and a lack of rigour in data analysis. Two main pitfalls associated with surveys are poor question design and inadequate response rates. For this reason, careful testing and refinement, included independent review of questions for the interviews and surveys, and pilot studies were undertaken. Survey response rates should be sufficient particularly where statistical tests need to be applied as proof of correlation, for example.

Although, recruitment to the interviews, focus groups and surveys was a challenge, largely due to not having direct access to potential participants, this led to different strategies and contingencies being employed in mitigation. While there are limitations in the study's design and methods selected, the strength of mixed methods provides potential to compare, contrast and interrogate findings and to offset some of the disadvantages of using a single method.

Positionality

I have a background in district nursing which provides some advantage in understanding the service context and language used by district nurses. At the same time there is a risk of over identification and potential for bias or assumptions about meaning. However, although I have practised as a district nurse in the past, I have other identities as a social scientist, academic and higher education manager. I would argue my more recent experience as an academic manager and scholar has honed my skills in an interpretivist approach, enabling me to explore multiple perspectives in the design, data collection and analysis of the findings.

However, like all research, there is never such a thing as an entirely neutral stance. For this reason, safeguards were put in place to ensure transparency of all research decisions and to reflect on potential bias, with the intent of ensuring rigour, credibility and authenticity regarding data collection and analysis. Selection of the most appropriate and feasible data collection methods that best addressed the research questions as well as rigour in data analysis were essential. As explained in the final section, independent cross checking was undertaken for data collected, including the transcripts, pilot studies and websites.

Patient involvement in research design

It is good practice and increasingly expected to involve patients in research design, reflected in principle four of the NHS research policy framework (NHS Health Research Authority, 2020). This ensures service user perspectives are included, power imbalances are redressed and co-production is fostered both in service and research design (INVOLVE, 2020; Crocker *et al,* 2016; Smith *et al,* 2005). Arguably, it is even more important to involve 'hard to reach' and more vulnerable patient groups, such as those who are older, sicker and housebound, and where service provision is less open to direct scrutiny, all of which apply to district nursing.

For this study, it was not practicable to involve patients and carers in the design: partly due to the scope of the PhD, with time constraints and difficulty in accessing patients and carers when designing the study. The intention was to conduct the research in and through NHS providers however, it proved hard to reach patients and carers using this route. Nonetheless, the focus on understanding experience meant patients' and carers' voices were central. Secondly, the phased sequential design enabled patients' and carers' responses to influence data collected in the surveys and websites.

How the research was conducted

Study sites

The study was conducted in London, based on convenience as there were many district nursing providers and I live and work in London. At the start of the study, there were three study sites included, consisting of three co-terminous PCTs operating respective district nursing services. In 2012 two PCT sites merged with an acute Trust to become an Integrated Care Organisation (ICO), with a single district nursing service for the same two local authorities.

Following NHS restructuring in 2013, the third PCT site was replaced with a Foundation Trust (FT) because of a lack of response and extensive organisational change (Health and Social Care Act, 2012; DH, 2013). The large FT provided district nursing to four local authorities, the district nursing service for one of its four local authorities became the study site. Study sites were selected based on convenience sampling and variations in deprivation in the populations within and between the sites (GLA, 2016; Lesser, 2016).

The respective GP practices, residential care homes and two general hospitals located within these study site boundaries were included as they were likely to engage with these district nursing providers.

Ethics and Research and development approvals

Ethics approvals were gained from the University and NHS research ethics committee prior to data collection (appendix 1). An amendment to ethics approval was obtained to change the data collection method for carers from focus groups to include semi-structured interviews (appendix 1).
Local NHS Research and Development permissions were gained to conduct the research in the original three NHS sites. Approval was sought and gained to include the FT and re-approval was also gained for the ICO when the original approval ran out.

Ethical considerations

The study conformed to ethical principles of health and social care research and social research (NHS Health Research Authority, 2020; Academy of Social Sciences, 2015). The exception was involving patients in research design discussed earlier. A participant information sheet was supplied to all focus groups and interview participants (appendix 3). It stated the purpose of the research, how to withdraw from the study, the complaints procedure and contact details. The information was also read to participants prior to the start of the focus groups and interviews. Confidentiality and anonymity was

assured: participants have been given pseudonyms in this thesis and any information, which might compromise anonymity modified or omitted.

All participants were given a copy of the consent form (appendix 4). Informed consent was obtained from all participants by the researcher prior to interviews. Most participants signed consent forms, except for those with sight problems and telephone interviews where verbal consent was obtained. For the surveys, participant information was provided with the self-completion questionnaires, electronically or in writing, with contact information. No separate consent was requested, participation was voluntary, and return of the questionnaire implied consent.

The ability of vulnerable patients and carers to give consent was identified as a potential ethical concern, as the initial recruitment strategy involved district nurses making suitable patients and carers aware of the study. District nurses were asked to give them an introductory letter and participant information sheet so that those interested could contact the researcher directly (appendix 2). District nursing staff were not required to recruit participants or gain informed consent. Even so, staff, patient and carer anonymity could be compromised and patients and carers might have felt unable to decline participation. It was also highlighted in the information that any poor or dangerous practice would be reported to a named staff member.

The interview questions were not in themselves sensitive or intrusive, but might have potentially triggered upsetting memories or emotions (appendix 5). Support had been agreed with the local collaborators should participants become distressed. Some carers reported they found the interview cathartic and perhaps provided some closure where the care recipient had died.

To encourage participation in the postal survey, a separate free prize draw ticket for a £50 John Lewis voucher was included, to be returned with a completed questionnaire. Incentives have been shown to increase participation in postal surveys (Pforr, 2016). Due consideration was given to research ethics principles: participation was voluntary, the incentive was proportionate and the researcher did not know any participant.

Data collection methods

Data were collected sequentially in three phases using the following qualitative and quantitative methods:

i) Focus groups conducted with patients and semi-structured interviews conducted with carers to understand their experiences of and preferences for access to district nursing
ii) Focus groups conducted with district nurses to understand referral processes and factors that impact access
iii) Surveys conducted with district nursing staff via an online survey and a postal survey of health and social care professionals who made referrals to the service. Both surveys sought to discover how the service is accessed, the referral criteria and methods and factors influencing access
iv) Content analysis of web-based service information supplied on district nursing providers' websites, to appraise ease of access, availability of information, for whom and any information gaps regarding access to district nursing.

Target population

The target population comprised four groups i) patients ii) carers iii) district nursing staff iv) health and social care staff.

Inclusion criteria

i) Patients receiving or who had received the district nursing service for three months or longer, who could travel - with support - and were capable of participating in a focus group discussion.
ii) Carers who provided informal unpaid care to care recipients who were receiving or had received the district nursing service for three months or longer, who could travel - with support - and were capable of participating in an interview
iii) District nursing staff employed in the service in the study sites
iv) Health and social care staff: GPs, practice nurses, hospital ward managers, residential care managers and adult social care social workers, working within the study sites' boundaries
v) Provider websites in London representing a range of providers by type, size, geographical spread and local authority deprivation scores for older people

Exclusion criteria

i) Patients who are acutely ill or more vulnerable, cannot give informed consent or are unable to participate in a focus group
ii) Paid carers who are employed directly or indirectly by care recipients
iii) District nursing staff working outside the study sites

iv) Health and social care staff working outside the study sites' boundaries

v) Provider websites outside London

Sampling strategy

A purposive sample was used for focus groups with patients and district nurses and interviews with carers based on convenience and the inclusion criteria. Probability sampling was used to survey district nursing staff and those health and social staff making referrals to the service. Purposive sampling was used to select websites from a range of different district nursing providers in London, including both study sites (appendix 12).

Sampling Frame

The sampling frame for the district nursing survey was based on staff databases held by both providers. For the health and social care staff survey, databases were constructed from publically available web data for GP practices, hospital wards for two general hospitals, residential care homes and adult social service departments in the respective provider sites (table 5.1). The subgroups were different sizes in each site.

Table 5.1 Sampling frame

Subgroup	Sample size
District nursing staff n=73 (ICO) n=70 (FT)	143
GPs n=78 (ICO) n=47 (FT)	123
Practice nurses n=78 (ICO) n=47 (FT)	123
Care home managers n= 60 (ICO) n=74 (FT)	134
Ward managers n=24 (ICO) n=29 (FT)	53
Social workers n=0 (ICO) n=19 (FT)	19
Total	**595**

Recruitment strategy

The target population was accessed through local research collaborators and managers. Different recruitment strategies and contingencies were used for each group, as accessing the respective participants groups was not straightforward.

District nursing recruitment

The Trust intranet was used to raise awareness of the research and encourage participation in focus groups: the research collaborators forwarded an email from the researcher, although, there were no responses to this. In parallel permission was sought to attend staff meetings to promote the study and encourage participation. Letters of invitation were left with staff to share with

patients and carers. This method led to one district nursing focus group. A further presentation was made to a Trust wide research event but this was poorly attended by district nursing staff.

During this period, 2011-2015, there were many staff changes and slow responses. Further negotiations with a senior manager led to another district nurse focus group. In addition, meeting two senior district nursing staff at a QNI conference, who became named collaborators via new research site approval and re-approval, led to two further focus groups.

Patient recruitment

The original recruitment strategy of asking district nurses to pass the study details to patients was unsuccessful. Alternatively, day centre managers were approached to recruit patients. After some abortive attempts, including unsuitable participants being recruited, two focus groups were held in a local authority and voluntary sector day centre. This strategy led to the inclusion of a patient who had not yet received the service, which would not have been possible if recruiting from district nurses caseloads.

Carer recruitment

As for patients, the original recruitment strategy for carers was to ask district nurses to pass on the study's details. Only one carer responded but at that time the intention was to hold carer focus groups so they were not interviewed. Alternatively, carer support groups were approached and three responded. One was an NHS carers support group and two were voluntary sector agencies. They were located outside the revised study site boundaries. The researcher visited the NHS group and recruited two carers while managers in the other centres recruited the rest of the carers.

Carers, however, though keen to participate, found it difficult to attend focus groups due to caring demands and time pressures. They requested telephone interviews leading to an amendment to ethical approval (appendix 1). Recruiting carers became easier once telephone interviews were introduced. One carer, whose care recipient had not received the service, would not have been recruited from district nurses caseloads.

District nursing survey

Local collaborators in each provider unit sent all staff an email via their respective intranets asking district nursing staff to participate in the online survey with the link to the self-completion questionnaire.

Health and social care professionals' survey

There were challenges in trying to distribute the online survey, as the researcher had no access to email addresses and it was difficult to get responses to requests. The CCG collaborator would only send the information and link in a monthly newsletter emailed to GP practices. After three months, only one practice nurse had completed the survey. As a contingency, the survey was converted to a postal survey, using publically available contact details, bypassing the need for intermediaries, and posted directly to the relevant organisations.

Selection of websites

Seven provider websites were selected from sixteen providers that supply district nursing to thirty-two London Local Authorities and the City of London (appendix 12). Providers vary in size, type of organisation, geographical area covered and relative deprivation of their populations. Of these sixteen, seven provide the service for one London local authority, a further seven supply two local authorities, one provider supplies four and the final provider supplies seven local authorities.

The district nursing service is co-terminous with each local authority boundary and all providers are NHS Trusts, except for one social enterprise. The NHS providers are diverse and include foundation, mental health or community health trusts. Some local authorities particularly those in inner London have high indices of deprivation (Lesser, 2016). The seven providers selected represent this range and collectively they provided district nursing to nineteen local authorities, over half of London local authorities. One local authority per provider was used to test the provider's site (table 9.1).

Design of the research instruments

Interview schedules were drawn up for the focus groups and semi-structured interviews (appendices 5 and 6). Each had three sections: general information about the service, accessing the service and future aspirations for the service. It was intentional to have similar questions to capture different perspectives and experiences of access from patients, carers and district nurses. Interview schedules were tested with two colleagues, a district nurse and public health specialist, for sense checking and the clarity and ordering of questions (Flick, 2018).

Surveys were designed for district nursing staff receiving referrals, and health and social care professionals making referrals. The self-completion questionnaires were almost identical as the purpose of the surveys was to

discover what respondents knew about the service, referral criteria and process in regards to barriers and enablers to access (appendices 7 and 8). Both surveys were designed for online delivery. Web survey software packages, for which the researcher's university held licenses, Bristol Online Surveys (BOS) and SurveyMonkey were used to design, test and practise set up.

The original surveys were designed using BOS, with 80 items and a predicted completion time of twenty minutes. This was too long and questions about service quality were removed to focus on access. Survey questions were further adapted to reflect an initial analysis from phase one to include questions about finding out about the service, contacting the district nurse, self-referral and being housebound.

The survey was streamlined to make it easy for time-poor practitioners to complete, and SurveyMonkey was used as it had a simpler layout using a linear multi-choice format. Radio buttons permitted a single response for closed questions (Toepoel, 2016). All questions required a response except the final open question. The postal version of the questionnaire, introduced for health and social care professionals, followed the same design as the on-line version.

The online questionnaires were tested by the researcher's supervisors (FR, NG) and took ten minutes or less to complete. The final pre-coded questionnaires, used in the pilot studies, had fourteen closed and four open questions each. Having almost the same questions in both questionnaires enabled comparisons between district nurses' and health and social care professionals' responses.

Website analysis of seven providers' web content about district nursing involved constructing a framework of ten questions to appraise accessibility and clarity of access information (chapter 9 box 1). This framework enabled consideration of the 'fit' between the service and service user, and supply and demand sides of access (Penchansky and Thomas, 1981; Goddard and Smith, 2001). The framework enabled analytical focus on web content, particularly nomenclature and organisation of information, its meaning and intended purpose rather than design or graphics (Scott cited in Flick 2018, p.379). Design is particularly relevant for older, disabled people and the digitally challenged, but this was beyond the scope of this study (MFKK, 2011). This framework of questions enabled each site to be reviewed systematically individually and to facilitate comparisons between sites.

The framework was informed by two sets of criteria. First, the Government's 2016 Digital Service Standard (GDSS): this standard has 18 criteria 'to create and run good services' (Gov.UK, 2016). Two of these criteria were particularly relevant for website appraisal: 'understand user needs' and 'make sure users succeed first time'. While users' needs were not asked about, the preliminary analysis of findings from phases one and two informed the questions, in particular where patients, carers and health and social care staff reported a lack of service information or difficulty finding it. Second, Dalhousie University's criteria for website research also informed the questions particularly, authority; purpose; coverage; currency and accuracy (appendix 13).

Pilot studies

Two pilot studies were undertaken to validate the on-line survey instruments (van Teijlingen and Hundley, 2011). The district nursing pilot study was conducted first. The information and link to the questionnaire was sent by email by the research collaborator to six district nurses, who had taken part in a focus group in one provider site but excluded from the main survey (van Teijlingen and Hundley, 2011). This enabled non-respondents to be followed up relatively easily and five responded over a three-week period. Two issues emerged i) the survey did not work well using Chrome and Explorer as browsers, although this was checked during pre-testing (Toepoel, 2016) and ii) a question was needed to enable a distinction between responses from each site.

The pilot study for health and social care staff was amended to include a further question to ask what part of London they worked in. GPs were targeted as they formed the largest single group of health and social care professionals who made referrals (McHugh *et al,* 2013). The survey information and link was sent to six senior GPs who served on a CCG in one study site. There was no direct access to the GPs and a collaborator in the CCG facilitated the pilot. Several follow up emails and calls to the collaborator yielded only two responses but no further adjustments seemed necessary. It was not possible to know if these GPs participated in the main survey. The final survey consisted of nineteen questions: fifteen closed and 4 open questions (appendix 8).

Data collection

Data were collected sequentially in each phase: phase one occurred between 2011-15, phase two between 2017-2018 and phase three in 2019. Six focus groups were conducted, two with patients and four with district nurses. Seven semi-structured interviews were conducted with carers, three of which were diploid. Survey data were collected from an online survey of district nurses and a postal survey of health and social care professionals. Data were collected from seven provider websites. An overview of all data collected in each phase is presented in table 5.2.

Data collection was considered complete at the end of each phase and prior to the start of the next phase. Data sufficiency was determined by a number of factors, methods used and if the analytical methods could be used effectively across the data corpus. Continuing data collection 'just in case' if additional data could not be used, was ruled out on ethical grounds (Carlsen and Glenton, 2011). The duration of each phase also signaled data sufficiency where the end of one phase led to the start of another.

Table 5.2 Data collected across all phases

Phase	Data collection completed	Data collection methods	Number of participants/ Sample size
One	2015	Focus group district nurses x 4	19
		Focus group patients x 2	10
		Diploid interviews with carers x 3	6
		Semi-structured interviews with carers x 4	4
Two	2018	Survey of district nursing staff	143 (sample)
		Survey of health and social care staff	253 (sample)
Three	2019	Documentary analysis of providers' websites	7 (sample)

Phase one

Focus groups: the change of administration occurred after data collection commenced. Two of the four district nurses' and one of the two patients' focus group interviews were completed before the study sites were revised (table 5.2). Each focus group comprised between three to six participants. These interviews took place in meeting rooms in neutral, accessible venues familiar to participants: health centres for district nurses and day centres for patients. All focus groups lasted up to an hour and half, and were facilitated by the researcher.

Semi-structured interviews: It proved difficult to conduct focus groups with carers, because of the unpredictable demands of caring. This led to last minute postponements or no shows resulting in three diploid interviews i.e. pairs of respondents. Telephone semi-structured interviews were conducted instead. All interviews were pre-arranged at a time convenient to the respondents. Diploid interviews were conducted in two carers' centres and an NHS building. All interviews were conducted by the researcher and lasted up to an hour.

Phase two

Both surveys were conducted in two study sites, comprising two district nursing providers across three local authorities. One provider was a FT serving an outer local authority in east London and the other an ICO serving two inner local authorities in north London. The focus group interviews with district nurses and patients were conducted in these providers, and the findings informed the survey questions, including questions about self-referral and being housebound. Both questionnaires had fifteen closed and four open questions. Almost all questions were the same to enable comparisons between the responses of district nursing staff and those making referrals (appendices 7 and 8).

The district nursing survey was administered online and a postal survey was administered for health and social care staff. Both surveys were intended to be online but this changed following difficulties accessing potential health and social care respondents. The local district nursing research collaborators emailed district nursing staff and sent the explanatory information and the link to the questionnaire, using the respective providers' intranet. The online survey required responses for all questions, except the last open question (appendix 7). Due to firewall security in the FT provider, district nursing staff reported they were unable to fill in the survey. Adjustments were made, including embedding the survey in email. The survey remained open for four months and collaborators sent reminders to staff (table 8.1).

The postal questionnaire was sent to professionals in health and social organisations most likely to make referrals to the district nursing service in the respective providers. This included GPs, practice nurses, residential care home managers, hospital ward managers and social workers in adult care (table 8.2). Each envelope included a covering letter, self-administered questionnaire and pre-paid return envelope. A separate free prize draw ticket was included to be returned with a completed questionnaire to encourage

participation. Compared to the on-line version, respondents could see all the questions at once, answer questions in any order or not answer all questions

Databases were constructed from on-line sources for these organisations and addresses accessed. All general practices were included, the survey was sent to the senior partner, and sent separately to practice nurses in the same practices. All wards in two hospitals and all care homes within both study sites were sent a questionnaire addressed to the ward manager or care home manager respectively.

Despite numerous attempts, there remained difficulty in accessing social workers in two local authorities in the ICO. It was not possible to find a contact willing to facilitate circulation of the questionnaire and confirm the number of social workers working in adult social care. A questionnaire was sent addressed to a social worker in each authority with no response. A follow up contact in the third local authority provided information to facilitate the survey in the FT.

Phase three

Websites: Web based information about the district nursing service was collected from seven provider websites over a period of a week. The providers were diverse and represented different types of NHS trusts, foundation, mental health, community health, integrated care organisations, and a social enterprise. Screenshots were taken of all web pages directly relevant to district nursing access in each provider (appendix 14). This was necessary as information can change quickly on the web and sites can disappear. Hard copies of additional information embedded on webpages, such as pdfs, were also included (appendices 15 and 16).

Data recording

The focus groups and semi-structured interviews proceedings were digitally recorded, with some field notes recorded. All data from interviews were fully transcribed (appendix 9). Data about participants' profiles were not systematically collected, these data were constructed from what was observed or revealed in the interviews and from the data transcripts. On-line survey data were held electronically and the postal survey data were transferred to Google Forms.

Data storage, management and data protection

All data were stored securely at London Metropolitan University and at home: in locked cabinets and offices and/or on a double password protected staff

drive on a secure server and Box. Data were organised into folders by chapters, all file titles were dated to ensure version control and inactive files placed in archive folders. As a backup, the draft email function was used to store active files securely as attachments. Data will not be released to a third party and will be handled in compliance with data protection and security requirements. All sound files will be destroyed 12 months after completion of the study.

Data analysis

Phase 1

Thematic analysis was used for the focus group and semi-structured interview data to find patterns in the data. Braun and Clarke's (2008) staged inductive process was used to search for and generate themes systematically, reflected in the following headings (Braun and Clarke, 2008). Fourteen interviews were transcribed verbatim, with initial comments made in the margins (appendix 9). The transcripts were set aside during the survey collection period. Prior to coding, all transcripts were re-read as a whole data set, ignoring the margin comments to become familiar with the data. Each data set was then systematically coded manually, exploring each line to identify areas of interest and what appeared significant in relation to the main research questions and sub questions.

Generating initial codes

Codes were drawn from the data extracts to classify meaningful categories and of relevance to the research questions (Braun and Clarke, 2013). Coding was carried out electronically using the notes function in Microsoft Word for each transcript (appendix 10). Data analysis software was considered; the advantages include organising and searching the data, but its weaknesses indicate the software cannot structure the data or make links with theory (Pope *et al,* 2000). However, the Word function permitted codes and data extracts to be viewed in context and could be searched easily, although it was not possible to see all codes across the data set.

Data extracts were coded more than once, reflecting the richness of the material and where they held different emphases or contributed to other recurring patterns (Hatch, 2002 cited in Saldana, 2008 p.6). The entire data set was coded being data driven rather than theory driven (Braun and Clarke, 2008).

Once all transcripts were coded, three separate Word documents for patients, carers and district nurses were constructed where the codes and data extracts were collated. One supervisor (FR) reviewed a sample of 15% of the coded transcripts for reliability. Usually 10% of the total content is considered sufficient to test inter-coder reliability (Mouter and Noordegraaf, 2012; Gomm *et al,* 2000). A composite matrix of all three documents was constructed to organize the whole dataset. This matrix framework had 150 pages of codes and data extracts, from which common and recurring concepts, themes and sub themes were identified and synthesized (appendix 11).

Searching for themes

The codes were reviewed for repetitions, similarities and differences, use of metaphors and where data were missing (Ryan cited in Bryman, 2008, p.555). The data were organised into meaningful categories with further degrees of abstraction (Gale *et al,* 2013). Attention was paid to recurrence of ideas and themes to identify what was dominant or in someway anomalous. All codes were reviewed and labelled with initial themes. As this process progressed recurring patterns and terms emerged from the data set for example, *communication*.

By the end of this initial process there were 22 themes - labelled alphabetically (a-v). Five of which were named as initial main themes with the remainder considered as subthemes. Each subtheme could relate to more than one main theme e.g. *continuity* could relate to *communication* or to *quality*. Searching for and defining themes is an iterative process and table 5.3 provides an overview of the phases (Braun and Clarke, 2008).

Reviewing the themes

At the start of the process, it seemed that all initial themes were shared by patients, carers and district nurses (columns 1 and 2, table 5.3). However, reviewing themes several times for recurring ideas and patterns enabled them to be grouped into higher levels of abstraction with three main themes named (table 5.3 column 3).

There were differences between these abstractions for patients and carers as one group and district nurses as another. The strength of themes and subthemes were mapped by frequency in relation to each group. So even where similarities occurred they appeared to have different emphases as well frequency.

Defining the themes

There was a need to manage and reduce the number of themes further so that the analysis of data could be managed in a coherent way. This had to be balanced with ensuring important themes and data were not lost.

Following further refinement of the main themes (table 5.3 column 4) two themes were defined for each group (table 5.4). The **control** theme appears to be shared by both groups but is defined differently as it reflects different underpinning concepts and patterns traceable back to the original coding (table 5.3).

Table 5.3 Overview of the phases in defining the themes

Initial themes	Initial main themes	Refining the main themes	Final main themes
Shared across groups a. Continuity b. Contacting the district nurse c. Information about service d. Referral e. Workload and staffing f. Quality of service g. Just turn up h. Expectations of service i. Time j. Understanding of service k. Role of DN l. Delay getting help m. Needs n. Communication o. Giving up/ acceptance p. Impact on carer q. Technology r. Security and safety s. Housebound t. Development of service u. Commissioning v. Training	***Shared across groups*** Communication (b, c, n) Referral process (d, q, s) Expectations of the service (g, h, j) Quality (a, f, i, l, o, p) Role of the district nurse (e, k, m, r, t, u)	***Patients and Carers*** Control of the district nursing service (c, d, e, k, m, n, r, s) Expectations of the service (a, b, f, g, h, i, j, l, o, p) ***District nurses*** Service designed around access (q, t, u, v)	***Patients and Carers*** Expectations of the service (a, b, f, g, h, i, j, l, o, p) Control of the district nursing service (c, d, e, f, k, l, m, n, r, s) ***District nurses*** Control (a, b, c, d, e, f, g, h, i, k, l, m, n, o, r, s, t, u, v) Appropriateness of referrals (c, d, e, f, h, j, k, m, n, q, r, s, u)

Table 5.4 Final themes and subthemes by group

Patients and carers		District nurses	
Expectations	***Control***	***Control***	***Appropriateness of referrals***
Expecting help *Expecting direct access* *Expecting a consistent service*	*Visibility of the service* *Influences on service availability*	*Visibility of the service* *Autonomy* *Organisational influences*	*Self referral* *Being housebound* *Receiving referrals*

Phase 2

For both surveys, data were available in electronic forms, as SurveyMonkey and Google Forms. All data from the postal survey were transferred to Google Forms. Statistical packages, such as SPSS, were not used to analyse the data, as there were insufficient data to apply statistical tests, due to a low response rate (Bryman, 2008). However, descriptive statistics were used to analyse the results for the closed questions based on frequency, expressed to the nearest whole number (Barnett, 2018). Results from closed questions were largely binary, however the analysis included selectively negative results where participants lacked knowledge about the service or where there were significant differences between participants in each survey, highlighting potential impact on referral practice. Themes were defined from the open-ended questions, based on frequency and important exceptions. Some respondents to the postal survey annotated closed questions providing additional explanations, which were addressed with the open questions.

Phase 3

Website content was analysed using the framework of ten questions, which consisted of a mix of quantitative and qualitative questions. Each site was analysed separately with a descriptive analysis of ease of access and the content. Once all the sites were analysed, a further analysis was undertaken across the data set to enable comparisons. The search strategy and frequencies of types of content were noted, and comparing similarities and contrasts in the service information. Although there was a great deal of content, as there were only seven provider sites, quantitative data analysis was not carried out. An independent check was made to validate the method used to search for the websites and check the descriptive analysis with the web pages at source.

As discussed in chapter four, Levesque *et al's* (2013) model of access was used to inform the analysis of the dataset, drawing on key dimensions of approachability and appropriateness and abilities to perceive and seek.

Summary

This chapter has set out the justification for and explanation of the study design, using an exploratory, sequential, mixed methods study. Consideration was given to different research paradigms and methods in relation to the research aim, objectives and questions and fit with district nursing. The research design chosen and decisions made were discussed in relation to selected frameworks of access and research literature, and limitations explored.

The researcher's position as a social scientist as opposed to a practitioner has been explained, where a social constructivist approach has been taken and underpins the study's rationale, design and analysis, including the use of Levesque *et al* to analyse the whole dataset. A detailed description was provided of the research process including contingencies adopted for data collection that arose from organisational and policy change. The following four chapters report on the findings from each phase of the study.

Chapter six: Patients' and Carers' views of access to the service – findings from interviews and focus groups

Introduction

This chapter presents the findings from two focus groups conducted with patients and seven interviews with carers. Two main themes were defined in relation to access to the district nursing service: **expectations** and **control**.

The chapter is organised into three sections. Section A introduces the participants, with patients' and carers' profiles presented in tabular form. Section B focuses on the **expectations** theme with three subthemes i) expecting help ii) expecting direct access and iii) expecting a consistent service. Section C focuses on the other theme of **control** with two subthemes: i) visibility of the service and ii) influences on service availability. The findings in Sections B and C are presented using these themes and subthemes. Evidence is presented from the data extracts for each sub theme and subheading; all data extracts are in *blue italics*. Where patients and carers experiences align they are referred to collectively as participants, and where they differ a distinction is made between patients and carers. Summaries are provided at the end of each sub theme and section and an overall summary of the main findings is presented at the end of the chapter.

Section A About the participants

The tables below provide the contextual background information about patients' and carers' characteristics in relation to the service. All participants have been given pseudonyms and any information that might compromise anonymity has been modified or omitted. They appeared to be diverse in terms of age, gender, ethnicity and class based on data participants revealed about themselves in the focus groups and interviews. However, none of these characteristics have been included as these data were not collected directly from participants. Issues arising from this approach are raised as a limitation in chapter eleven.

Patients' characteristics are shown in Table 6.1. Most patients had multiple long-term health conditions as well as secondary complications. Diabetes was the most frequently mentioned condition, affecting seven out of ten patients. The second patient focus group was conducted in a stroke club, accounting for all six having this condition. While this is recognised as potentially skewing their accounts of experiences, most patients also had other health conditions

and were not necessarily receiving the district nursing service because of their stroke.

Of the three patients not receiving the service: one had never received it, one was waiting to receive it and another had stopped the service. Of those receiving the service, six had the service for many years though not necessarily continuously. One patient had also cared for her husband, now deceased, who had received the district nursing service when she was caring for him.

Carers' characteristics are shown in table 6.2. Except one, all carers lived with their care recipients: their relationship was either a parent or spouse/partner. Two cared for both parents. Only two carers were in full time paid employment and another had recently given up work and moved into the family home to care for her father.

At the time of interview, five care recipients were receiving the service. Of the other five: one care recipient had died, one was in a residential home, one had yet to receive the service, another had withdrawn from it and the final care recipient was discharged from the service. Care recipients where reported, had multiple long-term conditions, often with secondary effects such as poor mobility, pressure sores or recurring infections. The most frequent conditions mentioned were dementia and incontinence. Most carers stated they found caring exhausting and stressful, but only one carer disclosed a physical health issue having had two hip replacements.

Table 6.1 Profile of patients

Name	Living alone	Health conditions disclosed	Duration of receiving district nursing service
Marcia	Yes	Hospital admission previous cause not disclosed	First received district nursing service 20 years ago. Currently waiting for district nurse visit following a referral
Helen	Yes	Diabetes Registered blind Cardiac problems Hypertension Incontinence	First had district nursing service over 40 years ago postpartum Service resumed intermittently - currently receiving the service Cared for husband who received the service
John	Yes	Diabetes Hip surgery Blood investigation Wheelchair user	First had district nursing service 15 years ago On district nursing service books
Clara	Unknown	Diabetes Hypertension Lymphoedema Cancer	First had district nursing service 5 years ago On district nursing service books
Mike	Yes	Diabetes Stroke Hypertension Leg ulcer	On district nursing service books Attends leg ulcer clinic too
Ian	Yes	Diabetes Stroke	Had district nursing service for less than a year
Irene	Unknown	Diabetes Stroke	Unknown
Therese	No	Diabetes Stroke	Stopped district nursing service
Elaine	Unknown	Stroke	Never had district nursing service
Lily	Yes	Stroke - severe speech problems Wheelchair user	On district nursing service books

Table 6.2 Profile of carers

Diploid interviews conducted with: Mary and Olenka; Hilary and Bernard; June and Yvonne

Name	**Relationship of carer to care recipient**	**Health conditions of care recipient disclosed**		**Duration of caring at time of interview/ Length of time receiving district nursing (DN) service**	**Living with care recipient**
Mary	Husband	Had been in hospital for unknown reasons		Over 6 years/ On and off 6years	Yes
Olenka	Husband	Cancer had surgery MRSA infected wound Stoma	Hernia Mild dementia	Unknown/ DN visiting intensively 1 month, husband discharged from district nursing service	Yes
Hilary	Husband	Frail complex needs Pick's disease	Bedbound Pressure sores Palliative care	At least 4 years/ Unknown	Yes
Bernard	Mother	Cardiac problems, Dementia Glaucoma - blind in one eye		Unknown/ Withdrew from the service	Yes
Alice	Father	Frail complex needs Stroke Hypertension, Cardiac problems Deaf	Pressure sores Ulcerated feet Cellulitis Mild dementia	5 years/ Several years	Yes
Delia	Partner	Diabetes Infected foot Doubly incontinent		Unknown/ patient died 6 months before interview	Yes
June	Husband	Dementia Diverticulitis Doubly incontinent		Unknown/ Still waiting to see DN	Yes
Yvonne	Mother and Father	Mother: Dementia Doubly incontinent Blind Poor mobility	Pressure sores Father: Dementia	Unknown/ DN on and off soon to be discharged	No
Philippa	Mother (and previously Step father)	Alzheimer's Urinary incontinence Pressure sores		Seven and half years/ Mother now in a residential home Stepfather: (deceased 2 and half years earlier): Dementia, incontinence	Yes
Julie	Husband	Vascular dementia Stroke – poor mobility Doubly incontinent		Since 2012 maybe before	Yes

About the themes

Following data analysis, two main themes, **expectations** and **control** of access, were determined from the data corpus. Though these themes have distinctive elements, there was inevitably some interplay between them, which is acknowledged in the analysis in an effort to understand the complexity. The quality of the district nursing service was also discerned as a main theme but was only pursued in the analysis where the findings related to access.

Section B Expectations

In this section, the findings are presented under three subthemes:

B1 Expecting help
B2 Expecting direct access
B3 Expecting a consistent service

B1 Expecting help

Prior to receiving the service, all participants i.e. patients and carers reported expecting to access help with physical health needs. Beyond this, expectations could vary between patients and carers depending on the sort of help they thought should be available. Expectations seemed to be shaped by what participants supposed the service offered and what others told them, particularly GPs and hospitals,

from what the GP had said the district nurse was going to do…the district nurse did what the GP said…so it wasn't anything other than I expected but…if you think that the system ought to be explained to people nobody did so…(Philippa carer).

Patients and carers seemed to modify their expectations on gaining access to the service: these expectations might be unmet, met or exceeded. Though Philippa's expectation was met initially, she seemed to suggest her GP's explanation was insufficient. Beyond the immediate health need, she appeared to want an explanation about the system, though she did not explain what she meant by this. Where participants' expectations were not met, they seemed to perceive this as their misconceptions about the service.

Carers' access to support *you're kind of on your own*

Carers reported expecting access to tailored support from district nurses. They indicated they needed this support to help them in their caring role, they expected district nurses to provide advice and reassurance, *you're really in a nightmare and then someone comes along who is going to help you but actually [is] a hindrance (Bernard carer).* Bernard's experience of being a carer and trying to run a business was that he had to modify his expectations of the support available on receiving the service.

Support appeared to include helping carers' sense of isolation in managing major health needs on their own, *so once he was diagnosed [with dementia]…there's no input really…you're kind of on your own …(Hilary carer)*. This view of being left to manage alone was common among carers. They also indicated they had little or no knowledge or experience of these conditions or services available. They revealed they found caring overwhelming and their expectation of tailored support seemed to be largely unmet. However, there were instances where this expectation was met and exceeded,

…I was sorry when it was no longer deemed to be necessary to have the district nurse cos he actually had been absolutely brilliant you know and things like if you don't know the system and you've just been thrown in to this kind of situation and you don't know who to ask for anything…(Philippa carer)

Philippa seemed to experience a sense of loss when this support was no longer available, and it was not clear if she could access this in the future. Carers' expectations of access seemed to be shaped by their own needs, care recipients' needs and what they had been led to expect by others.

Patients' access to care *it was good because they were doing what they were supposed to do*

Patients did not seem to have particular expectations of the service prior to accessing it. Their expectations appeared to focus on the care received. Compared to carers, patients felt their expectations of the service were being well met, *it was good because they were doing what they were supposed to do…(Helen patient)* and *they're doing a fantastic job (Clara patient),* though whether patients had lower expectations was not discernable. However, patients' expectations were also shaped by care plans and advice from hospitals or GPs, *in the book [notes in the home] it's written to say that every morning and*

evening but they don't turn up…(Irene patient). All patients and carers reported unmet expectations when planned care was not delivered.

Expecting a proactive service *great someone's coming in to keep an eye*

From the focus groups and interview responses, there was an expectation that the service should be more holistic and proactive. Patients expected monitoring of their long-term conditions, as part of routine care. However, Helen's expectations of being helped to manage her diabetes and hypertension were not always met,

…so they come and look at me …'Have you got blood pressure [sphygmanometer]?' some said 'No, I didn't bring it', 'You won't be taking my sugar?' [testing blood] 'We didn't bring it'…I want to know what my sugar and blood pressure and those kind of things…I've been seeing one recently who was good …and I ask about the blood pressure and the sugar measure and she explained to me… (Helen patient)

Because of Helen's sight difficulties, she was reliant on whoever visited to bring the equipment to monitor her conditions. Her experience was of different nurses visiting and a lack of clarity about monitoring which seemed unplanned, and therefore of limited value. Helen's expectations of a proactive service presented as continuing to ask for monitoring and valued this when it occurred. Patients and carers expressed the view monitoring patients would allow district nurses to pick up changes or problems, *they will phone up occasionally to ask how I am (Clara patient).* To Clara these phone calls were intended to check if her diabetes was stable. Carers seemed to expect general health surveillance of care recipients that shared the burden of responsibility they felt,

you just sort of feel very alone, adrift, so when I heard 'district nurse' I think I thought great someone's going to keep an eye on him medically cos I can do the social side of things…you know keep an eye see what's needed but it's not like that (Hilary carer)

Carers' initial reaction was positive and expecting that district nurses would provide surveillance but in practice this did not happen. Carers' assumptions and expectations about a proactive service and monitoring seemed to be largely unmet.

B1 Summary

Patients' and carers' expectations were based on their hopes and experiences of the service, prior to, or on receiving the service. They also seemed shaped by what GPs or hospitals had told them. All participants expected help with specific health problems and monitoring of health conditions. Expectations seemed to be needs led, with variations between carers and patients. Carers also expected tailored support, hoping district nurses would help relieve their caring burden. Patients' expectations of getting help seemed to be met, but all participants wanted care delivered as planned.

Once access was gained expectations could also be retrospectively re-evaluated with a lowering of expectations frequently reported. Where patients' and carers' expectations were met or exceeded, this seemed to indicate satisfaction with a holistic approach to care received. From these participants' perspectives, expectations of the service did not appear to be unrealistic but not always met.

B2 Expecting direct access

Contacting the service *I should be able to have a district nurse number*

Being able to contact the district nurses directly was expected by patients and carers, however for almost all participants it did not happen, *I think the most important thing is if I could contact her on the phone…so for me it is the most important thing to have opportunity to talk to nurse not only to her answering phone (Olenka carer).* As Olenka's husband received regular visits from the district nurse she did not need to contact the district nurse directly. However, as he was discharged from the service and now has mild dementia, she wanted to speak to the district nurse but did not have a contact number. It was not clear why she had not been given this number on discharge. Other carers reported the same expectation,

I was envisualising [sic] having to find some way to get hold of the district nurse to give an enema now we've just gone through it thank God…I should have been left with card or whatever with details of how to contact her in the future…I should be able to have a district nurse number so that if things got acute again (Julie carer).

Following this crisis, it was not clear why Julie had not been given a contact number though she implied she was not permitted to have it. For carers direct access to district nurses in an emergency seemed important. Clara was the only

participant who had the 24 hours district nursing service number for emergency access for her uncontrolled diabetes,

then they told me about the 24 hour service, how to get through to the district nurse, so I just phoned them up and tell them if I have any problem and they come…they don't give out the number (Clara patient).

Clara was aware that this number was not usually given out to patients, though it is not clear why that was the case. Indirect access mechanisms were used to contact district nurses, mostly via GPs although one carer asked palliative care staff to email the district nurse, *and when she does they take notice (Hilary carer).* Hilary's expectation of access seemed to change in the light of her experience when the district nurse did not respond to her requests. While participants reported expecting direct access to district nurses most were not provided with these contact numbers.

Leaving messages *they didn't pass on the message*

Patients and carers reported having a central number, on the notes at home, for an answering service. Messages were left that were relayed to the district nurse, *…we had a telephone number…for an answering service you left a message…you didn't normally get them…If in trouble phone us (Mary carer).* In Mary's experience, direct access did not seem possible via the messaging service and this service appeared to be used in emergencies. Despite having a central number, it did not appear to be possible for patients and carers to speak to district nurses, *I asked for this particular nurse…the message never even got to him and no one came in the end, no one responded and…so the communication is not good (Hilary carer).* Patients and carers reported negative experiences with the messaging service, they lacked assurance messages would be received and acted upon. This appeared to create dilemmas, if their situation was unknown to district nurses, they were uncertain what further action to take.

Lack of response *they never answer*

Patients and carers considered the messaging service to be unresponsive and designed as one-way communication. In Ian's experience it was particularly difficult for him to use the service due to his stroke, *ring never got an answer, I couldn't speak properly (Ian patient).* Because of his speech difficulties, this limited his capacity to leave a message, even if the phone was answered. Although Ian had not managed to speak to anyone, there was an expectation by participants that call handlers would respond in a professional way, *you get*

grumpy people answering (Hilary carer). At the very least patients and carers expected the messaging system to work,

It should never happen that…they never answer and it happens, so for me it is the most important thing to have opportunity to talk to nurse not only to her answering phone (Olenka carer).

Although it was not clear if Olenka had ever used the service, she was clear she wanted to speak to the district nurse. She seemed to suggest the answering service was a barrier between her and the district nurse. This perception of the messaging service operating as a barrier was not uncommon among participants.

B2 Summary

All participants (patients and carers) expected they should be able to contact district nurses directly and this did not happen, indirect methods were used, often their GP. The contact number provided was usually for a central messaging service which participants found unresponsive. They perceived this as a barrier between district nurses and them. Where they managed to leave messages, they reported uncertainty about whether messages were relayed to district nurses. Being able to contact the district nurse and have assurance of a response was what they felt they ought to have received from the service and this expectation did not seem to be met.

B3 Expecting a consistent service

Timing of visits *they turn up when they feel like turning up*

Patients and carers had a clear expectation of a consistent service aligned to their care needs. Poor timekeeping was frequently raised by patients and carers and seemed to be a source of frustration; *they never turn up on time (Therese patient)*. Therese expected district nurses to visit at a given time, it is not known if this was agreed with the district nurses, but she suggested late visits was the norm. Consequently, she terminated the service because of irregular visits and her daughter now does her injections. Other patients also shared this expectation of a given time for their visit, informed by their understanding of their clinical need,

I was getting a district nurse but whatever time they're supposed to come and inject me is late time …they never come the right time. In the first month they

come the right time though afterward no they just come whenever time they wants…(Irene patient)

Irene's perception was her insulin regime was now incorrect: the service was not delivered as she expected though she seemed resigned to it. All patients reported dissatisfaction with late visits but they seemed to have little control over this, *sometimes they don't come, so phone …they give you the time they will come but they're so busy now…they turn up when they feel like turning up (Helen patient)*. Though Helen did not know when to expect a visit but she implied that the visits were timed to suit the service rather than her. Sometimes visits were omitted all together, *a few times they didn't show up for the injection (Ian patient)*. In Ian's case as an insulin dependent diabetic learning to self-care, it was not known if these were errors rather than conscious decisions not to visit. Patients viewed unpredictable visits negatively.

Unplanned visits *someone would suddenly pop up and ring the doorbell*

Carers reported occasions when unexpected visits were made which had an impact on their daily routines*, we were taking him out…then someone would suddenly pop up and ring the door bell and I wouldn't know what it was for…. so I always asked for phone calls and those never happened (Hilary carer).* Hilary found unsolicited visits not only disruptive and wasteful but also they appeared to be limited and task focused. Participants expected to be able to work in partnership with district nurses, including arranging visits. Unplanned visits were not always welcomed by carers and perceived at times to be intrusive.

Waiting *everybody has to go out*

Patients and carers expected to be informed if there were changes to visits, so they could plan accordingly, *so that you know they will be running late…phone ahead at least you know they're coming (Mike patient).* Waiting for visits from district nurses was a source of frustration for participants. This was particularly difficult for carers in full time employment, *everybody has to go out …my daughter can't stay indoors cos they have to go work (Irene patient).* Irene's daughter waited to let the district nurse in and was late for work. Participants implied that waiting for district nurses created anxiety as well as uncertainty.

Continuity of service *everyday different people turn up*

Patients and carers expected service continuity with regular care provided by regular staff. Uncertainty about who would visit was common *…you never know*

who you are going to get (Hilary carer) and *…everyday different people turn up (Irene patient).* Participants reported having to start anew with unknown staff to explain their needs, suggesting too it was difficult to build relationships. A common experience reported by patients and carers was that agency staff were not properly briefed about the care to be given. Some participants implied that such visits were being covered, as a visit was made but the expected care was not delivered.

Carers of those with dementia viewed discontinuity of staff as unsatisfactory and upsetting: it was important to them someone who knew them, their needs and routine, gave the care. Philippa noticed a difference in service continuity by comparing the service her stepfather had received with her mother's, both had dementia and were incontinent,

most of the time that I needed the district nurse for my stepfather…it was the lovely gentleman, you know I'm a huge fan of his…when my Mother needed a district nurse…it was always someone different (Philippa carer).

Philippa experienced an effective and trusting working relationship with her stepfather's district nurse that was difficult to achieve with her mother, her perception was it was not the same service. Carers reported their attempts to establish consistent service delivery,

when I managed to fight and get it with them coming all the time and it was a regular nurse it was running sweet as a baby…you're just constantly waiting for the phone to ring… saying we can't come or there'd be times where I remember when I let the reins go you come home and look and the tablets were still in the blister pack you think, what? (Bernard carer).

However, for Bernard achieving consistency seemed to be short lived, he was continually vigilant in case of any break in service continuity. He appeared to have to explain constantly to different staff that they should ring him, as messages left with his mother would be forgotten because of her dementia. This appeared to be a source of stress for him as the service could break down up to twice a day. He revealed this lack of stability meant he could not leave for work until the nurse had called, as a result he withdrew from the service. Participants' expectation of a consistent service seemed to be unmet and they appeared to have no control over who visited or the care provided.

Section B Summary

Patients and carers had mixed expectations based on their hopes and experiences, held either prior to or on receiving the service. Advice from professionals also influenced expectations. Expectations seemed to be re-evaluated once access was gained, often these expectations were lowered. Participants' (i.e. patients' and carers') expectations seemed to be needs led: all expected help with physical care, direct access to district nurses and a consistent service. Participants held different assumptions about what help and advice should be provided. Carers expected that they should receive tailored advice and support for themselves. Comparatively patients' expectations seemed to be met in regards to getting help, perhaps this may indicate patients have fewer expectations than carers.

Although participants expected direct access to district nurses, their experiences indicate this did not happen and communication tended to be one way. Contact numbers supplied were usually for the centralised messaging service, which was perceived as a barrier, with participants left with feelings of uncertainty if messages were relayed to district nurses. All participants felt the need for a consistent service with planned care delivered by regular staff: inconsistency and unilateral changes to visiting times seemed to be a common source of frustration. Where expectations were not met, patients and carers appeared resigned to accept the service as delivered, and apart from withdrawing from the service, which two participants did, they had little other choice.

Section C Control

The findings relating to the theme of control of access to district nursing are presented under two subthemes, with summaries at the end of each subsection:

C1 Visibility of the service
C2 Influences on service availability

C1 Visibility of the service

A lack of information about the service *it didn't occur to me that [district nursing] still existed*

None of the participants (patients or carers) reported being given any written information in advance of accessing the district nursing service. They seemed certain about this, though it is possible that they did not remember. It was not clear whether such information existed, *no information about the service*

received, written or otherwise (Mary carer) and *I don't know what the service is all about, that's the trouble, I have to know what the service provides (John patient)*. Their experiences suggest that getting information about the district nursing service was not straightforward and in that sense the service was not visible to them.

Patients and carers recounted being aware of the service but this was limited, *I wouldn't have a clue how one gets hold of a district nurse…(Philippa carer)* and…*it didn't occur to me that [district nursing] still existed…(Julie carer).* Even though Julie had been a nurse, she implied the service was invisible to the general population and she only became aware of them on referral. Once referred, participants reported they waited to be contacted, *no I didn't [receive information] they said they would contact me (June carer).* However, waiting for the referral process to be realised did not always seem to go smoothly,

the nurse [at the hospital]…told me to get a district nurse…I haven't got her numbers…they [DN] gave me a…appointment card in my door got no phone number on it…more cards say they called…keep putting cards in my door… if only…I could get one [a district nurse] I'd say get one, I want one, I'd say I don't know [how], can't get one (Marcia patient).

It was unclear why Marcia was advised to contact the district nurse herself, though possibly without their contact number she might have contacted the hospital when she missed the district nurses' visits. As far as she was concerned, she was unable to negotiate access to the service. At the time of interview, neither Marcia nor June had received the service. They expressed their sense of powerlessness while waiting for professionals to visit; in June's case she had been waiting over a year since referral.

Patients stated they first found out about the district nursing service at the point of discharge from the hospital, when they were informed they had been referred to the service. Patients and carers stated that they would also approach GPs to access district nursing though *…in fact district nurses I would have thought would be the people would come along and give you a little booklet or something (Julie carer)*. Patients' and carers' experiences indicated that a lack of information impeded their understanding of the service.

Understanding of the district nurse's role *I still don't know what a district nurse is supposed to do*

It emerged through the patient focus groups discussions and carer interviews, participants did not seem to know what district nurses do and there was a lack of information about this, *I think it needs to be more specific so that people when they call for a district nurse [know] what to expect, who they must call, what they must call for…(John patient).* John seemed to infer that without understanding the district nurse's role it might in some way have an impact on his use of the service. Other participants expressed similar views,

I still don't know what a district nurse is supposed to do…I assumed that I knew but my assumption is wrong…so someone explaining to me what the district nurse does…that would help district nurses and the service…(Philippa carer).

All patients and carers wanted to understand the role but it was unclear whether anything in particular had prompted this. Carers also reported that a better understanding of the district nurse's role would help them to use the service appropriately,

I still don't know when, in what cases I should contact district nurse…I don't know how and when the district nurse can be helpful that I wouldn't ring her when I shouldn't expect her (Olenka carer).

Though Olenka and Philippa realised their assumptions about the district nurse's role were incorrect, it was unclear what they thought the district nurse's role was or how their assumptions differed to their experiences. Therefore, even though participants had experience of district nursing, often for many years, they still reported a lack of role clarity and what they could offer.

Qualifications and skills *I was wondering if they were qualified*

Most patients and carers seemed to make broad distinctions between visiting staff, mentioning health care assistants and agency nurses. Participants did not report distinctions between qualified staff working in the service. They seemed to view all staff as 'district nurses' and *wouldn't know the difference between them, we've had a few I was wondering if they were qualified (Alice carer).* Though Alice did not know who was qualified or more senior, there was a sense that she attributed dissatisfaction with some care to unqualified staff.

Carers seemed to make judgements about staff in relation to the level of skills experienced …*didn't ask about qualifications…I watch her everyday in my opinion she was highly qualified (Olenka carer)*. Patients and carers also appeared to draw their own conclusions based on their experiences. Delia supposed most nurses were qualified but seemed more concerned about whether staff were sufficiently skilled to deal with her partner's drain,

…because he was a diabetic he had a very bad infected foot and instructions that it should have been dressed every other day…and he had a gadget attached…so that the foot could be drained of all the pus...there was only one nurse who knew how to handle it…and when she was off it wasn't done and it could be days and it used to be smelling, it got so infected…most of the time there was a nurse from the agency and they say they don't know how to do it, so I had to wait until this particular nurse…I suppose all the nurses were qualified but I don't know how qualified or confident they were dealing with somebody like him (Delia carer).

From Delia's experience, the planned care was not given and the infection got worse which she attributed to a lack of this clinical skill. Like Delia, participants acknowledged particular district nurses' knowledge and skills and seemed to value them highly. Olenka concluded that*…without her my husband might be dead,* because she perceived the district nurse to be highly skilled when dealing with his life threatening infection.

Patients and carers also valued other skills, *they're reassuring they're professional they do what they're there to do they come to your house to do it which is fantastic…and you trust them as a medical professional (Philippa carer).* Getting a district nurse had been difficult for Yvonne but once she had access,

she was fantastic there was nothing she didn't know she had in 24 hours ordered…a pressure mattress, pressure cushion and we were into the incontinence pads conversation and she was asking me more questions than I could even answer so once I got her she was great (Yvonne carer).

From these participants' perspectives, judgements about performance and skills appeared to rest on holistic and responsive care: all seemed to convey they developed relationships with particular district nurses.

Gatekeeping role *it was a referral from the district nurse but no-one seemed to know*

Patients and carers seemed to be unaware district nurses were gatekeepers to other resources and services. Dealing with incontinence was frequently mentioned and appeared to be a challenging and stressful part of carers' role, *Mum became doubly incontinent…it happened very, very quickly and I didn't know how to handle it (Yvonne carer)*. Participants seemed to imply the service exists but it was not offered. Most participants approached GPs for help and carers reported purchasing products themselves,

…it wasn't apparent…that we were entitled to free incontinence pads … I was buying them for ages before the GP said 'well actually she's entitled to free ones'…it turned out that it was a referral from the district nurse but no-one seemed to know that not even the GP (Philippa carer).

Philippa's experience was not uncommon among carers, as GPs seemed to be unaware district nurses conducted assessments for continence products. For carers this gatekeeping aspect of the district nurse's role seemed to be hidden and difficult to discover.

Difficulty in finding information about the service *if I want to find it today, what should I do?*

Patients and carers reported it was not easy to find information about the service and they had not managed to find it themselves, *district nurses again I would have thought would be the people would come along and give you a little booklet or something (Julie carer).* Participants frequently suggested leaflets should be provided,

…I was at my GP surgery this morning and I had a look at the leaflets to see if there was anything for carers which there wasn't, and I can't remember there being anything about district nurses it was just like, 'Do you have diabetes?'…you know it was all about diseases there was nothing like 'Are you a carer?' 'Do you want some help?' 'Go to [name] carers' or 'District nurse services are available there' was nothing like that and they're a good GP…but I think that probably would be a good port of call to put leaflets in anyway (Hilary carer).

In her view, the information Hilary wanted was not available at her GP. Carers reported having searched information but none had found any about district

nursing. Their experiences suggested that service information was not in plain sight,

if you could make small leaflets what is district nurse and put them in surgeries, libraries, carers centre for us to learn from this, maybe because I'm a foreigner and I don't know how it works here but I'm afraid that many other…carers don't know either what district nurses are for, so it would be very helpful if you have budget to do these leaflets and put them you know in proper places I would find them…(Olenka carer).

Carers suggested GP practices as a potential information source for district nursing. Their perception was that not placing this information in public places was a lost opportunity to make service information more accessible.

Searching the internet *no other way on the website of getting hold of the clinic*

From the carer interviews, the Internet appeared to be an important source of information, particularly for managing incontinence. Carers seemed to find searches time consuming and frustrating. It was unclear whether they tried to find information about the district nursing service and which search terms were used. Carers seemed to be actively trying to find information and failing, not knowing where to search or if websites existed and in Olenka's case she seemed to be unclear how to search for it, *but on Internet that we can have a website or something, how can I find it on Internet? how? if I want to find it today, what should I do? I'll write it down (Olenka carer).* Some carers' experiences revealed that even finding services online did not necessarily lead to successful access. Even for those carers who felt they were skilled in using this technology, they were still unable to find the service they required,

…the Bladder and Bowel Clinic that number I fished off the internet and I found the clinic and found the name of the lady… and her number…I couldn't believe it I've…'struck gold'' and I got a recorded message saying whatever her name [said in a comical tone] 'Jasmine no longer works here' and without any number to call there was no other way on the website of getting hold of the clinic (Julie carer).

Despite Julie's web skills, her experience was not uncommon for carers who reported website information as inaccessible, inaccurate, incomplete or missing, including named working contacts and direct telephone numbers. However, none of the patients mentioned using the Internet at all.

Difficulty navigating the system *this is what you need to do*

All patients and carers reported that from the outset their lack of understanding of the service made it difficult to navigate. In their view, navigating the service was not intuitive, *if you think that the system ought to be explained to people, nobody did (Philippa carer)*. Carers' experiences of engaging with different services, including district nursing were confusing. How the system worked did not appear to be particularly obvious from participants' perspectives,

…you don't really come across the services you need until you need them desperately then it's hit or miss…you know someone has to give you something…I mean one is in shock and you don't know how you're going to manage (Hilary carer)

Hilary and other carers perceived being able to navigate the system as essential in helping them cope, especially on first becoming a carer. Being helped to do this seemed to go beyond written information,

…it's easier if they just had somebody who could come along and sit down with you for 10 minutes and say tell me your scenario this is what you need to do ring…these numbers or I can do that for you I'll do it better than you so I know who to call (Bernard carer).

Bernard's view was consistent with other participants who wanted help with interpreting information and signposting to services. No participants reported if this happened. Carers frequently revealed they felt exhausted and worn down by being a carer and any obstacles in finding help contributed to this,

…I thought 'that's brilliant' so she gave me a phone number and …it was a nightmare I phoned the number given me and after half an hour and 8 phone calls later including 3 to the original number I ended up talking to the district nurses' office who said 'someone will call back' and nobody did (Julie carer).

Having followed advice from the carers centre, Julie's best efforts did not result in access to continence services. Her experience of being bounced back and forth between services was common to participants.

Unaware of 24 hours service *I assumed it was the same as GP hours*

Patients and carers did not appear to know district nursing was a 24 hours service, It was not clear why they did not know the full service hours, especially

as most participants had received the service for some time, *I assumed it was the same as GP hours (Yvonne carer).* Clara was the only patient who reported having used this service, *I was on steroids and it was interfering with my diabetes so I had to have the nurses come in through the 24-hour services.* Clara was given the number by district nurses and told how to use it. It was not clear if Clara knew about the service before but she was aware this number was not given to everybody. Patients' and carers' assumptions about service hours suggest possibly they are not made aware of the full service on offer, though they may only be told should it be necessary.

Unaware of self-referral *I had always assumed that you had to be referred*

Patients and carers reported mixed levels of understanding and experiences of the referral process. They understood their referrals had been made by GPs or hospitals and understood only professionals could refer to the service,

…I had always assumed that you had to be referred to the district nurse I had never thought [about self-referral] and still don't think that you could automatically contact the district nurse…(Philippa carer).

Patients and carers, including Philippa, held the view that they could not refer themselves directly to the service. Helen was the only patient who had tried to self-refer but it was rejected because only a GP referral was acceptable, *I tried to call them myself but they can't come because they have to get [a referral from] the doctor (Helen patient)*. It was not explained why Helen decided to self-refer or how she got the district nurses' contact details, or why a GP referral was required. However, none of the other participants thought self-referral was even a possibility.

C1 Summary

Patients' and carers' experiences indicated that not only was it difficult to find information about the district nursing service but also that the system was not easy to understand or navigate. Service information did not appear to be visible or available with participants reporting no service information had been given to them prior to or on receiving the service. Patients and carers stated they did not know about the district nurse's role even though most had received the service for a long time. Participants were unaware of: district nurses' gatekeeping role and qualifications, self-referral and 24 hours service. Carers also wanted district nurses to explain the service to help them navigate the system. It appeared that participants could not easily work out for themselves how to access the service.

In that sense, the service appeared to be there somewhere, but intangible and elusive, the means by which to find or access it were hidden.

C2 Influences on service availability

Eligibility for the service *how can she not be housebound?*

Patients and carers did not seem to have much recollection of being referred, no one mentioned being assessed for eligibility for the service. The exception was a care recipient, who was refused access because the district nurse did not consider her to be housebound,

I said 'she can barely walk how can she not be housebound?…it often takes two people just to get her in and out of the chair' she said 'then she's not housebound because she can leave the house' (Yvonne carer).

It seemed to be essential that Yvonne's mother fitted a particular definition of being housebound. Yvonne's seemed to be incredulous about the district nurse's interpretation of being housebound as it did not appear to be obvious or transparent to her,

…in the end I asked…'OK could you tell me what you would consider a housebound patient to be?' and she said several of her clients would live in blocks of flats where they are on the top floor and they literally cannot get out of that block of flats or other patients are bedbound. I thought 'right well in that case Mum isn't housebound' but that's bedbound isn't it? (Yvonne carer).

Yvonne's view was her mother was not being offered the service because she was not bedbound. However, being known to this district nurse was advantageous, as she agreed to do an assessment and she acknowledged Yvonne's mother needed the service. It remained unclear whether there was any agreement about being housebound. Yvonne's perception was such decisions were having to be made due to staff shortages and service pressures.

Workforce and workloads *it seems they're overwhelmed and understaffed*

Patients and carers appeared to acquire insider knowledge of staffing problems and daily demands, *found out it's 16 people a day...to see which is too much to give any kind of quality of care (Hilary carer)*. Participants frequently mentioned district nurses were busy, perceiving this as reasons for delayed visits. Patients and carers reported knowing about changes and the use of agency staff, *she has*

been taken off community matron duties to do district nursing because they're too short of district nurses (Yvonne carer). It appeared district nurses shared workforce difficulties to explain disruptions to the service.

Both patients and carers appeared to be sympathetic to time pressures and workforce difficulties, and accepted that they may not be a priority, *it's a lot because the woman said about four or five of them she have [to] give the insulin…because I take…my tablets myself (Irene patient).* Irene seemed to accept the explanation offered of workload demands, as she was made aware of her relative need for the service.

Despite understanding workforce pressures, *it seems they're overwhelmed and understaffed…they're supposed to provide a service and they're not providing a service…(Julie carer)*. From Julie's perspective the reality of staff shortages and high workloads meant she did have not access to the service, suggesting too that the service did not exist. Participants perceived decisions about access were influenced by workforce considerations, over which they appeared to have no control.

Bureaucracy and decision making *a bottomless hole of misinformation and bureaucracy*

Carers reported bureaucratic systems that seemed to inhibit access to district nursing, *they put all these hurdles to weigh you down so you have to go through so many people (Bernard carer).* Participants frequently reported being bounced around the system, *she said you'll have to take her to the GP, but it's the GP who referred her [to DN] (June carer)*. Even though June's mother had been referred four times over a period of thirteen months, it was unclear why this did not result in a visit. June's experience seems to typify that of other carers seeking help, where information or referral did not necessarily lead to access. Participants revealed staff did not seem to know who provided what,

GP said 'well, I've no idea where you get commodes from, maybe you need a referral from the district nurse' so I contacted the district nurses and I mean no one came round but just over the phone said 'no, that's not district nurses that's social services' so I contacted social services and they said 'well, that's not social services, I don't know who refers you for that but it's not us' and so it was 4 different telephone conversations, in the end I went to back to the GP…it turned out that it was a referral from the district nurse but no-one seemed to know that not even the GP…but until you know that is the person [DN] who does the

assessment and arranges it, it's you know a bottomless hole of misinformation and bureaucracy (Philippa carer).

According to Philippa even the district nursing service did not appear to know they provided access to commodes. Carers reported additional district nursing assessments and reassessments were required to authorise access to continence products, *[District nurse] said to me 'Yvonne, I have to have that form back'…I said 'it's not worth the paper it's written on, it's complete nonsense', she said 'it doesn't matter, I've got to have it back I will not be able to issue any incontinence pads without it'…(Yvonne carer).* Even though a person with Alzheimer's filled out the form, Yvonne's view was this outweighed accuracy to gain access.

Carers perceived reassessments as an unnecessary barrier to a continuous supply of continence products, *I had to reapply…every year or whatever...to get another assessment from the district nurse…it was pointless (Philippa carer).* As far as Philippa was concerned these re-assessments were not only inconvenient, wasting her time and district nurses, but also as her mother had Alzheimer's nothing had changed. She perceived reassessments as necessary to control resources but her view was she only used the resources she needed. Carers also reported subsequent poor coordination and communication between these services, with delayed access to the right products lasting weeks and sometimes months, that increased carers' workloads.

Challenging district nurses' decisions *you're a bit of a troublemaker*

Patients and carers revealed they were not always satisfied with decisions about access to the service, but did not appear to challenge district nurses' decisions overtly. The exceptions were two carers who reported questioning such decisions. Yvonne wanted to know why her mother was not eligible for the service as, *'she's not housebound because she can leave the house', so we had a bit of a disagreement about that (Yvonne carer).* When Bernard questioned why his mother's visits were reduced, he believed the new medication regime was wrong, he felt this was not without consequence, *when you challenge them…they'll answer you, but back at head office you're a bit of a troublemaker (Bernard carer).*

Bernard did not offer any further explanation why he believed this, although having asked the district nurse to put her decision in writing for verification by the pharmacist might possibly be perceived as a threat to professional autonomy.

Even where patients perceived they had cause to challenge district nurses' decisions, including delayed or missing visits, they appeared not to, *it's written to say every morning and evening but they don't turn up, I can't make no fuss with them…I don't want to fight with them (Irene patient).* While Irene revealed she chose not to challenge the district nurses, it was unclear whether she felt unable to or worried about negative consequences. There was a sense that participants felt unable to express their concerns about district nurses' decisions.

C2 Summary

Patients and carers were aware of different organisational factors influencing their access to the service: service eligibility, staffing levels and workloads and bureaucracy and decision-making. All participants were sympathetic to pressures on staff but conscious of the impact of not receiving the expected service. In trying to access services, patients and carers experienced bureaucratic responses, causing delays. Patients and carers did not seem to have any control over district nurses' access decisions, tending not to challenge them. Participants seemed to attribute negative experiences of access as being resource driven.

Section C Summary

Control of access to the district nursing service was defined as a dominant theme. From patients' and carers' perspectives, control was seen in the way in which the service was not easy to find, access or navigate. Information, about the service and the district nurse's role including gatekeeping, was not provided at the outset. This seemed to prevent these participants from understanding fully what was provided, for whom and being able to make contact. Control could be seen as overt, such as declining self-referrals or missing visits due to workforce pressures. Covert control was experienced through bureaucratic systems, for example, "being bounced around", or patients' and carers' reluctance to challenge decisions.

Summary of the main findings

- Participants' (both patients and carers) expectations of district nursing did not seem unrealistic but they did not wholly match the service accessed. Expectations were revised on receipt of the service.
- Help with physical care was expected and patients felt this was met.
- Carers expected tailored support from district nurses, though this did not usually happen. A proactive service was expected, including general health surveillance and monitoring complex conditions though this appeared to be inconsistent. Where district nurses exceeded expectations, their skills and interventions were viewed as exceptional.

- Participants expected but did not have direct access to district nurses. Communication seemed to be set up as one way through the messaging service, and viewed as a barrier to access, participants were not confident messages were relayed to district nurses.
- Continuity of care was expected though participants' experiences indicated this fell short of expectations: the timing of visits, delays and uncertainty about whether the service would be supplied, workforce shortages and communication seemed to have a negative impact on this.
- The district nursing service was perceived as invisible, as service information and how the service operated was hard to find. Participants were not given information in advance of receiving the service. No one explained the system or services when first referred: participants, especially carers, would have liked someone to explain this to them. Searching for information about services was largely unsuccessful.
- Participants did not understand the district nurse's role; they viewed gatekeeping as a hidden aspect. They seemed to value highly access to skilled and knowledgeable district nurses providing holistic care.
- Participants were conscious of the impact of workforce shortages on access to their care. They experienced bureaucratic systems and being bounced between services delaying access. Unfavourable decisions about care were perceived as resource driven.

This chapter presented the findings under the main themes of **expectations** and **control**. These findings informed the survey questions in phase two, to understand what district nurses and health and social care professionals know about the service, and in particular how district nurses and health and social care professionals view being housebound and access to self referral. The next chapter presents the findings from the focus groups with district nurses.

Chapter seven: District nurses' views of access to the service - findings from focus groups

Introduction

This chapter presents the findings from four focus groups conducted with district nurses working in three provider organisations covering four local authorities in Greater London**.** With one exception, the focus group interviews were conducted post NHS reforms with the demise of primary care trusts (PCT) in 2013. This resulted in organisational change, new accountability relationships and staff changes in district nursing (Health and Social Care Act, 2012; QNI 2019a). Two main themes were identified from the analysis of the district nurses' data corpus: the use of **control** and **appropriateness** of referrals.

There are three sections; section A provides an overview of the participants and provider organisations. Section B provides the analysis of the **control** theme with three subthemes i) visibility ii) autonomy and iii) organisational influences. Section C focuses on the second theme of **appropriateness of referrals** with three subthemes: i) self-referral ii) being housebound and iii) receiving referrals. Evidence is presented from data extracts in *blue italics*. Summaries are provided at the end of each sub theme and section, with an overall summary of the main findings presented at the end of the chapter.

Section A Overview of participants and provider organisations

Background information about district nurses was derived from answers to direct questions in each focus group and presented in table 7.1. Three types of provider organisations were included: an integrated care organisation, a community trust and foundation trust. Collectively these provider organisations supplied district nursing to fifteen local authorities across Greater London. Participants were located in four of the local authorities. In focus groups one and four, participants were from the same provider, staff from focus group one were located in one local authority while those in focus group four represented the service in each local authority.

Participants were asked about generalist and specialist district nursing services, rather than other community based specialist services. Participants reported similarities in the generalist service provided, with the exception of one provider that did not administer oral medication. All stated they offered specialist district nursing services, though there were differences in how this was reported. Some services were not offered equally within the same organisation, for example

transport to leg ulcer clinics was not available to all patients across the same district nursing service.

All participants have been given pseudonyms. Any information, which might compromise anonymity, has been modified or omitted. The four focus groups consisted of a total of nineteen district nurses; fifteen were qualified district nurses, three were experienced community nurses seconded, as a student on the specialist practice district nursing course and one was a newly qualified staff nurse. Prior to the interviews, staff were asked about whether they were qualified district nurses and how long they had worked in the community. All had worked in the district nursing service for between five and twenty five years and usually in the same organisation. The exception was the newly qualified nurse who worked in the organisation for three months. Of the fifteen qualified district nurses, four were managers: three participants in focus group four were senior managers.

Table 7.1 Profile of district nurses, providers and district nursing services

Focus Group	District Nurse	Qualified District Nurse	Type of provider	Services provided	Service hours
1	Sheila	Yes	Integrated Care Organisation consisting of two Local authorities and an acute hospital Trust Caseloads are geographically based	Nursing care in patients homes and residential care homes Oral medication administered Specialist service provided by district nurses: Leg ulcer clinic; Tissue viability Eligibility criteria: Adults over 16 years and housebound with nursing needs	24 hours 7 days per week Day: 8 am-5pm Twilight: 5pm -10pm Night: 8.30pm -12am service contracted out
	Serbjit	No - student district nurse			
	Anne	No - student district nurse			
	Nell	No - newly qualified registered nurse			
2	Linda	Yes	Community Trust providing the service to nine local authorities in Greater London Corporate caseloads GP attached	Nursing care in patients homes and residential care homes Oral medication administered Specialist services provided by district nurses: wound care; palliative care; diabetes; continence promotion; enteral feeding; phlebotomy; IV support; Long-term conditions Eligibility criteria: Adults over 18 years and housebound with nursing needs	24 hours 7 days per week Day: 8.30am-7pm Twilight: 6.30pm-10.30pm Night: 10.30pm - 8.30am service contracted out
	Cerys	Yes			
	Carlene	Yes			
3	Louise	No - student district nurse	Foundation Trust providing the service to four local authorities in Greater London Caseloads GP aligned within geographical area	Nursing care in patients homes and residential care homes Oral medication not administered Specialist services provided by district nurses: heart failure; respiratory; diabetes; tissue viability; continence Eligibility criteria: Adults over 16 years and housebound with nursing needs	24 hours 7 days per week Day: 8am-5pm Twilight: 5 or 6pm-10 or 11pm Night: 11pm -8am Service contracted out
	Charlotte	Yes			
	Maria	Yes			
	Maryam	Yes			
	Siobhan	Yes			
	Esther	Yes			
4	Earl	Yes	Integrated Care Organisation – this is the same organisation as focus group 1	Nursing care in patients homes and residential care homes Oral medication administered Specialist services provided by district nurses: leg ulcer clinic; catheter clinic; palliative care; wound care; parenteral feeding Eligibility criteria: Adults over 16 years and housebound with nursing needs	24 hours 7 days per week Day: 8am-5pm Twilight: 5pm-10pm Night: 10pm -8am
	Monika	Yes			
	Bev	Yes			
	Tania	Yes			
	Neville	Yes			
	Winston	Yes			

Section B Control

The findings are presented under three subthemes:

B1 Visibility
B2 Autonomy
B3 Organisational influences

B1 Visibility

Information gaps *'…[patients] know we exist but they don't know how to get in contact'*

It seemed to be a common assumption that information about the district nursing service was available, usually on providers' websites. However, during the focus group interviews, it emerged that district nurses seemed less certain about what web-based information was available and how patients might access the service. District nurses recognised that access to web-based information is dependent on having particular resources, *…then our patient group would they really be on the Internet?...can't look it up it's farcical…(Sheila qualified district nurse).* Some district nurses were uncertain where patients got information about the service, …*somewhere out there, there must be some good information on a website…(Linda qualified district nurse)*.

District nursing not publicised *'there's nothing to say what the district nurse services will or won't provide…and it's not publicised anymore'*

Written information in the form of leaflets, provided when receiving the service and left in patients' homes, was mentioned by some focus group participants, *all of your patients get given a leaflet when [seen] (Serbjit student district nurse)* and *when we see them…we have them ready printed don't we? (Sheila qualified district nurse)*. However, it was not clear how the leaflets were received and what value they had for patients. Not all district nursing providers distributed leaflets: Esther perceived this as a gap, as viewing district nurses' records left in the home was inadequate as a source of patient information,

yes I think it would [help to have a leaflet] because the only actual information that they've got is when they have a set of notes, so they've already been taken onto the district nursing caseload which says you must be housebound and we don't do medication and where actually with the community treatment team, those leaflets are left I've seen them [in surgeries] everywhere but there's nothing to say what the district

nurse services will or won't provide…and it's not publicised anymore and even from [names provider]…(Esther qualified district nurse).

Esther implied that district nursing was being left behind, as other services were being made publically available. However, for some district nurses being below the radar may be preferred, *…we're pretty invisible really when you think about it, maybe we like it that way (Anne student district nurse)*.

Role confusion *'you weren't allowed to call yourself a district nurse'*

Other ways in which district nurses felt they were invisible included confusion about the multiple terms used to describe a district nurse and those practitioners working in the community. Louise felt that such terms were confusing for patients,

yes I guess patients understand that [district nurse] they don't understand community nurse, one of my nurses came from another area and she was calling herself a primary care nurse and well they had no idea what a primary care nurse was, but then when I started you were a community based staff nurse and you weren't allowed to call yourself a district nurse…I think district nurses and district nursing as a profession has been neglected and ignored for an awfully long time and so people were less aware of district nursing they don't know the difference between a practice nurse and a district nurse and a speciality nurse so it's not a very understood service any more (Louise student district nurse)

For some district nurses, patients' awareness of the term district nurse was insufficient, *they all know we exist but they don't know how to get in contact with us (Nell unqualified district nurse)*. Louise's experience of the change in status of the district nurse qualification over time indicated that it was not well understood. For all district nurses there was a sense that, *I don't think anybody knows what we do (Maria qualified district nurse)*. District nurses indicated a sense of not being valued, which they connected to a lack of recognition of their qualification, skills and seniority and which were not discernable by patients,

…the carers wear the same uniform as us…I've got a deputy manager in one of the homes and she wears exactly the same uniform as I do and sometimes I explain it cos…patients ask why do you wear the dark blue [uniform] then you explain it and 'Oh are they not proper district nurses?' It's like, 'No, no they're proper nurses but they just haven't got an extra qualification that's all, it's absolutely fine don't worry' (Siobhan qualified district nurse).

Though patients wanted to understand the distinctions, Siobhan indicated that patients would not be able to differentiate between a qualified district nurse, community nurse or a carer visiting them. Siobhan reported that she gave up trying to explain the differences; it was not clear if this approach reinforced views that there were no real distinction between staff and their qualifications or if such distinctions mattered.

Not surprisingly therefore, there was confusion about the different terms and roles for staff, though the term district nurse was recognised by patients. Despite this, for some district nurses, patients' awareness of the term district nurse was insufficient, *they all know we exist but they don't know how to get in contact with us (Nell unqualified district nurse)*. Awareness of the service and district nurse's role appeared to be accepted by district nurses as necessary to access the service and recognised as information gaps for patients.

GP role *'the GP is the main point of contact they point them in the right direction'*

From the district nurses' perspectives, GPs were a key source of information as they made referrals to district nursing or passed their contact details on to patients as *…most people seem to access their GP first and then the GP will suggest [DN service] (Esther qualified district nurse)*. Most district nurses assumed that GPs would act as gatekeepers and provide helpful information to patients, *the GP is the main point of contact they point them in the right direction (Linda qualified district nurse)*. Although not stated explicitly, this information seems to be passed on verbally.

Despite the fact that GPs are regarded as pivotal, district nurses questioned the accuracy of GPs' knowledge about district nursing which was illustrated by poor quality referral information in some cases, *I've had various referrals from GPs recently er 'Could you just pop in to this couple cos they're elderly?' so I don't think anybody knows what we do (Esther qualified district nurse).* However, district nurses also reported that, *sometimes information that's given in the hospitals might be way off what we actually do...(Earl qualified district nurse).*

District nurses did not mention how other professionals found out about the service and it was unclear if they played any role in supplying it. Serbjit found that it, *…depends whose referred them some give them good information and some [patients] are quite surprised by the service we can offer (Serbjit student district nurse)*. In this case, the district nurse suggested the information was

incomplete, although the point was not elaborated further, it was not clear what was considered good quality information or what was information missing.

I think a lot of patients really have no idea what our service is about…if there's somebody whose brand new to the service they very often don't have a clue as to what we do (Carlene qualified district nurse).

Service offered and expectations *'…seeing more complex patients…that would be in hospital'*

All district nurses considered that they were managing more complex care than in the past. Bev seemed to equate this to hospital level care and requiring a higher level of skills, *…seeing more complex patients that would generally be in hospital that are at home we're able to manage them more now (Bev qualified district nurse).* District nurses felt that they had higher levels of clinical skills than in the past.

District nurses viewed their service as preventing hospital admissions and enabling early discharge, *I would say hospital avoidance is something that we do a lot of (Winston qualified district nurse)*. Louise noted that district nurses' interventions could be calculated in savings to hospitals, *…we can do IV antibiotics in the community whereas before they would be in hospital for 2 weeks…in a bed that costs £500 a night... (Louise student district nurse).* Not only was complexity increasing but also district nurses highlighted increasing diversity of acute and long-term conditions. They described what they offered as a mix of general and specialist services (table 7.1).

Holistic care *'…[patients]…unaware of it...'*

It seemed from the data that some district nurses felt the holistic aspect of their role was hidden and patients only learned about this and the care co-ordination aspect once they received the service. At the same time district nurses were concerned that their role was not well understood and that unrealistic expectations were held by patients and many health professionals about their role, *…they don't have a full understanding of what district nurses do…they think we do everything and anything for instance to go and assess for a hoist… (Cerys qualified district nurse)*

…[DN] go in…they see the whole thing and then they send out the referrals to social services, they'll do the OTs, the physios and the patients are…unaware of it,

so astounded by the fact that we can actually open [access to services]…to give them even more holistic care (Nell unqualified district nurse).

B1 Summary

All district nurses presumed that service information was available from the internet and most accepted there were difficulties for patients in accessing information, whether leaflets, web-based or from GPs and hospitals. It was acknowledged by district nurses that only limited information appeared to be available prior to receiving the service. From district nurses' perspectives, GPs played an important role in providing service information to patients, although district nurses considered those making referrals did not understand their role or the service and the information may not be accurate. Some district nurses perceived the lack of bespoke service information and publicity as indicative of decline or undervaluing of district nursing.

Confusion over a plethora of roles and titles and a loss of status for qualified district nurses seemed to contribute to district nurses' sense of being invisible. District nurses felt that they were highly skilled and managing more complex care and delivering what was once considered hospital care. Though they asserted their key remit was to prevent hospital admission, they felt that their service was still misunderstood. Holistic care seemed to be the least understood or visible aspect of their role. There was some sense that district nurses were not in control of information about their service.

B2 Autonomy of the district nurse

Decision making *'…I just didn't say 'no'…covered everything, ticked every box…'*

District nurses reported exercising autonomy to control access at the point of referral. All district nurses reported that they carried out an initial assessment of patients' needs and their eligibility for the service, particularly whether patients met the housebound criterion, *…a service that provides nursing care within patient homes, these patients should meet the criteria and they should be housebound…(Neville qualified district nurse)*. District nurses often checked patients' housebound status over the phone prior to the first assessment and declined the service at that point,

...even though you've told the patient...'you're unsuitable for district nursing'...you may go and assess them...and say 'you know you're not really meeting the criteria'...then you'd phone the GP receptionist…(Linda qualified district nurse).

Although Linda decided that this patient did not meet the service criteria, it appeared there were circumstances under which patients could receive the service; in this case the GP had requested the patient contact the district nurse directly to arrange a blood test. It was unclear why the GP had not made the referral or why their request led to a reversal of Linda's decision.

District nurses reported their access decisions involved the interplay of different factors: patients' clinical and social circumstances, the presence or absence of other services as well as the likelihood of long term care. They considered that a degree of judgement was also needed, as these decisions were not necessarily straightforward,

it isn't a cut and dried thing …I've done a new assessment this morning and the lady's only discharged from hospital yesterday and to all intents and purposes at this moment in time she is housebound (Maria qualified district nurse) and *…some days you'll see a patient you'll assess them and you think 'ooh they're housebound' and then subsequent visits…actually you can move them onto the appropriate services (Esther district nurse).*

From the focus groups, decisions around eligibility were not necessarily fixed, so if a patient was deemed to be housebound initially and received the service, assessment was ongoing and the district nurse's decision could change, as the patient's condition changed.

District nurses' revealed their decisions to decline, discontinue or continue access to the service were usually overt and discussed with patients. District nurses did not always feel comfortable refusing the service where the criteria were not met as, *...it makes you look like the bad guy… (Louise student district nurse).*

Covert decisions *when I get there at four o'clock…she doesn't want to see me*

Some district nurses revealed more covert methods by which they controlled access, which often involved the frequency or timing of visits,

I will make a point when I know somebody's starting to mess around so we've had a particular lady who has been really obstructive, isn't housebound but insists on a visit on every Wednesday so I've been visiting her…I've been tied up quite a lot in the morning so when I get there at four o'clock and four thirty she doesn't want to see me cos she's already managed to dress it herself or she's gone out I got rid of her (Esther qualified district nurse).

Esther seemed to rationalise this decision to withdraw the service by manipulating the timing of visits, which she knew would not suit this patient. Because it lacked transparency in terms of her clinical decision-making, I have defined this as covert. Her decision seemed to rest on the belief that this patient was self-caring and not housebound, thus neither in need of the service nor eligible for it. There was also a sense that Esther felt the patient was being in some way uncooperative. Her decision also seemed to have an element of personal judgement rather than adhering to a clinical protocol.

Decisions undermined *'…but clinically he didn't fit the district nursing services…'*

However, some district nurses reported that their decisions to decline access were undermined by their managers. In these cases, district nurses felt unsupported and that such decisions were incorrect and contradicted the agreed service criteria,

…all the other services said 'it's for health, it's not social care', Matron said 'no, manky house, disgusting, patient awful' but that's what it came down to and it was a disgusting place but nobody else wanted to go into this patient but clinically he didn't fit the district nursing services…I just didn't say no did the whole Mental capacity the whole lot covered everything ticked every box (Charlotte qualified district nurse).

As other services appeared to step away and shifted responsibility to the district nursing service, Charlotte felt forced into taking on a patient as no one else wanted to visit. It was not known in what way he did not meet the district nursing criteria. Subsequently, she was able to block this patient's discharge despite having been over ruled earlier,

… I'm blocking his discharge [from hospital] because …the house had to be deep cleaned to the extent it was so bad it's in excess of a thousand pounds to clean the house inside so we don't know how cluttered it is inside so we need to get in there to see if we can get equipment in there…(Charlotte qualified district nurse).

Although Charlotte's decision to impose certain conditions prevented access temporarily but whether there was any covert element was not apparent. District nurses expressed a sense of resignation where their decisions were challenged however, often they acquiesced and visited the patient.

B2 Summary

District nurses suggested they had the power to control access to the service through assessment of patients' eligibility and needs. Though they recognised making such decisions was not straightforward, overt and covert decisions appeared to be used to control or rescind access. Overt decisions tended to be more transparent and objective, for example based on care needs, while covert decisions appeared to be more subjective with the potential for bias or being judgmental. However, exercising this autonomy and professional judgement seemed to be limited as their decisions were open to challenge and could be undermined by managers, GPs, patients' demands or the absence of other services. For district nurses, these contested decisions revealed wider organisational influences coupled with an underlying misunderstanding of their role and service.

B3 Organisational Influences

District nurses reported organisational influences on service access that included: commissioning, workforce shortages and a lack of service investment.

Commissioning *all they're worried about is 'did you make that contact?' tick*

District nurses appeared to be conscious of their responsibilities to fulfill commissioning requirements and they reported that managers influenced their decisions about access,

…I do think the emphasis from our management point of view [is that] they have to be housebound …we've had to become a little bit more rigid with respect of with the commissioner provider split…(Esther qualified district nurse).

Pressure to ensure that only housebound patients received the service to fulfil commissioning contracts was expressed by Esther and other district nurses. District nurses did not appear to have any control over what was commissioned but they were very conscious of the impact on their funding if they did not meet commissioning targets by recording patient contact data,

…unoutcomed appointments so this means a loss of quite a lot of money…she'd break it down per clinician…she'd say you've still got 70 unoutcomed appointments because each unoutcomed appointment is money for us (Linda qualified district nurse).

Every district nursing contact was monitored, district nurses were of the view that commissioners were not interested in whether they provided holistic care, *all they're worried about is 'did you make that contact?' tick, done it …(Esther*

qualified district nurse). District nurses reported they were only required to select a task from a list to record a contact. Recording any additional care undertaken was not seen as worthwhile by them, as it had no impact on the number of contacts commissioned, and required more time for data entry. All district nurses reported that they always exceeded their targets.

Workforce pressures and investment *'…the good old district nurses will mop it up'*

All district nurses reported having high workloads and feelings of being overwhelmed by daily referrals, we're *snowed under with work anyway…you're just inundated with referrals (Linda qualified district nurse).* District nurses explained managing their workload was challenging due to competing needs and complexity,

...the referrals you receive if they are bloods they're quite easy, but yesterday they were all new patients, new to the teams, just discharged from hospital 30 or 40, all of them time consuming (Monika qualified district nurse).

District nurses reported that triage was used to help manage referrals and decide priorities, usually staffed by qualified district nurses. There were mixed views about triage. Some district nurses saw it as timesaving for frontline staff as preparatory work, such as checking eligibility and that referral information, was completed prior to visiting. Others felt triage compounded staff shortages, as senior experienced staff would be better deployed visiting patients. As Tania reflected, if *we got them [referrals] all perfectly done in the first place we wouldn't have to do that (Tania qualified district nurse)* and for Louise triage alone did not address high staff workloads,

and the problem is that when you're on triage you're ringing people that have already got 13 or 14 visits and trying to give them extra visits and they're like 'really? I can't do any more'…so in the end you know it doesn't really help…(Louise student district nurse).

District nurses raised concerns about staffing levels and as Louise indicated there was a sense of unlimited capacity in taking referrals. Patient safety was raised in the focus groups in relation to workforce and workload pressures: district nurses stated managers were aware of workforce shortages and recruiting staff to vacancies was difficult however,

it's like when we're really dangerously short staffed they say 'did you Datix it?' and if you're doing 20 visits the last thing you're gonna do is come back and do a Datix about no staff as well… (Louise student district nurse).

Louise conveyed a sense of frustration that on top of a heavy workload there was a requirement to report staff shortages. It was not clear why this was required of front line staff. There was also a sense from them that reporting in this way would not make any difference given managers were aware of these shortages.

Lack of time

District nurses also explained the knock-on impact for patients of high workloads and staff shortage, as less time to spend with patients,

I don't think we have enough time with patients to do everything…you could go to [name] services and they've just got all that much more time…(Linda qualified district nurse).

Linda seemed to imply that a lack of time resulted in short cuts in care. While district nurses compared their experience with specialist intervention community nursing services, which they perceived as having more time, better staffing levels and fewer patients. District nurses also reported that they lost skilled staff to these new services,

…you get lots of good nurses in district nursing but they're just all sucked into different specialities because to be a [band] 6 you have to do your DN training so it's much easier to go to CTT or as matrons or somewhere else (Louise student district nurse).

As Louise asserted there was less incentive to stay in district nursing or qualify as a district nurse. District nurses seemed to resent investment in these new community services at what they saw as the expense of their service,

they can't use it [development money] to bolster existing services so we have these lovely teams set up and then when they have very strict criteria and then when it gets to the crux then there's the good old district nurses will mop it up……if you [look] at CTT and… community matrons we didn't need those services what we needed to do was use the specialist nurses we currently have and then bolster the district nursing teams to use these highly skilled [district nurses] (Charlotte qualified district nurse).

District nurses perceived these services as not only diverting investment away from district nursing unnecessarily but also increasing demand as district nurses were expected to pick up this care at a later point. As they reported under use of their skills, such developments seemed to reinforce district nurses' view that district nursing lacked investment and was undervalued,

even with community matrons as soon as they've done their bit being all dynamic then they'll dump what's left on the district nurses so we inherit a lot of everybody else's tut [rubbish] really (Charlotte qualified district nurse)

As Charlotte asserted other community-based services hand back patients to district nurses that they would have looked after in the past. District nurses seemed to feel that somehow they were second best and a service of last resort and therefore experienced access as beyond their control.

B3 Summary

District nurses were conscious of how their workload and decisions were influenced by commissioners and managers. Ensuring that the service was for housebound patients and that contacts were recorded accurately were seen as important to fulfill commissioner requirements, rather than meeting care needs. They perceived commissioners as focusing only on recorded activity and completed tasks rather than holistic care. Views about the benefits of triage to manage referrals were mixed.

Increased demand coupled with staff shortages were reported by district nurses including concerns about patient safety, reduced time for patients and lack of investment in the service. District nurses felt investments in new community specialist nursing services were not necessary and at their expense. This was twofold as they perceived these resources would be better spent on district nursing, secondly, the new services encroached on their role and they were left to pick up what others did not want to do. For district nurses, organisational influences appeared to cause further workforce strain and maintained uncontrolled demand.

Section B Summary

Control was revealed as ways in which access to district nursing seemed to be regulated either by district nurses or others, including those who made referrals. District nurses felt that it was their role to ensure that the service was provided only to those who were eligible, and they exercised autonomy in their decision-making in relation to this. District nurses' perceptions of how patients and carers

acquired information about the service seemed to rest on assumptions that the information was available on the internet or provided by those making referrals, though they recognised patients' difficulties getting information about the service and thought information was incomplete or inaccurate and more generally missing. They considered this information gap contributed to their sense of being invisible, reflecting their concern that their role and service was not understood.

Although involved in complex and skilled care, district nurses felt holistic care was the least well-known or visible aspect of their role. Related to this, there was a sense that district nurses felt they had little control about service decisions. They reported experiences of overt and covert control in relation to themselves, where their professional autonomy was over ruled. They identified managers, commissioners and GPs as those exercising control over district nurses' decisions about patients' access.

Paradoxically and perhaps in an effort to overcome this sense of powerlessness, district nurses seemed to exercise considerable autonomy in controlling access to the service and actively screened referrals to ensure patients met the eligibility criteria. Though they acknowledged difficulty in defining what being housebound meant, their access decisions appeared more overt when determining who was housebound. Covert decisions reported by some district nurses were used to modify access through the frequency and timing of visits. However, district nurses reported that managers and others could undermine their access decisions. Most district nurses seemed to feel that their role and service was misunderstood with a sense of confusion and that they were undervalued

Section C Appropriateness of referrals

This section is divided into three subsections:

C1 Self-referral
C2 Being housebound
C3 Receiving referrals

C1 Self-referral

Possible *'…they can self-refer but I mean how often does that happen?'*

Almost all district nurses asserted that it was possible for patients to self-refer to the service ab initio, though no one could think of an actual example where this had happened. During the course of the focus groups some district nurses recognised that prospective patients not only did not have access to service information and contact details until receiving the service but also that patients were unaware self-referral was possible,

they can self-refer but I mean how often does that happen?…it is permitted yeah but it's not a common occurrence… definitely you can but I've never known it…but I don't think patients are aware that they can actually do that, I don't think the information is out there that people think 'OK I'll ring this number and refer myself' (Anne student district nurse)

District nurses identified a type of self-referral where GPs gave patients the district nurses' contact details and advised them to make direct contact. This type of self-referral extended to former patients who had been given district nurses' contact details and encouraged to call when in need or palliative care, *…if we discharge them they can then phone back again (Serbjit qualified district nurse).* As Serbjit infers contact details are needed be able to self-refer. District nurses considered it appropriate for patients who were already known to them to be able to self-refer.

Most district nurses said they would accept self-referrals from carers though no one reported this in practice, although some said they would refuse and route carers back to GPs to make the referral.

Not a proper referral *'they'll just ring up…and you…haven't got a proper referral'*

District nurses accepted that self-referral was possible but expressed a range of concerns about accepting self-referrals ab initio. It was not clear whether these concerns were hypothetical or actual impediments to self-referral that they had encountered. From the focus groups self-referrals were perceived as unwelcome and inappropriate,

we don't really like or want people to self-refer because people you get phone calls from people with sort of totally out there expectations they want a nurse for say a toe dressing but they're mobilising and stuff like that you know they're not housebound…(Linda qualified district nurse)

It was not clear if Linda had actually experienced patients ringing up with unrealistic expectations or who did not meet the eligibility criteria. However, some district nurses seemed to assume those who were not housebound might self-refer, this seemed to convey an underlying fear that somehow self-referral might be for trivial reasons and increase demand that could not be met. Although self-referrals ab initio did not seem to have been received, District nurses seemed to acknowledge there was potential demand for self-referrals, *…because you know we don't have the resources to see everyone, every adult who wanted to be seen, who is not necessarily housebound (Winston qualified district nurse).*

Some district nurses appeared to have an underlying unease about the adequacy of self-referrals in that they were not proper referrals because they had not been processed on the various referrals systems. Self-referrals, unless initiated by another professional like a GP, might omit required information that would be on a referral form, *…I mean we're not just going to go in and see a patient without knowing their full background (Serbjit student district nurse)* and …*otherwise if people sometimes who sort of self refer but sometimes they'll just ring up the number and you go to RIO haven't got a proper referral (Siobhan qualified district nurse).*

Some district nurses raised staff safety with self-referrals seen as potentially unsafe. They implied professionals' referrals provided reassurance that the reasons for visits were specified and the patients were deemed to be genuine.

C1 Summary

District nurses believed it was possible for patients to self-refer ab initio, however no one had done this in practice. District nurses recognised that patients may not be aware they could self-refer and were without contact details to enable this. An alternative type of self-referral was in operation where patients made direct contact with district nurses at the request of GPs or where

patients were known to district nurses. For new patients, some district nurses raised concerns as self-referrals were not seen as proper referrals, and patients' motives for self-referral were also questioned. Though speaking hypothetically, district nurses expressed some anxiety about the impact of uncontrolled demand, incomplete patient information and staff safety arising from self-referral.

C2 Being housebound

Defining being housebound *'…if they're truly housebound they're gonna be in'*

District nurses reported the same two eligibility criteria were used to gain access to the district nursing service: being adults and housebound. District nurses cited being housebound the most and it seemed to be pre-eminent. District nurses stated that they offered broad coverage of health conditions but there were no clinical eligibility criteria. Many district nurses considered that seeing housebound patients was a distinctive characteristic of district nursing,

… there's plenty of other services for people that are not housebound…but…now we're having to be specific that we have to do housebound otherwise we'll just take everybody on and we just don't have the staff… we want to see the patients…like the palliative care patients, people that can't get out and need us and not the people who have got other options (Linda qualified district nurse)

From Linda's perspective establishing who was housebound ensured that only those with no alternative accessed district nursing. District nurses tended to mention both access and resources: they reported that they had to justify access in relation to resources when challenged,

…I feel that we are pressurized to make sure that they are totally [emphasising] housebound because of…the push on resources but it quite often comes back at us, 'well that patient wasn't housebound so why were you seeing them anyway?' so I feel that we have to be quite rigid…(Esther qualified district nurse)

There was a perception expressed by Esther that district nurses have to apply the housebound criterion in a rigid way, with underlying assumption of a shared understanding of what being housebound means.

Characteristics of being housebound

From the focus groups, a housebound patient was usually described as someone in need of nursing care at home. District nurses qualified this further by explaining being housebound also included consideration of the patient's age, mobility and ability to leave their home. Even so district nurses acknowledged that defining who was housebound was not necessarily clear cut and reported using different mechanisms, for example, professional judgement to check it, usually looking at the date of birth and ringing the patient to check their ability to go out.

District nurses also reported that if they visited a patient's house and they were not in that would confirm that they were not housebound, *we just turn up cos if they're truly housebound they're gonna be in (Charlotte qualified district nurse)*. As Charlotte implied the acid test of being housebound was that patients should always be at home though, *it's not that simple because I'd say unless they're completely paralysed in a bed most people do go out of the house at some point…(Louise student district nurse)*.

For some district nurses defining being housebound was more nuanced, where patients in need of considerable assistance to go out could be deemed housebound though some limited this to attending medical appointments, *…there's some argument that if they can go to the hairdressers then they're not housebound and…I mean it's very difficult to…draw that rigid line…(Esther district nurse)*. District nurses seemed to grapple with individual patient circumstances which may result in a less rigid definition of being housebound as Maryam's account shows,

…*I went to a patient and she said to me ' I'm just waiting for my taxi' and I said 'Where are you going?' and she said 'I'm going to the hairdressers' and I said 'We only see housebound patients and then I realised that this lady's actually blind and she had a cane, she couldn't [see] anything. I had to make that judgement that actually she couldn't be escorted when she went to have her blood taken in a clinic...yet the driver from the taxi could escort her to and see her in [to the hairdressers] so I had to say well actually she is housebound really and I took her blood...you have to make that decision (Maryam qualified district nurse).*

Variations in definitions

There were variations in how district nurses defined being housebound, some seemed to take quite a rigid approach where patients never left their homes

while others seemed to take a more nuanced approach which seemed to be personalised and context dependent. Some district nurses acknowledged that it was not always possible to tell immediately if a patient was housebound. Being housebound also did not appear to be a permanent state,

[housebound] these are patients debilitated by health condition or co-morbidities that make them not able to access their GP practice or practice nurse and therefore they would need a nurse to come in and provide the nursing care for a short period of time until they're well enough to access the GP practice or practice nurse or for a long period of time where they are bedbound (Neville qualified district nurse).

Although Neville made a distinction between short term and long-term district nursing needs, it was not clear what he meant by the term bedbound and if this was his definition of housebound. While most district nurses rationalised their decisions, about who was housebound, by taking into account patients' circumstances and the local context including resources and the proximity of other services. Cerys made a broader public health point that seemed to challenge the maintenance of the housebound criterion,

at the moment it's housebound but some of the population with long-term conditions some of them are not housebound yet but …if it can be managed early enough…(Cerys qualified district nurse).

Exceptions *'there are exceptions...it is a judgement call'*

Exceptions to the housebound criterion were stated by district nurses that permitted access to the service at home, *…I mean there'll be the exceptions and the website does make it quite clear that it's for housebound patients…(Winston qualified district nurse).* From Winston's comment it is not clear if the information about these exceptions was on the website or how those making referrals would know what they were. Exceptions included referrals from other professionals because they did not operate an out of hours service,

another exception would be weekends where there's no availability of the practice nurse there's no nearest walk in centre and so the practice nurses will refer the patient (Neville qualified district nurse).

District nurses did not seem to question these referrals and accepted that they would see these patients at home. They also reported that those seen in district nurse-led clinics could leave their homes …*and if they actually did have transport*

they wouldn't be housebound... (Siobhan qualified district nurse). District nurses viewed access to transport as a determining factor for who may be considered housebound. District nurses indicated that the presence or absence of particular resources or particular clinical conditions could determine whether patients were exceptionally defined as being housebound.

C2 Summary

District nurses reported it was essential that only housebound patients gained access to the district nursing service and necessary to be able to justify this access. District nurses seemed to use three key determinants in deciding if a patient was housebound: age, mobility and ability to go out. However, in practice, these definitions of being housebound varied; some considered this as being bedbound or never leaving their homes, while other more nuanced explanations were offered. Judgements were informed by individual patients' circumstances and the wider context of care provision, including being temporarily housebound. Taken together, there was some recognition that definitions were ambiguous, not clear-cut or permanent and there were exceptions. Exceptions to being housebound related to the absence of other services and resources or particular clinical conditions such as dementia, which were accepted for home visits.

C3 Receiving referrals

Poor referrals *'…it's known that the referrals are rubbish'*

District nurses described problematic referrals as either inappropriate or of poor quality. These referrals seemed to be a source of frustration because district nurses felt they increased their workloads and delayed patient access. Unrealistic expectations of the service were cited by them as a reason for poor referrals *…they don't have a full understanding of what district nurses do…(Cerys qualified district nurse)*. All district nurses reported receiving inappropriate referrals, commonly this was because the referred patients did not meet the service eligibility criterion of being housebound. Checking whether patients were housebound was a priority on receiving a referral, *…make sure they're appropriate and meets the criteria such as to make sure the patient is housebound… (Anne student district nurse).*

…for whatever reason you feel that they are not housebound we would ring and make those enquiries either of the hospital or whoever did the referral or even see the patient…(Tania qualified district nurse).

GPs deliberately refer

District nurses reported that at times GPs had knowingly made referrals that did not meet the criteria,

…sometimes it's actually deliberate because some of the referrals are 'surely you've worked with us long enough to know what the criteria are' …you would think the GPs should know the criteria…(Earl qualified district nurse).

It is unclear if Earl informed GPs directly about the criteria, his assumption that GPs would have picked them up shaped his view that it was not possible for GPs not to know the criteria and conclude inappropriate referrals were deliberate. However, other district nurses cited examples of such inappropriate referrals from GPs even where the criteria had been explained to the GP in person. This also seemed to reinforce district nurses' perception that they were seen as a service of last resort, if health and social care staff did not know where to refer they would be sent to them,

…I think some services use [the] district nursing service when they've come to the end of their…options… the district nurse she'll go in once a week and keep an eye on them because they won't accept any other service... you feel like you're sort of the last resort for a lot of patients that are not appropriate and it's difficult to refuse these patients... (Linda qualified district nurse).

Missing information

Unanimously district nurses reported that they received poor referrals: information appeared to be missing or incorrect on referral forms, for Linda this meant she was unable to contact patients,

people when they're filling in the form they forget phone numbers or often put wrong phone numbers and you can sometimes have old addresses for people because that's what was on the hospital notes…and they are not registered with that GP…you can't even ring up to check [to] make first contact with the patient cos then you find that's wrong and ring back to the hospital (Linda qualified district nurse)

District nurses reported they contacted patients prior to visiting to check the accuracy of addresses and basic information before visiting. Triage appeared to be used by district nurses as a mechanism to manage poor referrals.

Dealing with inappropriate referrals

District nurses reported that inappropriate referrals were rejected and sent back, *…I'm having to bounce back and say from our previous discussions this patient does not meet our criteria (Neville qualified district nurse).* Other than returning or refusing referrals, none of the district nurses reported whether inappropriate referrals had been dealt with pre-emptively. Louise, *…it would be good to provide [leaflets] so people understand the referral criteria cos you are sort of banging your head against a brick wall all the time…(Louise student district nurse).*

District nurses indicated that poor referrals was a chronic problem, and as Esther implies it seemed easier to put up with the problem than address it, *…it's known that the referrals are rubbish … but then it's a time thing…back to having the capacity to actually address this it's not worth the hassle (Esther qualified district nurse)*

Section C Summary

Self-referral ab initio was possible, however district nurses reported no one had done this in practice. District nurses recognised that patients may not be aware they could self-refer. Though they also expressed some anxiety about the impact of self-referrals on uncontrolled demand. Some district nurses raised concerns, as self-referrals were not seen as proper referrals. For district nurses, it was essential that only housebound patients gained access to the service, and they needed to justify access decisions. Definitions of being housebound varied and district nurses acknowledged this was not clear-cut; some definitions were more literal, while others were more nuanced and situationally determined. District nurses offered a range of explanations as to why professionals sent inappropriate referrals, including unrealistic expectations of the service and a lack of understanding of the referral criteria.

Summary of the main findings

- There were information gaps in how patients found out about the district nursing services
- Web and paper-based information appeared to be available but it was questionable how accessible or tailored the information was to patients' needs
- District nurses felt GPs played an important role in providing service information to patients

- District nurses felt that no one understood their role or the service, including many GPs
- A high degree of autonomy in decision making was exercised by district nurses in terms of permitting access to the service, revealing the use of overt and covert mechanisms
- District nurses did not always feel supported by their managers and decisions they made about access were overruled
- Expectations about their role and service revealed there was a sense of confusion about different roles within and across district nursing, with a sense of being undervalued
- District nurses were well aware of commissioning requirements but did not feel that commissioners were much interested in what they did beyond completing tasks
- Staff reported high workloads and shortages of staff
- There was a sense that district nursing was not an investment priority
- Self-referrals appeared to be possible but did not seem to be happening in practice
- District nurses seemed ambivalent about self-referrals fearing an increase in demand and that they were not proper referrals
- The housebound criterion was pre-eminent and district nurses sought to define it and apply certain criteria to check patients were housebound: age, mobility and ability to go out
- District nurses acknowledged that it was difficult to apply the housebound definition in the context of ambiguity and changing patient need, requiring some element of professional judgement
- Exceptions to the housebound criteria were made and the service provided
- Referrals were problematic and poor referrals arrived with missing information, and inappropriate referrals were those that misunderstood the service or referred patients who were not eligible particularly those who were not housebound.
- There was a sense that the district nursing service was a dumping ground for others
- Systems played their part in rendering referrals less efficient

This chapter presented the findings from four focus groups with district nurses revealing their views, perceptions and experiences in relation to access to their service under the two main themes of control and appropriateness of referrals. The findings here have informed the questions for both surveys in phase two to elicit how the service is understood in relation to referral, including knowledge of

the eligibility criteria understanding of being housebound and self-referral. The next chapter presents the results of two surveys of district nursing staff and health and social care professionals who make referrals.

Chapter eight: Results of surveys with district nurses and health and social care professionals

Introduction

This chapter presents the results of two surveys, one for district nursing staff and one for health and social care professionals, completed by self-administered questionnaire. The purpose of the surveys was to capture respondents' perspectives regarding referral to district nursing and eligibility criteria used for service access. Both surveys were conducted in the same two provider organisations covering the same three local authorities.

There are two sections in this chapter: section A provides information about the respondents and response rates. Reflections on the low response rates are raised here in addition to chapter five, with further reflections offered in chapter eleven. Section B presents results from both surveys in textual, tabular and chart forms under four subsections: referrals, eligibility criteria, patient and carer access and views of the service.

As the response rate for each survey was low, the data were insufficient to apply statistical tests. A descriptive analysis of the statistical data is presented, with numerical data rounded to whole numbers for clarity (Cole, 2015). Results from closed questions were largely binary, however the analysis included negative results signifying where participants lacked knowledge or information about the service or where there were significant differences between each survey group, highlighting potential impact on referral practice.

Different perspectives were captured from district nursing staff receiving referrals and health and social care staff making referrals. Together with findings from the focus groups and interviews, they inform the final phase of the study that analyses information about the district nursing service publicly available on provider web sites. A summary of the main points is provided at the end of this chapter.

Section A Overview of respondents

This section consists of information about the respondents derived from the surveys and the response rates.

District nursing

The respondents (n=22) included all grades of qualified and unqualified staff. Half (n=11) were community nurses; five were health care assistants (HCA) with even numbers of qualified district nurses (n=3) and other staff (n=3) (table 8.1). Other staff included a student district nurse, assistant practitioner and integrated care matron. The higher number of community nurses and HCAs and fewer qualified district nurses is indicative of the distribution of roles in district nursing teams. The presence of one student district nurse also suggests that one provider offered sponsorships to train district nurses.

There were no respondents from managers, community matrons or specialist nurses. This could be because the survey was not sent to them or they elected not to participate. However, even though one integrated care matron responded, community matrons and specialist nurses may be functionally separate from district nursing staff. The single assistant practitioner did not elaborate on their role within district nursing: as a skilled non-registrant it may be that they provide a discrete service such as phlebotomy. The respondents profile is indicative of the skill mix in district nursing in both provider organisations, however given the low response rate it is not possible to assert this definitively.

Almost all respondents reported that they worked in either the north or east of London (table 8.1). Both areas were represented with a fairly even split of responses, with eleven staff from the north and ten staff from the east. Across all the staff roles this divide was consistent.

Response rate for district nursing

A total of 143 district nursing staff in both providers were sent the link to the survey questionnaire. Twenty-two questionnaires were completed, a response rate of 15% (table 8.1). Follow up emails were sent to the Trust collaborators on three occasions to increase the response rate.

Table 8.1 District nursing survey response

Type of provider	Respondents (number sent out)	Number of responses and response rate
Integrated Care Organisation covering two local authorities (north London)	District nursing staff (73)	12 (16%)
Foundation Trust covering one local authority (east London)	District nursing staff (70)	10 (16%)
	Total 143	**22 (15%)**

Health and social care

All staff groups responded (table 8.2). Practice nurses represented the largest single group at a third (n=25), followed by GPs (n=22). Together with practice managers (n=3), the majority of respondents (n=57) were from GP practices. This proportion may be higher as some respondents identified themselves under other, such as nurse practitioner, and may be located in GP practices. Twelve were care home managers; five were ward managers and three social workers. The higher proportion of responses from GP practices may indicate their interest in referrals, although subgroup sample sizes were uneven.

Over half of respondents worked in north London (n=41) and the rest working in east London (n=34) (table 8.2). All staff groups were represented across both providers, with the exception of social workers in the north, as only those in the east participated, as discussed in chapter five. There appeared to be a sufficient geographical split such that data for both provider units could be captured.

Response rate for health and social care staff

A total of 452 questionnaires were posted to health and social care staff. Seventy-seven questionnaires were returned, two were returned incomplete: one GP practice had closed and a residential care home did not have contact with the district nursing service. There were seventy-five usable questionnaires and a response rate of 17% (table 8.2). This was a disappointing result despite a number of techniques were employed to elicit a higher response. For example making the questionnaire straightforward to complete, including a pre-paid return envelope and a prize draw (Edwards *et al,* 2002). Particular efforts were made to reach social workers, as discussed earlier. However, two strategies known to be effective which were not undertaken due to time, costs and lack of access to personal data: 1) sending out pre-information directly to participants and 2) sending follow up letters (Edwards *et al,* 2002).

Table 8.2 Health and social care staff survey response

Type of provider unit	Staff making referrals (and number of letters sent out)	Number of responses and response rate
General Practices	GPs (123) (one questionnaire per practice)	22 (18%)
General Practices	Practice Nurses (123)	25 (20%)
Residential Care Homes	Care Home Managers (134)	13 (10%)
Hospitals 24 wards in ICO 29 wards in FT	Ward Managers (53)	5 (9%)
Adult Care Services No response from ICO 19 Social Workers in FT	Social Workers (19)	3 (16%)
Unclear from the responses in which organisation these respondents worked. It is likely that practice managers and nurse practitioners work in general practice but their responses have been dealt with separately under other	Other respondents: Practice manager x 2 Receptionist/Administrator x 1 Advanced Nurse Practitioner x 1 Health Care Assistants x 2 Nurse Practitioner x 1	7
	Total 452	75 (17%)

Section B Survey results for district nursing and health and social care staff

In this section results from district nursing and health and social care surveys are presented under four subsections: referrals, eligibility criteria, patient and carer access and views of the service. Table 8.3 maps the surveys' questions to these subsections, excluding staff profile questions presented in section A.

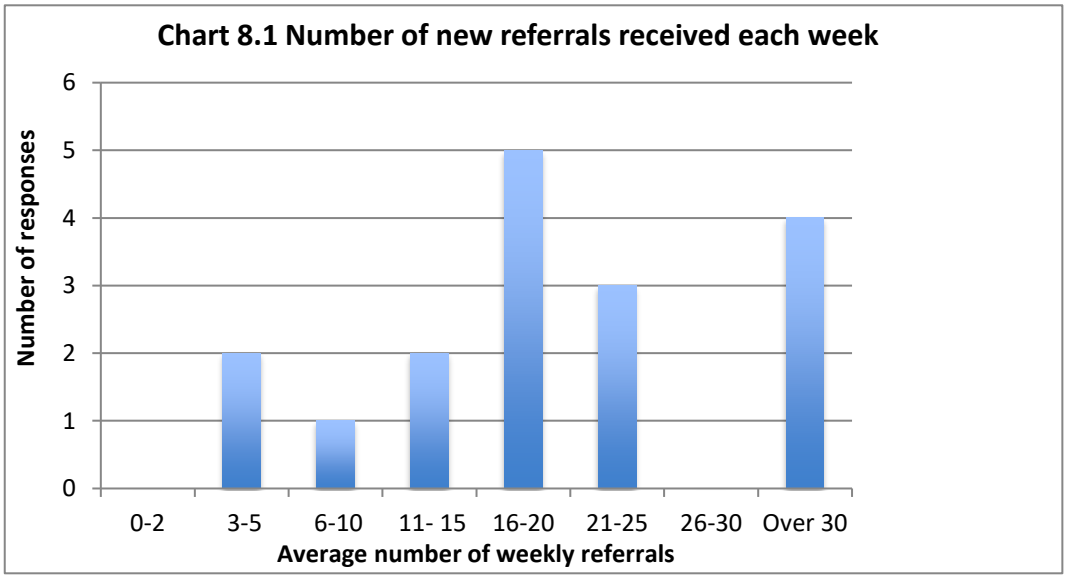
Table 8.3 Surveys' questions mapped to results subsections

Results subsections	District nursing staff survey	Health and social care staff survey
Referrals	Questions 3,4,5,6,7,8,9	Questions 2,4,5,6,7,8,9
Eligibility criteria	Questions 10,11,12,13	Questions 10,11,12,13
Patient and carer access	Questions 14,15,16	Questions 14,15,16
Views of the service	Questions 17,18,19	Questions 17, 18,19

As some of questions are in a slightly different order on each questionnaire, the question numbers in each subsection follow the number order on the district nursing survey questionnaire (appendix 7). Open question responses are presented in tables under main themes and quotes given in *blue italics*.

Referrals

Q.3 How many new referrals on average does your team receive per week?

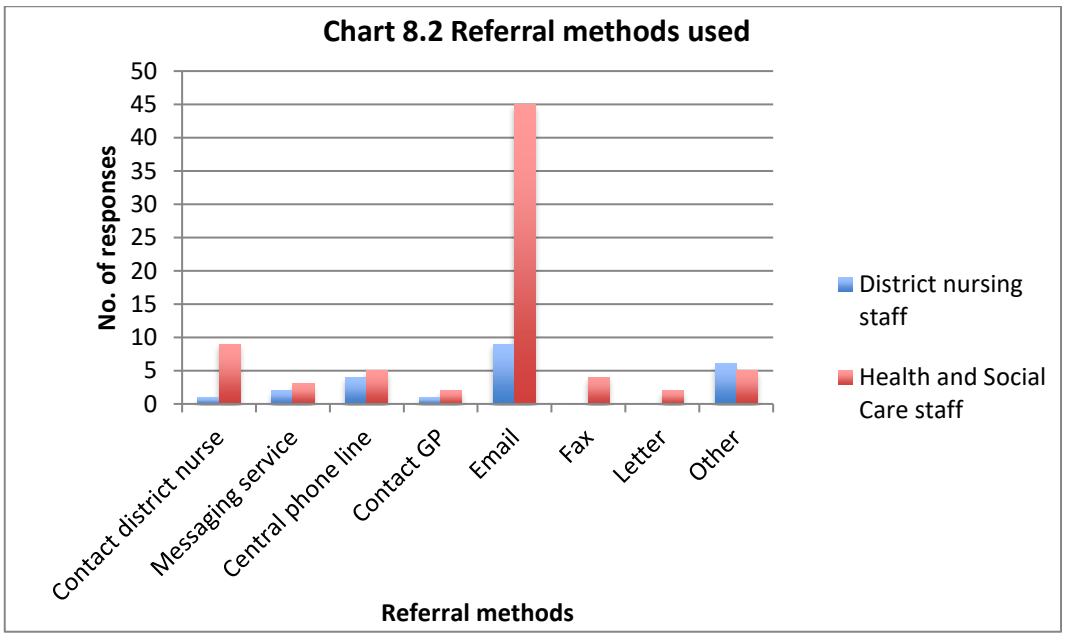


On average most district nurses received 16-20 new referrals a week (chart 8.1), and most health and social care staff sent referrals weekly. Under half (n=10) of all new referrals ranged between 11-25 weekly, but the most frequent was 16-20 (n=5). Though the second most frequent category was over 30 (n=4) referrals. However, five district nursing staff either did not know, thought it not applicable or were unsure how many referrals were received. It is likely that for some grades of staff their role did not include receiving referrals.

Over three quarters (n=58) of health and social care staff sent referrals ranging from daily to monthly, but weekly referrals were the most frequent (n=20). There was an almost even split between daily (n=13) and fortnightly referrals, with twelve indicating monthly referrals. Likewise, there was an almost even distribution across other less frequent referral patterns: two monthly (n=4), three monthly (n=4) and six monthly (n=3). Four respondents (did not know how often they made referrals and one never made referrals and another thought it not applicable. Although, some care home managers commented that they either did not make referrals, or did not think they could or made referrals through the GP.

All responses suggest that district nursing referrals are made frequently and at volume, no district nursing staff reported not receiving any referrals. Comparatively, care home managers seem to be less likely to make referrals themselves.

Q.4 How are new referrals usually made to the district nursing service?



A variety of referral methods were in use. Email was the most common single referral method for both district nursing staff (n=9) and health and social care staff (n=45), as indicated in chart 8.2. Beyond this, there were some differences in the methods used by both groups.

District nursing staff received half (n=11) of the referrals through central referral methods. These methods collectively included: central phone number (n=4); messaging service (n=2); single point of access (n=2) and triage service (n=2), or a combination (n=1). While for health and social care staff the second most frequent referral method was contacting the relevant district nurse (n= 9), followed by the central phone number (n=5). By contrast, only one district nursing respondent indicated new referrals being received from GPs.

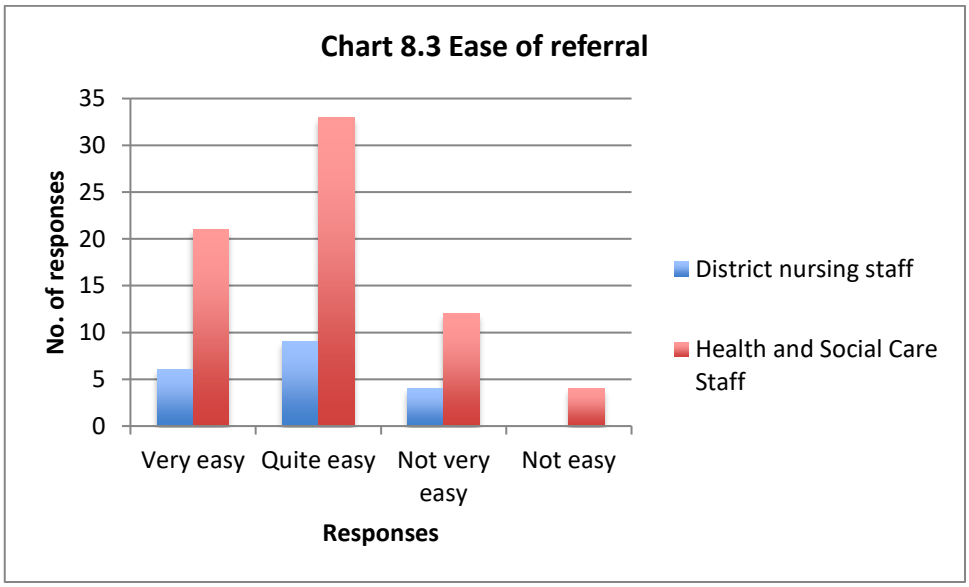
A small number of health and social care staff made referrals by fax (n=4) and post (n=2), though no district nursing staff received referrals by fax or post. This suggests these other methods have superseded them or perhaps district nursing staff do not have sight of these referrals if they are sent to a central access point. Referral forms were also used by a small number (n=3) of health and social care professionals, and one GP wrote,

'*We have to complete a long and complex form, getting scanned, send it electronically to a single point of access service then find out if they will accept it.' (GP)*

It may be, as illustrated by the GP's comments, referral methods and technologies are used in different combinations. From this example, it appeared that there was no electronic version of the referral form.

All referral methods were in use, with some variations between the methods each group used. Most methods were electronic and part of central referral systems. Both groups identified email as the most used referral method, which may be part of a central system, such as a single point of access or the means by which district nurses can be contacted.

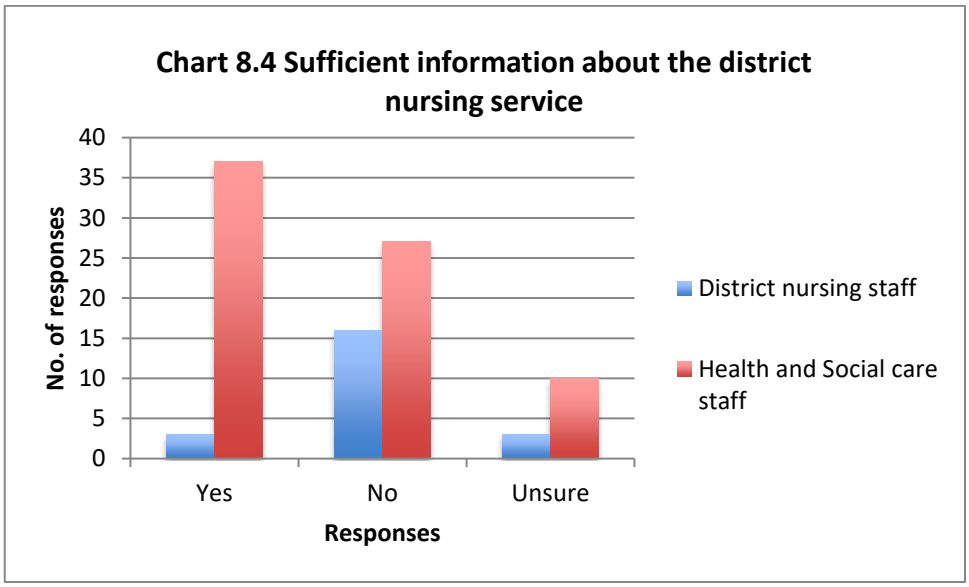
Q.5 How easy do you think it is to make a referral to the district nursing service?



The majority of all staff thought it was easy to make a referral but a sizeable minority did not (chart 8.3). Most district nursing respondents (n=15) thought it was either very easy (n=6) or quite easy (n=9) to make a referral. Similarly, most health and social care staff (n=54) found it very easy (n=21) or quite easy (n=33) to make referrals.

However, around a fifth of both staff groups thought it was not easy or not very easy: for district nursing staff (n=4) and for health and social care staff (n=16). This may reflect staff in both groups less involved in referrals, perhaps the referral process is complex or unclear to the uninitiated.

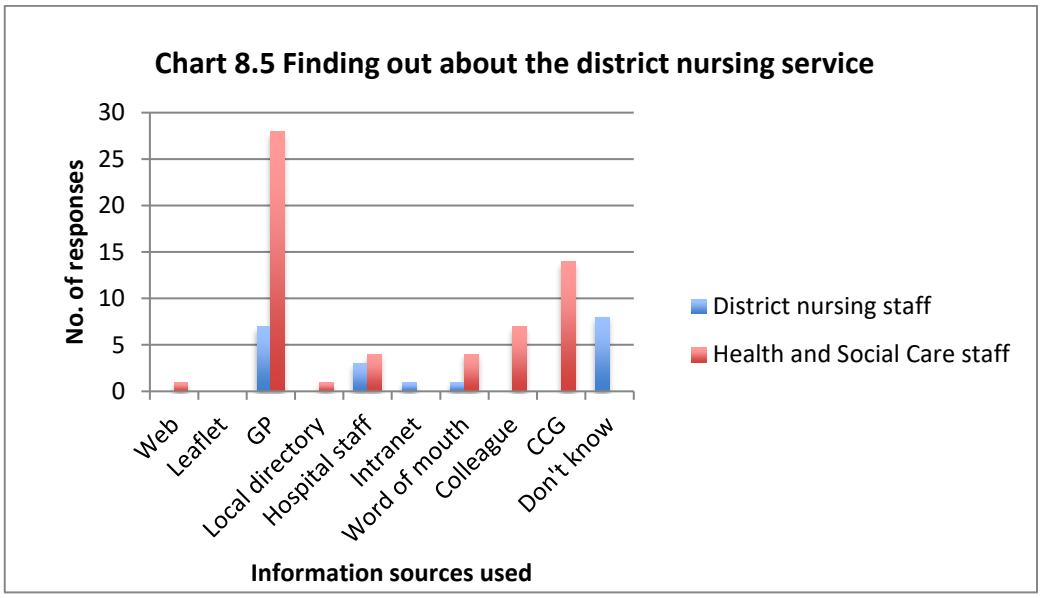
Q.6 Do you think that those making referrals have sufficient information about how the district nursing service operates?



There was a considerable difference between both staff groups (chart 8.4). Nearly three quarters of district nursing staff (n=16) did not think those making referrals had sufficient information about the service, while just under half of health and social care respondents (n=37) felt they had. A little over a third of health and social care staff (n=27) thought they did not have sufficient information, and a further ten were unsure.

These responses suggest perhaps that different understandings of the service exist. District nurses may also have different expectations of staff making referrals, and perhaps reflect negative experiences of referrals. However, for health and social care staff the wording was slightly different in their survey, as it did not specifically mention referrals (appendix 8 Q6) and it was open to interpretation. Even so the results suggest a potential gap in knowledge of the service for half of health and social care professionals.

Q.7 What do you think is the main way that those making referrals find out about the district nursing service?



Most respondents indicated that learning from others was the main way of finding out about the district nursing service (chart 8.5). Both staff groups saw GPs as the main source of information. This was just under a third (n=7) for district nursing respondents and well over a third (n=28) for health and social care staff respondents. However, more district nursing respondents (n=8) did not know how those making referrals found out about the service.

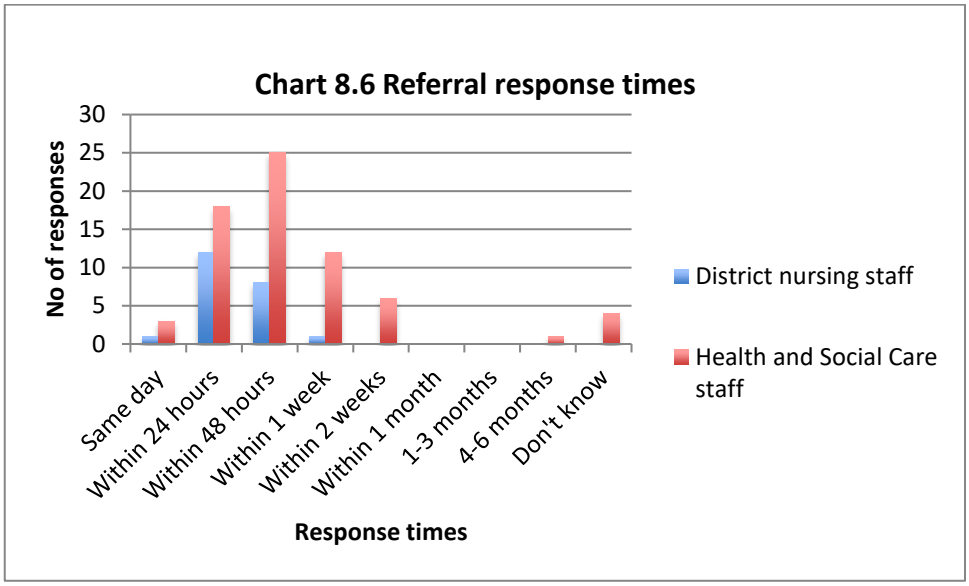
There was a difference between staff groups in the next highest category: health and social care respondents identified the CCG (n=14) and for district nursing respondents it was hospital staff (n=3). District nursing staff choices, GPs and hospital staff, may reflect that most referrals come from them. Health and social care also reported learning about the service from a colleague (n=7), word of mouth (n=4) and ward managers found out from hospital staff (n=4). Eight health and social care respondents, mainly GPs, commented on longstanding awareness of the service, arising from either training, previous experience or being in practice a long time. All these responses seem to reflect an informal approach to finding out about the service.

A small number (n=3) of health and social care respondents cited a local directory, the web and intranet as sources and one district nursing respondent also identified a local directory.

The results suggest that personal explanations about the service are widely used by these staff groups, especially from GPs. This method may be a preference,

although leaflets or web sources were barely used. There does not appear to be a system in place for staff to learn about district nursing.

Q.8 How long does it usually take from receiving a referral to getting a first visit by the district nurse?

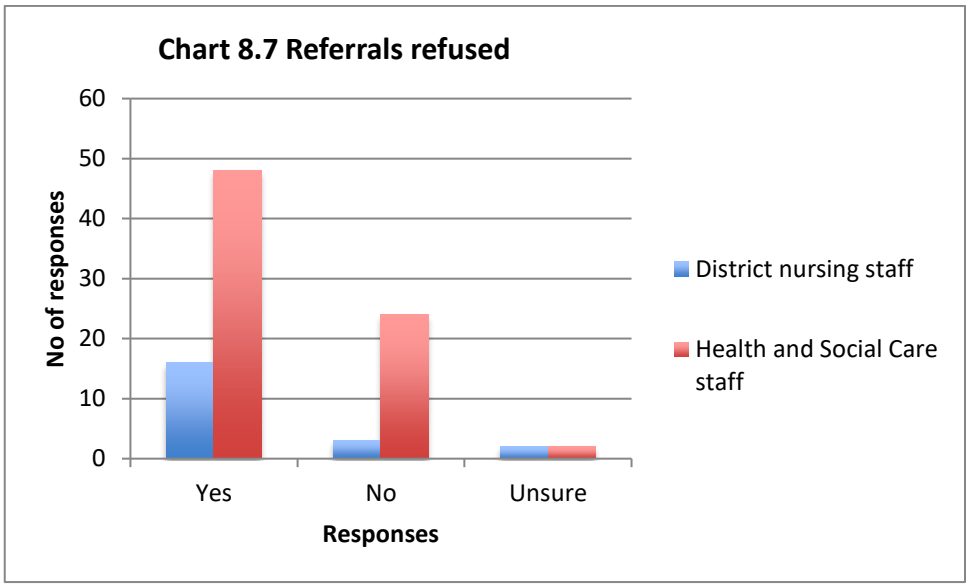


Both staff groups thought that a district nurse would visit within 24 hours or 48 hours following a referral (chart 8.6). The majority of district nursing staff recorded response times as within 24 hours (n=12) or 48 hours (n=8). For health and social care respondents it was well over half (n=43): within 24 hours (n=18) and within 48 hours (n=25). A small number in each group thought they visited on the same day.

There was more divergence regarding the longer response times. The maximum wait identified by one district nursing respondent was within a week. For health and social care professionals, one thought it was a maximum 6 months, though twelve (16 %) identified visits within a week.

These results suggest overall that district nurses are very responsive to referrals and visit quickly.

Q.9 Have referrals to the district nursing service ever been refused?

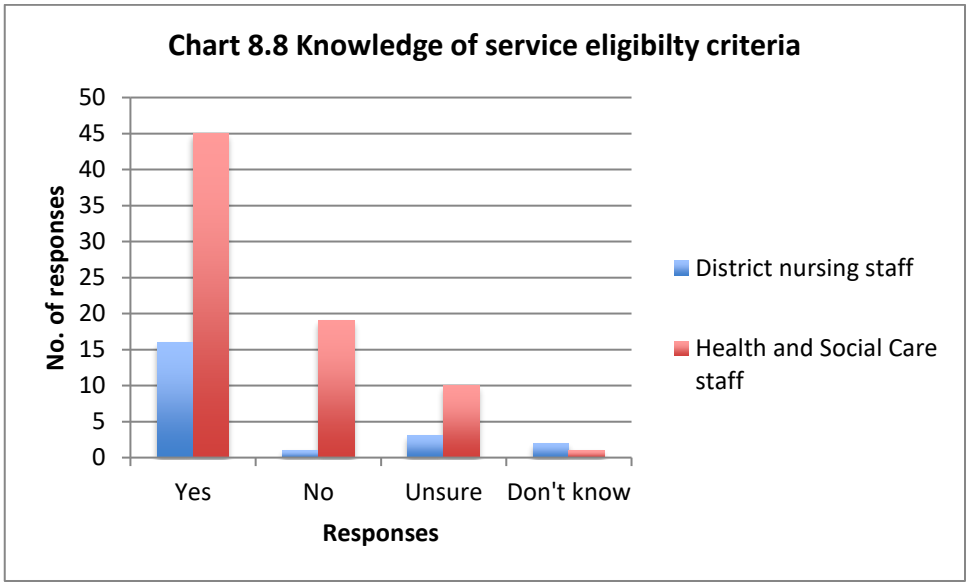


Both staff groups reported that referrals to the district nursing service had been refused (chart 8.7). The majority of district nursing respondents (n=16) had refused referrals and forty eight health and social care respondents experienced a refusal. While just under a third (n=24) of health and social care respondents had never had a refusal. Only three district nursing respondents reported having never refused referrals. Two respondents in each survey were unsure if this had happened.

Such a high number of referrals being refused suggests that referrals are lacking or considered inappropriate in some way. This may relate to the earlier results, where district nursing staff thought those making referrals did not have sufficient knowledge about the service and half the health and social care respondents either did not have sufficient information or were unsure. Sufficient information would include any referral criteria.

Eligibility criteria

Q.10 Do you know what the eligibility criteria are for the district nursing service?



Most staff in both surveys indicated they knew what the eligibility criteria were for the district nursing service (chart 8.8). For both district nursing (n=14) and health and social care staff (n=45) this was well over half. Though this response seems low for district nursing staff and around a fifth (n=4) either did not know or were unsure of the criteria. Although, almost two fifths of health and social care staff either did not know (n=10), or were unsure (n=19) what the criteria were.

It seems for a sizeable minority of health and social care staff respondents there may be a gap in their understanding of the service, where referrals have been refused, and may extend to a lack of knowledge of eligibility criteria. Although, these results may not apply to the same respondents.

A higher number of district nursing staff might be expected to know the eligibility criteria for the service they provide, though this may reflect the team skill mix, where some are not involved in applying the criteria. It may too indicate a gap in knowledge about the service for some staff, or reflect wider organisational change.

Q.11 What do you think are the eligibility criteria for the district nursing service?

This was an open response question and table 8.4 shows the responses. Being housebound was the most common eligibility criterion known to district nurses and health and social care respondents. This seemed to be frequently connected to patients' needs and/or the inability of patients to access other services. This was often related to mobility with examples of clinical conditions, although no specific clinical criteria were identified.

Table 8.4 Eligibility criteria for district nursing: respondents' views

District nursing respondents (n=22}	Health and social care respondents (n=63)
1. Being housebound (n=19) - The majority cited this criterion and just over half (n=10) further qualified this criterion as including: • inability to access other services especially practice nurses • immobility • nursing need • ongoing care • being bedbound Specified nursing needs were: • assessment post hospital discharge • care packages • medication • palliative care • observation • wound care - Two responses noted a recent change where the housebound criterion was no longer used and all patients were seen	***1. Being housebound (n=37)*** - Over half used the term housebound as the main eligibility criterion. In many cases the term nursing need also accompanied the term housebound (n=11). Being housebound was frequently qualified to include one or more of the following: • inability to attend GP or other services • poor mobility • temporarily housebound • out of hours cover • disability • elderly • visiting care homes • long-term conditions • at risk of admission A variety clinical reasons were included: • tissue viability • administration of medicines • continence assessment • catheter care • palliative care • post operative care • assessment • advice on pressure areas • blood tests • checking healing • blood pressure
2. Other criteria given (n=2) - Age threshold as over 16 years or over 18 years	***2. Other criteria (n=6)*** - Age threshold as over 16 or 18 years or excludes children or adults only (n=4) - Catchment area determined by borough (n=2)

Concerns were raised, mainly by GPs, about the interpretation and application of the term housebound to identify need:

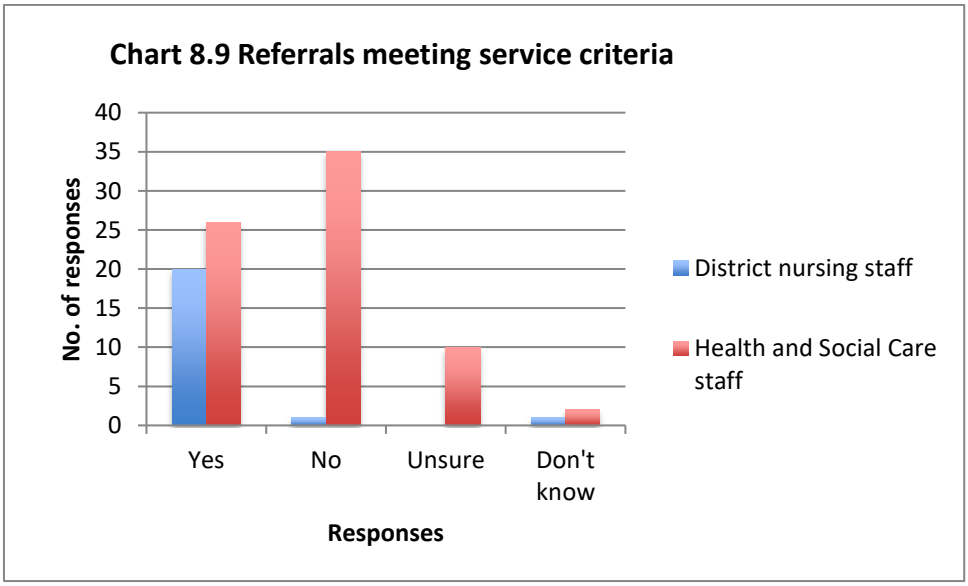
'Very arbitrary and not consistent' (GP)

'there should be some discussion about patients who are not housebound but still require medication services' (GP)

'…recently it appears the patient should be bedbound before a visit will happen. This is due to the cuts in funding DN services' (Practice nurse).

Such comments suggest that the term housebound was seen as not strictly applied, not open for discussion and possibly resource driven. Two district nursing respondents noted that being housebound is no longer required. The only other common criterion reported was age.

Q.12 Do you think referrals meet the district nursing service criteria?



Almost all district nursing respondents (n=20) thought that referrals mostly met the service criteria: only one said they rarely met the criteria (chart 8.9). This response seems to run counter to district nursing staff views of those making referrals, who lack knowledge about the service and where they refused referrals. On the other hand, this response may indicate that only accepted referrals meet the criteria, or that the interpretation of these criteria is more fluid, and refusing referrals is rare.

The corresponding question 12 for health and social care respondents asked if health and social care staff had ever made referrals that did not meet the district nursing criteria (chart 8.9). Almost two thirds (n=45) indicated they had either made referrals that did not meet the criteria (n=35) or were unsure (n=10). This is puzzling as a similar number claimed they knew what the criteria were, though the same proportion reported having referrals refused, however, they may not all be the same respondents. It is possible that they knowingly refer to the service irrespective of whether they meet the eligibility criteria.

Q.13 A common referral criterion is that patients must be housebound - what do you think this means in the context of the district nursing service?

This was an open question and there was a range of responses from both surveys covering common issues. Responses are organised by three themes: inability to leave home, mobility problems and inability to access other services (table 8.5). Respondents commented on one or more areas to explain their understanding of the term housebound. Responses that did not address the question have been excluded.

Table 8.5 Meaning of being housebound: respondents' views

District nursing respondents (n=22)	Health and social care respondents (n=69)
1. Inability to leave home (n=7) *- A range of patient circumstances were given that would prevent patients leaving home including:* Temporarily housebound e.g. post operative No family or friends to take to appointments Terminal Old age - A further two (9%) respondents recognised that not all patients were strictly housebound but received the service e.g. PICC lines and dementia.	***1. Inability to leave home (n=12)*** *- A range of patient circumstances were given that would prevent patients leaving home including:* Physical, mental health or cognitive health Temporarily housebound e.g. post operative Terminal Frail or very elderly patients Bedbound - Patients may be seen as being housebound where there were no carers or carers could not perform the care tasks, such as giving insulin.
2. Mobility problems (n=5) - Cannot walk at home or limited mobility - Need help to go out or were unsafe on their own	***2. Mobility problems (n=5)*** - Assistance needed with transport or input from carers, wheelchair or hospital transport required
3. Inability to access other services (n=3) - GP, wound clinic, palliative	***3. Inability to access other services (n=17)*** - Practice nurse, GP, leg ulcer clinics

There seemed to be a degree of consistency underpinning respondents' understanding of what being housebound meant but there was no single definition, although one equated housebound with bedbound. The three themes seemed to be closely interrelated as respondents often mentioned two of them.

Judgements about being housebound seemed to take into account patients' individual circumstances.

Five health and social care respondents challenged the housebound criterion,

'That's silly, if we want to keep people out of A&E we need support at home' (Ward manager)

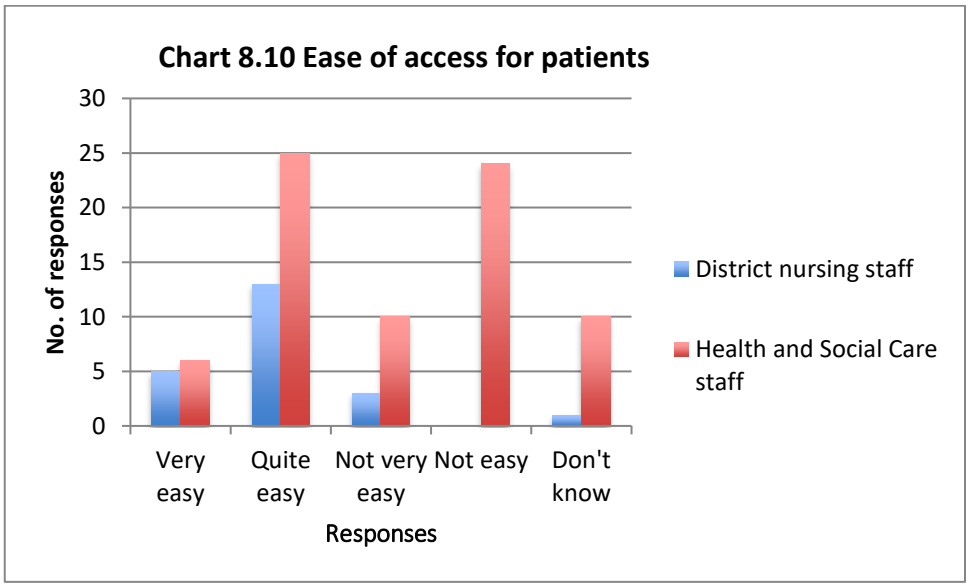
Others felt it was unfair on older frail patients to expect them to travel to the GP surgery. As one GP asserted this criterion was,

'Rubbish. ''Housebound' is a value judgement which is inconsistent. My practice nurses can't do all of these skills that DNs can do' (GP).

The responses explained what the term housebound meant for these professional groups and where the service now included non-housebound patients. The results suggest that the housebound criterion is not fixed and may be viewed in a situational way.

Patient and carer access

Q.14 How easy do you think it is for patients to access the district nursing service?

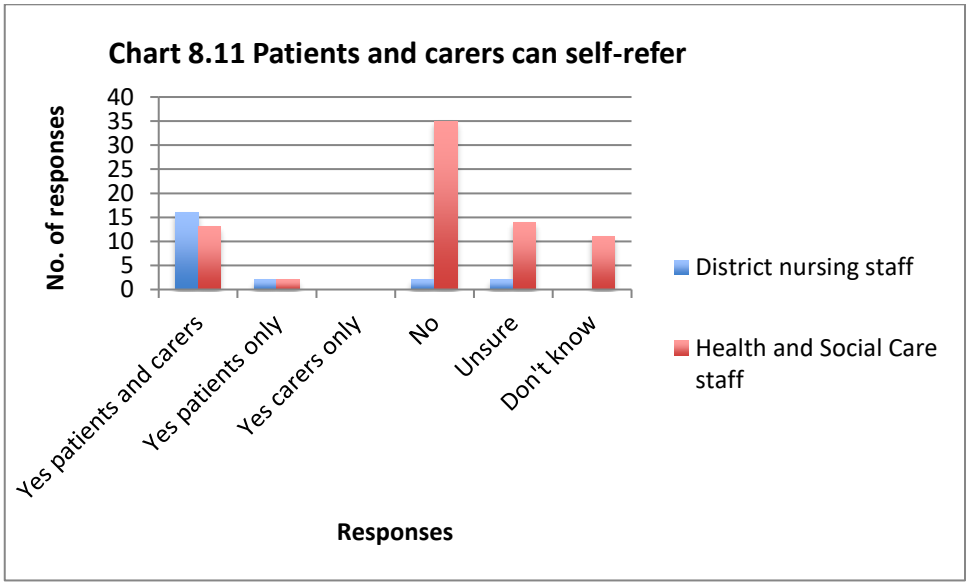


The responses in both surveys differed in that district nurses considered it easy for patients to access the service but health and social care respondents' responses were divided on this (chart 8.10). The majority of district nursing

respondents (n=18) thought it was easy for patients to access the service, of which five thought it was very easy and thirteen quite easy.

Health and social care responses were fairly evenly split between indicating access to the service was quite easy (n=31) and where access was not easy for patients (n=34). A further ten respondents did not know. These results suggest that district nursing staff perceive their service as accessible for patients, but health and social care staff are not certain of this.

Q.15 Can patients and carers refer themselves to the district nursing service?



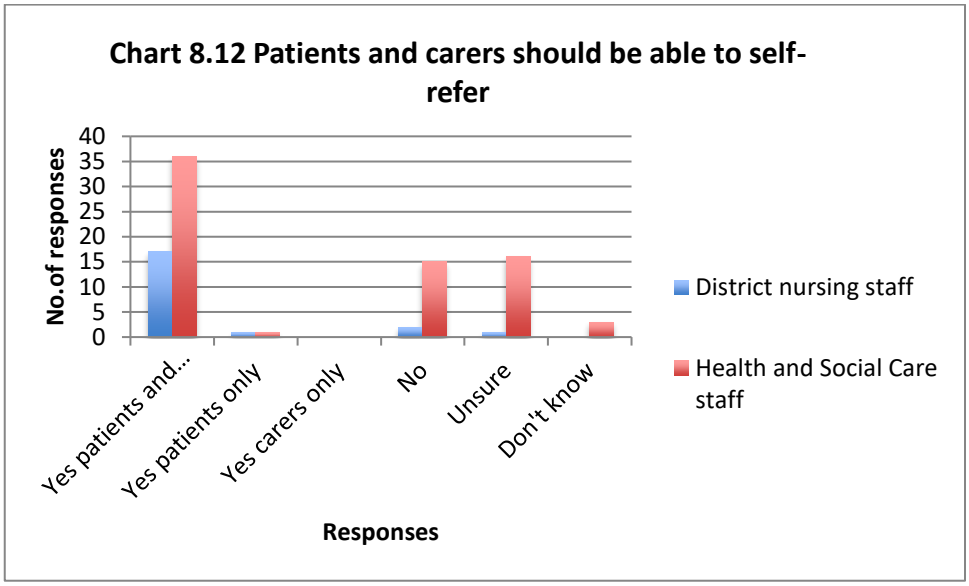
The responses between both staff groups varied considerably where district nursing respondents thought that patients and carers could self-refer but health and social care respondents did not (chart 8.11). Nearly three quarters of district nursing respondents (n=16) thought self-referral was possible for both patients and carers, while less than a fifth of health and social care respondents (n= 13) thought this. More health and social care respondents were unsure (n=14) or did not know (n=11) if self-referral was possible, compared to district nursing respondents (n=2).

About half of health and social care respondents (n=35) did not think patients and carers could refer themselves, while only two district nursing respondents thought this. No one identified carers alone as being able to refer but two respondents from each survey stated that only patients could self-refer.

This suggests that most district nursing staff accept self-referrals from patients and carers, though it might be expected that all district nursing staff would be

aware of this. As health and social respondents are not aware of the possibility of self-referral, suggesting a further gap in their knowledge and information available to them about the service.

Q.16 Should patients and carers be able to refer themselves to the district nursing service?



Over three quarters of district nursing respondents (n=17) and almost half of health and social care respondents n=36) thought that both patients and carers should be able to refer themselves (chart 8.12). Two health and social care respondents thought that only patients should be able to self-refer. A fifth (n=15) of health and social care respondents thought patients and carers should not be permitted to refer themselves compared to only two district nursing respondents.

However, a quarter of health and social care respondents were unsure (n=16) or did not know (n=3) if self-referral should be made available. Again, no one identified carers alone as being able to refer. In comparison to question 15, more health and social care respondents were in favour of patients and carers being able to refer themselves, while for district nursing this increased slightly. This suggests that around half of health and social care respondents endorse self-referral, though there may be some ambivalence among the other half.

Views of the service

Q.17 What do you think works best in the district nursing service?

This was an open question and there was a range of responses from both surveys covering common areas. Responses are presented as four themes: service quality, communication and teamwork, workforce and referrals (table 8.6).

There was clear congruence across all themes between both staff groups. Resource factors were raised including time, staff and skill mix, and investment in district nursing training. District nurses seemed to be more operationally focused. Strategic issues were mentioned by health and social care professionals, including district nurses' effectiveness in avoiding hospital admissions and workforce planning. They were highly complementary about the district nurse's role in providing skilled, holistic care and empathetic with regard to the demands on them. A key difference seemed to be around the workforce where district nurses implied that adequate or good staffing levels are in place, while health and social care staff recognised that district nursing was under staffed but still delivered a responsive service.

Table 8.6 What works best in district nursing

District nursing respondents n=21	Health and social care respondents n=63
1. Service quality (n=9) - Respondents focused on interventions and services they provided: • Wound clinics • Palliative care • Medication management • Teaching and supporting patients and Carers to be independent • Caseload management • 24 hours service Personalised care aspects included: • Response times • Planning care and the timing of visits • Continuity of care • Patients with long-term and complex health needs. *'District nursing needs to be more holistic, preventive and proactive. When staff are working in this way then outcomes improve' (Integrated care matron)*	***1. Service quality (n=35)*** Respondents mentioned how caring district nurses were and that they offered holistic care. Their expertise and professionalism was noted in supporting people to remain in the community rather than going into hospital or residential care. Particular care areas were identified: • Cancer • Continence • Expertise with wounds • Palliative care • Monitoring including long-term conditions • Phlebotomy • Administration of medication • Catheter and pressure area care • Continence assessments *'Brilliant service, compassionate nurses that 'go the extra mile' to meet their patients' needs' (Practice nurse).*
2. Communication and teamwork (n=7) - This included good inter-personal relationships in their teams, GPs and multidisciplinary teams. - Another positive aspect was technology, such as iPads, as it enabled faster and more efficient communication.	***2. Communication and teamwork (n=19)*** - This was identified positively in terms of *'good working relationships, 'Quid pro quo' (GP)* and the opportunity to have direct conversations. This included being able to discuss: any concerns, get immediate advice for quick action and joint working on CHC assessment. Communication with patients and carers to provide support was mentioned. *'The DNs locally are very responsive and they work well with other care providers such as home care agencies by sharing information...'* (Social worker)
3. Workforce (n=3) Staffing levels from adequate to well resourced Management structure and support Skill mix *'All district nursing team leader[s] should have the district nurse qualification' (Qualified district nurse)*	***3. Workforce (n=3)*** Need more district nurses and to expand the services - It was acknowledged by some that it was a *'caring service under great pressure' (GP)* with *'hard working nurses but under great pressure to provide a demanding service' (Receptionist).*
4. Referrals (n=3) - Hospital referrals and the SPA	***4. Referrals (n=11)*** - Prompt and efficient service noting DN response time from the time the referral is received. - Others aspects of efficiency: ease of referral, appointments available and once known to the service the patient can continue accessing it. *'Quick turnaround from referral to outcome' (Practice nurse).*

Q.18 What if anything could be improved in the district nursing service?

This was an open question and there was a range of responses from both surveys covering common areas. Responses are presented as three themes: workforce, communication and teamwork and referrals (table 8.7).

Workforce matters dominated both staff groups' comments, and were complementary. Responses indicated that increasing staffing levels and reducing caseloads would improve the core service and therefore access. This included changing the skill mix by reducing the number of agency staff and increasing qualified staff. Other areas that have an impact on access were highlighted including, reduced waiting times for patients, stronger partnership working and communication. Finally, the need for clarity about the district nurse's role and service with an efficient and effective referral process that promotes equity of access.

Table 8.7 What can be improved in district nursing

District nursing respondents n=22	Health and social care respondents n=67
1. Workforce (n=16) Increase staffing levels and training *'the level of staffing and training…their patient is their priority' (Community nurse)* Improve skill mix and support *'Skills are still not being used some band 6 nurses are not seeing/reviewing all complicated patients but handing them over to band 5, band 7 should go out and see patients at least once a week not just cover clinics…' (Community nurse)* Reduce caseloads and nurse holistically *'more substantive staff to ease pressure of[f] the caseload and nurse in the way we have been trained to' (Qualified district nurse)* Organisational and other factors Reduce administration Improve parking in London	***1. Workforce (n=35)*** Increase staffing levels *'The service is understaffed and individual DNs appear to be over burdened with very large caseloads' (Social worker)* Improve skill mix and recruitment More qualified DNs and HCAs Reduce the number of agency staff to improve continuity Fewer HCAs *'…more skilled nurses given the time to do what's needed, also need to be skilled up to be more autonomous/prescribe rather than asking practices to prescribe..' (Practice nurse)* Holistic care *'…need to return to good holistic nursing care from senior capable qualified nurses rather than just task orientation e.g. nurses go in to do one thing and won't do a blood test and another nurse has to go in to do that etc…..'(Practice nurse)* -Time: Time and GP attachment; Lack of time with patients; Appointment times for patients; Patients waiting for visits; Avoid meal times when visiting *'Try not to keep patients waiting - inform in advance' (Practice nurse)*
2. Communication and teamwork (n=8) Levels of communication - between professionals and boroughs	***2. Communication and teamwork (n=41)*** More feedback and meetings - between professionals - want to speak directly to DN

- GPs to respond to district nurses' requests for visits or repeat prescriptions - Understanding of role *'Patients and other professionals understanding of what the district nurses do and when to refer to the service' (Student district nurse)* - Quality of communication '*to be more polite, more human, more holistic, preventive and proactive' (Integrated care matron)* *'respect for new ideas and change better managers who care' (HCA)*	- contactable and approachable - attendance at practice meetings - District nurse link person for residential care *' Some patients who are not housebound need help at times and we should be able to discuss this' (GP).* *'Poor feedback - no details when patient was seen, what plan is, poor continuity of care' (GP)* *'Feedback to social services more, not just when it is a safeguarding [issue]' (SW)* *'unable to speak to someone, there is only a message taking service' (Practice manager)* GP attachment *Need to be attached to practices and therefore visible (Practice nurse)*
3. Referrals (n=3) Better systems Triage Gatekeeping to exclude inappropriate referrals GPs and patients understand the service and when to refer *'Some gatekeeping re the inappropriate referrals and over use of the service for very minor issues. The service should be for delivering clinical care to the most needy' (Community nurse)*	***3. Referrals (n=13)*** Better systems DNs to clarify referral parameters *'let every primary and secondary provider know what exactly they provide and stop confusing people' (Practice nurse)* Acknowledge receipt of referrals Hospital provides information about district nursing '*patients should not come to the GP, the hospital should advise patients about the district nurses' (Ward manager)* More flexibility in accepting referrals '*sometimes reject[ed] if wrong form done, despite all correct info given' (GP)* *'DN allowed to see any other patient when visiting the home not only the particular resident they are visiting' (Care home manager)* Speed up referrals Decrease bureaucracy and inequity *'Get rid of the Kafkaesque and Byzantine referral process which seems designed to restrict access inappropriately' (GP)*

Q.19 Anything else you'd like to add?

This was an open voluntary question. Half the district nursing staff responded and nearly sixty percent for health and social care staff. Responses from district nursing staff focused on their role, feelings of stress and demoralization (table 8.8). Health and social care professionals' responses were a mix of very positive comments about the service and negative aspects of referrals.

An underlying sense of loss was conveyed, particularly for district nursing staff

where the dissonance between the nursing care offered and the service they wanted to deliver was demoralizing. More seemed to be expected of district nursing staff as their roles and workloads expanded, with less time or opportunities for professional development, While they reported feeling demoralized, their concern for patient care seemed to be strong, and staff want to be involved in changes to the service. One respondent questioned the disparity of the service being provided to different boroughs, suggesting inequities.

Health and social care professionals noted that collaboration and communication was not as effective as in the past. They also articulated different frustrations with referrals, indicating built in system failure, such as rejected referrals, causing avoidable delays to access. Some GPs viewed these issues within a wider criticism of policy implementation, which seemed to foster silo working and competition. Collectively, these comments seemed to imply that respondents had a sense of a loss of control.

Table 8.8 Responses for any other comments

District nursing respondents (n=11)	Health and social care respondents (n=44)
1. Staff roles, stress and morale (n=5)	***1. Quality of service (n=22)***
'A great and flexible job, but stressed and stretched to the limit due to shortage of staff and some referrals that are not necessary and individuals who think it is their right to have the service. These individuals can be demanding, rude and have an expectation that a nurse arrives at their door 2 minutes after they request the service. Or that they are the only users waiting for a visit when they call' (Community nurse).	*'I feel services offered are excellent' (Care home manager)* *'Generally a friendly and responsive service from a professional group of people. Sometimes they are overwhelmed' (GP)*
'Maintaining and supporting existing staff, stress levels are high, Providing training for staff as skill mix is a problem at the moment. Talking to staff regarding the team and its future, staff are stakeholders, without involvement people feel disheartened and leave' (Health care assistant)	*'Presently the nursing service in our Care Home is excellent and working well' (Care home manager)* *'I am very grateful to the nursing service. They are a key part of the community' (GP)* *'I think community nurses do a great job with limited time' (Health care assistant)*
'Nurses were trained to do nursing and caring for those in their care. Now we are spending too much time doing various admin duties. We are constantly being told to keep up to date but changes are happening too fast, not enough time is given to learn new things before another is put on and this is very overwhelming' (HCA)	*'This service works well on the whole in spite of staff shortages' (Practice nurse)* *'District Nursing Services have traditionally been valuable and in demand. Demand has increased but staff and criteria reduced. I have concerns patients needing care may be missing out entirely due to cuts (Practice nurse).*

'I have been an auxiliary nurse for over 28 years. I used to enjoy my work. I have always wanted to work with the elderly. Over the years I have seen so many changes that I can no longer recognize my role. It seems that I am now doing the job of the trained staff, and likewise trained staff are doing the jobs of sister in charge' (HCA) *'I used to love my job, but have really been de-motivated because of the lack of support from Band 6's and the lack of knowledge from Band 7' (Community nurse).*	*'More commissioning should be put in place to re-organise the DN' (Practice nurse)* *'Not a job I would like to do they appear under a great deal of strain at present' (Practice nurse)*
2. Referrals (n=4) • Unnecessary referrals • Hospitals to order equipment before discharge rather than DNs • More information required • Operate an equitable service based on needs across boroughs *'Many boroughs make up [Trust name] but each work in different ways WHY? People are people and services should be according to their needs not demographics' (HCA)*	***2. Referrals (n=7)*** • More information about the service • Self-referral to be welcomed • Chasing referrals • Rejected forms *'SPA forms are rejected for the [most] trivial of things e.g. because the wrong box is ticked or forgot to tick falls box' (Practice nurse)* Avoid making referrals *'…patients are not happy with service why would someone turn up for wound care without any dressings' (Practice nurse)* IT system incompatible and untested *'I have been a GP for thirty years. It used to be good practice to meet the D/N regularly. One could refer with a phone call, now a very lengthy form has to be submitted by Email but our IT systems do not facilitate this - implementing this change without testing is a scandal' (GP)* Competition *'The new NHS has set us up against each other as competing tribes - everybody is 'gaming' against everyone else. This does not bode well' (GP)*

Section B Summary

The surveys' results highlight some similarities and differences between district nursing and health and social care staff groups in their understanding of the district nursing service, particularly in relation to referrals and eligibility criteria. This appears to indicate particular gaps in knowledge and information about the district nursing service, particularly for health and social care staff. However, as the number of respondents in both surveys was small, the results need to be viewed with caution.

Summary of the main points

- Most health and social care staff learned about the service from colleagues: written forms of information, including the web were almost never used.
- District nursing staff did not think health and social care staff had sufficient knowledge about the service, nor did they know how these staff learned about the service.
- Both staff groups identified GPs as the main source of information for those making referrals.
- A range of referral methods was in use but email was the most common. Most methods were electronic and central access systems were in place, though some referrals were made by contacting district nurses.
- All agreed that district nurses usually visited within 24-48 hours of receiving a referral. Most referrals were sent weekly and district nursing teams received between 11-20 new referrals per week.
- Most considered making referrals easy but around a fifth of all staff did not. Bureaucratic referral systems was raised in open questions
- Most reported that they knew what the eligibility criteria were, and district nurses felt referrals mostly met the criteria. However, most district nurses had refused referrals. Heath and social care staff had referrals refused and made referrals that did not meet the criteria.
- Being housebound was identified as the main eligibility criterion by most staff**.** This was explained as a mix of not being able to go out and access other services, mobility and/or health issues. Although understanding and applying this criterion did not seem to be necessarily fixed, indicating it was defined in a situational way.
- District nurses thought patient access to the service was easy and that patients and carers could self-refer but health and social care staff did not.
- Views of the service were consistent and collectively there was a sense of caring under pressure. District nurses were viewed as highly skilled and responsive, despite high demand and workforce shortages. For both staff groups, a sense of loss was conveyed about how the service was operating and affecting: holistic care, inter-professional working and overly bureaucratic referral systems that 'pit staff against each other'.

This chapter presented the results of the surveys for district nursing and health and social care staff making referrals to the district nursing service. There were some similarities in responses between both groups, although the number of respondents in both surveys was small, this constrains generalisation of the

results. However, health and social care staff appeared to have divergent understandings of referrals and levels of awareness of the service compared to district nursing staff. There appeared to be no definitive source of information used to find out about the district nursing service.

From a conceptual standpoint access to information is key to both supply and demand sides of access (Goddard and Smith, 2001; Levesque *et al,* 2013). The survey results provide a reference point for consideration of the supply side of access and inform the final phase of the study, which analyses information about the service and referral on provider websites. The results of this chapter, and findings from the focus groups and interviews, are reflected in the construction of the framework to explore and analyse service information, its accessibility and the availability of referral information and criteria, on selected websites. The next chapter presents the analysis of information about district nursing held on these provider websites.

Chapter nine: Findings from the analysis of providers' websites

Introduction

This chapter presents the findings of the documentary analysis of web-based information about the district nursing service offered in seven provider units. Data were captured from the websites as they appeared in the public domain. The purpose of this analysis was to discover what web-based core and additional information is available about the district nursing service for patients, carers and health and social care professionals.

Findings from previous chapters highlighted service information needs and limited use of web sources for information about the service. Analysis of the service information held on websites enabled consideration of the 'fit' between the service and service user, and supply and demand sides of access (Penchansky and Thomas, 1981; Goddard and Smith, 2001).

Paper-based documentation, such as leaflets and referral forms, on the webpages, were included as part of the analysis. The content of the sites and documents were publicly available and represent a snapshot in time. The focus of the analysis was on the accessibility and clarity of web-based information in providing access to district nursing.

The chapter is organised into two sections. Section A provides the characteristics of the providers and how the websites were located and appraised. Section B presents the website findings in four subsections: accessing the websites, about the service, eligibility and access and making referrals. This is followed by a summary of the main findings. The analysis shows that while all providers offered web-based information, there were variations in the way service information was conveyed and the services offered.

Section A Characteristics of the providers

The seven providers selected for website appraisal are shown in table 9.1 Providers' names have been given as the websites are in the public domain. They represent a range of London's provider organisations by type, size, geographical spread and indices of deprivation for older people (Lesser, 2016). One local authority per provider was used to test the provider's site; these local authorities are indicated in bold in table 9.1.

Process for finding the websites

Each provider's website was located via the Google search engine, using the term 'district nursing' alongside the name of an individual local authority. From each Google search, the websites were viewed in the order the results were listed to find the district nursing webpage and to assess how long it took to find the correct web page. Once the correct site was accessed from the list, a record of the search process was kept to determine how many clicks it would take to find the district nursing main page on each provider's website.

Table 9.1 District nursing providers

Type of district nursing provider	**London Local Authorities covered by the provider and if inner (i) or outer (o) London**	**Income deprivation affecting older people (IDAOP)- rank of proportion of LSOAs in most deprived 10% nationally***
1. *Whittington Health NHS Trust* - Integrated care organisation	**Haringey** (o) Islington (i)	8 5
2. *North East London NHS Foundation Trust (NELFT)*	Barking and Dagenham (o) **Havering** (o) Redbridge (o) Waltham Forest (o)	45 182 114 37
3. *Central London Community Healthcare Trust (CLCH)*	**Barnet** (o) Hammersmith and Fulham (i) Harrow (o) Kensington and Chelsea (i) Merton (o) Wandsworth (i) Westminster (i)	86 38 94 26 128 62 28
4. *Guy's and St Thomas' NHS Foundation Trust (GSTT)*	Lambeth (i) **Southwark** (i)	10 7
5. *Central and North West London NHS Foundation Trust (CNWL)* *- Mental health Trust*	**Camden** (i) Hillingdon (i)	25 131
6. *Homerton University Hospital NHS Foundation Trust*	City **Hackney** (i)	43 1
7. *Your Healthcare (Community Interest Company) - social enterprise*	**Kingston upon Thames** (o)	153

*Source: Indices of Deprivation 2015 (Lesser, 2016)

All seven providers sites were located using this method. Authenticity and authorship checks were made to ensure they were the official provider sites, guided by Dalhousie University's criteria for reviewing web content (appendix

13). This involved checking the URLs, stated ownership of the sites, consistent use of the NHS logo with the Trust name and the absence of any commercial element. All met these standards, although the social enterprise site, *Your Healthcare*, did not have an nhs.net URL and the NHS logo was used alongside others. Further verification was found on the home page explaining it was formerly part of NHS Kingston and held a contract with the Kingston CCG to provide district nursing. This was also verified on Kingston's CCG site.
The sites were accessed over the period of a week, 4-9 April 2019.

Screenshots were taken of each provider's website (appendix 14), including all webpages directly relevant to district nursing access as information can change quickly on the web. The ordering of the screenshots starts with the main district nursing page and any subordinate pages, tabs and/or hyperlinks directly related to district nursing. The ordering of the content is indicative of the relative emphasis on different areas, such as the referral criteria being presented on the main page. It is important to acknowledge that others using these websites may not follow this order.

Key questions for website appraisal

The focus of the appraisal was on content rather than design or graphics. Nonetheless, some elements of design are reflected in this analysis related to the construction, naming and ordering of webpages, as they influence accessibility. Ten questions shown in box 1 were formulated, informed by selected criteria from two sources, explained in chapter five. The questions were used to appraise each site individually and to facilitate comparisons between providers

While users' needs were not asked about, findings from previous chapters highlighted service information needs and limited use of web sources of information. Patients' and carers' views indicated that they lacked service information. Carers also reported searching the web for information about district nursing without success. These concerns are also reflected in the 10 questions.

Box 1 Key questions

1. How many search words were used to find the site? Which search words were used?
2. How many clicks were required to access information about the district nursing service?
3. Is it stated who this information is for?
4. Is there an explanation of the district nursing service?
5. Is it stated who is eligible for the district nursing service?
6. Is it stated how to access the service?
7. Is it stated whether self-referrals are accepted?
8. Is it stated how to make a referral, including self-referral?
9. Is it possible to make a referral directly from the site?
10. Is there any named person who may be contacted?

The first two questions were intended to review how easy it was to find web-based information about district nursing by local authority. It is appreciated that those searching the Internet for this information may approach it in a number of different ways and may not achieve the same result. The rest of the questions considered patients', carers' and health and social care professionals' needs to find relevant and usable information to access the service on each site. Where provided on the web, pdfs of patients' leaflets and referral forms have also been considered using questions 3-10. These ten questions were also designed to enable comparison with those asked in the focus groups, interviews and surveys.

Section B Findings from the provider websites

The findings are presented in four subsections, which have been mapped to the ten questions in box 1 above as:

B1 Accessing provider websites	Q 1-2
B2 About the service	Q 3-4
B3 Eligibility and access	Q 5-7, 10
B4 Making referrals	Q 8-9

Table 9.2 provides an overview of high-level findings, which are discussed in more detail in B1-B4.

B1 Accessing provider websites

Finding the district nursing webpages on the provider websites was relatively straightforward, four were found first time with a single click and one site required five clicks (table 9.2). Although the search approach was quite simple,

indicating users would succeed first time. However, without any prior knowledge of the service, different search approaches might yield different results.

Locating information about district nursing on the webpages was more mixed. It was not immediately apparent that the main webpage related to district nursing and not all providers used the term district nursing (table 9.3). There were considerable variations in the presentation of information on the provider websites seen by the naming conventions, order and location of information (table 9.3). Some information about district nursing was spread across webpages or obscured. For example, on Homerton's site, the case manager aspect of the district nurse's role seemed to be buried in a long description of palliative care, and without insider knowledge this might be missed.

Table 9.2 Overview of access to websites and information about district nursing

Questions	Whitting-ton	NELFT	CLCH	GSTT	CNWL	Homerton	Your healthcare
1. How many search words were used to find the site? Which search words were used?	Three District nursing Islington	Three District nursing Havering	Three District nursing Barnet	Three District nursing Southwark	Three District nursing Camden	Three District nursing Hackney	Three District nursing Kingston
2. How many clicks were required to access information about the district nursing service?	One	One	Two	Five	Two	One	One
3. Is it stated who this information is for?	No	No	No	No	No	No	No
4. Is there an explanation of the district nursing service?	Yes – limited	Yes – limited	No	Yes	Yes - limited	Yes - limited	Yes
5. Is it stated who is eligible for the district nursing service?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. Is it stated how to access the service?	Yes	No	No	No	Yes	Yes	No
7. Is it stated whether self-referrals are accepted?	Yes	Yes	Yes	No	Yes	No	No
8. Is it stated how to make a referral, including self-referral?	Yes	No	Yes	Yes	Yes	Yes	No
9. Is it possible to make a referral directly from the site?	Yes	Yes	Yes	Yes	Yes	Yes	No
10. Is there any named person who may be contacted?	No	Yes	No	No	No	No	No

Table 9.3 Organisation of information on district nursing webpages

Provider	Name of main district nursing web page	Names of subordinate pages or tabs	Patient Information located	Service information and contact details Located	Referral criteria and guidance located
Whittington	*District Nursing*	*- How to get treatment* *- District Nursing Teams* *- Health and Social Care Professionals*	*How to get treatment* *Patient leaflet pdf on main page*	Main page - sections headed: *Housebound; Range of services, Objectives, Referral, Contact, Further information*	Main page *- How to get treatment* *- Health and Social Care Professionals*
NELFT	*District Nursing*	*- For clinicians*	Main page - section headed *- Patient information*	Main page - sections headed *- District Nursing* *- Patient information*	Main page *- For clinicians*
CLCH	*District Nursing*	*- Vision and values* *- Night nursing* excludes Barnet	None	Main page	Main page - Drop down section for Barnet
GSTT	*Adult community nursing team*	*- Patients* *- Referrals*	*Patients*	Main page No sections on main page	*Referrals*
CNWL	*District nursing* services Accessed via hypertext *from Camden Integrated Primary Care Service* page	No other pages or tabs, a link back to *Camden Integrated Primary Care Service*	None on main page - Patient leaflets on *Integrated Care Team* for three health centres	Main page – one section headed *Eligibility criteria and referrals*	Main page and directed back to *Camden Integrated Primary Care Service – link to Key contacts in Camden*
Homerton	*Adult community nursing*	No other pages or tabs	None	Main page – sections headed: *District nurses and Community matrons, Community matrons, The specialist services, The discharge planning/continuing care team, Our service, Palliative/ end of life care*	Main page
Your Healthcare	*District Nursing*	*- Our Teams* *- Twilight District Nursing Team*	None	Main page No sections on main page	Separate *Referrals* tab for main site and all services

B2 About the service

None of the websites stated specifically for whom the information was intended (table 9.2). Although, the naming, order and language used on webpages suggest that information was intended mainly for a professional audience (table 9.3).

Three providers indicated patient information was available but only one provider referenced district nursing (table 9.3). Whittington's patient information was comprehensive, addressing potential district nursing patients. This included how to self-refer and what to expect at the first visit and how to get urgent advice (appendix 15). A separate patient information leaflet provided information about district nursing teams, the service and a contact number. Support for carers was also mentioned and by another provider but no information or further signposting was found.

Service organisation

Most providers offered brief explanations about the service, though some were clearer than others. The two largest providers provided the least information, NELFT and CLCH, possibly because of the complexity of the provision and commissioning requirements, or historic differences in the services.

Reference was made to the purpose of the service, which varied in emphasis and included the prevention of hospital admissions, promotion of independence and self-care. Most offered lists of care areas the service covered but the role of the district nurses was not generally explained, particularly on CNWL and Homerton sites.

Variations in service organisations included, geographic (Whittington, NELFT, Homerton) or GP attached (NCWL, Your healthcare), though it was not easy to find this information and not possible to discern this for GSTT. Although GSTT site highlighted the Dutch Buurtzorg model and a link to an evaluation report, it was not clear why the information was there or if or how it related to district nursing. CLCH did not provide any information about the organisation, either at Trust level or local authority level for Barnet.

Service hours

There was considerable variation between the information provided on service hours, though not all providers supplied this information, no two providers appeared to offer the same service hours (table 9.4). Few providers made explicit if the service was 24/7. A number of providers broke down the hours between day, twilight and night services. However, access across a 24 hours period seemed to vary between providers and there were gaps in the hours offered

within most providers (table 9.4). No provider seemed to have any overlap between the end of one service shift and the beginning of another.

Table 9.4 District nursing service hours

Provider	24 hours service stated	Day service	Twilight service	Night Service
Whittington	Yes 7 days per week 365 days a year	Not given	Not given	Not given
NELFT	Yes	Not given	Not given	Not given Mentions the service is provided by out of hours service (OOH) and a phone number from 5pm - 8.30am
CLCH	No	8am - 6.30pm	6.30 pm - 10.30pm	10.30pm - 7.30am
GSTT	No 365 days a year	8am-8pm	No distinction made with day service hours	No service provided OOH number provided for district nurses
CNWL	No Stated on *Camden Integrated Primary Care Service* page	Not given	Not given	Not given
Homerton	No Stated includes bank holidays and weekends	8am-11.30pm	No distinction made with day service hours	No service provided
Your healthcare	No 365 days a year	8.30am-5pm	7pm-12am	No service provided

It was not easy to determine the length of the day service, but the length of two providers day service differed by two hours: Your healthcare had the shortest day service hours and CLCH the longest. There was a four hours difference in the end of the twilight service for two providers (GSTT and Your healthcare).

The largest gap was for night service provision, as no hours were allocated, suggesting there was no night provision. Only one provider stated explicitly their night service hours and another directed patients to an out of hours number to contact the district nurse. It was not clear if this was an on call system rather than night service provision. Though CLCH gave their night service hours, Barnet's hours differed to the rest of the local authorities serviced by CLCH. There appeared to be gaps of up to twelve hours where no cover was provided. It is possible that cover is provided, and even outsourced, but this information is not available.

B3 Eligibility and access

Eligibility criteria

All providers stated their eligibility criteria and often this was the first statement on the main web page (table 9.3). Providers identified a number of eligibility criteria shown in table 9.5. The two criteria mentioned by all providers: were being housebound and age.

Housebound criterion

There were various explanations of the term housebound, though this often lacked detail (Homerton; CLCH). Being housebound also included related care areas: residential care (NELFT, CLCH, Homerton, Your healthcare) district nursing clinics such as leg ulcers (NELFT, Your healthcare) and palliative care (NELFT). Four providers (Whittington, NELFT, GSTT, CNWL) explained being housebound as the inability to attend the GP or other settings to receive nursing care. NELFT provided this example for referrers, *'if they are only able to leave home by ambulance'.*

Table 9.5 District nursing eligibility criteria

Provider	Housebound	Age threshold	Nursing need	Local authority resident	GP registration
Whittington	Yes	16 years	Not mentioned	Yes	Not mentioned
NELFT	Yes	16 years	Yes	Yes	Yes
CLCH	Yes	18 years	Yes	Not mentioned	Yes
GSTT	Yes	16 years	Not mentioned	Yes	Not mentioned
CNWL	Yes	18 years	Not mentioned	Yes	Yes
Homerton	Yes	18 years	Not mentioned	Yes	Yes
Your healthcare	Yes	18 years	Not mentioned	Not mentioned	Not mentioned

The emphasis on being housebound seemed to be important and some webpages repeated this more than once, Whittington made four references to it. Though another provider's 'housebound' section was not specific, concluding it was about working with colleagues *'to make sure patients received the right care in the right place'*. CNWL took a different approach and listed four specific exclusions for referral '*i) social care but do not have a nursing need or*

rehabilitation potential ii) admission to hospital iii) psychiatric medication or primary mental health problem iv) collection of prescriptions, delivery of incontinence equipment or purchasing equipment privately'.

There was a lack of uniformity and clarity about the term. Provider information suggests they used local interpretations oriented to particular referral patterns. Information seemed to be directed to those making referrals and this criterion featured prominently on the main and subordinate pages.

Age threshold criterion

As an adult service there was no upper age limit stated but the lower age criterion varied among providers (table 9.5). This discrepancy suggests that the service was not offered equitably to those aged 16 years and up to their eighteenth birthday in eleven local authorities, about a third of London's provision.

Other eligibility criteria

Three other criteria were identified with variations among providers though most stated patients should be living in the local authority and four included GP registration (table 9.5). Though only Homerton stated that they would see residents who were not registered with a GP. Even though some providers had not stated these other criteria, they may be tacit and could result in rejected referrals.

Accessing the service

All providers gave information about how to contact the service by phone. It was not always explicit whether these contacts were open to all potential users, apart from CLCH who specified their contact information was only for professionals to make referrals. It was not possible to discern if any of these contacts provided a direct line to a district nurse, but as many were centralised messaging services it seemed unlikely. Access by phone fell into two categories, either a single 24 hours phone line or multiple phone numbers covering day and out of hours (table 9.6).

Table 9.6 District nursing access information

Provider	Single 24 hours phone number	Multiple phone numbers	Patient leaflet	Self-referral information	Other
Whittington	Yes	No	Yes	Yes	Explained messaging service with 2 hours response time
NELFT	No	Yes	No	Yes	Two numbers covering 24 hours week days and OOH
CLCH	No	Yes	No	Yes	Contact information not on district nursing page, specified for professionals only
GSTT	No	Yes	No	No	
CNWL	Yes	No	Yes	Yes	
Homerton	Yes	No	No	No	
Your healthcare	No	Yes	No	No	

Single and multiple phone contacts

Single 24 hours phone numbers seemed to be more prominently displayed on webpages. The advantages of the single number suggest that it may be comparatively easy to find and was in operation 24 hours seven days per week. The disadvantage was the potential to become a bottleneck, as the central numbers covered many services, making it difficult to get through or uncertainty about messages being relayed or received.

Where multiple contact numbers were given, none of these providers specified if there was 24 hours access, except for NELFT (table 9.6). Sometimes the full coverage was not easy to find or interpret. For example, GSTT's daytime number had different start and finish times for different days of the week or that NELFT's first contact number covered 24 hours for Mondays to Fridays and the second number was for bank holidays and weekends. It was also unclear whom this information was for, whether patients could leave a message or speak to the district nurse or it was only for referrals.

The advantage of the multiple contacts approach suggested some separation with referrals, but as this approach was not explained this may not be the case.

Another advantage could be a more local approach with contacts for locality teams, and perhaps a greater likelihood of getting through more quickly and a more personal service. Disadvantages seemed to be that it was not always clear whether there was a messaging system and some providers' information did not seem to be particularly accessible.

Patient leaflets

Only two providers, Whittington and CNWL, supplied patient information leaflets accessed from their webpages (tables 9.3 and 9.6; appendix 15). Other providers may have held patient information elsewhere but there were no signposts to this. Both providers' leaflets supplied contact numbers though neither matched those on the main webpages: both leaflets were dated 2014. This suggested that reviews of web-based information had not taken place and it was unclear who had ownership of these documents as only the Trust name and address was given.

Self-referral information

There were variations in the information provided about self-referrals, but not all providers offered this, and one provider stated explicitly that self-referrals were not accepted (table 9.6). However as GSTT and Your healthcare highlighted that referral routes were only for health and social care professionals and in the absence of any signpost for self-referral it might be implied it was not available. As a result access to self-referral seemed to be variable and available to less than a third of London local authorities covered by these providers.

Named contacts

None of the contact information, web or paper-based, was accompanied by the name of any individual. The exception was NELFT that gave the name and contact details of the Integrated Community Services Manager on the *Clinicians* webpage. Other providers supplied emergency contacts, for some this was a duty nurse or manager, suggesting that this would require frequent name changes on webpages.

B4 Making referrals

Information about how to make referrals was provided on most providers' webpages; some had subordinate pages dedicated to referral guidance (table 9.3). Providers offered a number of ways to make referrals, with variations in the number and combination of methods used (table 9.7). Some providers' sites were clearer about how to refer than others, as the information was located in one place (CLCH; Homerton) and was comprehensive (GSTT).

Though most providers appeared to use a single point of access (SPA) for referrals, there were variations in the way the SPAs were described: a central booking service (Whittington), a central email or all encompassing phone line (Homerton), an SPA form (NELFT) or Central Access Team (NCWL). It appeared that SPAs might not necessarily operate as a single gateway, for instance having a central email for referral forms. How the various referral methods operated in a SPA was not clear.

Offering a number of referral methods could provide more access opportunities, though some methods, like fax, might be less efficient than others. None of the webpages indicated whether referrals could be sent directly to district nurses.

Table 9.7 Referral methods

Provider	Referral form	Single Point of Access	Phone	Email	Fax	Letter
Whittington	Yes	Yes	Yes	Yes	No	No
NELFT	Yes	Yes	Yes	Yes	Yes	No
CLCH	Yes	No	Yes	Yes	Yes	No
GSTT	Yes	Yes	Yes	Yes	No	No
CNWL	Yes	Yes	Yes	Yes	Yes	No
Homerton	No	Yes	Yes	No	Yes	No
Your healthcare	Yes	Yes	Yes	No	Yes	Yes

Referral forms

A referral form seemed to be an important aspect of the referral process: all providers required completion, except for Homerton (table 9.7). Providers placed their form or a link to it on their webpages (appendix 17). Whittington's form was missing, though it was found through a separate Google search.

Most providers' referral forms were shared with other community services, except GSST. The number of services that could be referred to varied by provider from four to fifteen, inclusive of district nursing. These forms appeared to be quite densely populated with tick boxes. Whittington had the highest number of services but, unlike NELFT and CLCH, it was possible to refer to more than one service using the same form.

NELFT had the fewest with four main services however under the therapy rehabilitation service, there were twenty three choices that included palliative care, wound care, community matrons, equipment need and podiatry. It was unclear how to complete this form as some of these areas might be considered district nursing. Though NELFT's form mentioned district nursing it was unclear if it was a separate service.

Shared forms did not seem to be particularly user friendly and appeared to assume some knowledge of district nursing and the other services. On some forms the term district nursing was not used: CLCH used home nursing and NWCL used community nursing service. Where patients had complex care or multiple needs most providers required separate referrals for each service, which suggests that these referrals were time consuming and the potential for error might increase. However, many forms provided additional contact details to facilitate referrals, such as, urgent palliative care or for queries. It is also possible this was not the only source of information for those making referrals, including their local intranet.

GSTT was the only provider with district nursing referral forms designed for referrals from: GPs, hospital staff and other health professionals. The same information was required for the GP and other health professionals' forms; questions were open rather than a tick box. By comparison, the hospital form was very structured, for example the medical history section had seventeen questions most required a yes or no response. It was not clear why there was a need for three different referral forms.

Referral forms though available electronically appeared to be designed as hard copy and it was not clear what the benefit was of a composite form where separate referrals had to be made to different services. Some forms could not be completed electronically, which presumably would require further processing to scan and email them or send by fax.

Referral advice

Most referral forms provided warnings that incomplete forms could be rejected (appendix 17). Four providers (Whittington, NELFT, CLCH, CNWL, Your healthcare) stated these warnings in red font, while GSTT seemed to adopt more of an advisory tone, signaling the impact of delay. Compulsory sections to be completed included the patient's personal details (Whittington, NELFT, CLCH) and the reason for referral (NELFT). Beyond this there were variations in what providers deemed compulsory information.

CNWL required the whole form to be completed for safe triage and prioritisation. A compulsory home environment section including access to the property was required by Your healthcare. Whittington and CLCH required GP or medical practitioner authorisation for district nurses to administer medication. Whittington also highlighted that if referral forms were sent directly to teams this would lead to delay. Providers gave a number of other directions including the impact on response times if referrals were not sent by certain deadlines.

These warnings and directions seemed designed to shape the understanding and behaviour of those making referrals about what was acceptable. It was indicated that accurate and complete referrals were an essential pre-requisite for access and perhaps guarantee a response. Those making referrals were expected to indicate urgent or time sensitive referrals, the forms show considerable variation in response times, and an urgent referral varied between 2 hours and 24 hours (table 9.8). It seemed that those making referrals determined the urgency of the visit, but where those making referrals do not have any hours as a reference point, this may influence whether a referral is urgent.

Table 9.8 Response times on referral forms

Provider	Urgent	Standard	Routine	Other issues
Whittington	2 hours 4 hours	24 hours	48 hours	Operated a traffic light system: Red 2 hours, Amber 4 hours, Green 24 hours, White 48 hours
NELFT	No hours stated Left open for referrers to complete	24-48 hours	No hours stated	Urgent care seemed to be covered by Rapid Response Service and Community Treatment Team
CLCH	24 hours	48 hours	No hours stated	Referrers may suggest ideal date of first visit Visit to be determined by triage and clinical screening
GSTT	4 hours	24 hours	7 days	Referrers may suggest date of visit
CNWL	No hours stated	No hours stated	No hours stated	Same day or next day referral has to be received before 4.30pm Mon-Fri
Homerton	-	-	-	Referral form not in use
Your healthcare	No hours stated	No hours stated	No hours stated	Referrers may suggest date of visit

Making referrals directly from the website

All providers gave signposts to facilitate referrals and it seemed to be possible to make a referral by phone from all sites. If the same information was required for a phone referral as the referral forms, this suggests that phone referral may take a long time. Compared to other methods, assuming that one could get through, phone referrals appeared to be the most accessible because of 24 hours cover. It also seemed to provide potential for dialogue with the administrator, and or a return call from the district nurse, if there was no direct contact possible by other means.

Making self-referrals

Those providers permitting self-referral (Whittington; CNWL) provided information directing patients to the central messaging service. It is not clear what would happen after that or whether full referral details similar to those on the referral forms would be required. In NELFT's case it was unclear how to self-refer as no contact information was provided. Self-referral seemed to be only available by phone and while this seemed a relatively straightforward approach, there is an assumption that it was possible to get through to the service and that administrators receiving calls were aware that self-referrals were permissible.

Section B summary

Seven providers were selected for a review of web-based information. Ten key questions were used to consider accessibility and clarity in making district nursing referrals. Two GDSS (2016) criteria informed the appraisal taking into account if user needs were understood and whether users could succeed first time. The findings indicate that the GDSS standards are at best partially met.

Summary of main findings

- Finding district nursing webpages on provider sites, using the term district nursing, seemed straightforward
- Information about the service was provided on all sites however, there appeared to be little consistency in what, where, how or how much information was given.
- Information appeared to be confusing or missing, including the term district nursing, the role of the district nurse and contact details
- Providers rarely supplied information specifically for patients and carers, or signposted them to other sources.
- Most information appeared to be directed to those making referrals and how to refer

- All providers articulated their eligibility criteria. A number of eligibility criteria were in use, though all cited being housebound and age. Different explanations were given for the term housebound but all highlighted it as important for referral.
- A range of referral methods appeared to be in use and in different combinations. Most providers identified the use of a SPA, though it was unclear if all referrals were channelled through a single point.
- Referral forms appeared to be essential for referral, but were complex and shared with other services. Incomplete or inaccurate forms could lead to referrals being refused
- Self-referrals were permitted by few providers
- Variations occurred in almost every aspect of the providers' information about district nursing: explanations of the service, the availability of patient information, self-referral, service hours, age criterion, referral methods, process and forms and response times to referrals.

The findings presented in this chapter showed marked variations in information about district nursing presented on providers' websites. Although it was not made explicit for whom the sites and corresponding information was intended, they appeared to be professionally focused, especially for those making referrals. Most of the content was concerned with guiding the referral process, including an emphasis on the eligibility criteria. The review represents a snapshot in time, so the findings need to be viewed in this context as websites change.

Nonetheless, these findings build on and reinforce the results from earlier chapters, particularly regarding information needs, where supply side considerations emerge, regarding service approachability notably, transparency, information and outreach (Levesque *et al,* 2013). Correspondingly, demand side considerations are highlighted in the findings, characterised in Levesque *et al's* framework as patients' (and carers') ability to perceive the service arising from: health literacy, health beliefs, trust and expectations (Ibid). In the next chapter these findings are discussed, alongside the data analysed from other sources, and in consideration of the research questions, theory and literature.

Chapter ten: Discussion

Introduction

This chapter integrates the main findings drawing on the research and policy literature and selected theoretical aspects of access to district nursing. The two cross cutting themes, equity and transparency, that emerged from the analysis of the findings are integrated into the discussion. An overview is provided at the start of the chapter of the selected theory of access and the combined and distilled findings relating to the research questions. A discussion of each main finding follows and the chapter concludes with a summary of the findings.

Overview of the theoretical framework and findings

Levesque *et al's* (2013) theoretical framework is used to inform the discussion of the analysis as it addresses both the supply and demand sides of access, mirroring the study's design which has been noted was based on Penchansky and Thomas (1981) and Goddard and Smith (2001). Through exploring multiple perspectives, my study enabled perceptions of access to be explored and analysed from both sides. Key concepts in Levesque *et al's* framework are considered in relation to the findings and the research questions, namely, how do patients, carers, district nurses and health and social care professionals experience access to district nursing? and secondly, what factors promote or hinder access to district nursing?

As argued in chapter four, this framework was selected because it is applicable to the context of district nursing, in that it is intentionally patient-centred and does not limit understanding of access in terms of service utilisation or initiation of care (Levesque *et al,* 2013). It is discussed in greater detail in chapter four and a summary is provided here.

Addressing the supply side of access, there are five dimensions of access characterized as*:* 'approachability', 'acceptability', 'availability', 'affordability' and 'appropriateness'. The demand side of access has a corresponding set of five abilities whereby service users may: 'perceive', 'seek', 'reach', 'pay' and 'engage' with the service. There is potential for interaction and gaps between these dimensions and abilities. Levesque *et al's* (2013) conceptualisation of access aligns with those district nursing values that ideally seek to provide holistic, patient-centred care which engages and empowers patients in their own care (Gough, 2018; Seddon, 2018).

A main critique of measuring access is that service utilisation is used as a proxy (Levesque *et al,* 2013; Gulliford *et al,* 2001). Although Dixon-Woods *et al* (2005) found that precise definitions of access and equity were elusive, Levesque *et al's* (2013) broader definition of access permits an 'appropriateness' dimension that includes care quality, continuity and resources necessary to achieve access. The corresponding ability of patients 'to engage' in the service results in empowerment, concordance with planned care and potential for self-care. It seems to allow for tensions to be played out in the way power may be exerted between the demand and supply sides of access.

The interplay between these dimensions and abilities indicates where power can be located, transferred or held in balance between the providers and services users. This aligns with Dixon-Woods *et al's* (2005 p.6) review where 'candidacy' denotes eligibility for healthcare, which is 'jointly negotiated between individuals and health services'.

Levesque *et al's* (2013) framework provides a lens through which to analyse the study's main findings by applying the germane dimensions and abilities across a continuum of access. Both the framework and district nursing lay claim to being patient-centred and with patient involvement so that patients (and by proxy their carers) 'engage' with the service to have 'appropriate' access (Levesque *et al,* 2013). Further, continuity of district nursing is an important element of access to care beyond initial service utilisation, to incorporate health outcomes. Though neither this framework nor district nursing have been studied fully to test such claims.

The different data sources have generated findings from diverse perspectives, which have been analysed to consider the extent to which they converge or diverge. Access to district nursing was perceived to be problematic by most participants as it appeared to be an invisible service. Information about the service seemed to be largely absent, and participants reported an inconsistent and often an absence of understanding about the role of the district nurse, including the gatekeeping aspect and this appeared to influence negatively expectations and experiences of access.

A commonly articulated view by all participants (patients, carers, district nurses and health and social care professionals) was that of high demand and limited resources, particularly the lack of district nursing staff. High demand seemed to influence the way district nurses managed access through the referral process, by screening referrals and determining who was eligible. Where the district nursing service was reached, access was experienced as a set of disruptions

across a continuum, from no access to full access. Participants' experiences of gatekeeping roles seemed to limit initial and ongoing access. However, where full access to district nursing was experienced, it was transformative for patients and carers, and district nurses' knowledge and skills were valued.

Across all findings, power emerged as an important aspect of access, with participants using metaphors and/or revealing certain tensions and paradoxes that expressed its impact on them, from either the supply and demand side of access (Dobratz *et al,* 2019; Dixon-Woods *et al*, 2005).

These findings indicate that participants from diverse perspectives expressed strong views. Dominant among these was the view that accessing district nursing, whether from the supply or demand sides, was not straightforward. The context within which district nursing occurred did not necessarily or neatly correspond to certain principles and concepts of access.

A key principle underpinning access to NHS services is that health care is equitable, open to all, irrespective of clinical need or ability to pay (Gulliford *et al*, 2002; NHS, 2015a; LHC, 2014). However, in my study, access to district nursing was not always seen as equitable or necessarily open to all, and paradoxically clinical need was not highlighted as an eligibility criterion for access. Most patients on district nursing caseloads are older and/or vulnerable people who are more likely to be poor (Victor, 1991; Graham, 2007) and 'do not enjoy the same access to or quality of service as those who are younger and better off' (Coote 2009, p.56).

Accessing district nursing is different to most other services in that it is brought to the patient rather than the other way around. My findings seemed to reveal hidden worlds where there is overt and covert control of access to district nursing. There is a sense of disempowerment articulated from different perspectives across the continuum of access, reflected across all five dimensions (Levesque *et al*, 2013).

Access may be seen as the interface between potential patients and providers, and influenced by those supplying the service and those already using it (Levesque *et al*, 2013). The nature of district nursing means that most care is conducted in private, in patients' homes and opportunities to see and monitor the service in action are limited (McGarry, 2003; QNI, 2019a; NHS, 2013).

An invisible service

My study reveals that district nurses considered themselves to be invisible, which corresponded with patients' and carers' experiences of the service. Although paradoxically for district nurses, a beneficial aspect of this invisibility emerged as *'maybe we like it that way',* intimating that invisibility provided a means to cope with or even assert some control over increasing demand and a workload that felt out of control and sometimes overwhelmed.

'We're pretty invisible really' (Anne student district nurse)

There is a body of research evidence supporting this view of district nursing as an invisible service (Goodman, 2000; Haycock-Stuart *et al,* 2007; Walshe and Luker, 2010; Thomas *et al,* 2006; Jackson *et al,* 2015; Drew, 2011). A review of caseload management by Haycock-Stuart *et al* (2008) found that much of district nursing work was invisible and characterised as 'a ward without walls' with open-ended service demand. A rising demand for the service, together with a dramatic decline in the numbers of qualified district nurses contributes to this sense of an invisible workforce (Jarvis *et al,* 2006; QNI, 2017a; QNI, 2019a).

The policy context to expand care closer to home seems to be disconnected from the reality of district nurses' working lives and their sense of being invisible resulting in powerlessness (Thomas *et al,* 2006; QNI, 2014c; NICE, 2018; NHS, 2019a). Jarvis *et al* (2006 p.18) asserted that there was a need '…to take control of where district nursing will sit in the increasingly complex political health and social care agenda'.

Invisibility was used as a metaphor by district nurses to 'express multiple truths about the nature of its practice' in Goodman's (2000 p.107) study. Different aspects of district nurses' invisibility are reflected in these studies but only from their perspectives. In Levesque *et al's* (2013) framework, the 'approachability' dimension corresponds to patients' ability to 'perceive' that a service exists.

While the former studies' findings described the service from district nurses' perspectives, Walsh and Luker's (2010, p. 1179) study of palliative care noted that,

> '…few studies examine the patients' and family carers' views of the district nursing service and even fewer integrate the opinions of patients and nurses within the same study'.

A strength of my study was to fill the gap in our understanding about the different views and perspectives regarding access. My findings suggest congruence with these studies, as district nursing seemed to be a well-kept secret, with invisibility manifest in a number of ways (table 10.1). Patients, carers and health and social care professionals highlighted a lack of understanding of what district nurses do, which possibly compounded their difficulty in accessing information about the service, which was further reinforced by the limited information available on websites.

> ***'I don't think anybody knows what we do' (Maria qualified district nurse)***

Surprisingly, perhaps, district nurses said their role was misunderstood not only by patients and carers but also GPs and hospitals, with inaccurate information being provided on referral, setting unrealistic expectations.

Unfulfilled promises post discharge caused disappointment for patients and carers in O'Brien and Jack's (2010) study. Worth *et al* (1995 cited in McHugh *et al* 2003, p.73) found that those with a better understanding of the service were more likely to refer to it. This was not necessarily the case in my study, as district nurses accepted most referrals from GPs and hospitals but their view was that they did not necessarily understand the role and thereby their service. The survey data also highlighted divergent views between district nurses and health and social care professionals, and revealed gaps in knowledge in relation to referral.

My findings suggest district nurses viewed incorrect information given by hospitals and GPs as detrimental to the nurse-patient relationship, and their discomfort in being the 'bad guys' when explaining that patients had been misinformed. Their view was that no one understood what they did, although patients and carers did not seem to have unrealistic expectations of the service.

In McHugh *et al's* (2003, p.76) study of district nurses' experiences of referrals, they too found that hospitals gave patients inaccurate information, such as the frequency and timing of visits; there were variations in patients' often unrealistic expectations of the service and when district nurses explained its purpose there was a sense of 'letting patients and carers down'. Other studies highlighted similar findings (Wilson *et al,* 2002; Jarvis *et al,* 2006; Thomas *et al,* 2006*;* Haycock-Stuart *et al* 2008; Walshe and Luker, 2010).

Table 10.1 Overview of aspects of invisibility

Information ➔	• Not supplied prior to receiving the service • Not found by patients and carers • Inaccurate • Limited web information • Not patient oriented • No information for carers • Service not promoted
Contacting the district nurse ➔	• No direct contact details • Messaging service - hard to get through • Lack of response • Uncertainty whether messages received
Role of the district nurse ➔	• Lack of understanding of the role and service • Unaware 24 hours service • Unable to navigate the system • Assessment • Care coordination • Gatekeeping
Self-referral ➔	• Unaware of self-referral • Did not happen in practice

Views on access to service information

A key finding was that access to service information did not seem to be consistently and systematically made available to patients, carers and health and social care professionals. Patients and carers did not recall being given information in advance of receiving the service, which is further reflected in the variation in the way service information was presented on websites.

Goddard and Smith's definition of access (2011, p.1151) includes being in possession of 'a *specified* amount of information' and for Levesque *et al* (2013) information was incorporated into their 'approachability' dimension. Information enables patients and carers to locate and connect with the service (Levesque *et al,* 2013, Wilson *et al,* 2002).

'I didn't receive anything…no I didn't get one' [leaflet] (Hilary carer)

Leaflets are commonly considered one way of providing service information, but my findings indicate that not all providers had leaflets and patients did not mention receiving them. When they were provided, this was at the first visit, and placed in the patients' notes at home. It seems they were not distributed anywhere other than patients' homes. District nurses appeared to question the

limitations of these leaflets, as they were not necessarily referred to and patients did not usually read them.

Carers in particular wanted district nursing support, indicating their own information needs and expectations of help. Patients and carers wanted contact details giving direct access to district nurses. That patients and carers were not aware of leaflets suggests they may be a tool for professionals; this is supported by other research.

Beaver and Luker's (1997) study of cancer patients, questioned whether information in patient leaflets met health professionals' needs rather than patients. A number of studies found carers experiencing a lack of information and support (Gerrish 2008; Greenwood *et al,* 2016; Buckner and Yeandle, 2015 Arber *et al,* 2013; Wilson *et al,* 2002; Arksey and Hirst*,* 2005; Nagington *et al,* 2016; Drennan *et al,* 2011). This may be compounded because, as Gerrish (2008) found, carers do not appear to be on district nurses' caseload in their own right. These studies seem to uphold a 'top down' approach to the production of information, and do not consider how patients and carers might be involved in influencing access to the information they need.

These studies do highlight the value of a professional explaining the service, which is then supported by written information (Beaver and Luker, 1997, Wilson *et al,* 2002). This supports my findings where patients and carers expressed a preference for a personal explanation of how district nursing worked and what it offered, which chimes with the need for greater personalisation, 'Yet universal access has for too long meant care that is too impersonal.' (Lord Ari Dari, LHC, 2014 p.7).

> ***'You don't really come across the services you need until you need them desperately' (Hilary, carer)***

District nurses saw provider websites as another source of patient information. With one exception, this web information was not oriented to patients and carers but to health and social care professionals. Searching for information about district nursing seemed to be straightforward and could be located on provider websites, however, carers did not seem able to locate this information and were uncertain if it existed. Some district nurses questioned whether their patients would use these sources or even the Internet.

Given the NHS drive to increase the use of technology to access services, including telehealth and telecare, housebound patients who are very elderly and

disabled may be unable to afford basic resources for Internet enabled devices or the skills needed to seek this service (NHS, 2019a; QNI, 2018). Levesque *el al,* (2013) include health literacy as an important aspect of service users' 'ability to perceive' a service. However, my findings showed that even those carers with significant web skills and resources found the time and effort required did not result in useful information. In fact, no carers reported finding the provider websites.

> ***'If only I could get one [district nurse] I don't know [how] I can't get one' (Marcia patient)***

The QNI (2018) survey found that the use of technology might act as a barrier to patient engagement. Bain (2018) cautions about assumptions made about older people being unable to use technology, although comparatively older people have lower participation in ICT activities and '…experience age related barriers in the use of web resources, which can be similar to those of disabled persons' (MFKK 2011, p.9). Patients on district nursing caseloads tend to be older, poorer and disabled and with rising levels of sight loss presenting added challenges (Graham, 2007; RNIB, 2015). They are less likely to have the means or motivation to use web-based resources and specific design principles need to be employed (MFKK, 2011, GOV.UK, 2016).

Although information was present on provider websites, *no one* including health and social care professionals cited these websites as their main source of information about the service. The web information was highly variable, lacked consistency and did not provide comprehensive information about district nursing, such as the service hours. Not surprisingly perhaps, most patients and carers seemed to be unaware district nursing was a 24 hours service.

Considerable variations have been found in district nursing services in England and such variations lead to inequity (Carter, 2018; Robertson *et al* 2017; Proctor, 2013). Carter (2018) advocated more efficient use of weekend district nursing services to facilitate hospital discharge, although NICE (2018) did not find evidence of the effectiveness of extended hours compared with standard access.

Provider websites in my study also showed considerable variations in the district nursing services offered, echoing concerns about equity and transparency. Patients and carers seem to have access to different district nursing services between boroughs, though websites may not accurately reflect the service offered. While all providers seemed to offer a core district nursing service to provide nursing care to

housebound adults. There was no single lower age threshold, it was either sixteen or eighteen years old, with local interpretations of what was considered adulthood.

The range of services offered varied by provider, for example, administration of oral medication, phlebotomy and district nurse-led clinics. Other variations included service hours, response times to referrals and the referral process. NICE (2018) found that standard access to district nursing was variable across the country. This further supports my findings, and that a uniform district nursing service was not available across London.

The survey data indicated that health and social care staff lacked knowledge about district nursing but did not use the web to learn about it. Instead, GPs were seen as the main source of this information for patients, carers and heath and social care professionals. District nurses also cited GPs as the main information source for patients and carers, though the survey showed they did not know how health and social care professionals found out about the service.

However, given the well-known difficulties in accessing GPs, this suggests a further barrier compounding access to district nursing (Goddard and Smith, 1998; Ware and Mawby, 2015; Dixon-Woods *et al*, 2005). My findings indicate that in the current climate, web-based sources may not be an effective means of making district nursing known.

'Just make it more visible in GP surgeries' (Anne student district nurse)

The right service information in the preferred form was rarely or consistently available at the right time. This appeared to create feelings of disempowerment, particularly for patients and carers, preventing them from 'perceiving' or 'engaging' with the service (Levesque *et al*, 2013, Dixon-Woods *et al,* 2005; Baxter and Glendinning, 2011). Dixon-Woods *et al's* (2005 p.36) review found that the,

> 'Lack of information thwarts people from using services in the way that would most benefit them at every stage of their interaction with health services.'

While it is important to acknowledge the limitations of the information available, the findings suggest that access to the service was subject to a variety of constraints and controls. From the websites reviewed, little information appeared to be provided about the district nurse's role or how the service

worked: important aspects were largely missing such as, needs assessment, care co-ordination or self-referral.

Thomas *et al's* (2006) study of a district nursing service found that not only was the role of the district nurse unclear but also that the referral criteria were unclear, leading to inappropriate referrals and attendant time wasting for district nurses. By contrast, my findings showed all websites were explicit about the referral criteria and the website information tended to be directed at professionals, emphasising the referral process, rather than being patient or carer centred.

Referrals and eligibility criteria

Referral criteria were originally intended to make transparent what the district nursing service would offer (Audit Commission 1999; RCN 2003; Ball *et al,* 2014). The benefits of specifying the referral criteria were intended to lead to greater role clarity, better caseload and demand management and service efficiency (Jarvis *et al* 2006; Bowers and Cook, 2012; Thomas *et al,* 2011). The need to articulate these criteria was also a recognition of the 'open door policy' of the service, illustrated by district nurses describing themselves as 'sponges' taking on more and more (ENB/QNI 2002 cited in McHugh *et al* 2003, p.78).

It is accepted that there is increasing and uncontrolled demand for district nursing (Haycock-Stuart *et al*, 2008; Jarvis *et al,* 2006; Bowers and Cook, 2012; QNI, 2019a; QNI, 2019b). District nurses,

> 'do not have the luxury of being able to state a service capacity like all other services - a hospital can declare all beds to be full' (McHugh *et al* 2003 p.73).

Despite the policy rhetoric to increase care closer to home, there is at the same time an imperative to contain costs and improve efficiency (Carter, 2018; NHS, 2019a; Bowers and Cook, 2012).

'You're just inundated with referrals' (Linda qualified district nurse)

My findings concur with the literature, as district nurses also experienced unlimited demand, and the referral criteria seemed to be important to help them manage demand by determining eligibility and refusing inappropriate referrals. Ross *et al's* (2014 p.8) research found that community staff, including district

nurses, experienced emotional stress and dissatisfaction due to work overload, constant policy change and a lack of time to do the job properly.

In a QNI (2014b) survey, district nurses reported receiving inappropriate referrals from GPs, social services and allied health professionals. Referral criteria appear to serve multiple strategic and operational functions. At a strategic level they were intended to inform commissioners about the service (Bowers and Cook, 2012). Operationally, referral criteria were intended to enable acceptance of appropriate referrals and rejection of those deemed inappropriate (Bowers and Cook, 2012; McCrory, 2019).

A number of studies and initiatives sought to develop these referral criteria: mainly they were clinical criteria or identified the range of care provided (Jarvis *et al,* 2006; Bowers and Cook, 2012). This approach has been criticised as reductionist and task focused, and arguably does not help to articulate the role of the district nurse (Jackson *et al*, 2015). It may also undermine the claim that district nurses provide holistic care based on needs assessment (Gough, 2018). Though having a nursing need was featured as an eligibility criterion, and the guidance required the criteria to be transparent, in order to ensure appropriate referrals and an equitable service (Jarvis *et al,* 2006). With one exception, none of these studies mentioned being housebound as a referral criterion (Bowers and Cook, 2012).

Being housebound - a key eligibility criterion

By contrast, my findings showed that two referral criteria were widely used, all district nurses and the websites specified the same two criteria: being housebound and age. Having a nursing need was included on some websites but there seemed to be no clinical criteria on any websites, although areas of care were listed. My findings show being housebound is a key eligibility criterion and district nurses reported feeling pressure to provide care only to those who were housebound. This related in part to their understanding of the commissioning requirements.

> ***'These patients should meet the criteria and they should be housebound' (Neville qualified district nurse)***

For the initial assessment McHugh *et al* (2003) found district nurses wanted as much information as possible from referral forms. Through the assessment process, district nurses determine who gains access to the service, what care is provided, how often, by whom and for how long the service is offered (Kennedy,

2004). Dixon-Woods *et al* (2005) found a traditional form of professional power was retained, where professionals decided what was best for patients. Though the review does not address patients' perceptions of their role in healthcare (Bentley, 2003; Ford *et al*, 2018). It could be argued this competed with what was best for the service, and the idea of 'an ideal user' fitting the service (Bentley, 2003; Dixon-Woods *et al,* 2005). Housebound patients may be considered ideal users, where all would be eligible for the district nursing service.

'She can barely walk how can she not be housebound?' (Yvonne carer)

My findings have implications for understanding equity of access, as on the one hand, the eligibility criteria were transparently stated but on the other, there seemed to be marked variations in the way district nurses interpreted the housebound criterion. Some reported defining the terms of being housebound rigidly, where a patient literally never left home, while others were more nuanced and flexible in their judgement, adopting a situational approach to consider the degree of assistance required to leave home or other mitigating factors. These variations in granting access could occur within the same provider, as well as between providers.

In my study, district nurses appeared to use the referral criteria, particularly being housebound, as a means to control their workload in the face of increasing demand. The district nursing service has been recognised as open ended and demand difficult to control (Goodman, 2000; Haycock-Stuart *et al,* 2008). As Robertson *et al* (2017 p.45) found, the housebound criterion was being more tightly defined and care shunted to carers and practice nurses,

> 'It is difficult for providers to limit demand for district nursing, however we heard some examples of providers attempting to do this by tightening access criteria. We also came across evidence of increasing delays for non-urgent referrals.'

It appeared from the surveys and district nurses' experiences that any referrals not meeting these access criteria, and in particular the housebound criterion, were deemed inappropriate and could be rejected.

'They're supposed to screen the referrals to make sure they're appropriate' (Anne student district nurse)

District nurses and some websites warned that referrals were and could be rejected if they were incomplete. Rejected referrals caused delays, which could

impact on care quality (Maybin *et al* 2016; Robertson *et al,* 2017; QNI, 2019b). Health and social care staff in the survey reported knowing what the criteria were but also experienced referrals being rejected for what they perceived as trivial reasons like incomplete forms. This suggests that perhaps referrals were treated in an overly bureaucratic way, which resulted in a form of rationing.

In my study, inappropriate referrals were simultaneously viewed by district nurses as a source of frustration and waste of time, and deprived eligible patients of the service. Some patients and carers experienced referral difficulties that also wasted their time and resulted in them being bounced around the system, and in some instances failing to get access.

District nurses reported receiving inappropriate referrals to undertake a generic monitoring role. For example, being asked to *'pop in'* without a defined nursing need was deemed wasteful. In some instances, district nurses felt those referring deliberately sent inappropriate referrals and they were used as the service of last resort.

> ***'the good old district nurses will mop it up…' (Charlotte qualified district nurse)***

GPs too may use referral to district nurses as a way of shifting the burden and managing their own workloads and risks. The survey results also suggest that some health and social care professionals knowingly sent inappropriate referrals. This aligns with a QNI (2014b) survey that found some health and social care professionals' referrals were inappropriate and 'passing the buck'.

My findings concur with other studies, for example, time wasted due to inappropriate referrals, inadequate referral information and district nurses filling gaps left by other services (Thomas *et al,* 2006; McHugh *et al,* 2003*;* Haycock-Stuart *et al,* 2008; McKenna *et al,* 2003). The findings also suggest that power is being exercised between health professionals by making autonomous decisions with limited reference to each other, with reduced communication and partnership working (McHugh *et al,* 2003*;* Speed and Luker, 2006; Cameron *et al,* 2012). Both policy and organisational factors seemed to underpin silo working with fewer opportunities for staff to meet and discuss patients,

> ***'The new NHS set us up against each other as competing tribes - everybody is 'gaming' against everyone else' (GP)***

Nonetheless, these decisions are likely to reflect the particular pressures facing district nurses and health and social care professionals and their respective organisational imperatives, especially avoiding hospital admissions. At the same time, it is accepted that increasingly district nurses manage complex care and treat patients who would have been hospitalised in the past, and there is some blurring of boundaries in terms of roles (McKenna *et al*, 2003; Gilburt, 2016).

Direct access a well kept secret

Direct access or self-referrals seemed to be theoretically possible, almost all district nurses stated this, and it was confirmed on three websites, but most patients and carers were unaware of this.

> ***'I had never thought that you could automatically contact the district nurse' (Philippa carer)***

Both examples of self-referral reported were rejected and re-routed back to their GPs: district nurses considered GP referrals as the required norm. It is possible that rejected self-referrals were also a means to manage demand. District nurses were concerned about self-referrals opening the floodgates to further demand. However, Greenfield *et al's* (2016) review found some evidence, albeit in other health systems, that direct access might reduce demand.

From the survey, health and social care professionals were also unaware that self-referral was possible. Paradoxically, district nurses could not provide any examples of successful self-referral. However, in certain circumstances patients who were previously known to the service were actively encouraged to self-refer. These findings suggest that barriers to self-referral originated from a lack of awareness of the service and information for patients, carers and health and social care professionals. Other than the origins of the district nursing service, there seems to be no reference to self-referral to district nursing in the literature.

Managing workload with reduced capacity

In my study, district nurses indicated that they determined which referrals were appropriate and seemed to exercise overt and covert control over access. This could be by rejecting referrals out right or deciding priorities and response times. At best, the consequences of these decisions could be delayed access, inappropriate referrals maybe recycled through the system until they were deemed appropriate. At worst, access was inequitable because different

outcomes could arise in determining who was housebound or where referrals could be rejected outright. It seems likely that district nurses may have employed these tactics to buy time to manage demand.

Paradoxically, this seems to be the antithesis of the policy rhetoric of integrated care service (ICS) delivery, delivered by flexible multi-disciplinary teams (NHS, 2014; NHS, 2019a). This suggests there may be a perverse incentive for district nurses to control demand in this way, to cope with a lack of capacity and it follows that without sufficient capacity, it would also be perverse to promote or publicise the service. The findings suggest that this bureaucratic approach was adopted to manage referrals by policing the access boundaries to screen out, send back, recycle or reject inappropriate referrals as a result of open-ended demand.

This resonates with Goodman's (2000) findings where district nurses felt overwhelmed and powerless in controlling their workload. In terms of Levesque *et al's* (2013) framework this could have the effect of making their service 'unapproachable' and 'unavailable' to service users. It was not possible to determine the extent to which district nurses refused referrals in my study, although a QNI (2014b) survey found that the majority of district nurses did not refuse referrals because of capacity issues. However, a more recent survey shows referrals are being deferred due to capacity constraints (QNI 2019b).

> ***'They'll dump what's left…so we inherit a lot of everybody else's tut [rubbish]' (Charlotte qualified district nurse).***

At the same time, my findings revealed that district nurses seemed to accept or at least recognise that they were seen as a service of last resort, when no one else was willing to see patients with challenging circumstances, or where other services operated in office hours. In the surveys, most participants thought it was easy to make referrals to the service. Where providers offered 24/7 cover, this may make it more difficult to decline access and easier for others to refer to out of hours services.

District nurses appeared to be very conscious of what services they were commissioned to provide, and seemed conflicted about restricting care delivery, whether due to staff shortages, a lack of qualified staff or refusing access where eligibility criteria were not met. It might be the case that it was easier for district nurses to reject referral forms rather than patients with whom they had begun to form relationships (Luker *et al,* 2009; Walshe and Luker, 2010). District nurses indicated they were unable to nurse in the way they were trained. Further to

this, Worth's study showed that district nurses were aware that they were bound up with the care offer and rationing themselves was alien to 'the nursing value of 'taking everything on' (Worth 2001, p.262).

> ***'You're just constantly waiting for the phone to ring saying "we can't come" ' (Bernard carer)***

My findings indicate that district nurses felt unable to control demand, and attributed this to workforce shortages. While patients and carers were sympathetic to district nurses' workloads, and often considered other patients had greater needs, aligning with Wilson *et al's* findings (2002). However, patients and carers experienced these shortages as unsatisfactory, late or missing visits and were conscious they were not receiving the service as planned. Their uncertainty about whether a visit would take place, scheduled or otherwise, and time spent waiting for a visit caused anxiety, and degrees of frustration. Patients and carers seemed to experience a loss of autonomy and had little control of their situation in terms of waiting.

This sense of powerlessness expressed by patients and carers was also reported in Walshe and Luker's (2010) review of the district nurse's role in palliative care. Greenwood *et al's* (2009) study found carers had similar experiences of waiting for health and social care services, which increased anxiety.

In my study, there were instances of poor quality care reported by patients and carers, which they linked to insufficient skilled staff, and the lack of continuity. District nurses also highlighted their concerns about safe levels of staff. These findings align with the wider literature. For example, QNI reports show district nurses working under pressure and to capacity, with unsafe staffing levels affecting their ability to provide consistent high quality care (QNI, 2014a; QNI, 2014c; QNI, 2019a; QNI 2019b).

To achieve access there is an expectation that a sufficient supply needs to be in place to meet demand (Goddard and Smith, 2002). The number of qualified district nurses has decreased from 7,716 in January 2010 to 4,441 in April 2020 and there are 44% fewer district nurses than ten years ago (NHS Providers, 2018; NHS Digital, 2020). The reduction in the number of skilled qualified district nurses is compounded further as this workforce is ageing (QNI, 2019a).

This dramatic fall in the national number of district nurses is compounded by short termism and the shift to localism, as workforce planning and service design are determined by CCGs (NHS Digital, 2020; NHS, 2019a; NHS, 2016a; Maybin e*t*

al 2016; NHS, 2016b; Wenzl *et al,* 2015). As CCGs are shaping services locally, national inequities in provision are emerging, alongside historical resource allocation (Tinsley and Luck 1998; Gerrish, 1999; NHS, 2016a; Carter, 2018).

An analysis of London CCGs showed they were not commissioning for equity of access, and that equity was an afterthought (Wenzl *et al,* 2015). They also found that the approach was clinically led i.e. demand led by GPs rather than population based (Wenzl *et al*, 2015). CCGs take an individualized approach to commissioning, that may have an impact locally but collectively this may not lead to equity between or across CCGs. Further, there does not appear to be any central direction or monitoring to promote equity (Wenzl *et al,* 2015). This does not bode well for ICS, even though longstanding barriers have been acknowledged, with increased investment to tackle them (CQC, 2016). The focus, however, remains on GP practices, and it is unclear if district nursing will receive any of the investment (Carter, 2018; NHS, 2019a; NHS Providers, 2018).

The lack of investment and long decline in the numbers of district nurses and those in training and need for long-term planning is well documented (Skinner and Burkitt, 1993; Ball *et al,* 2014; QNI and HEE, 2014; QNI 2014c; Maybin e*t al* 2016; QNI, 2017a; QNI, 2019a). Such reports have called for action to reverse the decline in district nursing, as well as the need for better tailored workforce planning to take account of the unique complexities of the service requirements, ensuring quality, equity and safety (QNI, 2019a; QNI, 2018; QNI, 2017b; QNI, 2016; QNI and HEE, 2014; RCN, 2012; Jackson *et al*, 2015; Drennan, 2014; Maybin e*t al* 2016).

Tasks versus holistic care

CCGs commission district nursing to provide care based on block contracts, with numerical targets of patient contacts recorded as proof of service delivery (QNI, 2014c; Robertson *et al,* 2017). It appears that utilisation is used as the proxy for access to district nursing.

In my study, district nurses' felt CCGs were only interested in task-based care and their skills were not valued. They did not think commissioners understood that complex care could not be recorded as a single task. For them, this was a reductive approach and there was no incentive to record all 'tasks' carried out during a visit as part of holistic care. In their view, commissioners were not interested in whether holistic care was provided. District nurses saw data recording of contacts as a tick box exercise, although they understood this was important to fund the service.

'The commissioners say the activity hasn't increased but the activity in itself isn't the marker' (Winston qualified district nurse)

By implication district nurses seemed to provide services that were not fully accounted for through commissioning, with complex patients, requiring more time and this was likely to contribute to how they managed demand. Paradoxically, district nurses were also masking demand and as care happened behind closed doors.

These findings align with the literature, where the QNI (2014b) concluded recording patient contacts was a crude measure of service delivery that overlooked complexity. This approach also appeared to be at odds with district nursing values and role, in providing holistic care (Walshe and Luker, 2010; Haycock-Stuart *et al*, 2008). Thorough assessments take time but workforce pressures and demand affect holistic assessment, adversely affecting the quality of care (Haycock-Stuart *et al*, 2008). Maybin *et al* (2016) assert that due to these pressures district nursing has become task oriented, challenging assumptions around holistic assessment and care as central tenets of district nursing. Ironically, the NHS (2015b) commissioning guidance indicated that person-centred outcome-based commissioning should be implemented rather than patient contacts, suggesting that it is possible to commission for holistic care.

'Seeing more complex patients that would be in hospital' (Bev qualified district nurse)

The focus of CCGs reforms has been on efficiency targets and reducing hospital admissions, with bed blocking remaining a focal point to control costs (Wenzl *et al,* 2015; NICE, 2018; NHS, 2019a). Here, district nurses perceived their service as one that prevented hospital admissions, often citing this as a 'raison d'etre'. Many reports acknowledge the role of the district nurse in preventing costly hospital admissions with policy directives to promote this (QNI, 2019a; QNI, 2018; QNI, 2017b; Drennan, 2014; DH, 2013; Carter, 2018).

As a result of such policy drivers, district nursing seems to have become an extension of acute services with its main priority to keep patients out of hospital (NICE 2018; Gilburt, 2016; QNI, 2019a; QNI, 2019b). This may well be better for patients although the resources do not seem to have followed patients into the community, with evidence of static or reduced funding (NHS Providers, 2018; Robertson *et al*, 2017). For example, a proposal to re-design catheter services led to resistance from managers in acute services where this meant losing income to

district nursing (Heavans, 2018). Hospitals and commissioners may have vested interests in deploying district nursing, as this controls costs and meets their targets. However, the strain on district nursing is continuous as it is seen as having unlimited capacity, while the impact on staff emotionally and practically does not seem to be acknowledged (QNI, 2016; Haycock-Stuart *et al*, 2008; Allan *et al,* 2014).

> ***'Hospital avoidance is something that we do a lot of' (Winston qualified district nurse)***

My findings indicate the way district nursing is being re-shaped, from one that provides long-term care and support, to one that also offers acute highly specialist care once provided by hospitals. District nurses are aware of this tension and work across the boundaries of primary, secondary and social care (QNI, 2019b; Gilburt, 2016). NICE (2018 p.54) recognised that these nurse-led community services 'dovetail with the UK health policy imperatives…'. However, expansion of care services to prevent and/or shorten hospital admissions requires resources and investment. A King's Fund report recognised that district nursing was one of the services experiencing the greatest financial pressures (Robertson *et al,* 2017). Local GPs could influence service configuration and investment as commissioning is GP-led (Wenzl *et al,* 2015).

Flight to specialist services compromising generalist provision

Some GPs and district nurses, in my study, highlighted the lack of investment in the service. District nurses described new community services receiving investment at their expense. From their perspective, new services were well resourced, often offering intensive support to patients for a limited time, such as reablement post hospital discharge. District nurses' viewed these initiatives as unnecessary and 'hived off' some of the more rewarding aspects of their roles, including holistic care. This aligns with other studies where district nurses would prefer to provide other caring services themselves, such as palliative care (Ball *et al,* 2014; Walshe and Luker, 2010). McGarry's (2003) research revealed that the presence of other services had an impact on holistic care and the rise of specialists can lead to fragmentation of care. Goodman *et al* (2003) also make the point that the presence or absence of other services influences district nursing provision.

District nurses also reported losing experienced staff to these new services. They experienced this as highly demoralising, where their skills were under used. Added to this, when these services had *'finished being all dynamic'* then district

nurses would be required to pick up where these services left off. Such initiatives seemed to fragment the service, and may make the role less attractive when recruiting staff (NHS, 2019c; Drennan *et al*, 2005). District nurses feel vulnerable as generalists because of the expansion of specialist services in the community, and this is a contested area (Haycock-Stuart *et al*, 2008; Goodman *et al,* 2003; Gilburt, 2016).

By contrast, an adapted Dutch Buurtzorg model was introduced as a pilot in one provider, empowering patients and district nurses to be able to provide care in a holistic and flexible way (Chilton, 2018). The evaluation showed high levels of satisfaction from patients, carers and staff, with indicative improved staff retention, however workloads were lower and staffing levels higher than the regular district nursing service (Drennan *et al,* 2018). It was not clear what the impact was for the rest of the district nursing service. Drennan *et al* (2018) recognised that sustainability needs to be addressed. Nonetheless, this model suggests that with similar leadership and investment directly into district nursing perhaps similar outcomes could be achieved.

District nurses, in my study, did not appear to consider that they were subsidising hospitals, by enabling them to meet targets or make savings, even though district nursing providers allocated resources to triage. District nurses had mixed views about triage. The benefits included time saved by screening referrals, retrieving missing information, ordering equipment and prioritising visits. The main disbenefit was highly qualified staff, who were in short supply, were not available for patient care. Though district nurses seemed well aware of pressures, arising from staff shortages, they did not perceive that allocating resources to triage might be perpetuating or even subsidising poor referral practices.

Health and social care professionals considered district nurses to be under pressure but also doing a good job: they found district nurses were very responsive to referrals, usually visiting within 24 hours. Ironically, this responsiveness may be masking their capacity to cope with demand, though they felt the pressure to demonstrate CCG contract requirements were met.

Powerless in the system

District nurses expressed feelings of powerlessness influenced by cumulative demands. Paradoxically, there appeared to be some attenuation of power in their relationships with GPs, as they were able to reject referrals, although on occasions managers could over rule their decisions. In the survey, GPs

commented that they wanted better communication with district nurses through regular meetings and feedback on referred patients. They indicated a sense of loss regarding inter-professional working previously experienced. This loss was echoed by district nurses, reflecting Allan *et al's* (2014) research finding on change where inter-professional working required time. By contrast, Speed and Luker (2006) found, that despite resistance by nurses, GPs retained power, though perceptions differ among professional groups' about where power lies (Freeman and Hughes, 2011).

The CCGs' role and service configurations may well have contributed to power shifts between district nurses and GPs and team working. The QNI report warned that locating district nursing teams away from GPs resulted in disjointed care across primary and community services (QNI, 2019a). It remains to be seen whether new primary care networks offer better partnerships, despite current arrangements indicating power and investment lie with GPs (NHS Providers, 2018).

Gatekeeping roles limiting access

My findings showed that GPs seemed to play a significant gatekeeping role to district nursing. Participants looked to them as either a source of information about district nursing and/or to make referrals on their behalf, particularly care home managers. This reliance on GPs (and hospitals) suggests that information is assumed to be accurate, although district nurses reported that inaccurate information was given about their service.

The gatekeeping model in the NHS is intended to control costs as GPs provide access to specialist services (Greenfield *et al,* 2016). Gatekeeping is important not only for cost containment but also service utilisation, health outcomes and patient satisfaction (Greenfield *et al,* 2016). In their review of gatekeeping in primary care, Greenfield *et al* (2016) conclude that there is scope to consider relinquishing this model, although evidence applicable to the UK is limited. They argue that in the light of policy change, gatekeeping counters the aims of promoting patient choice, inter-professional collaboration and integrated care (Ibid).

It is well documented that access to GPs has been and continues to be problematic, with patients experiencing long waits (Gulliford *et al*, 2017; Vernon *et al*, 2019; Ford *et al,* 2018). District nurses also have been identified as acting as gatekeepers to GPs for their patients (Ross and Tissier, 1997; Vernon *et al,* 2019). However, permitting direct access to services could reduce waiting times,

increase outcomes and patient satisfaction (Greenfield *et al,* 2016; Middleton, 2016). Riggere (2016) argues, albeit with reference to physiotherapy, that self-referral should be made as easy as possible because the benefits outweigh the risks.

District nurses work as autonomous practitioners and act as gatekeepers (Rodden, 2001; Downer and Shepherd, 2010). This includes admitting patients to the service and making onwards referrals, though this does not routinely include hospital referrals (QNI, 2019a; DH, 2013). Like GPs, district nurses are generalists whose wider gatekeeping role arises from holistic assessments, care planning and care co-ordination. Referrals to other health and social care services include sanctioning the supply of equipment and signposting patients and carers to other local resources (Bowers and Cook, 2012; Coldrick and Crimmons, 2019).

'[We] open the gateway to other services' (Serbjit student district nurse)

The findings in my study suggest a double jeopardy aspect to access arising from the district nurse's gatekeeping role. First, where patients and carers are unable to access the service itself and second, where they are unable to access other services requiring referral or approval by district nurses. Carers in particular, seemed to have difficulty finding out about how to access help with incontinence and were unaware, as were some GPs, that the district nurse was the gatekeeper (Neal and Linnane, 2002). This is supported by Drennan *et al's* (2011) study, of carers of people with dementia, who experienced difficulty getting access to the right advice, information and support. Dealing with incontinence was stressful and exhausting for carers (Age UK, 2016).

Carers in my study, also experienced difficulties with continuing access to continence products, as re-approval had to be gained annually. District nurses carried out re-assessments to sanction eligibility for continuing access, which were perceived as a bureaucratic, cost saving exercise by carers. They also identified that this uncertainty of supply and poor quality products caused considerable anxiety.

A current expectation is that district nurses might act as gatekeepers to prevent hospital admissions, re-admissions and facilitate earlier discharge (QNI 2019a; NICE, 2018; Carter, 2018). Although there is a clear remit across the NHS to avoid costly hospital admissions, as with much prevention work, it is difficult to demonstrate outcomes in district nursing (Maybin *et al,* 2016; Robertson *et al,* 2017).

However, a more recent study showed that district nurses were able to prevent re-admission through a simple intervention by phoning patients on discharge from hospital and offering a home visit, this 'nudge' approach was effective and cost effective (Vernon *et al*, 2019). Though, it was unclear if the community nurses involved had any other caseload responsibilities. A QNI (2018) survey found that district nurses increasingly used phone calls for triage, with text and email to contact patients about their care. Although district nurses' experiences of successfully using technology was variable and poor systems increased workloads (QNI, 2014b; QNI 2018; Carter, 2018). District nurses in my study had similar experiences that inhibited mobile working.

> ***'I don't have to go to hospital first [district nurses] can come and see me' (Helen patient)***

My findings showed, district nurses considered they were contributing to cost containment, especially in avoiding hospital admission. They routinely contacted patients by phone on discharge as part of triage and/or the assessment process, checking eligibility, missing information and making arrangements to visit.

Some patients and carers also reported that district nurses contacted them occasionally to see how they were getting on which they appreciated. Although, this did not appear to be universal, as carers expected district nurses to monitor care recipients, which they described as *'keeping an eye on'*. Though the QNI (2019b) survey found prevention and public health aspects of the role were being omitted due to capacity issues.

This 'nudge' aspect of district nursing seems to be invisible, but given Vernon *et al's* (2019) findings, this suggests this might be an effective way to monitor access and effectiveness and develop measurable outcomes for the service. Bowers and Cook (2012) asserted that district nurses need to demonstrate that their service is cost-effective and equitable. NICE (2018) concluded that community nurse-led care is cost effective, as its costs are partially offset through the avoidance of hospital admissions.

> ***'[District nurse] said you'll have to take her to the GP but it's the GP who referred her' (June carer)***

Patients and carers reported being 'bounced around' the system. Greenfield *et al* (2016, p.2) argue, 'A good gatekeeping policy is one that balances clinical needs, patient choice and system constraints'. One way of addressing gatekeeping barriers may be to ensure that patients and carers are able to 'engage' with the

service by having direct access to district nurses' contact numbers so they can speak directly to a district nurse and/or be able to self-refer. This would require a more visible service and empowered patients, avoiding referrals being shunted back to GPs (Middleton, 2016; Riggare, 2016).

Gatekeeping in district nursing is important for providing initial and ongoing access to services: Levesque *et al's* (2013) framework highlights continuity and quality of provision as integral to full access. However, my findings indicate that the gatekeeping role of the district nurse can act as a barrier to both.

A continuum of disruptions to access

Continuity of access appeared to be problematic in my study. Access to district nursing may be experienced as a continuum of care from the first contact with the district nursing service until discharge. Patients and carers experienced disruptions to access as a series of, usually unplanned, breaks to ongoing care. Several factors were identified by participants as influencing these disruptions including: high demand, insufficient staff, skill mix and lack of qualified district nurses, late or missing visits and/or gaps in service hours. Patients and carers reported disruptions to the continuity of visits, and in particular time spent waiting for the district nurse to visit. They felt their days were on hold and rushed visits were also part of their service experience (table 10.2). Such time pressures meant district nurses and the service were viewed as reactive and providing the minimum.

By contrast, McGarry (2003) discovered that district nurses felt care quality was better than hospital and care was not rushed. McGarry's findings may not reflect current pressures on district nursing, though compared to hospital, patients are more likely to get the nurse's undivided attention at home. While Nagington *et al* (2016) found patients and carers had no yardstick by which to gauge what district nurses could offer. This was disempowering for patients and carers and prevented access to the full service. Even so, patients and carers in my study equated the lack of time with poor care quality, and at the same time they were sympathetic to district nurses' high workloads.

> ***'You don't know people you're going to get coming in, everyday different people turn up' (Irene patient)***

My study found a strong sense of uncertainty and even anxiety from patients and carers about who might visit and when, intimating that not only was continuity uncertain but also the quality of care provided. They cited receiving

care from agency staff that could be hit or miss. Carers of people with dementia considered continuity essential to ensure care quality, and found disruptions stressful. In their view, better continuity would lead to nurses knowing patients by being familiar with their needs and providing necessary routine, benefitting patients and carers (Boot *et al,* 2013).

This is supported in the literature, where Gillies (2012) found that familiarity and continuity were important for those caring for people with dementia and Luker *et al* (2009) found knowing the patient and their circumstances was an important aspect of the district nurse's role and in providing care. For person-centred care to be provided relationships need to be established, however studies rarely mention maintaining these relationships, perhaps reflecting their focus on palliative care (Luker *et al,* 2009; Walshe and Luker, 2010).

Table 10.2 Overview of disruptions to access

Visits ➔	• Late • Postponed • Missing • Rushed • Task based • Unplanned • Time spent waiting • Carers filling in • Anxiety • Uncertainty who was visiting • Poor communication • Suffering in silence
Staff ➔	• Workforce shortages • Use of agency staff • Skill mix • Lack of qualified district nurses • Lack of continuity
Bureaucracy ➔	• Eligibility for service - being housebound • Being bounced around the system • Resource driven decisions • Reassessment for continued access • Referrals inappropriate or incomplete

Disruptions to care continuity potentially compromise health and wellbeing outcomes, and that in prioritising urgent visits this may have a negative impact for those with long-term conditions and self care needs (QNI, 2019a; Dimond, 2015). There is also a distinction to be made between being unable to access the service and a lack of response once receiving the service. Patients and carers reported unsatisfactory use of the messaging service, where they could not speak to a district nurse and they were uncertain if messages were received, and

may also lead to disruptions to access. NICE (2018 p.55) recognised that enhanced access would enable continuity for all patients as 'patients could be seen by their regular district nurse' rather than operating a skeleton service only for the highest priority patients.

> ***'When I managed to fight and get it, with them coming all the time and it was a regular nurse, it was running sweet as a baby' (Bernard carer)***

Although carers found visits from the district nurse reassuring, breaks to care continuity potentially strained relationships. Where breaks in care occurred, carers in the study reported stepping in by taking time off work, paying for private transport and continence products. Working carers reported a loss of earnings if self-employed, and strain from taking time off to provide cover, or to be present for what they viewed as unnecessary bureaucratic continence re-assessments. They reported being called upon to fill in when care continuity broke down. Exceptionally, patients and carers said they had withdrawn from the service because of continual disruptions.

McGarry (2003) found that district nurses thought patients had greater input and capacity to negotiate care because they were in control as they were in their own homes: this re-balancing of power between the professional and patient resulted in empowerment of the patient (Ibid). This contrasts with my findings as most patients and carers did not seem to have much power or choice as they could not 'shop around' for alternatives. They had to take or leave the service as offered (Victor 1991, p.161).

> ***'…they tell you no no no it's there [district nursing service] even though it doesn't work it's there…' (Bernard carer)***

From a conceptual viewpoint, the opportunity to utilise poor quality district nursing means access is restricted (Levesque *et al*, 2013). Service disruptions may prevent opportunities to 'have access' due to inadequate supply and the opportunity to 'gain access' may be limited or absent (Gulliford *et al,* 2002). As utilisation seems to be used as a proxy for access in district nursing, my findings indicate that although patients were in receipt of the service, access appeared to be restricted due to disruptions.

Levesque *et al* (2013) state that restricted access due to resources or breaks in continuity is not access. Even though my study indicates the service was available it did not meet the 'appropriateness' dimension or patients and carers 'ability to engage' with the service. Like Dixon-Woods *et al's* (2005 p.85) concept

of candidacy as negotiated access, there is 'a dynamic and contingent' interplay between these dimensions and abilities that reflects the relationship between patients and professionals, resources, policy and the broader context of care.

Most patients on district nursing caseloads have complex, specialist and/or long-term care needs, so continuity of care is required for the best outcomes and patient satisfaction (Goodman *et al* 2003; Greenfield *et al,* 2016). Therefore, caseloads need to be managed, as disruptions to access are likely to have an impact on equity as well as quality (Dixon-Woods *et al,* 2005; Robertson *et al,* 2017).

My findings suggest that even where access to district nursing is gained the 'appropriateness' dimension for optimal access may not be achieved or maintained. In the context of district nursing, access was not a single event for all time and disruptions to access could occur at any point across the care continuum. Conversely, without disruptions, there is potential for access to be experienced as regular, stable and deemed adequate and patients are able to engage with the service (Levesque *et al,* 2013).

Appropriate access experienced as transformative

In my study, a number of patients and carers appeared to have experienced 'appropriate' access to district nursing, which they found transformative regarding its impact on their individual circumstances. Patients and carers received what they viewed as high quality care and were 'able to engage' with the service, and did not experience disruptions.

> ***'When the system works well I can't offer a suggestion of how to improve it' (Philippa carer)***

Optimal care in district nursing stems from needs-led, patient-centred, holistic assessment, and seen as the hallmark of a qualified district nurse (Worth, 2001; Kennedy, 2004; Goodman *et al,* 2003; QNI, 2009; QNI 2019a). Worth (2001) found that district nurses considered they had always practised in a patient-centred way, concurring with other studies (Luker *et al,* 2009; McGarry, 2003). Comparatively, district nurses felt they had more time to build relationships with patients (McGarry, 2003). Increasingly, a person-centred approach is expected across health and social care, and in that sense district nurses have long been ahead of this curve (NICE 2015).

> ***'She was fantastic there was nothing she didn't know' (Yvonne carer)*.**

Where access to district nursing worked well for patients and carers in my study, they experienced the service in a completely different way. They valued highly their encounters with district nurses, and developed trusting relationships and good communication. They had access to personal, tailored, timely and skilled care. The district nurse was also seen as an invaluable a resource, being knowledgeable about the patient's condition, and knowledgeable about other services. They experienced coordinated care, where district nurses made referrals and signposted to other resources.

Full access led to continuity of care and a sense of partnership, which carers in particular found supportive. District nurses seemed to be accessible and flexible, as determined by patients and carers. Even though, participants seemed to be unclear about the district nurse's role, these features were highly valued. District nurses remarked that patients were often amazed by what they could do.

The district nurse's role continues to develop in response to clinical advances, such as administering intravenous chemotherapy (Worth, 2001). District nurses were the first nurses to become prescribers and are highly qualified (DH, 1989; NMC, 2006; QNI, 2017a; Ball *et al*, 2014). A number of studies support such findings where the full extent of district nurse's role is misunderstood so that full access is restricted (Nagington *et al* 2016; McHugh *et al* 2003; Goodman *et al*, 2005).

> ***They're reassuring, they're professional…and you trust them as a medical professional (Philippa carer)***

In my study, patients and carers described having personal relationships with district nurses, who were referred to as friendly and responsive. Carers reported feeling supported by district nurses by being given time and could contact them for advice. District nurses also reported the importance of establishing friendly relationships.

This aligns with Coulter's (2005) findings where patients wanted knowledgeable and skilled professionals who were also good communicators, interested, sympathetic and involved them in decisions. In district nursing the nurse-patient relationships were long-term, reciprocal and mutually beneficial (McGarry 2003 p.429). Freeman and Hughes (2011) found relationship continuity was particularly important for older people. Such relationships were developed through the assessment process, resulting in agreed care plans to instruct staff

and provide care continuity and also helping patients know what care to expect (Fanning, 2013).

'Without her my husband might be dead' (Olenka carer)

Patients, carers and GPs, in my study, were aware of the high level of knowledge and skills of district nurses and some carers experienced their interventions as lifesaving, metaphorically and, in some circumstances, literally. Valuing staff and their skills is increasingly recognised as important to develop and retain staff (NHS Improvement, 2019). However, access to a qualified district nurse is increasingly scarce, and as a result they may be limited to conducting first assessments, triage and management roles (NHS, 2019c; QNI, 2017b; QNI, 2019a).

Holistic needs assessment is an important long held value in district nursing and seen as good practice (Worth, 2001; McHugh *et al,* 2003; McGarry, 2003; QNI, 2014b). Assessment encompasses physical, emotional, psychological, spiritual, social, environmental and sexual health needs and support care needs of patients and family carers (McHugh *et al,* 2003). The initial assessment forms the basis of care planning and coordination and should be conducted in partnership with patients and carers (McGarry, 2003). District nurses deliver care to patients with complex and often long-term needs, necessitating partnership working across health and social care boundaries (Goodman *et al,* 2003; Worth, 2001; QNI, 2014a; DH, 2013).

A number of studies found palliative care was the benchmark against which district nurses judged quality of care (Goodman *et al,* 2003; McHugh *et al,* 2003; Luker *et al,* 2009; O'Brien and Jack, 2010; Walsh and Luker, 2010). This was the area of practice that district nurses found rewarding and could spend time with patients and offer care continuity (Ball et *al,* 2014). Ball et *al's* (2014) survey found that district nurses sought to provide high quality care and spent longer with patients compared to unqualified staff. However, all staff provided care at considerable cost to themselves as they consistently worked longer hours, this was also found in other surveys (QNI, 2019a; NHS Improvement, 2019).

In my study, district nurses seemed to be able to navigate systems on patients' and carers' behalf, but also to justify their access decisions where, for example patients were not strictly speaking housebound but required care or particular resources. District nurses referred to knowing patients and their circumstances, particularly when re-admitting returning patients. This suggests that these nurse-patient relationships were enduring and helped fast track referrals to provide

direct access (Luker *et al,* 2009; Greenfield *et al,* 2016; Middleton, 2016). However, it is also possible that direct access may be more difficult where the relationship was contentious, for example if district nurses thought patients should not be using their service.

Positive relationships with patients aid compliance with treatments and also help reduce hospital admissions (Vernon *et al*, 2019). District nurses can anticipate health problems and potential deterioration through assessment and reassessment (Kennedy *et al,* 2011). This encompasses social aspects too, particularly environmental safety and a risk monitoring role (Worth, 2001).

Three unique values encapsulate district nursing: i) knowing the patient and care context by building relationships, ii) providing individualised, holistic care that promotes independence and iii) care continuity (Luker *et al*, 2009; Kennedy, 2002a; Gerrish, 2000; McGarry, 2003; McGarry, 2004; Kennedy *et al,* 2011). These critical aspects of the district nurse's role, the home context and the quality of the relationship are difficult to capture and reduce to metrics. This may contribute to the marginalization and invisibility of district nursing (QNI, 2019a, Ball *et al,* 2014; Proctor, 2013).

Summary of the main findings

Perhaps not surprisingly, as district nursing appeared invisible, the overwhelming experiences of patients and carers were described in terms of difficulty accessing information about the service. Limited information was available about the role of the district nurse, and provider websites revealed a lack of service information available and variations in the district nursing services offered, indicating inequities of provision.

GPs appeared to be the main source of service information for patients, carers and health and social care professionals, though concerns were raised by district nurses about the consistency, completeness and accuracy of information from GPs and hospitals. Most web information was directed to those making referrals, with an emphasis on the referral criteria, and not written in a patient or carer centred way.

Demand for district nursing seemed to be open ended and difficult to control, which district nurses attributed to workforce shortages and reduced capacity. All participants acknowledged the pressure facing district nurses due to workforce shortfalls. In managing demand, district nurses seemed to use overt and covert

means to control access. Applying eligibility criteria strictly and adjusting the timing of visits were commonly used forms of control.

The housebound eligibility criterion appeared to be the most important but deciding who was housebound was complex and not clear cut. While, there was no agreed definition, district nurses' interpretations of being housebound were often situational. District nurses, could make different access decisions about who was housebound, leading to inequitable access.

District nurses reported feeling pressure to demonstrate the service was being delivered to housebound patients, and also prevented hospital admissions. Despite these pressures, district nursing was seen as a responsive and accessible service by health and social care professionals, usually visiting within 24 hours of referral. Nonetheless, district nurses felt unable to provide care as they were trained. They thought commissioners required task based care rather than holistic care, indicating service utilisation was used as a proxy for access.

Barriers to access could, to an extent, be attributed to poor understanding of the role of the qualified district nurse. Patients, carers and health and social care professionals knew little about district nurses' skills, such as care coordination and this was unclear on websites. The gatekeeping aspect of the role was unknown, including some GPs, inhibiting referrals to secondary services. District nurses felt there was poor awareness and understanding of their role and that their skills were not fully utilised. Receiving inappropriate referrals, that did not meet the eligibility criteria or were incomplete, led to referrals being delayed or rejected and feelings of frustration. Bureaucratic systems seem to inhibit or delay access, and referral requirements varied.

Theoretically, self-referral was available, though few other participants were aware of this. The exception was if patients were already known to the service, access could be fast tracked where patients had access to the district nurses' contact details. Most patients and carers wanted to be able to contact and speak directly to district nurses, and found messaging services unsatisfactory. GPs also wanted better communication and partnership working with district nurses.

Access to district nursing was experienced as a series of disruptions within the continuum of care, for patients and carers. Workforce shortages were perceived as the reason for these disruptions. Disruptions took the form of missing or delayed visits or provision of resources. Patients and carers experienced uncertainty and anxiety about who would visit, whether a visit would take place,

and care quality. They had little influence over these disruptions and the importance of continuity of care cannot be over emphasised.

By contrast, the experience of full access to a qualified district nurse was revealed as transformative. Patients and carers reported receiving a high standard of care that was person-centred, holistic, proactive and provided continuity. District nurses were recognised as highly knowledgeable and skilled by patients, carers and health and social care professionals. The quality of the nurse-patient relationships and direct access to district nurses were central to this experience of full access, fostering a sense of partnership working and security. This mirrors Levesque's framework where appropriate access to district nursing may only be achieved when patients and carers have the ability to engage with the service.

Conclusion

This chapter discussed the integrated findings, drawing on the wider literature and Levesque *et al's* (2013) theoretical framework. Accessing the district nursing service was not experienced as straightforward, and it appeared to be invisible, from the perspectives of patients, carers, district nurses and health and social care professionals. As an invisible service, where care is brought to patients in their homes, it has been possible to explore the demand and supply sides of access. Hidden worlds emerge where issues of equity, transparency and power reveal the interplay between participants in the way that access is operated, control is exerted and barriers experienced.

Patients and carers seemed to experience access as a series of disruptions over which they had little control, while district nurses appeared to be overwhelmed by demand and staff shortages. Holistic care and continuity emerged as important for patients, carers and district nurses, and appeared bound up with fully accessing the service.

In the final chapter the implications of these findings are discussed in relation to theory, practice and policy. A model of access for district nursing is proposed that draws on the findings from the study and on conceptual aspects of Levesque *et al's* framework.

Chapter eleven: Implications and conclusions

Introduction

This final chapter presents the implications of the research for theory, practice and policy and my conclusions for advancing knowledge and understanding of access to district nursing. I consider the strengths and limitations of the study and the extent to which I have addressed the research questions and make suggestions for future research. A new model of access is proposed for district nursing that is located in the wider literature, draws on the study's findings and Levesque *et al's* (2013) model. The final part of the chapter is a personal reflection on the PhD research journey, its challenges and lessons learned, and how this informs my practice as a senior manager in Higher Education.

Implications for theory

Access in district nursing has emerged as a continuum, with continuity bound up with timeliness and a gatekeeping function to other services and resources. Continuity, overcoming disruptions, and the interplay and negotiation between patients, carers and district nurses emerge as important factors in enabling full access (Levesque *et al,* 2013; Dixon-Woods *et al,* 2005).

A strength of the findings is in terms of advancing knowledge about the realities and nuances of the experience of access from the perspective of multiple stakeholders. Access to district nursing was experienced by patients and carers as complex, lacking transparency and fraught with disruptions. From a theoretical perspective, such barriers seem to emanate from a lack of stakeholders' understanding of the unique context of district nursing and the role of the district nurse.

As discussed in chapters four and ten, Levesque *et al's* (2013) framework was valuable for my study as it aligns well with district nursing by being patient-centred, considers supply and demand sides of access and adopts a definition of access that goes beyond a narrow understanding of utilisation to include continuity and care quality. Two of its five dimensions were particularly applicable: approachability and appropriateness. The approachability dimension and patients' 'ability to perceive' the service seemed to be derived from a traditional view that patients attend the service rather than the other way around. This presents challenges in considering how patients may be able to 'perceive' 'seek' or 'reach' for district nursing including direct access to the service.

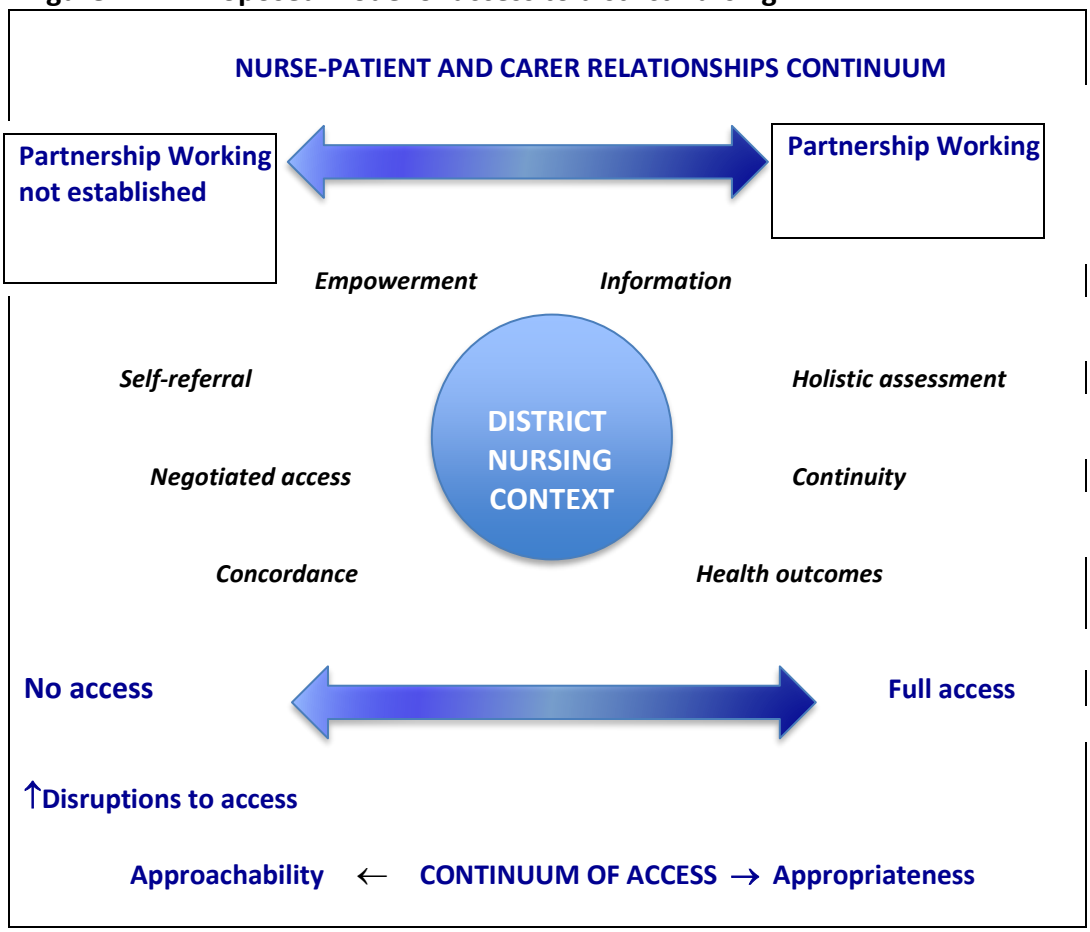
From my study, there seems to be a gap in regard to carers who play an important role as advocates in mediating access for and to patients, and who also require access to meet their needs. While this model has a number of strengths, in considering them alongside my findings, an enhanced access model emerged that better reflects the unique context of district nursing.

A simple but enhanced model of access for district nursing is suggested in figure 11.1. This model reflects an idealised version of access based on the findings from my study. The concept of full access is understood as a continuum, arising from the positive experiences of patients and carers, and health and social care staff, as discussed in chapter ten. The model is informed by the strengths of Levesque *et al's* (2013) dimensions and abilities as indicated in the previous chapter. In particular, the dimensions at each end of the 'continuum' i.e. approachability and appropriateness and the corresponding abilities to perceive, seek and engage with services. My proposed model acknowledges that the service is brought to the patient, rather than the other way round, thus requiring matching expectations and concordance as important aspects.

My model has three inter-related sections necessary for ideal access, each section may be read horizontally across figure 11.1. My findings highlighted, in chapters five and six, that for patients, carers and district nurses, the service and access to it is bound up with the district nurse's role and nurse-patient relationship, and district nurse-carer relationship. This is augmented by effective communication permitting direct contact and access to district nurses, which patients and carers wanted but did not always receive (Goodman *et al,* 2005; Greenwood *et al,* 2010).

The top section of figure 11.1 illustrates this relationship as a continuum, where it needs to be established and maintained, and when working effectively leads to partnership working for appropriate access. Partnership working is a recurrent theme in the literature, as discussed in chapters three, four and ten and seeks to ensure that the balance of power is maintained between patients and carers and district nurses (Dixon-Woods *et al*, 2005; Nagington *et al*, 2016). As discussed in the previous chapter, the invisibility of the service and care offered behind closed doors highlights the vulnerability of those on district nursing caseloads (Graham, 2007; Walshe and Luker, 2010; O'Brien and Jack, 2010). Carers too are included in this relationship continuum, as the study highlighted the importance of carers' relationships with district nurses, and that in their caring role they have particular needs, requiring access to the service in their own right (Arksey and Hirst, 2005; Greenwood *et al,* 2015; Greenwood *et al,* 2016).

Figure 11.1 Proposed model of access to district nursing



The second section in the centre of figure 11.1 indicates different factors influencing the success of access that arose from my findings. These include patients, carers and health and social care professionals expressed need for accurate and timely information about the service, and clarity about referral and self-referral. Together, they redress potential power imbalances and the invisibility of the service experienced by patients and carers, and also health and social care staff making referrals (Dixon-Woods *et al*, 2005; McHugh *et al,* 2003; Coldrick and Crimmons, 2019). Patients, carers and district nurses described how far they valued and understood the need for holistic needs assessment, seamless gatekeeping and continuity of care as necessary for full access to the service.

All these factors need to be considered as inter-related concepts: they may act individually or in combination as enablers or barriers to access. Those factors on the left side of figure 11.1 offer patients and carers the ability to perceive, seek and engage with the service and those on the right side correspondingly enable district nurses to provide approachable, acceptable and appropriate access (Levesque *et al,* 2013). They also ensure that both supply and demand sides of access to district nursing are addressed (Goddard and Smith, 2002).

These factors are positioned within the orbit of the *District nursing context*, which include for example, appropriate workforce numbers and skilled staff, commissioning requirements and professional values and norms (DH, 2015b; NICE, 2018; NHS, 2019a; NHS Providers, 2019; QNI, 2015a; QNI 2015b; QNI, 2019b Wenzl *et al,* 2015). The impact of this context was highlighted time and again by patients, carers and heath and social care professionals, in chapters five and eight,] respectively, where this negatively affected access.

The *District nursing context* in turn may impact on the factors influencing access, and the quality of patient and carer relationships, and ultimately health outcomes. The degree of stability among these factors also reflects continuity of access which was highlighted in the findings, for example, patients' and carers' uncertainty about who would visit and when.

In the last section, at the bottom of figure 11.1, there is a representation of the access continuum, from no access to full access. In my study, disruptions to access were identified and are located here. Disruptions may take the forms of poor quality care and a lack of continuity undermining full access (Coldrick and Crimmons, 2019). Patients and carers experienced these disruptions, which illustrate the gaps that occur between different dimensions of access in Levesque *et al's* (2013) framework. As indicated in the central section (figure 11.1), different factors and the *District nursing context* and/or patient and carer relationships may act as barriers contributing to disruptions or may operate as enablers to full access. In this way, any definition of access needs to acknowledge that in the context of district nursing access should be seen as a continuum, which in addition highlights patient engagement.

Implications for practice

A number of factors that promote or hinder access to district nursing have been highlighted by my study and can inform practice. Principally, they include the absence or effectiveness of timely service information, the ability to self-refer and a lack of staff, especially qualified district nurses.

A tailored and comprehensive service information strategy, designed by district nurses and patients and carers, is recommended. Accurate information needs to be easy to discover, offered in timely and appropriate forms, so that patients and carers are empowered and have clear expectations about the service. Careful consideration needs to be given to the value of web-based information sources, and district nurses need greater ownership of the information provided. This

service information strategy could contribute to greater visibility of district nursing, transparency about self-referral and the role of the district nurse informing health and social care professionals too, and relieving pressure on GPs.

However, this strategy is insufficient on its own if the workforce planning issues are not addressed. Given the sharp and continuing decline in district nursing numbers, an ageing workforce and sense of being a 'Cinderella' service, a more comprehensive and integrated approach to develop and sustain the service needs to be taken. This includes greater acknowledgement of district nurses' role and skills, and their success in avoidance of unnecessary hospital admissions. Based on existing district nursing practice, and evidence of the effectiveness of using initial telephone contacts on referral, there is potential to develop a method to assess the extent and effectiveness of district nursing access, including avoiding hospital readmission (Vernon *et al,* 2019).

Demand for home-based services continues to rise, district nurses play an important role in not only keeping older people with complex health needs out of hospital but also out of residential care. To maximize the benefits of district nursing, the service needs to be made visible to patients, carers and health and social care staff. Secondly, this requires investment, in terms of training district nurses and providing consistent support to foster holistic care, utilising all the skills of highly qualified district nurses.

Implications for policy

District nursing continues to face an existential crisis that has yet to be resolved (QNI, 2019a). This is played out in the policy paradox that on the one hand argues district nursing is central to policies espousing care closer to home, whilst on the other has failed to value or invest in the service (Robertson *et al,* 2017; NHS Providers, 2018). This reflects a policy ambivalence towards the service, that promotes district nurses providing increasingly complex care, but at the same time expects them to pick up the work of others, and where possible fill workforce gaps with less well qualified and cheaper community nurses (QNI, 2019a).

As the population continues to age with evermore complex needs, due to multiple long-term conditions, a skilled and flexible nursing workforce is essential. For CCGs re-shaping district nursing services locally, there is a familiar pattern that adopts a task oriented approach based on activity data rather than relationships, and frequently results in further fragmentation due to a proliferation of specialist services. This reductionist approach whereby the

number of contacts is recorded means service utilisation is being used as a proxy for access to district nursing, but overlooks the importance of relationship based care.

Lessons could be learned from the adapted Buurtzorg model in re-orientating district nursing to deliver a generalist service that is flexible, holistic, patient centred, collaborative and cost effective (Drennan *et al,* 2018; Abrams *et al,* 2020). Self-referral is a missed opportunity to empower patients and carers, offering earlier access and interventions to pre-empt costly care later.

It is clear from the literature that district nursing demand is uncontrolled, compounded by insufficient staff and capacity (QNI, 2019a; QNI, 2019b). It takes a minimum of five years to train district nurses, while CCGs manage demand locally, there is a need for a comprehensive national workforce plan. Attracting and retaining the right people into district nursing will include empowering district nurses to be able to use all their skills, including holistic care that is good for patients and carers and contributes to job satisfaction for district nurses. Increasing specialisation is leading to fragmentation with less holistic care, and the health and social care divide is not working in the community for older people and their carers.

Access to district nursing does not appear to be equitable or transparent. The service was seen as invisible that emerged through hidden worlds, and on that basis I would argue it seems to fall short of the NHS principles (NHS, 2015a).

Strengths and limitations

The experiences and perceptions of access to district nursing gained from multiple perspectives revealed barriers and enablers in terms of both demand and supply. The research questions were answerable and answered, showing that from these different perspectives, access to district nursing was not straightforward.

There were two strengths related to the study's design that had been highlighted in the literature as gaps in previous research (Walshe and Luker, 2010; Goddard and Smith, 2001). Firstly, bringing together different perspectives, and not just focusing on one group, provided a more nuanced and interconnected set of issues to inform understanding of access to district nursing. Secondly, exploring both the demand and supply sides of access allowed theoretical as well as policy and practice issues to emerge.

My study's limitations are considered together with their potential impact on the findings and suggested conclusions. There were three main limitations: first, as a former district nurse and district nurse educator, I was aware of the potential for bias in influencing not only the subject of the study, but also the lens through which information was interpreted (Guccione and Wellington, 2017). Albeit that my background is that of a district nurse, my stance remained that of a social scientist in terms of my role in the research, as described in chapter five. Even so, steps to address bias involved challenging any irrational defence of district nursing, including for example its claims to be patient centred and holistic, reporting accurately what was found, and reflecting on the balance of voices heard (ibid).

Secondly, there were low response rates for both surveys, despite contingencies being used to maximise recruitment and participation, as explained in chapters five and eight. The limited participation of social workers in the survey as the smallest group may have meant their 'voice' was lost. Their responses were considered for points of difference, but they were consistent with those of other health and social care professionals.

Thirdly, as the data were collected sequentially over a period of five years, I had to consider the potential impact of the passage of time on the findings. However, having thoroughly located the study's findings in the literature and policy context, I am reassured that my findings are well supported by other research and the wider literature.

Furthermore, patient and carer profile data, such as age, ethnicity and gender were not collected directly from participants and while patients and carers (and district nurses) disclosed information, indicating heterogeneity in terms of age, gender, ethnicity and class, this was deemed not sufficiently reliable and therefore not usable.

Though the study's aims and objectives were not intended to focus on such differences between patients and carers, it is very important to recognise the existence of structural inequalities and the impact on health care, particularly for older and poorer people and black and minority ethnic communities (BAME). They are often under-represented and disproportionately disadvantaged, experiencing greater health inequalities and especially for BAME groups (Marmot *et al,* 2020). Indeed, gender and ethnicity have been found to act as barriers to access to health care, alongside cultural and power differentials, as discussed in chapter three (Dixon-Woods *et al,* 2005; Bentley, 2003; Ford *et al,* 2003; Cameron *et al,* 1989; Gerrish, 1999; Peckover and Chidlaw, 2007). While a

few studies have found district nurses lack of awareness of cultural diversity, district nurses were also aware of structural factors that contributed to lack of provision for BAME (Childlaw and Peckover, 2007; Gerrish, 1999). More recently, there has been notable resistance in acknowledging racism in tackling structural health inequalities (Moore, 2020).

For older people from BAME groups, who may be doubly disadvantaged, there is scope and value in designing a larger study enabling comparisons of experiences of access between participants based on particular characteristics. This would require a non-purposive sampling strategy and recruitment to ensure adequate representation. Nonetheless, the patients and carers recruited to this study were on district nursing caseloads in London, and in the spirit of qualitative inquiry not ever intended to be representative. Having carefully considered this lack of this data, and the research questions, there was no discernable impact on the findings, which demonstrated that access is problematic for all. Given the study design, sample sizes and response rates and major qualitative components, it was never intended to claim generalizability, rather to generate new insights and understanding of access in district nursing.

Making a contribution

As little research has been conducted into access to district nursing, this exploratory study provides useful insights and sheds light on to hidden worlds from multiple perspectives. It reveals access was experienced by many in relation to confronting barriers and enablers, and was located in a system whereby in order to control workload district nurses described exercising overt and covert means of control. The findings have been discussed in relation to the existing body of district nursing research to highlight similarities and differences. While the invisibility of district nursing, uncontrolled service demand and workforce shortages were already known, their impact, as barriers to access were unknown. These barriers were experienced as preventing initial access, gatekeeping and continuity of access, reducing district nursing to task based care.

Two findings that are not found in the literature or earlier research were: the importance of the housebound criterion in determining access to district nursing, and the absence of self-referral as a policy driver, or its implementation in practice. From a conceptual viewpoint, the findings indicate a restricted definition of access to district nursing that does not reflect its unique context and that continuity of access is important for full access to be achieved. Particular

access for carers is also highlighted, whereby this is required not only in their advocacy role but also to address their needs as carers.

The impact of full access when experienced by patients and carers was viewed very positively, as district nurses were able to spend time with patients, support carers and provide what was described as holistic care and continuity. It is hoped that this study's findings will make a contribution to the current body of knowledge and may be of some use to policy makers, researchers and practitioners.

Suggested areas for future research

Areas that focus on theory, policy or practice perspectives could inform future research. As this study was exploratory, selected findings might be pursued with four potential studies suggested here.

The first is to develop and test a conceptual framework of district nursing access, informed by the initial conceptual framework suggested earlier (figure 11.1). Secondly, a comparative study to develop and test a new service information strategy regarding its impact on access and the quality of referrals, including self-referrals. Thirdly, a related study could be designed to capture the impact of triage activities in preventing hospital re-admission and cost efficiency, building on Vernon *et al's* (2019) research.

Lastly, a larger study to consider the use and effectiveness of qualified district nurses' interventions as nudges across a range of areas: hospital re-admission, compliance with treatment, care coordination, reablement, self-care and support for carers.

Reflections on undertaking the PhD

This is a personal reflection of my research journey, covering my development as a researcher, key challenges, lessons learned and ways in which this has influenced my practice. My interest in this topic was sparked by my former career as a qualified district nurse and subsequent move to higher education to teach on the specialist practice district nursing course. I completed a literature based master's dissertation on district nursing but never intended to do a PhD but as time went on I found myself thinking about it more.

Development as a researcher

I registered for my PhD at Kingston in 2013, having transferred from a professional doctorate (PD) at Bath. I did not tell colleagues or family I was doing a doctorate, partly because I enjoyed having something just for me, but mainly I was uncertain about the journey. Although I had been involved in a number of research projects over the years, I felt I did not have sufficient knowledge, experience or confidence to call myself a researcher.

Key PD milestones for me were, the completion of the research portfolio, the transfer interview and NHS ethics approval. The PD required a practice supervisor as subject expert paired with a director of studies from Bath. There was no one in my institution with the right expertise, so I approached Professor Fiona Ross to ask if she would act as my practice supervisor, and though there was no benefit to her or Kingston, she kindly agreed. However due to problems with supervisors at Bath, this precipitated my transfer to Kingston where Professor Nan Greenwood agreed to join the supervisory team. I felt this was the real start of my researcher development, with a constructive mix of challenge and support. Over time the study's scope, research questions and methods were refined: a number of such 'Aha' moments occurred throughout this journey.

Challenges and lessons learned

As a part time student with a demanding full-time job, as a senior manager in higher education, the major challenge has been time to complete the work. Collecting the data took a long time, as everything had to be mediated through NHS third parties, with frequent staff changes, continually having to provide my credentials and research being seen as a low priority in a busy service. These delays were quite disheartening, though my supervisors were encouraging and made helpful suggestions. Little went to plan, I had to be persistent, flexible and creative to adopt different and innovative recruitment strategies, working

instead with the voluntary sector, enlisting support from delegates at a QNI conference and converting an online survey to a postal one.

Completing data collection was a huge milestone and relief, but analysing so much data was also a challenge. I struggled to get the analysis and chapters into an acceptable written form, and finishing the PhD felt even further away. At my supervisors' suggestion, I paid for a writing consultant to give me some feedback on a chapter that was very useful.

I needed the time and head space to work on the thesis, I tended to be over optimistic about the time activities would take, but finding time to work on my PhD was a constant challenge. Eventually, I took three months unpaid leave, this was invaluable to get some momentum and produce four draft chapters. It also gave me licence to disclose and discuss my study with colleagues, having only shared this with one colleague. Colleagues were most sympathetic and supportive offering to read chapters I had yet to write.

Reflecting on what I have learned, I am quite resilient, and I don't like giving up, but I tend to get bogged down in detail and find it hard to let go. I need to be better at asking for help.

What I'd do differently

What I would do differently is to push harder for responses from NHS colleagues. I would try harder to enlist support from my managers at the outset; negotiating research time and managing my time better, and discuss my research with others earlier.

Over the study's duration other significant events happened - family illness and bereavements, personal health challenges, major organisational change and applying for more senior posts. It feels as though my life has been on hold for many years now, and though irrational I feel I oughtn't do other things. I think I knew this already but I have a long-suffering husband, whose life has also been on hold, who faithfully prays for me everyday to finish my PhD in the shortest time possible!

Influence on my practice

When I started this journey district nursing was nowhere on the policy agenda, even the term district nurse was being eroded. There has been a resurgence of interest in district nursing, and though at my university we no longer run the specialist practitioner course, it is my intention to publish my research. It has

been a long, and at times lonely and frustrating road but ultimately a very satisfying one.

I am now more confident in engaging in research discussions and decisions with colleagues. I have been proactive in improving the experience of research students at my institution, being able to see things from their perspective. I am more equipped to support those staff wishing to do PhDs and the research active staff. I want to continue to build a research culture in my School, and respond to the renewed emphasis on research in the University.

I can't say at what point a transition occurred, but I can say now with a modicum of confidence that I have acquired and refined research skills that enhance my role as a leader.

Conclusion

In this exploratory study, hidden worlds emerged revealing ways in which access to district nursing was experienced from multiple perspectives. District nursing appeared to be an invisible service, where there was poor understanding of the role of district nursing, and how gatekeeping to the service functioned. Access to district nursing appeared to be controlled through overt and covert means. Being housebound was identified as an essential eligibility criterion for access, though determining who was housebound was open to interpretation and professional judgement. Variations, within and between providers, of the services offered and the way access operated, suggest that district nursing is not offered equitably or transparently. Decisions about access were influenced by contextual and resource factors, particularly workforce shortages and commissioning.

The main implications raised, in this chapter, have suggested positive ways to influence access to district nursing. A model of access has been proposed that better fits the unique context and characteristics of district nursing, and is informed by positive experiences of full access. A modified definition of access and model need to recognise such characteristics as, the centrality of home as the place where the service is accessed, holistic care based on the nurse-patient relationship and the understanding that access is a continuum. From my findings, it is strongly suggested that access to district nursing should not be based on utilisation alone, as it is offered across a continuum of complex care that is liable to disruptions.

District nursing is a unique service that provides skilled nursing care at home, tailored to individual needs, which remains in the vanguard of personalisation. It

is also central to the policy agenda of providing care closer to home and preventing unnecessary hospital admissions. However, access to this service is compromised because of a lack of visibility, capacity and investment and a model of access that is not reflective of its singular context and characteristics. While district nursing is central to policy, it is not a priority, and to address the interrelated issues of invisibility, capacity and investment a national strategy with dedicated leadership for district nursing is needed. This would necessitate a review of commissioning to provide transparent and equitable access to the full district nursing service.

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Appendices

Appendix 1

Ethical approvals

National Research Ethics Service
Southampton & South West Hampshire REC (A)
Building L27
University of Reading
London Road
Reading
RG1 5AQ

Telephone: 0118 918 0566
Facsimile: 0118 918 0559

21 March 2011

Mrs Jo Skinner
Academic Leader
London Metropolitan University
Ladbroke House 62-66 Highbury Grove
London
N5 2AD

Dear Mrs Skinner

Study Title: **Behind closed doors: Patients' and carers' experiences of gaining access to district nursing services**
REC reference number: **11/SC/0043**
Protocol number: **N/A**

The Research Ethics Committee reviewed the above application at the meeting held on 08 March 2011. Thank you for attending to discuss the study.

Ethical opinion

The CI, Mrs Jo Skinner, was called into the room and thanked for her attendance.

- The Committee asked the researcher whether a translator will be available for the ethnic minority groups. The researcher explained that it is difficult to conduct a group with a translator unless all the participants speak the same language. This however is not what she wants, as it is a mixed ethnicity group that she would rather. The researcher went on to explain that she has never used a translator in a group setting, but she does not feel there will be issue since these participants will be able to speak English albeit it is not their first language.
- The Committee questioned whether the researcher can include in the PIS about reports of poor or dangerous practice being revealed, mindful of participants' confidentiality. The researcher agreed that she can include this point, especially in the PIS for district nurses and is happy to discuss the point verbally with patients and carers, so as not to confuse them by simply writing it in the PIS.

The researcher left the room.

The Committee considered the researcher's responses and was happy that all the ethical issues had been resolved.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

The Committee gave a favourable opinion of the application. The following conditions were agreed:

1. The Committee requests that a sentence regarding reports of poor or dangerous practice is included in the PIS. It should read to the effect of "In the even that poor or dangerous practice is revealed this will be reported to the relevant authority in the organisation, mindful or protecting anonymity and confidentiality, unless it is a safeguarding issue".

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Interview Schedules/Topic Guides		
Interview Schedules/Topic Guides	District nurses; 1	07 February 2011
Questionnaire		
Advertisement		
Letter of invitation to participant		
Letter of invitation to participant	District	07 February 2011

	nurses; 1	
Investigator CV		
Investigator CV	Judge	08 February 2011
Participant Information Sheet		
Protocol		
REC application		
Participant Consent Form		
Covering Letter		10 February 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/SC/0043 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

[redacted]

Dr Iain MacIntosh
Chair

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

NHS
Health Research Authority

NRES Committee South Central - Hampshire A
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Tel: 0117 342 1380

16 July 2015

Mrs Jo Skinner
[redacted]

Dear Mrs Skinner

Study title:	**Behind closed doors: Patients' and carers' experiences of gaining access to district nursing services**
REC reference:	**11/SC/0043**
Protocol number:	**N/A**
EudraCT number:	**N/A**
Amendment number:	**Substantial Amendment 1**
Amendment date:	**12 June 2015**
IRAS project ID:	**72152**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee approved the following changes:

1. Change of sponsor
2. Chief Investigator (Phd Student) has moved from the University of Bath to the Kingston University.
3. Methods to include individual interviews (by telephone or in person) (original design relied on focus groups only.)

Non-Substantial changes:
1. New site ([redacted])
2. Extension of study (new end date now 30 November 2016).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Letters of invitation to participant [Revised letter of invitation to carers clean copy 02.04.2015 version 2]	2	02 April 2015
Letters of invitation to participant [Revised letter of invitation to carers with tracked changes 02.04.2015 version 2]	2	02 April 2015
Letters of invitation to participant [Revised letter of invitation to district nurses clean copy 28.05.2015 version 2]	2	28 May 2015
Letters of invitation to participant [Revised letter of invitation to district nurses with tracked changed 28.05.2015 version 2]	2	28 May 2015
Notice of Substantial Amendment (non-CTIMP) [AmendmentForm_ReadyForSubmission]	1	12 June 2015
Other [Fiona Ross short CV]		
Other [Sponsorship Jo Skinner PhD student]		20 April 2015
Other [REC_Form_01072015-2 (signed by new sponsor)]		28 June 2015
Participant information sheet (PIS) [Revised participant Information sheet clean copy 02.04.2015 version 2]	2	02 April 2015
Participant information sheet (PIS) [Revised participant Information sheet with tracked changes 02.04.2015 version 2]	2	02 April 2015
Research protocol or project proposal [Revised Research protocol clean version 05.06.2015]	2	05 June 2015
Research protocol or project proposal [Revised Research protocol with tracked changes 05.06.2015]	2	05 June 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

11/SC/0043:	Please quote this number on all correspondence

Yours sincerely

pp Dr Ronja Bahadori
Chair

E-mail: nrescommittee.southcentral-hampshirea@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Professor Fiona Ross,* F.Ross@sgul.kingston.ac.uk

Appendix 2

Letters of invitation and response card

February 2011

Dear Patient/Carer

Re *Patients and Carers experiences of accessing district nursing services*

I am writing to ask whether you would be interested and willing to take part in a research study into district nursing services. I am interested in learning about patients' and carers' experiences of gaining access to the district nursing services. I do not have your personal details and so I have asked your district nurse to give this invitational letter to patients and carers who would be able, with help, to participate in the discussion.

In short, it would require that you take part in one small group discussion for either patients or carers lasting about an hour and half, hopefully in April*. Please find enclosed an information sheet that gives further details about the research.

I have received research ethics committee approval and permission from the NHS to do the work in x. I am doing this study for my Professional doctorate at the University of Bath where I am a part time student. I work full time as an academic at London Metropolitan University and my background is in district nursing. It is hoped that the research will contribute to our understanding of patients and carers preferences.

It is important for you to know that this research is totally independent, it is not connected in any way to the care that you receive and it will not effect your subsequent care. Whether you chose to take part is entirely voluntary and you do not have to disclose your decision to your district nurse. If you do take part, your responses will be anonymised; no person will be identified in any communication without their consent.

I do hope you will consider taking part. If you would like to know more, be involved or have questions – please contact me. You may do this by either completing the enclosed card and returning it in the stamped addressed envelope provided or by email j.skinner@londonmet.ac.uk or direct line 0207 133 5016 or my personal mobile 07XXXXX.

I really hope you will want to take part and I look forward to hearing from you in due course.

Yours faithfully,

Jo Skinner

RESPONSE CARD

Patients and Carers experiences of accessing district nursing services

1. Are you a

   Please only chose *one*

   Patient receiving district nursing services ☐

   OR

   Carer of someone receiving district nursing services? ☐

2. Please tick *all* that apply:

   I am interested in participating in a small group discussion ☐

   I would like some more details ☐

   I have some questions ☐

Within approximately a week of receiving this card I will contact you probably by phone I will not visit you at home.

Please provide YOUR contact details in CAPITALS below and return it in the stamped addressed envelop enclosed.

Your contact details

Title: _____ Forename:_____

Surname:_____

Telephone:_____ Mobile:_____

Address:_____
_____

_____

Email address:_____

May 2015

Dear Carer

Re *Patients' and Carers' experiences of gaining access to district nursing services*

I am writing to ask whether you would be interested and willing to take part in a research study into district nursing services. I am interested in learning about patients' and carers' experiences of gaining access to the district nursing services. I do not have your personal details and so I have asked for the help of a third party to give this invitational letter to carers who would be able to participate in the discussion.

In short, it would require that you take part in either an individual interview or a small group discussion with carers lasting about an hour. Please find enclosed an information sheet that gives further details about the research.

I have received research ethics committee approval and permission from the NHS to do the work and from Kingston University, London where I am doing this study for my PhD as a part time student. I work full time as an academic at London Metropolitan University and my background is in district nursing. It is hoped that the research will contribute to our understanding of patients and carers preferences.

It is important for you to know that this research is totally independent, it is not connected in any way to the care received and or subsequent care. Whether you chose to take part is entirely voluntary and you do not have to disclose your decision to anyone. If you do take part, your responses will be anonymised; no person will be identified in any communication without their consent.

I do hope you will consider taking part. If you would like to know more, be involved or have questions – please contact me. You may do this by completing the attached card and returning it in the mail to the address below or by email j.skinner@londonmet.ac.uk or direct line 0207 133 5016 or my personal mobile 07XXXXXXX.

I really hope you will want to take part and I look forward to hearing from you in due course.

Yours faithfully,

Jo Skinner
London Metropolitan University
Faculty of Social Sciences and Humanities
166-220 Holloway Road
London N7 8DB

RESPONSE CARD

Patients and Carers experiences of accessing district nursing services

1. Are you a Carer of someone receiving district nursing services or who has received district nursing services?

   Yes ☐

   No ☐

2. Please tick *all* that apply:

   I am interested in participating in a small group discussion/ individual interview ☐

   I would like some more details ☐

   I have some questions ☐

Within approximately a week of receiving this card I will contact you probably by phone I will not visit you at home unless at your request.

Please provide YOUR contact details in CAPITALS below and return it by mail or just give the details in to my email address j.skinner@londonmet.ac.uk.

Your contact details

Title_____ Forename:_____

Surname:_____ _____

Telephone:_____ Mobile:_____

Address:_____
_____

_____

Email address:_____

Appendix 3

Participant Information sheet

What is this research study about?

District nursing services provide nursing care at home to those in need. There are different ways in which people may first receive this service and we need learn more about this. In particular this study is trying to find out people's experiences of gaining access to district nursing services and factors that influence this. This is an independent study, undertaken by Jo Skinner who is a doctoral student at Kingston University.

Why have I been chosen?

As someone with first hand experience of the service ***or*** a desire to use the service, I would very much like to get your views. This is why you have been contacted to ask for your help by taking part in a group interview. Though I hope you do, it is your choice whether or not you wish to take part.

How it will be done?

There will be group interviews or individual interviews. Small groups of patients, carers and district nursing staff will be interviewed *separately* in order to learn about their experiences and views of accessing district nursing services. There will also be a review of available information about the services. Later on there will be a survey for health and social care professionals who are involved in referrals to the district nursing services.

What next?

If you agree to take part, you will be contacted to make arrangements for your attendance at a group or individual interview, as works best for you. This interview will take about an hour to an hour an half. Interviewees are free to withdraw at anytime, without giving a reason and may choose not to answer any questions. You will not be asked to divulge any sensitive or embarrassing information. I will conduct the interviews. With your permission I will record the interview, the data recordings will be used for transcription purposes only, stored securely in compliance with data protection requirements and erased within one year of the study's completion. The transcripts will be destroyed after 3 years.

How will what I say be kept confidential?

All information will be treated as confidential and no names are recorded. What you say in the interview will not be attributed to you personally. No persons will be identified in any thesis, report or publication. In the event that poor or

dangerous practice is revealed this will be reported to the relevant authority in the organisation, mindful of protecting anonymity and confidentiality, unless it is a safeguarding issue.

What will happen to the information collected?

All the information will be anonymised, analyzed and compiled into the thesis for the doctorate and submitted to the University of Kingston. It is expected the study will be completed by the end of 2016. The outcomes of the study will be shared with participants in an event following submission of the work: all participants will be invited and a newsletter with a summary of the study provided. There will also be further publications of the findings.

Contact for further information

If you have any questions about this study or wish to be involved, please do not hesitate to contact me, Jo Skinner at my workplace Email: j.skinner@londonmet.ac.uk or Direct line: 020 7133 5016 or Mobile: 07XXXXXX, Centre for Primary & Social Care Faculty of Social Sciences & Humanities, London Metropolitan University, 166-220 Holloway Road, N7 2DB

If you have any concerns or complaints then please contact my supervisors: Professor Fiona Ross or Dr Nan Greenwood, Faculty of Health, Social Care and Education, Kingston University and St George's, University of London, St George's Hospital, Cranmer Terrace, London SW17 0RE

Appendix 4

Consent Form

Behind closed doors: Patients' and carers' experiences of gaining access to district nursing services

The study intends to explore the patients and carers experiences of accessing district nursing services and to discover if there are any factors that promote or hinder access to these services

Please read the accompanying information sheet and complete this form.

Have you read the information sheet?	Yes	No
Have you had the opportunity to ask questions and discuss the project?	Yes	No
Have you had satisfactory answers to all your questions?	Yes	No
Do you agree to be interviewed?	Yes	No
Do you agree to the interview being recorded?	Yes	No
Do you understand that you are free to withdraw from the interview at any time without having to give a reason?	Yes	No
Do you agree that quotations may be used?	Yes	No

I understand the University Ethics Committee, NHS Research committees or approved auditors may review this form as part of a quality monitoring process. The forms will be stored securely and destroyed 3 years after the research has been completed. You will be given a copy of the information sheet and signed consent form to keep.

Your help is greatly appreciated, thank you

.

Name [in capitals]

_____

Signature _____ Date_____

Name of person obtaining consent

_____

Signature _____Date_____

Name of witness

_____

Signature_____Date_____

Jo Skinner j.skinner@londonmet.ac.uk 0207133 5016
London Metropolitan University
Centre for Primary Health & Social Care,
Faculty of Applied Social Sciences,
62-66 Highbury Grove, London N5 2AD

Appendix 5

Interview schedule for focus groups for patients and carers

About the district nursing services

1. [Ice breaker] How long have you/person you care for been receiving the district nursing services? Is this the first time you have had the DN service?
2. How did you find out about the district nursing service? Receive information? From whom/where? in what format?
   How did you know who to contact? How easy was it to find information? What was the quality of the information?
3. When did you first start using the district nursing services? When was your first visit?
4. Can you tell me about your first experience of the DNS; first assessment? Was this what your were expecting?
5. Did the district nurse visit when you expected?
6. What has been your experience of accessing the service?
7. Who visited you? Do you know if the person who visited was a qualified district nurse? How often do you see this person?
8. How often do you see the DN?
9. How do you contact the DN? service?
10. Is the service 24 hours?

The process of gaining access to services

11. What is your experience of getting access? Were you referred? By whom? Did you have to complete any forms?
12. In your experience how does the referral system work? How long does it take from being referred to receive a visit?
13. Did you refer yourself/cared for person to the DN to initiate the service? Can you?
14. In what form did the information take? written verbal information sheet; web based; notices; told by health and social care professional; neighbour; friend other
15. What was the quality of the information like? How accurate
16. Who is responsible for contacting the district nurse to ask for the service? Self; GP; hospital; SS other
17. How easy was it to get a visit from the district nurse
18. How soon after the referral did you receive a visit?
19. How easy is it to resume services e.g. after hospitalisation? What is the process?

20. What works well? Are you involved in service design?
21. If someone asked your advice about the best way to get access to a DN, what would your advice be?

About the future

22. If you were designing access to the service what would that look like?

Is there anything you'd like to see changed to improve access to the services? Any other comments?

Appendix 6

Schedule for district nurses focus groups

About the district nursing services

[Icebreaker]

How do current district nursing services work?

1. What services are offered and how? Specialist, nurse led clinics, 24 hour service
2. Nature of provider? Trust, Social enterprise?
3. How are caseloads organised? GP attachment, geographical, corporate other?
4. Recent changes
5. Who does the first assessments?
6. Staffing; skill mix? Are there vacancies? Continuity of care/visits
7. Workload or caseload analysis done; are matched to what priorities, commissioners, populations, needs?
8. Data systems, RIO, how does this work? Do you get data analysis what happens to it
9. Working with others SS/GPs/3rd sector – specialists i.e. palliative care, Community matrons
10. Training; R&D

Accessing the district nursing services

How do patients get access to the district nursing services?

11. How do they find up to date, user-friendly information that is culturally sensitive 24 hours a day?
12. Are they able to talk to someone who is knowledgeable about the service? Who?
13. Do patients have any choice with regard to where services are delivered?
14. Are they able to self refer? Carers?
15. How well are the district nursing services understood by new patients, carers, health and social care professionals?
16. Are there referral criteria? What are they, why are they there? how developed, with or tested by patients and carers? How frequently are patients refused the service because they don't' meet these criteria?

17. Are you aware of any gaps in accessing information about the service – from the patients or carers perspective or health & social care? Inaccuracies
18. Are there any groups of people who do not feature on your caseloads that? any you might expect?
19. Any groups over represented? What about those living in residential care homes? Carers?
20. How do patients who live in the area but are not registered with a GP gain access to a district nurse?

About the referral process

How does the referral process work?

21. Who refers to the service?
22. What for?
23. How easy is it for people to discover the referral process?
24. Are referrals increasing/declining? How do you know?
25. Has the referral process changed at all? In what way, why and when?
26. What is the standard or target for responding to a referral? Within 4hours 24 hours etc.
27. Who can refer? How many patients/carers self refer?
28. What are the patterns of referrals – which gets referred for what?
29. What is the quality of the referrals received?
30. Are the services meeting needs of the whole caseload/ practice population?
31. Are there any sections that are missed out? If so why is that
32. Are there referral criteria? How do they work?
33. How do people contact a district nurse? How easy is it for people including patients to contact a district nurse?
34. What data are collected bout referrals? Who is responsible for collecting, inputting and analysis of the data? Can you give an example of how used?
35. What works well in access to your service?

36. How are needs /access targets being met
37. Patient/carers referral
38. Needs led – whole population has access

What are the barriers or gaps to accessing district nursing services?

39. Are there any complaints/ problems with referrals? Inappropriate or inadequate referrals?
40. What has been the impact of these barriers/gaps?

About the future

What would you like to see change?

- what would make the biggest difference to improving access to services? Why?
- If you were redesigning access to the services what would you do?

Appendix 7

Survey questionnaire for district nursing staff - electronic

What is this research study about?
The study is an exploration of access to district nursing services. This survey is for those working in district nursing services that provide nursing care to people in their homes. This is an independent study, undertaken by Jo Skinner who is a doctoral student at Kingston University, London.

How long will it take to complete? There are 17 questions in total: 13 multiple choice questions and 4 open questions: the survey is based on your experience and should take ***less that 10 minutes*** to complete. Should you have any difficulty with survey please email me on j.skinner@londonmet.ac.uk

1 Are you a?

Qualified district nurse	Community nurse
Specialist nurse	Community matron
Community nurse manager	Health Care Assistant
Other	

2. How many *new* referrals, on average, does your team receive per week?

0	1-2	3-5	6-10	11-15	16-20
21-25		26-30	30-35	over 35	Unsure
Don't know	Not applicable				

3. How are new referrals usually made to the district nursing service?

Sent directly to relevant district nurse	Messaging service	
Central phone number	GP	Email
Fax	Letter	Other

4. How easy do you think it is to make a referral to the district nursing service?

Very easy	Quite easy	Not very easy	Not easy
Don't know	Not applicable		

5. Do you think that those making referrals have sufficient information about how the district nursing service operates?

Yes No Unsure Don't know Not applicable

6. What do you think is the main way that those making referrals find out about the district nursing service?

GP	Hospital staff	Leaflet	Web
Word of mouth	Colleague	Local directory	Intranet
CCG	Other	Don't know	Not applicable

7. How long does it usually take from receiving a referral to getting a visit by the district nurse?

Same day	within 24 hours	within 48 hours
within 1 week	within 2 weeks	within 1 month
1-3 months	4-6 months	Don't know
Not applicable		

8. Have referrals to the district nursing service ever been refused?

Yes No Unsure Don't know Not applicable

9. Do you know what the eligibility criteria are for the district nursing service?

Yes No Unsure Don’t know Not applicable

10. What do you think are the eligibility criteria for the district nursing service?

11. Do you think referrals meet the district nursing service criteria?

Always Mostly Rarely Never Unsure
Don't know Not applicable

12. A common criterion is that patients must be *housebound* - what do you think this means in the context of the district nursing service?

13. How easy do you think it is for patients to access the district nursing service?

Very easy Quite easy Not very easy Not easy
Don't know Not applicable

14. Can patients and/or carers refer themselves to the district nursing service?

Yes patients only Yes carers only Yes both patients and carers
No Unsure Don't know Not applicable

15. Should patients and/or carers be able to refer themselves directly to the district nursing service?

Yes patients only Yes carers only
Yes both patients and carers No
Unsure Don't know Not applicable

16. What, if anything, do you think works well in the district nursing service?

17. What, if anything, could be improved in the district nursing service?

18. Anything else you'd like to add?

Thank you for participating in this study

Appendix 8

Survey questionnaire for health and social care staff - postal

What is this research study about?
The study is an exploration of access to district nursing services. This survey is for those making referrals to NHS district nursing services. District nurses provide nursing care to people in their homes. This is an independent study, undertaken by Jo Skinner who is a doctoral student at Kingston University, London.

How long will it take to complete? There are 17 questions in total: 13 multiple choice questions and 4 open questions: the survey is based on your experience and should take ***less that 10 minutes*** to complete. Should you have any difficulty with survey please email me on j.skinner@londonmet.ac.uk

1. Are you a?

GP	Social Worker	Adult Social Services staff
Care Home Manager	Ward manager	Practice Nurse
	Receptionist/ Administrator	Other

2. How did you find out about the district nursing service?

GP	Hospital staff	Leaflet	Web
Word of mouth	Colleague	Local directory	Intranet
CCG	Other	Don't know	Not applicable

3. How often do you make referrals to the district nursing service?

Daily	Weekly	Fortnightly	Monthly
2 monthly	3 monthly	6 monthly	Never
Don't know	Not applicable		

4. How do you usually make a referral to the district nursing service?

Contact relevant district nurse	Messaging service	Contact GP
Central phone number	Email	Fax
Letter	Other	

5. How easy is it to make a referral to the district nursing service?

Very easy Quite easy Not very easy Not easy
Don't know Not applicable

6. How long does it usually take from making a referral to getting a visit by the district nurse?

Same day within 24 hours within 48 hours
within 1 week within 2 weeks within 1 month
within 1-3 months within 4-6 months Don't know
Not applicable

7. Do you think that you have sufficient information about how the district nursing service operates?

Yes No Unsure Don't know Not applicable

8. Has a referral that you've made to the district nursing service ever been refused?

Yes No Unsure Don't know Not applicable

9. Do you know what the eligibility criteria are for the district nursing service?

Yes No Unsure Don't know Not applicable

10. What do you think the eligibility criteria are for the district nursing service?

11. Have you ever made a referral where the patient did *not* meet the district nursing service criteria?

Yes No Unsure Don't know Not applicable

12. A common eligibility criterion is that patients must be *housebound* - what do you think this means in the context of the district nursing service?

Very easy Quite easy Not very easy Not easy Don't know
Not applicable

14. Can patients and/or carers refer themselves to the district nursing service?

Yes patients only Yes carers only Yes both patients and carers
No Unsure
Don't know Not applicable

15. Should patients and/or carers be able to refer themselves directly to the district nursing service?

Yes patients only Yes carers only Yes both patients and carers
No Unsure
Don't know Not applicable Other

16. What, if anything, do you think works well in the district nursing service?

17. What, if anything, could be improved in the district nursing service?

18. Anything else you would like to add?

Thank you for participating in this study

Contact details j.skinner@londonmet.ac.uk

Appendix 9

Transcript of phone interview with Philippa (Carer)

Philippa Hello

Interviewer Hi are we good to go

Philippa Yep absolutely

Interviewer Fantastic um I just need to ask you have you had a chance to read the em information sheet?

Philippa I've scan read it yeah

Interviewer OK

Philippa Yes

Interviewer Um so well OK shall I just explain a little bit what the research is about I'm trying to find out what carers and patients experiences are of trying to access or accessing district nursing services

Philippa Yep

Interviewer So I'm talking to groups of carers, groups of patients and groups of district nurses, [clears throat] and its difficult to get groups of people together for all obvious reasons cos caring is very sporadic in that sense

Philippa Yes

Interviewer And so with your permission I I would like to record the um the interview because I transcribe everything, everything will be er nobody will be identified in the study and um you know er there will be you don't have to answer any questions you don't want to erm you can stop at any point you don't have to give me a reason why you want to stop

Philippa No that will be fine, everything's fine

Int Oh OK good alright well let's start then [clears throat] um could I just ask you first um how long has the person that you are caring for been receiving district nursing services?

Philippa Um well they aren't currently

Interviewer Aha

Philippa Erm if I can just explain about er um seven and half years ago my mother and my step father were living in [European country]

Interviewer Hmm

Philippa they became too ill to be able to cope there on their own any longer and so therefore we brought them back to the UK and they came to live with myself and my husband

Interviewer OK

Philippa Erm my stepfather died about two and half years ago and my mother stayed on for six years and she went into I had to put her into a care home last [pause] April (Interviewer Ok) over a year ago erm so for a period of in total six years but more intensely while my step father was alive because he needed more district nursing care (Interviewer Uhun) erm so for a total period of about six years was the only time that I had anything to do with district nurses

Interviewer Right so that's quite along time um so um obviously how did you find out about the service then?

Philippa Er by referral from the GP

Interviewer Aha so did you know anything about the district nursing services before then?

Philippa I know that they existed but as I thankfully have very good health I had no idea you know beyond what you see on television what they were for or or how they operated

Interviewer Uhum and was that the first time that your Mum and Step Dad had district nursing services?

Philippa Um as their health was fine before they moved to [European country} which was about 18 years before I imagine so but I wouldn't know and in any

case I particularly wouldn't know because that was in [West country} and not in London

Interviewer Ok ok got you, so you say you got your found out about the services from your GP did you receive any information from em the GP and em in any particular format?

Philippa No none whatsoever it was 'Oh well if that's the issue a district nurse will be coming round at some point to sort it out'

Interviewer Oh ok fine so and and did you know to contact or was it that you had to wait for them to contact you

Philippa I think in the first instance and this is only working by memory so, you know

Interviewer Uhum

Philippa It might be wrong but I think in the first instance the GP sent the district nurse or commissioned the district nurse or whoever it was and after that certainly from the point of view of my step father um I had a telephone number to ring and therefore if I needed the district nurse I rang it (Interviewer Uhum) erm it wasn't massively immediate or effective but I was given the contact for the district nurse

Interviewer Ok so the GP gave you that number?

Philippa I imagine so

Interviewer Right OK uhum so erm so in a way um you didn't have to find the information for yourself somebody gave that to you at some point

Philippa No and I had as a result I had always assumed that you had to be referred to the district nurse I I had never thought and still don't think that you could automatically contact the district nurse it was a referral from the GP and it just happened to be because of the situation that it was erm easier um if I contacted the district nurse directly

Interviewer Right aha

Philippa so I I wouldn't have a clue how one gets hold of the district nurse unless the GP refers them

Interviewer Ok that's really helpful um so so as far as you know your involvement in terms of starting to use the district nursing service with your Mum and Step Dad was when they came back from [European country] and so on and do you remember when your first visit was from being referred to you know how long did it take do your remember how long it took

Philippa Um I don't remember but I think that it was [pause] um very soon afterwards it would have been a day or so (Interviewer Uhum) if that (Interviewer Ok) and it was kind of I don't know whether the the referral worked as quickly as it did because it was issues with my Stepfather's catheter (Interviewer Right) it was quite urgent (Interviewer Uhum) or whether it would always work that quickly (Interviewer Right OK) but it seemed to be you know within a day

Interviewer Uhum ok that sounds about right um can you tell about the first experience of the district nursing visit and whether you had an assessment when they arrived

Philippa [Coughing] erm [exhales] I yes [thinking] I imagine there was some kind of assessment but as I say because I had assumed that it was an automatic process having been to the GP (Interviewer Hmm) erm [brief pause] if there was an assessment as such it would have simply been um asking further questions that were pertinent to the help that I needed or that he needed from the district nurse (Interviewer Hmm) rather than on so Mr M what's your problem da da da whatever (Interviewer Hmm) it was it I can only remember it being a sort of follow up

Interviewer Right OK so I mean as far as you can tell was this what you were expecting the visit to be or did you have any expectations

Philippa erm I [thinking] from what he GP had said what the district nurse was going to do it was, the district nurse did what the GP said [soft laughter] (Interviewer [laughs] OK ok) it was as I expected

Interviewer OK good erm maybe you really can't exactly answer this question but did the district nurse visit when you expected were you aware of when they were going to visit oops sorry [drops recorder]

Philippa Erm it would [exhales] there was a period when I was away when they first came to live here so I think there was an arrangement for a fairly regular visit

Interviewer Uhun

Philippa Certainly when I was here um casting my mind back when I was here it was when I expected but generally I I'd needed to make the phone call first

Interviewer Right

Philippa So yes he was entitled and he received a regular visit (Interviewer Hmm) but I wasn't here all the time it wasn't necessary all the time but as far as I can remember from a few years ago when I expected at that time that particular district nurse because things changed subsequently (Interviewer Uhun) and um my mother's erm my experience with my mother of district nurse changed erm at the time as far as I can recall the district nurse came when the district nurse was supposed to come the activities were performed when they were supposed to be performed and it was reassuring and helpful

Interviewer Ok thank you and erm so what your experiences of accessing the service you had the number so if you needed it just rang them up and that was fine was it or?

Philippa Erm it was not the easiest it's really difficult I'm sure that you will be experiencing this with other carers

Interviewer uhun

Philippa when you are a carer the slightest hiccough in the system becomes [pause] monumental

Interviewer Right

Philippa so I would phone a telephone number that I'd been given and I have to say I think for a while whether I hadn't listened properly because it was just one of the many things I had to do or whether it wasn't explained properly that there was kind of like which not department I cant remember the the the district nurses that I was entitled to were M [mentions HC].which I think that might be a M is it's possibly a um [struggling to remember] erm [whispering] Oh God, I don't know what the word is a not a department

Interviewer A health centre, would it be a health centre, no?

Philippa Yeah a health centre, yes

Interviewer Uhum

Philippa and so I wasn't I don't remember being informed in the first instance which was the health centre that I was supposed to be contacting (Interviewer Right) but I do remember that there's a centralized number (Interviewer hmm) and then I had to ask for M (Interviewer Right) and then I had to ask for a particular district nurse not because my Stepfather only wanted that district nurse cos its seemed to be that was the fastest way of getting a response (Interviewer uhu) erm and from the point of view of the contact from the erm initial point of call I wasn't all together sure that I was going to get the person that I wanted in the end

Interviewer Right so did you know (sorry, [Philippa still speaking])

Philippa it wasn't straight forward erm it wasn't straight forward from the point of view of which health centre I had to go through and it wasn't straight forwards in terms of oh [sounds paned] it's no reason why it should be phoning for an ambulance but the GP surgery were so fantastic and as I say when you're a carer everything becomes impossible to cope with it was not that easy to to appreciate that your were speaking to the right person who would pass the message on and that the right person would get the message

Interviewer uhu so did erm did you have any sense of the person when you're ringing the central number that the end person that you spoke to, was that a nurse did you know or your had?

Philippa No, no it didn't sound like it (Interviewer OK) I mean they're oh [sounding resigned] this is going to sound racist and I'm not but half the time their English wasn't even very good

Interviewer Right no that's factual um ok so the person who visited you erm do you know if the person who visited you was a qualified district nurse?

Philippa [Bursts out laughing] I don't know I didn't ask for his paperwork

Interviewer Right [laughs]

Philippa He was absolutely fantastic

Interviewer Right and and how often I mean it might be difficult cos its over a period of time how often did you see that particular person how often

Philippa erm for a while until things stabilised a bit I think it was every week and then when there were issues like erm urinary infection whatever um less often (Interviewer Hmm) erm and I yeah I I was sorry when it was no longer deemed to be necessary to have the district nurse cos he actually had been absolutely brilliant (Interviewer Hmm) you know and things like [pause] if you don't know the system and you've just ben thrown in to this kind of situation and you don't know who to ask for anything (Interviewer Uhum) things like [pause] finding out that it's the district nurse who has to authorise incontinent pads and stuff like that if that element works efficiently then masses of your anxiety goes out the window (Interviewer Hmm) but until you know that is the person who does the assessment and arranges it its you know a bottomless hole of misinformation (Interviewer Hmm) [inaud] ? and bureaucracy?

Interviewer Hmm hmm

Philippa and then with respect to incontinence pads erm my Mother has Alzheimer's and that is not something that you get better from so as far as I was concerned the system was a little bit faulty in that I had to reapply (Interviewer Right) I don't know every year or whatever it was (Interviewer Uhum) to get another assessment from the district nurse and its well it's like what are you going to go do come around and check her shitty bottom? (Interviewer laughs) [laughing] what is the point? Someone is incontinent or they're not and they are incontinent as a result of their condition and if their condition is not going to get better (Interviewer Hmm) then what are you going to assess when you come round insisting that she's there and I'm there what are you going to assess?

Interviewer Hmm, yes

Philippa so we weren't as far as the care for my Stepfather was concerned that seemed to be less of an issue and I don't know whether it was [pause] as a result of his myriad diagnoses (Interviewer Right) of his many erm medical conditions he had or whether it was simply a change of system and district nurses and erm because the GP had stayed the same (Interviewer Hmm) so that shouldn't have altered but it did seem to be more difficult when it was just my Mother

Interviewer You said the system changed what what did do you mean by that?

Philippa I don't know if the system changed but initially my Stepfather got the incontinence pads and no one was saying to me we have to come round and reassess him (Interviewer Right) whereas with my Mother erm

Interviewer Presumably that was later

Philippa I put in an order for incontinence pads and they would arrive and then I would phone up again to order the next batch and I would be told 'oh she's got to be reassessed by the district nurse' I don't remember that happening with my Stepfather and on the other hand you know he was with us two years maximum so maybe it just hadn't come up (Interviewer Right) but it seemed like the system changed (Interviewer OK) and therefore I had to keep reapplying for my Mother's incontinence pads (Interviewer Ok) and you know I can't blame the NHS but it wasn't apparent that from initially that we were entitled to free incontinence pads anyway I mean I was buying them for ages (Interviewer Right) before I guess the GP said 'well actually she's entitled to free ones'

Interviewer Yeah hmm that's interesting um so I I I can understand why you felt like the system had changed because there was there were regular sort of assessments required to continue with the incontinence pads (Philippa Yeah) and that there was a change in service but was there a different district nurse at that point as well or was the same district nurse?

Philippa But my most of the time that I needed the district nurse for my Stepfather it was the, yeas my Mother just at the time that I needed a district nurse for my Stepfather, it was the lovely gentleman that you know I er I'm a huge fan of his (Interviewer [laughing]) erm my Mother when she needed a district nurse and I think it's possibly [clears throat] my memory on 3 or 4 occasions it was always someone different (Interviewer Right) she never had the nice guy

Interviewer Right and what was it that you cos I think from what you some of the things you were saying earlier in terms of what the was offering he seemed to know about how to about you in touch with things or was it more than that you found I mean you said he was fantastic but in what way?

Philippa Erm no it wasn't that he knew how to put me on touch with things but as I say you know it was seamless getting the incontinence pads to the extent that I didn't even know that I had to apply for them (Interviewer uhum) erm and

it was seamless you know once I'd got hold of the correct telephone number and was phoning up and he came his approach was calming and he was reassuring to me as well as to my Stepfather (Interviewer uhum) erm I had more issues with erm my Mother and [exhales] again I have tried to think about experiences with district nurse since S asked me last night [person who asked if she would like to participate in the research] but um it's only as we're talking that I am remembering things like [pause] erm so the incontinence pads and not knowing that I had to reapply for them and the district nurse [pause] the *less* amenable district nurse saying I have to come and do an assessment (Interviewer hmm) erm and by this stage I think 4 years on I was getting to be a grumpy carer (Interviewer uhum) erm so this is why I'm saying 'well what are you going to come and assess' cos it was like the day the only day this person could come was the day which I took Mum to erm her Dementia club and so therefore I felt that if someone needed to come and talk to me you know it would be good enough if I was there (Interviewer Yup) and rather than my Mum not being able to go to her club because she had to sit around waiting for district nurse but she had to sit around waiting for district nurse cos she needs to be assessed (Interviewer Hmm) and the district nurse came and asked her questions which through the Alzheimer's at the time she was saying what she thought someone wanted to hear (Interviewer Yes) so unless you were going to pull her pants down and investigate the poo on her bottom, what is there to assess? (Interviewer Hmm) so being adamant that the person had to be there I mean I know I understand yes I could be saying 'ooh yes I want hundreds and hundreds (Interviewer laughs) of incontinence pads for no other reason than I don't know that to put them on my dog (Interviewer Hmm) but it was pointless (Interviewer Yep) erm and I felt that the attitude of these district nurses that we ultimately got for her was completely uncaring and there was things like oh well the district nurse has got to come and do and organize a blood test for whatever it must have been a urinary thing (Interviewer Uhum) and before I knew it and you know just purely by chance I happened to be there and two out of the blue phlebotomy nurses turned up took blood sample I didn't know they were coming I mean they looked official erm and I then a day later the district nurse turned up and said I've got to I've come to take a blood test I went well you came yesterday (Interviewer Hmm) 'no we didn't' well what were they then were they vampires? (Interviewer laughs) erm I'm not blaming the district nurse for that but it was like duplication of (laughs) (Interviewer yes) of effect and she wasn't terribly sympathetic

Interviewer How strange

Philippa Yes it was a bit odd I was there was a bit of a failure from that point of view and I was kind of because I saw someone different every time I was almost (Interviewer Hmm) blaming the individuals rather than the system but I shouldn't have done you know not their fault it was like well if you're gonna turn up and be shirty with me (Interviewer Mmm) erm rather than sympathetic and caring towards the person (Interviewer Yes) erm then then I don't actually like your attitude and ooh there's another one I don't like your attitude either

Interviewer Hmmm so that that does seem like a breakdown in communication somewhere along the line doesn't it?

Philippa Yes

Interviewer So did you ever discover where those two phlebotomists came from?

Philippa No I didn't at all and it was you know like a big joke between myself and my husband like we've got vampires (Interviewer laughs) In B [names place she lives] (Interviewer laughing) because the blood tests didn't go anywhere

Interviewer Oh no

Philippa but the district nurse looked into it and she said well there aren't blood tests being followed up

Interviewer How bizarre

Philippa maybe as the carer paranoia was, 'you must be lying' [laughs] (Interviewer Well you) 'what do you think that plaster's doing on her arm then?' I didn't do it

Interviewer Gosh how strange

Philippa I think it was one of those odd things, one off communication things

Interviewer Yep mmm em ok [laughs] ok let's draw a line under that one then

Philippa [Laughing] Don't put that in your report

Interviewer [Laughing] I'll see what I can do with it, um the service the district nursing service was it 24 hour service?

Philippa I've no idea I never had to have a district nurse after hours so I don't know

Interviewer hmm and it was 7 days a week? Was it presumably or not necessarily?

Philippa Umm [pause] um [blows air] I had assumed that it wasn't but then I never it wouldn't have occurred to me to ask for it at the weekend

Interviewer Hmm oh really if you had had a difficulty you wouldn't have rung that number at the weekend or anything

Philippa No I I assumed it was the same as GP hours

Interviewer So nobody explained to you how the service worked?

Philippa No

Interviewer Ok alright um so I think you've answered these questions um let me just check [turning papers] well you've answered all those questions without me answer [sic] asking them that's very um er so you haven't had any information hmm so um

Philippa I must admit as I say although thankfully I knew very little about the NHS (Interviewer Uhu) because of my health and also so physically my Mother's health was good and I've never had children so I thankfully haven't had to have many encounters with the NHS

Interviewer Uhun

Philippa but as I say from and so therefore my only experience of district nurses would have been what I've seen on television (Interviewer sure) so it wasn't anything other than I expected (Interviewer Hmm) but that was primarily because if if you think that the system ought to be explained to people um nobody did so I just you know the name district nurse is someone who in a more rural area wanders around and changes peoples dressings and does a really good job and in an urban area came out when you know my Stepfather had a problem with his catheter (Interviewer Hmm) erm so I didn't think there was anything else that they should be doing and so therefore I didn't think that it should be necessary for them to explain to me what they did

Interviewer OK so you've talked about when you needed to get hold of the district nurses for whatever reason you rang the central number during office hours and so on and you said that you went through you had to say it was M and so on and maybe had to talk to 2 to 3 people before you go to the end point of leaving your message

Philippa Yeah

Interviewer Did you feel that was an easy process? Was it easy to actually get a visit as a result of that? You implied a bit earlier that you weren't always entirely sure whether the message got through

Philippa Um I wasn't no I didn't think it was an easy process (Interviewer Hmm) but as I said in the first instance that could be carers 'oh God not another thing I've got to go through' (Interviewer Hmm) as er you know as a professional person you now if you're trying to get hold of someone and you speak to 3 PAs and you get through to them and you've left them a message that possibly isn't such an issue when you're a carer and there's an issue with the catheter or whatever and you've got to go through four processes and you have had that in other areas as well then you get kind of a bit stressed about it (Interviewer Hmm) so, no it wasn't nearly as easy as it could have been

Interviewer Hmm so is there anything what in your view what works well about the service, is there anything that you?

Philippa Um [exhales] when you've been referred by a GP and they say a a district nurse will be turning up and will do X,Y and Z and they do it um that works supremely well um if the and and if you're phoning on your own behalf and you know that you need the district nurse but it's not a weekly changing of bandages which would be booked in anyway if you're doing it on your own behalf unless you're very very ill or in an awful lot of pain I imagine the system's fine as well because some of the district nurses when they turn up they're reassuring they're professional they do what they're there to do they come to your *house* to do it which is fantastic and you know you haven't go to go to the surgery to do it and you trust them as a medical professional (Interviewer Hmm) when it's when you're stressed in any way and you're a carer and er as I say for the assessment or something like erm no the other thing that was difficult was and it erm no it's really confusing and and probably not relevant to a lot of people but there was a period where I thought it would be really really helpful if my Mother could have a commode (Interviewer Uhu) and it was partly because

erm in the house my husband was having the bathroom re-done, one of the bathrooms with wet room to help my Mother and that meant that of the 2 bathrooms in the house one of them was out of action and so therefore when my Mother got up in the night and wanted to go to the toilet the one that she was more used to going will be out of action and I didn't want her wandering around in the night erm getting lost and and I dunno peeing on the floor or whatever so I started off getting her up every night and taking her to the appropriate bathroom and then I said gosh it would make life so much easier if I could borrow a commode for the for the period (Interviewer Yup) erm and so went to the GP and said 'well I've no idea where you get commodes from (Interviewer laughs) maybe you need a referral from the district nurse' so I contacted the district nurses and I mean no one came round but just over the phone said 'No that's not district nurses that's social services' so I contacted social services and they said 'well that's not social services I don't know who refers you for that (Interviewer laughs) but its not us' and so it was 4 different telephone conversations in the end I went to back to the GP and [sighs] I don't like wasting their time [sounds pained] and at that stage what I should have done is say 'oh sod it we'll just buy a commode' but I wanted to get to the bottom of it cos people have said on no no no you've got to phone this number, you've got to phone this number in the end it turned out that it *was* a referral from the district nurse (Interviewer Hmm) but *no*-one seemed to know that not even the GP and the district nurse round for an assessment and yet again it's like well no you need to do the assessment at 2 o'clock in the morning when I'm taking her to the toilet not now in the afternoon (Interviewer Yes) cos I can get her to the toilet in the afternoon (Interviewer Hmm) so maybe I should have said well alright no one knows what they're talking about um I'll just buy one so I only needed it well at the time I thought I only needed it for a short time and they're not cheap um as and as it turned out it was ultimately what what I ended up needing full stop even once the toilets were done she still needed help at night you know whatever (Interviewer Ok so) that is not a specific district nurse issue but it turned out the district nurse had to do an assessment and once again it was what are you going to assess?

Interviewer Hmm hmm and why they are assessing I suppose which it isn't clear to you why they're doing it

Philippa Well [questioning] erm it's you know it was something that was on loan so it needn't be hugely costly to the NHS (Interviewer No) because even after a couple of years when she no longer needed it it was still pristine it could have been loaned to someone else (Interviewer Yeah) but it is you know but it didn't appear to be an NHS saving money issue it was whose responsible for this? issue

and noone seems to know um but you know assess my mental state if your like but you can't assess her need to go to the toilet in the middle of the night

Interviewer No so Ok I probably know the answer to this but I'm going to ask you anyway was there any stage have you ever been involved in service design thinking abut anybody asked you about how the services work or evaluate the service that you've had?

Philippa Um I've no no-one's asked me to evaluate it I have very recently joined the local GP surgery the Patient Participation group [laughing] (Interviewer Yeah hmm) erm currently I've been to one meeting and I volunteered myself as secretary but as far as I can see the main evaluation there would be what a patient participation group is not the service to the GPs cos so far no-one can tell me [laughing] what a patient participation group does (Interviewer ok laughs) I would I would you know welcome being able to some take part in some input in evaluation but I think possibly having worked in the private sector all my life I might get a bit impatient bureaucracy and people not doing what they're supposed to do

Interviewer Hmm well there's always opportunities in the group you're in to well it depends what the GPs have set it up for but it could be everything that comes through that people experience

Philippa I don't know [laughing] it appears to me without blaming the GPs surgery they have to have a PPG so (Interviewer they do yeah) so they are doing it even though no one knows what the PPG group is supposed to be doing [sounds amused] previously GPs surgeries were apparently paid to have a PPG erm now they're no longer getting paid but they have to have one but no one seems to know what they're supposed to do (Interviewer Hmm) and as I say I went to one meeting and I said I'm ever so sorry I'm not could someone explain to me and they sent me through some terms of reference from other PCG [sic] (Interviewer Hmm) which is not what they do erm or how they do it [laughing] or why they do it erm so I would be happy to be involved but I can't be if if nothing happens

Interviewer Hmm so if if some was to ask your advice about the best way to get access to a district nurse what would your advice be?

Philippa I would be happy if it was only through [Interviewer coughing] direct referrals you know like a physiotherapist whatever direct referral through the GP and then like with physiotherapists once you have you know a course of act it's

different for physiotherapy because that is a regular thing erm but you have your point of contact and you make a regular appointment or if the case isn't for a regular appointment you have a direct point of contact (Interviewer Uhum ok) rather than round the houses you know I wouldn't have minded and I'm sure he [DN} wouldn't have minded me leaving him a message on his answering machine and saying at some point this week can you pop in and see my Stepfather

Interviewer Uhum so some direct access would be helpful?

Philippa Yes um and if that is not erm the most appropriate way of going about it then a regular monthly appointment to cover off issues unless something comes up in the meantime (Interviewer Uhum) as I say without knowing specifically and I still don't know what a district nurse is supposed to do I'm not I don't know if that's er most appropriate use of their time (Interviewer Uhum well) If I don't have an ulcer that needs bandaging and cleaning every week then maybe it's not appropriate for the district nurse to come round regularly but it's not appropriate for a carer to be spending you know half an hour being transferred to different places and then not even knowing if the person concerned is going to get the message

Interviewer Yeah

Philippa Give me an answering machine

Interviewer Right you prefer an answering machine to being pushed round by different people

Philippa Mmm

Interviewer OK so this question relates sort of kind of some of the things you've been saying Philippa it's about looking to the future, if you were designing access to the service what would it look like? so I know you've suggested an answering machine or direct access to things are there other things that you think would help in terms of access to the service>

Philippa Well only help in terms of access [exhales] I mean you've partly answered one of the things by saying well didn't anybody explain to you what the district nurse did? And I assumed that I knew but my assumption is wrong possibly erm so someone explaining to me what the district nurse does erm but then that would help I guess the district nurses and the service and myself because if I know what they do then like GP surgeries are telling you all the time

don't come to us for that go to a chemist erm so it would eliminate the need for the district nurse potentially by going to a pharmacist whose supposed to know what they're doing um but if you don't know what the district nurse does then you can't make that decision um apart from that when the system works well I can't offer a suggestion of how to improve it

Interviewer Uhu OK [clears throat]

Philippa when it didn't work well it's don't send this woman round to me or these women don't have someone answering the phones who doesn't really speak English or understand unless they were deliberately not speaking very good English to get rid of me but then that's not very helpful when you want one (Interviewer No) and um and don't waste your time, dah don't waste your time doing assessments because the GP could tell them whether my Mother was doubly incontinent or not they didn't need to come round and not look at her pooey backside or talk to me just order the next year's worth of incontinence pads

Interviewer Mmm

Philippa Um and argh I can't think of any other way (Interviewer No that's alright) of giving access to them

Interviewer Uhum is there anything else you would like to see changed to improve the services generally or anything else or any other comments that you would like to make

Philippa Erm [pause] no

Interviewer I suppose I don't want to put words in your mouth but one thing you kept you were saying earlier is about this change you had one district nurse that you saw more regularly for your Stepfather and then you had lots of different people as well in terms of for your Mum that were every week somebody different

Philippa Yeah but I I've no idea if that's a system change or erm just this particular individual was had patients who were allocated to him or her and the patients erm and had regular needs whereas if you are just being referred to a district nurse for [clears throat] I dunno a blood test or or incontinence pads you you don't need to see a regular person I mean it it I think it would have only have helped me if it had been a regular person and I'm not the the one that

needs to be helped, you know maybe stressed carers do need to be helped but you know it's not as imperative as having particularly an elderly person or some one who's particularly in need it's probably helpful for them to see the same person if you're going to be seeing them every week if possible erm but I you know it would have helped me a bit if I hadn't had to explain the same thing over and over again erm and admittedly with my Mother it was only 3 or 4 times but that's 3 times (Interviewer too many) more than I could deal with bearing in mind that her condition was particularly well logged with the GP erm so [clears throat] so no you know bit of continuity

Interviewer Yeah, continuity OK. Well that's pretty much it Philippa you've answered all the questions I had written down and more which is very, very helpful to me, thank you

Philippa Oh well you're very welcome that was quite easy and it does me good to sound off

Interviewer No it's good but I do think it's hard for people to find the information and to know you know what it is and how it works you know it's quite hard

Philippa But in your research are you finding and this I'm just asking from my own point of view cos you asked the question?

Interviewer I'm going to turn off the tape now, (Philippa still speaking) sorry I'm just going to turn off the tape so we can have a a conversation

Appendix 10

Coded transcript District Nurses Focus Group 3

The group comprised of 6 district nurses (5 qualified district nurses and 1 district nursing student nearing the end of her training). Apologies were received from two others due to illness and workload. All female, white and qualified had been district nurses for a minimum of 5 years to over 25 years

Interviewer Yup that seems to work [referring to recorder] so um thank you very much again for agreeing to take part in this research um so if you don't mind when we go round the table if you just say your first names it's just that when I'm listening back to the thing I'll be able to distinguish your voices who said what and you're all gonna be numbers I'm afraid so it won't be names it would just help me that would be great thank you so L if you want to start [pseudonyms applied here]

District nurse 8 my name's Louise

District nurse 9 Charlotte

District nurse 10 Maria

District nurse 11 Maryam

District nurse 12 Siobhan

District nurse 13 Esther

Interviewer Thank you I'll get them all muddled up no doubt but [laughs] thank you very much but as you know it's about erm access to district nursing services so sort of I just want the areas the sort of areas I'm going into sort of roughly in three about the services then about erm how people get access and then thinking about the future that sort of thing. So just sort of erm just to help me understand how do the district nursing services work and this might be a more complicated answer than I'm expecting but how do they actually work in in your area?

District nurses you mean [a couple speaking together to clarify question] inaud

Interviewer Yes so how not necessarily offered but you know how does it operate, what sort of services are offered you know do you have I see you have a nurse led clinic here [Health Centre where interview is taking place] but um do you have a 24 hour service how does it work?

District Nurse x and 13 [speaking together] Yes 24 hours

District nurse 13 we're commissioned to provide nursing care to patients who are housebound we are not providing any care to people who are not housebound so we're quite strict on that we do provide erm [clears throat] what's classed as specialist services so we deal with erm patients who are palliative or intravenous medication even if they're not housebound [Interviewer uhun] and erm compression bandaging erm which we offer most of us most clinics provide leg ulcer clinics for the use of compression bandages but I think that's all that's the basic sort of remit of it [Interviewer uhun] referrals come through single point of access which is one point erm which is run by admin staff erm it's a 24 hour service and then it's usually erm the referrals are sent out to each individual team

Interviewer Ok I'll come back to that and em the provider it's all Foundation trust? Everybody?

District nurses Yes

Interviewer Ok so and and how are your caseloads organised are you geographical or attached to GPs? How do

District nurse 12 It's a mix

District nurse 13 it's primarily GPs aligned but we are within specific geographical areas

Interviewer Right ok ok

District nurse 13 Yeah

Interviewer And have there been any changes to the organization?

District nurses pause [laughter]

Interviewer Sorry [laughing] I heard you talking about management of change earlier [conversation among DNs before interview started] so I might regret asking this question

District nurses [all laughing]

District nurse 8 it's constantly changing really [DNs Yeah] is the easiest answer I mean it's there's always new things being introduced at the moment they're trying to bring

Jo Skinner 8/5/2019 17:41
Comment [1]: 24 hours service
District Nurse 13 Yes 24 hours (Q1)

Jo Skinner 8/5/2019 17:41
Comment [2]: Housebound criterion strictly applied
District nurse 13 we're commissioned to provide nursing care to patients who are housebound we are not providing any care to people who are not housebound so we're quite strict on that... (Q1)

Jo Skinner 8/5/2019 17:41
Comment [3]: Exceptions to housebound rule
DN13 ...we do provide what's classed as specialist services so we deal with patients who are palliative or intravenous medication even if they're not housebound...(Q1)

Jo Skinner 8/5/2019 17:41
Comment [4]: Specialist DN services
DN13 ...classed as specialist services... palliative or intravenous medication leg ulcer clinics for the use of compression bandages (Q1)

Jo Skinner 8/5/2019 17:41
Comment [5]: SAP for Referrals
DN13 Referrals come through single point of access which is one point which is run by admin staff it's a 24 hour service and then it's usually the referrals are sent out to each individual team (Q1)

Jo Skinner 8/5/2019 17:41
Comment [6]: SAP run by admin
DN13 Referrals come through single point of access which is one point which is run by admin staff it's a 24 hour service and then it's usually the referrals are sent out to each individual team (Q1)

Jo Skinner 8/5/2019 17:41
Comment [7]: Foundation trust
District nurses Yes (Q2)

Jo Skinner 8/5/2019 17:41
Comment [8]: Caseloads a mix of geographical and GPs attachment
DN13 it's primarily GPs aligned but we are within specific geographical areas (Q3)

social care in um so that our teams are far more integrated [Interviewer uhun] we've got therapists now as part of the teams and I think they're talking about bringing in all the specialist teams

District nurse 9 in but there weren't enough specialist nurses to fit were in five, six? [DN 13 six] clusters yeah and it ought to have one specialist nurse in each

Interviewer Different types of specialist nurses?

District nurse 8 It's a heart failure team, respiratory team diabetes um [inaud]

Interviewer and they are not necessarily district nurses they maybe outreach from the hospital or how does that work?

District nurse 13 No we have our specialists nurse are employed by X [names Trust] so we have our own teams but um they are sort of [clears throat] based in one specific te[am] yeah one specific locality

Interviewer Inaud

District nurse 8 They're not cluster based [other agreeing in background] [Interviewer Right] they there's no logic they're sort the respiratory team are in Y [names other HC]

District nurse 12 TVNs [tissue viability nurses] are here

District nurse 8 Continence nurses in Z

Interviewer So are they resources for you or do they directly have their own patients they see

District nurse 9 They have their own caseloads as well they get their own referrals but there are re-referrals from us in to then [Interviewer mm]

Interviewer Ok ok so and in your area who does the first assessments for patients?

Pause

District nurse 8 Well district nurses and staff nurses [others agreeing] depending

Interviewer OK so it doesn't have to be a qualified district nurse?

Jo Skinner 8/5/2019 17:41
Comment [9]: Constant organisational change
DN8 It's constantly changing really…I mean there's always new things being introduced at the moment they're trying to bring social care in so that our teams are far more integrated we've got therapists now as part of the teams and I think they're talking about bringing in all the specialist teams (Q4)

Jo Skinner 8/5/2019 17:41
Comment [10]: Integration with social care
DN8 …new things being introduced at the moment they're trying to bring social care in so that our teams are far more integrated…(Q4)

Jo Skinner 8/5/2019 17:41
Comment [11]: Expanded integrated service
DN8 …at the moment they're trying to bring social care in so that our teams are far more integrated we've got therapists now as part of the teams and I think they're talking about bringing in all the specialist teams (Q4)

Jo Skinner 8/5/2019 17:41
Comment [12]: Not enough specialist nurses
District nurse 9 …there weren't enough specialist nurses [heart failure, diabetes, respiratory] to fit…[six] clusters and it ought to have one specialist nurse in each (Q4)

Jo Skinner 8/5/2019 17:41
Comment [13]: DN has own specialist nurses
District nurse 13 No we have our specialists nurse are employed by X [names Trust] so we have our own teams but they are…based in one specific te[am] one specific locality (Q3)

Jo Skinner 8/5/2019 17:41
Comment [14]: Illogical organisation of DN specialisms
DN8 They're not cluster based there's no logic they're sort the respiratory team are in …

Jo Skinner 8/5/2019 17:41
Comment [15]: DN specialists services have own caseloads
DN9 They [DN specialist services] have their own caseloads as well they get their own …

Jo Skinner 8/5/2019 17:41
Comment [16]: DN specialists services referrals
DN9 They [DN specialist services] have their own caseloads as well they get their own …

Jo Skinner 8/5/2019 17:41
Comment [17]: First assessments
DN8 Well district nurses and staff nurses depending [not necessarily a qualified DN] (Q5)

District nurse 8 No

Interviewer So and in terms of the mix of you know numbers of qualified nurses and and things like that health care assistants what's your staff skill mix like?

District nurse 10 Every cluster has a band 7 erm and then there's either two or three band 6's each team have 3 may be 4 band 5s plus or minus an HCA

[Others agreeing]

Interviewer So quite heavily oriented towards more qualified staff

District nurses Yes

Interviewer OK is that a conscious decision or has it always been like that or

District nurse 9 It's a nice decision whether it would always be like that I think it's what we need but we are trying to up skill the 3's. We did have a couple of assistant practitioners which were 4's for a while but that sort of fell by the wayside but they're now trying to up skill the 3s but not for any financial [Interviewer mm] reward

District nurse 13 I think where we're moving towards is more complex care there's less and less work for the HCA so they're looking at sort of

District nurse x Yeas

District nurse 13 So less and less work for the HCAs so they're looking at [inlaid]

District nurse 9 so yes years ago when I started it was they were the bath nurse [Interviewer mm] and then they gradually as social services took over that element yeah and then they did minor dressings

Interviewer So there's not really a role for them

District nurse 13 No

District nurse 9 Definitely not at the clinic I'm at I don't feel there is really [Interviewer mm] a role

District nurse 10 I mean I do make good use of our HCAs in regard most of them do the phlebotomy [**Interviewer mm**]

Jo Skinner 8/5/2019 17:41
Comment [18]: Skill mix of DN cluster
DN10 Every cluster has a band 7 and then there's either two or three band 6's each team have 3 may be 4 band 5s plus or minus an HCA (Q6)

Jo Skinner 8/5/2019 17:41
Comment [19]: Nice to have qualified staff mix
DN9 It's a nice decision [having more qualified staff in clusters] whether it would always be like that I think it's what we need (Q6)

Jo Skinner 8/5/2019 17:41
Comment [20]: More qualified staff fits needs
DN9 It's a nice decision [having more qualified staff in clusters] whether it would always be like that I think it's what we need (Q6)

Jo Skinner 8/5/2019 17:41
Comment [21]: Concern balance of qualified staff mix will change
DN9 It's a nice decision [having more qualified staff in clusters] whether it would always be like that I think it's what we need (Q6)

Jo Skinner 8/5/2019 17:41
Comment [22]: Up skilling staff
DN9 ...we are trying to up skill the [band] 3's. We did have a couple of assistant practitioners which were [band] 4's for a while but that sort of fell by the wayside b...

Jo Skinner 8/5/2019 17:41
Comment [23]: More complex care
District nurse 13 ...we're moving towards is more complex care there's less and less work for the HCA (Q6)

Jo Skinner 8/5/2019 17:41
Comment [24]: Less need for HCAs
District nurse 13 ... we're moving towards is more complex care there's less and less work for the HCA (Q6)

Jo Skinner 8/5/2019 17:41
Comment [25]: Health and Social Care divide
District nurse 9 ...years ago when I started...they [HCA] were the bath nurse a...

Jo Skinner 8/5/2019 17:41
Comment [26]: District nurse 9 Adapting skills of team...years ago when I started...they [HCA] were the bath nurse and then gradu...

Jo Skinner 8/5/2019 17:41
Comment [27]: Bath nurse
DN9 ...years ago when I started...they [HCA] were the bath nurse...and then they did minor dressings (Q6)

Jo Skinner 8/5/2019 17:41
Comment [28]: HCAs do phlebotomy
District nurse 10 ...I do make good use of our HCAs...most of them do the phlebotomy (Q6)

District nurse 12 There's certain ones that are a lot better than others

District nurses Yes

District nurse 9 But you could say that probably about qualified nurses

Laughter

District nurse 12 They probably should be recognised a bit more for what she does

District nurse 9 Yes

District nurse 12 that's really

District nurse 9 Financially. When you match the 3 of them here up she really should actually get financially

District Nurse 12 She should be a 4 shouldn't she?

District Nurse 9 Yes

District nurse 12 You know she's brilliant at what she does so

District nurse 8 It's kind of up to the team leaders cos our my HCA does continence assessments, phlebotomy, [Interviewer Right] she does dressings the only things can't do is compression and I wouldn't send her out to palliatives and things but I mean she's you know just picked up those skills as she's gone along it's kind of it depends how motivated they are as well

DN Yeah

Interviewer So you have more a bit more choice about how you use them [HCAs] in that sense?

District nurse 8 I mean I'd include her as a regular member of staff I wouldn't think Oh I've only got an HCA working you know to me there's no real difference

Interviewer So what about your workload and caseload analysis you've sort of touched on it a little bit by talking about your skill mix but in terms of how would you sort of um

Jo Skinner 8/5/2019 17:41
Comment [29]: Some HCAs more skilled and should recognition higher pay
District nurse 12 they [HCAs] probably should be recognised a bit more for what she does she should be a 4 shouldn't she you know she's brilliant at what she does so (Q6)

District nurse 9 financially when you match the 3 of them [HCAs]...she really should actually get financially [rewarded] (Q6)

Jo Skinner 8/5/2019 17:41
Comment [30]: HCAs limitations
District nurse 8 ...my HCA does continence assessments phlebotomy ...dressings the only things can't do is compression and I wouldn't send her out to palliatives and things... (Q6)

Jo Skinner 8/5/2019 17:41
Comment [31]: Flexible use of HCAs
District nurse 8 It's ...up to the team leaders...my HCA does continence assessments phlebotomy...dressings the only things can't do is compression and I wouldn't send her out to palliatives and things...Q6)

Jo Skinner 8/5/2019 17:41
Comment [32]: HCA pick up skills
District nurse 8 ...my HCA does continence assessments phlebotomy... dressings ...you know just picked up those skills as she's gone along it's kind of it depends how motivated they are as well (Q6)

Jo Skinner 8/5/2019 17:41
Comment [33]: Skilled HCA seen as regular staff member
District nurse 8 ...I'd include her as a regular member of staff I wouldn't think 'Oh I've only got an HCA working you know to me there's no real difference (Q6)

characterize the caseloads I think you were saying it's getting more complex you've got more complex care more people living on their own or how does that work

District nurse 13 I mean I think from my opinion where we've er become a little bit we've had to become a little bit more rigid with respect of with the commissioner provider split and we've had sort of more emphasis I think on those that are housebound I think and potentially more dependent [Interviewer Hmm] on services and that and I think from that point of view we are seeing more dependent patients

Interviewer Cos you mentioned housebound earlier as one of your referral criteria – how do you actually define housebound is there a definition of that [general laughter]

District nurse 13 Well that's a very good question yeah that's the thing [clears throat] there's some argument that if they can go to the hairdressers then they're not housebound and it I think I mean it's very difficult to sort of draw that rigid line but I think I feel that we are pressurized to make sure that they are totally [emphasizing] housebound um because of the limited sort er well the push on resources but it quite often comes back at us well that patient wasn't housebound so why were you seeing them anyway [Interviewer Ya] so I feel that we have to be quite rigid in as much they

Interviewer When you are making your judgments about that each of you visit you know are there triggers that make a difference for you I don't know

District nurse 13 I don't know I think some days you'll see a patient you'll assess them and you think ooh they're housebound and then subsequent visits they're not in or they've [DNs yeah] gone here then it's like actually you can move them onto the appropriate services

Interviewer So does housebound mean that they never go out?

District nurse 13 Yes

District nurse 8 But it is a difficult it's not that simple because I'd say unless they're completely paralysed in a bed most people do go out of the house at some point with family or and I think it kind of depends on the locality you work in as well in what people's expectations are

Interviewer So what do you mean by the locality? What did you mean access to transport, what?

Jo Skinner 8/5/2019 17:41
Comment [34]: Impact of commissioning on caseloads
District nurse 13 ...we've had to become a little bit more rigid with respect of with the commissioner provider split and ...more emphasis on those that are housebound and potentially more dependent...(Q7)

Jo Skinner 8/5/2019 17:41
Comment [35]: Housebound criteria
District nurse 13 ...we've had to become a little bit more rigid with respect of with the commissioner provider split and we've had sort of more emphasis I think on those that are housebound... (Q7)

Jo Skinner 8/5/2019 17:41
Comment [36]: Defining housebound
District nurse 13 ...there's some argument that if they can go to the hairdressers then they're not housebound and...I mean it's very difficult to...draw that rigid line... (Q7)

Jo Skinner 8/5/2019 17:41
Comment [37]: Resource driven pressure to apply housebound criterion
District nurse 13 ...I mean it's very difficult to sort...draw that rigid line but...I feel that we are pressurized to make sure that they are totally [emphasizing] housebound because of the limited er well the push on resources... (Q7)

Jo Skinner 8/5/2019 17:41
Comment [38]: Challenged if patients not totally housebound
District nurse 13 ...I feel that we are pressurized to make sure that they are totally [emphasizing] housebound because of...th...

Jo Skinner 8/5/2019 17:41
Comment [39]: DN use judgment about who's housebound
District nurse 13 ...I think some days you'll see a patient you'll assess them and you think...

Jo Skinner 8/5/2019 17:41
Comment [40]: Assessment of housebound may change
District nurse 13 ...some days you'll see a patient you'll assess them and you think o...

Jo Skinner 8/5/2019 17:41
Comment [41]: Bedbound or housebound
District nurse 8 ...it's not that simple because...unless they're completely paraly...

Jo Skinner 8/5/2019 17:41
Comment [42]: Not easy to determine housebound
District nurse 8 But...it's not that simple because I'd say unless they're completely ...

Jo Skinner 8/5/2019 17:41
Comment [43]: Locality and expectations may influence housebound rule
District nurse 8 ...it's not that simple because I'd say unless they're completely paralysed...

District nurse 8 Yeah and what the historically what's happened so if the district nurses have always gone in there it's difficult to turn around and say well actually you know you can get out of the house and get on a bus or get a taxi because it's difficult you know they put in a complaint and you just end back up at square one so there's lots of people that aren't really strictly housebound

District nurse 12 And if they actually did have transport they wouldn't be housebound and someone is not going to be willing to pay for a taxi to bring them to the health centre to have an injection everyday

District nurse 8 Yeah

District nurse 12 You know

District nurse 8 Yeah

District nurse 11 I had to make a choice last week I went to a patient and she said to me ' Oh I'm just waiting for my taxi' and I said 'Oh where are you going?' and she said 'Oh I'm gong to the hairdressers' and I said 'Oh we only see housebound patients and then I realized that this lady's actually blind and she had a cane, she couldn't anything I had to make that judgment that actually she couldn't be escorted when she went to have her blood taken in a clinic there wouldn't be anyone to escort her or around x [names hospital] yet the driver from the taxi could escort her to and see her in so I kind of had to say well actually she is housebound [DNs some saying yes] really and I took her blood and I would keep her to take her blood next time but erm you have to make that decision

District nurse 10 It it isn't a cut and dried thing is it? [DNs No [agreeing]] I've done a new assessment this morning and the lady's only discharged from hospital yesterday and to all intents and purposes at this moment in time she is housebound [DN 13 yes absolutely] after you know she's had major quite major surgery but she's not if it was an ongoing thing for example then you've got to remember to kind of reassess or look at things in the future.

Interviewer mm

District nurse 13 I feel the emphasis is very much

District nurse 9 I think I'm much too harsh I am harsh

Cross talking some inaud

45

Jo Skinner 8/5/2019 17:41
Comment [44]: Difficult to withdraw established service if not housebound
District nurse 8 ...so if the district nurses have always gone in there it's difficult to turn around and say well actually you know you can get out of the house and get on a bus or get a taxi ...so there's lots of people that aren't really strictly housebound (Q7)

Jo Skinner 8/5/2019 17:41
Comment [45]: Managing potential complaints
District nurse 8 ...so if the district nurses have always gone in there it's difficult to turn around and say well actually you know you can get out of the house...they put in a complaint and you just end back up at square one... (Q7)

Jo Skinner 8/5/2019 17:41
Comment [46]: Access to transport not housebound
District nurse 12 And if they actually did have transport they wouldn't be housebound... (Q7)

Jo Skinner 8/5/2019 17:41
Comment [47]: Cost of accessing service
District nurse 12 And if they actually did have transport they wouldn't be housebound and someone is not going to be willing to pay for a taxi to bring them to the health centre to have an injection everyday (Q7)

Jo Skinner 8/5/2019 17:41
Comment [48]: Exercising judgment with housebound criterion District nurse 11 ...I went to a patient and she said to me ' Oh I'm just waiting for my taxi' and I said 'Oh where are you going?' and she said 'Oh I'm gong to the hairdressers' and I said 'Oh we only see housebound patients and then I realized that this lady's actually blind and she had a cane, she couldn't [see] anything I had to make that judgment that actually she couldn't be ...

Jo Skinner 8/5/2019 17:41
Comment [49]: Not housebound
DN 10 ...I've done a new assessment this morning and the lady's only discharged from hospital yesterday and to all intents and purposes at this moment in time she is ...

Jo Skinner 8/5/2019 17:41
Comment [50]: Reassessment to ensure meet referral criteria
District nurse 10 it isn't a cut and dried thing ...I've done a new assessment this morning and the lady's only discharged from hospital yesterday and to all intents and purposes ...

Jo Skinner 8/5/2019 17:41
Comment [51]: Difference tolerance in applying housebound criterion
District nurse 9 I think I'm much too harsh I am harsh [applying housebound criterion] (Q7)

District nurse 13 No but I do think the emphasis from our management point of view they have to be housebound

District nurse 9 I think we have to be and we don't have the services we don't have the back filling there isn't the funding and we have to be very strict in our criteria and so we shouldn't be bringing patients in to clinic for services other than a specialist service like compression bandaging we shouldn't bring patients in for dressings

District nurse 10 No

District nurse 9 If they can come into clinic for dressings they go to their practice nurse

All talking [inaud agreeing]

District nurse 10 Oh yeah absolutely

District nurse 9 inaud

Interviewer Because you bring them in by transport

District nurse 9 if they can come to clinic to have their dressing done then they can go to their practice nurse

District nurse 10 Oh yeah

District nurse 12 Quite often you'll ring the doctor's surgery and you'll say 'Ooh there's not a practice nurse' and I'll say 'that's actually not my problem'

District nurse 10 Yeah

District nurse 12 I've had that a couple of times recently that's nothing to do with us

District nurse 10 or the practice nurse is on holiday

District nurse 12 yeah well we can't cover the care for 2 weeks because the practice nurse

District nurse 9 but It's quite harsh we have *always* supported the GPs in that infrastructures [DNs yeah], I think when we had GP fundholding we did support them and now we don't

Jo Skinner 8/5/2019 17:41
Comment [52]: Management directive on housebound rule
District nurse 13 ...I do think the emphasis from our management point of view [is that] they have to be housebound (Q7)

Jo Skinner 8/5/2019 17:41
Comment [53]: Resources driving eligibility criteria
District nurse 9 ...we don't have the services we don't have the back filling there isn't the funding and we have to be very strict in our criteria...(Q7)

Jo Skinner 8/5/2019 17:41
Comment [54]: District nurse 9 ...we shouldn't be bringing patients in to clinic for services other than a specialist service like compression bandaging we shouldn't bring patients in for dressings ...If they can come into clinic for dressings they go to their practice nurse (Q7)

Jo Skinner 8/5/2019 17:41
Comment [55]: No practice nurse
District nurse 12 Quite often you'll ring the doctors surgery and [they]'ll say 'Ooh there's not a practice nurse' and I'll say that's actually not my problem... we can't cover the care for 2 weeks because the practice nurse [is on holiday] (Q7)

Jo Skinner 8/5/2019 17:41
Comment [56]: Assumption DN will cover for PN
District nurse 12 ...you'll ring the doctors surgery and [they]'ll say 'Ooh there's not a practice nurse' and I'll say that's actually not my problem... we can't cover the care for 2 weeks because the practice nurse [is on holiday] (Q7)

Jo Skinner 8/5/2019 17:41
Comment [57]: Impact on IP and team working with GPs
District nurse 9 it's quite harsh we have *always* supported the GPs in that infrastructures [cover for PN], I think when we had GP fundholding we did support them and now we don't (Q7)

District nurse 12 They don't support us now, do they?

District nurse 9 No it has to be well no it's the weekend or they have to go to the polyclinic cos that's who you have your contract with

District nurse 12 Yep

Interviewer That's a question I was gonna ask you in terms of erm commissioners, the the influence of commissioners in shaping or influencing how what you're doing how does that actually work? Are there particular things you've absolutely got to nail that, get that cos that's a requirement for the contract or something I don't know

District nurse 8 There are lots of target things that we're supposed to do like with palliative care we've got to record certain decisions that like you know forward planning decisions like preferred place of care um

District nurse 13 And we get fined for a lot of things

Interviewer Do you? Really?

District nurse 13 yeah, the CCG will fine the organization if they don't meet certain criteria say for example the statutory manager training, PDRs and things like that

Interviewer ok

District nurse 13 So it's

Interviewer but so in terms of services what is there anything for which they you would get fined

District nurse 13 I think they do fine if KPIs yeah

District nurse 8 pressure ulcers if they're erm proven to have been avoidable and it happened when the patient was in our care [Interviewer Right] and there's no um what's that new thing er duty of [DN13 candour] yeah duty of candour they can get fined for that and so there's a lot more pressure on the nurses to like recording *every* little thing that happens and things that patients don't do as well as the the things they do do yeah um

Click to delete comment
Comment [58]: DN don't feel supported by GPs
District nurse 12 They don't support us now, do they? (Q7)

Jo Skinner 8/5/2019 17:41
Comment [59]: Contract impact on IP working
District nurse 9 [DN cover for PN is at] ...the weekend or they have to go to the polyclinic cos that's who you have your contract with (Q8)

Jo Skinner 8/5/2019 17:41
Comment [60]: Targets to meet
District nurse 8 There are lots of target things that we're supposed to do like with palliative care we've got to record certain decisions ...

Jo Skinner 8/5/2019 17:41
Comment [61]: Record decisions for forward care planning
DN8 ...we've got to record certain decisions that like you know forward planning decisions like preferred place of care (Q8)

Jo Skinner 8/5/2019 17:41
Comment [62]: Fines from CCG
District nurse 13 And we get fined for a lot of things...the CCG will fine the organization if they don't meet certain criteria say for example the statutory manager training, PDRs and ...I think they do fine if KPIs [are not met] (Q8)

Jo Skinner 8/5/2019 17:41
Comment [63]: Duty of Candour
District nurse 8 pressure ulcers if they're proven to have been avoidable and it happened when the patient was in our care and there's...duty of candour they can get fined for that and so there's a lot more pressure on the nurses to like recording *every* little thing that happens...(Q8)

Jo Skinner 8/5/2019 17:41
Comment [64]: Pressure on DNs to record
District nurse 8 ... so there's a lot more pressure on the nurses to like recording [sic] *every* little thing that happens...(Q8)

Interviewer And is there any sense that I mean that's like a preventive thing [DN8 Yeah] to some extent because they want to keep everybody put of hospital and it's part of why they invest in this service but I was just thinking also about outcomes are there health outcomes that are attached to it I know it's difficult for things like obviously palliative care and so on

District nurse 9 with palliative care the problem is that outcome is we have to record where their preferred place of care is and where the actual place of death is so that in there should be a correlation between we've just started recording that

District nurses 10 and also we've just brought back the end of life care planning we're supposed it's not called the end of life care plan anymore but there's a a care plan we're supposed to implement before someone dies I think that's being audited again isn't it? [DNs Mmm [agreeing]] so there are for the palliatives there are outcomes

District nurse 13 targets

Interviewer Targets

District nurse 9 historically it's always been in the recent last couple of the activity and contacts numerically but now they are more looking at outcomes and how we're providing the services we are providing

Interviewer Yeah so in terms of your activities they're captured as well are they? Is that all through RIO or how is that?

District nurses yeah, through RIO

Interviewer Ok is that working for you?

District nurse 13 No [all laughing] no

Interviewer Sorry to add to your pain [laughs]

District nurse 8 It doesn't feel like it's a tool that helps us like if we had access to the GP system and you know pathology system and stuff like that but RIO just feels like a tool for using against us and for like you know 'Oh well no you've got to put it on Rio or you've gotta or you've not recorded it

Interviewer Hmm

Jo Skinner 8/5/2019 17:41
Comment [65]: Monitoring outcomes
District nurse 9 [palliative care] …we have to record where their preferred place of care is and where the actual place of death is so that in there should be a correlation … (Q8)

Jo Skinner 8/5/2019 17:41
Comment [66]: End of life care planning
District nurses 10 …we've just brought back the end of life care planning …we're supposed to implement before someone dies I think that's being audited again…so there are for the palliatives there are outcomes (Q8)

Jo Skinner 8/5/2019 17:41
Comment [67]: Beyond numerical contact data
District nurse 9 historically it's always been…the activity and contacts numerically but now they are more looking at outcomes and how we're providing the services… (Q8)

Jo Skinner 8/5/2019 17:41
Comment [68]: RIO unhelpful
District nurse 8 It doesn't feel like it's a tool that helps us like if we had access to the GP system… (Q9)

Jo Skinner 8/5/2019 17:41
Comment [69]: Access to GP system would be helpful
District nurse 8 It doesn't feel like it's a tool that helps us like if we had access to the GP system and you know pathology system and stuff like that… (Q8)

Jo Skinner 8/5/2019 17:41
Comment [70]: RIO used against DN
District nurse 8 …RIO just feels like a tool for using against us and for like you know 'Oh well no you've got to put it on RIO…or you've not recorded it (Q8)

District nurse 12 you've got 100 unrecorded outcomes on RIO other things get on to it

District nurse 8 Yeah it doesn't seem to help us with anything really

Interviewer mm

District nurse 9 I think it's when particularly you're clinically pushed for time to have to sit down and do your RIO cos you're

Interviewer Cos you have to come back into specifically do that

District nurse 9 time infrastructure they're more interested in actually the contact was done and one activity and I mean

InterviewerI mean obviously when you went to a patient or family situation there's multiple things you're doing it isn't always one thing are you able to capture that on RIO or does it have to be separate episodes?

[Talking over each other]

District nurse 8 You could if you had the time

District nurse 13 they're not worried about that it's a huge list all they're worried about is did you make that contact? tick, done it they're not worried about the actual quality of the care that you've provided [Others No [agreeing]] justify services

District nurse 9 so much so we could spend put in 10 12 different things that you've done in somebody's house if you're behind with your RIO then you'll have admin support somebody will outcome your RIO and it will just be for a 10 minute slot advice

DN 13 Hmm [agreeing]

Interviewer Right ok

District nurse 10 I won't allow it [meaning allowing admin to outcome her RIO]

Interviewer So it doesn't reflect what you do

District nurse 13 Doesn't reflect it at all, no

Interviewer OK

Jo Skinner 8/5/2019 17:41
Comment [71]: Admin burden
District nurse 12 you've got 100 unrecorded outcomes on RIO... (Q8)

District nurse 9 I think it's when particularly you're clinically pushed for time to have to sit down and do your RIO cos ...they're more interested in actually the contact was done and one activity... (Q8)

Jo Skinner 8/5/2019 17:41
Comment [72]: Recording contacts
District nurse 9 ...they're more interested in actually the contact was done and one activity [recorded on RIO] ... (Q8)

Jo Skinner 8/5/2019 17:41
Comment [73]: Task recorded – tick
District nurse 13 they're not worried about that [multiple areas dealt with in a single visit] it's a huge list all they're worried about is did you make that contact? tick, done it ... (Q8)

Jo Skinner 8/5/2019 17:41
Comment [74]: Quality of service v Justifying service
District nurse 13 ...they're not worried about the actual quality of the care that you've provided [concern to] justify services [completing RIO] (Q8)

Jo Skinner 8/5/2019 17:41
Comment [75]: Care includes multiple tasks time not recorded
District nurse 9 ...we could put in 10 12 different things that you've done in somebody's house [but] if you're behind with your RIO ... (Q8)

Jo Skinner 8/5/2019 17:41
Comment [76]: Inaccurate record of care on RIO
District nurse 9 ...we could put in 10 12 different things that you've done in somebody's house if you're behind with your RIO then you'll have admin support somebody will outcome your RIO and it will just be for a 10 minute slot advice (Q8)

Jo Skinner 8/5/2019 17:41
Comment [77]: RIO doesn't reflect what DN do
District nurse 13 [RIO] Doesn't reflect it at all, no (Q8)

District nurse 12 I won't allow them to outcome my RIO

Interviewer Do you actually get the analysis back from RIO then?

District nurse 13 You can ask for it but it's not going to be a true reflection because admin will outcome it you're not really gonna get a true reflection

Interviewer Do you know what happens to it then? [In background No] who looks at it?

District nurse 13 We do get lists of the numbers of contacts and it is er but that's about all you do get isn't it?

District nurse 9 yeah well when it was introduced we were going to be able to go on and make caseload analysis [others yeah] and particularly for those who have DN students they can go in and see how many diabetics, how much how many Pick lines you've done but actually it's not about that it's literally just about bums on seats how many you've seen

District nurse 13 they've been commissioned to provide x number our district nurses services been commissioned to see x number of contacts per year we've done this many can we have some more money off the commissioner

District nurse 8 And I think we always do too many don't we whatever they commission us for we [DN 13 Absolutely] always do a lot more

District nurse 13 we're already over by 10% or something [DNs Yeah] they're always trying to renegotiate but

Interviewer So that's important to be seen to meet more than meet your contract

District nurse 8 Yeah

Interviewer Sure presumably that's not so difficult to do [laughs]

District nurse 13 No [All laughing]

District nurse 9 No that's the easy bit [laughs]

Interviewer So erm I earlier when you were talking about the service or when you mentioned that there might be integration with social services [are you all right there?

Jo Skinner 8/5/2019 17:41
Comment [78]: DN exercise control over RIO outcome recording
District nurse 10 I won't allow it [meaning allowing admin to outcome her RIO] (Q8)
District nurse 12 I won't allow them to outcome my RIO (Q8)

Jo Skinner 8/5/2019 17:41
Comment [79]: Data available to DN not useful
District nurse 13 You can ask for it but it's not going to be a true reflection because admin will outcome it …we do get lists of the numbers of contacts … but that's about all… (Q8)

Jo Skinner 8/5/2019 17:41
Comment [80]: Caseload analysis RIO
District nurse 9 yeah well when it [RIO] was introduced we were going to be able to go on and make caseload analysis…and see how many diabetics…how many Pick lines you've done… (Q8)

Jo Skinner 8/5/2019 17:41
Comment [81]: RIO just bums on seats
District nurse 9 …we were going to be able to …make caseload analysis and particularly for those who have DN students they can go in and see how many diabetics …how many Pick lines…but actually it's not about that it's literally just about bums on seats how many you've seen (Q8)

Jo Skinner 8/5/2019 17:41
Comment [82]: RIO for monitoring contract usage
District nurse 13 …our district nurses services [have] been commissioned to see x number of contacts per year we've done this many can we have some more money off the commissioner (Q8)

Jo Skinner 8/5/2019 17:41
Comment [83]: Do more than commissioned
District nurse 8 …we always do too many don't we whatever they commission us for we always do a lot more (Q8)

District nurse 13 we're already over by 10% or something they're always trying to renegotiate (Q8)

laughs] and so obviously you work closely with GPs, social services who else do you work with and then how is the integration thing going to work?

District nurse 9 We've integrated with therapists for a year? [Others considering] longer than a year

Interviewer So that's OTs, physios, is that?

District nurses Yes

District nurse 9 So that was a big [said with emphasis] change cos they came into our room

Interviewer oh inaud

District nurse 13 there was certain desk clusters

District nurse 9 yes we don't have that at y [names other clinic]

District nurse 13 because the idea of us obviously co-located but we don't have the actual infrastructure so it's only 2 clinics that actually have the therapists integrated at the moment

Interviewer mm

District nurse 13 and it will only be those 2 that will have these social workers integrated with them at first so although we're in integrated teams but we're not actually integrated [laughing]

District nurse 12 Tis really disappointing

District nurse 9 it is

District nurse 12 Cos like this morning I asked someone for um like a rail to help her get out of bed and they said to me 'Oh yeah like quickly do the SPA, print it off and then we'll get to her this morning' [Interviewer is that inaud] I'm like you don't' have that you would have had to waited for that to go SPA [District nurse 13 what six weeks?] and then I don't know

District nurse 13 I even don't get access to those services though

Jo Skinner 8/5/2019 17:41
Comment [84]: Integrated services
District nurse 9 We've integrated with therapists [OTs, physios] for...longer than a year so that was a big [said with emphasis] change cos they came into our room (Q9)

Jo Skinner 8/5/2019 17:41
Comment [85]: Infrastructure limiting integration
District nurse 13 ...the idea of [being] co-located but we don't have the actual infrastructure so it's only 2 clinics that actually have the therapists integrated at the moment and it will only be those 2 that will have these social workers integrated with them at first so although we're in integrated teams but we're not actually integrated (Q9)

Jo Skinner 8/5/2019 17:41
Comment [86]: Integrated teams but not integrated
District nurse 13 ...the idea of [being] co-located but we don't have the actual infrastructure ...so although we're in integrated teams but we're not actually integrated (Q9)

Jo Skinner 8/5/2019 17:41
Comment [87]: Integration speeding up referrals
District nurse 12 ...this morning I asked someone for a rail to help her get out of bed and they [OT] said to me 'Oh yeah like quickly do the SPA, print it off and then we'll get to her this morning' ...you would have had to waited for that to go SPA [could take weeks] (Q9)

District nurse 12 Oh do you not?

District nurse 13 No with OT and physio it's like not being funny they've got to be pretty bad to think Oh I'll get OT or physio there because I don't really understand what their role is

District nurse 12 and I needed another Zimmer frame for someone I went over there and she said oh you can take this one so she got a new Zimmer frame today one of the girls'll take it in

District nurse 13 Yeah so there's a massive advantage but because we've never [inaud interjection] I've never experienced that

District nurse 9 being all on one site I can see a difference a real big difference

District nurse Yeah

District nurse 9 there is no therapy back up at all where we are

District nurse 12 And just things like that time I needed to get a dying man in the bed and T one of the physios went with her and like assisted her to get the patient in the bed and they will help with things like that

District nurse 9 This also goes back to with TVNs and diabetes being here you guys will nip round the corridor to see diabetes [DN 12 oh definitely] we don't have that even when the continence nurse is in on a Thursday you can nip in and say ooh can I just have? but we don't have that

District nurses 13 We're still working very isolated

District nurse 12 that's so true yesterday we took a picture of a wound so we thought she might have pemphigoid and took it round there showed to the tissue viability nurse just to get her opinion then and there [DN 9 which we] rather having to go though a process and then wait 2 weeks for an appointment whereas she said she doesn't think it is try she thinks it might be colonised try a silver dressing if not come back to me so

Interviewer speeds it up a lot

District nurse 10 Even with our matrons we rarely see our matrons do we?

District nurse 9 Very rarely

52

Jo Skinner 8/5/2019 17:41
Comment [88]: Lack of integration and clarity about roles of AHPs
District nurse 13 I don't get access to …OT and physio it's like…they've got to be pretty bad to think oh I'll get OT or physio there because I don't really understand what their role is (Q9)

Jo Skinner 8/5/2019 17:41
Comment [89]: Advantage of co-location
District nurse 9 being all on one site I can see…a real big difference [DNs and therapists] (Q9)

Jo Skinner 8/5/2019 17:41
Comment [90]: Team work
District nurse 12 …like that time I needed to get a dying man in the bed and T one of the physios went with her and assisted her…and they will help with things like that (Q9)

Jo Skinner 8/5/2019 17:41
Comment [91]: Nip in – easy access to specialists
District nurse 9 …with TVNs and diabetes being here you guys will nip round the corridor to see diabetes we don't have that even when the continence nurse is in on a Thursday you can nip in …but we don't have that (Q9)

Jo Skinner 8/5/2019 17:41
Comment [92]: Working in isolation
District nurses 13 We're still working very isolated (Q9)

Jo Skinner 8/5/2019 17:41
Comment [93]: Quicker higher quality service – co-location
District nurse 12 …yesterday we took a picture of a wound…might have pemphigoid …showed to the tissue viability nurse just to get her opinion then and there rather having to go though a process and then wait 2 weeks for an appointment… (Q9)

Jo Skinner 8/5/2019 17:41
Comment [94]: Community matrons rarely seen
District nurse 10 …we rarely see our matrons (Q9)

District nurse 12 no

District nurse 10 So we're are just we're still working as district nursing teams

Interviewer And is that still primarily because of the physical [DNs yeah] infrastructure

District nurse 10 yes

District nurse 12 it is, this building's purpose built isn't it it's large, there's rooms whereas X clinic it's tiny and

District nurse 10 it's an old house

District nurse 9 And even in y as well you could have more people in your district nursing room couldn't you easily

District nurse 12 oh loads yeah

District nurse 9 There's a lot of space

District nurse 12 It's a big room isn't it?

District nurse 9 you could easily have social services without

District nurse 12 It's the biggest out of all yeah

District nurse 9 yeah

Interviewer Er so you were saying that you've got continence nurses they're not specialist district nurses or district nurses with special interest they are purely so then you don't do continence assessments?

District nurses oh loads yes we do

Interviewer Ok [all laughing] ok nice try, Jo

District nurse 9 They see patients in nursing homes and residential homes

Interviewer They do [continence nurses] did you say?

Jo Skinner 8/5/2019 17:41
Comment [95]: Working in DN teams
District nurse 10 ...we're still working as district nursing teams (Q9)

Jo Skinner 8/5/2019 17:41
Comment [96]: Continence nurses visit residential home
District nurse 9 They [continence nurses] see patients in nursing homes and residential homes (Q9)

District nurse 9 like pads or products for those

District nurse 10 and they will see people who they can cure the incontinence

District nurse 8 people who are like complex you know that are going to have sort of studies what do you call it [DN 10 [prompting] urodynamics] urodynamics and all that sort of thing [DN 13 laughter]

District nurse 9 but if you're the district nurse and you want somebody bladder scanned then you have to make the visit with the specialist nurse they won't visit patients on their own

Interviewer oh I see

District nurse 9 so really

Interviewer What's the reason for that then?

District nurse 9 So really I can't be bothered so I just don't

District nurse 13 I've no idea

District nurse 12 With most of the specialist nurses a lot of them will not go on their own

District nurse 9 No Diabetes will, the TVNs won't

District nurse 12 TVNs won't I find that vey odd

Interviewer mm ok

District nurse 8 Respiratory and heart failure go on their own

District nurse 12 yeah

Interviewer palliative care presumably do, do they

District nurse 8 Er that's with B [names hospice] really we do most of the care and daily visits they're just like specialist input

District nurse 10 yeah

Jo Skinner 8/5/2019 17:41
Comment [97]: Incontinence provision
District nurse 9 like pads or products [provided by continence nurses] (Q9)
District nurse 10 and they [continence nurses] will see people who they can cure the incontinence (Q9)
District nurse 8 [continence nurses see] people who are like complex you know that are going to have …urodynamics (Q9)

Jo Skinner 8/5/2019 17:41
Comment [98]: Specialist nurses won't visit alone
District nurse 9 but if you're the district nurse and you want somebody bladder scanned then you have to make the visit with the specialist nurse they won't visit patients on their own Diabetes will the TVNs won't (Q9)
District nurse 12 With most of the specialist nurses a lot of them will not go on their own (Q9)

Jo Skinner 8/5/2019 17:41
Comment [99]: Some specialists visit alone
District nurse 8 Respiratory and heart failure go on their own [to patients' homes] (Q9)

Jo Skinner 8/5/2019 17:41
Comment [100]: DNs do palliative care
District nurse 8 …really we do most of the [palliative] care and daily visits they're just like specialist input (Q9)

Interviewer ok thank you for that

District nurse 12 a lot of the time they want to meet you don't they

District nurse 9 yeah

District nurse 10 or they want to have feedback,

District nurse 13 or just an update [slightly sarcastic]

Interviewer So I'm going to move on and talk about access a bit more specifically now em so how to patients get access to the district nursing services? You said there's a central number

District nurse 10 There's a variety of ways [Interviewer uhun] really um often it will be through the GP

District nurse 13 via SPA still SPA

District nurse 12 Yeah everything has to go SPA

Interviewer SPA?

District nurses [said to together] single point of access

Interviewer uhun yes sorry

District nurse 9 that will open up its actually sets up like an elect electrical electronic [laughter] [Interviewer that's later] electronical record and then that's it then

District nurse 12 and then it opens a referral for us to be able to go onto RIO and outcome visits because otherwise if people sometimes who sort of self refer

District nurse 9 and self refer

District nurse 12 but sometimes they'll just ring up the number and you go to RIO haven't got a proper er referral

District nurse 10 or the GP will fill out this form

District nurse 12 xx

Jo Skinner 8/5/2019 17:41
Comment [101]: Ways to access DN
District nurse 10 There's a variety of ways [to gain access to DN] often it will be through the GP the GP will fill out this form the patient can ring us (Q11)

District nurse 12 everything has to go SPA [single point of access] and then it opens a referral for us to be able to go onto RIO and outcome visits because otherwise if people sometimes who sort of self refer (Q11)

Jo Skinner 8/5/2019 17:41
Comment [102]: Self referral not proper referral
District nurse 12 everything has to go SPA [single point of access] and then it opens a referral for us to be able to go onto RIO and outcome visits because otherwise if people sometimes who sort of self refer but sometimes they'll just ring up the number and you go to RIO haven't got a proper referral (Q11)

Jo Skinner 8/5/2019 17:41
Comment [103]: Need proper referral
District nurse 12 ...they'll [patients] just ring up the number and you go to RIO haven't got a proper referral (Q11)

Interviewer there's a form you actually fill out?

District nurse 10 the patient can ring us

District nurses Yeah

District nurse 12 or sometimes do you know what sometimes I just create a referral [Others yeah]

Interviewer You just what sorry

District nurse 12 create a referral, if you can get the patients name up but sometimes if they've not ever been known to us we can't even find their information so then it definitely has to be faxed

Interviewer Just walk me through it so let's say I'm a patient and I want to refer myself I get the number how do I get that number?

District nurse 8 It's on the X [names Trust] website um so if you look at community services in x [mentions area] or something [Interviewer Right] um the liaison numbers do come up

District nurse 13 or if they do ring the clinic we do give them the single point of access number

District nurse 8 yeah

District nurse 13 inaud

Interviewer OK so they have to either find it on the website or have to know which clinic is relevant

District nurse 10 Yep

District nurse 12 or the GP speak to the GP you know cos most people you know that would be the first point of call and then they would say right the majority of the time the GP will then just do a referral to us contacted

District nurse 8 I mean I think we are quite flexible in Z [names area] and a few weekends ago some one called whose next door's neighbour's friend had given him our

Jo Skinner 8/5/2019 17:41
Comment [104]: DN create a referral
District nurse 12 ...sometimes I just create a referral... (Q11)

Jo Skinner 8/5/2019 17:41
Comment [105]: Known referrals
District nurse 12 ...sometimes I just create a referral...if you can get the patient's name up but sometimes if they've not ever been known to us we can't even find their information so then it definitely has to be faxed (Q11)

Jo Skinner 8/5/2019 17:41
Comment [106]: Finding DN number to refer
District nurse 8 It's on the X [names Trust] website so if you look at community services in x [mentions area] or something [um the liaison numbers do come up (Q11)
District nurse 13 if they do ring the clinic we do give them the single point of access number (Q11)

Jo Skinner 8/5/2019 17:41
Comment [107]: GP refers to DN
District nurse 12 ...speak to the GP...most people you know that would be the first point of call and then they would say right the majority of the time the GP will then just do a referral to us... (Q11)

number [Interviewer Right] cos he'd been sent home with a drain and it had all gone wrong and so we did go in it was like a Saturday and I think I don't want to send him all the way back up to L so we are quite you know he had no real referral well he didn't have a referral we got it all sorted out on Monday so we could back date um er our visits so it's not if like if someone rang up and you say oh well

District nurse inaud

District nurse 8 We would always just try and facilitate

Interviewer I'm just trying to understand how people can get to that point

District nurse 13 Yeah

District nurse 8 well he had our number from his next door neighbour's friend or something [laughter]

Interviewer So that's interesting to know how he got the number

District nurse 8 ok

District nurse 13 [laughing] it was written on the bus shelter [all laughing]

District nurse 10 I have to say that hasn't always been my experience when I've tried er to refer patients on to other members of our district nurses

District nurse 12 Really?

District nurse 10 Yep

District nurse inaud

Interviewers Is that going through the central number you mean [DN 10 Mmm] or contacting the health centre directly

District nurse 10 They would want this single point of access completed er [DN 12 before] before they made a visit

Interviewer Before Ok that's interesting

All talking inaud

Jo Skinner 8/5/2019 17:41
Comment [108]: Accepting self referral
District nurse 8 ...we are quite flexible in [names area] and a few weekends ago someone called whose next door neighbour's friend had given him our number he'd been sent home with a drain and it had all gone wrong and so we did go in it was like a Saturday ...he had no real referral ...we got it all sorted out on Monday so we could back date our visits... (Q11)

Jo Skinner 8/5/2019 17:41
Comment [109]: DN number out there
District nurse 8 ...someone called whose next door neighbour's friend had given him our number cos he'd been sent home with a drain and it had all gone wrong and so we did go ... (Q11)

Jo Skinner 8/5/2019 17:41
Comment [110]: Flexible and responsive to needs
District nurse 8 ...someone called whose next door neighbour's friend had given him our number cos he'd been sent home with a drain and it had all gone wrong and so we did go in it was like a Saturday ...I don't want to send him all the way back up to [hospital] ... so it's not if like if someone rang up and you say oh well (Q11)

Jo Skinner 8/5/2019 17:41
Comment [111]: Adjusting records retrospectively
District nurse 8 ... it had all gone wrong and so we did go in it was a Saturday and ...you know he had no real referral...we got it all sorted out on Monday so we could back date our visits... (Q11)

Jo Skinner 8/5/2019 17:41
Comment [112]: DN always try to help
District nurse 8 I don't want to send him all the way back up to [hospital] ...he had no real referral... so it's not if like if someone rang up and you say oh well we would always just try and facilitate (Q11)

Jo Skinner 8/5/2019 17:41
Comment [113]: DN referrals difficult to other DN
District nurse 10 I have to say that hasn't always been my experience when I've tried to refer patients on to other members of our district nurses they would want this single point of access completed before they made a visit (Q11)

Interviewer so the information that's on the website for example is that pretty up to date and user friendly would you say or?

District nurse 13 I don't think it's too bad the X [names Trust] website actually [Others No [agreeing]]

District nurse* It was done last year

Interviewer That's recent it's been recently changed

District nurse 8 yeah and there is a thing like community services you click on it it will give you a whole list of services that are available so

Interviewer so do your services come under district nursing services or community nursing services what do they how would you find them?

District nurse 13 I'm sure it comes under the integrated care

Interviewer OK

District nurse 9 and that may be an issue

District nurse 10 yeah

District nurse 13 I'm sure it comes under the integrated care

District nurse 12 whereas if you say district nurse

District nurse 9 yeah and that's it now isn't it

District nurse 13 I'm sure it comes under integrated care cos that's our new label

District nurse 9 We shouldn't be called district nurses anymore

District nurse [unsure who] No

District nurse 12 Sometimes as well at the weekends get calls from the out of hours doctors don't you asking to visit patients [DN 9 Yeah] another way and also

District nurse 9

Jo Skinner 8/5/2019 17:41
Comment [114]: Website as source of DN contacts
District nurse 13 I don't think it's too bad the [names Trust] website... (Q11)
District nurse 8 ...there is a thing community services you click on it it will give you a whole list of services that are available (Q11)
District nurse 13 I'm sure it comes under the integrated care (Q11)

Jo Skinner 8/5/2019 17:41
Comment [115]: DN listed under Integrated Care
District nurse 13 I'm sure it [district nursing] comes under the integrated care [on website] (Q11)

Jo Skinner 8/5/2019 17:41
Comment [116]: Uncertainty how listed on website
District nurse 13 I'm sure it [district nursing] comes under the integrated care [on website] I'm sure it comes under integrated care cos that's our new label (Q11)

Jo Skinner 8/5/2019 17:41
Comment [117]: DN name understood
District nurse 12 whereas if you say district nurse [name understood] (Q11)

Jo Skinner 8/5/2019 17:41
Comment [118]: Should not be called DN
District nurse 9 We shouldn't be called district nurses anymore [post development o new integrated services] (Q11)

Jo Skinner 8/5/2019 17:41
Comment [119]: OOH referrals
District nurse 12 Sometimes...at the weekends [DN] get calls from the out of hours doctors asking to visit patients (Q11)

District nurse 12 call sometimes yep and also from CTT the community treatment team they might see a patient who's fallen they'll go assess everything and then if they've sustained a wound or something then refer it onto us

Interviewer mm

District nurse 12 take over the care

Interviewer mm so if somebody wants to find out about the service say district nursing services community nursing integrated care [clears throat] however er who could they talk to to if you know who is knowledgeable who could actually talk to to find out about the service

District nurse 9 it would be the GP really wouldn't it [others agreeing] but if I think if you look at a local area most people know their clinic [DN 12 Yeah]

Interviewer Do you

District nurse 10 Well

Interviewer Do they? I'm interested to know do they?

[All talking inaud]

District nurse 12 I think they do here [others inaud] but only because we're [DN 10 this building] and we're with the doctors' surgeries but maybe elsewhere not

District nurse 10 cos we get a lot of people asking where we are when we say it's that old house and people say oh I didn't realise it was even a clinic [DN 12 Yeah] inaud

Talking together

District nurse 12 ours will say to us [DN 10 yes] oh you're with the doctors so yeah yeah we're upstairs and then they're kind of like oh yeah but the at the health centre we've got 4, 5 GPs downstairs [DN 9 yeah] um

Interviewer Is there a notice downstairs saying district nursing?

District nurse 8 No PCT isn't it PCT still?

Jo Skinner 8/5/2019 17:41
Comment [120]: Referrals from CCT
District nurse 12 ...[referrals] also from CTT the community treatment team they might see a patient whose fallen they'll go assess everything and then if they've sustained a wound or something then refer it onto us

Jo Skinner 8/5/2019 17:41
Comment [121]: DN provide ongoing care
District nurse 12 ...the community treatment team they might see a patient whose fallen they'll go assess everything and ...then refer it onto us [we] take over the care (Q11)

Jo Skinner 8/5/2019 17:41
Comment [122]: GPs knowledgeable about service
District nurse 9 it would be the GP really....if you look at a local area most people know their clinic [where DNs located] (Q12)

Jo Skinner 8/5/2019 17:41
Comment [123]: People know their local clinic where DNs located
District nurse 9 ....if you look at a local area most people know their clinic [where DNs located] (Q12)

Jo Skinner 8/5/2019 17:41
Comment [124]: Know about DN as co-located with GPs
District nurse 12 I think they do here [health centre] but only because...we're with the doctors' surgeries but maybe [not] elsewhere (Q12)

Jo Skinner 8/5/2019 17:41
Comment [125]: DN service invisible
District nurse 10 we get a lot of people asking where we are when we say it's that old house and people say oh I didn't realise it was even a clinic (Q12)

Jo Skinner 8/5/2019 17:41
Comment [126]: Understanding of DN location in relationship to GP services
District nurse 12 ours will say to us 'oh you're with the doctors' so yeah we're upstairs and then they're kind of like 'oh yeah' but at the health centre we've got 4, 5 GPs downstairs (Q12)

End of extract

Appendix 11

Extract of Framework document

Theme 1: Control of Access

	Invisibility of service	***External control***	***Internal control***	***Role of the District Nurse***
Carer 1	***Unsure who referred to DN*** *Carer 1 GP sent them I suppose (Q2)* ***No information about DN service*** *Carer 1 no they just turned up when they were asked to (Q2)* ***Unclear what service is provided by whom*** ***Consent form*** *Carer 1 Patient 'had to sign a consent form' (Q4)* *Carer 1 consent form requirement 'I can't understand why' (Q4)* ***Services unexplained*** *Carer 1 hadn't asked for them (Q4/5)* ***Hospital referred to services*** *Carer 1 Hospital said would send in services (Q4)* ***No information about the services received*** *Carer 1 No information about the service received, written or otherwise (Q 14)*	***Did not seek DN service*** *Carer 1 Didn't ask for service (Q2)* ***Confusion who visited from hospital and why*** *Carer 1 Hospital sent nurses from another hospital my husband kicked them out (Q4)* ***GP referred to DN*** *Carer 1 done through GP (Q6)*	***Promised care not delivered*** *Carer 1 younger ones would come and say they'd do this once a week and then of course didn't (Q23)* ***Variability of care depending on age/experience*** *Carer 1 two older ones were having multiple problems with my husband's catheter and both…assured me that nothing could be done about it and I believed them unfortunately (Q 23)* *Carer 1 fortunately my husband found the solution and ripped out the catheter got rid of it marvellous all our problems disappeared…why does it take a frail old man with dementia to solve a problem which nurses can't solve? (Q23)* *Carer 1 We didn't need them anymore (Q23)*	***Qualifications of DN*** *Carer 1 don't know…presume they're qualified (Q 7)* ***Recording care*** *Carer 1 They had the…red book…the carers and nurses wrote down.. (Q 14)*

Carer 2	***Unsure how got DN*** *Carer 2 maybe the hospital (Q2)* ***Potential other source of information about DN service*** *Carer 2 I would maybe ring NHS Direct – (Q 16)* ***Improvement to visibility and access DN service*** *Carer 2 if you could make small leaflets what is district nurse and put them in surgeries, libraries, carers centre for us to learn from this, maybe because I'm a foreigner and I don't know how it works here but I'm afraid that many other…carers don't know either er what district nurses are for so it would be very helpful if you have budget to do these leaflets) and put them you know in proper places I would find them Q23 Internet?* *Carer 2 on internet that we can have a website or something how can I find it on internet? (Q23)* *Carer 2 How? If I want to find it today? What should I do? I'll write it down (Q23)*	***Did not seek DN service*** *Carer 2 Didn't ask for service (Q2)* ***GP referred to DN*** *Carer 2 rang this (stoma) nurse and could make an appointment sometimes she could come to our house (Q6)* ***Advice to get a DN - GP*** *Carer 2 Difficult making requests to GP if spouse has different GP (Q 21)* *Carer 2 His GP refused to talk about my husband's health telling me about confidentiality…I think it's totally wrong I'm a carer, I'm a wife…husband has signs of dementia (Q 21)*		***Happy DN visiting*** *Carer 2 DN first visit – I was happy someone was coming to help (Q4)* ***DN seen as lifesaver*** *Carer 2 without her my husband might be dead (Q4)* ***Qualifications of DN*** *Carer 2 Didn't ask about qualifications Q7* *Carer 2 I watch her everyday in my opinion she was highly qualified (Q 7)* ***Recording care*** *Carer 2 She made notes everyday about condition of my husband and what's she's done (Q 14)* ***Role of DN unclear*** *Carer 2 I still don't know when in what cases I should contact district nurse…I don't know how and when the district nurse can be helpful that I wouldn't ring her when I shouldn't expect her help I mean in wrong situation I wouldn't like to ring her when she shouldn't help and I don't have this knowledge when I can ring her and I shouldn't ring her (Q23)*
Carer 3	***Referral to DN via care package***	***Staff high workload***	***Bedbound*** *Carer 3*	***Folder left in home***

	Carer 3 *..part of my care plan…funded by continuing care in the NHS or rather my husband is, part of his care plan Q2* ***Unaware referred to DN*** *Carer 3 I don't think I saw them for 3 years, so I didn't really know what they were supposed to be doing when I cottoned on to the fact they were supposed to be coming. Q2* ***Understanding of service*** *Carer 3* *I didn't know what they were supposed to be doing...then someone would suddenly pop up and ring the door bell and I wouldn't know what it was for basically they would just come to check his pressure sores that was it Q3* ***No info received about service*** *Carer 3 No nothing Q2* ***Information about service*** *Carer 3 I didn't get anything Q2* ***Did not occur could self refer*** *Carer 3 No Q13* ***No information about service received***	*Carer 3..from what I've heard they're very, very overworked and they have something like 15,16 patients to see a day and the good ones leave, they get disenchanted and fed up Q2* ***Works around DN access using palliative care to refer*** *Carer 3 well I'll tell you what I do now I mean because it's you know towards the end of P's life now I've got a palliative care nurse and I just call her up and when she comes to see him and I just say I need this ok and she emails the district nurses you know I'm lucky in that sense because she'll do it and when she does they take notice Q7* ***Other services handover to DN OOH*** *Carer 3 (Palliative care) They stop work at 5.30 and then you're handed over to the district nurse Q10* ***Ask GP to refer*** *Carer 3 I would have thought if I didn't have anything I would have just gone to the GP and asked them to refer Q13*	*Now he's bedbound and they are supposed to come once a month unless he has a pressure sore and they're supposed to come once a week Q2* ***Not consulted or informed about service*** *Carer 3 I looked at the care plan eventually …something that the care manager put in place I wasn't really..consulted about it…I didn't know what they were supposed to be doing Q2* ***Housebound*** *Carer 3 when my husband was still walking around we might have been out on the days when we were taking him or wheeling him and then they'd come on those days and times Q2* ***Management awful*** *Carer 3 I don't know what the management is like but from what I have experienced it's pretty awful Q2* ***Manager not proactive*** *Carer 3 when my husband had a review meeting...I asked in the past the manager from the district nurse team's come but he just sort of sat there saying nothing and you know not very proactive in my view Q2* ***Good DN*** *Carer 3 finally got a good district nurse that came when he had a review meeting…I asked for this particular nurse to come because he seemed to really have a view and was really interested in his case. Q2*	*Carer 4 I think they left a folder in the house Q2* ***No assessment – task focussed*** *Carer 3 no assessment..they just..came in pressure sores, checked them he's alright off they go Q4* ***Don't rely on DN*** *Carer 3 I wouldn't like to have to rely on the district nurses for anything honestly… you never know who you are going to get Q6* ***Task focus*** *Carer 3 it was very…cut and dried pressures sores ok if I'd known that from the beginning maybe it would have helped Q6* ***Proper first assessment*** *Carer 3 they'd sort of said on the first visit we're gonna come and look at his pressure sores every so often fine and it wasn't till I got that very good district nurse and that was last year sometime who really did a proper assessment Q6* ***Unclear what DN do*** *Carer 3 I think it would have helped if in the very beginning I'd known what they were there for what they were there to do what their remit was what they covered Q6* ***No idea if qualified DN*** *Carer 3 No idea Q7* ***Distinguish between HCA & DN***

	Carer 3 I didn't receive anything… no I didn't get one [leaflet] Q14 ***No information for Carers at GP surgery*** *Carer 3 …I was at my GP surgery this morning and I had a look at the leaflets to see if there was anything for carers which there wasn't and I can't remember there being anything about district nurses it was just like, Do you have diabetes?…you know it was all about diseases there was nothing like Are you a carer? Do you want some help? go to X carers or district nurse services are available ere was nothing like that and they're a good GP they're not a crummy one but I think that probably would be a good port of call to put leaflets in anyway Q15* ***GPs don't signpost to DN*** *Carer 3 [GPs] don't call up and say would you like district nurses none of that so, maybe that's not the role of GPs anymore I don't know but it doesn't seem like there's anybody else particularly Q22*	***Surmise Care manager referred to DN*** *Carer 3 I would have thought that the care manager who funnily enough used to be the team leader for the district nurses before she went to continuing care would have contacted them directly because she was responsible for making sure you know she would have had the contract with the care worker agency and there I would have thought she would have gone to them directly Q12* ***Different levels of input CPN v Continuing care Reluctant monitoring*** *Carer 3 …when he was with the CPN I got more input when you switch to continuing care that all stops. You don't get any social worker or anything its just care manger which as I say is just care package manager she never comes to see P Q15* ***Improvements to community services*** *Carer 3 in theory it's quite a good service… there's definitely room for*	***Giving up – hurdles*** *Carer 3 you give up in the end Q5* ***Staffing the service*** *Carer 3 There's a lot of agency nurses Q6* ***Bounced between services*** *Carer 3 so you call up the district nurses ok no we don't provide them mediquip do, call them no we don't provide them the district nurses (so go on and on for ever like that Q6* ***Known problems with DN service*** *Carer 3 started hearing about these giant mistakes that they were making there was a big sort of meeting and they said they were bringing some one in to trouble shoot the district services…and it did get better for a bit and the it went plonk down Q10* ***Investment in DN services*** *Carer 3 I don't know what the answer is I don't think it's just throwing money at it Q10* ***Staff demoralised*** *Carer 3 everyone gets demoralised very quickly Q10* *Impact of policy change on service* ***Keep them in the community*** *Carer 3 they just…pull the plug on community services and maybe they were shoving everyone into homes and hospitals but now of course the thinking is to keep them in the community but [the DN service] hasn't kept up Q10* ***GP trying to resume service following a complaint***	*Carer 3 I know the district nurse that came yesterday funnily enough is not she's a health care assistant Q7* ***No faith in DN to call as OOH*** *Carer 3 why don't you call the district nurse I had no faith in them now it's possible the night time ones are all professional and you know that they would be good but because I had not good experiences with them in the day time I didn't in the end Q10* ***Don't have much confidence in DN*** *Carer 3 as I don't really have much confidence you're kind of on your own really unless you want them to go to hospital which I don't Q10* ***Don't know about DN service/role*** *Carer 3 …At the beginning I didn't even know what they did, who they did, who they are. Q21*

	Carer in shock at beginning *Carer 3 You know someone has to give you something…I mean one is in shock and you don't know how you're going to manage Q21* ***Carer need information from the start*** *Carer 3 You know someone has to give you something…Q21* ***Carers desperate for service*** *Carer 3 so you don't really come across the services you need until you need them desperately then it's hit or miss Q21*	*improvement and it would be good if it worked basically Q23*	*Carer 4 I heard was the GP was talking to them and they said they won't come back to mine while there's a complaint that's not resolved Q10* ***Staff work loads*** *Carer 3 I found out it's 16 people a day...to see which is too much to give any kind of quality of care Q20*	
Carer 4	*F**inding out about DN service*** *Carer 4 I was told about the district nurse through the Memory clinic and X Carers, a friend recommended [name] Carers Q2* *Carer 4 after we coming in to this path of dementia and carer that name [district nurse] you sort of hear it thrown up Q2* ***Uncertain if information received prior to service*** *Carer 4 I think maybe at some stage…there was some information Q2* *Carer 4 I know I came into this scenario confused Q2*	***Getting help entitled to*** *Carer 4 so she paid National Insurance…so now I'm trying to get help what she's paid for and seems like I'm begging Q5* ***Trying to get help*** *Carer 4 so I confronted the doctor and she said to me the bottom line is the NHS is going to collapse if carers stopped caring tomorrow the only way to look after you Mum properly is to do it yourself and I said to her thank you very much and that's what I'm going to do and thank you for your honesty…you saved me a lot of time…Q6*	***Staffing problems shared*** *Carer 4 they come along and they've got their own problems Q2* *Carer 4 They just come in and say we'll do this like we're doing you a favour mentality. Q2* ***Challenging DN and consequences*** *Carer 4…stop asking…and you know when you challenge them it's a bit, they'll answer you but back at head office you're a bit of a trouble maker Q2* ***Carer wants to cooperate*** *Carer 4 I explained what dementia is and they said ok and then they carried on ringing the house…I explained to them it would make my life easier I'm wiling to work with you if you call and tell me you're running late and it's*	***No idea if qualified DN*** *Carer 4 No idea Q7* ***Good to have someone visit*** *Carer 4 it was good to have someone coming in Q8* ***Proactive care –noticing changes*** *Carer 4 cos they can say she looks a bit pale today let me take her temperature I'm not happy with what I'm seeing Q8*

	A nightmare *Carer 4 it's for me a bit of a nightmare scenario Q2* ***Unclear if information received*** *Carer 4 it's probably sitting on the table somewhere Q14* ***Personal explanation needed of what's available and help to access it rather than a leaflet*** *Carer 4 …talking about leaflets…they know that…we know the leaflet's there but when you take the scenario and how the person is feeling sometimes its easier if they just had somebody who could come along and sit down with you for 10 minutes and say tell me your scenario this is what you need to do ring… these numbers or I can do that for you I'll do it better than you so I know who to call Q15*	***Care to be provided is insufficiently funded*** *Carer 4 …I don't think the money's in the pot and I think they're under a lot of pressure and they're just being used like everybody else… Q12* ***Improvements to community services*** *Carer 4 it would be great if it could be improved because as so many people are staying in the community Q23*	*covered it's fine just tell me…it's not a problem. Q2* ***Effort and time to effect co-operation*** *Carer 4 ...but that went on for about 3 months you know fax and emailing and I had to get it in writing and stuff just for them to ring and say we're running late can you do it or we can't come that took months to sort out Q2* ***Service a hindrance*** *Carer 4 you're really in a nightmare and then someone comes along whose going to help you but actually a hindrance Q4* ***Incorrect care challenged*** *Carer 4 I said to the chemist what's all this twice a day? I thought here we go more headaches cos now this means 2 sets of meds the district nurse said no no no you give the 2 at once I said fine all you got to do is put it in writing and I can go back to tell him cos I'm not a doctor Q5* ***Rationing visits?*** *Carer 4 everything sounds pretty she said she got onto her pharmacist said no no no the chemist's talking rubbish you can have all the tablets in one go which means they only have to make in the morning its still 2 visits cos its two sets of eye drops I think they were trying to get it down to one visit a day anyway* ***Hurdles*** *Carer 4 what they try and do if they go wrong they put all these hurdles to weigh you down*	

			so you have to go through so many people… Q5 ***Overworked*** *Carer 4 I think they're overworked Q5* ***Carers understands unpredictable demand*** *Carer 4 if the woman at no 9's had a heart attack she's not going to get to you on time, the district nurse, I totally understand Q5* ***DNs happy when service delivery problems*** *Carer 4 but it seemed with them…you know I don't know why but there kind of like if it goes smooth they're not happy if there's a problem they're all over the moon about it Q7* ***Impact of poor services*** *Carer 4…by the time…do these things which aren't impossible …then they tell you no no no it's there even though it doesn't work it's there [meaning the dn service] Do you know the reality of it yeah? Q13*	
Carer 5	***Self referral*** *Carer 5 I would have gone for the doctor really and then he might say 'well the district nurse can do that' (Q13)* ***Just make it easier to access DN*** *Carer 5 …but just making easier when initially you do try to get in touch with somebody (Q23)*		***Patient known to DN service*** *Carer 5 I think they were aware of him various services, the doctor aware of the cellulitis can't remember whether and also the flu jab, they used to give him the flu jab if he didn't go off to the surgery he'd have it at home (Q2)* ***Knowing DN*** *Carer 5 ...if I made a call E I think she's called there were a few of them came in er Australian or New Zealand very, very nice and um really helpful (Q20)* ***Confusion over supplies***	***DN managing multiple conditions – acute and LTC*** *Carer 5 2012 he had the stroke in 2013 so it could have been for various things he had cellulitis I think in around 2009 (Q1)* ***DN preventive work flu jabs*** *Carer 5 I think they were aware of him…also the flu jab, they used to give him the flu jab if he didn't go off to the surgery he'd have it at home (Q2)* ***DN providing aftercare***

			Carer 5 another big thing I remember was actually getting the supplies for Dad's ulcers, there was confusion there one of them was saying well that you've got to get that I was told the district nurse was supposed you get that (Laughs) and then they'd arrive and there weren't enough bandages (Int Oh dear) y'know I was thinking well (Q20) ***Get it organised between you*** *Carer 5 Yeah I'm sort of saying well hold on but we need stuff (would care supplies) so between you can somebody get it organised (Q20)*	*Carer 5 he had ulcers on his feet after his stroke…because they had to dress it and do aftercare (Q2)* ***Checking proactive care*** *Carer 5 They'd ring…you and then they come in and they check him for sores like bed sores because he's sitting a lot, he's got a special cushion um…and sometimes he gets an outbreak…(Q6)* ***Helpful advice*** *Carer 5 they have been very helpful…advising a better um cream 'something plus' they advised me...it seems to be keeping away (pressure ulcers) at the moment (Q6)* ***Wonder if qualified*** *Carer 5 …wouldn't know the difference between them we've had a few I was wondering if they were qualified (Q7)* ***Safety monitoring*** *you have to step into the bathroom and…'Oh this is dangerous' y'know he's never tripped on it yet and he's lived here so many years (Q7)* ***Don't know whose senior/ had trainees*** *Carer 5 I wouldn't know if they were senior or what…a couple of them came in with trainees...(Q7)* ***Confusion over DN role*** *I was told the district nurse was supposed you get that and then they'd arrive and there weren't enough bandages (Q20)*

Appendix 12

London District nursing providers and respective local authorities

District nursing provider	London local authority served
Barnet, Enfield and Haringey Mental Health NHS Trust	• Enfield
Bromley Healthcare NHS	• Bromley
Central London Community Healthcare NHS Trust	• Barnet • Hammersmith and Fulham • Harrow • Kensington and Chelsea • Merton • Wandsworth • Westminster
Central and North West London NHS Foundation Trust	• Camden • Hillingdon
Croydon Health Services NHS Trust	• Croydon
East London Foundation Trust	• Tower Hamlets • Newham
Epsom and St Helier NHS Trust (mid Surrey)	• Sutton
Guy's and St Thomas' NHS Foundation Trust	• Lambeth • Southwark
Homerton University Hospital NHS Foundation Trust	• Hackney + City of London
Hounslow and Richmond	• Hounslow • Richmond upon Thames
Lewisham and Greenwich NHS Trust	• Lewisham • Royal Borough of Greenwich
London North West University Health Care NHS Trust	• Brent • Ealing
North East London Foundation Trust	• Barking and Dagenham • Havering • Redbridge • Waltham Forest

Oxleas NHS Foundation Trust	• Bexley
Whittington Health	• Islington • Haringey
Your healthcare Community Interest Company (Social Enterprise)	• Kingston upon Thames

Appendix 13

Dalhousie University websites criteria

6 Criteria for Websites

These six criteria deal with the content of Web sites rather than the graphics or site design. Apply these criteria when you research on the internet.

1. AUTHORITY

Authority reveals that the person, institution or agency responsible for a site has the qualifications and knowledge to do so. Evaluating a web site for authority:

- Authorship: It should be clear who developed the site.
- **Contact information** should be clearly provided: e-mail address, snail mail address, phone number, and fax number.
- Credentials: the author should state qualifications, credentials, or personal background that gives them authority to present information.
- Check to see if the site supported by an organization or a commercial body

2. PURPOSE

The purpose of the information presented in the site should be clear. Some sites are meant to inform, persuade, state an opinion, entertain, or parody something or someone. Evaluating a web site for purpose:

- Does the content support the purpose of the site?
- Is the information geared to a specific audience (students, scholars, general reader)?
- Is the site organized and focused?
- Are the outside links appropriate for the site?
- Does the site evaluate the links?
- Check the domain of the site. The URL may indicate its purpose.

3. COVERAGE

It is difficult to assess the extent of coverage since depth in a site, through the use of links, can be infinite. One author may claim comprehensive coverage of a topic while another may cover just one aspect of a topic. Evaluating a web site for coverage:

- Does the site claim to be selective or comprehensive?
- Are the topics explored in depth?
- Compare the value of the site's information compared to other similar sites.
- Do the links go to outside sites rather than its own?
- Does the site provide information with no relevant outside links?

4. CURRENCY

Currency of the site refers to: 1) how current the information presented is, and 2) how often the site is updated or maintained. It is important to know when a site was created, when it was last updated, and if all of the links are current. Evaluating a web site for currency involves finding the date information was:

- first written
- placed on the web
- last revised

Then ask if:

- Links are up-to-date
- Links provided should be reliable. Dead links or references to sites that have moved are not useful.
- Information provided so trend related that its usefulness is limited to a certain time period?
- the site been under construction for some time?

5. OBJECTIVITY

Objectivity of the site should be clear. Beware of sites that contain bias or do not admit its bias freely. Objective sites present information with a minimum of bias. Evaluating a web site for objectivity:

- Is the information presented with a particular bias?

- Does the information try to sway the audience?

- Does site advertising conflict with the content?

- Is the site trying to explain, inform, persuade, or sell something?

6. ACCURACY

There are few standards to verify the accuracy of information on the web. It is the responsibility of the reader to assess the information presented. Evaluating a web site for accuracy:

- Reliability: Is the author affiliated with a known, respectable institution?

- References: do statistics and other factual information receive proper references as to their origin?

- Does the reading you have already done on the subject make the information seem accurate?

- Is the information comparable to other sites on the same topic?

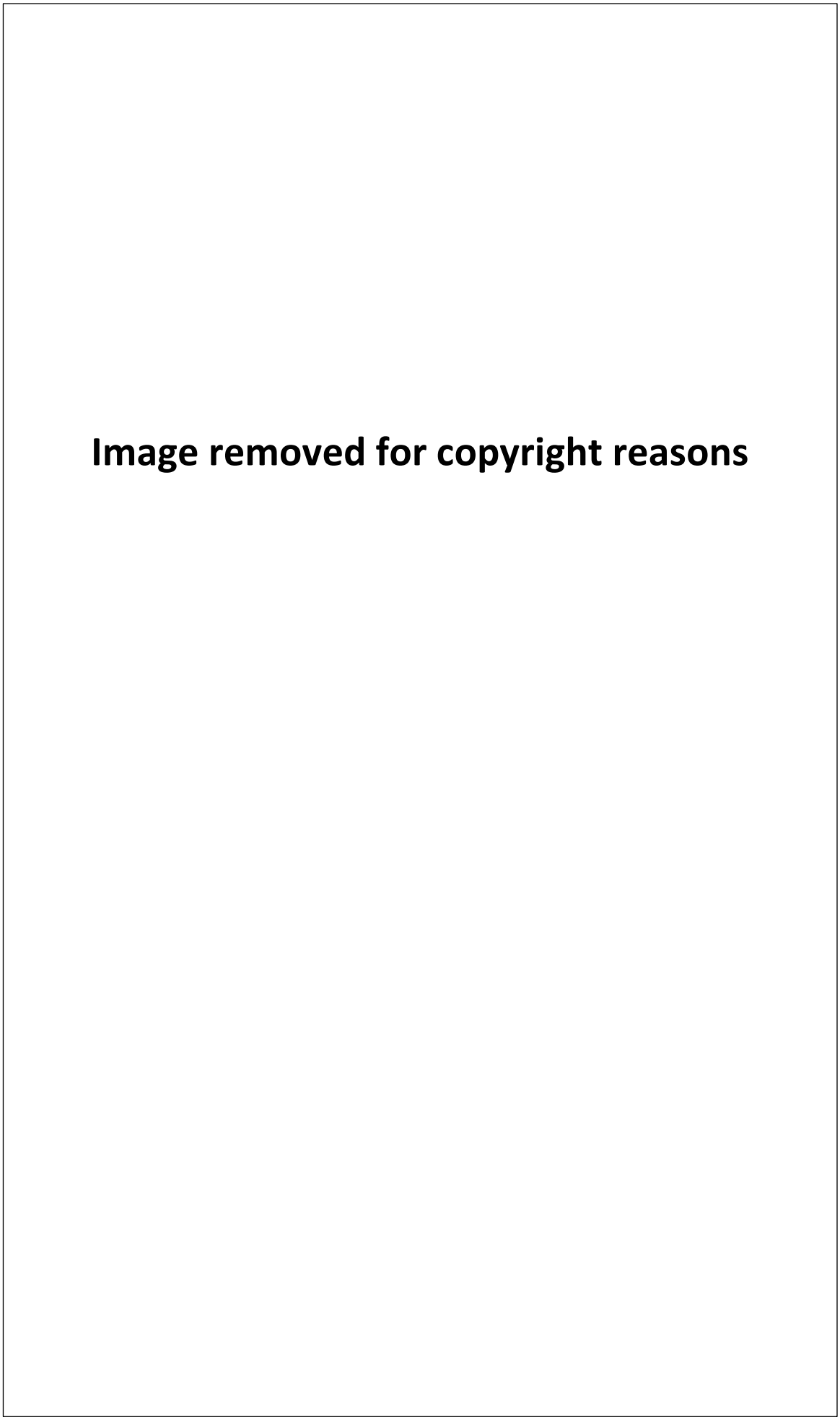
- Does the text follow basic rules of grammar, spelling and composition?

- Is a bibliography or reference list included?

Appendix 14

Screenshots from provider websites

1. Whittington Health ***district nursing main page (subordinate pages follow)***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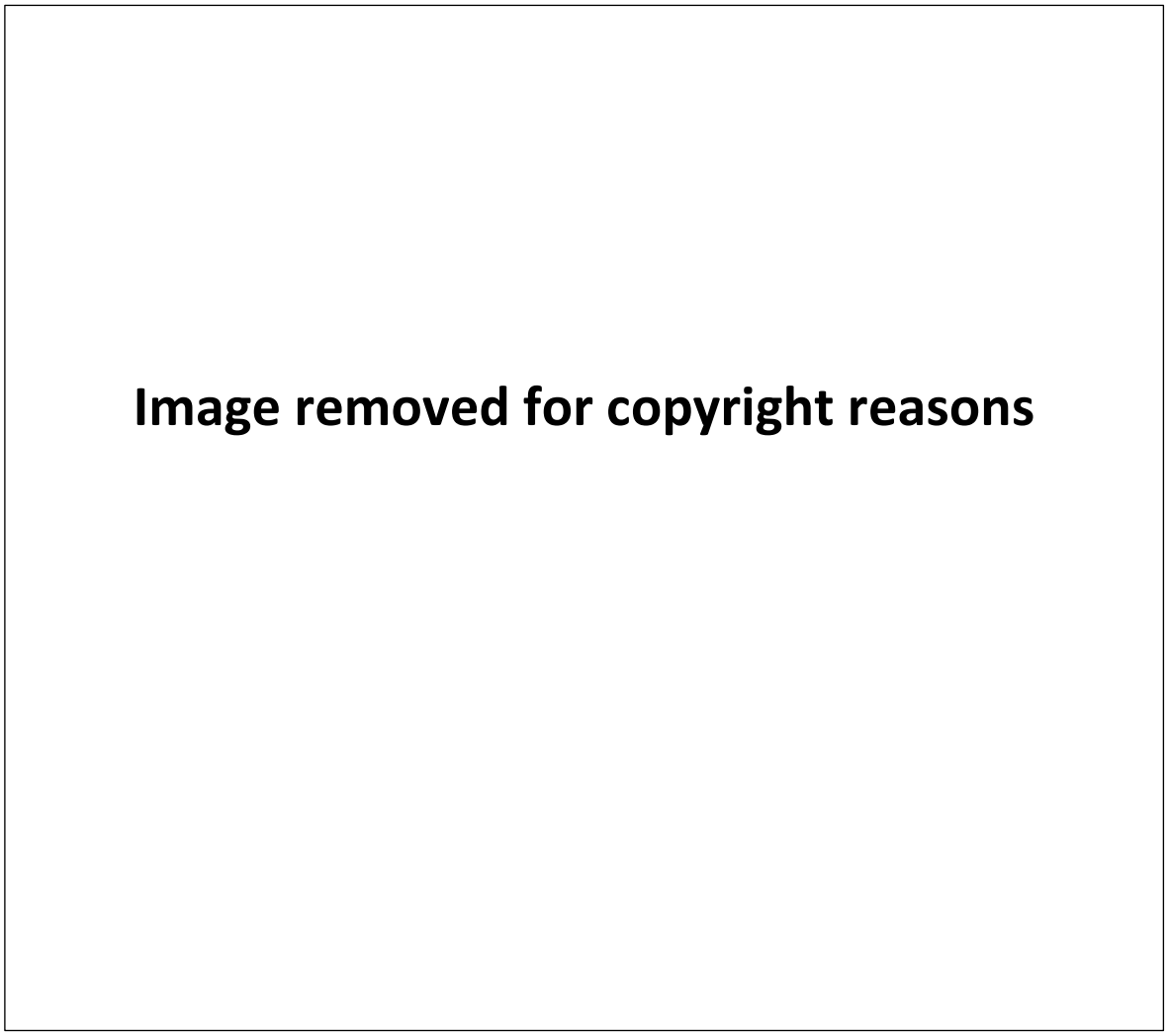
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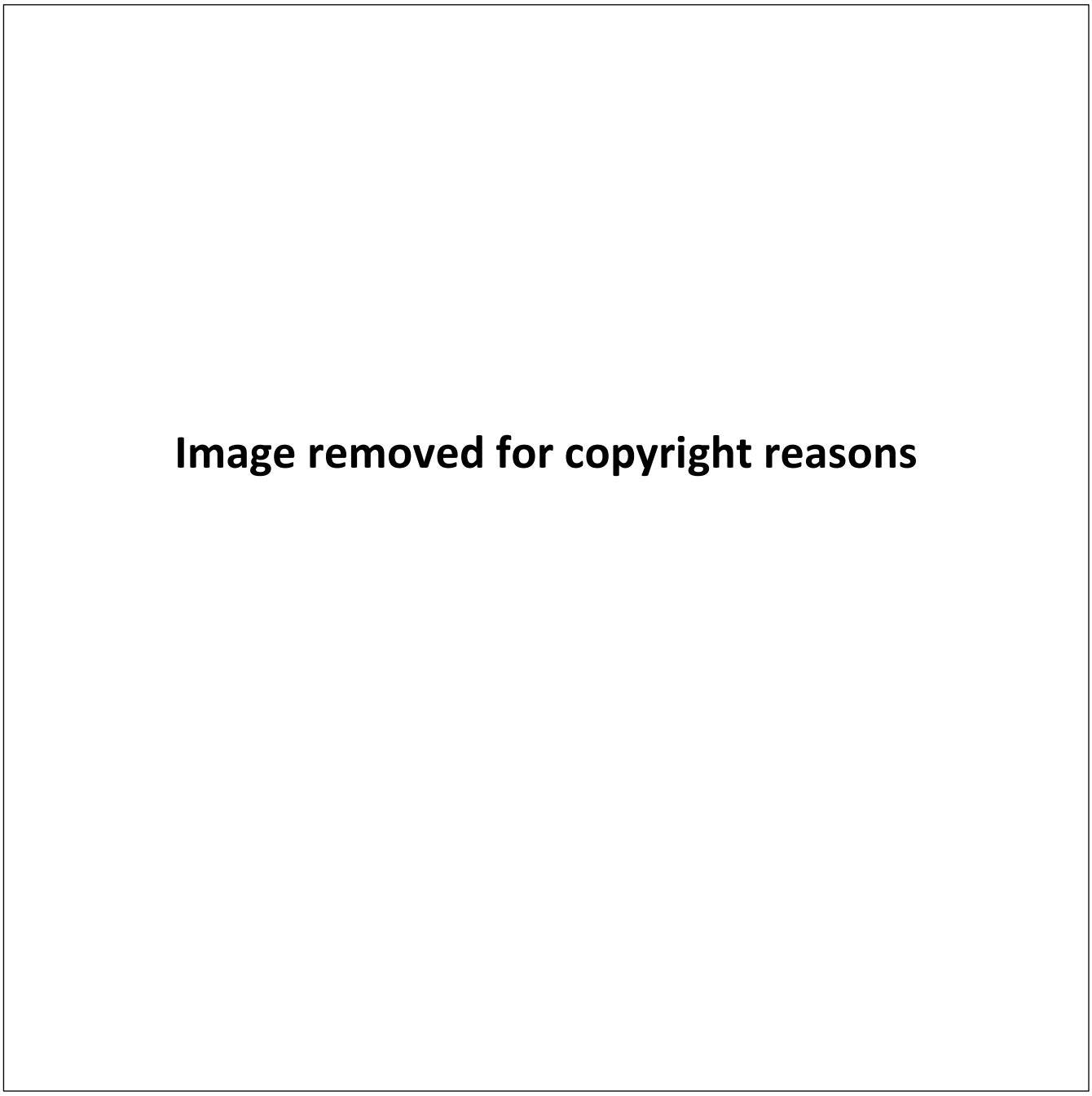
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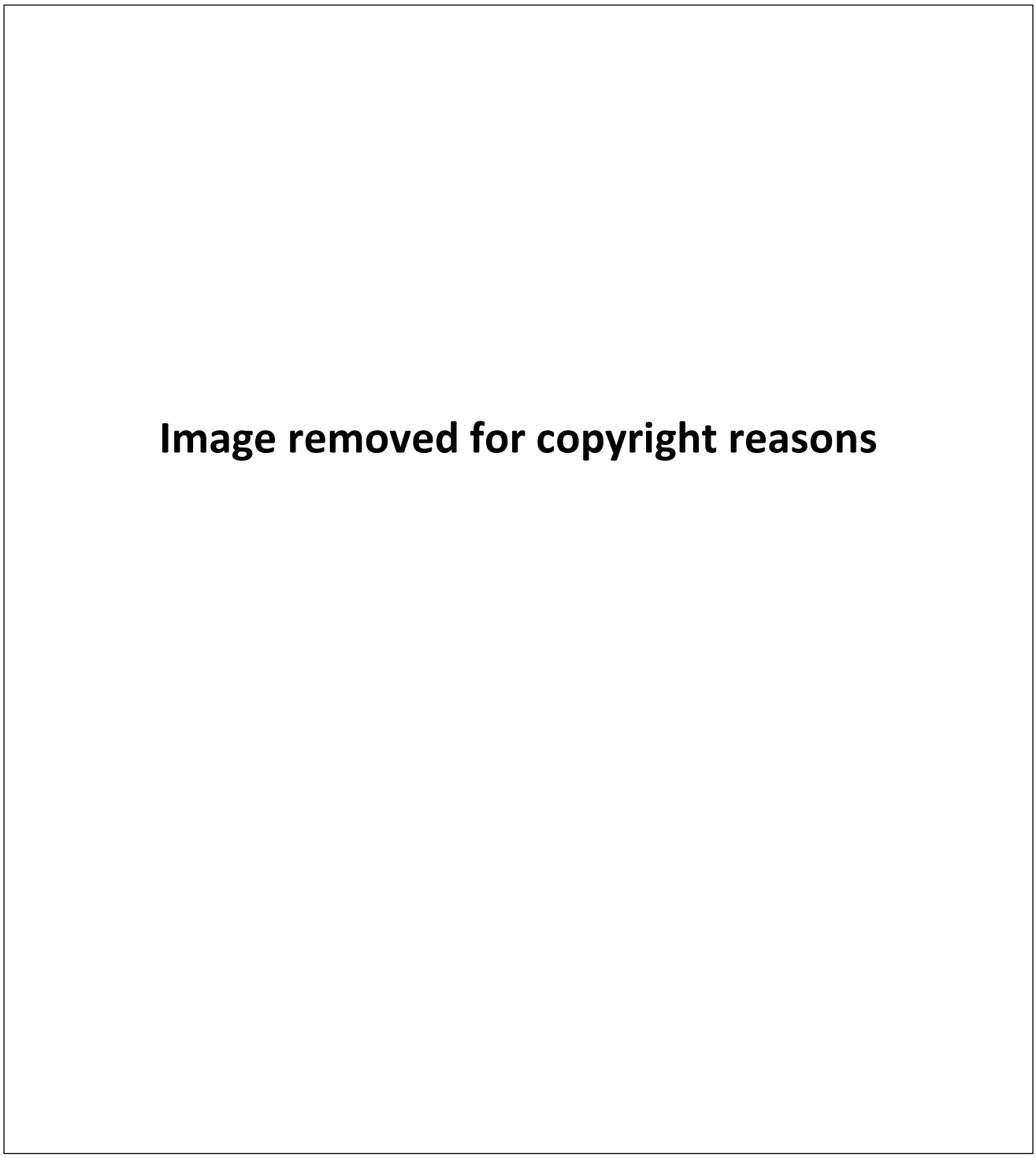
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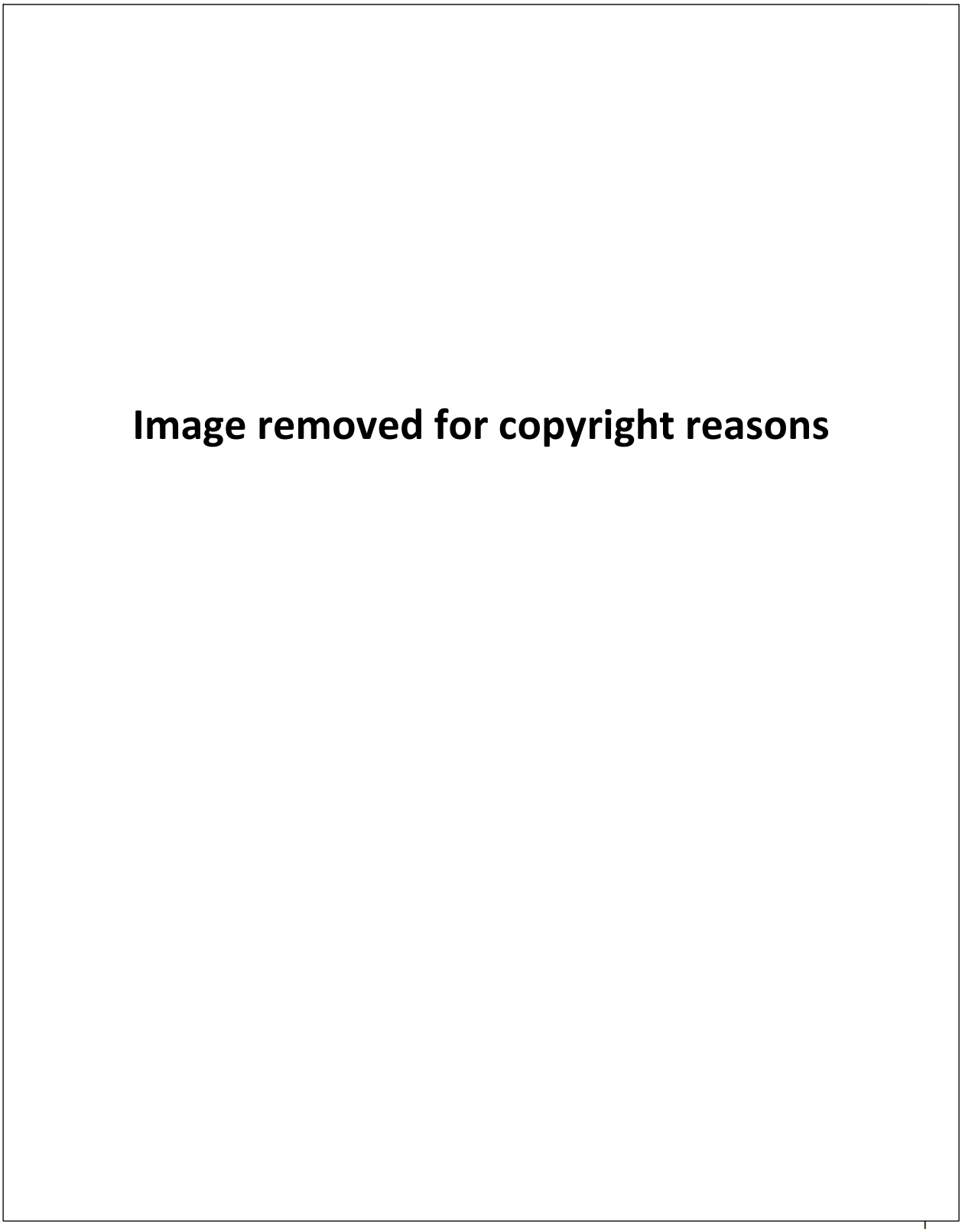
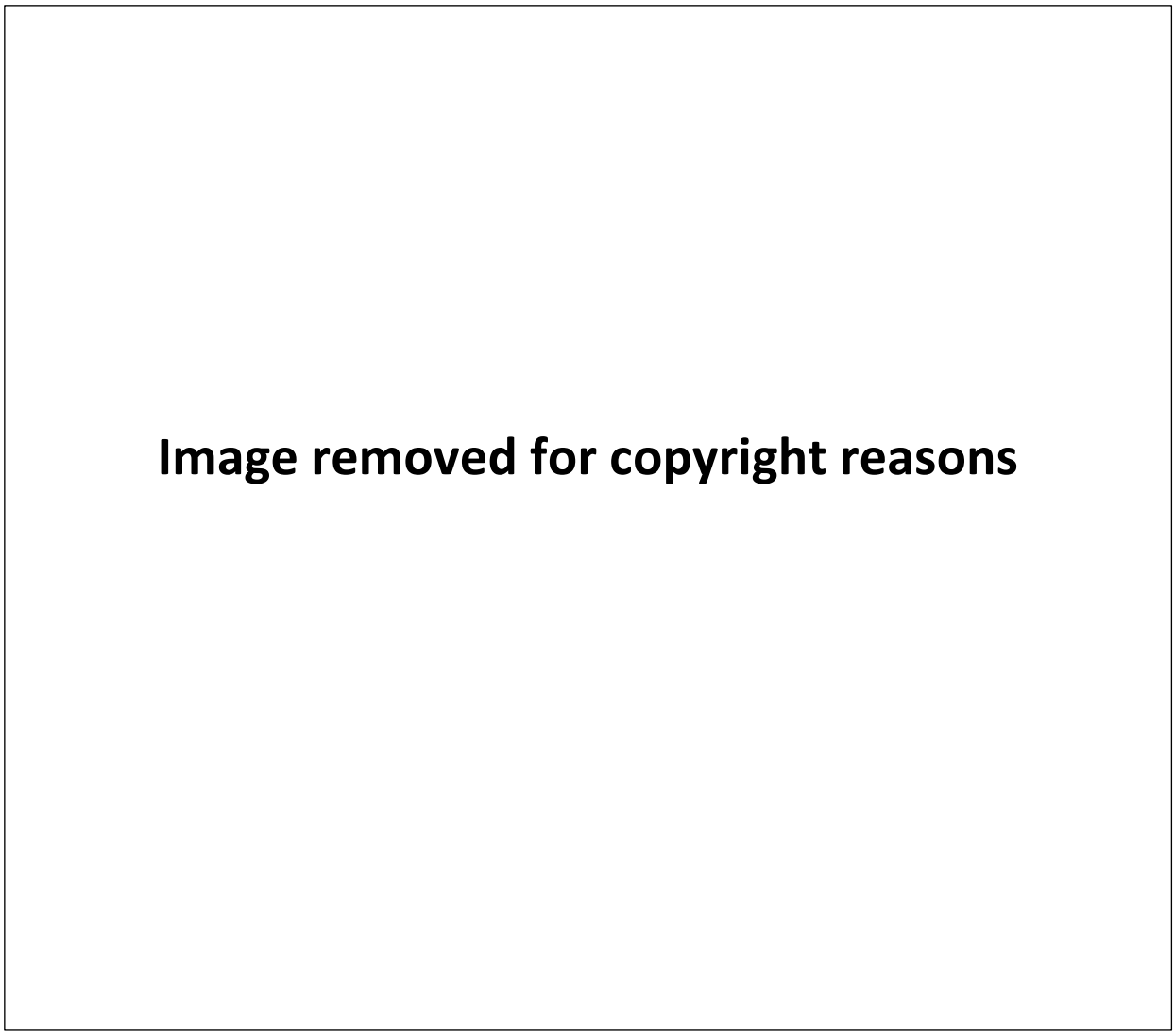
2. NELFT ***District Nursing main page***

There are three pages – this first page is the main district nursing (Havering) page, the second is *Clinicians* and within the Clinicians page is the third page, *Single Point of Access*

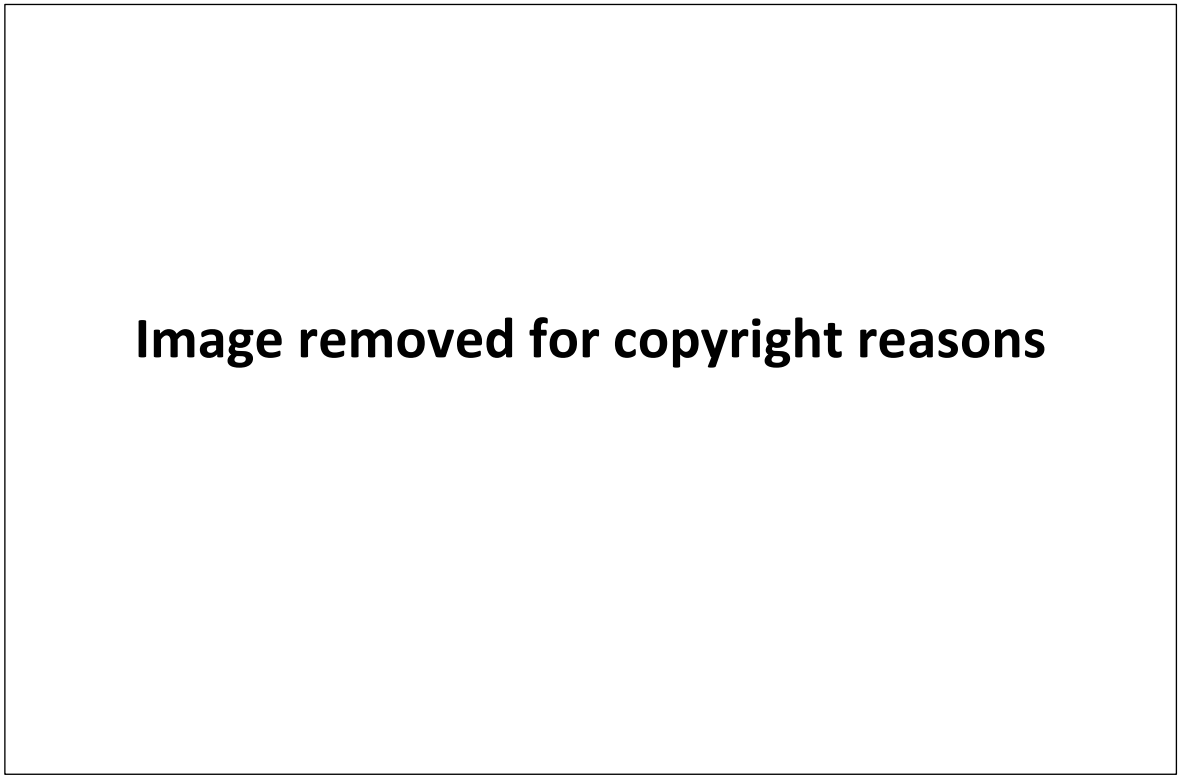


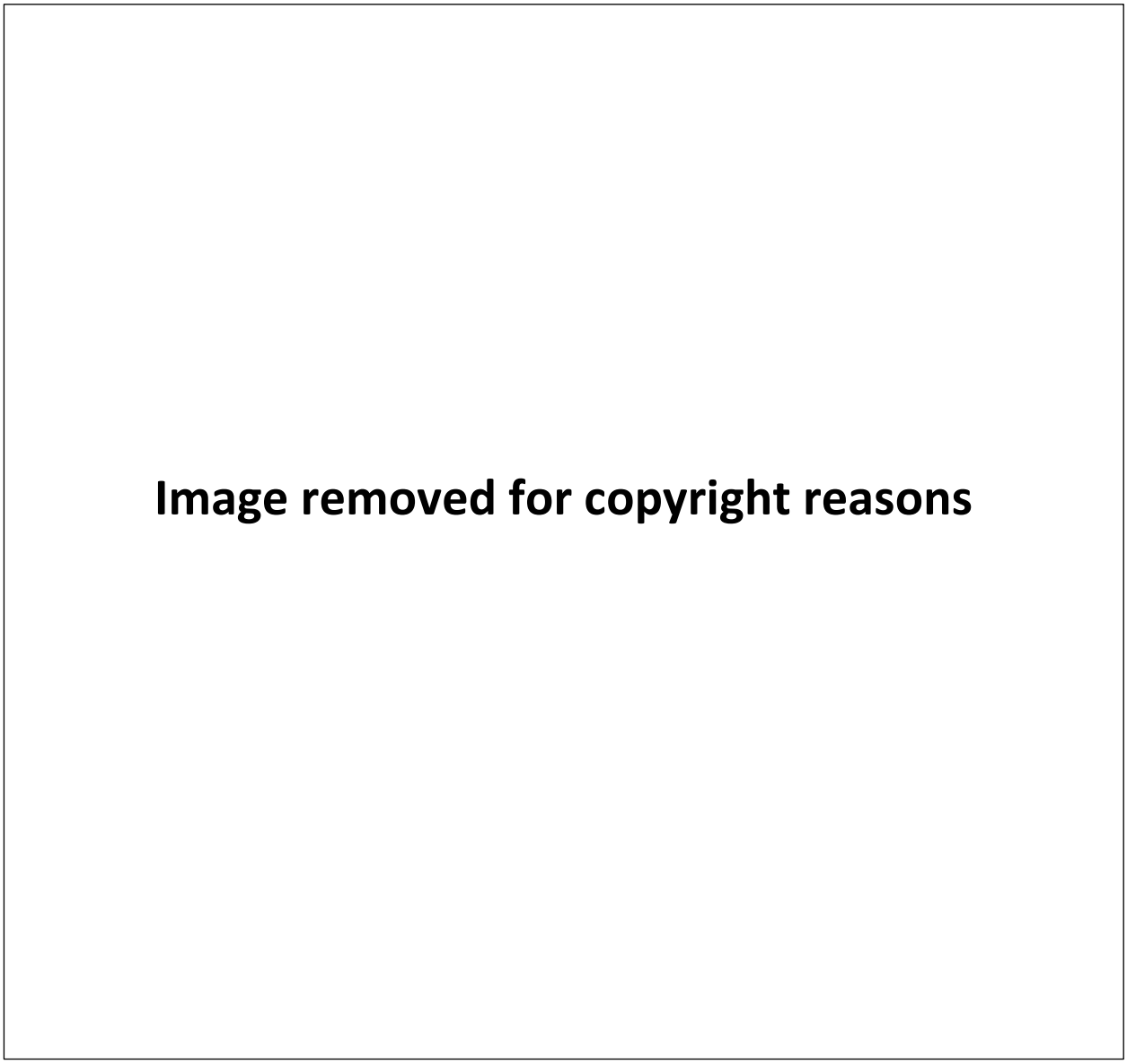
Subordinate page - Single Point of Access

3. CLCH ***District nursing main page***



There were no subordinate pages - dropdown boxes are provided on the main page

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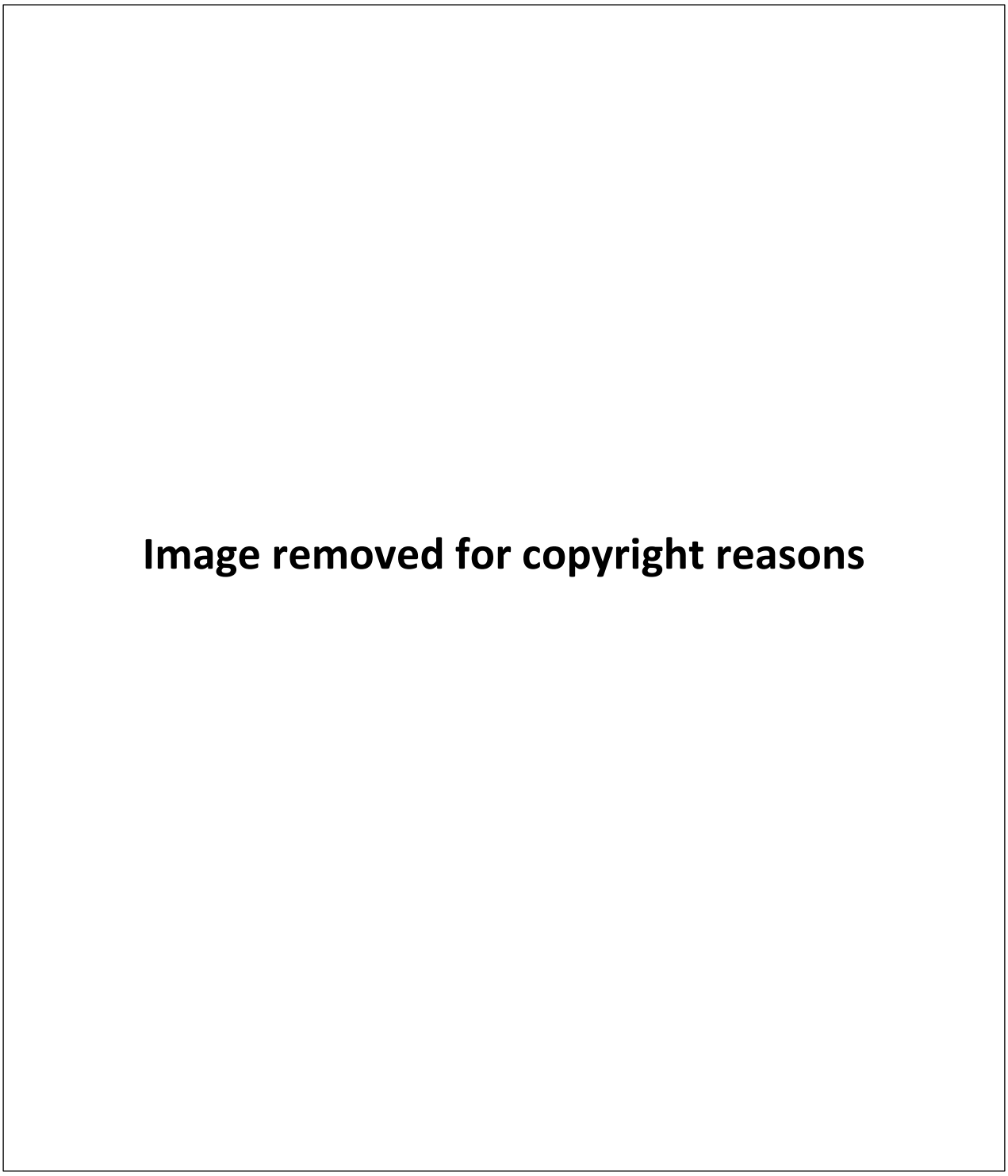
4. GSTT ***District nursing main page***

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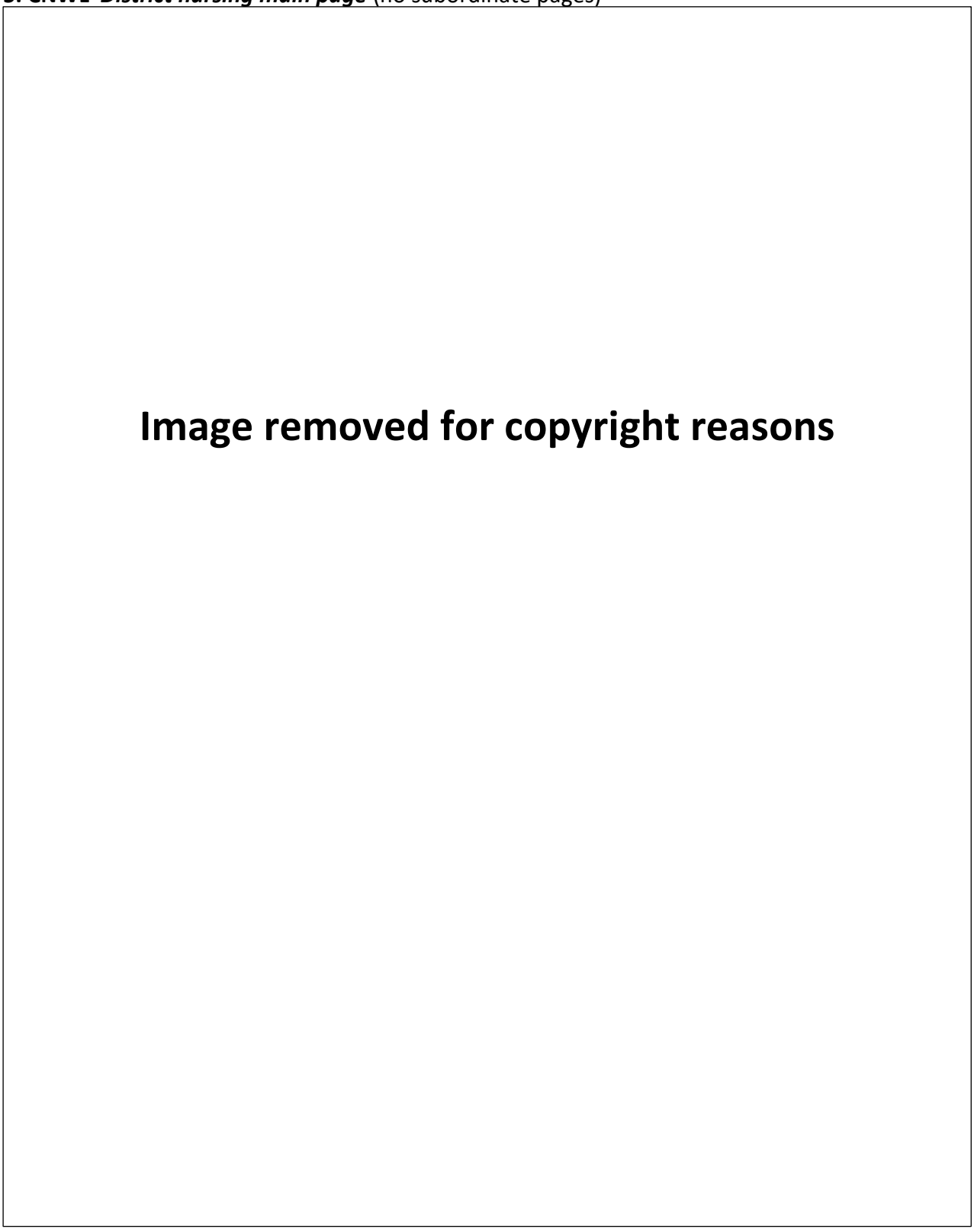
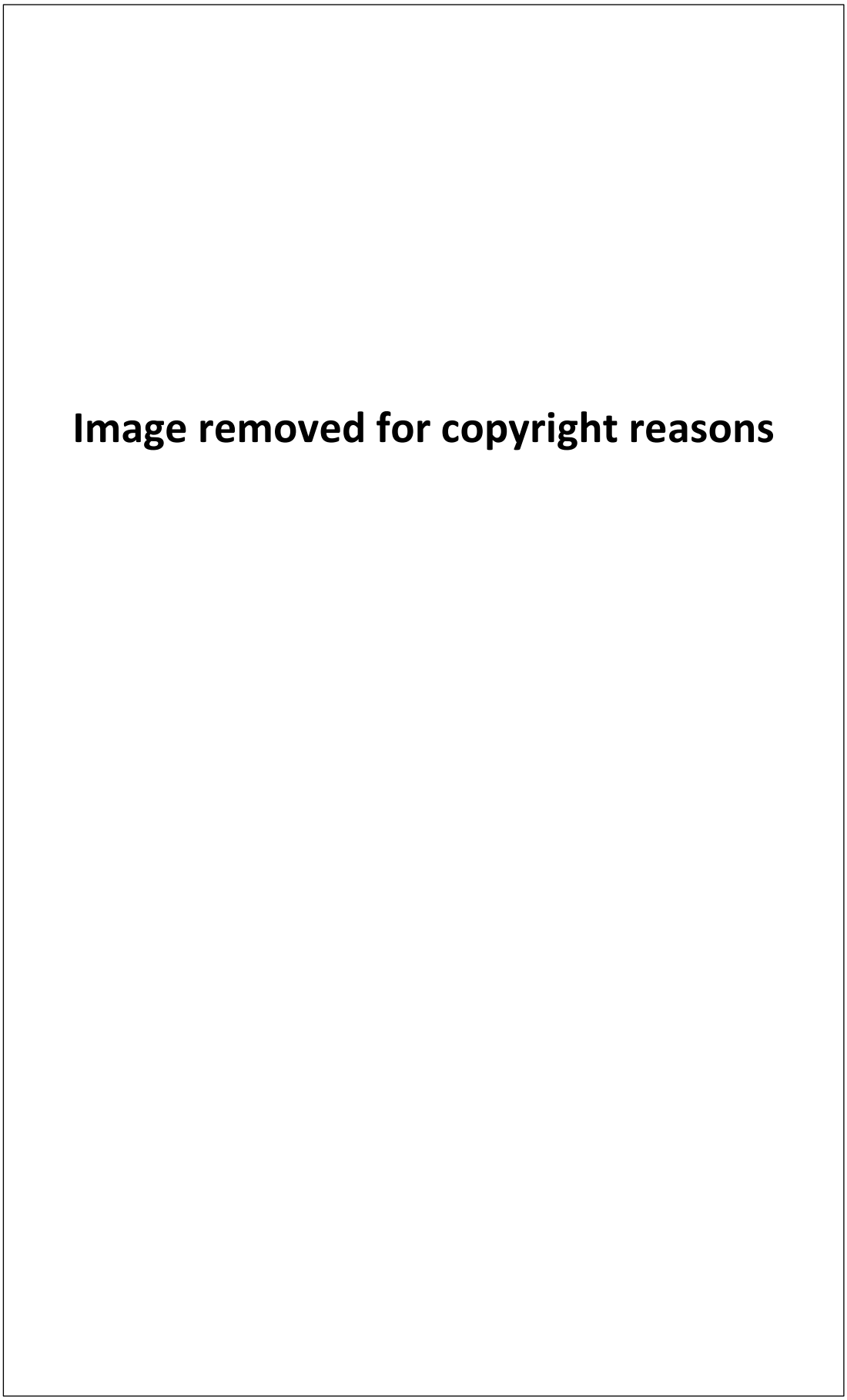
5. CNWL ***District nursing main page*** (no subordinate pages)



6. Homerton ***District nursing main page (no subordinate pages)***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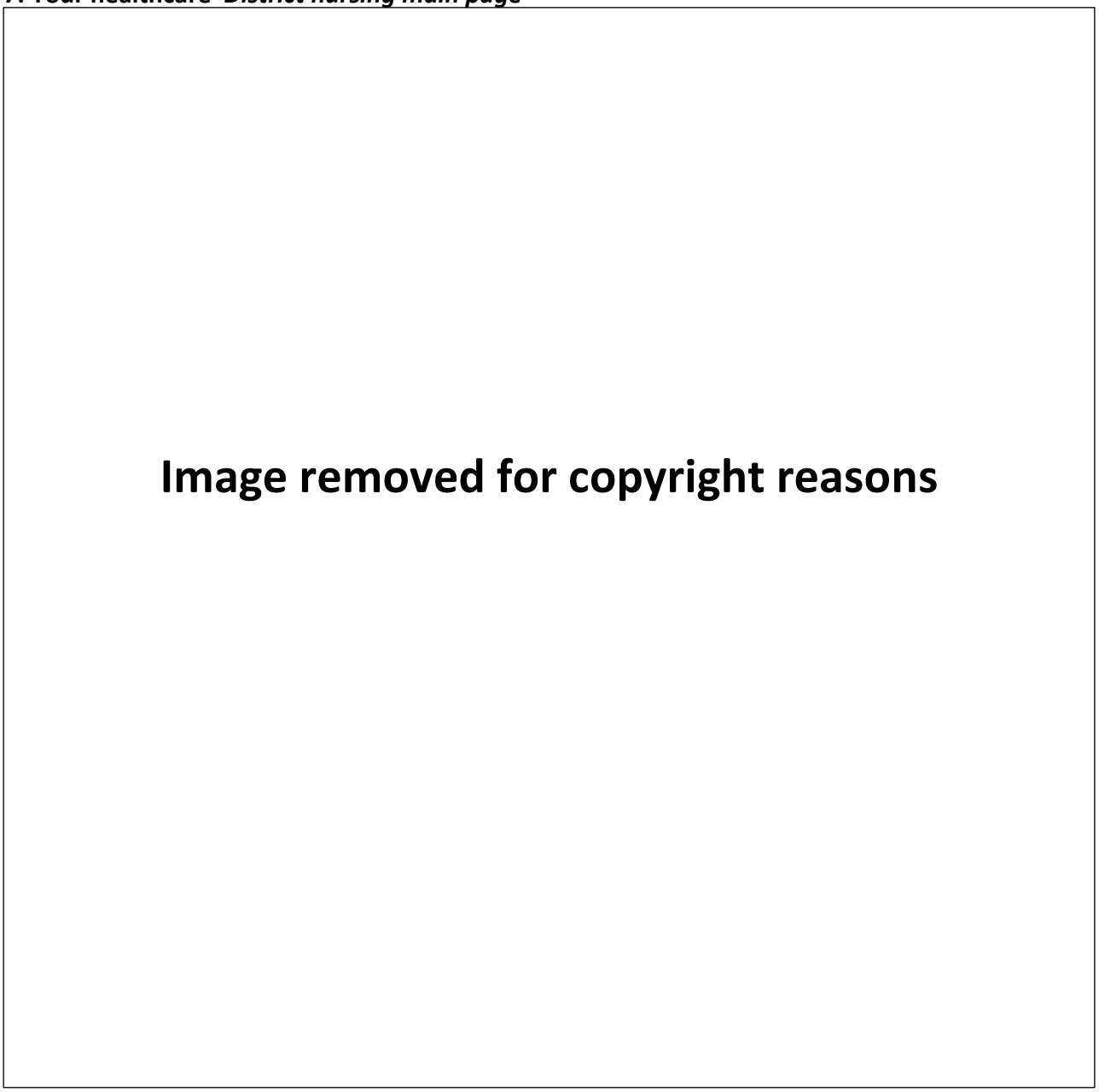
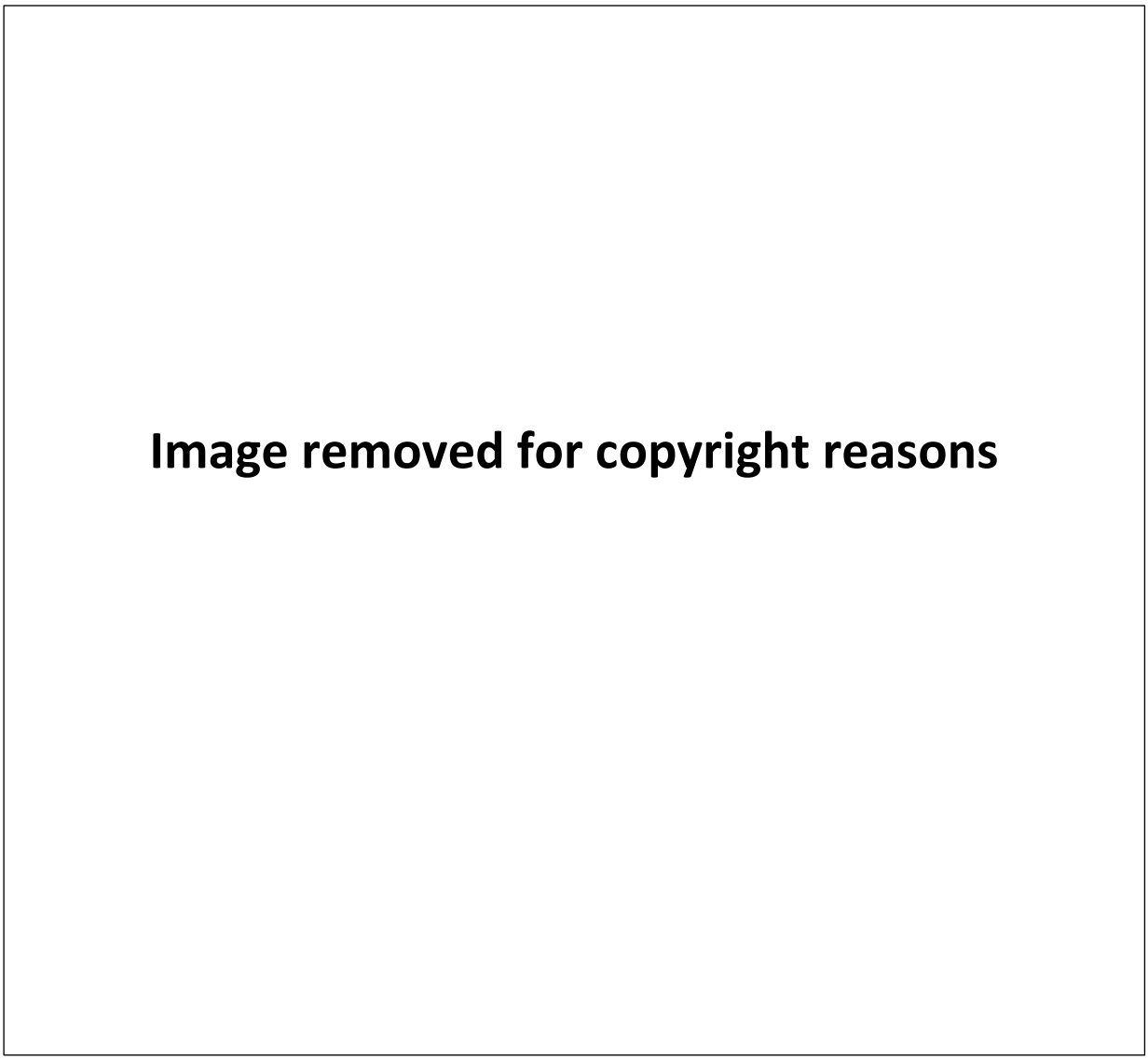
7. Your healthcare ***District nursing main page***

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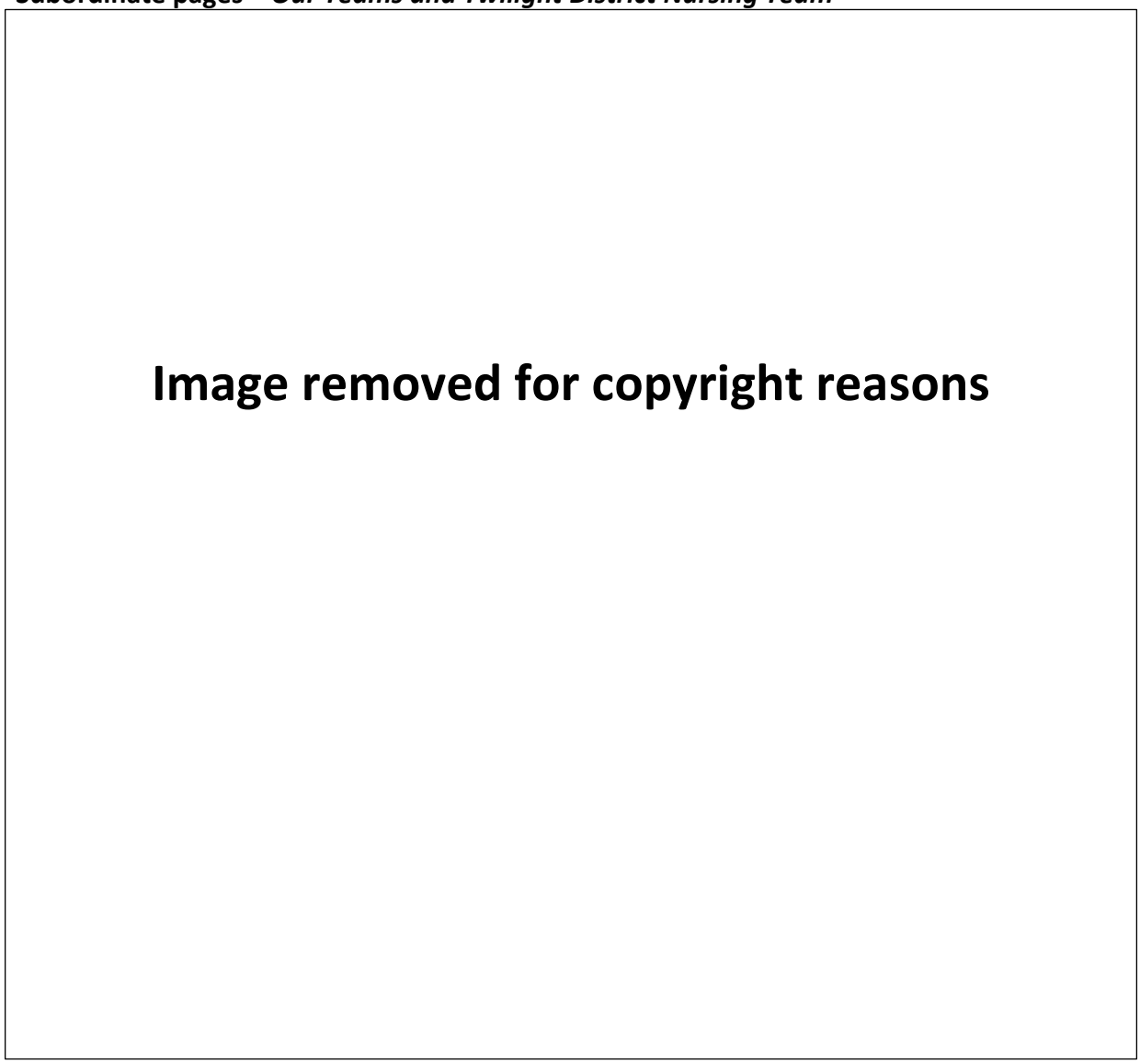
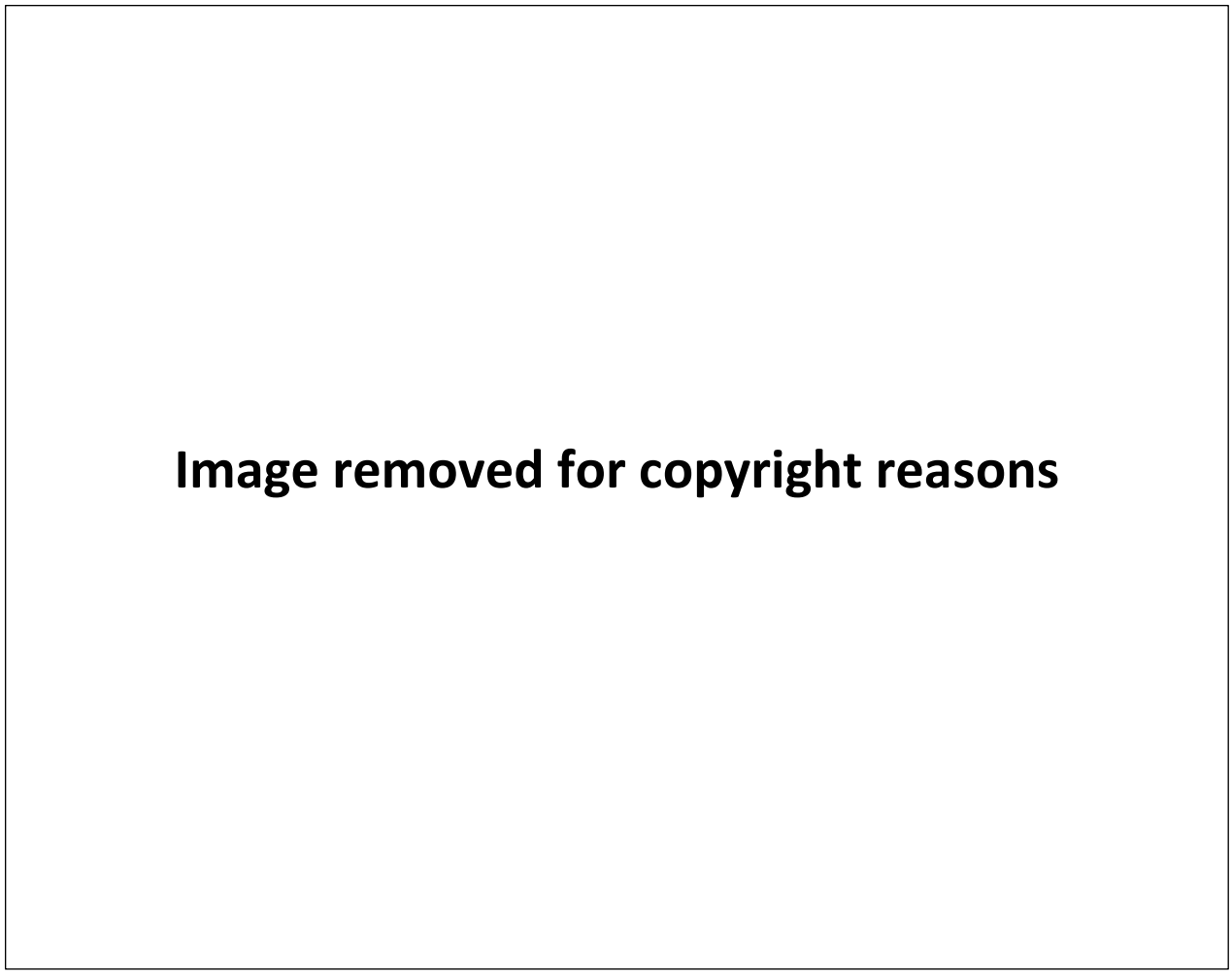
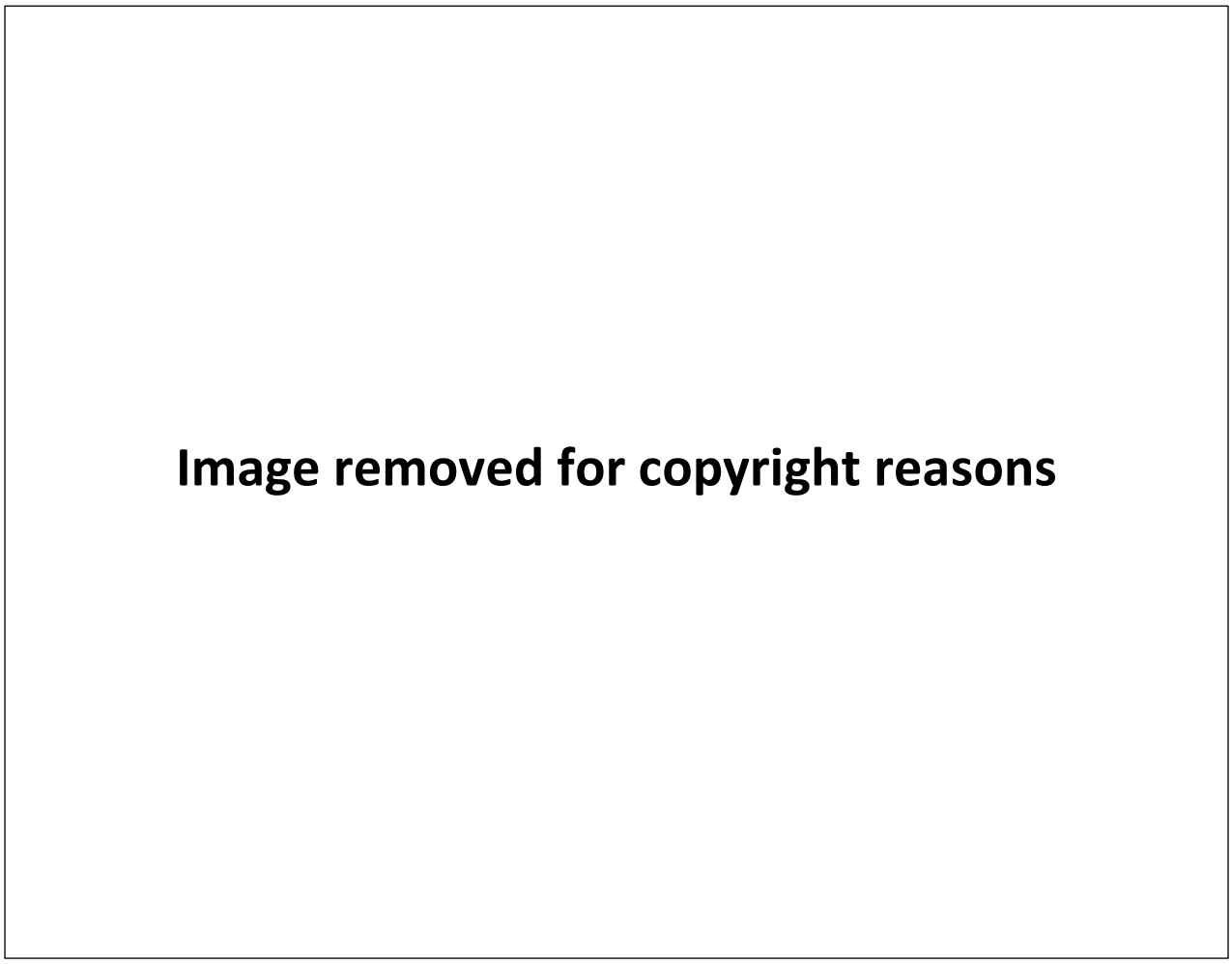
Subordinate pages – *Our Teams and Twilight District Nursing Team*



Appendix 15

District nursing leaflets available via websites

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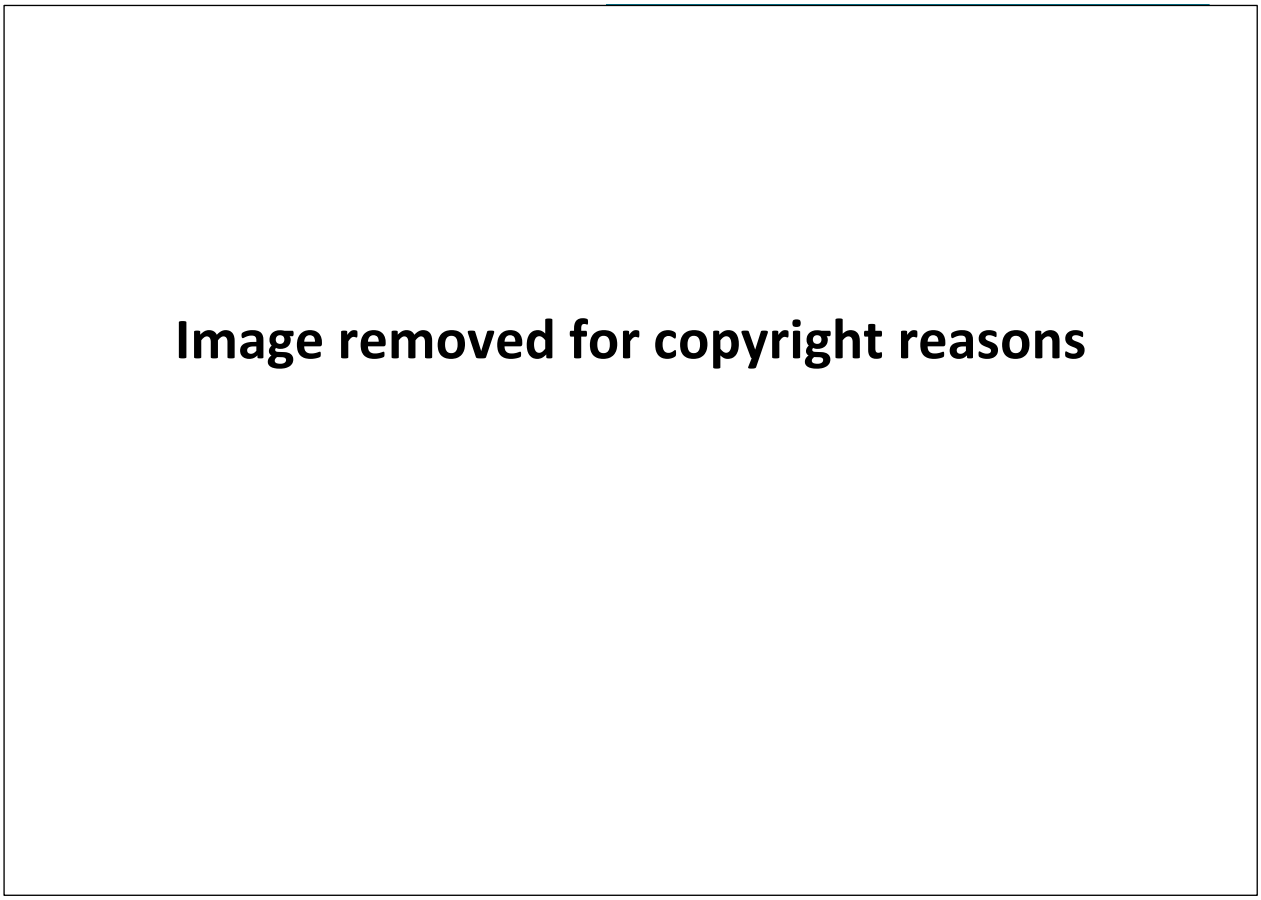
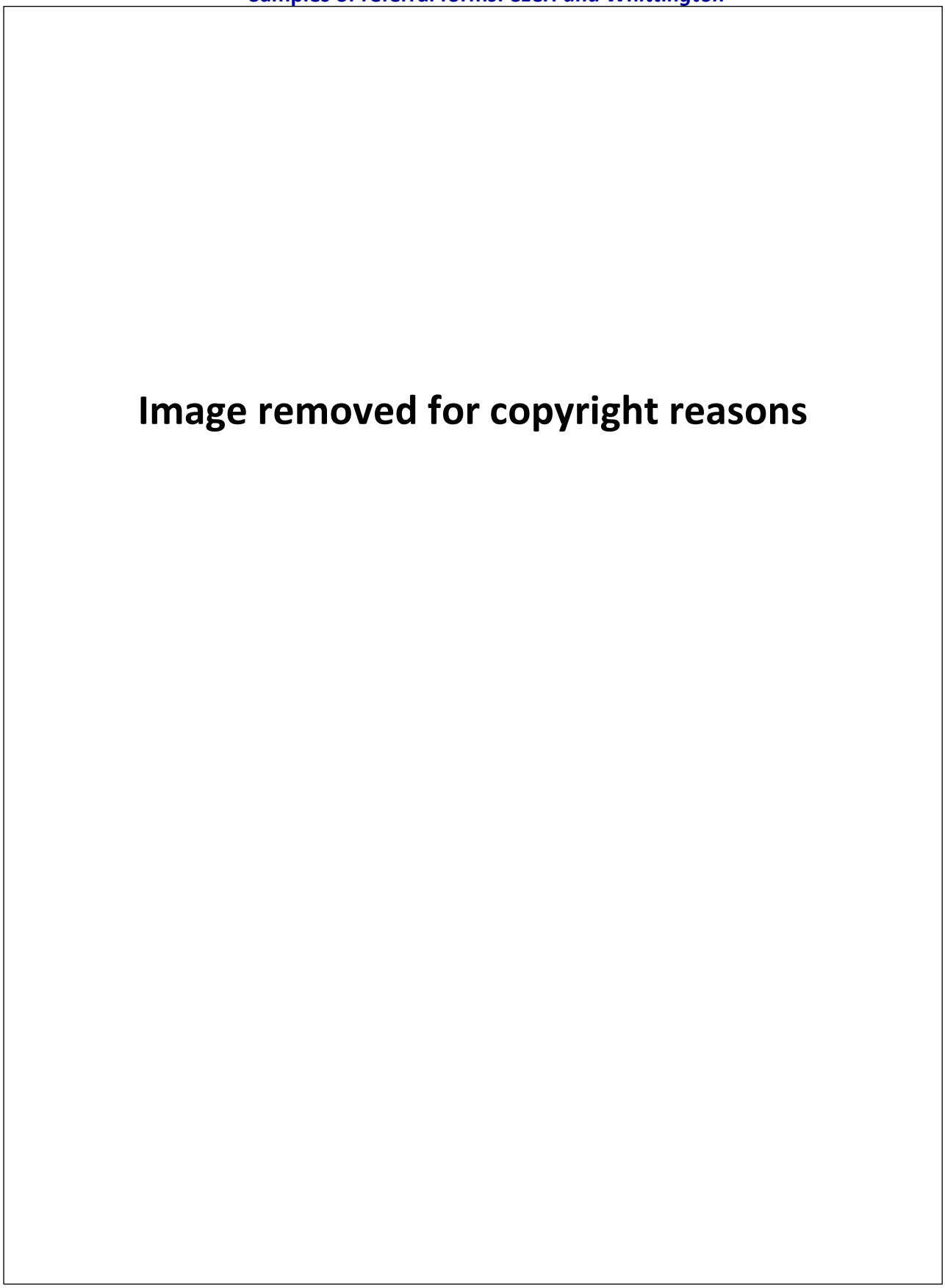
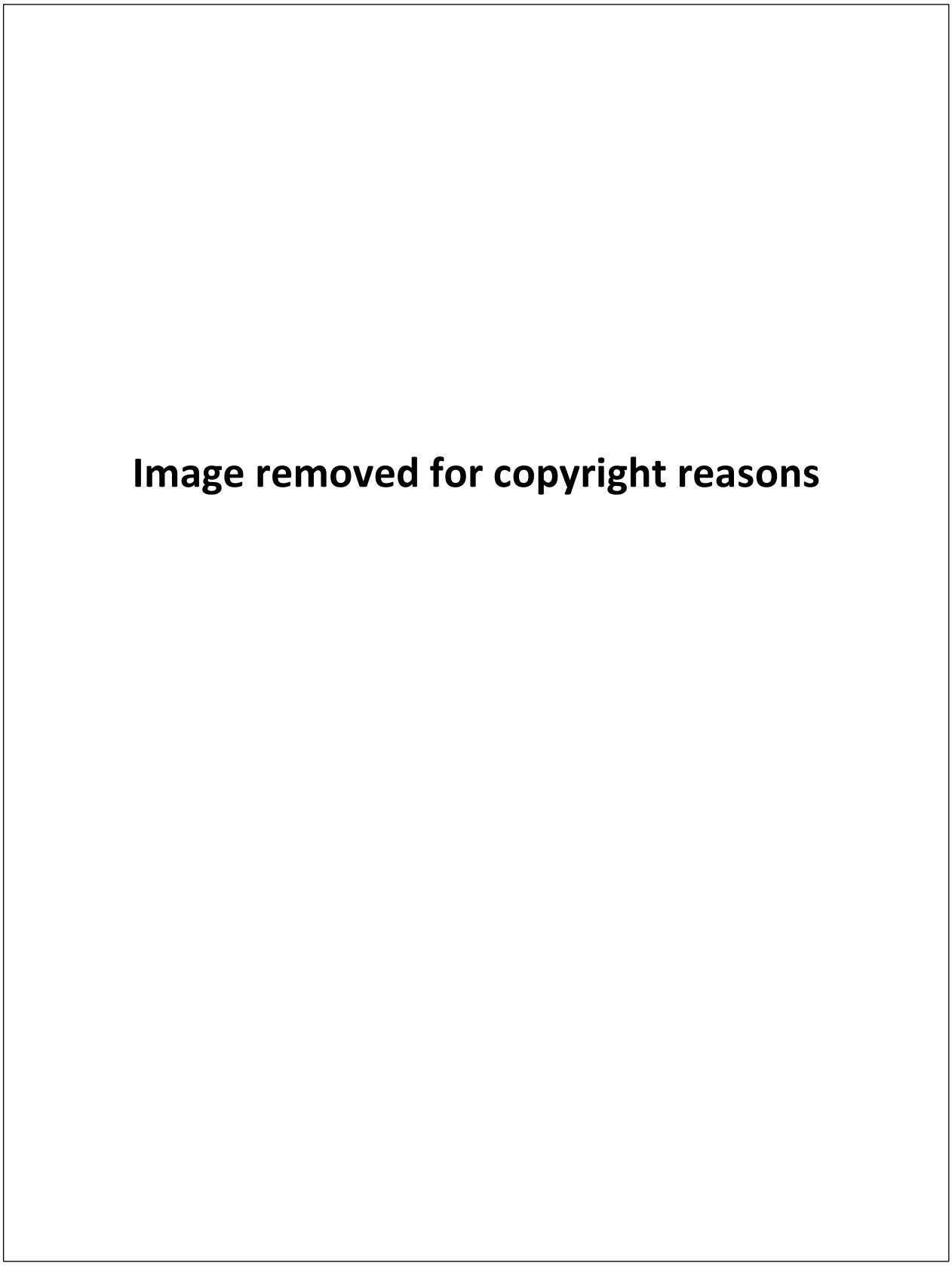
CNWL Patient Leaflet on Integrated Care



Samples of referral forms: *CLCH and Whittington*

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Whittington Health referral form