

# The barriers and facilitators of supporting self care in Mental Health NHS Trusts

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*Report for the National Institute for Health Research Service Delivery and Organisation programme*

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prepared by

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# Contents

<b>1</b>	<b>Rationale.....</b>	<b>8</b>
1.1	<i>The funding brief .....</i>	8
1.1.1	<i>Other SDO funded self care projects .....</i>	8
1.2	<i>Self Care policy .....</i>	9
1.3	<i>Background.....</i>	10
1.3.1	<i>The conceptual self care literature.....</i>	10
1.3.2	<i>Delivering self care support .....</i>	12
1.3.3	<i>The organisational change literature .....</i>	13
1.3.4	<i>Service user involvement in mental health research.....</i>	15
1.4	<i>The research team .....</i>	15
<b>2</b>	<b>Aims and framework .....</b>	<b>18</b>
2.1	<i>Statement of aims .....</i>	18
2.2	<i>The theoretical framework.....</i>	18
<b>3</b>	<b>Method.....</b>	<b>21</b>
3.1	<i>Study design .....</i>	21
3.1.1	<i>Local Self Care mapping exercise .....</i>	22
3.1.2	<i>Case studies.....</i>	22
3.1.3	<i>National Self Care mapping exercise .....</i>	22
3.2	<i>Selection of sites .....</i>	22
3.3	<i>Local Self Care mapping exercise .....</i>	23
3.4	<i>Case studies .....</i>	24
3.4.1	<i>Service users .....</i>	24
3.4.2	<i>Carers .....</i>	27
3.4.3	<i>Staff .....</i>	28
3.4.4	<i>Organisational interviews .....</i>	29
3.4.5	<i>Quantitative analysis strategy.....</i>	29
3.4.6	<i>Qualitative analysis strategy.....</i>	31
3.5	<i>Data synthesis.....</i>	33
3.5.1	<i>Feedback conferences.....</i>	33
3.6	<i>Generalisation of findings.....</i>	34
3.6.1	<i>National Self Care mapping exercise.....</i>	35
<b>4</b>	<b>Findings .....</b>	<b>37</b>
4.1	<i>Describing the sites.....</i>	37
4.1.1	<i>Local mapping – policies and provision.....</i>	38
4.1.2	<i>The projects – WRAP, SUN and creative arts .....</i>	43
4.1.3	<i>Organisational interviews .....</i>	44

4.2	<i>Quantitative findings</i>	60
4.2.1	<i>Recruitment and retention</i>	60
4.2.2	<i>Describing the samples</i>	64
4.2.3	<i>Engagement with the self care project</i>	75
4.2.4	<i>Change in outcomes</i>	80
4.2.5	<i>What factors are associated with outcomes?</i>	83
4.2.6	<i>Predictors of engagement with self care</i>	86
4.2.7	<i>Staff relationships with service users</i>	86
4.2.8	<i>The carers sample</i>	87
4.3	<i>Qualitative findings</i>	89
4.3.1	<i>A qualitative thematic framework for understanding self care support</i>	90
4.3.2	<i>Feedback conferences – exploring emerging themes</i>	92
4.3.3	<i>Understandings of self care</i>	96
4.3.4	<i>Expectations of self care support</i>	99
4.3.5	<i>The experiences of service users and carers</i>	103
4.3.6	<i>The structure of the self care project</i>	107
4.3.7	<i>Working in self care support</i>	117
4.3.8	<i>The organisational context</i>	123
4.4	<i>Data synthesis</i>	128
4.4.1	<i>Change related to empowerment and mental health confidence</i>	129
4.4.2	<i>Change related to quality of life</i>	129
4.4.3	<i>Within site changes in primary outcomes</i>	131
4.4.4	<i>Factors related to outcome at follow up</i>	133
4.4.5	<i>Service user characteristics associated with engaging in the self care projects</i>	137
4.5	<i>National mapping of self care support</i>	138
<b>5</b>	<b>Discussion</b>	<b>141</b>
5.1	<i>Barriers and facilitators – revising the framework</i>	141
5.1.1	<i>Organisational context</i>	141
5.1.2	<i>Service users and carers: identities and expectations</i>	145
5.1.3	<i>Self care staff: individuals and teams</i>	150
5.1.4	<i>Self care projects: structure, process and philosophy</i>	151
5.1.5	<i>Processes: engagement and relationships</i>	153
5.1.6	<i>Outcomes</i>	155
5.2	<i>An empirical framework for supporting Self Care in Mental Health NHS Trusts</i>	156
5.3	<i>Generalising across mental health care</i>	159
5.3.1	<i>Generalising to Mental Health Trusts nationally – national mapping of self care support</i>	160
5.4	<i>Generalising across health services</i>	162
5.5	<i>Reflections on the study design</i>	162
5.5.1	<i>Limitations of the study</i>	163

5.5.2 Reflections on service user involvement and the collaborative approach.....	165
<b>6 Conclusions.....</b>	<b>167</b>
6.1 Recommendations .....	169
6.2 Future research .....	171
<b>References .....</b>	<b>174</b>
Appendix 1 Funding call from the National Institute for Health Research's Service Delivery and Organisation (SDO) Research and Development Programme .....	180
Appendix 2 Local self care mapping questionnaire .....	187
Appendix 3 A timeline for the study, indicating how the case studies fit with both the local and national mapping exercises.....	194
Appendix 4 Client Socio-demographic and Service Receipt Inventory (CSSRI) - adapted version .....	195
Appendix 5 Service user baseline schedule .....	202
Appendix 6 Service user follow up schedule.....	206
Appendix 7 Carer interview schedules.....	209
Appendix 8 Staff interview schedule .....	216
Appendix 9 Referring staff interview schedule .....	220
Appendix 10 Organisational interview schedule .....	223
Appendix 11 Protocol for qualitative analysis .....	227
Appendix 12 Example theme Venn diagram.....	238
Appendix 13 Online survey mapping self care support at a national level .....	239
Appendix 14 Ratings for each feedback conference themes by site and stakeholder .....	245
Appendix 15 Full responses to the national mapping survey.....	250

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## Commonly used acronyms

AFC	Agenda For Change (NHS pay scale/ job profiles)
BDI	Beck Depression Inventory
CBT	Cognitive Behavioural Therapy
CMHT	Community Mental Health Team
CORE	Clinical Outcomes in Routine Evaluation
CPA	Care Programme Approach
CRB	Criminal Records Bureau
CSQ	Client Satisfaction Questionnaire
DH	Department of Health
ES	Effect size
HPFT	Hampshire Partnership Foundation Trust
HRM	Human Resource Management
LPFT	Leeds Partnership Foundation Trust
MRC	Medical Research Council
NICE	National Institute of Health and Clinical Excellence
NVivo	Qualitative data analysis software
PCT	Primary Care Trust
PD	Personality Disorder
R&D	Research & Development
RIO	NHS electronic care record system
SDO	Service Delivery & Organisation (DH research funding programme)
SEIQoL	Schedule for the Evaluation of Individual Quality of Life
SGUL	St George's, University of London
SPSS	Statistical data analysis software
SUN	Service User Network (London case study project)
SWLSTG	South West London & St George's Mental Health NHS Trust
SWYPFT	South West Yorkshire Partnership Foundation Trust
T0	Baseline data collection point
T1	Follow up data collection point
WRAP	Wellness Recovery Action Planning (Hampshire case study project)

# *The Report*

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## 1 Rationale

This study was undertaken in response to a specific funding call from the National Institute for Health Research's Service Delivery and Organisation (SDO) Research and Development Programme (see Appendix 1). The joint principal investigators felt from the outset of developing the protocol that studying the provision of support for self care by Mental Health NHS Trusts would be best informed by the discourses of organisational change and service user involvement in research. These discourses therefore respectively inform both the theoretical model that underpins the study and a collaborative approach to undertaking the research.

### ***1.1 The funding brief***

The funding brief called for empirical studies to increase knowledge about the ways in which the NHS can support self care. This study sought to explore the implementation of support for self care in the context of mental health services and the support offered by Mental Health NHS Trusts (as well as those PCTs that directly provide services for people with more severe and enduring mental health issues). The study addressed the key research questions articulated by the SDO: mapping self care support in Mental Health NHS Trusts in terms of development of strategy, delivery and models of service provision; integration of self care support within and between partner agencies in statutory and voluntary sectors; identifying barriers and facilitators of effective implementation of self care support (including organisational, change and human resource management issues, as well as the expectations and experiences of self care for people who use mental health services and their carers).

#### **1.1.1 Other SDO funded self care projects**

Three other studies - exploring self care support for younger people, for older people, and the interface between self care and case management – were funded alongside this study. Research teams were briefed to work together to identify how findings in each area might offer transferable insight into supporting self care across health services.



## **1.2 Self Care policy**

The Department of Health has signalled clear support for self care over recent years. The NHS Plan (2002) highlighted the importance of self care, and this was expanded in the white paper *Our Health, Our Care, Our Say* (DH, 2006a). This emphasised the importance of helping people with long term conditions take control of their conditions and care through self care and self management, and stipulated that commissioners and service providers should consider self care as a high priority. Aspirations included providing all those with long term conditions and their carers with information about their condition and access to self care support and to influence professional education in order to develop a culture and skills to support empowerment and self care. A subsequent DH paper provided guidance on supporting local strategies and developing practice to support self care (DH, 2006b).

The Darzi report on providing high quality care for all (DH, 2008a) also emphasised the importance of self care principles and announced the future publication of a new Patients' Prospectus "to provide patients with long-term conditions the information they need about the choices which should be available to them locally and to enable them to self care in partnership with health and social care professionals" (DH, 2008a, page 40). The report also highlighted the importance of personal care plans, packages of care to meet the needs of the patient and the importance of involving carers in this process. Improved choice and control over care is also a key principal underlying the reform of public services through the personalisation agenda (DH, 2008b).

Mental health is a clear priority in the government's definition of self care: 'the care taken by individuals towards their own health and wellbeing' and includes the actions taken to 'maintain good physical and mental health' and 'meet social, emotional and psychological needs' (DH, 2005a). Recent developments in mental health care have begun a move towards an environment more conducive to self care. The National Service Framework for Mental Health (DH, 1999) stimulated the diversification of services and roles to ensure services are more responsive to individuals. Principles of the recovery approach which underpin mental health services are consistent with self care (e.g. DH, 2001; DH, 2002) and include greater involvement of patients in their care to support recovery and social inclusion. Directives for mental health practitioners also champion the principles of recovery, and recommend service user involvement in care planning and promoting the acquisition of self management skills (DH, 2006c, Skills for Health, 2006). However, it is unclear whether self care models transferred from physical health can be effectively implemented in mental health, where service user attitudes to engaging with services exist that do not impact on physical health services (Davidson, 2005). This demonstrates a clear rationale for a separate study exploring the implementation of generic self care policy in mental health. Such a study would offer learning that can be translated across health service areas where issues of engagement with service provision do arise. In particular, the issues raised in *Delivering Race*

Equality in Mental Health Care (DH, 2005b) around delivering equality of access, experience and outcomes for people from Black and Minority Ethnic communities are potentially well served by the objectives of the self care White Paper (DH, 2006a), self care providing the opportunity for community driven solutions for engaging people in appropriate and effective support for their mental health needs (Thomas et al, 2006).

We will relate the findings of this study – identification of barriers and facilitators to providing self care support in Mental Health Trusts - back to the policy context. In particular we will reflect on the extent to which generic self care policy is appropriate in mental health settings and how the implementation of such policies can be supported.

### **1.3 Background**

A preliminary review of self care literature was undertaken in order to inform the development of the study protocol. That review incorporated both the conceptual self care literature which explores understandings of self care from a range of perspectives, and a more empirical literature which explores support for self care in both the statutory (NHS Trust) and voluntary sectors. Alongside the study the team also undertook a more comprehensive review of both of these bodies of literature. This more extensive review, summarised here, will be used to present discussion of our findings in a wider empirical context. We will also present the organisational change literature that informs the study's underlying theoretical model, and the current literature on service user involvement in research that has shaped our collaborative approach to research.

#### **1.3.1 The conceptual self care literature**

In order to understand how self care should be supported in mental health services it is important to review not only self care approaches but developments that have drawn on overlapping concepts. Our conceptual review identified three concepts that overlap with self care and which have been developed within mental health services - self management, self help and recovery.

Self management is advocated in the management of long term health problems, including mental health problems such as psychosis and depression. Rethink, a mental health membership charity, have developed a self management programme and provided a definition of self management as: "whatever we do to make the most of our lives by coping with our difficulties and making the most of what we have" (Martyn, 2002).

Self help approaches are well established in mental health. Cognitive Behavioural Therapy (CBT) based guided self help interventions are recommended by the National Institute for Health and Clinical Excellence (NICE) for mild to moderate anxiety and depression (NICE, 2004a, b), including computerised CBT (NICE, 2006). These structured self help interventions are types of low intensity interventions to be provided in the new Improving Access to Psychological Therapies (IAPT) services within

stepped care service models. Other self help options may involve no or very little professional support (Lewis et al, 2003). Although self management and self help are similar terms, self management has tended to be used to describe strategies people use to manage their lives and their health problems whilst self help has been used to describe the more structured, professionally led interventions. These can therefore be seen as representing a continuum of approaches, from strategies people use in their day to day lives without professional involvement, to structured professionally led, formal self help interventions. Formal self help interventions have been developed as a technical solution for managing demand for psychological therapies by people with common mental disorders in primary care (Richards et al, 2003) as a cost-effective method to improve access. They are therefore based on psychotherapeutic and theoretical models, particularly CBT. Alternatively, developments led primarily by service users and voluntary organisations in relation to serious mental illness have brought the concepts of wellness, recovery and empowerment into mental health services (Richards, 2004), and it is this concept of self care that this study will investigate further. Here, the aims of self care relate to a broader philosophy of healthcare incorporating lifestyle strategies, social networks, and challenging exclusion, which is consistent with the recovery approach. Recovery has become an overriding principle in mental health services (e.g. Department of Health, 2001) in which the possibility of recovery from mental illness is acknowledged and supported. As with self care, recovery approaches support empowerment of individuals to live fulfilling and meaningful lives and having more control over treatment and their lives. Recovery encompasses a number of themes, including an emphasis on positive health and well being, and the approach encourages a focus on strengths, positive coping and resilience. Recovery has been defined as: "The uniquely personal and ongoing act of claiming and gaining the capacity to take control of life that is personally meaningful and satisfying, with opportunities to perceive her/himself as a valued citizen. The person may develop and use their self determination to grow beyond and thrive, despite the presence of the limitations and challenges invited and imposed by distress, its treatment and the personal and environmental understandings made of them." (Coleman, Baker and Taylor, 2000). The approach recognises that people with mental health problems have multiple needs, not simply confined to symptom relief, and recovery aims to impact on these factors as well as the experience of ill health (Anthony, 1993; Repper and Perkins, 2003). Recovery is not viewed as an endpoint but is conceptualised as a journey: the recovery model approach helps service users develop the capacity to cope through participation, increasing self esteem and self determination.

It is clear from this review of the conceptual literature that the principles of self care are central to many approaches to mental health services, even though they may not be labelled as self care. Furthermore, these approaches range from specific therapeutic interventions to a broad service philosophy and the type of self care support they provide varies greatly between approaches. In exploring the concept of self care and approaches to self care support in this study we will therefore not define or confine

understandings of self care. Rather we will seek to explore the range of conceptualisations of self care, and approaches to providing self care support, as understood by different stakeholders to supporting self care in Mental Health NHS Trusts.

### 1.3.2 Delivering self care support

A recent DH/MORI survey in England (DH, 2005) found that 82% of those who had a long term health condition reported they play an active role in caring for their condition themselves, with more than 9 in 10 expressing an interest in being more active self carers. In contrast, the majority of people who had seen a care professional in the previous 6 months said they had not often been encouraged to self care and a third said they had never been encouraged to self care by the professionals. This is evidence of a desire for people with long term conditions to self care which is not yet being adequately supported by professionals, raising the possibility that barriers exist to the support of self care by health service provider organisations.

An ongoing review of evidence for the effectiveness of self care support across all health problems identified 160 systematic reviews and 240 primary research studies of self care support interventions (DH, 2007). In an interim report the authors concluded the evidence supported the effectiveness of self care support in leading to improved health outcomes and more appropriate use of health and social care services and that self care support should become an integrated part of the healthcare system. It is significant that, in relation to mental health, this review included a wide range of psychological and psychosocial interventions, including formal psychological therapies, which illustrates problems defining self care and what should be considered as self care support. Given the overlap of self care and the related concepts outlined above, in deciding what constitutes self care support in mental health, it is reasonable to include service developments that promote the principles of, for example, social inclusion and recovery as well as self care strategies. In addition to formal psychological therapies, many of these approaches are characterised as part of the recovery approach and have their origins in the voluntary sector or in the service user/ survivor movement. Examples are a 'Self management' approach for people living with a diagnosis of schizophrenia (Rethink 2003), a self management programme (<http://www.mdf.org.uk/?o=1622>) developed by the Manic Depression Fellowship, the TIDAL model (<http://www.tidal-model.co.uk>) and Wellness Recovery Action Plan (WRAP) ([www.mentalhealthrecovery.com](http://www.mentalhealthrecovery.com)).

Clearly there are a number of current approaches to providing mental health services that include self care support. These are many and varied, and indicate that the main aim of this study – identification of barriers and facilitators to providing self care support – would be well served by an attempt to capture this range and variety through empirical study.

### 1.3.3 The organisational change literature

Achieving the policy recommendations outlined in section 1.3.1 above will have significant consequences for the delivery of health care at both an organisational and individual practitioner level. For individual practitioners self care represents a fundamental shift in the practitioner-user relationship. Enabling users to be more involved in decision making has been termed a 'cultural revolution' (Pietroni et al, 2003) and 'paradigm shift' (Wilson et al, 2005) for practitioners and services, from 'doing to' to 'doing with'. In attempting to identify the facilitators and barriers to implementing this major change a number of factors need to be considered. These include "goodness of fit" of the programme objectives with the wider organisational and agency context; the organisation and management of project resources, both human and capital; the expectations of care providers (individuals and teams), users and carers; the quality of the therapeutic process and delivery mechanisms, and the outcomes in terms of the objectives of the self care projects and major stakeholders. The theoretical framework the study is based on is shown in Figure one, section 2.2 below.

The first of these is "goodness of fit" of the project with the culture, structures, processes and procedures of the wider organisation and agencies on which they depend. Where self care programmes' aims are at variance with those of the host organisation and partner agencies, and where the structures, processes and procedures of the organisations create a culture that impedes innovation, then it follows that those aims are more difficult to achieve (Wright and Snell, 1998; Butterfield, Edwards and Woodall 2004, 2006). Achieving "fit" in part depends upon the flexibility of agencies and organisations in response to change (Wright and Snell, 1998) notably in terms of the ability to modify current culture and practices and to shift and re-configure human and other resources. A clear shared strategy and well defined goals which are implemented consistently down and across the organisation is essential. Thus, for programmes to succeed there must be both vertical and horizontal alignment of programme and organisational values, policy and practice. Even where there is consensus and commitment at the top, the task of policy formulation and implementation is at risk of distortion or failure at each organisational level. The role of middle and line managers in implementing and interpreting policy and strategy in order to 'action' them is often neglected, yet a number of studies bear witness to this key role (Gratton and Truss, 2003; McGovern et al, 1997). For instance, Edwards and Robinson's research into the introduction of flexible working in nursing demonstrated how policies strongly supported by senior management can be undermined by the inability or unwillingness of line managers to implement policy effectively (Edwards, Robinson and Woodall, 1999; 2004). The cross agency, departmental and multidisciplinary working typically required by these programmes also highlights the need for horizontal alignment of policy and practice.

The ultimate success of these pilot programmes lies with staff at the point of service delivery. There is a great deal of research showing the critical contribution of HRM policy and practice to staff performance and service outcomes (West et al, 2002; Marchington and Zagelmeyer, 2005). Thus the

study will need to focus on the way in which the management of staff supports the programme objectives in terms of recruitment, selection, performance management, reward, development, career progression, stress management, and how staff are motivated and engaged (Gratton et al, 1999; Hope-Hailey, 2001; Truss, 2001; Truss et al, 2001). Self care requires practitioners and organisations to be trained to work in a different way, and the effectiveness of education and training programmes with this aim will also need to be considered (DH, 2005a). Self care involves a significant reorientation of the caring role, and some may see it as diminishing the status and role of the professional in the healing process. In mental health in particular it might be seen as highly risky (Gerrity et al, 1995), and increase levels of stress and diminish job satisfaction. There may be problems in gaining a shared understanding of self care and how it should be delivered by different professionals (Engestrom, 1996). Thus understanding the role, expectations and experience of individuals and teams and how they define and operationalise the concept of self care is an important focus of the study. Teams have been shown to be more likely to take risks and innovate, especially if supported by good human resource management practice (Shipton et al, 2006). It raises the questions as to what is the best composition of teams, and how management systems and practices can support them to avoid conflict and enhance performance. For example, is care best delivered by close knit teams dedicated to the programme, or by staff who contribute specific tasks as part of broader duties?

The expectations of users and carers and attitudes to risk and empowerment, and the demographic, cultural and personal characteristics that may influence their response to self care are important considerations. Previous research has highlighted the discrepancy between practitioner and user understandings of self care with practitioners focused on structured educational programmes while users view it as a process to bring about order in their lives (Kralik et al, 2004). Finally there are processes through which self care is delivered. These, together with the components described above will, we hypothesise, determine the outcomes of the self care programmes. Outcomes can be measured in terms of "hard" performance data such as referrals to inpatient care, or to other direct interventions, as well as the experiences and satisfaction of the main stakeholders in the process - users, carers and service providers. Outcomes can relate to specific objectives set by the projects, as well as to more general policy considerations set by the NHS.

The organisation and management of pilot initiatives present a number of topics for investigation. An obvious question is whether project managers have the skills, authority and the resources (human, capital and technical) necessary to implement the programme effectively. Do they have the cooperation of other managers, agencies and resource holders? Careful management of the change process, and in particular the active participation of the main actors, not only can overcome resistance but also enhance outcomes even in the most challenging therapeutic settings, as demonstrated by Bowers et al's (2005) study of a Dangerous and Severe

Personality Disorder unit. The ways in which knowledge is managed within peer networks and communicated to users and carers are important features of these projects. Knowledge transmission is problematic in that it may be tacit and not easily codifiable into clear instructions, and because interpretation and application depends on competence, context and shared culture and meanings which may vary from person to person (Lindqvist, 2005). Related issues concern the amount of direct contact with users, and whether investment in user training and self selection improves outcomes. The models underlying the approach of these projects must be understood in addition to these operational considerations, as these will determine the specific objectives and methods of the project in terms of the desired outcomes for users, carers and service providers.

### **1.3.4 Service user involvement in mental health research**

The importance of service user involvement in research in the NHS has been advocated in policy guidelines since 1999 (Department of Health, 1999) with NHS Trusts being required to demonstrate service user involvement in research as part of good research governance (Department of Health, 2005). There is increasing evidence of its application in mental health research (Telford and Faulkner, 2004) and this involvement can range from an advisory role to a lead role in the whole research process (Rose 2003; Trivedi and Wykes, 2002; Faulkner and Layzell, 2000). Comprehensive guidelines for supporting the involvement of service users in the research process have been developed by INVOLVE (INVOLVE 2004). It is considered important to involve service users at all stages in research (Thornycroft et al, 2002) and this would seem to be particularly appropriate in the case of self care. Self care aims to build participatory relationships between professional and users, therefore research into self care would do well to follow similar principles. People experiencing mental health problems will have vast experience of managing their lives on a day-to-day basis (Mental Health Foundation, 2001; Faulkner and Layzell, 2000). Research into self care should be conducted as a genuine partnership between service user-, academic- and clinical researchers in order that expertise by experience and expertise by profession work together (Faulkner and Thomas, 2002) to offer a richer understanding of self care and its support in the Mental Health NHS Trust context.

## **1.4 The research team**

Responding both to the funding brief and to the organisational change and service user involvement discourses that inform the research, this study was conducted by a broad and varied research team. Reflecting the ethos of service user involvement behind the project, the research team – investigators, research assistants and academic advisors – included a number of people with personal experiences of mental health issues, using mental health services, or caring for someone using mental health services. Those personal experiences were integral to all stages of the project, from

development of the original proposal, refinement and piloting of data collection tools, the collection and analysis of data, to the writing of this report. This was to ensure that service user and carer, as well as academic and clinical expertise, informed and shaped the research process. Service user researchers were supported using a comprehensive set of guidelines developed at St George's, University of London (SGUL) – *Balancing Best Research with Best Mental Health: a step-by-step guide to involving and employing mental health service users as 'researchers by experience'* – and with an accredited service user and carer research training course – REACT (REsearch in ACTion) – developed by South West Yorkshire Partnerships NHS Foundation Trust.

The team was led jointly by Dr Steve Gillard, a Senior Research Fellow specialising in mixed methods study design and service user involvement in research at the host institution – the Division of Mental Health, SGUL – and Professor Christine Edwards, Professor of Human Resource Management at Kingston Business School, Kingston University.

Co investigators included Ms Sarah White, Senior Biostatistician in the Division of Mental Health, SGUL, Dr Lucy Simons, then Senior Research Fellow at the School of Health Sciences, University of Southampton (lead for the Hampshire study site) and a nurse by background, and Professor Mike Lucock, Professor of Clinical Psychology at Huddersfield University, and Associate Director and Consultant Clinical Psychologist with South West Yorkshire Partnerships NHS Foundation Trust. Ms Kati Turner, an experienced service user researcher in the Division of Mental Health at SGUL, and Mr Barrie Holt (first eighteen months of the project), an experienced service user researcher and trainer working with the West Yorkshire NHS Research and Development Consortium, were co investigators involved in developing the proposal and supporting the involvement of service user researchers throughout the project. NHS managers from all sites were also co investigators, ensuring the research reflected their priorities as end users of the research and facilitating access to case study projects and populations. Dr Virginia Minogue, then Head of the West Yorkshire NHS Research and Development Consortium and a social worker by background, led the West Yorkshire study site. Dr Stephen Miller, consultant psychiatrist in psychotherapy at South West London and St George's Mental Health NHS Trust was clinical lead of the London case study project. Ms Katherine Green of Hampshire Partnership Foundation Trust was manager of the Hampshire case study project. In the final year of the study Professor Lucock became lead of the West Yorkshire site as Dr Minogue moved to the North East Strategic Health Authority, and Dr Simons moved to INVOLVE, although remaining Hampshire lead.

The research assistants for the project were Ms Katie Adams (West Yorkshire), Ms Rachel White (London), and Ms Lucy Davies and Ms Karen Akroyd (job sharing Hampshire post). For the final year of the study Dr Christine Nugent replaced Ms Akroyd.

Further academic input into the project was provided by Mr Trevor Kettle, Lecturer in Nursing in the School of Health Sciences, University of



Southampton, Dr Helen Elsey, then Senior Research Fellow at the Southampton and South West Hampshire Research and Development Support Unit and a specialist in participatory research methods, and Professor Judith Lathlean, Professor of Health Research in the School of Health Sciences, University of Southampton.

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## 2 Aims and framework

In order to take a systematic approach to identifying, empirically, the barriers and facilitators to providing self care support in Mental Health NHS Trusts, we developed a theoretical framework for understanding the range of factors that might impact on the health service organisation as it seeks to implement self care policy. This framework was informed by the organisational change literature identified above (section 1.3.3), as well as the multi-disciplinary insight offered by the research team. The framework enabled us to form a series of research questions that will address study aims.

### ***2.1 Statement of aims***

The primary aim of the study was to identify barriers and facilitators to providing self care support in Mental Health NHS Trusts.

A secondary aim of the study was to identify learning about providing support for self care from the mental health service experience that can be applied to other health service areas.

### ***2.2 The theoretical framework***

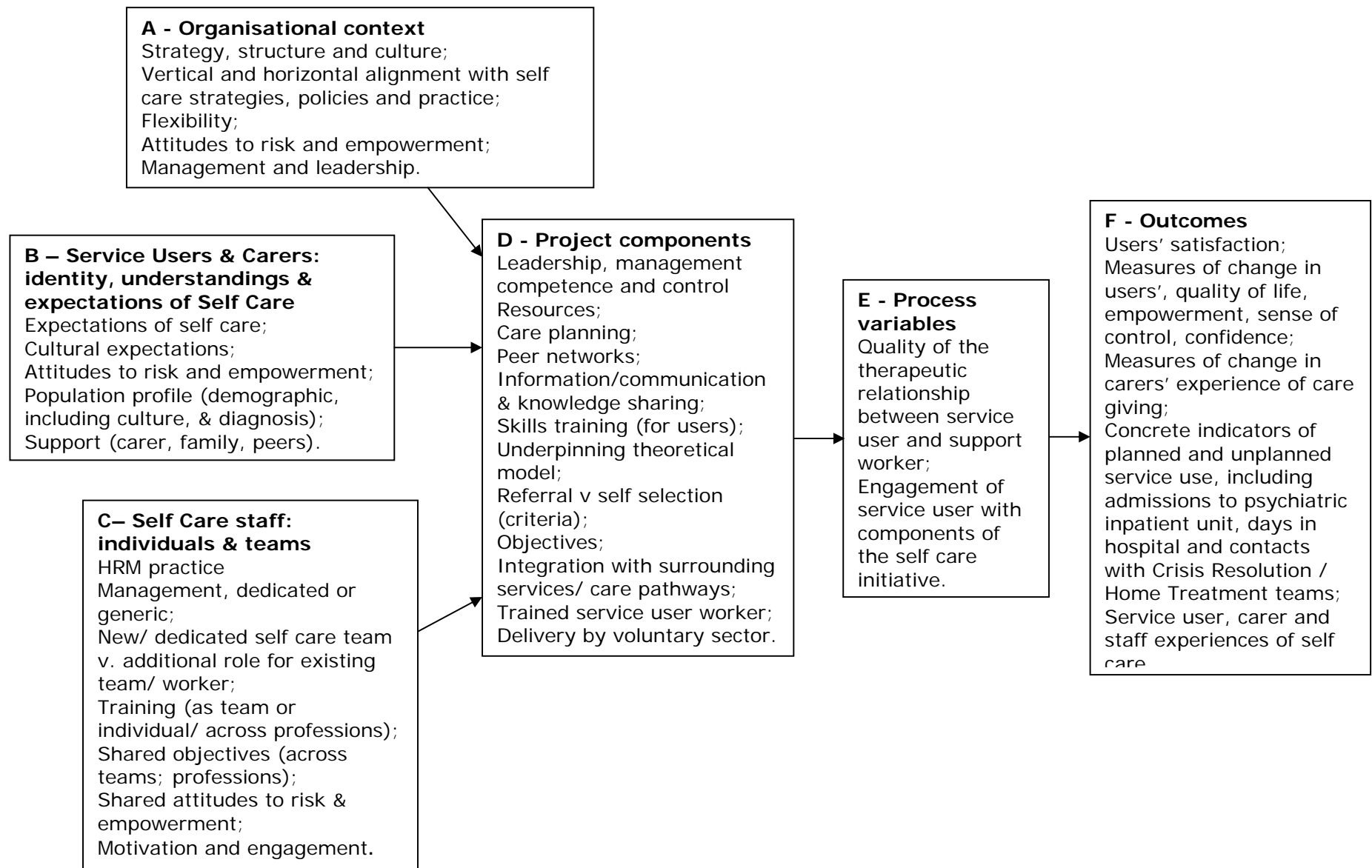
The theoretical framework identifies potential barriers and facilitators to providing self care support in Mental Health NHS Trusts in a number of domains: organisational context; frontline staff – managers, individuals and teams; self care project – structure and components; service user and carer – identity, expectations and experiences; processes. These domains are indicated in Boxes A-E respectively in figure 1 below. Each box contains a number of factors within each domain that might be expected to function as barrier or facilitator to self care support.

In addition, the framework identifies a number of outcomes that might be associated with effective support for self care by Mental Health NHS Trusts. These outcomes are largely derived from the team's reading of the self care literature presented above (sections 1.3.1 and 1.3.2). Self care outcomes are indicated in Box F of figure 1.

The figure given below is essentially literature driven. It is the intention of this study to re-present the figure in our conclusions (section 6.1), populating the domains with barriers and facilitators to supporting self care that we have identified by systematically testing the theoretical framework over the course of the study: to present an empirical framework for supporting self care in Mental Health NHS Trusts.

This framework poses a number of different research questions best addressed using a range of methods and at a number of levels of enquiry. The study design is detailed in section 3.1 below.

Figure 1. Theoretical framework for supporting Self Care in Mental Health NHS Trusts



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## 3 Method

Given the primary aim of the study – the identification of barriers or facilitators to supporting self care – we felt that an innovative approach to examining the processes at work in self care support was appropriate, as recommended in recent Medical Research Council (MRC) guidelines on studying complex interventions (Craig et al 2008). Taking a controlled trial approach (for example, to determine the effectiveness of a self care intervention in comparison to a control sample using NHS Trust mental health services as usual) would not fulfil the research funding brief because, as has been shown above (section 1.3.2), the evidence base for self care support indicates that current practice is extremely varied. Not enough is yet known about how self care might be supported in mental health (either generically or for specific conditions) to identify or develop an intervention that could be widely applied in mental health services and tested using trial methodology. Instead, we designed a study that would identify factors in the support of self care, at a range of levels, which might either moderate or mediate self care related outcomes.

Our review of self care literature also indicated a lack of an evidence base defining ‘self care outcomes’ (section 1.3.1). However, self care policy does indicate a range of outcomes that are the patient benefits of support for self care: increased service user independence, satisfaction with services and quality of life; reduced use of Accident and Emergency and other mental health crisis services (DH 2005a). It seems appropriate therefore, given the policy driven rationale for undertaking this study, to use a complex intervention approach in order to explore the extent to which potential barriers and facilitators of self care support are associated with self care related outcomes, as identified in the policy literature.

It is important to note that, in line with the complex intervention approach, analysis of change in outcomes was exploratory in nature and was used in order to identify factors that might be moderators or mediators of change in outcome. As such, a sample size calculation was used to guide the design of the study (for a range of quantitative measures), rather than to determine the size of sample required to detect meaningful change in a designated primary outcome measure, as would be the case in an effectiveness study.

Finally, given the exploratory nature of this approach, and the fact that improved service user experience lies at the heart of a number of the ‘self care outcomes’ cited above, it also seems appropriate that qualitative, as well as quantitative methods are used in order to identify and understand the range of possible factors related to the support of self care.

### 3.1 Study design

This study integrated qualitative and quantitative methods, incorporating a main stage comprising case studies of existing self care support initiatives, preceded by a local mapping exercise in the Mental Health NHS Trusts hosting the case studies, and followed by a final national mapping exercise.

### 3.1.1 Local Self Care mapping exercise

A local self care mapping exercise surveyed strategic managers in Mental Health NHS Trusts in order to investigate the implementation of self care policy and the provision of self care support in the Mental Health NHS Trusts in which case studies took place. This exercise provided organisational context for the case studies, as well as providing part of the data informing Box A (Organisational Context) of the theoretical model described above (section 2.2).

### 3.1.2 Case studies

A parallel set of in-depth case studies of initiatives providing support for self care - either directly provided or routinely referred to by Mental Health NHS Trusts - used mixed methods in order to identify barriers and facilitators to the provision of self care support by Mental Health NHS Trusts. Central to each case study was a mixed-method cohort study of people attending or using the self care initiative, plus their main, self nominated, informal carer (family member, partner or friend). Qualitative interviews were also conducted with staff and managers of the self care initiatives, as well as strategic managers in the host Trusts. Other documentary data were collected about the self care initiatives and host Trusts as appropriate.

Case study data informed the impact of organisational issues (box A of the theoretical model – see 2.2 above), staff teams (box C), project components (box D), service user and carer characteristics, expectations and experiences (box B) and process variables (box E) on self care related outcomes (box F).

### 3.1.3 National Self Care mapping exercise

A national self care mapping exercise sought, through online survey of strategic managers in all Mental Health NHS Trusts in England, to identify the extent to which case studies findings – barriers and facilitators of self care support – could be generalised to Mental Health NHS Trusts nationally.

## 3.2 Selection of sites

Sites were selected in order to offer a range of urban/ rural and socio-demographic environments, as well as contrasting examples of self care support initiatives, either provided directly by local Mental Health NHS Trusts or to which those Trusts routinely referred their service users. Because of the collaborative approach underpinning the study it was important that NHS or Higher Education institutions hosting local study sites had the capacity to properly support service user researchers. For that reason the initial search for research partners was made by the London based Principal Investigators through the invoNET database of researchers with an interest in public and patient involvement in research, hosted by INVOLVE. The partnership of the School of Health Sciences at the University of Southampton and Hampshire Partnership Foundation Trust, and the West Yorkshire NHS Research and Development (R&D) Consortium best fulfilled these combined criteria. They joined the lead partnership of the Division of Mental Health at St George's, University of London, Kingston Business School at Kingston University and South West London and St George's Mental Health NHS Trust. For the

remainder of the report the three study sites will be referred to as London, Hampshire and West Yorkshire.

At the London site the host Mental Health Trust was South West London and St George's Mental Health NHS Trust, and the self care project on which the case study was based was the Service User Network (SUN) project for people with Personality Disorder (see section 4.1.2 for detailed descriptions of case study projects), the only diagnosis specific project in the study. In Hampshire the host Trust was Hampshire Partnership Foundation Trust, and the self care project was the Wellness and Recovery Action Planning (WRAP) project. In West Yorkshire two Trusts hosted the study: Leeds Partnership Foundation Trust and South West Yorkshire NHS Partnerships Foundation Trust. This was because the self care project on which the West Yorkshire case study was based comprised of a range of creative arts projects operating within the West Yorkshire NHS R&D Consortium area, and the local research team considered that recruitment targets were unlikely to be met from a single Trust. The third Mental Health NHS Trust in the Consortium area – Bradford District Care Trust – agreed to participate in the research, and site specific ethical approval for the Trust was obtained as a contingency in case recruitment was insufficient at the other two Trusts.

### ***3.3 Local Self Care mapping exercise***

Face to face and telephone interviews were conducted with strategic managers in the Mental Health NHS Trusts hosting case study self care projects (in addition, some managers filled in the questionnaire by email where it was not possible to arrange a time for interview). Questionnaires were based closely on the questionnaire tool used in the 2005 DH study *Self Care Support: baseline study of activity and development in self care support in PCTs*, adapted slightly to suit the Mental Health Trust context.

The mapping exercise was conducted in order to provide organisational context for the case studies, as well as providing part of the data informing Box A (Organisational Context) of the theoretical model described above (section 2.2). In addition, responses to the local questionnaires were used in the development of the online survey tool for the final national self care mapping exercise (section 3.6.1).

Questionnaires elicited information on organisational strategy, leadership of self care, self care activity, staff training and risk management. The questionnaire can be found in Appendix 2.

Initial telephone enquiries were made of at least one board level Director within each Trust. Directors were asked if they would either complete the questionnaire themselves (by telephone) and/ or nominate someone else in strategic management in the Trust who was well placed to complete the questionnaire. Sampling continued in this way until at least two people in each Trust had completed the questionnaire, *and* there were complete answers for all items on the questionnaire (it was anticipated that some respondents would be unable to answer every question on the questionnaire because of lack of relevance to their area of responsibility in the organisation).

Documentation from each Trust – e.g. strategy and policy documents – was collected where they were referred to by respondents in order to inform the analysis of organisation issues in the case studies.

### **3.4 Case studies**

The generic recruitment, data collection and analysis plan for all three case studies is given below. Where there were local variations in the approach taken to data collection (due to local access and recruitment issues) these are indicated and the possible impact of any local variations on findings discussed where appropriate. Participants included people using the self care project selected for the case study, their principal informal carer (for example, partner, family member or close friend) and frontline staff working in the project (including project manager).

References are given in the text below to the box in the theoretical framework (section 2.1, figure 1) which is informed by each data set. A timeline for the study, indicating how the case studies fit with both the local and national mapping exercises is given in Appendix 3.

#### **3.4.1 Service users**

##### **Recruitment and sampling strategy**

At each case study site consecutive new referrals (or self referrals, depending on the structure of the project) to the self care project over a six month period were invited to take part in the study (the recruitment window was extended to nine months at all sites because of slower than expected take up of the self care initiatives by service users at each Trust). We aimed to recruit 40 participants at each site (see sample size calculation below). Potential participants were identified by self care project staff, given information about the research project and asked if they were willing to be contacted by a member of the research team. The preferred contact details of interested individuals were passed to the local research assistant who then contacted each person and, if they were still interested, made an appointment for an interview. All interviews took place in NHS Trust locations. Before interviews commenced research assistants secured the informed consent of participants. The recruitment process was reviewed and approved by an NHS Research Ethics Committee and all researcher assistants received Informed Consent training from an experienced researcher and research trainer on the project team (VM).

The recruitment process varied slightly from site to site, because of the different ways in which people accessed services. However, all sites included an element of self referral in the access process: having been informed of the project, service users exercised a high degree of choice over if and when they entered the project. This meant that there was no clear recruitment window between referral and first use of the service in which to conduct baseline interviews with service users. As a result, many participants had already attended introductory, or a small number of sessions at first interview. Interview questions asked about participants' expectations of the project (see below) were inevitably shaped by their reflections on early experiences of attending the project. Differences in access processes



between sites were explored in the baseline qualitative interview schedule (see below).

The inclusion criteria for the research project were in all cases the same as the inclusion criteria for the local self care project. The only additional exclusion criterion was at the West Yorkshire site. This was because some of the creative arts projects were provided outside of the Trust by voluntary sector providers. Where potential participants had no contact with the Mental Health Trust at all (for example, they had come from Primary Care) they were excluded from the study. This was because the study was about support for self care from Mental Health NHS Trusts. There were no other inclusion or exclusion criteria. This meant that the sample was different at each site. These differences are explored through quantitative and qualitative analysis throughout the report.

Sample size for the study was guided by the quantitative analysis strategy (section 3.4.7 below). In brief, recruiting 32 participants in each site would enable meaningful change in the range of outcomes detailed below - a within study medium effect size=0.49 - to be detected with 80% power at a 5% significance level. To allow for 20% attrition of the sample between baseline and 9 month follow up, 40 service users would need to be recruited at each site. Members of the research team had conducted studies with similar populations over similar follow up periods that had indicated that a 20% attrition rate was a realistic expectation.

On the basis of experience of studies with similar populations previously undertaken by members of the team, as well as discussion with members of the research team who were also NHS managers at case study sites (VM, SM, KG), both recruitment and retention were deemed to be feasible. Research assistants used newsletters, greetings cards and text messages to support retention. However, as WRAP groups were set up on an ad hoc basis in Hampshire, and a limited number of new groups were set up in community settings in the recruitment period, a decision was made to recruit from inpatient rehabilitation settings, in addition to community services as originally planned. There were implications for this decision for findings, discussed in section 4.2.4 below.

### **Baseline data collection**

At baseline all service user participants took part in an interview that comprised quantitative and qualitative components. The quantitative component, scheduled to last for 45 minutes, comprised the following:

A version of the Client Socio-demographic and Service Receipt Inventory (CSSRI) (Beecham, J and Knapp, M, 2001), adapted with the permission of the authors in order to collect data on gender, age, ethnicity, most recent psychiatric diagnoses, chronicity (length of time since first diagnosis), medication, accommodation, work and marital status (box B), as well as mental health service use over the 9 months preceding the interview (including, for example, admissions to psychiatric inpatient unit; number of contacts with psychiatric Accident and Emergency, Crisis Resolution and Home Treatment services; planned versus unplanned contact as above (box F). See Appendix 4;

A widely used, standardised measure of Clinical Outcomes in Routine Evaluation (CORE-OM) (Evans et al 2002) – a measure of clinical severity comprised of four subscales of wellbeing, symptoms, functioning and risk, that can also be

converted to give Beck Depression Inventory scores (Leach et al 2006) – in order that each case study sample could be described clinically at baseline (Box B);

A range of well validated, standardised measures of outcomes that have been indicated in the policy literature has being associated with self care (DH 2005a) (Box F):

User Empowerment Measure (Rogers *et al.*, 1997);

Schedule for the Evaluation of Individual Quality of Life – Direct Weighted version (SEIQoL-DW) (McGee *et al.*, 1991);

Mental Health Confidence Scale (Carpinello et al 2000).

It should be noted that the initial data collection plan also included a standardised measure of Locus of Control (Craig et al 1984). However at piloting both interviewers and participants felt that, because of the length time taken to complete the interview and because this measure was comprised of items that were similar to many of those in both the Empowerment and Mental Health Confidence scales, unnecessary burden was being placed on participants by its inclusion. The range of outcome measures used in the study is discussed in section 5.1.6.

The qualitative component consisted of a 45 minute, semi-structured interview that explored service users' understandings of self care, how they became involved in the self care project, their expectations of the self care project and their previous experiences of self care, both within in the Trust and with other agencies (Box B). A mixture of open and more specific questions were used in order to both enable interviewees to explore the issues that were important to them, and to ensure that certain data was routinely collected. The interview schedule was developed by the research team through an iterative process of team discussion and piloting with mental health service users who were similar to study participants. In particular, the views and experiences of research assistants, co-applicants and project advisors who had personal experiences of mental health issues were used to guide the development of the schedule. The baseline interview schedule can be found in Appendix 5. Interviews were digitally recorded and transcribed verbatim.

### **Follow up data collection**

After 9 months all service user participants were invited to take part in a second interview. The quantitative component comprised, at follow up;

The service use, accommodation, work and medication questions of the CSSRI only, asked about the 9 month period between baseline and follow up (Box F);

Structured questions about use of the self care project (for example, attendance at group sessions; production of a care plan; production of a crisis plan) tailored to reflect the structure of each case study project (Box E);

The set of outcome measures used at baseline (User Empowerment Measure; SEIQoL; Mental Health Confidence Scale) (Box F);

A standardised measure of satisfaction with the self care project – Client Satisfaction Questionnaire 8 (CSQ-8) (Nguyen et al 1983) (Box F);

Experience of the therapeutic relationship, measured by asking the participant to complete STAR (patient version) (McGuire-Snieckus, R. et al 2007) about the member of staff on the self care project with whom they had the most contact in the preceding 9 months (Box E).

All participants also undertook a semi-structured qualitative interview at follow up, again developed iteratively by the team and tailored where necessary to reflect the structure of the self care project at the three sites. Topics invited interviewees to explore their experiences of the self care project over the preceding 9 months (or for those research participants who had stopped attending the self care project, exploring why they chose to stop attending the self care project), changes in their understandings of self care and the care they received from the Mental Health Trust and other mental health service providers, their relationship with self care project staff and any changes in their views on self care, their mental health and in their wider lives that they felt might be associated in some way with their experiences of the self care project (Box F). The follow up interview schedule can be found in Appendix 6. Again, interviews were recorded digitally and transcribed verbatim.

Service user participants were paid £15 for their time for attending each one and a half hour interview.

### 3.4.2 Carers

#### **Recruitment and sampling strategy**

After their baseline interview each service user participant was asked if they identified with, for example, a partner, family member, or close friend as a primary informal carer. If they did so they were asked to give information about the study to that individual and to ask them if they would be interested in participating in the study. The service user participant was asked to give their carer the local research assistant's contact details if they were interested, in order that the nominated carer could contact the research assistant directly. Where carers were interested in taking part in the research, informed consent was taken prior to interview as above. From the research team's previous experience it was anticipated that because not all service user participants would nominate a primary carer and not all nominated carers would wish to participate, that recruitment rates would be low. Analysis of any quantitative carer data would therefore be wholly exploratory in nature. As this proved to be the case attempts were made to recruit additional carers at follow up.

#### **Baseline data collection**

At baseline all carer participants took part in an interview of one hour in length that comprised a qualitative and quantitative component. Interviews took place by telephone where it was not possible to arrange face to face interviews with carers in working hours. A semi-structured interview explored a range of issues similar to those covered in the baseline service user qualitative interview, about their understandings and expectations of self care for the person they cared for. Members of the research and advisory team who had personal experience of caring for someone using mental health services played a key role in ensuring the schedule explored carer perspectives on self care. The baseline carer schedule can

be found in Appendix 7. Interviews were recorded digitally and transcribed verbatim (Box B).

The quantitative component of the interview required only that basic demographic information (gender, age, ethnicity and relationship to service user participant) was collected, and that carers completed the Experience of Care Giving Inventory (ECI) (Szmukler et al 1996) (Box B).

#### **Follow up data collection**

At 9 months follow up, carers undertook a second semi-structured qualitative interview. This explored their experiences of the intervening 9 months in relation to their caree's use of the self care project and any changes in their lives and relationship over that period. The follow up carer schedule can also be found in Appendix 7. Again, interviews were recorded digitally and transcribed verbatim. Carers also completed the ECI again (Box F).

Carer participants were paid £10 for their time for attending each one hour interview.

### **3.4.3 Staff**

#### **Recruitment and sampling strategy**

Between 12 and 15 staff were recruited from the self care project at each of the three sites. As staff data was predominantly qualitative, sampling of staff participants was purposive. We sought to recruit as wide a range of staff roles as possible, including project manager, project workers representing the range of professions represented on the project team and, where appropriate, service user workers and voluntary sector staff involved in delivering the project. We also included up to five members of Trust staff at each site who did not work directly with the project but who had experience of referring service users to the project. Recruitment of staff was facilitated by the member of the research team who was involved in Trust management at each site (VM, SM, KG).

#### **Data collection**

Staff participants were interviewed once during the course of the study, with most interviews taking place in the window between the end of baseline service user recruitment and prior to service user follow up interviews. Semi-structured qualitative interviews covered a range of topics including project management and the structure of the project; whether teams/ managers were new/ dedicated to the self care project or existing/ fulfilling additional roles supporting self care; training received (individually or as a team); resources; team and individual objectives; attitudes to risk and empowerment; cultural understandings; motivation and sense of engagement with the self care initiative. Interviewees were also asked about having worked on other interventions and invited to reflect on which interventions they consider to be more effective in terms of outcomes that are important to them (Box C). Interview schedules were developed iteratively and piloted with Mental Health Trust staff. NHS managers on the research team (VM, SM, KG) and the study joint PI (CE) with expertise in Human Resource Management contributed in particular to the development of the schedule to ensure that it collected data and organisational issues that were of relevance to Trusts and their staff teams. The

interview schedule for staff working on the self care projects can be found in Appendix 8 and the interview schedule for staff who had experience of referring service users to the project can be found in Appendix 9. Interviews were digitally recorded and transcribed verbatim.

Finally, following service user follow up interviews, those staff that were identified by service user participants as being the member of the self care project staff team with whom they had had most contact, and about whom service user participants had completed the STAR (patient version) measure of the experience of therapeutic relationship (section 3.4.1 above), were asked to complete the STAR (professional version) about the service user (Box E). This was completed by telephone or by post, as was most convenient for the staff member, and re-completed for each service user as necessary.

It should be noted that London project staff refused to complete the STAR (professional version) about those service user participants who had nominated them. The team explained that the ethos of the SUN project meant that the individual service user's relationship was with the peer group, rather than individual staff members – that one of the aims of the project was to reduce dependence on individual staff members – and so it would be inappropriate for them to complete the measure. (However, it should also be noted that service user participants in London were happy to nominate and complete the STAR (patient version) about SUN staff.) The implications of this missing data for findings are discussed in section 5.1.5.

#### **3.4.4 Organisational interviews**

In order to understand the organisational barriers and facilitators to self care from the perspective of the care providers we conducted in depth semi structured interviews with between five and eight senior Trust managers and service leaders at different organisational levels and with varying roles and responsibilities in relation to the projects at each case study site (a total of 19 interviews were conducted across the sites). Participants were sampled purposively following the identification of key personnel involved in the implementation of self care policy in the local mapping stage, and then by snowball sampling as interviews took place. Interview questions were largely open ended in order that issues could be explored that were relevant to participants' areas of responsibility. Interview topics were informed by the theoretical framework for the study (section 2.2.) and included strategy and policy and their alignment within and between organisations, organisational attitudes to risk and empowerment, management and leadership, human resource issues, training and resourcing of staff teams and self care projects. The interview schedule can be found at Appendix 10.

The interviews were digitally recorded and transcribed verbatim, and were then analysed thematically.

#### **3.4.5 Quantitative analysis strategy**

Participant characteristic (sample) and outcomes data were first analysed descriptively. Subsequent detailed analysis proceeded in three distinct stages.

### **Stage 1 - Has there been significant change in the primary outcomes over 9 months?**

Continuous outcomes, which were normally distributed, were compared between baseline and 9 month follow up by the calculation of the mean difference and 95% confidence intervals. Effect sizes (ES) were calculated by dividing the mean difference by the baseline standard deviation. The discrete variables - number of psychiatric A&E attendances, use of Crisis Resolution and Home Treatment Teams, number of planned and unplanned admissions - were compared between baseline and 9 month follow up using the Wilcoxon signed ranks test. For ease of presentation these discrete variables have been categorised into appropriate intervals and the count and percentage of patients falling into each interval is presented. The p-values presented refer to the Wilcoxon signed ranks test result on the raw discrete variable. These analyses have been conducted within each site and overall.

### **Stage 2 – What indicators of service user engagement, experience of therapeutic relationship and user demographics are related to outcome at 9 months?**

In this analysis five dependent variables were analysed. These were quality of life (SEIQoL-DW), empowerment, mental health confidence, satisfaction (with self care project) at the 9 month follow up interview and whether hospitalised or not in the 9 month follow up period. The first four were analysed using analysis of covariance, the final one analysed using logistic regression.

The following baseline variables were tested for a univariate association with all five dependent variables: age; gender; marital status; highest education achieved; living situation; accommodation status; employment status; site; on typical antipsychotics, on atypical antipsychotics, on mood stabilisers, on antidepressants, on depot injections, number of psychotropic medications, choice whether or not to take medication as prescribed; excessive or problem drinking, problem drug use, chronicity (length of time since receiving mental health diagnosis), number of lifetime psychiatric admissions, CORE Well being score, CORE Problems and symptoms score, CORE Functioning score, CORE Risk score, CORE Non-Risk items score, CORE Overall score, BDI, STAR - patient version total. Engagement with the self care project, as defined in section 4.2.3 below, was also tested.

For the first four dependent variables, analysis of covariance was used to test for associations between each of the above variables and the dependent variable, while controlling for the baseline level of the dependent variable (except in the case of satisfaction, as there was no baseline measure of satisfaction). For the hospitalisation outcome, logistic regression was used, and whether someone was hospitalised in the 9 months prior to the study was included as a covariate. Variables found to be univariately associated with the dependent variable at the 10% significance level were retained for consideration for entry into a final model. Before conducting the final model, an assessment of whether these retained variables were independent of each other was made. Where variables were significantly associated, a decision would be made as to the most appropriate variables to enter simultaneously into the final model. The decisions made are described in section 4.2.5.

### **Stage 3 – What patient characteristics are associated with engaging in a self care project?**

The dependent variable in this analysis was binary and indicated whether someone opted for a higher or lower level of engagement with the self care project. This engagement variable is defined in section 4.2.3. Independent variables tested for possible association with engaging were age, gender, marital status, highest education achieved, living situation, accommodation status, employment status, on typical antipsychotics, on atypical antipsychotics, on mood stabilisers, on anti-depressants, on depot injections, number of psychotropic medications, choice whether or not to take medication as prescribed, excessive or problem drinking, problem drug use, chronicity (length of time since receiving mental health diagnosis), number of lifetime psychiatric admissions, CORE Well being score, CORE Problems and symptoms score, CORE Functioning score, CORE Risk score, CORE Non-Risk items score, CORE Overall score, BDI, STAR - patient version total, hospitalised in previous 9 months, SEIQoL, Empowerment, Mental Health Confidence Scale, all at baseline (baseline will be referred to as T0 and follow up as T1 in the results tables that appear subsequently).

Logistic regression was used and each independent variable tested univariately for an association with engagement. Variables found to be univariately associated at the 10% significance level were retained for consideration for entry into a final model. Before conducting the final model, an assessment of whether these retained variables were independent of each other was made. Where variables were significantly associated, a decision would be made as to the most appropriate variables to enter simultaneously into the final model. The decisions made are described in section 4.2.6.

#### **3.4.6 Qualitative analysis strategy**

The analysis of the qualitative data was a collaborative process involving the entire research team. It commenced early in the study after the collection of baseline data from the service user and carer participants and progressed in an iterative fashion throughout the remainder of the study. The process involved three key phases: (i) the development of an organising framework for analysing interview transcripts; (ii) writing concise analytical reports based on discrete sections of the data; (iii) producing an analytical narrative that articulates understandings of self care and experiences of self care support from a range of stakeholder perspectives. The analysis of the qualitative data was facilitated through use of the qualitative analysis software NVivo.

##### **Development of a qualitative thematic framework**

The organising framework which was applied to the service user, carer and staff data was developed through a three stage process. First, at each site, local researchers carried out a preliminary thematic analysis on a subsample of service user, carer and staff interviews – selecting to offer a range of contrasting views and experiences of the self care projects, using the ‘open coding’ tools of Grounded Theory (Strauss and Corbin 1998). This process generated themes emerging from the data.

Secondly, a matrix approach (Averill 2002) was adopted, with preliminary local site analysis presented to the entire study team by local researchers using a large visual matrix. This enabled comparison of the emerging themes across the three case study sites and across stakeholder groups, and the iterative development of a thematic framework that could be applied to the whole qualitative dataset. Themes were revised, refined or collapsed, and new themes generated using this process. Through whole team discussion, the full range of interpretative perspectives – service user and carer, academic and clinical – represented within the research team informed the development of the thematic framework. These discussions were audio recorded and, along with researchers' notes and 'memos' in the NVivo database, inform the final analytical narrative.

Finally, the framework that emerged was used to organise the entire dataset in NVivo. In NVivo, an individual theme is referred to as a 'node'. Descriptors for each node were developed and with the use of NVivo this consistency was promoted across the three study sites, while retaining the flexibility to respond to local variation: new themes were discussed and created, and the framework further developed, where data did not fit into existing themes. Once all the interview transcripts were coded into the thematic framework the local databases were merged into a master database to allow each site to have access to and work with the entire dataset in subsequent stages of the analysis process.

### **Producing a 'library' of thematic reports**

The second stage of the qualitative analysis strategy involved researchers at each site working across the dataset with discrete sections of coded data. An extensive list of 'queries' were identified from the framework, while additional queries were identified from emerging findings from the feedback conferences (section 3.5.1), and the results of quantitative analysis of covariance (section 3.5). The Matrix Query tool in NVivo enables a cross-tabulation of objects within the database: for example, particular nodes can be cross tabulated with a characteristic of the sample (called an 'attribute'), e.g. gender or study site. These attributes were derived from the quantitative data and imported into the NVivo database. Guided by a protocol (see Appendix 11), researchers used the matrix query outputs to produce concise written reports of the main analytical theme contained at each intersection of data. These reports highlighted the experiences which were common across the particular attributes and where differences were observed (for example, between study sites or between stakeholder groups). Quotations were selected from the NVivo database to provide evidence for this analysis and included in the thematic reports. As such, a library of reports was built up to be used as a resource from which to write this final report and other outputs stemming from the study.

### **Producing an analytical narrative**

The third stage of the analysis of qualitative data involved working with the query reports to draw out the key findings from the data. These findings were written up in the form of analytical narrative that, informed by the iterative process described above, captures the range of interpretive perspectives represented on the research team (that is to say, the analytical narrative was informed as much by service user and carer researcher perspectives as it is by clinical and academic researchers perspectives). This final qualitative analysis fulfilled three distinct functions:



- (1) To produce analytical narrative of understandings of self care, and expectations and experiences of self care support from the perspective of service users, their informal carers and the staff working in self care services (this is written up in sections 4.3.3 to 4.3.7);
- (2) To facilitate the synthesis of quantitative and qualitative data through exploration of interview accounts that reflect on findings from the quantitative analysis (section 4.4);
- (3) To complement analysis of the organisational context with relevant data from qualitative interviews (section 4.3.8).

This analytical narrative was produced through cycles of writing, reflection and revision undertaken by a number of members of the research team.

### **3.5 Data synthesis**

Case studies generated a large amount of both qualitative and quantitative data, from number of different stakeholder groups. A strategy for data synthesis was necessary in order to make sense of different data sets in relation to each other. Two main approaches were used to synthesise data generated in the case studies.

Firstly, the analysis of covariance described above (section 3.4.5) was used to guide a complementary analysis of qualitative interview data. Where there was statistical evidence of significant relationships between change in self care outcomes and moderating and mediating variables, these relationships were explored through queries addressed to the qualitative data, implemented using NVivo software (as described in section 3.4.6). This approach generated qualitative output that was explored in terms of congruence and incongruence with quantitative findings. This enabled qualitative data to be used to complement, explain and illustrate quantitative findings or, where there was incongruence, to indicate and illustrate where, for example, heterogeneity in the populations sampled was not articulated by the quantitative analysis (Thomas et al, 2004; Hay and Wilson, 2002).

Secondly, *feedback conferences* were used to provide a range of stakeholders at the case study sites the opportunity to discuss emerging quantitative and qualitative findings (see section 3.5.1). This offered the research process a degree of respondent evaluation from the perspective of the different case study sites and the different stakeholder groups involved. This provided the project with a further degree of data synthesis, enabling reflection on the relative importance of different data from a number of different perspectives.

#### **3.5.1 Feedback conferences**

Feedback conferences were held in each local Trust area in Trust premises, or premises routinely used by and accessible to Trust service users and staff. Feedback conferences have been widely used in Primary Care research as a means of eliciting the perspectives of a range of stakeholders on complex data sets (Iliffe et al, 2004). Conferences were held following the completion of case study data collection and preliminary analysis of both qualitative and quantitative data. Invited participants included: all participants in the study; other service users of, and staff

working in, the self care initiatives included in the case studies; staff and service users of other self care initiatives in the Trusts; Trust strategic managers and other stakeholders with an interest in self care, as identified by the research team over the course of the study. Conferences provided an opportunity to thank participants and to feed back preliminary findings to local Trusts, as well as enabling the synthesis and participant validation of preliminary findings.

At a whole research team meeting, preliminary analyses of qualitative data sets (service user and carer baseline and follow up interviews and staff interviews) were discussed in order to identify a range of factors that were emerging as potential barriers or facilitators to supporting self care in Mental Health Trusts. Those factors were grouped into themes, and each given a heading and a short definition.

The feedback conferences began with a description of the project, and a brief presentation of some of the headline quantitative data describing the sample of participants in each site and some of the main changes in outcomes that had been observed across all three sites. Qualitative data in the form of anonymised quotes from interviewees from the local case study were then used to illustrate the emerging themes we had identified.

A workshop format was devised for the conferences that would enable mixed stakeholder groups of 5-8 people to consider each theme in turn and discuss the factors making up the theme in terms of their personal experiences. Group facilitators took notes of the discussions. Large Venn diagrams were used to represent each theme and, following discussion, group participants were given stickers in order to rate whether they considered each factor to be a facilitator, a barrier, or both facilitator and barrier to the support of self care by Mental Health Trusts, or not relevant in terms of their personal experiences. For clarity we used the term 'help' for 'facilitator' and 'difficulty' for 'barrier'. People from different stakeholder groups (service users; carers; frontline staff; strategic managers) were given stickers of different colours. See Appendix 12 for an example of a theme Venn diagram.

Scores for different factors, as well as comments made by group participants, were briefly summarised and fed back to each conference at the close.

Local researchers wrote up summaries of comments on each of the themes, while the scores given to each factor were collated across sites and described statistically in order to compare how factors were related between sites and between stakeholder groups.

### ***3.6 Generalisation of findings***

A range of approaches were adopted to explore the generalisation of findings on a number of different levels:

- (i) Where identified barriers and facilitators to supporting self care can be generalised across mental health care, or where they are specific to particular sites, populations or services;
- (ii) Where findings from our cases studies can be shown to generalise to Mental Health Trusts across England;

(iii) Where identified barriers and facilitators to supporting self care can be generalised across health service sectors, or where they are specific to Mental Health services.

The synthesis of quantitative and qualitative data described in section 3.5 above enabled us to explore the extent to which findings could be generalised across mental health care. Where quantitative findings were significant across sites we did not assume the generalisability of findings because of the heterogeneity of the sample. Instead, we used these findings to direct in depth exploration of the qualitative data in order to consider whether approaches to supporting self care were core to the mental health service context, or represented micro-level approaches that were specific to particular service user groups, modes of service delivery and so on.

National mapping of implementation of self care policy in Mental Health Trusts in England (see 3.6.1 below) offered some indication of the extent to which findings from our case studies could be reasonably expected to be reflected nationally.

Finally, comparison of our findings with those of the other SDO self care teams (see 1.1.1 above), was indicative of the extent to which our findings were generic to self care across health services, or were particular to mental health.

### 3.6.1 National Self Care mapping exercise

A database of contact details of Board level managers in all Mental Health Trusts (including Primary Care Trusts providing mental health services directly) was compiled using listings provided by NHS Choices at:

<http://www.nhs.uk/servicedirector/Pages/MentalHealthTrustListing.aspx>

Web pages of listed Trusts were searched for the names and email addresses of the following Board level managers, selected to represent a range of strategic perspectives on the implementation of self care policy:

- Chief Executive
- Medical Director or equivalent
- Human Resources or Workforce Director or equivalent
- Director of Nursing or equivalent
- Director of Operations or Chief Operating Officer or equivalent

Trusts were then contacted by telephone through their switchboard and asked to verify the name, role and email address of each individual. Email requests for that information were submitted where requested by the Trust. Where Trust websites did not list individuals in the roles indicated they were asked by telephone to identify individuals in those or equivalent roles.

An online survey was prepared using Survey Monkey software. The survey comprised an adapted version of the questionnaire used in the Local Mapping exercise (section 3.3). The national survey was adapted on the basis of answers to the local survey (for example, because respondents to the local survey referred extensively to strategic initiatives related to self care – e.g. Recovery; Social Inclusion – the national strategy asked explicitly about other strategic initiatives).

Most 'open box' type questions were also removed in order to avoid collecting too much unstructured data that would not efficiently inform our assessment of generalisation. The national survey also included a range of questions about activity in support of self care in Trusts informed by our case study findings. This was in order to assess the extent to which similar findings were observed nationally. The questionnaire for the national survey can be found in Appendix 13.

All managers on the database were sent an email explaining the study and containing a web link directing them to the survey. There was a one month deadline to complete the survey. Two further email reminders were sent to all managers. The email also contained a unique reference number for each Trust, which managers were asked to include in their survey response. This was to enable us to identify the range of Trusts from which we received responses while maintaining the anonymity of the individuals concerned.

Responses to the survey were analysed using descriptive statistics only.

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## 4 Findings

Findings will be presented below in a sequence that allows each dataset to provide context for the data that follows, gradually building up a mixed method, empirical narrative that describes support for self care in the three case study sites. As such we will begin by describing the case study sites (section 4.1) geographically, demographically and by host Mental Health NHS Trust. The local self care mapping exercise (section 4.1.1) will provide data on self care strategy and activity in each of the host Trusts, before describing the self care projects that will be the focus of the case studies (section 4.1.2). Analysis of the qualitative interviews with senior and strategic management within each Trust will follow (section 4.1.3) in order to provide strategic level insight into issues around implementing self care policy in each site.

Section 4.2 will present quantitative findings, beginning by illustrating recruitment and retention to the case study cohorts (section 4.2.1). The samples at each site will then be described (section 4.2.2), as will those who dropped out of the study. The implications of this drop out for findings will be discussed. The specific operationalisation of the 'engagement with self care' variable at each site will be explained (section 4.2.3). The three phases of quantitative analysis, as described in the quantitative analysis plan (section 3.4.7) will then be presented and discussed. Finally the therapeutic relationship variable will be analysed and discussed (section 4.2.7).

Section 4.3 will present qualitative analysis, again in phases as described in the qualitative analysis plan (section 3.4.6). The section will begin by introducing the qualitative thematic framework produced over the course of the qualitative analysis process (section 4.3.1), before presenting analysis of 'understandings and expectations of self care' data, largely collected at baseline qualitative interviews (section 4.3.2). The feedback conferences held at each case study site are then reviewed, with consideration given to how the respondent validation achieved through this process has shaped the emerging qualitative analysis (section 4.3.3). The analysis of the main qualitative dataset, comprising service user, carer and self care project staff experiences of the self care project, is then presented in some detail (section 4.3.4).

Presentation of findings concludes with a systematic synthesis of quantitative and qualitative analysis (section 4.4), carried out as detailed in section 3.5.1 above.

### ***4.1 Describing the sites***

The three sites covered South West London (South West London and St George's Mental Health NHS Trust - SWLSTG), Hampshire (Hampshire Partnership Foundation Trust - HPFT) and West Yorkshire (Leeds Partnership Foundation Trust – LPFT - and South West Yorkshire NHS Partnership Foundation Trust – SWYPFT). The London site includes both inner city boroughs with a highly diverse population

and high levels of economic deprivation, as well as more affluent suburban boroughs. The general population served by SWLSTG is 996,500 (Male 487,800 (49%), female 508,700 (51%), white 808,300 (81%), black 50,800 (5%), Asian 77,900 (8%), Chinese or other ethnic group 30,800 (3%), mixed 28,700 (3%), not stated 500). For West Yorkshire, LPFT serves the metropolitan district of Leeds with a highly diverse population in terms of socio-economic status and ethnicity. The general population served by LPFT is 715,402 (Male 345,754 (48%), female 369,648 (52%), white 657,082 (92%), black 10,318 (1%), Asian 32,290 (5%), Chinese or other ethnic group 5,975 (1%), mixed 9,737 (1%). SWYPFT serves a wide geographic area including urban and rural communities and a highly diverse population in terms of socio-economic status and ethnicity. The general population served by SWYPFT is 703,739 (Male 342,042 (49%), female 361,697 (51%), white 640,709 (91%), black 5,683 (1%), Asian 48,536 (7%), Chinese and other ethnic 1,950 (<1%), mixed 6,861 (1%). HPFT serves the areas of rural Hampshire (excluding Portsmouth) and the city of Southampton. The total general population served is 1,457,548 (Male 714,198 (49%), female 743,350 (51%), white 1,413,674 (97%), black 5588 (<1%), Asian 17,418 (1%), Chinese or other ethnic group 9028 (1%), mixed 11,943 (1%).

Of the four Trusts that were included in the study, LPFT gained foundation status as data collection was beginning, HPFT as data collection was ending and SWYPFT as the study came to a close. At the time of the study, SWLSTG was in the process of applying for foundation status. SWLSTG employs 2,700 staff and received a 'good' healthcare commission ratings on Quality of services and Use of resources for 2007/2008. HPFT employees over 4,500 staff and received Healthcare commission ratings of Excellent for Quality of services and 'Good' for Use of resources in 2007/08. LPFT employs 2,800 Staff and received 'Good' for Quality of services and 'Excellent' for Use of resources in 2007/08 Healthcare Commission ratings. SWYPFT employs approximately 2,300 staff and received 2007/08 Healthcare commission ratings of 'Excellent' for quality of services and 'Fair' for use of resources.

#### 4.1.1 Local mapping – policies and provision

Local mapping questionnaires were completed by telephone at all four case study Trusts, following snowball recruitment of senior managers in each Trust. A total of 14 managers participated, comprising three respondents at each of SWLSTG, SWYPFT and HPFT, and five respondents at LPFT. The range of roles of respondents included Medical and Operational Directors, Heads of various policy driven initiatives (e.g. Recovery), Nursing Directors, Human Resources Directors and a range of other board level and strategic management roles. The data reported below provides organisational context to the case studies that follow, and was also used in the development of the national self care mapping exercise, reported in section 5.4.1.

##### Note

It is important to note that the data reported below represents the opinions of respondents and **not** the Trust's official position on self care strategy and activity.

*Self Care strategy*

There was broad similarity across the four Trusts in responses to the opening questions about self care strategy. Respondents indicated that none of the Trusts currently had a formal self care strategy, and only one Trust – Hampshire Partnership Foundation Trust – was in the process of developing a self care strategy. Instead a broad range of other strategies and strategic initiatives were indicated by respondents as incorporating elements of self care:

**Table 1. Trust strategies incorporating self care**

<b>Trust</b>	<b>South West London and St George's Mental Health Trust</b>	<b>Leeds Partnership Foundation Trust</b>	<b>South West Yorkshire Trust</b>	<b>Hampshire Partnership Foundation Trust</b>
<b>Strategy or Initiative</b>	Recovery and Social Inclusion Strategy Co-creating Health Initiative Personalisation and Self Directed Care	Care Programme Approach Recovery Model Essence of Care Social Inclusion Workplace Employment and Training People Involving Strategy Council Vocational Skills Group Social Enterprise WRAP Crisis Planning	Integrated Packages of Care Strategy Day Services Social Inclusion Review Policy Recovery Model Patient Centred Care Psychological Interventions Strategy Practice Effectiveness Strategy Essence of Care Nursing Strategic Plan	Clinical Governance Strategy Public Health Strategy WRAP Occupational Therapy Service Safeguarding Children and Adults policies Planet Psychosis Physical Health and Wellbeing Strategy (in development)

#### *Self Care leadership*

Respondents from three Trusts stated that they had a named self care lead (SWLSTG had two) and, reflecting findings on self care strategy, respondents from all Trusts indicated that responsibility for self care leadership fell to a number of roles, at a range of strategic, service and professional management levels:

**Table 2. Trust roles with leadership responsibility for self care**

<b>Trust</b>	<b>South West London and St George's Mental Health Trust</b>	<b>Leeds Partnership Foundation Trust</b>	<b>South West Yorkshire Trust</b>	<b>Hampshire Partnership Foundation Trust</b>
<b>Role</b>	*Director of Quality Assurance and User and Carer Experience *Head of Recovery and Social Inclusion Borough Recovery and Social Inclusion Leads Chief Operating Officer Director of Social Work	*Service User Involvement Facilitator Lead Manager of the Patient and Public Involvement Directorate	Director of Nursing, Compliance and Innovation Medical Director Modern Matrons Head of Nursing	*Lead for Physical Health and Wellbeing Care Programme Approach Lead WRAP staff Consumer Advisor

\* Trust lead for self care

Note: roles indicated above are not a list of respondents.

### *Self Care activity*

Respondents reported that their Trusts had the following types of self care support projects in place, with care planning approaches and peer support networks represented in all Trusts:



**Table 3. Self care activity**

<b>Project</b>	<b>Trust</b>	<b>SWLSTG</b>	<b>LPFT</b>	<b>SWYPFT</b>	<b>HPFT</b>
Patient education/ self care skills training (e.g. Expert Patients Programme)		Yes	Yes	No	Yes
Health and social care information		Yes	Yes	No	Yes
Care planning approaches		Yes	Yes	Yes	Yes
Self diagnostic tools/ monitoring devices		Yes	Yes	Yes	DK
Peer support networks		Yes	Yes	Yes	Yes
Home adaptations		Yes	Yes	Yes	No
Community pharmacy scheme		Yes	Yes	No	Yes

DK = Don't Know

All respondents reported a range of initiatives. These included a number of smaller projects at each Trust that were taking place within single or small groups of teams or services within the Mental Health Trust (e.g. a service user Buddying scheme in a High Secure Forensic service in HPFT, a Health and Wellbeing pilot project in Community Mental Health Teams and peer support groups in a small number of inpatient wards in SWLSTG, and use of the TIDAL model in one inpatient ward in SWYPFT). There were a number of externally financed initiatives (e.g. the Care Services Improvement Partnership funded Futuresteps exercise programme in HPFT), some of which were national pilot projects (e.g. the Co-creating Health self management for depression project, delivered by SWLSTG in partnership with the local PCT and Health Foundation as one of seven national pilots, and a national pilot of a New Directions Team, delivered in partnership between SWLSTG, Social and Housing Services, and local police). There were a number of healthy living or wellbeing type projects, often with a physical health component (e.g. a Lottery funded Improving Health project in HPFT, employing Health and Wellbeing workers), some taking place in partnership with PCTs (e.g. Healthy Living groups for obesity, and a Self Help Access in Routine Primary Care project delivered with the local PCT by SWYPFT). There were a number of social care type projects run in partnership with Social Services Departments (e.g. links with the New Forest District Council Leisure Services and Hampshire Libraries in HPFT and an Individualised Budgets pilot in partnership with one Local Authority in SWLSTG). There were a number of Social Inclusion type projects, (e.g. the Buster Cafe social enterprise project in LPFT) some of which were delivered by, or in partnership with voluntary agencies (e.g. the Arts and Minds Network delivered by voluntary partners with LPFT). There were few Trust wide initiatives within the Trusts themselves (e.g. a Pharmacy Helpline and Patient Information Leaflets from the

pharmacy in SWLSTG, as well as a Trust wide roll out of SWLSTG's home grown Personal Recovery Plans, in addition to WRAP in HPFT).

#### *Training for Self Care*

Respondents reported a wide range of training broadly in support of self care, some of which were Trust wide or linked to new staff induction, others associated with specific roles or initiatives:

**Table 4. Training in support of self care**

<b>Trust</b>	<b>South West London &amp; St George's Mental Health Trust</b>	<b>Leeds Partnership Foundation Trust</b>	<b>South West Yorkshire Trust</b>	<b>Hampshire Partnership Foundation Trust</b>
<b>Training</b>	Recovery Training Recovery Awareness Co-creating Health Training Support, Time and Recovery Worker Training	Staff Induction Course Staff Shadowing Scheme	Training for Wellbeing Nurses Guided Self Help PSI Awareness Training Recovery Medicines Management Tidal Model	Health Trainers training National Step-O-Meter training CPA Awareness and Coordinator training Assessment and Positive Risk Taking Smoking Cessation

#### *Risk and Self Care*

Respondents acknowledged that their Trust risk policies and risk training does not specify self care, but that aspects of self care, for example, positive risk taking and risk assessment, were covered by current risk policies and training, or in the case of one Trust, would be covered in a risk policy in development. A respondent from SWYPFT stated that the Trust's Advance Directives policy covered elements of self care.

#### **4.1.2 The projects – WRAP, SUN and creative arts**

##### **London - The SUN (Service User Network) Project**

The SUN Project is a Service User Network, which runs regular peer support groups in the community for people with personality disorder (although a formal diagnosis is not essential). The groups are open access through self-referral and new members are required to fill out a crisis and support plan. Support is ongoing and there is no discharge. Members can choose when and how often to go, without being excluded if they do not attend for any length of time. As well as general support groups, members can access practical support groups, social activity groups and an Out of Hours Peer Support (OHPS) Service. The SUN Project is jointly led by service users and professionals. Members can apply to become paid support facilitators of the groups. The project is informed by Coping Process Theory (Lazarus 1993). The SUN was initially set up as one of eleven national pilots of personality disorder community services and was originally funded by the Department of Health and. The project is now commissioned and funded by local Primary Care Trusts.

##### **Hampshire - WRAP (Wellness and Recovery Action Planning)**

The WRAP approach was developed in the USA by Mary Ellen Copeland from her personal experience and is based on Recovery and Self management approaches. The approach focuses on wellness and the development of a personal plan, made up of eight sections which include wellness tools, identification of signs of crisis and the development of plans for times when the individual is less well. The WRAP Project is supported by Hampshire County Council Adult Social Services, is located within HPFT and comprises a small team of WRAP trainers. The project aims to train, supervise and support staff and service users across HPFT to become WRAP facilitators. These facilitators then support service users to develop their own WRAP, primarily in groups but also on an individual basis. The WRAP Project was initially funded by Skills for Care for four years and since March 2007 has been funded by Hampshire County Council and HPFT. During the course of the project a number of partnerships with local service user-led organisations have developed.

##### **West Yorkshire - creative arts Projects**

In West Yorkshire 11 different creative arts projects were included in the study. A small proportion were fully or part funded by the local Trust: either LPFT or SWYPFT. The majority were run by the voluntary sector and were funded through competitive tender to a variety of funding sources, statutory and third sector, often on an annual basis. All projects are delivered in partnership between the Trusts and the voluntary services. The creative arts projects were quite diverse and worked with many different mediums, such as music, dance, drama, singing, art, crafts, printing, upholstery, digital photography and media. Some of the projects were time-limited lasting on average between 6 to 8 weeks, whilst others were ongoing and all involved group-based work. Projects are broadly informed by the Social Inclusion approach.

### 4.1.3 Organisational interviews

A total of 19 senior managers were interviewed across the 3 sites. Their roles included managers within nursing, governance and risk management, general management (including those specific to mental health), human resources, medicine, Care Programme Approach, education and training, and service commissioning. Analysis of the interviews yielded a number of themes, which were largely consistent with the issues identified in the organisational literature and incorporated into Box A of the theoretical framework. Sources are indicated using a six digit code, the first two letters of which signify the case study site (LO = London; HA = Hampshire; WY = West Yorkshire), followed by OR (signifying organisational interview) and a two digit source number for the site (e.g. LOOR01 signifies the first organisational interview completed at the London site).

#### Alignment in strategy

Since the inception of the research in 2007 a number of strategic priorities in health and social care have been developed that incorporate core elements of the original self care strategy, including, specific to mental health, Recovery (SCIE 2007) and aspects of the revised Mental Health Act Code of Practice (DH 2008c) related to decision making, and more generally, but with specific reference to mental health, Personalisation (DH 2008b) and the NHS Next Stage Review DH 2008a). These include or supersede many aspects of self care. Recovery, in particular, was seen by respondents to encapsulate many of the self care elements.

In order to explore these issues we examined documents related to trust strategy in the four case study Trusts. All had some form of Recovery, Social Inclusion or Wellbeing strategy in place, or were in the process of developing one. Other initiatives mentioned were wellbeing, personalisation and the impact of revision to the Mental Health Act in terms of, for example, Advanced Directives. Our management interviewees were asked what they understood by the term self care and to discuss how far it is different or similar to existing Trust strategies. Views varied as to the extent to which the core elements of self care were included. Nonetheless, all acknowledged significant overlap between the self care objectives of the case study projects and those of recovery and social inclusion. Perhaps even more salient was that case study projects were seen by managers and staff as a means of delivering or at least contributing to the delivery of these key strategies.

In the case of the SUN project, alignment with Trust strategy appears to be close: the Trust Recovery and Social Inclusion Strategy embraces all the elements of self care, and puts service users at the heart of its operations. A top manager commented on the close relationship between self care and recovery and also noted that SUN was a good example of the expert patient approach:

'It [SUN] fits really, really well [with Recovery] because they embody actually what recovery is about, because recovery doesn't mean that you get better and you're symptom free, it just doesn't, you know, it does in layman's terms, but not this, that isn't what this is about. Recovery is saying that we recognize that you have an illness, often a chronic illness that will be with you forever, if you've got diabetes it's the same, but we also recognize that you know generally what helps and what makes you feel better.

'I would put them under the heading of Expert Patient Program because I think that not only are they learning about themselves therapeutically, and how to cope with whatever symptoms they have, but they're also helping other people, and they're helping professionals to learn, about how to look after people, who have whatever it happens to be...' (LOOR04)

This did not mean however, that the link between the Trust's recovery strategy and the SUN project was obvious to everyone:

'Some would say in a way, they've been doing Recovery since its inception ... because it is about putting the user at the centre and saying, 'what are your goals and aspirations, how do we support you to get down that path?' The organization probably hasn't linked them quite as powerfully as they could, although the staff with the experience have, have been part of both. From a local implementation point of view, for all five boroughs, the SUN is very much seen as our flagship, service user-led services ...' (LOOR02)

Others saw SUN as a useful, but small, contribution to delivering overall recovery objectives and only one model:

'I think I would regard the recovery concept and its principles to be much broader than just projects like the SUN project ... The fact of the matter is for some people it is good and right to have very little medical involvement and let them flourish and help themselves and help each other in the SUN project-type setting, for other people that setting will not do and they will require more structured delivery of care, they will require more directed type care delivery depending on their condition, but always bearing in mind the principles of the recovery approach.' (LOOR05)

The Trust hosting WRAP had also embarked on a recovery strategy and other initiatives which include elements of self care. WRAP was seen by some interviewees to be a model for the delivery of the Trusts Recovery Strategy, and to have had wider influence on the culture of the organisation:

" I think what [WRAP] does is it helps to move the culture of the organisation forward; it does mean that we'll be key national drivers; it does give the Trust kudos; it does put us in a good position when we look at personalisation, when we look at choice,, we're not starting from scratch, we're starting from a good position – if you think about what I said about us getting into much more partnership work with our voluntary sector, it helps us with that – we already know a lot of the voluntary organisations out there, probably have a relationship with them too; so it does all of that really.' (HAOR04)

However, WRAP was not seen as the only model for the delivery of the recovery strategy nor that it was necessarily appropriate for all services:

'Within this Trust there are probably two or three different types of models around and WRAP is probably the predominant one ... there are other models of recovery around, such as the TIDAL model of care, and different experiences or different understandings of what recovery means in some of the different Directorates. So WRAP is seen very much I think as an Adult Mental Health thing that has more recently I think expanded into learning disabilities with the – 'About Me' heading.' (HAOR05)

'I have never done any of the WRAP training ... but the concept of people determining their own care plan isn't new ... for some people the term 'WRAP and Recovery are synonymous. For others it's absolutely two fundamentally different things, and people can get very passionate about it. And it's about seeing the wood for the trees.' (HAOR03)

Overall however, alignment with the recovery strategy was felt to be beneficial for the project:

'I think there is always going to be barriers to new ways of working. And I think the Trust have tried to overcome some of that by setting some strategic goals. One of the good strategic goals that they have tried to set was ... was the fact that they said that 75% of all Care Plans should be Recovery focused. And having a Recovery focused Care Plan could be evidenced by somebody having their own WRAP Plan, and I think that was a driver.' (HAOR05)

As it was in West Yorkshire:

'I think given the Organisation's overall mission and vision by using goals, it fits in very well with that; it's completely compatible with that.. It fits in as part of the journey towards recovery.' (WYOR05)

'I think it sits nicely. I think the two go hand in hand ... if we look at the overarching concept of recovery it's about for me putting a marker down and saying that people can recover from mental illness. That recovery is about what they perceive as being recovery and not what other people may perceive as being recovery.' (WYOR04)

It was clear from interviews that projects had been 'sold' to the Trust, and to commissioners and social care partners, because they incorporated key elements of recovery and related policies (for example, the importance of individualised budgets to the Personalisation agenda), often fitting well with the Trust's wider social care objectives:

'I see it as, as something also in line with the new social care big organisation. But in fact the whole idea of, you know, direct payments, or you know, individuals actually in charge of their finances, in order to be able to work out their own care pathway, so we've been selling it, reinforcing it, I think at a Board level and then at an executive director level it is very well sold. And our last big PR thing was over the local improvement plans. And we did a big PR thing saying, 'well you all know, you've got a SUN Project in your borough, what do you mean, we're not service user led? We're awesomely service user led'. You know, most Trusts don't, can't sincerely say they've got proper service, user-led service. So we did a really big, 'look, we can do you a favour, you've just got to know we exist and support us'. (LOOR03)

'It seemed to be health but if you actually sat down and thought about it, it is about social care because it's about giving people ways of coping with their everyday lives not just their clinical presentation ... About giving them strategies to deal with a relationship or a particular situation. So it does cross the boundaries. It does fit nicely into other [Personality Disorder] services that we have locally.' (LOOR08)

'WRAP kind of fitted in with other work that we were doing around recovery. ... It's being piloted, again it's national, it's about individualised budgets and all of that which is being rolled out across adult services throughout the country It includes mental health ... I'm not just talking about mental health here, it's self care, self directed support, services in control, etc , that is all where it's going at the moment and so WRAP fits in with that and so that is one of the reasons I think why adult services are funding WRAP now.' (HAOR02)

'I think that things like our recovery model, the strategies we've talked about that are incredibly integrated within our organisation and we do have a practice effectiveness group across that looks at things like the [NICE guidance] etc. At that level its fine and we know about some of the projects and encourage people to go and facilitate people to engage into projects.' (WYOR01)

### **Resistance to change**

Alignment of self care projects with related strategies, both at national (Department of Health) and Trust level, with social care priorities and with the priorities of senior managers did not guarantee support at the lower levels of the organisation. While there may be agreement on aims there may not be consensus on the means by which they are to be achieved. All three of these projects were employing novel ways of delivering care. Recovery and self care strategies entail significant cultural change for some staff, and there was evidence of a degree of difficulty in implementation, and tension in the working relationships with host organisations:

'I think the problem is, I think a big difficulty is that – and I guess I'm talking about the recovery approach and self management in that context – a big difficulty is that it is such a culture change, it is a completely different approach to all of our interactions with each other, with service users, in terms of organizing ourselves around a, and with a person. And I think that's a big challenge isn't it? Because everybody's really up to their ears with the work they're doing already, to start thinking about things differently is very difficult.' (HAOR13)

'Draft NICE guidelines came out recently that say people should have access – this Trust says everybody should ... But there are clinicians who are very uncomfortable with people with personality disorder so they try to discharge them and say 'I've got nothing for you so I'm discharging you from the service', you know the remnants of discomfort and in some cases hostility. So it's patchy, it's patchy.' (LOOR01)

There was also the view that the traditional medical model and the power structures and professional cultures that support it are not easily shifted:

'Our organizational structures fit with a traditional medical model, and so that's a challenge. And (recovery) also challenges people in powerful positions, so traditionally psychiatrists have been very powerful, and if we are starting to think about self management, then that power structure is likely to be, well actually challenged. That's a challenge for all those individuals. That's not to say that individual psychiatrists are not adopting this approach, because I know many that are. But organizationally, that's going to be difficult.' (HAOR13)

Pressures of work mean that other priorities take precedence and there is a failure to implement at the middle management level:

'So we try to raise awareness about the need for self management or to offer opportunities to work through these tools, WRAP in particular. Trying to support clinicians working in the units and indeed community, who are using WRAP. I think the tricky thing is that again, because people are up to their ears with the demands of work and there's so little slack in the system, because this is not a kind of a 'must-do', and because perhaps managers aren't prioritizing this because it's not a 'must-do' for them, then it can quite easily fall off the edge, really, because there's so many other things that people have to do.' (HAOR13)

'I think people are becoming more familiar with the term 'recovery'. It's used in some strategic documents, but there's a gap between that and the WRAP; there's a gap in the middle. The gap in the middle is "how do we operationalise strategy to change the culture?"' (HAOR03)

'I guess one of the barriers has always been lack of time, because when you are looking at lots of organisations working together some of whom in the arts world are very much funded on the results and the activity that they do, this is something above and beyond.' (WYOR03)

And, as one interviewee noted in West Yorkshire, top level endorsement of a strategy of working together may not be sufficient to overcome the cultural difference between large NHS Trusts and small arts organisations:

'There are organisational barriers around a potential conflict. The Trust for instance is a very large organisation; organisations like [creative arts organisations] are small arts organisations, different cultures, different ways of working, there have been I guess, cultural barriers around people's perception of the validity of the arts having a role within mental health. Although that I have to say at the top of the organisation there is a lot of support, but when it comes to getting money ... it's been seen as less of a priority.' (WYOR03)

## **Training**

A picture of training for self care support emerged from local mapping of the three sites: none mentioned training programmes for self care per se, but elements of self care were included in training related to a number of Trust initiatives, particularly around recovery, well being and social inclusion. Thus the delivery of self care training was fragmented, and it was only in London that there was a Trust-wide training programme specifically designed to support the implementation of the recovery strategy. Nonetheless, West Yorkshire interviewees spoke about relevant training:

'I think training that enables people to put themselves in another person's shoes can be very helpful to see things from another perspective. With the Arts and Minds we do actually run training for staff around how to use creativity in their practice and we use very creative and experiential approaches so they actually do some of the work they might be doing as service users.' (WYOR03)

'One of the positive things that we have done, that we employ the Hole in the Head Theatre Company who can film a piece of art, at our six weekly Trust induction. And that's the induction programme that every member of staff has



to go on to as part of their Terms and Conditions of Employment. And – they actually deliver a play but they don't like you to say that's a piece of art I think, and after that it talks about the service user journey and the experience of some of the people who are delivering the artwork, because they've all been service users. And then there's a private facilitated discussion to the people who are delivering and the participants on the induction programme. And it evaluates extremely well because it's not just clinical staff who are attending that, it's people in finance, and facilities. It's absolutely for everyone.' (WYOR05)

Training was at the centre of the WRAP project and, as has been noted above, it was generally recognised as a programme supporting the Trust's recovery strategy. However, in the view of one interviewee there had been a failure to integrate it into mainstream training, and this was felt to be to the disadvantage of both Trust and to the integration and expansion of the WRAP project:

'What seems to me is what's missing is this coordinated trans-trust approach to recovery, the approach, what does it mean? What does the philosophy mean? How are you going to embed that in lots of different training courses? ... So I wouldn't be surprised if there was a sense of frustration ... that somehow things have got stymied at a certain level because I am not sure that the structure or the people are involved to be able to make something happen beyond local courses based on somebody's enthusiasm.' (HAOR03)

The role – and challenges - for training programmes to not only facilitate self care, but to achieve significant cultural change was widely discussed:

'Well I suppose there are two issues for me really. There is obviously if you are looking at somebody coming into the profession, then there is something about pre-reg. education training, has to focus on a philosophy around self care and has to promote this notion of nursing being, working with, rather than doing to.

If you are looking at working within services already and you are trying to promote more self care, then I think what you have to do is look at the culture of the environment that you are working in because sometimes it's a cultural shift. So for me that's very much about leadership. You have to lead by example, you have to develop role models within your team or service area that can actually demonstrate what self care, working with somebody in a self care way, would look like. So it's actually teaching by example rather than in a classroom setting ... So it's about us embedding into the organisation that value and our aspirations, and I'm not sure ... running the odd course on WRAP will do that for an organisation, it's bigger than that ...' (HAOR03)

'The SUN staff would say, 'why do we need to go on Recovery training?' "Because that's what we do" I would say. "You need to go and make sure you've up-skilled all the rest in your group, because you'd be really fabulous to have there." (LOOR02)

'... I think you've made me think about how we probably haven't sold ourselves properly to ... to have helped do the Recovery work. Because I think that's a shame that we could have, we could have supported [delivery of the recovery strategy]. Whether they would have wanted it, I don't know, but seeing as it doesn't clash, it perfectly mirrors, it does seem a bit bonkers that, we don't sit

around together straight away, even if it was for a one-off bit of learning.’  
(LOOR03)

### **Funding and Resources**

The issue of funding and resources was a major concern for virtually all the managers we interviewed. As was reported in section 4.1.2., sources of funding for these projects varied. The West Yorkshire creative arts projects were variously jointly funded by Trust and the Local Authority, commissioned by Primary Care Trusts (PCTs), or funded competitively through the third sector, often on an annual basis. The SUN project initially had central funding from the Department of Health, before being commissioned by local PCTs during the lifetime of the research project, and similarly, WRAP was initially externally funded by Skills for Care before being jointly funded by the Trust and Local Authority.

Funding that was independent of the Trust granted a degree of autonomy and allowed the development of services that were in some way experimental, risky or, of lower priority as in the case of the SUN project:

‘PD’s particularly vulnerable because ... historically, personality disorder wasn’t seen as a mental health problem ... partly because it was seen as not treatable. There’s always been people with personality disorder in services but to a greater or lesser extent they were actively excluded.’ (LOOR01)

It also gave such projects the chance to demonstrate effectiveness:

‘And the way things develop in Hampshire is that they tend to get piloted in a particular locality and if it works, it tends to get adopted by other localities ... so it’s been developed that way. .... I have seen it develop over the years, sort of – and that’s a good concept in terms of both recovery and advanced decision making.’ (HAOR05)

‘Skills for Care really liked us and to be frank, if you want to know, that’s it. He thought we were a really good project and he was really keen on the services in the involvement side of the project and ... after the first 2 years then most projects didn’t receive any further funding and WRAP was one of only ... 6 or 8 projects that received continuation funding, so we got given 2 more years funding and it was doubled.’ (HAOR02)

However, external, time-limited funding also led to a sense of vulnerability to cuts owing to not being seen as a core service at a time of anticipated financial pressure:

‘I think there is a difficulty in creating innovative pieces of work that are not evidence based that can sometimes be seen as icing on the cake. And in a cash strapped organisation where sometimes it’s very hard to even do some of the basic things right. It can stifle innovation and creativity. And some of the things that are not as easy to measure can be the first to suffer.’ (WYOR01)

One of the Trusts supporting projects was also preparing for foundation status, and it was feared that efficiency savings being made in preparation for this change of status might have an adverse effect:

‘We are working within the very harsh economic climate. Now I would hope that we can continue on this journey; it feels right, I do believe the Chief Executive

and everybody else they are absolutely sincere in that continuing ... but there are financial constraints imposed upon us. I think that it is absolutely right and proper that we do have some very, very enthusiastic people, who are trying to deal with this, but they have got some challenging priorities and sometimes conflicting priorities.' (WYOR05)

However, even where there was support from a Trust, this did not guarantee funding. The future of several projects lay in the hands of the commissioning PCTs, rather than the Trust who hosted them:

'I hope [the SUN] will become a completely mainstreamed part of the care pathway, that commissioners will see it as an essential part of service provision. I don't think we're there yet ... As an organization we've absolutely embedded it in, mainstream, CMHT and Tier 3 PD services, the commissioners have been part of that ....they're completely on board with how it works. So I hope that's where it's going, it's becoming a proper mainstream service, but you never know. They'll suddenly need a cost improvement and they'll say, 'well it doesn't actually, you know, it's not early intervention, it's not assertive outreach, it's not crisis intervention.' (LOOR02)

"The problem we're having now is convincing commissioners that you can roll it out and it might help. You see, a lot of these patients are patients that PCT's would never see because they are too chaotic to engage with GP's. So.., because for the GP it doesn't happen in their face, they're not going to say, 'well I'll fund that then', because they don't necessarily see the benefit." (LOR004)

'We don't [fund projects ourselves]. We are given money for the services that we provide. If the Primary Care Trust so chose, they can move resources around, so they can stop giving us money because they might deem that a voluntary agency could do it better, or would give them the outcomes they wanted. So they may move the money at a year end. And that could move from – for example one of our Counselling services has gone to a private counselling service. We lost the contract.' (WYOR01)

Uncertainty also impacted on the project's ability to secure support from Trusts. In the view of one manager, Trust staff were sometimes reluctant to put effort into establishing working relationship with projects that are temporary or preoccupied with finding funding:

'I do think outside agencies are constantly struggling for funding, so they come and go. So sometimes ... from a Trust point of view, is it worth making the effort to make the connection? Because it's here one day, gone the next, because the funding has gone. Or you start getting embroiled in funding issues, they are that busy chasing the funding that sometimes they can't deliver what they are doing. That is the worst sides of it. Yeah, those are the big negative issues.' (WYOR01)

The fact that project funding was not guaranteed from year to year, left staff and service users subject to periodic anxiety about project survival. In the case of the SUN, staff retention and recruitment was affected, leading to understaffing and increased pressure on those who remained. Staff turnover also affected continuity in terms of management and delivery of the service, affecting staff morale:

'... certainly the lack of being able to recruit was to do with that [lack of permanent contracts], and then the other ... members of staff had all applied for jobs elsewhere, so I came back to a team that nearly collapsed, had nearly gone ... The Trust has not, has deliberately not wanted to hold the risk for these people, financial risk. Because its future wasn't certain, and that's meant in effect that the individuals have held the risk, which they got tired of doing, and they're still tired of doing after, it's four years now, so it'll be five by 2009, so people are fed up with that.' (LOOR01)

### **Partnerships and working across boundaries**

In the context of strategies to integrate health and social care services, projects of this kind can provide a means of linking across sectors. Certainly there was a view that projects standing outside of Trusts seemed to operate more flexibly across organisations and sectors and that partnerships with them were valuable:

'Partnering as a term is a new way that we need to be working, and we do look for opportunities and we have worked with other partners and been able to access money that as Health we wouldn't have been able to access ... I don't think they're are an add on or instead of, I think there is a whole cluster of services and different things that suit different people. And that's why you've got to have that whole range. There are things that voluntary and independent groups do far, far better ever than Health or Local Authority or almost even some of the voluntary groups that I call them the secondary health, because they are that tied into the structure, there's not that much difference.'

(WYOR01)

The Trust managers interviewed fully supported the concept of partnership working with projects but had experienced difficulties in making it work in practice. There were the complications of working with organisations with different regulatory systems, the time spent negotiating how to work together, communication and access problems for patients, and inter-professional rivalry. These views are captured neatly in a number of quotes from one West Yorkshire manager:

'Oh, there are huge issues actually in terms of partnership working. ... it is very challenging. And the reason why it's very challenging is because for me the more organisations you link with, the more policies and procedures that you have to understand and have to get to grips with, the more negotiation you have to go through to get some outcomes. So what happens is the cogs of the organisation they just turn extremely slowly and in the middle of that you might have a service user who is not getting a service while you are sat around the negotiating table.

So whilst I would want to embrace partnership working, I think there are – I would hedge my bets and say after all these years we are still not there yet. It's still quite challenging, particularly when we have people that say work in our integrated teams where we have health and social care integrated together. However, the person managing that team has to understand social care policies and procedures as well as health policies and procedure'. (WYOR04)

The location of services could also be seen as an impediment:

'Sometimes a postcode can get in the way because we have such a big area and we have people who live in Wakefield that have a Huddersfield postcode and it's all very problematic. That is the problem, geography. And also the size of the area, the geography we've got, some of the places are two or three bus rides away, which makes it inaccessible.' (WYOR05)

Apart from practical difficulties of communication and co-ordination, the nature of funding put some professionals and trusts in competition with projects:

'Another thing I think that you get with partnership working is that people can get very territorial and there can be a reluctance to share information, there can be a reluctance to work together, there can be inter professional rivalry.' (WYOR05)

'I think more and more in Mental Health you are seeing the emergence of the voluntary and independent sector providing parts of, as well as private companies, providing services that traditionally would have been provided by a large hospital ... and when services are out for tender and we bid to provide those services, we may not always get them because another provider might be chosen above us as it were.' (LOR004)

### **Perceptions of risk**

Projects which stand outside bureaucratic structures and which are not controlled by routine practices and procedures could be perceived as risky. Not surprisingly, the management of risk was one of the most frequently mentioned issues for self care projects. Risk was a complex problem taking a number of different forms. The first view that emerged was that self care was by its very nature inherently risky:

'Because in terms of as Health Care Professionals we need to be continually assessing individuals and looking at what the risks might be. We need to be looking for subtle changes in somebody's mood, obviously mental state, and if you are not with somebody and supporting somebody and engaging with them, then you might be missing that. So it's about making sure that whilst self care is going on or the concept of self care, that you have also got good engagement with your service user.' (WYOR04)

'I think it's all part of a long line. The principles of recovery mean that people have got to be equally empowered and recovery models very clearly talk about the individual has got to take control. But are you only going to let individuals take control if they make the right choices? And there is a line and Mental Health often struggles with what is that line. So for example, is it all right for people to stay in bed all day and only get up, when they are on an inpatient ward, in the middle of an afternoon because that's the pathway that they've chosen for themselves?' (WYOR01)

'The new thing about the SUN project that got a few people a little bit worried was the element of risk. I think, especially the 90's there has been a very high profile of individuals with emotional difficulties or mental health problems who have not been appropriately managed and controlled by medication or other means or who have committed acts of violence and there is always this tension between the desire to allow individuals to form networks, give each other

support, give each other the acceptance that they need in order to join a group so that they can begin to learn from the group. There's always this fear that it might get out of control and some risky behaviour might happen and then somebody might get hurt so there's tension between giving the individuals the freedom to help themselves and help each other and making sure that somebody keeps an eye on them to keep it safe.' (LOOR05)

The view was expressed that there is a risk from the organisational perspective that the public may not understand or accept the risks involved in allowing greater patient autonomy, and that reputation and funding could suffer:

'As an organisation, we have got to rely on being commissioned to provide services, so we are a political animal. We don't work in a vacuum. We are part of a food chain when it comes to funding, and therefore the public's opinion counts, especially as a Foundation Trust where we are all members, we have got 10,000 public members, we are answerable and accountable to them ... And the public's opinion can be fickle. On one hand they don't want people to be incarcerated or sectioned because it's deprivation of liberties, but on the other hand, they don't realise that if you allow people to go out, they might decide to engage in self harm or take their own lives ... and then there will be an outcry". (HAOR03)

Worries of this kind acted as a constraint on support for novel services such as those in the creative arts:

'I think that we are obviously very, very concerned about risk in Mental Health Services and sometimes when individuals want to come in and do things that are absolutely fantastic, we sort of think 'oh my goodness me what about this, what about that, what if something goes wrong? What if the person is attacked? Do we need extra insurance?' (WYOR04)

Some professionals were reluctant to refer to projects because they were uncertain about the quality of care on offer, and found it difficult to relinquish control:

'It's not mistrust because it's a voluntary agency, it's just because exercising beyond our own sphere of influence, and that can be just the same if we refer people back to the Primary Care, we become nervous that they won't receive the quality of care they have been having.' (WYOR05)

There was also the fear that innovative projects external to the organisation did not observe the same rules with regard to risk, and Trust staff therefore would not refer patients to them:

'Well I think whenever you set any service up you've got to do a full risk assessment. I don't think it's unique to that but you've got to think around that and there has been some, and I can think of one creative project, where staff were happily discussing with another service user how somebody else was doing ... there are certain services that you really wouldn't encourage people to go to because of either bad practice or you know, and those are the things that do tend to fold quicker then.' (WYOR01)

However, other interviewees felt that the problems posed were not insurmountable:

'We probably need to think much more about positive risk taking and what recovery principles have to say and self care principles have to say about all aspects of our interactions, and not just WRAP, but how we make risk assessments, what we do when there are disagreements and to negotiate that collaboratively ... and again that takes time and understanding the complexity of that process ... Those kinds of conversations I think need to be had. I think there probably is a move towards that with security plans with collaborative risk assessments and Sainsbury symptom-based risk assessments, those kinds of things.' (HAOR13)

Thus there is a widespread view that self care does pose new challenges in terms of risk, and one which requires new approaches to risk management.

#### *Risk and self referral*

Self referral was a significant characteristic of self care in some of these projects, and presented a challenge to established practice. The relationship between the issue of self referral and risk is illustrated well in the case of the SUN project, including the unpredictability of who might turn up:

'I would like to say that it's not risky, but I do think it is. Because there is a very much an openness, easy access, you can have off days and just present to the group and talk about different ideals or idealisms that you had, I heard that people come in and say, 'I'm thinking of doing X', or 'I did X' or ... or they might just turn around and like you've got your bag there and say, 'and I'm thinking of swinging this,' and it's a knife. So you know, I think it is quite risky, you don't know what's going to happen, you've not really got a lot of backup, because you're out in the community, you're out at a village hall or a community centre.' (LOOR02)

Another aspect of risk was the fear that these self care projects could be dumping grounds for patients, or that participants would be cut off from mainstream services:

'My only personal concern with it is where a psychiatrist in a very busy CMHT thinks they've "referred" to SUN, told them to go off to SUN, and somebody doesn't go or engage, and is there potentially therefore a hole in the net for somebody to fall through. Technically you can't refer to SUN, and obviously technically a psychiatrist wouldn't cross somebody off their case-load without a proper transfer discussions, but there, but that is always a concern ... they can farm off their PD clients to the SUN and see them as "sorted". I'm not saying it happens, but with self-referral, there is always that potential.' (LOOR03)

A further risk of self referral might be patients accessing a service which was unsuitable for them. In the case of SUN but the presence of professional staff in the group and the close link with the Trust ensured this would not occur.

'... there's a very extensive risk assessment done, and of course everything is in a group so there's no lone working ... I think that the service has got it very well sorted from a government's point of view, and we did run this all through [the Trust risk manager]. So I think from that point of view it's all been very

positive, it's very different from the original plan ... in fact what we thought we'd do wasn't at all what we did. It's a lot more bureaucratic, a lot more secondary mental health, risk assessed, thought about, than the aspiration originally' (LOOR03)

*Risk and employing service users as staff*

An innovative feature of these projects was the employment of users as members of staff. Although some Trusts have a policy of recruiting staff with experience of mental health problems this did not normally include the direct recruitment of current service users. Thus this aspect did present a number of challenges for the organisation's human resource managers. In the case of SUN there were major issues around employing service users as staff which were initially were focussed on the status of contracts:

'... trying to get other parts of the Trust involved and just to be able to free their thinking up a bit about developing different services has been a huge hurdle, so HR, recruitment, that's been enormously difficult to get support facilitators in post and paid...' (LOST01)

However, the need to conform to Trust HR practice had benefits in that it required the team to think through what was expected of the support facilitator role in order to produce a formal job description:

'...getting them banded as part of , under AFC, that was a stumbling block and took a long time getting ... Because all the posts within the Trust have to be banded so that people are paid so ... they have to fit certain criteria for doing the banding of a job. So that had to be done and which really kind of meant that we had to knuckle down on what were the essential things that we were asking the support facilitators to do...' (LOST01)

Some user staff were unable to commit to work on a regular basis owing to the nature of their illness, and they often do not have the usual employment history or references normally required from job applicants. In consequence, in one Trust:

"... there were huge problems, and I know that [a colleague] got very cross with somebody in our department because they were meant to be being paid and they weren't paid, because they hadn't been CRB cleared, or something, you know, some stupid rigidity that made no sense whatsoever." (LOOR06)

At an operational level the opportunities offered by the service user employee's personal experiences of mental health problems were acknowledged, but some a managers found working with them a challenge:

'Personally speaking, I actually find them, as a manager, very hard to work with, because maybe I'm not on their same wavelength, because obviously I don't, it's taboo to go into groups, I don't know, I mean I don't know what they talk about ... and because they are not, as well as you and I ... they try to hide always behind this blanket of you know, 'I am the patient' type of thing, but at the same time, we are paying them, it's on a bank basis so it is ad hoc, but they are being paid, because obviously these people, some of them are on benefits so you, there's a threshold that you can't go above, because obviously they'll lose their benefits. Their sickness is high, when they don't want to do something, they don't want to do it, and then you feel like you, you know



actually, I've had other team managers say 'well actually, in normal standard workplace I would discipline you for that'. (LOOR02)

Judging when a user is ready to take on the responsibility of paid employment can be difficult, as illustrated by this quote about the SUN project:

'Because does going back and listening to other people's scenarios, so akin to your own, – abuse, devaluing behaviour, fundamentally, being let down, demoralized, let down from being a child often, inability to have cohesive relationships with anybody, right from parents and siblings, then often highly abusive, more mature relationships – of course going back and then listening and supporting others with that, getting the balance of how that doesn't then start to potentially weaken one's wellness, is a difficult one. ... we didn't get it right to begin with and we're still redefining it, because they were working sort of on a bank system, so they could sort of work as much or as little as they wanted, but we've actually found that the cohort of LSU's that were doing that probably weren't well enough.' (LOOR03)

While co-workers valued the employment of users, responsibility for training and supporting service users who may not always be well put additional burdens on permanent staff who are already working under considerable pressure, a fact that was not anticipated at the outset of the SUN project:

'I hadn't thought about it ...that the sort of support and supervision they need is actually different to other members of the team and the flexibility or working with somebody who may have their own health crises for one reason or another, needing more support ...' (LOST01)

### **The future of the projects: Charismatic leaders**

Interviewees acknowledged that foundation of innovative of projects typically owes much to the leadership, advocacy, commitment and expertise of a single leader or small teams of dedicated individuals. They expressed awareness that such dependency might leave projects vulnerable if significant players moved on:

'A lot can be driven by the personalities and the energy of individual Team Members and the interests that they have ... because if you are lucky enough to have somebody who's enthusiastic and skilled enough to take that sort of thing, it will happen. If your Team by chance doesn't have that person, then it might not happen.' (WYOR05)

'I think that it might have been an element of personal choice in that rather than Trust strategy. I think it was tolerable because [the project leader] was very involved, was very enthusiastic, appeared to be quite successful in doing what she was doing. So the broader picture was that people were benefiting from her involvement. It didn't make sense from a strategic perspective because it was based on individuals. It was based on personal passion and motivation. But sometimes that's what it takes to get things to happen.' (HAOR03)

The importance of having a well developed model of working, in order that the project might survive a change of leadership or key personnel was recognised:

"I mean for example, the clinical model of working, that's all written down and very clearly understood. I think we're not that far off getting to a point where it

would survive me if I wasn't here and as I've got no plans to go anywhere in the immediate future, I'm fairly confident we'll get there before I go". (source removed)

### **Long-term futures: Mainstreaming**

There was considerable discussion of where self care projects sat in relation to mainstream mental health Trust service provision, and the challenges and potentials of mainstreaming self care support:

'If you have an approach that is grass-roots-up that has a very different flavour to one that comes down from management and senior clinicians. So I think one of the real barriers is that, I mean maybe it's not a barrier, maybe it's inevitable, but because this is coming bottom-up so to speak, the people that I'm aware of that are very enthusiastic about it, are often individual clinicians who don't necessarily have a lot of the power, and more ... senior managers perhaps are less familiar with recovery approaches and self management approaches. So some of the changes that might be needed structurally, perhaps managers aren't aware of or need a lot of persuading about, that might seem very clear to clinicians working with service users.' (HAOR13)

In the case of WRAP there is some evidence that leadership was becoming more dispersed, but still had some way to go before it was mainstream practice:

'... there are particular people who are kind of championing it, WRAP, into parts of the service, and I kind of want to encourage that and support those individuals, so, but it often, I think it relies on a lot of the enthusiasm from the individuals. And I think probably people take, use their own time to read up on it and develop groups, that kind of thing.

'I guess the challenge for managers is finding ways of allowing people to have that time. I think if managers are serious about self management, they need to find ways of allowing clinicians to spend time with individuals in order to develop those relationships and work through those packages with them, and I think that must be very difficult when they have budgets that have to be balanced and I'm sure staff costs are what cost most of the budget. I don't know what the answer is, but I think time is absolutely essential. Time and understanding of what self management means in practice.' (HAST13)

In the case of the SUN project a degree of integration took place over the life of the project, radically changing its relationship with the Trust from one of near independence to that almost of a core service. Two drivers of this change have already been described above: the need to clarify who was responsible for risk management of the project; the insistence on the part of HR that if service users were to be paid they had to become employees. The introduction of computerised patient records also caused problems at first:

'Sometimes trying to accommodate the Trust policy and procedures, can sometimes delay things or make things harder to do, or we've had to adapt things slightly ... like the implementation of RIO has shifted things, the computer system, because we didn't used to use that... some members have found that difficult because it's a change. You know suddenly we've got access to their notes which we didn't have before, and that's one of the things in the SUN is

like you get to know members as they talk about things, rather than reading their case history and then meeting them.' (LOST04)

Nonetheless in the view of one interviewee this had strengthened the link with the CHMT to the benefit of service users:

'Although of course a member of the SUN doesn't need to disclose to their CMHT, because, even though everybody goes on RIO, our electronic patient record, if somebody said, "no I don't want my psychiatrist to know, I don't want my CMHT to know", then we wouldn't actually put them on RIO, because of course, it is a voluntary service to belong to. But I think it's helped people with more severe symptoms, I think that whole relationship with the CHMT is key. For those who really were self-harming greatly, it is key to getting that relationship right. It would probably be more beneficial to the CMHT's.'  
(LOOR03)

In this way bit by bit the project was brought into mainstream Trust procedures. One manager expressed the view that the main impetus for integration came from the service users themselves:

'The original project bid was that it in fact would move out of mainstream services and become much more user dominated. But actually it's not what they wanted – they wanted a psychiatrist still there providing the supervision, being part of certain groups, being part of the governance – they wanted to keep a team manager post. They wanted it much more sort of tiered to be bureaucratically set-up. So I think it's also about getting that balance right, but we may have great aspirations to have completely user-led services. But interestingly, when you do listen to our users, if they are really ill and vulnerable, they, it appears as though they feel quite supported by having some of that governance framework of a classic institution in one way.'  
(LOOR02)

These significant changes then raised questions about whether movement into the mainstream has compromised the fundamental objectives of the project. However, it kept its distinguishing characteristics of open access, self referral, delivery in the community and delivery in partnership with service users:

'So I think from my perspective a bit of a concern is how's it, how the users going to view it if it's part of the mental health trust. But I think the trust has overcome that and I think the particularly with the clinicians that work in the service it's been able to kind of overcome those obstacles. I don't know whether the service user would say that they found that, they don't feel that it's necessarily got that kind of mental health trust feel to it. It's very much their project ...'  
(LOOR08)

Furthermore, it still was seen to enjoy an unusual degree of independence:

'It was separate when it started, that was important, you see, because they wanted to set it up as a separate entity, and so we just wanted to recognize the risks. It is now part of the Trust, but I think we still allow them more leeway than we allow services that we directly and actively merge and control'.  
(LOOR04)

## ***4.2 Quantitative findings***

Section 4.2 will present quantitative findings, beginning by illustrating recruitment and retention to the case study cohorts (section 4.2.1). The samples at each site will then be described (section 4.2.2), as will those who dropped out of the study. The specific operationalisation of the 'engagement with self care' variable at each site will be explained (section 4.2.3). The three phases of quantitative analysis, as described in the quantitative analysis plan (section 3.4.5) will then be presented and discussed. Finally, the therapeutic relationship variable will be analysed and discussed (section 4.2.7).

### **4.2.1 Recruitment and retention**

In total, 121 service users were recruited into the study and 95 were interviewed at nine month follow up. A total of 15 carers were recruited into the study and 14 were interviewed at follow up (including one new carer recruited at follow up in London). Flow diagrams of recruitment and retention of service user and carer participants at all three sites are given in figures 2, 3 and 4 below.

Figure 2. Recruitment in London

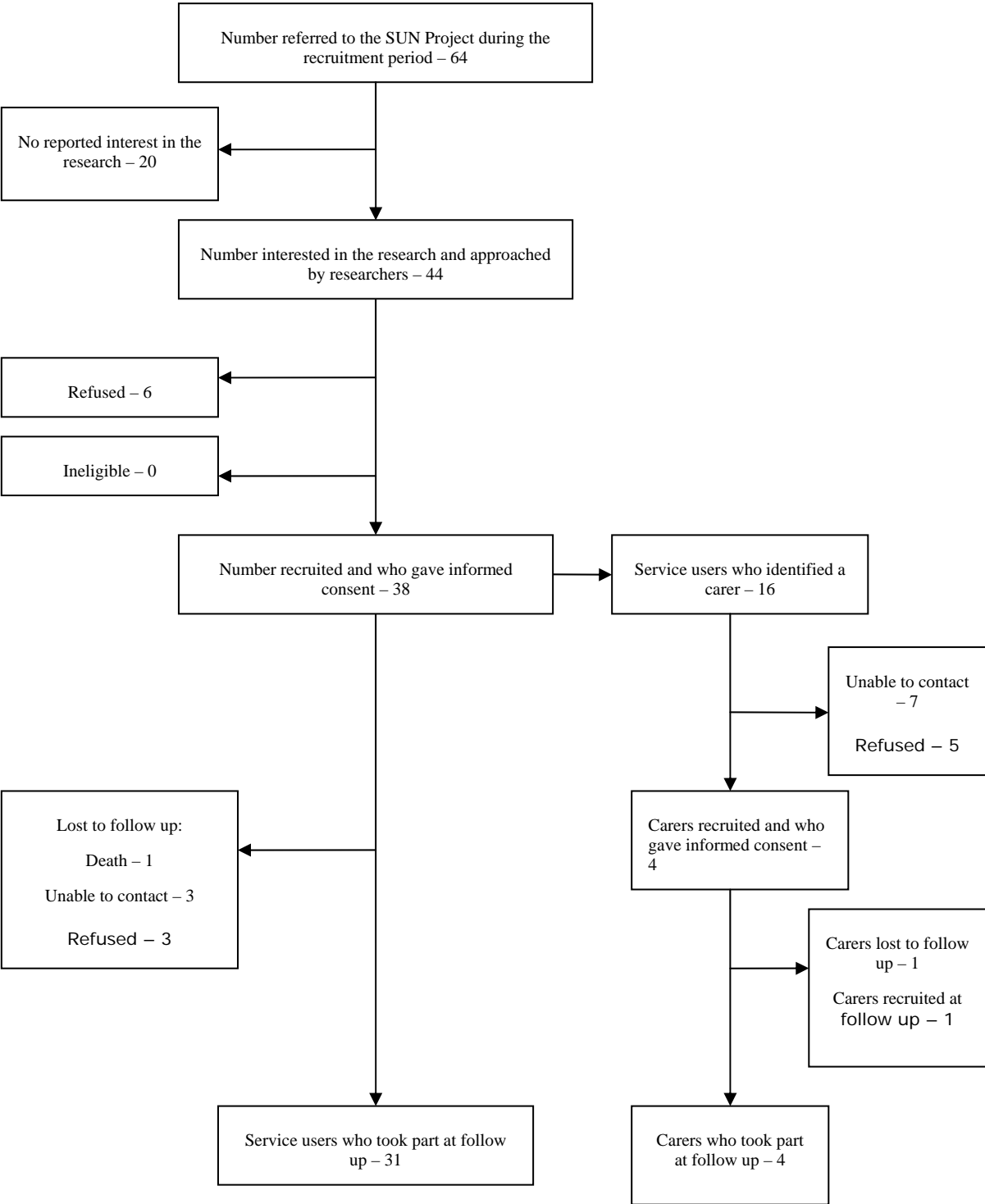


Figure 3. Recruitment in West Yorkshire

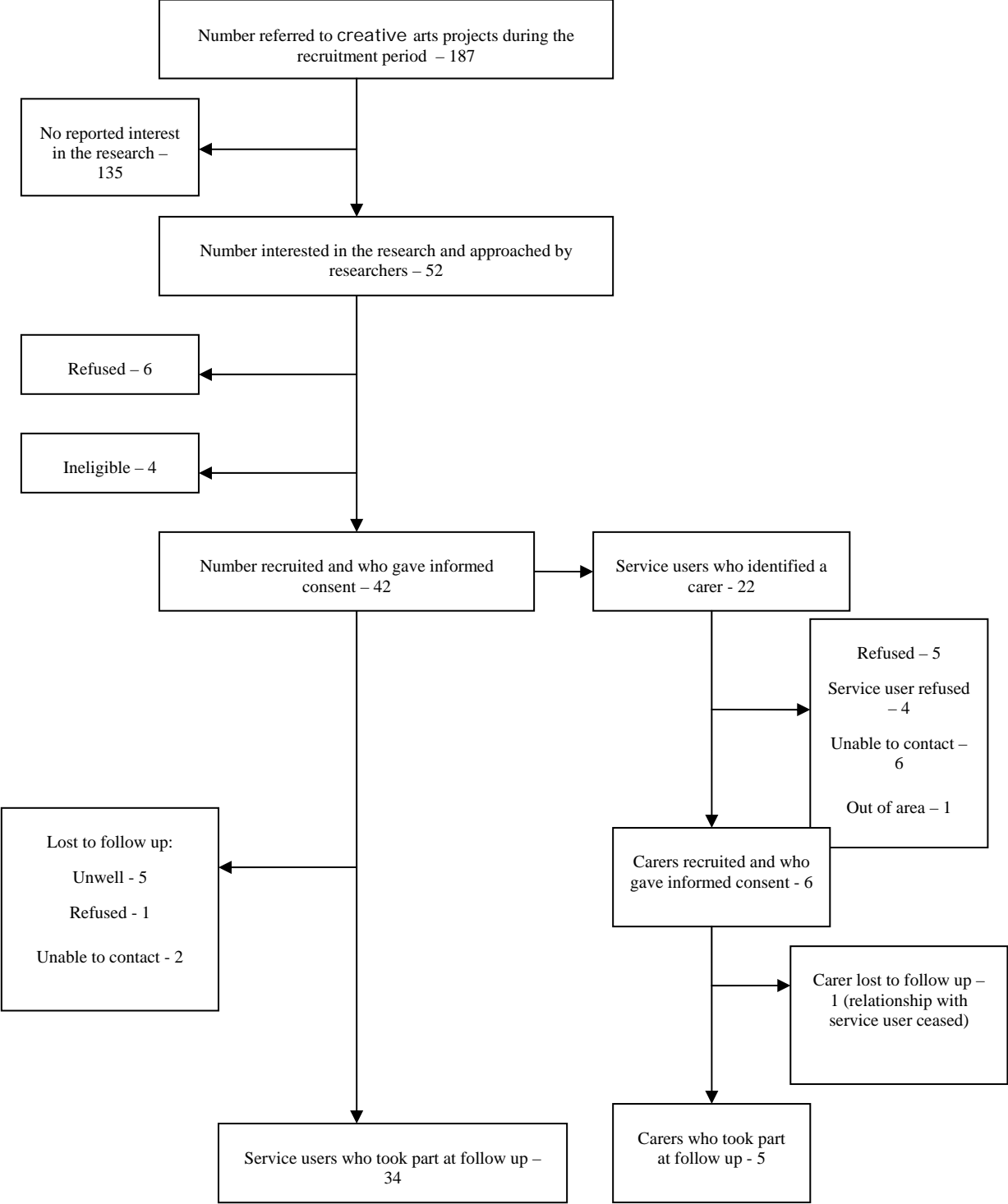
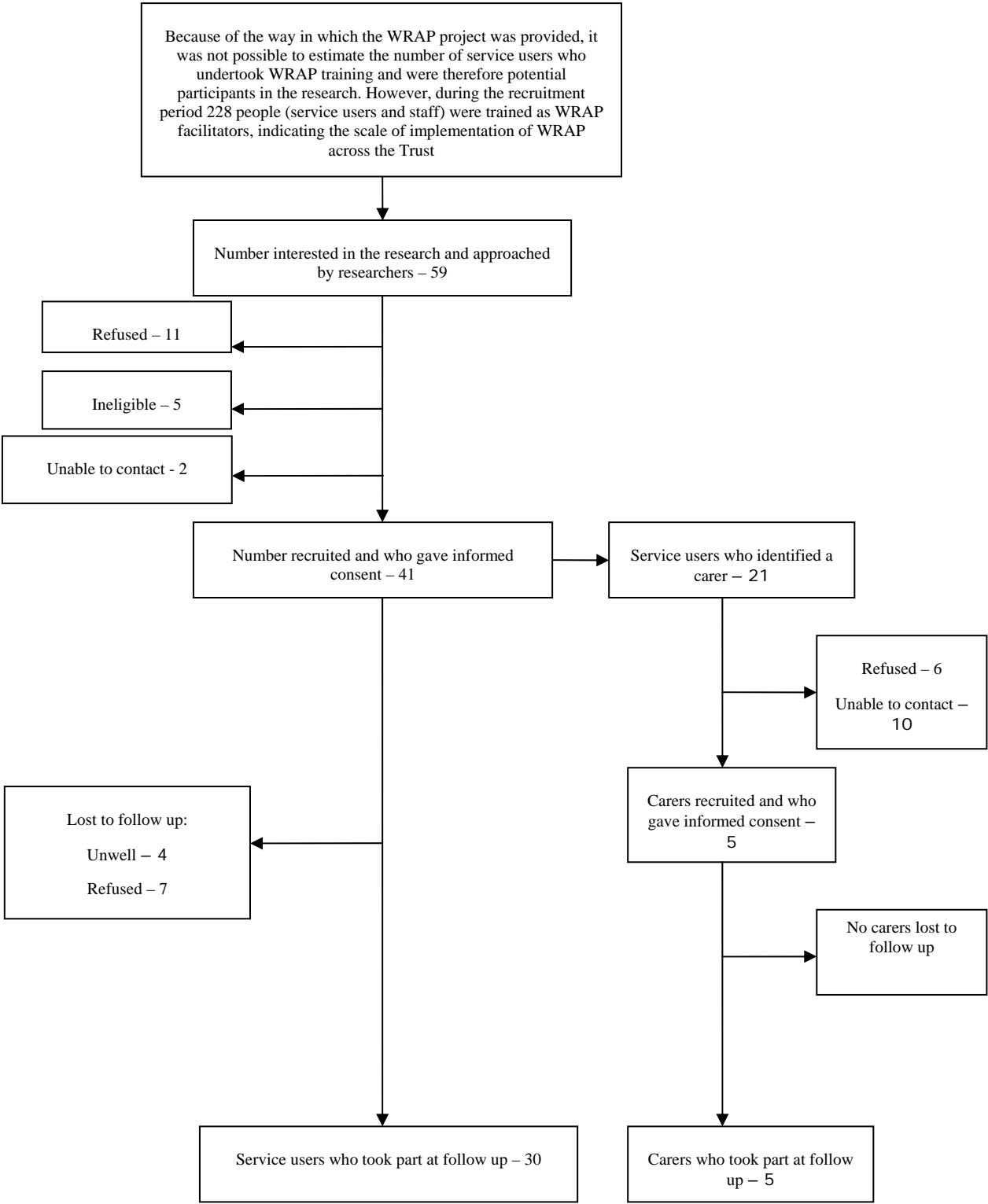


Figure 4. Recruitment in Hampshire



## 4.2.2 Describing the samples

The baseline characteristics of the sample and comparison between the samples will be described in four areas: demographics; service use; psychiatric history; psychological measures.

### Demographics

The overall sample ranged in age from 18 to 65, with a mean age of 41.5, and was predominantly female (68%). 84% of the sample was White-British, 12% White-Other and 3% was from other ethnic groups. Just over half of the sample (55%) was single and a similar percentage, 57%, lived alone. 74% of the sample had no dependants. Nearly half of the sample was educated above GCSE level (47%). The majority was in supported accommodation (60%) and slightly more (68%) were unemployed. The sample received a wide range of state benefits: 6% were in receipt of Jobseekers Allowance; 46% Income Support; 46% Incapacity Benefit; 50% Disability Living Allowance; 29% other benefits.

### Service use

The sample used a range of primary and secondary services with 84% seeing a GP in the previous 9 months, 77% seeing a psychiatrist, 12% a psychologist, the same percentage a drug or alcohol adviser, 29% a social worker and 40% a Community Psychiatric Nurse (CPN). While only 43% reported receiving Care Programme Approach (CPA), 78% reported receiving a service from a mental health team. This suggests that receipt of CPA is underreported as all users of mental health teams are required to have a CPA. 54% of the sample used some form of day care services and 12% had undertaken some form of education or training in the previous 9 months. 35% of the sample had had a psychiatric admission in the previous 9 months, 19% had used a crisis or home treatment team and 17% attended Accident and Emergency (A&E) for psychiatric reasons. 59% of the sample received support from friends or relatives in the previous 9 months.

### Psychiatric history

39 (33%) service users had never been admitted to hospital previously for psychiatric reasons. 9 (8%) service users had been admitted more than 10 times for psychiatric reasons. The sample had been in contact with mental health services for an average of nearly 15 years, the shortest being 1 month and the longest being 46 years. Service users had received their first diagnosis on average 13 years prior to interview, with one having received a diagnosis only 1 month previously and one having received a diagnosis 46 years previously. 42% of the sample reported a primary diagnosis of an anxiety or depressive disorder, 17% a diagnosis of schizophrenia, the same percentage a diagnosis of personality disorder, 12% bipolar disorder, 8% reported some other diagnosis and diagnosis was unknown for 1 service user. The sample was taking just over two psychotropic medications on average, ranging from 0 up to 6. The most commonly taken type of psychotropic medication was anti-depressants, with 75% taking this kind of medication. 16% of the sample was taking typical antipsychotics, 40% taking atypical antipsychotics, 7% on depot medication, 11% were on mood stabilisers. 7% of the sample responded that their alcohol use was harmful, 2% for drug use.



### Comparison of demographics between sites

The demographic characteristics were compared between the three sites. The average age differed significantly between the sites with Hampshire having the oldest sample (average age 44.2), compared to West Yorkshire (average age 43.7) and London having the youngest sample (average age 36.3 ( $F(2, 117) = 5.9, p = .003$ )). Marital status differed significantly between the sites with London having a higher proportion of single people (74%), compared to Hampshire (42%) and West Yorkshire (52%) ( $\chi^2 = 9.8, df = 4, p = .044$ ). The distribution of ethnic group differed across the sites (Fishers Exact  $\chi^2 = 18.3, df = 4, p < .001$ ). London had a more diverse sample with only 63% of people classified as White British, compared to Hampshire (100%) and West Yorkshire (86%). There was also a significant variation of employment status across the sites ( $\chi^2 = 6.7, df = 2, p = .035$ ), with West Yorkshire (74%) and London (71%) having similar rate of unemployment, and Hampshire having a much lower rate (49%). There was a significant difference in the number of dependent children across the sites ( $\chi^2 = 6.7, df = 2, p = .036$ ), with West Yorkshire having more dependent children compared to Hampshire and London. For the other demographic characteristics, no significant differences between the sites were found (see Table 1).

### Comparison of service use between sites

Sites were compared with respect to their use of services. There was a significant variation in use of Care Programme Approach (CPA) across the sites (Fishers Exact  $\chi^2 = 25.6, df = 4, p < .001$ ), with a smaller proportion of participants using a CPA in London (24%) compared to Hampshire (51%) and West Yorkshire (52%). Notwithstanding the underreporting of CPA noted above, this reflects the open access criteria of the London case study project. There was a significant variation in use of a drugs or alcohol advisor across the sites ( $\chi^2 = 17.1, df = 2, p < .001$ ), with a much higher percentage of participants seeing a drug or alcohol advisor in London (29%) compared to Hampshire (0%) and West Yorkshire (7%). There was a significant variation in contact with a CPN across the sites ( $\chi^2 = 18.1, df = 2, p < .001$ ), with a higher proportion of participants in contact with a CPN in Hampshire (63%) compared to London (18%) and West Yorkshire (36%).

There was a significant variation in use of day care services across the sites ( $\chi^2 = 11.7, df = 2, p = .003$ ), with a higher proportion of participants using day care services in Hampshire (73%) compared to London (53%) and West Yorkshire (36%). Specific day care services (not tabulated) found to have a significant variation across the sites included: day care or day hospital ( $\chi^2 = 2.4, df = 2, p = .300$ ), with 11% and 10% of users in London and Hampshire respectively using these service and only 2% in West Yorkshire; drop-in centre ( $\chi^2 = 8.1, df = 2, p = .017$ ), with 37% of users in Hampshire, 19% in West Yorkshire and 11% in London using them; and drug and alcohol services ( $\chi^2 = 8.0, df = 2, p = .018$ ), where there was a higher proportion of participants in London using these services (18%) compared to Hampshire (5%) and West Yorkshire (2%).

There was also a significant variation in previous admissions into hospital across the sites ( $\chi^2 = 7.7, df = 2, p = .022$ ), with a higher proportion of participants in Hampshire having previous admissions (51%) compared to West Yorkshire (29%) and London (24%). There was a significant variation in psychiatric use of A&E across the sites in the previous 9 months ( $\chi^2 = 18.1, df = 2, p < .001$ ), with a

higher proportion of participants using A&E in London (45%) compared to Hampshire (5%) and West Yorkshire (5%). There was no significant variation in previous use of crisis and home treatment teams across the sites ( $\chi^2 = .4$ ,  $df = 2$ ,  $p = .814$ ). There was also a significant variation in the use of friends and relatives for support across the sites ( $\chi^2 = 6.4$ ,  $df = 2$ ,  $p = .041$ ), with a higher proportion of participants receiving support from friends and relatives in Hampshire (68%) and West Yorkshire (64%) compared to London (42%). There was no other significant variation across the sites for the remaining types of service use (see Table 1).

### **Comparison of psychiatric history between sites**

The sites were compared in terms of the sample's psychiatric history. There was a significant variation in mental health diagnosis across the sites ( $\chi^2 = 39.9$ ,  $df = 10$ ,  $p = .001$ ), with London having higher percentage of participants reporting a primary diagnosis of personality disorder (42%) compared to Hampshire (10%) and West Yorkshire (2%). There was a significant variation in use of depot injections ( $\chi^2 = 8.4$ ,  $df = 2$ ,  $p = .015$ ), with a higher percentage of participants receiving depot injections in Hampshire (17%) compared to London (3%) and West Yorkshire (2%). There was also a significant variation in harmful drinking across the sites ( $\chi^2 = 26.0$ ,  $df = 6$ ,  $p < .001$ ), with a higher percentage of participants in London drinking to harmful levels (21%) compared to Hampshire (2%) and West Yorkshire (0%). There was also a significant variation in drug use across the sites ( $\chi^2 = 12.7$ ,  $df = 6$ ,  $p = .048$ ), with higher percentages of participants using drugs in London (21%) compared to Hampshire (10%) and West Yorkshire (5%). There were no other significant variations found across the sites relating to psychiatric history.

### **Comparison of psychological measures between sites**

The baseline levels of the CORE outcome measure were compared across the three sites. There was a significant difference in the overall CORE mean score between the sites ( $F(2, 118) = 18.4$ ,  $p < .001$ ), with London having a higher CORE mean score (21.7) compared to Hampshire (15.2) and West Yorkshire (17.8). Significant differences between the sites were also found in the following CORE subscales: CORE symptom scores ( $F(2, 118) = 17.9$ ,  $p < .001$ ); CORE functioning scores ( $F(2, 118) = 2.9$ ,  $p = .059$ ); CORE risk scores ( $F(2, 118) = 14.6$ ,  $p < .001$ ); CORE non-risk scores ( $F(2, 118) = 16.3$ ,  $p < .001$ ); BDI transformed score ( $F(2, 118) = 18.5$ ,  $p < .001$ ). London scored the highest on all of these compared to the other sites. There was no significant variation in the CORE wellbeing subscale across the sites ( $F(2, 118) = 1.944$ ,  $p = .148$ ). Higher scores on all CORE subscales indicate worse outcome, i.e., poorer functioning, more symptoms, higher risk, lower wellbeing.

There was a significant variation in SEIQoI scores across the sites ( $F(2, 117) = 4.8$ ,  $p = .010$ ), with West Yorkshire having a higher SEIQoI score (61.2) compared to Hampshire (58.1) and London (46.7). There was a significant variation in Mental Health Confidence across the sites ( $F(2, 117) = 5.0$ ,  $p = .008$ ), with Hampshire having a higher Mental Health Confidence score (3.6) compared to West Yorkshire (3.5) and London (3.0). There was no significant difference in Empowerment scores between the sites ( $F(2, 117) = 2.6$ ,  $p = .081$ ). Higher

scores on SEIQoL, Mental Health Confidence, and Empowerment all indicate higher levels of quality of life, mental health confidence and empowerment.

Table 5. Baseline characteristics and comparisons between sites

Variable	Label	London (n = 38)	Hants (n = 41)	West Yorks (n = 42)	Total (n = 121)	
<b>Demographics</b>						
<b>Age</b>	<b>Mean (SD)</b>	36.3 (10.8)	44.2 (12.5)	43.7 (10.7)	41.5 (11.8)	F (2, 117) = 5.9, p = .003
	<b>Min – Max</b>	18 – 61	24 – 64	19 – 65	18 – 65	
<b>Gender</b>	<b>Female</b>	28 (74%)	28 (68%)	26 (62%)	82 (68%)	X <sup>2</sup> = 1.3, df = 2, p = .529
<b>Ethnic group</b>	<b>White-British</b>	24 (63%)	41 (100%)	36 (86%)	101 (84%)	x <sup>2</sup> = 20.3, df = 6, p = .002
	<b>White-Other</b>	10 (26%)		5 (12%)	15 (12%)	
	<b>Other</b>	3 (8%)	1 (2%)	4 (3%)		
<b>No. dependents</b>	<b>0</b>	27 (71%)	36 (88%)	27 (64%)	90 (74%)	Kruskall Wallis x <sup>2</sup> = 6.7, df = 2, p = .036
	<b>1</b>	4 (11%)	3 (7%)	6 (14%)	13 (11%)	
	<b>2</b>	3 (8%)	1 (2%)	4 (10%)	8 (7%)	
	<b>3 +</b>	4 (11%)	1 (2%)	5 (12%)	10 (8%)	
<b>Marital status</b>	<b>Single</b>	28 (74%)	17 (42%)	22 (52%)	67 (55%)	x <sup>2</sup> = 9.8, df = 4, p = .044
	<b>Married/co</b>	3 (8%)	11 (27%)	11 (26%)	25 (21%)	
	<b>Sep/div</b>	7 (18%)	13 (32%)	9 (21%)	29 (24%)	
<b>Highest education</b>	<b>GCSE</b>	16 (42%)	22 (54%)	24 (57%)	62 (51%)	x <sup>2</sup> = 6.4, df = 4, p = .172
	<b>Above GCSE</b>	22 (58%)	19 (46%)	16 (38%)	57 (47%)	
<b>Living situation</b>	<b>Living alone</b>	25 (66%)	20 (49%)	24 (57%)	69 (57%)	x <sup>2</sup> = 2.3, df = 2, p = .312
<b>Accommodation</b>	<b>Supported accom</b>	24 (63%)	24 (59%)	24 (57%)	72 (60%)	x <sup>2</sup> = .3, df = 2, p = .851

<b>Employment status</b>	<b>Unemployed</b>	27 (71%)	20 (49%)	31 (74%)	78 (65%)	$x^2 = 6.7$ , df = 2, p = .035
<b>Service Use</b>						
<b>Receive care from Mental Health Team</b>	<b>Yes</b>	25 (66%)	35 (85%)	34 (81%)	94 (78%)	$x^2 = 4.8$ , df = 2, p = .093
<b>Type of Mental Health Team</b>	<b>CMHT</b>	22 (58%)	26 (63%)	21 (50%)	69 (57%)	$x^2 = 11.1$ , df = 6, p = .085,
	<b>AO</b>	0	4 (10%)	1 (2%)	5 (4%)	
	<b>Other</b>	3 (8%)	3 (7%)	10 (24%)	16 (13%)	
	<b>NA/Unknown</b>	13 (34%)	1 (2%)	1 (2%)	2 (2%)	
<b>Receive CPA</b>	<b>Yes</b>	9 (24%)	21 (51%)	22 (52%)	52 (43%)	$x^2 = 28.2$ , df = 4, p < .001
<b>Seen GP in previous 9 months</b>	<b>Yes</b>	36 (95%)	33 (81%)	32 (76%)	101 (84%)	$x^2 = 5.3$ , df = 2, p = .072
<b>Seen Psychiatrist in previous 9 months</b>	<b>Yes</b>	32 (84%)	33 (73%)	31 (74%)	93 (77%)	$x^2 = 1.5$ , df = 2, p = .484
<b>Seen Psychologist in previous 9 months</b>	<b>Yes</b>	6 (16%)	5 (12%)	4 (10%)	15 (12%)	$x^2 = .7$ , df = 2, p = .699
<b>Seen Drug/</b>	<b>Yes</b>	11 (29%)	0 (0%)	3 (7%)	14 (12%)	( $x^2 = 17.1$ , df =

<b>Alcohol advisor in previous 9 months</b>						2, p < .001)
<b>Seen Social Worker in previous 9 months</b>	<b>Yes</b>	16 (42%)	9 (22%)	10 (34%)	35 (29%)	$x^2 = 4.5$ , df = 2, p = .104
<b>Seen CPN in previous 9 months</b>	<b>Yes</b>	7 (18%)	26 (63%)	15 (36%)	48 (40%)	$x^2 = 18.1$ , df = 2, p < .001
<b>Used Day care service in previous 9 months</b>	<b>Yes</b>	20 (53%)	30 (73%)	15 (36%)	65 (54%)	$x^2 = 11.7$ , df = 2, p = .003
<b>Undertaken Education or training in previous 9 months</b>	<b>Yes</b>	1 (3%)	9 (22%)	4 (10%)	14 (12%)	$x^2 = 7.5$ , df = 2, p = .024
<b>Attended sheltered workshop in previous 9 months</b>	<b>Yes</b>	0 (0%)	2 (5%)	0 (0%)	2 (2%)	$x^2 = 4.0$ , df = 2, p = .138
<b>Psychiatric admission in previous 9 months</b>	<b>Yes</b>	9 (24%)	21 (51%)	12 (29%)	42 (35%)	$x^2 = 7.7$ , df = 2, p = .022

<b>Attended A&amp;E for psychiatric reason in previous 9 months</b>	<b>Yes</b>	17 (45%)	2 (5%)	2 (5%)	21 (17%)	$x^2 = 18.1, df = 2, p < .001$
<b>Used Crisis/Home Treatment team in previous 9 months</b>	<b>Yes</b>	8 (21%)	7 (17%)	8 (19%)	23 (19%)	$x^2 = .4, df = 2, p = .814$
<b>Received help from friends/relatives in previous 9 months</b>	<b>Yes</b>	16 (42%)	28 (68%)	27 (64%)	71 (59%)	$x^2 = 6.4, df = 2, p = .041$
<b>Psychiatric history</b>						
<b>Number of life-time psychiatric admissions</b>	<b>Never</b>	17 (45%)	10 (25%)	12 (29%)	39 (33%)	$x^2 = 0.1, df = 8, p = .173$
	<b>1 – 2</b>	8 (21%)	11 (28%)	8 (19%)	27 (23%)	
	<b>3 – 5</b>	6 (16%)	7 (18%)	15 (36%)	28 (23%)	
	<b>6 – 10</b>	5 (13%)	9 (23%)	3 (7%)	17 (14%)	

		11+				
		2 (5%)	3 (8%)	4 (10%)	9 (8%)	
<b>Time since first contact with services (years)</b>	<b>Mean (SD)</b>	13.8 (9.6)	16.6 (13.0)	13.6 (10.2)	14.7 (11.0)	F (2, 117) = .9, p = .401
	<b>Min – Max</b>	.25 – 40	.25 – 46	.08 – 37	.08 – 46	
<b>For how long had diagnosis (years)</b>	<b>Mean (SD)</b>	12.0 (8.3)	14.2 (12.8)	12.0 (10.2)	12.8 (10.7)	F (2, 111) = .5, p = .589
	<b>Min – Max</b>	.08 – 36	.25 – 46	.08 – 37	.08 – 46	
<b>Primary Diagnosis</b>	<b>Personality disorder</b>	16 (42%)	4 (10%)	1 (2%)	21 (17%)	x <sup>2</sup> = 39.9, df = 10, p = .001
	<b>Schizophrenia</b>	1 (3%)	12 (29%)	7 (17%)	20 (17%)	
	<b>Bipolar</b>	2 (5%)	4 (10%)	8 (19%)	14 (12%)	
	<b>Anxiety/depression</b>	16 (42%)	18 (44%)	17 (41%)	51 (42%)	
	<b>Other</b>	1 (3%)	2 (5%)	7 (17%)	10 (8%)	
	<b>Not known</b>	0 (0%)	0 (0%)	1 (2%)	1 (1%)	
<b>Number of psychotropic medications</b>	<b>Mean (SD)</b>	2.2 (1.6)	2.4 (1.6)	2.5 (1.2)	2.4 (1.2)	F (2, 118) = .3, p = .749
	<b>Min – Max</b>	0 – 5	0 – 6	1 – 5	0 – 6	
<b>On typical anti-psychotics</b>	<b>Yes</b>	4 (11%)	9 (22%)	6 (14%)	19 (16%)	x <sup>2</sup> = 2.0, df = 2, p = .360
<b>On atypical anti-psychotics</b>	<b>Yes</b>	10 (26%)	20 (49%)	18 (43%)	48 (40%)	x <sup>2</sup> = 4.4, df = 2, p = .109



<b>On mood stabilisers</b>	<b>Yes</b>	2 (5%)	6 (15%)	5 (12%)	13 (11%)	$\chi^2 = 1.9, df = 2, p = .387$
<b>Anti-depressant</b>	<b>Yes</b>	30 (79%)	26 (63%)	35 (83%)	91 (75%)	$\chi^2 = 4.8, df = 2, p = .089$
<b>Depot injections</b>	<b>Yes</b>	1 (3%)	7 (17%)	1 (2%)	9 (7%)	$\chi^2 = 8.4, df = 2, p = .015$
<b>Medication taken as prescribed</b>	<b>Yes</b>	23 (62%)	34 (83%)	30 (71%)	87 (72%)	$\chi^2 = 9.4, df = 6, p = .153$
	<b>Partially</b>	11 (29%)	5 (12%)	9 (21%)	5 (21%)	
	<b>No</b>	1 (3%)	1 (2%)	3 (7%)	5 (4%)	
<b>Alcohol use</b>	<b>No problem</b>	21 (55%)	36 (88%)	33 (79%)	90 (74%)	$\chi^2 = 26.0, df = 6, p < .001$
	<b>At risk</b>	9 (24%)	2 (5%)	9 (21%)	20 (17%)	
	<b>Harmful</b>	8 (21%)	1 (2%)	0	9 (7%)	
<b>Drug use</b>	<b>No problem</b>	30 (79%)	37 (90%)	40 (95%)	107 (88%)	$\chi^2 = 12.7, df = 6, p = .048$
	<b>Receiving help</b>	6 (16%)	2 (5%)	2 (5%)	10 (8%)	
	<b>Harmful</b>	2 (5%)	0	0	2 (2%)	
<b>Psychological measures</b>						
<b>SEIQoI</b>	<b>Mean (SD)</b>	46.7 (20.8)	58.1 (23.6)	61.2 (21.4)	55.6 (22.7)	$(F(2, 117) = 4.8, p = .010),$
	<b>Min – Max</b>	9 – 85	12 – 100	14 – 95	9 – 100	
<b>EMP</b>	<b>Mean (SD)</b>	69.3 (8.8)	74.6 (12.9)	74.0 (11.3)	72.7 (11.3)	$(F(2, 117) = 2.6, p = .081)$
	<b>Min – Max</b>	52 – 90	33 – 106	41 – 96	33 – 106	
<b>MH Confidence</b>	<b>Mean (SD)</b>	3.0 (1.0)	3.6 (1.0)	3.5 (.9)	3.37 (1.0)	$(F(2, 117) =$

	<b>Min – Max</b>	1 – 6	2 – 5	2 – 5	1 – 6	5.0, p = .008),
<b>CORE wellbeing</b>	<b>Mean (SD)</b>	19.5 (3.9)	18.2 (5.0)	20.3 (5.4)	19.3 (4.9)	(F (2, 118) =
	<b>Min – Max</b>	10 – 28	10 – 35	10 – 33	10 – 35	1.9, p = .148)
<b>CORE problems and symptoms</b>	<b>Mean (SD)</b>	28.3 (8.1)	16.5 (8.8)	21.2 (9.4)	21.8 (10.0)	(F (2, 118) =
	<b>Min – Max</b>	7 – 38	2 – 33	3 – 38	2 – 38	17.9, p < .001),
<b>CORE functioning</b>	<b>Mean (SD)</b>	19.8 (3.8)	17.8 (3.1)	19.1 (4.4)	18.9 (3.9)	(F (2, 118) =
	<b>Min – Max</b>	11 – 29	11 – 25	6 – 28	6 – 29	2.9, p = .059)
<b>CORE risk</b>	<b>Mean (SD)</b>	14.2 (8.3)	5.3 (7.5)	7.3 (7.8)	8.9 (8.7)	(F (2, 118) =
	<b>Min – Max</b>	0 – 30	0 – 25	0 – 28	0 – 30	14.6, p < .001)
<b>CORE non-risk</b>	<b>Mean (SD)</b>	23.3 (4.5)	17.1 (4.7)	19.8 (5.3)	20.0 (5.4)	(F (2, 118) =
	<b>Min – Max</b>	12 – 32	10 – 28	11 – 33	10 – 33	16.3, p < .001)
<b>CORE mean score</b>	<b>Mean (SD)</b>	21.7 (4.6)	15.2 (4.7)	17.8 (5.3)	18.1 (5.5)	(F (2, 118) =
	<b>Min – Max</b>	10 – 31	8 – 27	9 – 31	8 – 31	18.4, p < .001)
<b>BDI</b>	<b>Mean (SD)</b>	28.0 (6.9)	18.4 (6.6)	22.0 (7.7)	22.7 (8.0)	(F (2, 118) =
	<b>Min – Max</b>	12 – 43	11 – 36	11 – 43	11 – 43	18.5, p < .001),

### Who dropped out?

An analysis was conducted to compare those who were interviewed at the 9 month follow up stage (n = 95) and those who were not (n = 26). There were no significant differences between those who were interviewed and those who were not in age ( $t = .1$ ,  $df = 118$ ,  $p = .941$ ), gender ( $X^2 = .2$ ,  $df = 1$ ,  $p = .653$ ), ethnic group ( $X^2 = 1.3$ ,  $df = 3$ ,  $p = .737$ ), education ( $X^2 = 1.5$ ,  $df = 2$ ,  $p = .465$ ) and employment status ( $X^2 = .8$ ,  $df = 1$ ,  $p = .380$ ).

However, there was a significant difference in time since first contact with mental health services ( $t = -2.2$ ,  $df = 118$ ,  $p = .030$ ), with participants who were not interviewed at follow up having a shorter time since their first contact with services. There was a significant difference in average number of medications ( $t = -2.1$ ,  $df = 119$ ,  $p = .038$ ), with participants who were not interviewed being on less medication (1.9) compared to those who were interviewed (2.5). There was a borderline significant difference in both the Empowerment ( $t = -1.945$ ,  $df = 118$ ,  $p = .054$ ) and Mental Health Confidence score ( $t = -2.0$ ,  $df = 118$ ,  $p = .052$ ), with participants who were not interviewed at follow up scoring slightly higher compared to those who were interviewed. There was a significant difference between participants who were interviewed and those who were not in CORE mean scores ( $t = 3.0$ ,  $df = 119$ ,  $p = .003$ ) and BDI transformed score ( $t = 3.045$ ,  $df = 119$ ,  $p = .003$ ), with those who were not interviewed having a slightly lower score. There was also a significant difference in CORE risk scores ( $t = 2.2$ ,  $df = 119$ ,  $p = .027$ ), with those who were not interviewed having a higher CORE risk score (11.0) compared to those who were interviewed (8.2). There was also a significant difference in CORE non-risk scores ( $t = 2.1$ ,  $df = 119$ ,  $p = .040$ ), with those who were not interviewed having a slightly lower score (19.5) compared to those who were interviewed (20.1).

In summary, those participants who were not interviewed at follow up had been in contact with services for a shorter period of time and were on less medication. They scored higher on Empowerment and Mental Health Confidence and had lower CORE mean scores, CORE non risk scores and BDI scores. However, they tended to score higher on the CORE risk scores. The implications of this drop out are discussed in section 5.1.2 below.

### 4.2.3 Engagement with the self care project

As noted in the method (section 3.4.1), service user participants were asked a series of structured questions at follow up about the extent to which they chose to engage with the self care project. These questions were tailored to reflect the structure of the project at each site. Site research teams discussed these questions with staff working on the projects in order to identify features of engaging with their project that most appropriately described levels of engagement at each site. This enabled us to operationalise a dichotomous engagement variable for all sites, identifying service users who opted for either a high or a low level of engagement with each self care project.

### West Yorkshire

*Service users attending creative arts projects were classified as having a high level of engagement with the project if they had attended at least 60% of possible sessions.*

In West Yorkshire, 79% of service users who were interviewed at follow up had a high level of engagement with the self care project. They were more likely to take part in all the activities offered within the sessions and take part in producing a final piece of creative work. 26% of the high engagement group had taken on extra responsibilities within the self care project - such as volunteering - compared with none in the service users classified as having low engagement with the project. A higher percentage also continued to do the creative activities they had learned within the projects in their own time, compared with those who were not engaged. A higher percentage of service users in the high engagement group also attended other community arts projects (see Table 6).

**Table 6. West Yorkshire Engagement data**

	<b>High engagement with Self Care</b>	<b>Low engagemen t with Self Care</b>	<b>Total</b>
	<b>N = 27 (79%)</b>	<b>N = 7 (21%)</b>	<b>N = 34</b>
<b>Attendance at group sessions</b>	32.8 (32.2)	7.2 (6.9)	28.0 (30.8)
	1 – 105	0 – 20	0 – 105
<b>Attendance at individual sessions</b>	58.4 (39.5)	0	58.4 (39.5)
	1 – 108		1 – 108
<b>Did the service user take part in all the activities offered? YES</b>	24 (89%)	3 (43%)	27 (79%)
<b>Did the service user participate in producing a final piece? YES</b>	19 (70%)	3 (43%)	22 (65%)
<b>Is the service user continuing to attend the project? YES</b>	23 (85%)	5 (71%)	28 (82%)
<b>Has the service user taken on more responsibilities (volunteering)? YES</b>	7 (26%)	0 (0%)	7 (21%)
<b>Has the service user continued to do the activities in their own time? YES</b>	14 (52%)	1 (14%)	15 (44%)
<b>Is the service user involved with any other community arts projects? YES</b>	12 (44%)	2 (29%)	14 (41%)

**Hampshire**

*Service users involved in WRAP were classified as having a high level of engagement with WRAP if they had partially or fully completed intended sections of their WRAP plans during sessions AND at least partially continued to work on those sections after sessions had finished.*

In Hampshire, 63% of service users that were interviewed at follow up had a high level of engagement with the self care project. Compared to service users with a low level of engagement with the project, high engagers attended more individual sessions as demonstrated by the higher mean number of attendances. There was a similar mean number of attendances to the group sessions. However, those highly engaged service users had a higher range, attending up to 12 sessions compared to 10 sessions for the low engagement group. Those who engaged more also worked on more sections of the WRAP plan, with a higher proportion producing the wellness toolbox and crisis plan sections of the WRAP. Those who were highly engaged with the project were also more likely to use their WRAP plan or the ideas generated from it in practice and a higher percentage used their WRAP plan on a daily, weekly and monthly basis compared to the low engagement group (see Table 7).

**Table 7. Hampshire Engagement data**

	<b>High engagement with Self Care</b>	<b>Low engagement with Self Care</b>	<b>Total</b>
	<b>N = 19 (63%)</b>	<b>N = 11 (37%)</b>	<b>N = 30</b>
<b>Attendance at group sessions</b>	5.5 (3.0)	5.7 (3.0)	5.6 (2.9)
	0 – 12	0 – 10	0 – 12
<b>Attendance at individual sessions</b>	6.3 (7.7)	1.6 (3.6)	4.2 (6.4)
	0 – 20	0 – 8	0 – 20
<b>Number of WRAP sections worked on</b>	7.0 (.54)	4.8 (2.6)	6.2 (1.9)
	6 – 8	0 – 7	0 – 8
<b>WRAP was completed to the extend intended YES</b>	10 (53%)	3 (27%)	13 (43%)
<b>Continued development of WRAP plan once project had finished YES</b>	9 (47%)	0 (0%)	9 (30%)
<b>Production of Wellness Toolbox YES</b>	15 (79%)	6 (55%)	21 (70%)
<b>Production of Crisis Plan YES</b>	13 (68%)	6 (55%)	19 (63%)
<b>WRAP plan/ideas used YES</b>	18 (95%)	6 (55%)	24 (80%)
<b>WRAP plan/ideas used how</b>			
<b>Daily</b>	5 (26%)	1 (9%)	6 (20%)
<b>Weekly</b>	7 (37%)	3 (27%)	10 (33%)

<b>often</b>	<b>Monthly</b>	2 (11%)	0 (0%)	2 (7%)
	<b>Less Often</b>	4 (21%)	2 (18%)	6 (20%)
<b>Service user has shared their WRAP with others? YES</b>		9 (47%)	5 (46%)	14 (47%)
<b>Service user has introduced WRAP to someone else YES</b>		11 (58%)	6 (55%)	17 (57%)

### London

*Service users were classified as having a high level of engagement with the self care project if they were still attending SUN at the time of their follow up interview or expressed intent to return after a gap.*

In London, 48% of service users that were interviewed at follow up were classified as having a high level of engagement with their self care project, which was less than the other sites. Service users who were highly engaged had been attending the SUN project for longer and had also attended more groups, compared to the less engaged group. Those who were highly engaged used the SUN project at varying intervals - including monthly, fortnightly and weekly - but with the majority attending two or three times a week compared to the less engaged group who mostly attended weekly. When comparing the different types of groups service users could attend at the SUN project, those who were highly engaged had similar attendance levels to the less engaged group at welcome groups but had much higher levels of attendance at the support and practical groups. A higher percentage of service users classified as highly engaged had also completed and used a crisis and support plan (see Table 8).

A similar percentage of service users either classified as more engaged or less engaged with the SUN project showed an interest in being a support facilitator, but it was those who were more engaged that were more likely to be asked about becoming a support facilitator by a member of staff. A higher percentage of those classified as more engaged had peer support outside the project and took part in social outings. Those that were classified as more engaged were also *more* likely to have a gap in their use of the SUN project, and for some, up to five gaps compared to the less engaged sample.

**Table 8. London Engagement data**

	<b>High engagement with Self Care</b>	<b>Low engagement with Self Care</b>	<b>Total</b>
	<b>N = 15 (48%)</b>	<b>N = 16 (52%)</b>	<b>N = 31</b>
<b>Number of groups attended</b>	67.3 (34.4)	10.0 (11.3)	37.7 (38.3)
	3 – 108	2 – 48	2 – 108
<b>Number of months attended</b>	8.6 (.68)	2.1 (1.6)	5.2 (3.5)
	7 – 9	.00 – 5	.0 – 9
<b>How</b>	<b>2/3 times a</b>	11 (73%)	3 (19%)
			14 (45%)

<b>often the service user attends</b>	<b>week</b>	2 (13%)	13 (81%)	15 (48%)
	<b>Weekly</b>	1 (7%)	0 (0%)	1 (3%)
	<b>Fortnightly</b>	1 (7%)	0 (0%)	1 (3%)
	<b>Monthly</b>			
<b>Social contact and practical group</b>	<b>Regularly</b>	7 (47%)	1 (7%)	8 (26%)
	<b>As required</b>	1 (7%)	0 (0%)	1 (3%)
	<b>Periodically</b>	1 (7%)	1 (7%)	2 (7%)
	<b>Never</b>	2 (13%)	5 (33%)	7 (23%)
<b>Welcome group</b>	<b>Regularly</b>	9 (60%)	10 (67%)	19 (61%)
	<b>As required</b>	2 (13%)	1 (7%)	3 (10%)
	<b>Periodically</b>	3 (20%)	4 (27%)	7 (23%)
	<b>Never</b>	1 (7%)	0 (0%)	1 (3%)
<b>Emotional support group</b>	<b>Regularly</b>	10 (67%)	3 (20%)	13 (42%)
	<b>As required</b>	2 (13.3%)	2 (13.3%)	4 (13%)
	<b>Periodically</b>	0 (0%)	3 (20%)	3 (10%)
	<b>Never</b>	6 (40%)	12 (80%)	18 (58%)
<b>Has the service user had a gap in using the SUN project? YES</b>		10 (67%)	3 (19%)	13 (42%)
<b>Number of gaps in use of project</b>	<b>One</b>	4 (27%)	1 (6%)	5 (16%)
	<b>Two</b>	3 (20%)	1 (6%)	4 (13%)
	<b>Four</b>	2 (13%)	1 (6%)	3 (10%)
	<b>Five</b>	1 (7%)	0 (0%)	1 (3%)
<b>Completed a Crisis and support plan YES</b>		15 (100%)	14 (88%)	29 (94%)
<b>Used the Crisis and support plan YES</b>		8 (53%)	1 (6%)	9 (29%)
<b>Spoken to about being a support facilitator YES</b>		7 (47%)	4 (25%)	11 (36%)
<b>Interested in being a support facilitator YES</b>		3 (20%)	3 (19%)	6 (19%)
<b>Peer support outside project YES</b>		7 (47%)	1 (6%)	8 (26%)
<b>Social outings YES</b>		6 (40%)	3 (19%)	9 (29%)

#### 4.2.4 Change in outcomes

The first stage of the quantitative analysis plan (section 3.4.5) addressed the question of significant change in outcomes - psychological measures and concrete indicators of service use - over 9 months. It should of course be noted that, without a controlled study design, any change in outcome presented here cannot be attributed to the self care intervention. Rather, the intention of this analysis is to enable, in section 4.2.5 below, identification of factors that may be associated with change in outcome.

##### **Change in psychological measures**

Overall, significant improvement was found in the total sample in quality of life, empowerment and mental health confidence, with effect sizes of 0.25, 0.26 and 0.32 respectively.

Within each site, changes were as follows:

##### *London*

In the SUN Project effect sizes of 0.30, 0.41 and 0.50 were found in quality of life, empowerment and mental health confidence. However, the improvement in quality of life was not statistically significant at the 5% level. There was an increase in empowerment of 3.9 points and in mental health confidence of 0.5 points.

##### *Hampshire*

In the WRAP project, effect sizes of 0.11, 0.22 and 0.17 were found in quality of life, empowerment and mental health confidence. These changes were not statistically significant at the 5% level.

##### *West Yorkshire*

In the creative arts projects effect sizes of 0.35, 0.19 and 0.31 were found in quality of life, empowerment and mental health confidence. The changes in quality of life and empowerment were not statistically significant at the 5% level, but the improvement in mental health confidence was significant: an improvement of 0.28 points. These findings are presented in table 5 below:



**Table 9. Overall and within centres change in psychological measures**

<b>Quality of Life</b>					
	<b>n</b>	<b>T0<sup>a</sup></b>	<b>T1<sup>a</sup></b>	<b>Change<sup>b</sup></b>	<b>ES</b>
<b>SUN</b>	31	47.9 (21.5)	54.4 (20.5)	-6.5 (-14.6, 1.5)	0.30
<b>WRAP</b>	26	58.2 (25.2)	60.9 (22.9)	-2.7 (-16.5, 11.0)	0.11
<b>Creative</b>	34	61.0 (20.5)	68.1 (18.0)	-7.1 (-14.9, 0.8)	0.35
<b>Arts</b>					
<b>Total</b>	91	55.7 (22.7)	63.4 (20.9)	-5.6 (-11.1, -0.2)	0.25
<b>Empowerment</b>					
<b>SUN</b>	31	70.0 (9.4)	73.9 (9.3)	-3.9 (-7.0, -0.8)	0.41
<b>WRAP</b>	28	73.2 (13.9)	76.2 (9.4)	-3.0 (-6.4, 0.4)	0.22
<b>Creative</b>	34	72.6 (11.7)	74.9 (9.7)	-2.2 (-5.7, 1.2)	0.19
<b>Arts</b>					
<b>Total</b>	93	71.5 (11.7)	75.0 (9.4)	-3.0 (-4.9, -1.2)	0.26
<b>Mental Health Confidence</b>					
<b>SUN</b>	31	3.08 (1.0)	3.58 (0.9)	-0.50 (-0.78, -0.22)	0.5
<b>WRAP</b>	28	3.58 (1.1)	3.77 (1.0)	-0.19 (-0.55, 0.17)	0.17
<b>Creative</b>	34	3.39 (0.9)	3.67 (0.9)	-0.28 (-0.56, 0.00)	0.31
<b>Arts</b>					
<b>Total</b>	93	3.35 (1.0)	3.67 (0.9)	-0.32 (-0.50, -0.15)	0.32

a Data is mean and (standard deviation)

b Data is mean difference and (95% confidence intervals)

### Change in concrete indicators of service use

Overall, there was a significant decrease in the number of psychiatric A&E attendances and planned and unplanned admissions at the 5% level. There was no significant change in the use of Crisis Resolution and Home Treatment teams.

Within each site, changes were as follows:

#### *London*

In the SUN Project there was a significant reduction in the number of psychiatric A&E attendances but no change in the other concrete indicators.

#### *Hampshire*

In the WRAP project there was a significant reduction in the number of unplanned admissions but no change in the other concrete indicators.

#### *West Yorkshire*

In the creative arts projects there were no changes in any of the concrete indicators. These findings are presented in table 10 below:

**Table 10. Overall and within centres change in concrete indicators**

<i>Number of psychiatric A&amp;E attendances (in previous 9 months)</i>								
		T0			T1			p-value <sup>a</sup>
	n	0	1 - 5	6 - 10	0	1 - 5	6 - 10	
<b>SUN</b>	<b>31</b>	17 (55%)	11 (35%)	3 (10%)	28 (90%)	2 (7%)	1 (3%)	0.005
<b>WRAP</b>	<b>26</b>	25 (96%)	1 (4%)	0 (0%)	26 (100%)	0 (0%)	0 (0%)	0.317
<b>creative arts</b>	<b>33</b>	31 (94%)	2 (6%)	0 (0%)	31 (94%)	2 (6%)	0 (0%)	0.705
<b>Overall</b>	<b>90</b>	73 (81 %)	14 (16%)	3 (3%)	85 (94%)	4 (5%)	1 (1%)	0.007
<i>Number of days of use of CRT or HTT (in previous 9 months)</i>								
		T0			T1			p-value <sup>a</sup>
	n	0	1 - 7	8 - 42	0	1 - 7	8 - 42	
<b>SUN</b>	<b>29</b>	22 (76%)	6 (21%)	1 (3%)	26 (90%)	1 (37%)	2 (7%)	0.593
<b>WRAP</b>	<b>26</b>	22 (84%)	2 (8%)	2 (8%)	23 (89%)	1 (4%)	2 (7%)	0.917
<b>creative arts</b>	<b>34</b>	27 (79%)	7 (21%)	0 (0%)	28 (82%)	6 (18%)	0 (0%)	0.323

Overall		71 (80%)	15 (17%)	3 (3%)	77 (87 %)	8 (9%)	4 (4%)	0.626
<b>Number of planned admissions (in previous 9 months)</b>								
	n	T0			T1			p-value <sup>a</sup>
		0	1	2 +	0	1	2 +	
SUN	31	29 (94%)	2 (6%)	0 (0%)	31 (100%)	0 (0%)	0 (0%)	0.157
WRAP	29	24 (83%)	5 (17%)	0 (0%)	26 (90%)	3 (10%)	0 (0%)	0.317
creative arts	33	30 (91%)	2 (6%)	1 (3%)	33 (100%)	0 (0%)	0 (0%)	0.102
Overall	93	83 (89 %)	9 (10%)	1 (1%)	90 (97%)	3 (3%)	0 (0%)	0.021
<b>Number of unplanned admissions (in previous 9 months)</b>								
	n	T0			T1			p-value <sup>a</sup>
		0	1	2 +	0	1	2 +	
SUN	31	26 (84%)	3 (10%)	2 (6%)	26 (84%)	4 (13%)	1 (3%)	0.803
WRAP	29	16 (55%)	10 (35%)	3 (10%)	23 (79%)	6 (21%)	0 (0%)	0.026
creative arts	33	26 (79%)	6 (18%)	1 (3%)	30 (91%)	1 (3%)	2 (6%)	0.317
Overall	93	68 (73%)	19 (20%)	6 (7%)	79 (85%)	11 (12%)	3 (3%)	0.035

a Wilcoxon signed ranks test

#### 4.2.5 What factors are associated with outcomes?

The second stage of the quantitative analysis plan (section 3.4.5) asked which indicators of service user engagement, experience of therapeutic relationship (Box E of the theoretical framework) and service user demographics (Box B) were related to outcome at 9 months, across all three sites. This analysis is presented below by outcome, where those relationships were shown to be significant.

##### Quality of life

Being on typical antipsychotics, on depot injections, the number of psychotropic medications, CORE Non-risk, CORE Wellbeing and CORE Problems and Symptoms scores (all as measured at T0) were all univariately associated with quality of life (SEIQoL-DW) at follow up at the

10% level. Being on typical antipsychotics, depot injections and number of psychotropic medications were all significantly associated with each other. As a variable with a broader focus on medication, number of psychotropic medications was retained to enter into the final model. The CORE Non-risk, CORE Wellbeing and CORE Problems and Symptoms scores were all associated with each other and so the CORE Non-Risk was retained as this score includes the information from the two subscales.

It was found that a higher number of psychotropic medications and a lower CORE Non-risk score at T0 were both associated with higher quality of life at 9 months follow up.

### **Empowerment**

Number of psychotropic medications and choosing to take medication as prescribed (as measured at T0) were associated with Empowerment at 9 months follow up at the 10% level. These variables were not related and so were entered into the ANCOVA model together.

It was found that a lower number of psychotropic medications and taking medication as prescribed at T0 were both associated with higher empowerment at follow up.

### **Mental Health Confidence**

Age, accommodation status and choosing not to take medication as prescribed (as measured at T0) were all found to be associated with mental health confidence at follow up at the 10% level. These variables were not related and so were entered into the ANCOVA model together.

Age and accommodation status were no longer significant when entered into the ANCOVA model with not taking medication as prescribed. Choosing not to take medication as prescribed at baseline was associated with higher mental health confidence at follow up.

### **Satisfaction**

Being on atypical antipsychotics, CORE Problems and Symptoms, CORE Non-risk, CORE Total and Beck Depression Inventory (BDI) (all measured at T0) were all associated with satisfaction with the self care project at the 10% level. The four CORE related variables were highly correlated with each other and so only the CORE Total score was further analysed. However, CORE Total score and being on atypical antipsychotics at T0 were also significantly related. As both variables are of interest, the results of the univariate ANCOVA models are presented in Table 11.

A higher level of clinical severity (as measured by CORE) at T0 was associated with higher satisfaction with the self care project. People on atypical antipsychotics at T0 had a lower level of satisfaction with the self care project.

### **Hospitalisation**

As there were very few people with multiple admissions during the 9 months of the study, this variable was analysed as a binary variable: hospitalised or not hospitalised during the 9 month follow up period.

Being on mood stabilisers, number of psychotropic medications, length of time since receiving mental health diagnosis (all measured at T0) and being hospitalised during the 9 months prior to T0 were all associated with being hospitalised during the 9 month follow up period. Being on mood stabilisers and number of psychotropic medications were related. Therefore, in order to be consistent with other models, number of psychotropic medications was retained to enter into the multiple logistic regression model.

It can be seen that the more psychotropic medications being taken at baseline and being hospitalised during the 9 months prior to t0 increased the odds of being hospitalised during the 9 months follow up period of the study. In addition, the longer the duration of illness at T0, the less likelihood there was of being hospitalised during the 9 months of the study (Table 11).

**Table 11. Association between baseline variables and outcomes at follow up**

Variable		<i>B or Mean (95% CI)</i>	<i>F<sup>a</sup></i>	<i>P</i>
<b>SEIQoL-DW (n = 91) (R<sup>2</sup> = 13.9%)</b>				
Number of psychotropic medications		2.7 (-.14, 5.5)	3.6	.063
CORE Non-risk score		-.83 (-1.6, -.05)	4.5	.038
<b>Empowerment (n = 90) (R<sup>2</sup> = 48.5%)</b>				
Number of psychotropic medications		-1.1 (-2.2, -.13)	5.0	.027
Do you take this medication as prescribed?	Yes	76.4 (74.7, 78.0)	5.3	.007
	Partially	71.3 (68.4, 74.2)		
	No	71.2 (65.2, 77.1)		
<b>Mental Health Confidence Scale (n = 90) (R<sup>2</sup> = 46%)</b>				
Age		-.01 (-.02, .00)	1.8	.178
Do you take this medication as prescribed?	Yes	3.8 (3.6, 4.0)	3.0	.056
	Partially	3.4		

		(3.1, 3.7)		
	<b>No</b>	4.0		
		(3.4, 4.7)		
<b>Accommodation Status</b>	<b>Supported</b>	3.6	2.1	.156
		(3.4, 3.9)		
	<b>Unsupported</b>	3.9		
		(3.5, 4.2)		

a Analysis of covariance

#### 4.2.6 Predictors of engagement with self care

The final stage of the quantitative analysis plan (section 3.4.5) asked which service user characteristics are associated a high level of engagement in a self care project.

High engagement with the self care project in each site was defined separately for each site as described in 4.2.3.

Variables found to be univariately associated with being engaged with the self care project were age, SEIQoL at T0, the STAR subscales of 'positive collaboration' and 'positive clinician input' at the 10% level. The two subscales were highly correlated, therefore STAR 'positive collaboration' was included in the model as the univariate association with engagement was stronger and felt to be more relevant in this context. It was found that patients with a higher quality of life at T0 and who rated the STAR 'positive collaboration' subscale higher were more likely to stay engaged with the self care project (Table 12). Age was not significant at the 5% level.

**Table 12. Predictors of engagement with self care**

<i>Engagement with the self care project (n = 93) (Nagelkerke R<sup>2</sup> = 9.2%)</i>			
	<b>OR</b> <b>(95% CI)</b>	<b>Wald</b>	<b>p</b>
<b>Age</b>	1.0 (1.0, 1.1)	2.9	.091
<b>SEIQoL at T0</b>	1.0 (1.0, 1.1)	4.0	.047
<b>STAR 'positive collaboration'</b>	1.1 (1.0, 1.3)	5.4	.020

#### 4.2.7 Staff relationships with service users

Simple demographic data was collected on the staff members nominated by the service user participants as being the member of the self care project

staff team with whom they had had most contact, and about whom service user participants had completed the STAR (patient version) measure of the experience of therapeutic relationship. This data was not collected about staff in the SUN project. This was because SUN project staff refused to complete the STAR (professional version) about those service user participants who had nominated them. The team explained that the ethos of the SUN project meant that the individual service user's relationship was with the peer group, rather than individual staff members and so it would be inappropriate for them to complete the measure. (It should also be noted that service user participants in London were happy to nominate and complete the STAR (patient version) about SUN staff, as has been analysed in sections 4.2.5 and 4.2.6 above).

In West Yorkshire, 18 staff members generated STAR ratings about 22 service users. 13 of the 18 staff members (72%) were female. Ethnicity was available for 16 of the 18, 15 of whom were White-British and 1 White-Other. One of the staff members was a social worker, one was an occupational therapist, while the remaining 16 were from other disciplines that were not health related.

15 of these staff members completed the STAR about 1 service user each, 2 completed STAR ratings on 2 service users each and 1 completed STAR ratings on 3 service users.

In Hampshire, 12 staff members completed the STAR about 20 service users. 10 of the 12 staff members (83%) were female. Ethnicity data was not available. Four of the staff were Registered Mental Nurses (RMNs), three were Support Workers, two were occupational therapists, and the remainder a social worker, a MIND worker and a 'mental health professional'.

8 of these staff members completed the STAR about one service user each, three completed STAR ratings on two service users each and one completed STAR ratings on six service users.

STAR ratings were therefore available on 42 service users by 30 staff members. There was no significant association between service user and professional rated STAR,  $b = 0.04$ , 95% CI: 0.29, 0.36) when including a random effect of professional discipline. No association was found between CORE Total or subscales, Quality of Life, empowerment, mental health confidence at baseline or follow up and professional ratings of STAR.

Of the 42 service users, 8 were categorised as having a low level of engagement with the self care project. Those who were no longer engaged with the self care project had professional rated STAR values that were 4.1 points lower than those who were still engaged (95% CI: -0.84, 9.0), but this was not statistically significant ( $p = .101$ ). There were no significant differences between those who were still engaged and those who were not in terms of the professional rated STAR subscales.

#### **4.2.8 The carers sample**

At baseline, 15 carers were interviewed (1 did not complete the ECI). The carers sample had a mean age of 51.8 (SD 12.4), ranging from 29 to 66

years old. 60% were female. Overall, the carers sample was White-British (87%), with a small percentage being White-Irish (7%) or White-European (7%). The majority of carers were married or in a long term partnership and worked either full or part time. Nearly half of the carers lived with the service user they cared for (47%). This may be a result of the high percentage of carers in London being parents of the service user (75%). In West Yorkshire and Hampshire, the majority of carers were parents, partners or spouses of the service user. Overall, carers considered themselves to be the main carer (93%). The carers sample is small so any differences by site cannot be analysed or tested for significance.

Descriptive statistics of the ECI are given in Table 13. It can be seen that there was a slight reduction in both the positive and negative appraisals of care giving. However, among the 12 carers who completed ECI at T0 and T1, no statistically significant change was found in either the positive or negative appraisals of care giving:  $p = 0.109$  and  $p = 0.116$  respectively.

**Table 13. Experiences of Caregiving Inventory**

		T0		T1	
		Mean (sd)		Mean (sd)	
	n	Min, Max		n*	Min, Max
<b>ECI – Positive Total Score</b>	14	32.6 (9.5) 15 – 47		14	29.7 (11.5) 9 – 53
<b>ECI – Negative Total Score</b>	14	74.1 (24.1) 44 – 114		14	64.6 (26.3) 21 – 122

\* 12 of the 14 at T1 are in the 14 at T0



### **4.3 Qualitative findings**

Qualitative data from the case studies is presented in stages below, as described in the qualitative analysis plan (section 3.4.6). We begin by presenting a qualitative thematic framework for understanding self care support in Mental Health NHS Trusts (section 4.3.1).

As can be seen from the thematic framework, the categories or codes that constitute the framework are many and varied. The framework represents very much a first level analysis, aiming primarily to organise the data in order to facilitate a deeper analysis (Mason 1996). That deeper analysis sought to draw out experientially grounded understandings, both of self care and mental health, and of the barriers and facilitators to supporting self care in the Mental Health Trust context. The qualitative analysis strategy (section 3.4.6) described an iterative, collaborative team process of producing analytical narrative that captured the experience of self care and self care support from the different stakeholder and self care project perspectives. We also described how emerging themes would be subject to a degree of respondent validation through feedback conferences at each site (section 3.5.1). The feedback from those conferences is presented below (section 4.3.2) in order to illustrate how our ongoing analysis was shaped by that respondent validation.

We then present analysis of understandings of self care (4.3.3) among service users, carers and staff, as well as expectations of self care support (4.3.4) among service users and their carers as they were referred to, and began to use, the different case study self care projects, contributing to discussion and revision of the 'service user and carer expectations and identities' component (Box D) of our theoretical framework for understanding self care support in section 5.1.4.

This is followed by an in-depth analysis of service user, carer and staff experiences of self care support in the case study projects (4.3.5), interviewees' reflections on the way those projects were structured (4.3.6), staff experiences of what it was like to work in self care projects (4.3.7) and interviewees' thoughts on the wider organisational context in which the projects were situated (4.3.8). This analysis will contribute to the discussion and revision of many elements of our theoretical framework for understanding self care support in section 5.1.

Further qualitative data is analysed in section 4.4 through the systematic synthesis of quantitative and qualitative findings, again contributing to the revision of the theoretical framework in section 5.1.

#### **Key to sources**

Throughout the presentation of qualitative data below, direct quotes from interview transcripts are given a six or seven digit unique identifier. The first two letters signify the case study site (LO = London; HA = Hampshire; WY = West Yorkshire). The second two digits signify the stakeholder status of the participant (SU = Service User; CA = Carer; ST = Staff). The third pair

of digits is the number of the participant as recorded in the local site participant database (e.g. LOSU15 refers to London service user number 15). Finally, for service user and carer participants, the last lower case digit signifies whether the quotation was from their baseline or follow up interview (b = baseline; f = follow up).

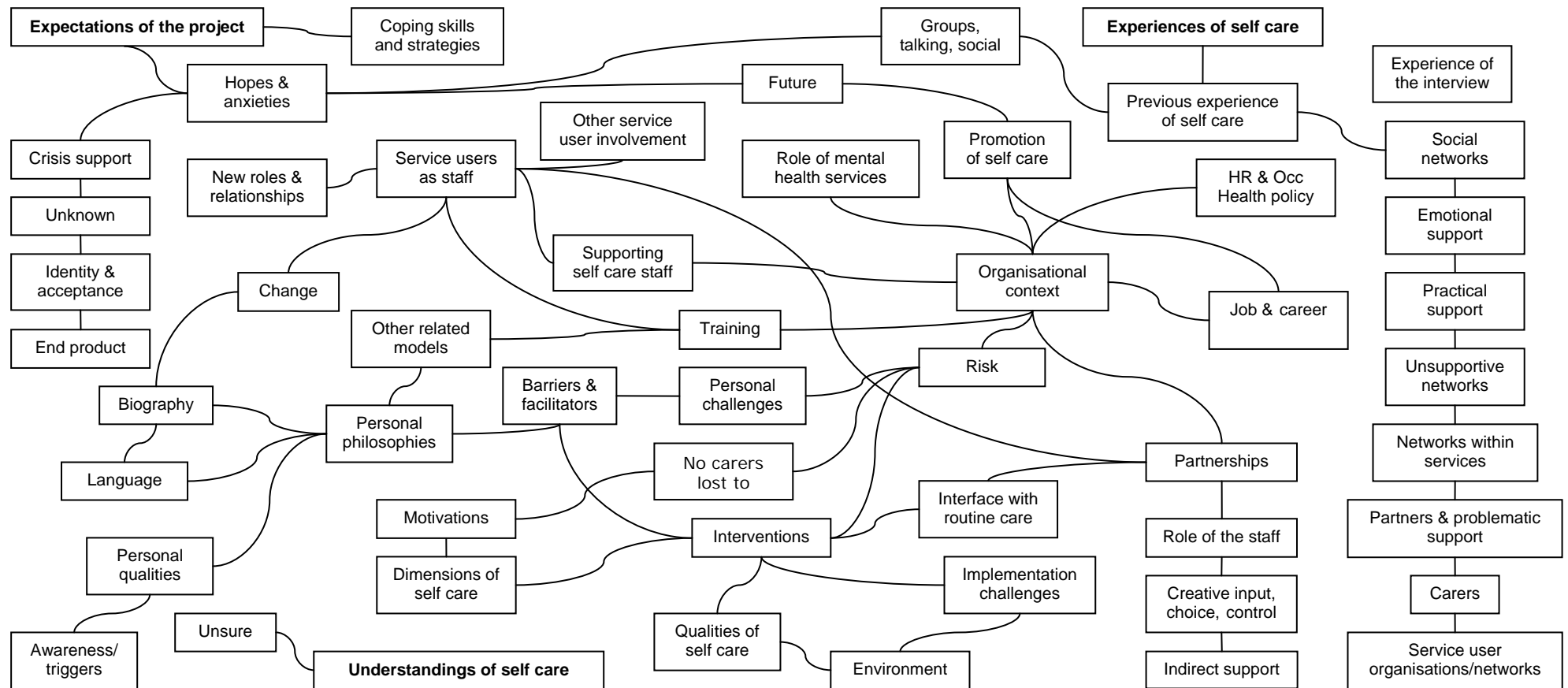
### **Staff sample**

The service user and carer samples have been described elsewhere (4.2.2 and 4.2.8 respectively). In total 31 members of staff had a qualitative interview, 12 in London, 14 in West Yorkshire and 15 in Hampshire. Of the 12 interviewed in London 9 (75%) were female, 5 (42%) were White British, 4 (33%) were White Other, 2 (17%) Asian and 1 (8%) Black African. Seven (58%) worked for the SUN project, 1 of whom was the Manager, 3 were support facilitators and 3 were Senior Personality Disorder Liaison Workers. The referring staff were 3 psychiatrists, 1 community psychiatric nurse and 1 social worker. In West Yorkshire 8 (57%) of the 14 staff interviewed were female, 12 (86%) were White British, 1 (8%) was White Other, and 1 (8%) Black Caribbean. 8 (57%) of the 14 staff referred service users to creative arts projects and worked either in CMHTs or day services. The remainder were creative arts project workers and managers of various professional backgrounds working for voluntary sector providers, including 1 service user facilitator and 1 chief executive of a voluntary sector organisation. In Hampshire 14 (93%) were Female, the same number were White British and 1 was White Other. Four were WRAP project staff and 1 was a member of the WRAP advisory group. Seven were WRAP facilitators and 1 was a supervisor to WRAP facilitators. One had started and then stopped using WRAP with the service users they supported, and the final person referred users to the WRAP project.

#### **4.3.1 A qualitative thematic framework for understanding self care support**

As described in the qualitative analysis plan (section 3.4.6) a thematic framework for analysing the qualitative dataset (service user and carer baseline and follow up interviews, and staff interviews) was generated in stages, through whole team discussion, as interviews were transcribed and analysed. The final thematic framework is given in Figure 5 below:

Figure 5. Qualitative thematic framework for understanding self care support



### 4.3.2 Feedback conferences – exploring emerging themes

A set of six broad themes exploring understandings of self care and self care support was generated through group discussion of emerging qualitative interview data and the qualitative thematic framework. Each theme comprised a number of subthemes, or factors that might be facilitators or barriers to the provision of self care support by Mental Health Trusts. Those themes and subthemes were as follows:

- 1) Groups, talking and social contact
  - Peer support
  - Social support and activities
  - Identity and acceptance
  - Being in a group
- 2) Qualities of self care support
  - Pathway into the project (referral/ self referral)
  - Structure and set up of the project (ongoing and flexible support)
  - Philosophy and approach to support
  - Routine and structure
  - Focusing outwards into the community
  - Personal plans
- 3) Links between self care and other services provided by the Trust
  - Access to the self care project through NHS Trust mental health services
  - Access to NHS mental health services through the self care project
  - Interaction between self care and other mental health care
  - Relationships and communications between organisations and services delivering mental health support
  - Risk and risk management
- 4) The role of staff in supporting self care
  - Service users as staff and volunteers
  - Relationships between staff and service users
  - Type of support
  - Job and career
  - Staff training and experience
  - Staff attitudes and values

## 5) Links with other types of support

- Support from informal carers
- Access to social networks
- Links to voluntary services
- Accessing other services (e.g. social services)

## 6) Personal challenges

- Personal challenges to self care
- Shared understandings of what self care means
- Appropriateness of self care support for an individual

Four feedback conferences were held in total, one each in London and Hampshire and two in West Yorkshire at venues (Huddersfield and Wakefield) that were accessible to people from both the Leeds Partnership NHS Trust and South West Yorkshire Mental Health Trust areas. Attendance at each conference was as follows:

**Table 14. Feedback conference participants**

	<b>Service users</b>	<b>Carers</b>	<b>Frontline staff</b>	<b>Strategic managers</b>	<b>Total Site</b>
<b>London</b>	7	1	7	5	<b>20</b>
<b>Hampshire</b>	7	0	5	4	<b>16</b>
<b>Wakefield</b>	5	1	6	3	<b>15</b>
<b>Huddersfield</b>	9	2	7	2	<b>20</b>
<b>Total Stakeholder</b>	<b>28</b>	<b>4</b>	<b>25</b>	<b>14</b>	<b>71</b>

Because of time constraints placed on the conferences, it was not always possible for participants to consider all of the six themes in their groups. In London and Hampshire, three groups of participants discussed and rated four themes each. Each theme was discussed and rated by two groups at each site. Wakefield and Huddersfield participants considered all six themes.

#### **Feedback from the rating exercise**

The overall ratings for the each subtheme, by site and by stakeholder group, are presented in graphic form in Appendix 14. It is important to treat this data with some caution. Conference participants were not representative of a cross section of people using or providing Mental Health Trust services. They were invited firstly because they were also research project participants and secondly because they might have other involvement or interest in self care. They then self selected through

deciding whether or not to attend the conference. In addition, some participants were more interested in the group discussion and did not always rate every subtheme. Also, some of the strategic managers and frontline staff were not able to stay for the whole conference and therefore did not rate all themes.

With those reservations in mind, it can be observed from the graphs that conference participants of all stakeholder groups and at all sites broadly recognised the themes we had identified through our preliminary qualitative analysis as important barriers ('difficulty') and/ or facilitators ('help') to supporting self care in Mental Health NHS Trusts. Very few participants rated themes as not relevant, with eleven of the twenty eight subthemes not rated as 'not relevant' by any of the participants. Many participants rated subthemes as both a barrier and facilitator – including subthemes comprising the *Personal Challenges* theme. This reflected discussion feedback (see below), which indicated that people had mixed experiences and that barriers could become facilitators where Trusts 'got it right' or where challenges were overcome.

Within stakeholder groups, strategic managers and frontline staff in particular rated *Qualities of self care support* as facilitators, with frontline staff also rating *Staff Roles in supporting self care* as facilitators. Carers, although small in number, expressed the most ambivalence, with many themes rated more or less entirely as both barrier and facilitator. This also reflects group discussion (reported below), indicating that self care support seems to be a 'double-edged sword' for many carers, creating challenges for their relationship with the person they care for as well as offering benefits and opportunities. The diversity of responses from service user participants reflected the diversity of experiences they described in the discussions.

Because of our reservations about the quality of the rating data, we will not report individual subthemes that appear to be rated somewhat differently by different stakeholders or at different sites. There were no patterns in the way in which the overarching themes had been rated at the different conferences.

### **Feedback from the group discussions**

Feedback from the group discussions at all sites was that, broadly speaking, the themes and subthemes we had identified did reflect the experiences of all stakeholder groups, although some felt more themes were relevant than others in terms of participants' personal experiences. Some issues were raised, both across sites and locally, that helped refine our preliminary analysis. We will not report discussions in detail as the purpose of this exercise was not to collect further qualitative data. A summary of the main themes from the group discussions is reported below:

**Table 15. Feedback from group discussions**

<b>All sites</b>
<p>Many themes were both barriers and facilitators (becoming facilitators where Trusts 'get it right' and/or where individuals overcome challenges)</p> <p>Timing of self care support must be appropriate to individual's needs (must be well enough, but also if too well can be experienced as infantilising or depressing; the importance of choice about when to seek support for self care and self referral)</p> <p>Self care experienced as 'abandonment' by the Trust (in the absence of parallel, ongoing access to Trust services)</p> <p>Positive staff attitude towards self care essential</p>
<b>London and Hampshire</b>
<p>Unclear relationship between (self care) crisis plan and access to Trust crisis services</p> <p>Staff anxiety about changing roles (a more relaxed way of working in London; running groups and giving up responsibility in Hampshire)</p> <p>Risk of becoming 'too comfortable' in the Self Care project</p> <p>Under-developed links into voluntary sector services/ opportunities</p>
<b>London</b>
<p>Shared risk issues with related projects (self management and depression; supported employment)</p> <p>Anxieties around groups (e.g. personal disclosure of difficult issues)</p>
<b>Hampshire</b>
<p>Supporting self care being empowering for staff</p> <p>Not separate enough from Trust services</p> <p>WRAP can be shared with family, GP etc</p>
<b>West Yorkshire</b>
<p>Difficulties in providing statutory services in the voluntary sector (continuity of funding; access too restrictive)</p> <p>Creative arts as a vehicle for overcoming personal challenges and accessing mainstream community opportunities</p>

### 4.3.3 Understandings of self care

All interviewees were asked what they understood self care to mean: service users and carers in their baseline interviews and staff in their single interview part way through the data collection phase. Service users were also asked at their follow up interviews in their understandings of self care had changed at all.

Accounts from all stakeholders could be characterised by the simple statement, 'looking after yourself' (e.g. LOSU17b, HAST12). Further emphasis was placed on 'living on my own in the community' (HASU26b) and independence (HACA05f).

#### *Service users*

Many service users said self care was about doing more things on their own and being more independent:

'I suppose self care can also mean being able to do more things on your own instead of not being able to do them because you feel too anxious about it.' (HASU05b)

'... being able to, well, obviously being able to function on your own, which is where the independence comes in again' (LOSU01b)

Some service users spoke about taking more control:

'I think self care is a very good direction for mental health care to be moving in because nobody knows what's going on inside somebody's head except that person. I think the only person who can come up with the absolute answers whenever there are answers, is the person themselves.' (HASU24b)

'... it's taking sort of charge a little bit, I think a lot of the sort of problems are you are sort of losing control, a lack of control, suddenly you feel you're completely out of control and the self help is getting back in control but recognising that there are certain things, that you can't control everything in your life that happens, you can't control everything.' (WYSU16b)

Some service users discussed specific aspects of self care, such as breathing techniques for anxiety, recognising triggers and taking regular exercise:

'Yes because you know it's all to do with breathing techniques, part of it is stuff like that because if you are having a panic attack it's really hard to control that so you have to find ways of alleviating that so it's not so bad.' (HASU05b)

'I mean for me personally, self care is recognising the triggers that lead me into self-harming and recognising, becoming more keenly aware of my own moods and being able to identify triggers that lead me to self-harm or self-injure or attempt suicide, and being able to utilise the support networks that are in place.' (LOSU25b)



Some felt self care was more about coping with daily tasks, such as washing and dressing:

'Getting up at a good time in the morning, and getting through the routine of washing and cleaning and everything, and sorting out your clothes, what you're going to wear. And doing the housework, walking the dog, all that before I come out every day.' (HASU14b)

'I think it's about looking after yourself and being aware that certain things are your responsibility and just be more self aware about I need to look after myself now whether that be exercise or decent food rather than eating rubbish all the time or attending courses and realising you need to get out of this place and mix with other people and do something rather than staring at the walls or the tele' that's self care to me.'  
(WYSU22f)

Some service users thought having a social network formed part of their self care:

'... but also for me it's one of my inadequacies it's social relationships you know I'm a bit introverted when I'm with people I get on really well but it's forming those situations where I might be with people. So looking after myself for me is trying to find areas where I might try to meet people.' (HASU33b)

'I've got a mum and my sister and my niece you know, so family time and keeping in contact with them. I've got loads of really nice mates, I haven't quite picked up my social life yet, well I've started my day time social life if I go to a bar in town and drink coffee or herbal tea when I'm not drinking coffee but I haven't started going out of an evening yet but that will pick up soon.' (WYSU17b)

In some cases, service users were unsure about the meaning of self care:

'I'm not sure it's actually a term I've ever heard before, so I mean I guess like just, when you first hear it I sort of thought 'well, you know, what does that mean? Does that mean how I work with my mental health problems and does that mean me trying to sort things out and trying to, I guess, be in charge of my own treatment and take a more active role in, if I get therapy or what medication I'm on or making sure I'm honest and ... well I guess, I'm, 'cos I'm still a bit confused about self care.' (LOSU08b)

### *Carers*

As noted above, carers' understandings of self care were concerned with their caree's independence and reduced reliance on themselves as carer:

'Being able to develop a strategy so that you do not have to be dependent on people to be able to get on with your life as normal, or as normally as possible.' (HACA03b)

'I suppose it is ... being independent, being able to look after yourself independently really from anybody else in, from as basic as washing yourself and getting yourself up in the morning to going out and

socialising or getting a job or something. It's, it's being independent of someone, looking after yourself.' (WYCA04f)

However, they felt self care should not mean being left to deal with problems on their own, that there was a role for mental health services:

'I mean it's not leaving you to your own devices as it were, it's giving you some tools and knowing where you can get the help as it were is my take on it and a certain amount of follow up as well, but I'm very much aware that self care is not just leaving you.' (HACA03f)

'... you do want a person to be as independent as possible but really a lot of support has to be in place for them to achieve that ... and they really do have to feel like there's a safety net before they'll dare look after themselves.' (WYCA03f)

### *Staff*

For some staff, the focus of self care was on broad day to day needs:

'I sort of defined self care as supporting members to be able to manage doing their own shopping, looking after their own personal needs, managing their flat or wherever they lived and being able to go out and do things that they wanted to do, to see things that they wanted to do'. (LOST01)

For many self care was more holistic, including mental health as well as physical and other personal needs:

'I think my understanding of self care changed over the years and I think self care means to me the whole holistic looking after yourself and that can mean your mental health, your physical health, about everything you do because if you don't look after what's good for you then, then you're going to have problems.' (WYST12)

'... it's actually sort of getting yourself up, dressed, washed, fed and so on and so forth, in a fairly limited way. But then extending it on from that is also basically looking after your mental or physical health needs, work might be included in it, leisure, spiritual, everything really, I guess.' (HAST10)

Staff also thought that self care was having an understanding of what keeps you well and being empowered to do things to keep yourself well, overlapping with related concepts of recovery, wellness and self determination:

'Um, well perhaps it empowers them and makes them more independent, so less dependent on others, so it promotes self esteem and promotes recovery.' (LOST05)

'... self care to me is being empowered to actually do stuff that I know will encourage my wellness, will encourage me to feel better.' (HAST07)

'I think it probably gets away from the idea of people going into sick roles or living in sick roles or being victims of or martyrs ...' (WYST02)

Some staff discussed their own self care not just what it means to service users.

'Self care for me, um, is my well being. It's me having a life where I can look after myself but also my employment or when I go out ... My self care, is looking after myself and making sure that I'm ... at my optimum.' (HAST08)

'I've asked for management because [my line manager] didn't want to get into management supervision and I said I, you know that's about self care ... saying actually I need to be sitting down with you as my manager once a month or something, so I'm asking.' (source removed)

#### 4.3.4 Expectations of self care support

All service users and carers were asked in their first, baseline interview, what their expectations were for the project. It is important to note that, because of the practicalities imposed on the recruitment process by the project entry procedures at all sites, many participants had already attended an initial session or sessions of their respective projects. In some of the data cited below interviewees are reflecting on their expectations in the light of those early experiences. Some interviewees volunteered reflections on their initial expectations at their follow up interview.

##### Service users

Although there were many commonalities across the sites, service users' expectations of self care did reflect different issues at different sites. A range of expectations were expressed from very high, through 'not knowing what to expect', to varying degrees of cynicism about the projects. Again, those expectations reflected site differences. While there was an expectation in London that the SUN project would become their new main contact with services, the format of the project surprised some:

'I think I thought it would be more rigidly structured ... And I thought there would be a clearer format. I mean there is a format and it's sort of check in and then everybody talks and then crisis support and then check out, something like that ... I was used to there being more input from the facilitator ... I thought there would be more support, I thought there would be more guidance from them. I thought it would be – but it's more – it's peer based support isn't it so it's peer-led ... I didn't anticipate that. I was quite ... unaccustomed to the route – to the format.' (LOSU25b)

Expectations among Hampshire service users were largely, but not exclusively, positive about the personal planning aspect of the WRAP project offering insight into their mental health, especially around developing and sharing awareness of their triggers, staying well and avoiding crises:

'And my understanding of this is to have a better understanding of my illness so I can work out my triggers and things that can help me stay well.' (HASU28b)

Exceeded expectations characterised many West Yorkshire accounts, where typically initial apprehension about the particular creative art activity was followed by a range of benefits:

'It's been more than I expected, I just thought I'd come along and play drums but it's been like getting involved with people, having the opportunity there to do things for free mostly as well ... learning to play the drums and the guitar, you can't beat that for me that's just like the best you could be doing.' (WYSU06f)

In some cases, expectations were influenced by past experiences of self care, particularly for those who had bad experiences:

'My expectations, my thoughts of the mental health system aren't that great anyway because of my experiences of before.' (HASU01b)

Some service users looked forward to the benefits of increased social contact:

'Because sometimes when you've got somebody else saying like "I think you can do it" and stuff, it's a lot better than you just trying to say it yourself and I think it's also better when it's coming from somebody who isn't closely related to you, like a friend or a family, because you kind of think "well, you've got to say that" ... like when your mum says "you're beautiful", and you're like, "you've got to say that, you're my mum".' (LOSU24b)

'I think if I try to get out more and do some work, whether it's voluntary or paid or whatever, I'd like to start meeting new people, making friends you know, and not necessarily friends that have got mental illness you know. People in the real world.' (HASU18b)

But for at least one service user, the wider community was not a welcoming place to look for support:

'How do you find support when you haven't got, you are not part of this society? ... people look at you in a suspecting sort of way ... very often you get more prejudice than anything else ... the community just sees you as somebody they should get off your ass and do work. And so you are told you are a bum and you are sucking on the community, you are a drain on the economy.' (HASU13b)

## **Carers**

Carers on the whole were very positive about the project and had high expectations around increased activity, social contact, independence and future employment prospects for the person they cared for:

'I am just delighted that he is going to meet people because he doesn't meet anyone, he's at home, he's got one friend who is mentally ill also ... that he goes over to see and that is it. So meeting people would be such a good thing ... I would like him to get a part time job, and then get a full time job is it was possible. You know if he could work for a gardening centre or, that is what he is trained in, or whatever you know he started

off you know doing carpentry so I mean the practical things anyway.'  
(HACA02b)

'I think it could only be good for her, rather than bad for her, if you see what I mean. I just see it as she's actually doing something really.'  
(LOCA04b)

'I think it's good because if anything ever happened to me he's got to carry on with life so things like that and going to clubs that he goes to really gives him another outlook on life instead of just depending on me all the time' (HACA05b)

Others were more ambivalent:

'I didn't have particularly high expectations of it, which is maybe wrong of me, but everything I thought it was going to be, it was. Because of people, I did find it hard, I mean maybe I wasn't open to it, like I just, I suppose it met what I thought it was going to be like.' (LOCA05b)

'... I suppose I didn't have any at the beginning because I didn't know such a place existed until he was put on it, we've not, I'd no contact with anything like this before. Since he has been coming ... he's not got any worse but I don't feel that he isn't making another step, of, I think one day he might get back to what he was before. I think I've come to the conclusion now he won't ... I think my expectations were higher.'  
(WYCA04f)

### **Hopes and anxieties**

In their baseline interviews service users and carers were also asked if they had any particular hopes or anxieties as they began the self care project.

#### *Service users*

When discussing their hopes and anxieties associated with taking part in the self care project, there were common themes across the sites, including coping skills and strategies; peer support; social contact and interaction; group dynamics; identity and acceptance and personal qualities such as confidence and self esteem. Overall, many service users hoped they would get better. Many talked about recovery, wanting to learn how to stay well and being more 'normal':

'I just wanna ... I don't know, it's really, really silly, but I just want them to make me better if that makes any sense, do you know what I mean? I just wanna be normal.' (LOSU14b)

A prominent theme was coping skills and strategies. Across the three sites, service users hoped to learn better ways of coping with their illness and many achieved this as demonstrated in the follow up interviews:

'I can also look back and see how I have coped and how I felt, sometimes I can think well I've done alright this week or how did I cope with that there oh right I'll know now and do that.' (WYSU02f)

This was a major theme in London where service users particularly wanted to learn ways to prevent self harming behaviours:

'I'm hoping – or what I'm trying to find, more to the point, is understanding why, for one, I self harm. I mean I've got a history of bad things anyway so it could be just a build up of everything.'  
(LOSU34b)

In contrast, there was more reference to the importance of understanding and writing down triggers in Hampshire:

'And my understanding of this is to have a better understanding of my illness so I can work out my triggers and things that can help me stay well.'  
(HASU28b)

In West Yorkshire, service users discussed learning creative skills that could help them to cope with their problems.

'... to gain more skills from an arts and crafts point of view ...'  
(WYSU29b)

### *Carers*

When discussing their hopes and anxieties associated with the self care project, these mirrored their expectations. Overall, carers hoped that the self care project may aid the recovery process and discussed the possibility of the person they cared for not having the illness anymore or being more 'normal':

'My hopes are that she can manage her own illness, I mean what would be great is if one day she didn't have it. And who knows, that's not beyond the realms of possibility I mean you know that would be wonderful, um and maybe by managing it maybe she can manage it out of herself. That seems a bit daft but you know what I meant.'  
(LOCA03b)

Carers described the sort of things they did in terms of supporting the person they cared for such as domestic chores, providing emotional support and practical support such as with shopping and transport. In particular, many carers talked about providing encouragement:

'I'll encourage her to things outside of the home, I'll make sure that if she needs transport I'll get her there and bring her back and I'll take her to meet family and I'll make sure she can get out of the house when I'm not working yeah so I'll do those sort of thing for her and generally everything else gets done for her as well.'  
(WYCA01b)

In the baseline interviews, carers described the relief they felt that there were other people involved and that they were no longer the sole support, thoughts also echoed by one service user:

'Well the benefits for me will be I won't have to worry that I'm the only person that he has really got.'  
(WYCA03b)

'She doesn't live with me but she tries to support me but because she doesn't understand about ... me being down and me wanna self harm.'

She just doesn't understand it so sometimes it's really hard for her ... because you know when I am really at rock bottom she, I think she just doesn't know what to do really.' (LOSU04b)

#### 4.3.5 The experiences of service users and carers

##### Personal challenges and overcoming them

There were personal challenges to engaging in self care and accepting the support offered by self care projects. We got a sense from some interviews that self care may not suit everyone, and could be experienced by some service users as having to take on too much responsibility:

'I mean I felt a bit as though [my key worker] just sort of dumped it all on me.' (HASU18f)

'I think some people won't want to take responsibility. If you become used to leaning on something or being supported by something and some of it is not an easy process to go through.' (HASU22b)

The isolation associated with experiences of stigma related to mental health was identified as a challenge to accessing support for self care:

'I do think that obviously people that suffer from mental illness, the very nature of it can be an isolating experience, be it because of the stigma attached to the mental illness or be it because in some mental illness or I think in a lot of different ones, like with me when I get bad, I'll withdraw, I'll isolate myself.' (LOSU20b)

While some service users found the whole concept of self care a challenge in comparison to the way she was routinely coping:

'... it's really difficult because in an ideal world, self care – for instance – it depends on how people deal with certain things like I – I would self harm if I'm having a crisis, so to self care for somebody that self harms, I actually don't know what to do because my – still now, would be to self harm. So I don't know about what other self – what

I can do other than do that ... so as far as self care, I haven't done any self care because it's just been, um, self harm really, in every aspect since – since I was young.' (LOSU14)

Anxieties around support provided in a group setting were often identified as a challenge, particularly in London, and will be discussed in more detail in section 4.3.6.

Changing relationships between the service user and carer, as the service user took on more responsibility and needed the carer's support less, was identified as a potential challenge:

'He likes to be in the caring mode, he's always done it, all our married life he's sort of looked after me and the children when I've been ill and that's just been his role, now I think he's lost, he don't know what to do with himself.' (HASU09f)

However, these changes were often positive:

'My experience as a carer is, I now feel that I've got an adult son who's got some health problems that he's managing whereas my experience for a carer, as a carer for the previous sort of fourteen or fifteen years was of being on the verge of hysteria ... crisis after crisis, my heart broken, having to abandon all hope literally in order to get through. It was, it was drastic and now it's like I've got an adult son that's my mate. I mean it couldn't be more different, it's very dramatic.' (WYCA03f)

'... because my sister in law, I don't rely on her as much as I used to do and it feels like I can cope with taking my own medication and stuff like that. I'm confident to go out and shop.' (WYSU07f)

Similarly, service users described a sense of achievement if they overcame challenges to accepting support for self care from the Trust:

'It took quite a lot of effort to go to the group but I was so glad that I did. But I can, yeah, I can remember the time. Yeah. I had to, a lot of effort to make myself go but I was glad that I did.' (WYSU40f)

In particular, service users in West Yorkshire described how the creative arts projects could motivate them to overcome personal challenges:

'This charity is making me want to actually get over all this fear in my head so that I can travel and once I start travelling to Huddersfield, maybe it will broaden my horizons to travel elsewhere. Like if I get a job I will be able to travel to it, without worrying "well outside is so many miles so I won't be able to walk it".' (WYSU11b)

Some service users associated overcoming personal challenges – engaging in the self care project despite difficulties – with an increased sense of confidence, self esteem and empowerment:

'It's made me feel more stronger and I've got more self esteem cause I know I can put things to the test and I know I can do activities as well.' (WYSU14f)

Carers echoed that view:

'Well I've seen it happening, they are very kind they are very understanding, they are very supportive and very encouraging of other service users as well but in my case my son to really feel that he can go out and play the drums, he can sing and turn up for performances and that is the affect they are having on him really, they are contributing a lot to him gaining self confidence and self esteem.' (WYCA03b)

However, other service users felt they needed to recover confidence before they were in a position to self care:

'You've got to get your confidence back before you can look after yourself, I think cause if you haven't got the confidence.' (WYSU05b)

### **Timing it right**



Many interviewees – service users, carers and staff – echoed this belief that the individual needs to be ready to take responsibility for self care and that support for self care therefore needs to be timed correctly. Many people said that meant being well enough to self care:

‘When the time is right, yes. I’ve got no doubt I will do it, it is just a question of when the time is right to do it.’ (HASU24f)

‘It would be dangerous to try and force myself if I was really ill to do it’ (WYSU30f)

‘You’ll have to build it up first and then maybe they’ll get to a point where they can accept self care. I don’t think you can just go on week one and then suddenly get self care, it wouldn’t work like that.’ (LOCA02b)

‘It’s getting the timing right. It’s getting the person, the person, you know not everybody is the same you know, and I think you’ve got to treat each person you know as an individual, you’ve got a package that’s suitable for that individual person, not, what suits one doesn’t suit another.’ (WYST07)

### **The relevance of diagnosis**

It was only at the London site – the SUN project being the only self care initiative in the study that was diagnosis specific – that the service user’s diagnosis was raised as an issue, by a staff member, in relation to self care:

‘Self care is really important, because, it does mean greater independence and empowerment and self-enabling, which are all really challenging to people who have personality disorder. I think that it can often be heard by service users as quite punitive, because many service users haven’t had the experience of being cared for adequately. So when you say ‘self care’ to them, it doesn’t, empowering and enabling, doesn’t actually always spring to mind.’ (LOST06)

It is important to note that a formal diagnosis was not essential for admission to the SUN project. Some service users thought not knowing their diagnosis was a barrier to accessing support:

‘The amount of people that don’t seem to know what their diagnosis is, just seems a bit ... if you don’t know what’s wrong with you, it’s harder to get the correct help.’ (LOSU23b)

One interviewee pointed to a lack of services for Personality Disorder resulting in the SUN project was being used by the Trust as a service to refer people to who could not be helped elsewhere, questioning whether people were receiving appropriate support:

‘It kind of made me feel a bit sad, if I’m honest. I’d go there and I’d see people and even though obviously I’m the same as them but ... I just think like you know we’ve got a diagnosis and we’re just thrown in here because it’s NHS funded. No one’s really getting the support and the right treatment.’ (LOSU38f)

However, some service users felt that it was the insight they gained into Personality Disorder through going to the SUN project that facilitated their self care:

'... the more you understand an illness or a problem you've got, the more you can do, like you say, self care. You know it gives people more confidence in themselves ... I think a lot of people feel quite passive, they sort of feel like the recipient of a service but they feel like they can't stand up themselves and ask you know questions and stuff, they feel like they just have to accept what they're told – "Take this medication", "Do this, do that", "Come to see a psychiatrist once a month" or whatever, and they sort of feel in the dark themselves about what's sort of wrong with them.' (LOSU20f)

A shared diagnosis of Personality Disorder was also cited as a facilitator, enabling some service users to identify positively with the group:

'Maybe just the fact that it was actually for people with a personality disorder made a big difference in my head. Rather than going to, like I don't know, some other group that they just called, I don't know, an anxiety group or... so maybe in my head it was like, okay, perhaps this is somewhere that I could belong.' (LOSU03f)

### **Issues of identity**

Many service users talked about being able to identify with other people with similar difficulties and therefore feeling less alone and stigmatised with their problems:

'... you don't like to mix with people because you feared what they might ask you and why you're doing stuff and you tend to isolate yourself a hell of a lot, and this place it isn't like that, you know, you can be who you are.' (WYSU01b)

'... it makes me feel a bit more normal listening to all these other people ... it's strange but it's comforting as well that there's other people that are experiencing these problems.' (LOSU05b)

In West Yorkshire, identification with the arts activity they participated in through the project facilitated development of an identity that was broader than a shared mental health problem:

'People say to me "what do you do?" I'd be like "I don't do much, I've been in hospital ..." But now I say "I'm an artist" you know, so that's a huge, huge, huge thing to be able to say I am an artist rather than "oh I am a manic depressive" you know.' (WYSU17b)

'... keeps me involved in the community as well rather than just ending up like a patient ...' (WYSU06b)

'... which feels like you are taking more part in the normal world outside ...' (WYSU12b)

One service user spoke of project staff trying to support a broader sense of identity, as did a carer:

'... I am just a service user and the [WRAP] facilitator would always bring me up on it and say "you are not just a service user, that is a small part of you".' (HASU25b)

'I might use it to ... remind her what she has achieved ... talk about things like the photography exhibition where she did something which was very worthwhile.' (WYCA06b)

However, some people felt less positive about identifying with the other people using the self care project, as reported by one staff member and a service user:

' "Oh why do you have to send me to all these nutters?" ... you know, excluding themselves from the group. "I don't think I fit in there".' (LOST08)

'I mean the thing that linked us in the room was mental health but I didn't seem to be linked in any other way to any of the people there.' (HASU12f)

#### **4.3.6 The structure of the self care project**

##### **(Self) referral and access to the project**

As noted in the description of case study projects (section 4.1.2), all projects operated some form of self referral or service user choice to participate in the project. The importance of that choice was recognised by some service users:

'I was told it was a self referral project as opposed to something that you are referred to, the onus is on you to go yourself ... is your control whether you go or not ... I didn't want to go because someone had told me to go, I wanted to go because I wanted to go in itself.' (LOSU20b)

The experience of many service users at all sites was, however, that they found out about the project through a mental health professional who had some responsibility for their care (typically a Community Psychiatric Nurse, Social Worker or Occupational Therapist who was also their Care Manager, or the Consultant Psychiatrist that they saw on a regular basis; in West Yorkshire this professional was sometimes a GP) who recommended that they refer themselves to the project (or in Hampshire, arrange to attend an initial WRAP training session). Nonetheless, service users felt on the whole that they retained choice about whether or not to participate:

'I felt as though I had the choice, yeah. I felt as though I was given the choice.' (HASU12b)

Others felt they had less choice in the matter:

'I am here on section and well when they interviewed me, the staff here, they said "Oh what groups would you like to do? Would you like to do this, that and the other?" and I said "No thank you" they said "well no [the doctor] wants you to do this that and the other". I had to.' (HASU30b)

'I kind of more or less went to please [my social worker] more than anything for myself.' (LOSU30b)

Or went because they felt they had run out of other treatment options:

'Basically I think due to lack of government funding really there was nothing available for me apart from the SUN Project ... So that was another sort of route really, you know to sort of – as part of a care plan, you know, I left my rehab and help was sort of running out for me really, you know, so she said "Well why don't you try that?" ... so yeah, that's how I ended up there.' (LOSU28b)

While one person went despite being advised by their psychiatrist not to:

'I did show it to my psychiatrist and he didn't think that it was appropriate ... I think he wants me with mainstream people.' (LOSU31b)

A number of service users noted that they needed support, both in making the decision to participate in the project (including receiving accessible information) and with the practicalities of attending for the first time. However, experiences of support for self referral were mixed:

'My CPN had already told me about this WRAP plan at home but I didn't really, he give me the forms but I put them in the bin, I don't know why I just you know, I didn't even read them. But when I was in here they explained to me, explained what the WRAP programme was and I thought I was quite good and I said I would like to do it.' (HASU09b)

'... because it was really difficult for me to get out, I became quite agoraphobic and because [my social worker] was taking myself and another lady to the project it basically made sure we got there, it sort of spurred me on to going out.' (WYSU09b)

'... it literally was "here's a leaflet, you might find them helpful" and that was it, and I actually hadn't been offered any other kind of help from the psychiatrist so I thought well, I'll try it and go along.' (LOSU08b)

The role of carers in supporting service users to attend was also evident:

'I went with her the first time and sat outside in the car because it's the support and it's getting there on the bus ... going to a new place she usually gets herself in a bit of a state ... if I take her she's just got to concentrate on getting herself through the doors if that makes sense.' (LOCA03f)

One staff member in London acknowledged that clinicians retained a role in the referral process:

'We too have our own criteria of what people we can refer to the SUN Project, because we don't want to send them to a place where they are going to tell them they are not treatable, so we sort of do our own assessment here first. That's why discuss it at team meeting.' (LOST08)

## **Self care support as ongoing, flexible and responsive support**

### **– ‘but don’t abandon me!’**

Once through the door, the flexibility in the way support was provided was particularly important to a great many service user interviewees. That flexibility took many forms and did not always respond to what the individual needed. The open ended nature of the London project and some of the West Yorkshire projects was contrasted with previous experiences of time limited services:

‘You weren’t allowed to be there after six weeks, you were discharged or if you got sick and didn’t turn up twice you got discharged. You can’t help it if you’re sick.’ (WYSU07b)

‘There’s a lot of short term therapy that people struggle to do ... we’re not one of them. We’re [here] as long as people need it, for three times a week.’ (LOST11)

With similar reflections on those West Yorkshire creative arts projects that were time limited:

‘It were for only five or six weeks, once a week for an hour, an hour and a half and then you’ve got to wait again, or you can’t just go again unless you’re referred, you need to be referred and then again if you’re not referred that’s six week then, that’s it, finished and then you’re back isolating yourself back in the flat again and then your depression and all that kicks back in again so you’re in a constant circle.’ (WYSU03b)

Some people valued more frequent access:

‘I put my opinion across that I thought it should be weekly instead of fortnightly ... Because if it’s weekly you tend to think about it more and it’s fresh on your mind, rather than if it’s two weeks it’s a bit longer to maybe and then you have to look back on what’s been said.’ (HASU06f)

‘They offer a lot of consistency... because it is 3 times a week. That’s really – it’s a lifeline for me.’ (LOSU31b)

For some service users, flexibility meant being able to choose when and how to use the support, including in a crisis, and being able to have breaks from the projects without being excluded for disengaging:

‘You don’t know when you’re gonna be poorly ... you can’t forecast it and to ring up and for them to understand that you’re not well ... and to give you another chance to come next week instead of discharging you.’ (WYSU07b)

‘That’s a sort of recognition of the way that people’s problems work, is that they may turn up for a while then not turn up for a while and ... they don’t exclude you because of that.’ (LOSU20b)

‘They keep you up to date, I mean even with me who haven’t been for ages and I thought, they, they’re keeping me up to date with what’s

going on, it's still giving me a lifeline if I need it. Which I thought was quite good.' (LOSU18f)

For many people, the flexibility and accessibility of support in the projects was encapsulated in the relatively informal and relaxed manner in which support was provided. This included being able to move and engage at their own pace and not being put under pressure:

'There'll be times where you don't wanna speak but you're just there just because you need to be there and they'll say to you "Well at least you've come, you don't have to say nothing today but you've come"' (LOSU29f)

'They support you but they are not actually looking over your shoulder, it's not an uncomfortable type of support and I think that is how it works, you know, that's why it works so well for me I think, it's relaxed but directed as well if you know what I mean.' (WYSU13b)

Nevertheless, sometimes people experienced the project as being too relaxed, moving too slowly and lacking in structure and direction:

'It's a bit like going for a walk. You've got to pitch it with the slowest walker ... otherwise you are all going to get left behind.' (HASU11f)

'Actually that's one of the things that perhaps wasn't done as professionally as it could have been ... It was all a bit low key and a bit laid back, and a bit ... sometimes almost being wishy-washy really ... Not enough ... direction.' (HASU12f)

'It helps some people obviously but for me it wasn't no way near intensive enough.' (LOSU32f)

While a few people expressed a fear that self care meant being abandoned by the Mental Health Trust:

'See if you look after yourself people tend to think 'alright, we'll leave him, he's alright now', but they don't realise you do get down and depressed when you're living on your own.' (WYSU05b)

'Well self care, I think in terms of independent living rather than being abandoned, self care definitely doesn't mean being left to it with somebody with a severe mental health condition like my son, he definitely needs a lot of support if he is going to achieve self care' (WYCA03b)

'So because I'd joined the Sun group and I just recently earlier on this year joined the psychotherapy group she decided to take a back step from me right. So that's what was going on but she never told me any of that. I'm hearing this when I was called to this meeting, I was sitting there, so I had a go at her and I said ... "Who did you tell that you, that you're deciding to take a back step from me?" I said, "If it's to do about me don't you think that the first point of communication should be towards me?"' (LOSU30f)

### **Self care support providing routine and structure**

**– ‘but I don’t want to get too comfortable here!’**

While wanting a flexible and responsive service, many people also said that they benefitted from the routine and structure – as well as sense of purpose – that attending the self care project brought to their lives:

‘... having a purpose to get up, to get washed, to brush my teeth, to look respectable to go somewhere and do something positive that helped me.’ (WYSU25f)

These views were echoed by both carers and staff:

‘It's mainly the routine and the fact that there's somewhere to go, there's something to do apart from trying to entertain yourself.’ (WYCA01f)

‘They can get a lot of benefit from it in their life and it can help them to build a structure, build a routine, feel as if they're useful and feel as if they've got something to do and somewhere to go and they're making a difference in the world’ (WYST04)

However, a number of service users expressed a concern about over identifying with or becoming dependent on the self care projects, and that dependence being a potential contradiction to the concept of self care:

‘... it's something I shouldn't do but I'm starting to depend on the place a bit and I think that's a bad thing really. I shouldn't depend on it but I am, I can't help it, it's because I feel kinda at home here. Like I say it's a controlled environment.’ (WYSU02f)

‘I don't know whether they're all like it but they, it just struck me that they weren't trying to get better.’ (LOSU17f)

‘I think [my son] is so entrenched in his, and it's a security blanket that he does all these things and I think it's almost, “touching wood, if I do the same thing each day” ...’ (HACA02f)

‘... the SUN group was also problematic in this respect in that the people that went there went there for their social life, for they were all needed ... but it becomes your identity and all the conversations ... it's comfortable, it's nice, I like this, I like this, I like the social, everything's comfortable. There's no, you don't feel left out, you've all got a common bond ‘cos you're all mental, in one regard or another. And it's comfortable and it's supportive. Of course you never get better, I don't think, because of that, I think that's the only problem. Some people need that and they can't do anything else.’ (LOSU22b)

**Using peer groups – a ‘double edged sword’**

Accounts by all participants were shaped by their particular experiences of the project they used, and the approach or philosophy that informed the way that project worked. In London, the SUN project used peer groups, facilitated by Mental Health Trust staff, to develop the individual's social and personal coping strategies. Accounts from participants at all sites revealed the peer group to be a double edged sword. For example, the experience of

peer support was often a positive one for many service users, a view also shared by one West Yorkshire staff member:

'I could leave a group at the SUN project feeling more positive, simply from what I felt I did for someone else.' (LOSU15f)

'... other people'll be there so they can sort of like shed fresh light onto how you can best cope with it ... Usually they tend to be going through the same situation as well, so we can talk like – share experiences.' (LOSU11b)

'I think the group makes it, if you were like just sitting on your own in a room doing it with whatever staff, but the group makes it more fun ... plus it gets all the patients to know each other better.' (HASU30f)

However, anxieties about hearing other people's problems, and for some a sense of responsibility for supporting others in the group, made the peer group experience in London difficult enough to put some people off attending:

'It felt like I was really trying hard to come up with solutions for them or small steps they could take and they were just like, "No it's too hard, I can't do that. No I'm upset coz I can't do that". And it became really too much' (LOSU17f)

'I just don't like to hear the arguments and the clash of personalities there and that kind of puts me off as well I think "blimey I don't need to be around this". So there've been a couple of times when I haven't sort of gone because of that.' (LOSU11f)

However, the social contact provided by the group was important for many, enabling further contact outside the group itself:

'They give you hope. I don't feel like it's my life's finished with them. That you can go there one morning feel awful that your life's not worth living but then come out with a little bit of hope, because another member will say, "Do you fancy a coffee?" or a phone call, I never used to have anyone text me or ring me, now I get texts and things.' (LOSU31f)

'It's not really been therapeutic except for the way that it's made me more sociable, less isolated things like that ... The main thing was, is that it centres around the real world.' (LOSU16f)

'It's social interaction, before I wasn't doing that I was just locked in my flat even days a week. I'm starting to see more of the family now.' (WYSU11f)

Even so, the dynamics with the group itself were challenging to a number of interviewees:

'I suppose I was still worried about confidentiality, because speaking about yourself in a group where maybe you don't know the people very well, you don't know if they would quite casually mention the things that



you hoped would be confidential, so I suppose yeah, that is the worst sort of thing I am thinking.' (HASU08b)

'There were a couple of people that were pestering me, always wanting my number and you know wanted me to go out for coffee afterwards and I find it very hard to say no and I had to keep pulling away, pulling away and making excuses, which just in turn made me feel really shit.'  
(LOSU02f)

'9 times out of 10 there were far too many people in the group. Everybody feels that they're important and wants to have a say and you're lucky if you can get a few minutes.' (LOSU02f)

High turnover of group members, related to the open access nature of groups, was also challenging for some:

'In the SUN group I think that the turnover of people changes on a quicker level than at the psychotherapy group. I have no connection whatsoever to anyone of the Sun group.' (LOSU30f)

'I think they've got to have a certain amount of wellness and motivation to stick with it, because if too many drop out I think it's not so good for the rest of that group, because they see people dropping out.' (HACA04f)

'... whilst I'm quite happy with new people, there were times when some people, I just took an instant dislike to and, but they were new and I didn't know them, so I just couldn't talk.' (LOSU02f)

And staff echoed these concerns from a more clinical perspective:

'I suppose it's identifying risk because it's what the other patients have to deal with in terms of say, someone's released some information, and how confidential do you keep information such as if someone's planning to harm themselves, how do the other service users deal with that? What's their framework? Does that lead them into difficulty? You know, this information is confidential, what do they do about that information? So it might make them sort of deteriorate, in terms of their mental health' (LOST10)

'Do they want to do it? Would they be able to commit to it? Cognitively would they be able to manage it? Would they be able to manage to get here, would they be able to manage to work in a group?' (HAST11)

However, some people discussed feeling better and more confident about being in groups after attending the project, as well as enjoying the groups:

'I never ever thought that I would ever be able to do any sort of group work. Even my mum can't believe that I'm still going! I never thought I'd be able to do it. So one thing I always say if I do a welcome group is like, "If I can do it, anyone can do it".'  
(LOSU03f)

'... just helped me to be a bit more confident about trying [another support group] and being in the groups regularly meant I didn't feel as phased and as upset or freaked out by being in a group full of people that I didn't know ... it gave me more confidence in approaching that

thinking, "Oh that might be useful". And when you see things on the wall, like little posters or fliers about something, some other activities, sort of kind of made me look out a bit more.' (LOSU36f)

'I feel like I've opened up a bit more and opened up to the possibility that maybe people aren't as scary as I used to think, and that they are friendly and kind and they've not all judgemental and they are caring and I'm able to speak to them and have a laugh with them and I feel that I've learned about people when I've been here.' (WYSU13f)

### **Using personal plans – taking control of your mental health**

While the SUN project also included an element of personal and crisis planning, the WRAP project in Hampshire centred on developing and using personal plans. Service users valued their plans because they enabled them to assert a measure of control over their care, some contrasting their personal plan directly with their formal care plans:

'And also, you know, whereas a care plan is basically, this is what is going to happen, with a WRAP, it is basically you taking control, and you taking responsibility for what happens to you.' (HASU25f)

'And also, my WRAP, I made sure that it was my word, how I'd describe it. So my Mum's word for 'grump', which is nice for her, but that's her word to describe how I feel, and I wanted my words to describe, whereas I think – I mean I haven't even seen my CPA – but I think it will have technical terms in it ...' (HASU16f)

'I think the most useful thing for me is the fact that it involves writing things down and it's like a record that you can use in the future. And also add and take away from I suppose, it's something that I can use physically to remind me what I need to do to keep well, avoid getting ill again.' (HASU35b)

Those benefits were echoed by staff:

'So I think for me as a manager it's provided a, a more structured understanding. Do you know what I mean? It's where that person wants to go, and when to pull the reins and when not to.' (HAST07)

For a number of Hampshire service users, their WRAP provided a new way to involve their family in their mental health issues:

'Until [my mother] had that WRAP paperwork that she could read or look and say, "Oh, hang on, I've got to look out for this", or "look out for that" ... all my life I've been ill since I was a young child, and all my life, in my eyes, she's never asked questions or never seemed, to me, that she was interested.' (HASU06f)

'... my Dad's really dyslexic, he can't read, and I primarily wanted to do it for my family. So I wanted it to have pictures to show how I felt when I'm well, and how I'm ill. So it was quite good trying to find out different ways of ... either find photos, or ... find ways to represent it, different feelings and what goes on.' (HASU16f)

'Mum said 'well I better have a look at this WRAP then and see what it is', so I took it up and she added a few things' (HASU21f)

'The only reason I think why ... I'd want to share this with my husband is that because he's always been an outsider with my mental health problem.' (HASU32f)

One carer would have liked the opportunity to complete their own WRAP:

'What might have been a nice idea is if carers were invited, if they wanted to, to go for a short, as I say only a 10 to 15 minute discussion about, you know, what they felt about it and then they could go on and from there go off and do their own WRAP.' (HACA04f)

Planning in London often focussed on self harm and responding to crisis:

'... self harm was something that I wanted some help with as well and I thought that they would be able to help me with that because I was told that they can help you with, you have to do like an action plan, all behaviours that aren't very good.' (LOSU05b)

'I had to change it though 'cos I ended up on a bender ... trying to score drugs which was a bit mad. But I'm slowly learning to recognise the, the signs ... hasn't happened again which is good. So, but the crisis and support plan isn't set in stone anyway. You can go back and update it every two weeks if you, if you wish to ...' (LOSU31f)

However, difficulties could arise when actually doing the plan, as some people found the paperwork difficult:

'To be honest with you, paperwork is one thing that stresses me out ... It really does. I just don't like paperwork. I'd much rather sit and talk to someone ... I mean it is quite overwhelming when you look at it and you see how many pages there is. It does feel as though there's quite a lot of work to do.' (HASU18f)

'I think for a lot of us it was much easier to just discuss it than to write it.' (HASU36f)

Some people expressed anxiety about having to develop a crisis plan because it forced them to confront difficult issues they generally kept suppressed:

'I don't know what it's called but I think they call it a crisis plan where you will have to do some writing and it's information sheets to give to people about how you want to be helped and I am dreading that because for me it is something that I keep very hidden most of the time.' (HASU36b)

'I think there's one part on it where you have to work through your triggers and when you go into a personal crisis and what you do after you've gone through your crisis. It's about being ill and that's probably the hardest thing is to actually sit and think about, it brings up a lot of, it's kind of like a counselling session you know it starts bringing up lots of things that you try not to talk about or you deliberately push to one side

or you don't want to open up about and you have to talk about it and you have to write it down.' (HASU15b)

While in London, some of those anxieties were because the plan was produced with the peer group:

'It's difficult because it's also a tool between you and the group so they know you and they know what to watch out for but I find like all things it's so hard to report. I mean, it comes up in the group about if you really feel like you don't belong on this planet and you shouldn't be alive, that's very hard to communicate or demonstrate.' (LOSU15f)

And some cynicism was expressed whether or not mental health services would respect what someone had written in their plan:

'They said "well you've done all these things, the things that you think make you feel worse and things that make you feel better. Now go and do your crisis plan" ... As far as I can remember I think they sort of talked about it and made a start but they said "well, this is a private thing, this isn't something to necessarily do in the group or with us, this is your decisions, your private decisions, when you've done it then give a copy to" and they mentioned, you know, "your psychiatrist and it can go in your file, your care social worker, your doctors", but nobody has got a copy, particularly because nobody seemed that bothered.' (HACA04f)

### **The productive project – focusing on wellness**

Service users in Hampshire talked about WRAP helping them to keep well:

'... it is more about how to keep yourself well so that you can look at your early warning signs and say I think I need to speak to somebody because I am getting these and that's what I like about it.' (HASU25f)

However, many interviewees in West Yorkshire noted that the creative arts projects they were involved in required them to focus on an end product – an art work or performance – that was not defined in terms of mental health:

'... although we do discuss what I do in the group it's more about my own emotional problems and just dealing with life and things, and the drama group in a way is much less dwelling on problems, it's more setting those aside.' (WYSU32f)

'... the painting and drawing and making cards and, I did get pleasure out of doing it because it were ... I mean it's like you look at pictures, I mean I've done things like that, and that is what you've achieved yourself. So it's important.' (WYSU03f)

In West Yorkshire, staff thought that the level of difficulty of the activity was important and should be challenging but not overwhelming:

'So I think you have to be very careful not to do it in such a way that it's at such a low level people can feel you know patronised really but not pitched at such a skilled level that people think 'oh I can't do this, I daren't go in there, people are too good for me' you know and it has to

be enjoyable and I think it's nice to have an end product of some kind.'  
(WYST04)

Many service users in West Yorkshire reflected on an ethos of wellness, focusing on the individual and looking at wider aspects of their lives and drawing the focus away from illness and towards recognition of the whole person – on their own strengths, capabilities and achievements:

'They are always immensely good fun, laid back, you never feel as if you're attending something that is to do with mental health, that was what I found, which feels like you are taking more part in the normal world outside.' (WYSU12b)

'It doesn't make you feel as if you are an ill person, they make you feel like you are perfectly sane.' (WYSU14b)

'I think with [the creative arts project] is they look at everybody as individuals.' (WYSU18f)

'[The creative arts project] really, really, really got me back functioning again as a human being so it was ace.' (WYSU17b)

#### **4.3.7 Working in self care support**

##### **'Doing with, not doing for' - renegotiating roles and relationships**

Staff described a facilitative relationship in their work on self care projects, seeking to enable the strategies and capabilities within service users, rather than imposing solutions:

'I might sit with a new member and three existing members and I might say something like um oh you know" does someone want to explain what a crisis support plan is", and sort of ask questions to get other members to explain what it is to a new member and you know "has anyone got any other suggestions of coping strategy that this person might find helpful" or "is anyone else got overdosing on their crisis support plan and have got some strategies".' (LOST04)

'I think what it really brought out was they all had talents which they'd kind of developed over the course of their lives which had maybe kind of fallen into disuse.' (WYST06).

One West Yorkshire staff member contrasted the new role directly with work in a conventional Community Mental Health Team:

'You start having commonality with the people you're working with which you didn't have before. So I like music, I can play a bit of the guitar. I'm not great but I can play a bit of guitar, so can Joe Bloggs, "oh, what's that music?" We can start talking about music. I know a bit about the internet, "oh, have you tried this website". I like taking pictures, so do other people, might start talking about a particular artist or, we talk about things that are very normal, so it's common, it's something I share and they share with me and this whole idea of being a professional is being questioned because I don't feel and neither do I want to be a

professional, and I say that in quotes because I think acting like a professional is very important but I think this is if you separated the two things out maybe it's being a professional and professionalism. I think you, you've got two very different things and I think in the community health team it was all about professionalism, filling in bits of paper, going through the risk assessments, doing the care management, so it's a lot about the professionalism, it's more focused on the organisational needs and demands, where here I think it's more human, it's more natural, it's more looking at people's strengths and skills rather than their problem.'

(WYST02)

And service users and carers, on the whole, recognised that facilitative role, compared it to their normal care from the Mental Health Trust, and were appreciative of the more relaxed, less formal quality of the relationship:

'I get on better with the facilitators at SUN than my own key worker because you've got to remember she sees tonnes of people one to one and I only see her once every four weeks, whereas people like [the SUN staff member] ... I see her every single week of my life ... I see her far more so then you just get to know.'

(LOSU03f)

'... they are not judgemental and they have been so supportive ...it feels less formal, they seem very caring...it's less formal than with doctors or occupational therapists ... it just seems more of a genuine relationship.'

(WYSU13f)

'So this was the first time that people said, "ok come in here and well treat you just like anybody else" ... very accepting ... their accepting attitude to [my son] and the ability to continue to treat him like an equal adult through those times, that's what got through to him I think.'

(WYCA03f)

However, the importance of trained, professional staff providing a safety net in times of crisis was also acknowledged:

'The need to be supportive can run into a little bit of trouble and then again that's where the staff come in more, to sort of like, I don't know, to sort of like a emergency brakes or a sort of, just as a sort of non-invasive safety net ... Watching the way that fights and squabbles get resolved ...'

(LOSU36f)

And sometimes service users and staff alike felt that staff needed to do more to provide boundaries and safety within the project, or that for more medical support it was necessary to go to conventional Mental Health Trust services:

'Basically the people in the SUN Project are too nice. They don't tell, you know if someone's going on about something, they don't tell you to be quiet, "you've said enough". In one incidence I can remember I was the one that turned around and said "can we stop about this now we've talked about it enough?" And I think the staff are a bit weak in that respect. Whereas if you go and see a psychiatrist or something like that, if you've gone on and on they'll tell you ... In other words in a way in that

respect I don't think they're professional enough. I don't think they know enough.' (LOSU32f)

"I think they were too easy going, I don't think they put clear enough boundaries in for staff and service users sometimes...people push boundaries and I think you need to be clear about boundaries and about what's expected as well...". (WYST02)

'But I think I'd rather ... see the CMHT team rather - for professional ... medication and give me some sort of sound advice really. And I don't know whether it's like an authority thing or respect thing I sort of look to them you know.' (LOSU28f)

While one Hampshire service user felt that staff took too much control in the group, a London staff member noted the lack of clarity in the role:

'The group didn't gel, or bond, so there wasn't really much in the way of exchanges between each other. It was mostly the facilitator standing up and saying ...' (HASU12f)

'There is that "Why aren't you doing something? Can you not phone somebody up, all it takes is for you to make one phone call", so there is that, but generally once people have been in groups a few times, they understand how we work ... sometimes it's the other way, they get really angry when we do intervene and take away the control. Because you learn very quickly you've signed up for a support group, so you're expected to do the work yourself, so they're actually quite good at that, and then when we put on our therapist hats and say "Right we're ringing up the team, you're not safe to go home" ... the anger comes out more about that.' (LOST01)

All projects incorporated an element of service users working in staff roles. This was most prominent in the SUN project, where former service users of the project were employed by the Mental Health Trust to work as Support Facilitators alongside members of professional staff facilitating groups. In Hampshire, service users were trained to work as WRAP trainers - introducing WRAP plans to other service users - while in West Yorkshire, some of the creative arts projects were co-facilitated by service users. This was largely appreciated by people using the services because of the first hand insight into shared mental health issues that service user staff members brought to the project:

'I particularly liked and warmed to the fact that [the service user trainer], the leader was not, that it wasn't an 'us and them'. I think that really impressed me, that she had been there done that and bought the T-shirt and that she was open and honest enough to share it ... so for her to say, "yeah, there were days when I got in my pyjamas and I stank and I didn't wash", Wow! ... One of the wonderful things with [the service user trainer] was that - it definitely touched me, and other people said this privately - was "Did you see she had a folder?", "Did you see she's got her own folder?" And it wasn't just throwing the bits of paper at us. She'd go, "yeah, in my WRAP, when I was feeling like this

and I did that, this is what I put" ... I think then we didn't have that 'us and them' thing going on.' (HASU36f)

And one member of professional staff was able to point out where service user staff had a different view on the best course of action to take:

'The support facilitators are very good in pointing that out because they don't have a professional background so they tell us off, and they will say "Why did you contact Dr such and such? Was that really necessary?" and "you're doing your 'risk'". "Well because I know – I was worried, and the group members as well". I really struggled last week because I wanted to contact somebody's care coordinator because she was quite suicidal in group and they said "Were you doing that just to make yourself feel better?"' (LOST02)

There were tensions noted around having service users as staff from service users, professional staff, and the service user employees themselves:

'Well I think they had more baggage than we had really. Sort of working through things when we should have been ... so it was taking away from the patients really.' (HASU33f)

'... at first, some of the staff were quite negative you know, "oh, we can't do that, what if he becomes ill", or there's also the, but now they're used to him and see that he's a very good worker and that he works really well and everybody's very fond of him, you know we all get on very well so it's worked out.' (WYST08)

'It's quite a hard place to have that middle ground and being not quite professional, not a service user ... I also think that um, you have to be on your best behaviour, because if you get upset, if I get upset I'm worried that people are going to think, 'ooh, she's having a service user moment'.' (LOST06)

There were also organisational challenges and investment in the service user staff role:

'There is a lot of checking that needs to be gone on, if you want to make sure that you have got the people who you were employing were going to get sufficient support and training ... the sort of support and supervision they need is actually different to other members of the team and the flexibility or working with somebody who may have their own health crises for one reason or another, needing more support. I think that getting them, getting the whole thing, you know getting them banded as part of, under [Agenda for Change], that was a stumbling block and took a long time getting.' (LOST01)

Service users valued the experience of working on the project, despite the challenges:

'I think the relationships have to change because, although I don't see the role of the facilitator as the same as a traditional health care professional ... there are still boundaries, and the boundaries are there for people to sort of come up against and give limits. So it has been quite



hard to assert myself sometimes and, you know, try and be a professional ... But I think I've gained more confidence.' (LOST06)

### **The impact of attitudes, background and training**

The perception among service users that staff members on self care projects were willing to enter into less formal relationships with service users was noted above, and this attitude was valued by service users:

'... they are sort of like, their attitude is really good. If it wasn't for, because it's for mental health, they've got insight into what it might be like for me coming along to a new group on the day and being a bit nervous about joining in and that, very understanding.' (WYSU06f)

Staff themselves acknowledged the importance of having a positive attitude towards the specific job within their project:

'I think it's just kind of my own personal experience and my own interest in art and mental health as well really I feel has benefited me most.' (WYST13)

'I'm always someone who's sort of listened to service users' experiences and learnt about their lives or the way that they are or the things that have happened to them, and learnt about mental health through listening to service users as opposed to reading about depression and how you experience it. It's something that's interested me anyway which is probably why I ended up here in the first place.' (LOST04)

Particular professional backgrounds were only occasionally attributed as being more suitable to a role supporting self care:

'I think the social work model and the [Occupational Therapy] model are a lot more enabling, but the nursing model and the medical model are slightly different. It's more caring and it is quite, is there such a word as disabling?' (WYST04)

Staff at all sites described a hands on approach to training as helpful, engaging themselves in the activity that the project provided alongside service users:

'We instituted a sort of monthly creative session for staff. We decided it would be a good idea if once a month we spend an afternoon together being creative so we sat around last week deciding what we were going to do. We managed to come up with some stuff about animation and clay. So I think in terms of staff training what we're trying to do is create a space because we're meant to be a creative organisation.' (WYST08)

'I think the most helpful bits were probably actually going through it, you know, we did it, it was very hands-on, it wasn't sort of talk and chalk presentations, it was actually going through it yourself, doing your own sort of wellness tool box, and all those sorts of things. Actually using a WRAP, writing your own WRAP while you did it which was really useful.' (HAST10)

'... the role plays in T and I – Training and Implementation – are really good, they're really useful.' (LOST06)

'In the WRAP training it was very useful to be able to have service users who have actually used it and are really able to sell it to you, because they're actually using it daily.' (HAST10)

In London, training was very specific to the model informing the SUN project, and aimed at ensuring a consistent approach:

'... using the SUN model is very specific, so how you run a SUN group is very clearly set out, "you do this at the first part of the group and this is what you can expect to happen, and then you do this in the middle bit, and this is how you end the group", so regardless of your background.' (LOST01)

In Hampshire, it was found that under-preparation for the role of WRAP facilitator could have a direct impact on the experience of support for self care:

'But I don't think I've ever had any proper training on doing it and I remember doing it with one service user and I think because of my lack of training I made some mistakes with it that I wouldn't do now if I was gonna do one. And it was about not letting them or thinking I was being helpful but actually doing the writing myself, that kind of thing and I really since then have realised that actually it needs to be by them more and the member of staff can support [them].' (HAST15)

'... it was a bit bitty and a different facilitator each week and everyone scrambled through their notes to see what they should be talking about because they obviously hadn't done the course before.' (HASU12f)

### **Working in self care support as a career pathway**

Staff expressed high levels of motivation and satisfaction for working in the self care projects, reflecting the positive attitudes to self care noted above:

'I love doing groups, that's something I really enjoy doing, so something, I've really enjoyed doing that, so yes it has given me job satisfaction and it's really nice to be able to do WRAP with a variety of people and actually see people coming out with something at the end of it, that they've done and they've achieved and that's really nice.' (HAST10)

'It's a very varied job, it's constantly changing ... I've found it very stimulating ... I find I get a lot of satisfaction in helping people to manage their illness ... Personally I think if you create a culture that's based on values, on shared beliefs about people that are positive then your outcomes and your job satisfaction are the people on that team will be a lot happier ...' (WYST02)

'I like my job, I like my job so much, so much, because I'm able to do something for somebody, because if you move, this was bad for the person and you move the person here, and the person feels where you move them to is good for them, you are enabling that, you facilitate it, and the person says "Thank you for what you've done", it's a reward for

me, it's more valuable than any money I can have ... Yes, personal gain. It's an achievement for me too, to promote people's wellbeing, so that's how I see it anyway.' (LOST08)

Again, like positive attitude, high levels of staff motivation were tangible to at least one service user:

'It was a learning experience for [staff] and they were perhaps also energised by it rather than ground down by it which is often I think I get from the staff at the CMHT.' LOSU36f

Staff also felt well supported in their new role within the immediate working environment:

'It's a very unique place because you know a lot of people focus on the service user but it also is a great place to work in because I think that care and flexibility, maybe if you feel anxious about certain things, that support is there for you as well, d'you know what I mean? It's not just, so it's a whole package of, the organisation hopefully is there to support everyone in a similar way.' (WYST13)

'Other jobs have been stressful in different ways but this job has got more support and supervision in it, which is why it's different, because although it's difficult, we've got really good supervision and support structures in this team, which helps, it really, a lot, which I haven't had before in previous jobs, it's been much more sporadic.' (LOST04)

However, issues around the temporary nature of funding for the London project meant that job security was low:

'We've not got ourselves a permanent contract, so anybody with any common sense wouldn't apply for it.' (LOST02)

Difficulties with recruiting and retaining staff were picked up by London service users, impacting on the way they used the service:

'... they hit some difficulty with the staffing and I think that's probably just a hazard of it being a pilot, there's finite budget and there wasn't the authority or presumably it was too specialist an area, they can't just get an agency, somebody to put a bum on a seat. And so it, that had a difficult effect because it, it meant for a time, communication went a little bit haywire and I didn't know where the group's were meeting and I turned up to a Tuesday group and it had been, it had long stopped.' (LOSU36f)

#### **4.3.8 The organisational context**

From all case study sites there was data from service users and staff that complemented the issues raised by organisational interviewees (4.1.3).

##### **Alignment**

The positive effect on SUN of the convergence between Trust and Department of Health policy was noted by a SUN staff member:

'... it's on more people's radar than it was before because I think there's other changes happening in personality disorder services, the new mental health act is making people think more about it ... I think the culture probably fits in with where the Trust wants to be moving in terms of the recovery model ...' (LOST12)

### **Resistance**

Resistance to changing practice implied in the self care approach – both in terms of challenging philosophy and time required to add self care support to a busy role - were echoed by staff at all sites, and by a carer:

'I think for some people it's an entirely new approach, and people that have been working in the services for 20 years or more ... might be familiar with some concepts of recovery, but this is such a comparatively new way of working ... that it might be a challenge for them ... to take it on board, you know.' (HAST12)

'I think you've got some staff who actively support me in the fact that I've done that. I think you've got other staff who are quite resentful of that, that I'm changing or trying to get them on board to change outside their 9 to 5 box ... you've got some staff who act and encourage, encourage clients ... to actually baulk against that change. And you can't prove it but fairly obvious what's going on and I think it's trying to get the whole staff team motivated in the same direction ... sometimes they've got into a routine of and I think over the years of just same whatever ... and I think it's hard to change.' (WYST12)

'They might not bother to take the approach on board because they just haven't got the energy to be enthusiastic. They've just tried and tried and tried in different ways, and they may not be getting the results they want, and they may be dealing with people who, you know, their case load's too big ... And you watch somebody's visit, you know see twelve people in a day, and not sit down for a lunch break and you wonder how that's gonna impact on their mental health eventually ... expectations of the staff, and this, I don't know. I just feel they're expected to be super human sometimes.' (HAST06)

'I think the psychiatrist thinks [WRAP] is nothing to do with him, he is the one who diagnoses and decides on treatment or medication and ... he thought he was a bit above that.' (HACA04f)

### **Role of the Trust**

Service users felt that there was a definite role for the Trust to play in self care:

'... well from my point of view because I need help you can't do it on your own, I've tried doing it on my own and it just didn't work you know you need somebody there.' (WYSU27b)

Service users discussed specific roles the Trust could play in order to facilitate self care, including an educative role, offering support to prevent crises developing, making links with the community and developing the service beyond the dispensing and prescription of drugs. Promoting information about services, community facilities and resources was highlighted by all stakeholder groups as an important role the Trust could play. A lack of communication was often cited as a barrier:

'... self care from a personal point of view, yes, because I've had to go out and find these services, they haven't come to me and that would be half the battle won if we share and communicated information better because there is a lack of communication between the clinicians and the patient ... because all the services are there, they just need to talk to each other, just have a network.' (WYSU25f)

While members of all stakeholder groups were concerned about whether self care projects would be properly funded, some people saw the potential cost savings for the Trust of providing self care as a facilitator:

'I see the WRAP as being the front line again – I know it sounds awful really, but it's the front line in saving money and I think that's why it's such a good thing, 'cause it's good anyway, it's effective, it's good and it also stops money being burnt up.' (HASU20b)

### **Partnership working and inter-service relationships**

Tensions between self care services and Trust or mainstream mental health services were acknowledged:

'There's a bit of conflict between the SUN and CMHTs ... the CMHTs quite like, they got this slight power thing ... they're not working together ... they won't liaise together ... I think the SUN are a bit of a pain to them.' (LOSU31f)

'They were very suspicious, the social services staff, that they were going to be taken over by the health service ... 'cos we got paid more money ... there was a lot of feeling of injustice ... a kind of animosity ... and it took me a long time.' (WYST04)

It was seen as important to build and maintain links with more mainstream services and work creatively together to give services the appropriate support:

'CMHTs have been told that they also have to discharge so many patients a week, and so a natural assumption has been "oh well, this person with personality disorder - oh they are going to the SUN project - oh well we can discharge them then" and we have had to go back and have some discussion ... we have come to I think a very creative agreement with one CMHT who has said, "we may discharge people when we know that they are coming to the SUN regularly, but if there's ever any crises we will take them right back and they won't have to go through a sort of - that they can get access" and I think that's really creative way of working with CMHTs.' (LOST01)

'We're one of those creative partners and so my job is to try and sustain links with you know the local authority, the cultural sector, they have creative partner meetings so all that kind of networking stuff.' (WYST08)

### **Awareness of self care projects among other teams and services**

There was a feeling that NHS Trusts needed to be more aware of their local resources so that they might refer people to them; and that a lack of awareness could prevent service users being able to access what was available to them:

'Just sort of working together really ... making them more aware of what help is available ... the NHS needs to make itself more aware of what else is going on to support people ... you can't tell people to take advantage of the things that are available if you don't know that they are available.' (WYSU16b)

Staff in the self care projects saw training and awareness promotion as part of their role:

'We've done some training on recovery for [CMHTs] ... We've done some for carer support groups ... supporting people in the community.'  
(HAST03)

### **Self care – 'a risky business'**

Reflections on the risks involved in the support of self care by the Trust were evident in the accounts of service users, carers and staff at all sites, covering a range of issues around employing service users as staff, self referral and open access, and withdrawal from, or lack of access to mainstream mental health services when people were less well:

'But also being able to sort of hold the boundaries of the group and contain group which I think you have to have professional training to do...I mean you can't have somebody who is not trained.' (LOST01)

'...so they don't even know who's coming into the group and what's wrong with them; not as far as I know. I mean as far as I know, the facilitators don't know anything about you, unless you share it within the group ... I think that's wrong. I think if a new person's coming, a facilitator should know, because of the danger of, you don't who these people, or who any of us are.' (LOSU06f)

'...you do feel a little bit at risk because people do talk about suicide and things ... But then I suppose that's because maybe it touches your own buttons really, you know sort of brings up feelings in you.' (LOSU31b)

'If someone comes to the group and I'm approached by someone and I'm feeling particularly uncomfortable with them, I will speak to the ward staff and ask them if there's any risk issues I should be alerted of. If there are risk issues and I'm going to work with that client, I will pass it on to my colleagues that there are risk issues, in the event that they have to cover in my absence.' (WYST01)

'Well I think there is a disadvantage 'cos someone might develop this belief that they can self care for themselves and they might be totally wrong. They might believe that they don't need to take the tablets, that they don't need to go to [the project], that they don't need therapy, they don't need anything, they can do it all on their own and they might not have any insight into the fact that they're not able to...' (WYST03)

'...people might see disadvantages if they actually are quite institutionalized and actually have been used to services telling them what is best for them. That could be quite a culture change for them, and something that if it's not done gradually people can end up feeling quite rejected by the service.' (HAST05)

'Well there is meant to be some level of support there but ... the people that were there were very poorly. I felt that [son's name] was the sanest one there ... but he sunk right down to their level.' (HACA02b)

However, it is important to note that service users and staff also talked about the benefits of support from the Trust for positive risk taking:

'I was surprised actually by how brave, honest people were, by how they just kind of took things head on. But I think in many ways that's what's, what could be due to the quality of the work and that people actually benefited from that. I mean clearly there is a risk there but with experience of this project I would say that kind of the benefits far outweigh the risks, the benefits people got from if you like re-enacting painful, painful episodes actually helped them.' (WYST06)

'So around self care the expectations are that the person will achieve a good, a much greater level of independence and self care, but you've got to put greater risks in there to get, people won't move on unless they take risks. And we're asking, self care is about people moving on to a further point. Recovery is about people moving on to a further point.' (WYST11)

'...it's got me being more adventurous, it's got me being more prepared to take appropriate risks ... I think it encourages people to think in a different way so I think it's positive, you're not in a, so much in your safety zone all the time but there is a safety zone, it's hard to describe. You're not in the comfort zone to the point where you feel going to the bowling is a, is a, "oh do I stay here in the hospital and where it's safe. Or do I go out bowling and be adventurous?" ... and it, it just feels more natural and less contrived and attainable.' (LOSU36f)

'...one at the moment who has decided to come off his medication ... and try and self manage without medication it's really exciting. We've got the doctor on board, as well and it's all planned; he's off the meds now; it's been about two weeks, um, you know, there's a really strict collaborative plan we've agreed about how, if he becomes unwell, he can go back on the medication, and stuff like that.' (HAST09)

'Pushing yourself a little bit further, but knowing that without putting yourself in any danger and knowing that if you can't do it, it doesn't

matter, it's not, you know you can try it again, so you fail the first time it's not that, oh God, I've failed and it's not about, it's not about being told "oh you are schizophrenic, that's it you've got to sit in a chair for the rest of your life and not do anything and you'll be hearing all these voices".' (HASU21f)

While in London and West Yorkshire in particular the instability of funding and the consequent insecurity of jobs supporting the projects was seen by service users as well as staff as putting the projects themselves at risk:

'...so it's a bit like everyone in the organisation is going to have to be fairly adaptable and pick up a bit of that and do a bit of that and that's inherent in the beast I'm afraid and if you don't like that then don't go and work for small independent voluntary organisations ... we're often up against some kind of crisis or other ... it's very difficult to work out rational staffing structures when the basis on which the organisation is funded is quite volatile. So the money will come in for this project and then that will go away ... a lot of anxiety when we get to the end of a project because that's people's jobs involved d'you know what I mean and they kind of say well is there another job you know and I'm saying I'm trying to get this project together and it should come in by then, but of course it never quite dovetails and you've got to finish one project off ... What we're doing here is running a small business. We call it a charity or social enterprise or you know it doesn't matter what you call it, we're running a small business. We're competing for contracts to deliver services.' (WYST08)

'...were kind of separate and I suppose now we're learning more about what we need to accommodate becoming part of the Trust, because we're kind of now devolving into Trust structures, so we're having to accommodate more because we haven't got the luxury of being funded by the Department of Health ... now it comes out of the Primary Care Trust's pocket, so now we're kind of fighting for funding along with all the other services which includes things like ... do you fund the SUN Project or do you buy more incubators for babies.' (LOST04)

#### **4.4 Data synthesis**

As shown above, the three case studies generated a large amount of both quantitative and qualitative data, and from a range of stakeholders of self care support in Mental Health Trusts. Separate analyses have been presented above, but it is necessary to synthesise all data sets in order to reflect comprehensively on the data. A systematic approach was taken to the synthesis of qualitative and quantitative data, as follows, in order to provide richer insight into potential barriers and facilitators of self care support.

Section 4.2.5 above reported a range of statistically significant relationships between outcomes at follow up and factors moderating and mediating change. As described in section 3.4.6 above, additional qualitative analyses enabled us to use qualitative data in order to further explore those



statistically significant findings through discussion of complementarity and tension between the datasets. Matrix queries run on the NVivo qualitative interview database in support of data synthesis are described in Appendix 11.

#### **4.4.1 Change related to empowerment and mental health confidence**

Quantitative analysis revealed significant improvement for the overall sample in empowerment and mental health confidence. While it is not possible to directly attribute those changes to use of self care projects, it is possible to re visit qualitative data in order to explore how these changes were reflected in service users' views and experiences of the self care projects. The changes described included being more active and independent; increased confidence and self esteem; having a more positive outlook; increased self awareness; improved health and reduction in self harm:

'And the days that I do get out of bed, I do shower, even if it is a bit of an effort those are sort of positive tick marks that are able to say I have achieved this today.' (HASU24f)

'I felt confident enough to put myself in a situation where I was needed rather than needy.' (LOSU36f)

'It's made me feel that I'm more competent with myself than I thought.' (WYSU08f)

'I've not been relying on [mental health services] as much, I've had a bit more initiative.' (WYSU09f)

Experience of mental health itself had sometimes improved, sometimes stayed the same or occasionally become worse. Regardless of whether there had been any improvement in mental health symptoms, when people talked about changes in mental health they often talked about an increased ability to understand and cope with their symptoms:

'I've got a bit more control over my symptoms and I think that's partially to do with my self confidence also.' (WYSU02f)

'At times [my symptoms] have been worse but I've managed them better ... they've sort of changed in emphasis and ... I mean I feel very bleak and depressed but I'm managing it OK.' (LOSU36f)

#### **4.4.2 Change related to quality of life**

Other changes that service users described at follow up supported quantitative findings of improvement in quality of life, predominantly related to social networks. This included increased social interaction, particularly in West Yorkshire and London, and seemed to be associated with increased confidence and independence:

'Now I've got friends [I'm] more confident and I'm not so dependent on my relationship ... on Sunday I actually invited a friend round, who's not in the group, for dinner, I would never have done that.' (LOSU31f)

'I'm a lot more communicative with people and getting involved with things and being less isolated, which again is beneficial to my health and I think that is a great difference and I think that's where the stability comes from I think having contact with people as opposed to rejecting everyone because I think they're too scary and wanting to go hide under a rock.' (WYSU13f)

Changes in social networks also included managing interpersonal relationships more effectively and improvements in the quality of these relationships. We asked about change in relationships in the follow up interview with service users, and interviewees of all age groups made an explicit association between change in relationships with family members and partners, and the experience of the self care project they attended. This was talked about mostly by younger interviewees, and often about their relationship with their mothers:

'...with my Mum it definitely, definitely has changed the way she looks at me, and the way I look at her...' (HASU06f)

'...it's helped her and it's helped me and it kind of, being me and mum together because she's an artist as well our relationship is so much stronger and healthier and we're so supported now whereas before we were too isolated but now it's a lot better.' (WYSU13f)

Changes in relationships with partners were also discussed:

'I've started a relationship with a girl now. I'm seeing a lot of people a lot of friends at the moment. Yeah. I've met some old friends, I've met some new friends, yeah. I've got quite social, good social interaction which I hadn't had for a long time.' (LOSU27f)

'I think that is me having a better understanding of myself and [my partner] having a better understanding of me.' (HASU28f)

'I've got like a new boyfriend, yeah, that's going well, that's been for about seven months, yeah, and that's good. And I think the way I'm in relationships is different, because my boyfriend before him was quite violent and aggressive with me, yeah. And I think I sort of just accepted that and I almost sort of felt that was quite normal and I think that's one thing – it's taken me quite a long while to realize that not everyone gets whacked around and that people are nice. And I think this is the first non-abusive relationship that I've had, and it's been like shocking to be, it's been very odd.' (LOSU05f)

However, that change in awareness about personal relationship was also sometimes complex and problematic:

'I am having relationship troubles with my partner and I would really like to leave but at the moment I am on incapacity benefit and can't see how I can actually afford to leave which is making things very, very difficult.

A lot of the time I am sort of biting my tongue and staying out of the way rather than dealing with the actual issue which is that I am not really happy there any more and I want my own space and I think that is part of coming out of the whole illness thing and starting to change as a person ... I am starting to get back to normal if you see what I mean and I have found that actually what I want now isn't necessarily what I wanted 2 to 4 years ago. I feel very differently about things and really I want some space and time to myself to find myself ... to come to terms with who I am again and evaluate what I actually want out of things.' (HASU24f)

The relationship with partners seemed especially important for older people where their partner was caring for their physical, as well as mental health:

'It gets gradually worse for her because ... as I get less and less able to walk and she, have to rely on her for making me a cup of tea, as I tend to drop it, I can't carry, once I've made it. So her support is vital. She's my rock.' (WYSU23f)

A widely acknowledged area of change related to quality of life was increased routine and structure in people's daily lives, whether this is leisure activities or employment and responsibility:

'I'm getting up and wanting to do things, which is a whole, whole different ball game to what I was before, I'd stay in bed and not want to get up.' (WYSU28f)

For some people, change in routine was about reducing stress and having more enjoyment in their lives:

'I've decided to carry on working, and just reduce my hours by half. Just to give ... down to the three days a week, just to get me out of the house. Meet other people apart from [my partner], and just a bit of extra spending money, for me.' (HASU01f)

### 4.4.3 Within site changes in primary outcomes

#### West Yorkshire – creative arts Projects

##### *Mental Health Confidence*

Quantitative analysis revealed that for service users attending creative arts projects, there was a significant increase in Mental Health Confidence after nine months. Once again, while this cannot be directly attributed to attending the projects, analysis of qualitative data from this group suggested that people experienced greater access to community activities and services, felt included and became more confident with other people:

'I've been doing the percussion group so that gets me to mix with people, getting me to socialise again and it's quite a confidence building thing in a way, hitting drums, you've got to be confident enough to hit them so you can't just sit back, which is what I was tending to do just sit back and not do very much.' (WYSU16f)

'I feel like I'm really part of it and I have a role to play within it and a contribution to make.' (WYSU30f)

'I suppose it's more of a liking for myself, more appreciation of myself and that I am responsible for myself, instead of I suppose being responsible for others.' (WYSU40f)

### **London – The SUN Project**

#### *Mental Health Confidence and Empowerment*

As well as a significant increase in Mental Health Confidence, service users who attended the SUN Project showed a significant improvement in Empowerment at follow up. These changes were clearly echoed in the qualitative data. In comparison to the other sites, service users in this group talked more about being more active and confident with regard to seeking help from mental health services:

'I have to look at the SUN group as sort of spurring me on to be a little bit more open in my thinking about ways and means by which I can get elements of the support that I need.' (LOSU36f)

'It's helped me be more confident with my psychiatrist. And I think he's taking me more seriously because of the Sun ... I was really intimidated by him but they helped me to deal with him, write letters how I felt.' (LOSU31f)

'I think the most important value for me was ... the sense of being connected to the services I needed on a regular basis rather than a sort of haphazard appointments with a CPN or my consultant which ... would feel contrived because they were appointments and I wouldn't be able to talk about things perhaps so close to the things which had upset or had been worrying me. So the group was very useful in that respect.' (LOSU36f)

The significant decrease in number of psychiatric A&E admissions after 9 months observed in London might in part be attributable to this more confident service use.

### **Hampshire – WRAP**

Although a within site analysis showed no significant change in primary outcomes in Hampshire, there was a distinctive theme of increased self knowledge and self awareness. This was brought about through enhanced understanding of signs of illness and wellness - including early warning signs and triggers - brought about through completing the WRAP:

'It's made me more aware of early warning signs generally. So it's down here in black and white, so if you refer to it, and see, yeah, that's not going too well. What's the reason for that. Can I do anything about it?' (HASU08f)

'I think part of it is to empower you yourself, to bring about your own mental healthy state sort of thing. There's still things that I do that have helped me, and they're still the same as they were prior to doing the

WRAP, but I do think knowledge and introspection is power – power to affect your mental health state.’ (HASU06f)

#### 4.4.4 Factors related to outcome at follow up

We identified, quantitatively, factors at baseline that were significantly related to outcome at follow up. It was possible to further explore those relationships by running a series of qualitative analysis queries on the qualitative data. These included the relationship between CORE score and change reported in qualitative interviews (comprising general change; change in self care; change in mental health; change in care; rationale for change), as well as the relationship between choosing to take medication as prescribed and change.

##### **Medication**

Quantitative findings revealed a complex relationship between medication and outcomes, which was echoed in qualitative data. Whereas a higher number of psychiatric medications taken at baseline was associated with higher quality of life at follow up, a lower number of psychiatric medications taken at baseline was associated with a higher level of empowerment at follow up. Furthermore, people on atypical antipsychotics at baseline had a lower level of satisfaction with the self care project.

##### *Views and experiences with medication*

A text search query on the key word ‘medication’ was performed, creating a new node that encapsulated differing views and experiences with regard to medication and its relationship with self care.

For some people, medication was identified as something that helped them to feel well:

‘I’ve had periods where I haven’t really felt like even getting out of bed. And it’s only fairly recently, when I got my psychiatrist, she’s changed my medication ... and that’s been a big help. Yeah. I’ve improved a lot since she changed my medication.’ (HASU18f)

‘... the change of medication, it’s, it’s all multifaceted and everything has kind of fitted in like a jig saw and my phobias and anxieties have got a lot better.’ (LOSU19f)

Whereas for many other people, medication and its side effects were perceived as a hindrance to wellbeing:

‘I always have a problem taking medication and that’s why I’m always prone to relapse ... I’ve never seen it as something that helps me, I’ve always seen it as something that makes me worse.’ (LOSU30b)

‘And because of all the medication he’s on you know I think it just actually whacks him out and he can’t cope with the everyday things of the flat.’ (HACA05f)

‘It’s getting myself motivated to come along and pay attention and try and learn but they are not pressurising me to do that but with being on

medication I find doing anything a chore, my medication does slow me down...’ (WYSU06f)

#### *Choosing whether or not to take medication*

A similarly complex picture emerged with regard to the relationship between choosing whether or not to take medication and outcome. Quantitative analysis showed that taking medication as prescribed at baseline was associated with greater empowerment at follow up, whereas choosing not to take medication as prescribed at baseline was associated with higher mental health confidence. In order to explore these seemingly contradictory findings, queries were performed on the qualitative data by comparing accounts and views of medication among people who took their medication as it was prescribed to them, people who took their medication some of the time, and people who chose not to take their medication. Change after nine months was also examined across levels of concordance.

#### *Beliefs about the role of medication in self care*

It emerged that people who chose to take their medication as it was prescribed talked more about medication as being part of their overall self care and stopping medication as being a trigger for relapse. The importance of not relying on medication was emphasised:

‘Giving [medication] a go again and making sure that I commit to it, sort of feels like self care ...’ (LOSU08b)

‘...with me it took a long take to get my medication sorted out and once you’re on a stable level with that then you can start caring for yourself but before that there’s nothing much they can do to get you to go out and to do different things because if you feel crap in yourself and you feel ill you’re not going to do it, no matter what they say.’ (WYSU09b)

‘... actually being actively involved in it, and discussing your care and what works for you and what doesn’t work for you, and perhaps wanting to understand a bit about the medication you are being prescribed rather than actually just taking a tablet ...’ (HASU12b)

‘I know a trigger is when I stop taking my medication.’ (HASU06f)

People who chose not to take their medication, however, talked about the importance of self care coming from the individual rather than from medication:

‘I didn’t want to take medication. I don’t take any medication for panic or anxiety at all. Even though the doctor prescribed it, I said, “No. I don’t want it. I want to go to the counselling and whatever way”.’ (WYSU20f)

‘... trying to get better on my own without the help of medication...’ (WYSU20b)

‘I try not to rely on my medication. Because a lot of people when they’re put on medication, they tend to rely too much on it working. And in the end the only way to make myself well was to confront my fears a bit and not rely on it ... I’ve stopped relying on it” (HASU05f)

'I have actually come off of the sleeping tablets I was on, because I am not very keen about putting chemicals and tablets into my body. I've written a letter to my psychiatrist, who I am actually seeing next week for the first time, 'cos there have been lots of changes, just writing down my views on medication.' (HASU12b)

Nonetheless experiences of taking psychiatric medication remained problematic, and attitudes ambivalent, for some:

'I have to remember to take me medication, which is a shame 'cos I don't want to be on it 'cos it doesn't really work, but at the same time I don't know what I'd be like without it ...' (WYSU06b)

'And that's helped me come to terms with the medication and trying to work out what I would be happy with in the future, because that I find quite stressful the whole thing of medication, because I suffer quite badly from side effects.' (HASU12b)

### **CORE score (level of wellness)**

People with lower Core Non-risk scores at baseline (people who were more well) had a higher quality of life at 9 months follow up. Conversely, a higher CORE Non-risk score at baseline (people who were more unwell) was associated with higher satisfaction with the self care project.

In exploring change across different levels of wellness according to CORE score, it was apparent that people with a mild to moderate CORE score talked more about becoming more independent, improvements in routine, focusing on keeping well and spotting triggers and early warning signs:

'Before I had the WRAP in black and white to look on, and I was becoming unwell, I couldn't see it. And other people weren't aware of my triggers, or what to look out for, so they couldn't even tell me that I was becoming unwell until it was too late and I'd already hit the bottom.' (HASU06f)

'... knowing or recognising that I'm getting ill and thinking "No way, go home, take your tablets", and that's nice. I can recognise it now. Yes. It's nice. And I think to myself, "No. Take your tablets. Go to bed".' (WYSU04f)

'I'm doing, I'm doing a bit more for myself than I used to. Coz I used to let my husband just do everything.' (WYSU08f)

People in the moderate to severe and severe groups – primarily those in London who were more likely to have higher CORE scores at baseline - talked more explicitly about the usefulness of the project and of other services:

'I think there the benefits of the Sun project. I've learned to talk about it, not bottle it all up.' (LOSU28f)

'I go to the GPs, which I don't normally do.' (LOSU33f)

'I have to look at the Sun group as sort of spurring me on to be a little bit more open in my thinking about ways and means by which I can get elements of the support that I need.' (LOSU36f)

### **Other factors related to outcome at follow up**

By exploring change qualitatively, other factors associated with change were identified. These included accommodation and living situation, care from other professionals and services, job and occupation, relationships and other life events.

#### *Importance of living situation and accommodation*

Some people talked about living situation or accommodation causing a positive change:

'I've like moved out and I'm living on my own now, and I think that, yeah I do, I think you know, I buy nice food and no one's going to eat it, and I've got time for myself, and I think that makes me not get as stressed out as well.' (LOSU05f)

'I've managed to get the location and the type of accommodation I wanted, so the fact that I'm very happy with my accommodation is really good. And it's so nice not to be in hospital.' (HASU33)

'Now I've got permanent accommodation I have my own house, my benefits are sorted so I have a regular income and I've got people around me who care so much about me and it's making me feel stronger as if I'm wanted so obviously I'm gonna try not to go back down hill unless anything major happened.' (WYSU14f)

But changes in living arrangements weren't always positive:

'I've got a lodger at home, I've had problems with, and that's sort of got me a bit low and upset and down. And that goes into the depression, and the illnesses that I've had.' (HASU11f)

### **Other care, treatments and therapies**

#### *Being able to access other services alongside or instead of the self care project*

Positive changes identified at follow up were sometimes attributed to other therapies or having a combination of the self care project and support from other professionals or services.

'I suppose without the SUN Project in the first place, I wouldn't have been able to maintain ... they sort of kept me going, so, while I was getting all the support from the various places, I was able to keep going there. So therefore it was keeping me put of harms way as such. So yeah they did, they do play a major part ... it's a bit difficult to explain it to you because, without them, I would have fell apart.' (LOSU06f)



#### 4.4.5 Service user characteristics associated with engaging in the self care projects

##### Quality of life and engagement

###### *Importance of timing and readiness when engaging in self care projects*

It was found that patients with a higher quality of life at baseline were more likely to stay engaged with the self care projects (section 4.2.6). In line with this, people highlighted the importance of the timing being right and being well enough when referred or self referring to the projects (see also 4.3.5):

'I think it is when you are ready to do a WRAP. It's no good sitting there doing it when you're sitting there thinking I don't want to do this, I don't think this is right and you, you have to be in the right place to do it.' (HASU21f)

'There's not a lot you can do and until they're ready to help themselves, and I truly believe that because so many times I've felt like I haven't been ready to talk about things or find sort of things out, and then you – there is really nothing that anybody can do.' (LOSU03b)

'I suppose a lot of people might just not want to get involved and they are harassed enough as they are, patients who get a bit harassed, so its timing it so they get the right input when they should.' (WYSU06b)

##### Age and engagement

Another service user characteristic associated with engaging in the self care projects was age, with older people being more likely to engage in the projects. While this association was weak we decided to explore relevant qualitative data because of the possibility that this may be related to the importance of timing and being ready to engage in the projects, as discussed above. The majority of qualitative data supporting this was derived from service users from the SUN Project. This is reflected in the quantitative findings on the London sample, that was less likely to engage and that included younger people (section 4.2.6).

###### *Expectations vs realities of 'getting better' through the self care project*

In the London sample, younger people were more concerned with making progress and moving on and in this way, the project did not meet their needs:

'It's comfortable and it's supportive. Of course you never get better I don't think because of that, I think that's the only problem. Some people need that and they can't do anything else ... I set my sights a little higher or I have done in the last couple of years.' (LOSU22f)

*Age appropriateness of the project*

Younger people also talked about the project not being appropriate to their age group and not fitting in as a result:

'I'm the youngest member there and a lot of people there are a bit like quite older than me, and that's something that I was concerned about because it just makes you feel a bit of a sort of outcast.' (LOSU05b)

Qualitative data from service users in the middle and older age groups in London reflected a higher level of engagement with the self care project, by talking about going to groups more often and the project being incorporated more into their routine:

'I have quite a structured routine, because I am at the SUN Project on a Monday, Tuesday, Wednesday, and then I do other things in between that.' (LOSU04f)

**Gender and engagement**

While there were no statistically significant associations between gender and engagement we felt it was important to revisit the qualitative data in order to explore gender specific experiences. In London and West Yorkshire project activities were deliberately located in community, rather than Trust locations as part of their outward looking approach. We found that men said they were more confident with using public transport, while women (more often than men) raised this as an access issue, especially where this made travel arrangements difficult, after dark and in the winter.

'I can't catch public transport on trains and buses, stuff like that, well not being able to do those kinds of things stops you doing a lot of things in life.' (WYSU11b)

In addition, in discussing coping strategies men seemed more likely to talk about the benefits of acquiring new skills, including using books and the internet as a resource, while women talked more about developing strategies through meeting new people and sharing experiences. However one woman did warn that this was difficult if there were too many men in the support group.

'... there's been more and more men coming ... I suppose that makes me feel a little bit nervous because it's not balanced.' (LOSU31b)

**4.5 National mapping of self care support**

A total of 73 Trusts were identified while compiling the database for the national mapping survey. During the verification process 5 Trusts were excluded as they did not provide mental health services directly (comprising four Primary Care Trusts and one Learning Disabilities Trust). All Trusts verified, by telephone, names, roles and email addresses of Board level managers as identified from Trust websites. Emails were sent to between 4 and 6 managers at most Trusts, although emails were sent to 3 managers at one Trust and to 7 managers at two Trusts because of particular configuration

of roles in those organisations. During the survey a total of 4 emails were returned as invalid after being checked and reverified by Trusts. A total of 310 emails were sent to managers at 68 Trusts that were both verified and valid. A summary of main findings are presented here. Full findings can be found in Appendix 15. It must be noted throughout that the findings reported here represent the opinions of individual respondents, rather than the published policy or activity of Trusts.

#### Response rate

A total of 57 replies (18% of recipients) were received from 44 different Trusts (65% of all Mental Health Trusts). However, in 17 replies from 10 Trusts only the basic questions about the Trust were answered, and none of the questions about self care. These replies were not included in the analysis below. A total of 40 replies (13%) from 34 different Trusts (50%) are included in the analysis. There was a single reply from most (29) of those Trusts, two replies from 4 Trusts and three replies from 1 Trust.

#### Responding Trusts

There was at least one reply from each of the ten Strategic Health Authorities (SHA), although over half of all replies came from three SHAs (London SHA – 8; South West SHA – 7; Yorkshire and the Humber SHA – 6). Most respondents were from medium and large sized Trusts, with 17 reporting between 2001 and 3000 employees, and 13 reporting more than 3000 employees (only 7 respondents reported 2000 or less employees, with 3 not answering the question). 22 replies came from Trusts that already had Foundation status, 10 from Trusts currently applying for Foundation status, 7 from Trusts not currently applying for Foundation status with 1 respondent not answering the question. Respondents came from Trusts which scored Good or Excellent in their most recent Health Commission Annual Health Check of Quality of Services and Use of Resources in 85% and 76% of cases respectively.

#### Responding individuals

There was a broad range of roles represented among respondents and a high degree of variation in the labelling of similar roles. Of the five key roles we initially searched for in building our database, 4 respondents were Chief Executives, 12 respondents had a strategic nursing roles (Director; Associate Director; Head; Executive), 7 were Medical Directors and 2 were Director of Operations (1 of whom was also a Director of Nursing). There were no replies from Directors of Human Resources or Personnel. Other Director, Associate Director, Head or Lead roles included Services (5), Adult Mental Health, Social Inclusion, Practice Governance, Practice Development, Director (not specified – 2), and Director of Finance and Business. Some replies came from lower tiers of management (recipients had been given the option of delegating completion of the survey), including General and Service Managers (2), Nurse Consultant and Project Lead. One respondent did not indicate their role.

#### Self Care strategy and leadership

Only 10% (4) of respondents said their Trust had a formal self care policy in place: 78% (31) said their Trust did not, while 13% (5) did not know. 73% (24) respondents said that self care was covered by their Recovery strategy,

55% (18) by their Social Inclusion strategy, 52% (17) by their Wellbeing strategy and 18% (6) by their Self Management strategy (respondents could name more than one strategy). Other strategies cited as also covering self care included Care Programme Approach (5), Personalisation (2), Carers (2), People Participation, Advanced Statement, Every Adult Matters, Medication, Mental Health Promotion and Public Health.

Similarly, only 13% (5) respondents said that their Trust had a named self care lead, while 68% (27) respondents said their Trust did not (6 respondents did not know and 2 did not answer the question). 47% (15) reported that self care was the responsibility of the Recovery lead, 41% (13) said the Social Inclusion lead, 31% (10) the Quality lead, 28% (9) the Medical Director, and 22% (7) each for the Wellbeing lead and the Director for Patient Experience. 6 respondents named other roles include leads for Care Programme Approach, Choosing Health, People Participation, Staying Well and professional leads (for Social Work and Occupational Therapy).

60% (24) of respondents was their Trust did provide staff with specific self care training 20% (8) said their Trust did not, 15% (8) did not know and 5% (2) did not answer the question). 40% (16) respondents said that their Trust's Risk policy covered self care 25% (10) said theirs did not, 25% (10) did not know and 10% (4) did not answer). 45% (18) of respondents said that their Trust's risk training covered self care 20% (8) said theirs did not, 25% (10) did not know and 10% (4) did not answer).

#### Self Care activity

A third or more of respondents reported that, to the best of their knowledge, the following features constituted an important part of self care initiatives in their Trust: group work 58% (23) respondents; peer support networks 53% (21); self referral process 48% (21); formal referral from other Trust services 33% (13); open access to initiative from outside of the Trust 33% (13); development of personal plans 58% (23); service users as members of staff 63% (25); initiative is goal orientated 35% (14); initiative is service user led 40% (16); support for service users' informal carers 43% (17). Other features all scored less than 33%.

#### Attitudes to Self Care

Only 33 of 40 respondents completed the attitude questions. Of those 51% agreed (48%) or strongly agreed (3%) with the statement 'self care support has lower funding priority than other service provision' (15% disagreed, none strongly). 50% disagreed (25%) or strongly disagreed (25%) with the statement 'awareness of self care policy across the organisation is high' (34% agreed, none strongly). 53% either agreed (47%) or strongly agreed (6%) with the statement 'it is difficult to coordinate support for self care across organisational boundaries' (25% disagreed, none strongly; there were 32 responses to this question). No other responses attracted either 50% agreement or disagreement.

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## 5 Discussion

Discussion of the analysis reported above will begin by revisiting and revising our theoretical framework for understanding support for self care in Mental Health NHS Trusts (section 2.2). We will take a systematic approach to revising the elements within each box of the framework (section 5.1), drawing on and cross referencing analysis from section 4 above, in order that we arrive at a new, 'empirical framework' that identifies the barriers and facilitators to supporting self care (section 5.2), as evidenced in our case studies. We will follow this with discussion of how these findings might be generalised across mental health care (section 5.3), considering which elements of supporting self care might be core across mental health service provision, and which might be specific to particular populations or service provision environments. We will then present findings from our national self care support mapping exercise (section 5.4.1) in order to consider the extent to which the findings from the four case study Trusts can be generalised to Mental Health NHS Trusts nationally, before considering finally the implication of our findings for supporting self care in other health service areas (section 5.5).

### ***5.1 Barriers and facilitators – revising the framework***

The theoretical framework introduced in section 2.2 above was primarily literature driven. This study has employed a range of research methods in order to explore, empirically, the extent to which the factors identified theoretically in the framework can be shown to act as barriers and facilitators to the support of self care by Mental Health NHS Trusts. Throughout the report we have indicated findings from the case studies that can be shown, with some degree of empirical confidence, to facilitate and militate against the provision of self care support by the host Mental Health Trusts. We will summarise those findings below within the domains of the theoretical framework, before presenting our new, empirical framework for supporting self care in Mental Health NHS Trusts (section 5.2).

#### **5.1.1 Organisational context**

Evidence of barriers and facilitators to the support of self care at the organisational level were for the most part elicited in the local mapping of self care policy and practice in case study Trusts (section 4.1.1) and the interviews with strategic managers in the Trusts (4.1.3). However many of the issues raised by managers were echoed by frontline staff, service users and carers from their particular perspective at the level of service delivery (4.3.8). These findings are summarised below.

##### **Alignment in strategy**

Theories of change emphasise the importance of the alignment of innovative projects with organisational strategy, both horizontal and

vertical, if they are to succeed. Our study has revealed a fairly high degree of alignment with formal strategy as espoused by managers at the top of the case study organisations. While only one had a self care strategy per se, elements of self care were included in strategies labelled as recovery, inclusion, self management and personalisation. However, the absence of a dedicated strategy could indicate a degree of fragmentation in the delivery of self care, and the extent to which self care in its fullest sense is included in the strategies of these trusts is uncertain. Nonetheless, there is no doubt that there has been a significant policy shift towards self care *concepts* over the lifetime of these projects.

The projects were seen by most managers to contribute to the delivery of key organisational strategies, particularly around recovery and social inclusion. Although views on the degree to which they were central to the strategies varied, their relevance was not questioned, and indeed they were sometimes seen as models for other services. A high degree of alignment was acknowledged and top level Trust support secured. The projects also depend upon support (funding and collaboration) from commissioning PCTs, the social care sector (local government) and voluntary organisations. The projects were felt to be relevant to a number of government guidelines and initiatives within social care: for example, personalisation and individualised budgets. A facilitating factor, therefore, was that the objectives of these projects were broadly in alignment with key strategies being pursued by the organisations on whose cooperation and resources they depended.

Alignment was not so apparent at the operational level where the acceptance of the concept of self care and changes in practice it implied were not well embedded. Thus while recovery and other 'self care' strategies are in place, the organisational culture, values, power relationships and ways of working lag behind. In particular, self care can be perceived as entailing a loss of control for professionals. There clearly was resistance to change, but the reasons for it are complex, and are not necessarily based only upon a rejection of the ethos of self care or the project itself.

### **Resistance to change**

The radical nature of these projects presented significant challenges to professional cultures, bureaucratic structures and established ways of working. These challenges were exemplified by issues relating to the management of risk, self referral, and the employment of current service users as members of staff. Several managers noted that self care was inherently risky and that this was a barrier to its more widespread use. The perennial organisational problem of putting strategy into practice was also evident in our case studies. Cultural differences, vested interests, workload concerns and lack of priority at the middle and lower organisational levels all threaten to undermine attempts at transformation.

### **Perceptions of risk**

The way in which some of these projects operated - outside the control of professionals, not covered by organisational standard operating procedures,

and at a distance from trust premises - was felt to increase risk. Self referral was an innovation which was perceived to pose risks to service users of inappropriate care and to staff safety. Self referral also potentially removes control of access to rationed services from the budget holders. Employing current service users also raised questions of risk, but posed initial difficulties to staff unsure how to relate to individuals who had crossed the boundary from patient to colleague, and created considerable problems to do with the formal processes of recruitment and appointment. Less easily resolved was the additional work of training and support that is placed on other staff. The SUN project provides an extreme case of all these difficulties, but demonstrates how, with determination, they may be largely overcome. This negative concept of risk at the organisational level was, however, balanced by the perceived therapeutic benefits of 'positive risk taking' advocated by both service users and project staff. As shown in sections 4.1.3 and 4.3.8, risks, perceived or real, did necessarily constrain the operation of these projects. Traditional attitudes towards 'health and safety' tended to prevail, although there was increasing recognition – particularly among frontline staff and service users - of the importance of positive risk taking as a major aspect of self care. Nonetheless, in the case of The SUN Project, the Trust's response to perceived risk was one of the main reasons given for integrating SUN much more closely into the structures of the Trust. In this way, the problem of risk was resolved, although at the cost of some loss of autonomy.

### **Funding and Resources**

One major barrier remained unresolved. A theme from the staff team interviews was the additional burden placed on individuals required to change their working routines and relationships. Change entailed additional time and effort and this cost was rarely taken account by those making a business case for innovation. Unless extra resources are provided the change process will be slow and operational managers will be unlikely to give it high priority.

### **Training**

Most prescriptions for effective change management emphasise the importance of a training strategy designed to support organisational strategic objectives. While for some staff adapting to self care practice requires little change, for others it can entail a significant transformation in their role and relationships with service users, colleagues and carers. Moreover, with many different definitions and expectations of what self care might mean in practice, developing a shared understanding and model of best practice would appear to be an essential requirement for effective change. Training therefore might be expected to have a central role in the implementation of self care strategies. One potential facilitating factor would be to systematically embed self care values and practice into training programmes. There appears to be a significant amount of training in place in case study Trusts, associated with a number of initiatives including our case study projects. The projects are contributing to learning both by demonstrating self care practice and providing training. WRAP, in particular,

clearly played a significant role in Hampshire. However, self care is not generally integrated or systematically linked into a Trust wide training strategy, limiting its influence.

### **Partnerships and working across boundaries**

A significant advantage of the self care projects was that they worked across the health and social care sectors, often with central or independent funding, providing the opportunity to develop novel services, and to prove their value to commissioners. However, all projects suffered from uncertainty about their future generating insecurity in staff and in users. Not only was direct funding far from secure, they were also dependent on organisational resources and the support of managers, clinicians and staff in order to operate effectively. Project staff spent considerable time and effort in advocacy 'selling' the project internally and externally to the organisations and agencies they worked with and to those who could secure their future. Uncertainty about future funding had negative effects, but it also lent urgency to the task of justifying the project's approach to self care. In this way staff were actively engaged in promoting a culture change, which could be seen as unexpected positive outcome. The future position of the creative projects is therefore perhaps least certain, but by the close of our study the future of SUN and WRAP appeared to be more secure. Thus there are positive advantages to independent funding, especially if it is ring fenced. However being placed outside of mainstream services and with no guarantee of future funding left the projects with an uncertain future.

### **Long-term futures: Mainstreaming**

While being recognised as a core service and being integrated into mainstream organisations structures would appear to be a means of securing the future of innovative projects, fitting projects such as the SUN or creative arts into Trust structures may not be so easily accomplished. While it does seem possible to maintain innovative features of projects within large scale bureaucracies, mainstreaming inevitably entails compromise on both sides and large organisations find it difficult to respond flexibly. Unless there is a secure source of independent funding, long-term survival of these projects would appear to require a degree of integration with Trusts.

### **The future of the projects: Charismatic leaders**

Finally, the foundation of innovative projects typically owes much to the leadership, advocacy, commitment and expertise of a single leader or small teams of dedicated individuals. Ironically, the charismatic leadership which secures initial success can also be transient and unstable. Long-term survival will therefore require there to be much more routinisation of leadership and wider dissemination of self care expertise.



### 5.1.2 Service users and carers: identities and expectations

This component of our theoretical framework – Box B – sought to identify how, (i) who the people using self care support services were (demographically and clinically) and, (ii) their understandings of self care and their expectations of self care support from the Trust (and those of their carers) represented barriers and/ or facilitators to the provision of self care support by the Trust. ‘Who people were’ – the characteristics of service users - was explored using standardised measures and structured questionnaires (section 4.2.2), and associations between those data and change in a number of outcomes related to self care in the policy literature (empowerment, mental health confidence, quality of life and satisfaction with services) were tested for statistical significance (section 4.2.5). It should be stated that this analysis is based on the combined, heterogeneous sample. As such, findings cannot be generalised to a specific population. Rather, these findings indicate a range of possible associations that might apply to similar populations. Findings are summarised below, along with key findings from a synthesis of this analysis with qualitative data from interviews with case study participants (section 4.4). While the issue of engagement with self care support is discussed elsewhere (section 5.1.5), who chose to engage with the projects was shown to be related to service user characteristics (section 4.2.3). Again, this analysis was synthesised with qualitative data (section 4.4) and the main findings summarised below. Understandings and expectations of self care were explored through qualitative interviews with service users and carers (sections 4.3.3 and 4.3.4), and were also reflected on as interviewees discussed their experiences of the self care projects (section 4.3.5). These findings are also summarised below.

#### **Who does self care work for?**

##### *Timing of support for self care*

Statistical analysis of the association between a range of service user characteristics and outcomes revealed that people who were generally more well at baseline (as measured by their non-risk CORE scores; i.e. independently of their risk CORE score) had higher quality of life at follow up. However people who were less well at baseline (on the combined CORE score) reported higher satisfaction with the self care project. These findings were reflected in qualitative data that emphasised the importance of ‘timing’ support for self care. There was a strong sense that the individual needed to be ‘well enough’ to engage in the more facilitative, less ‘provided care’ type of support on offer in self care projects, and conversely that where the individual felt more well than most other people at the project, then self care support began to feel less useful or even detrimental. These findings – both qualitative and quantitative – were consistent across sites, including at the London site where participants were, on the whole, less well than in Hampshire or West Yorkshire. This suggests that the ‘timing’ of self care support is more an issue of a good match between the individual and the

group as a whole using the self care service, than any absolute measure of how well the individual needs to be to self care.

It is of interest to reflect here on the characteristics of participants who dropped out of the study after the baseline interview. Those who dropped out had higher Mental Health Confidence and Empowerment scores, lower CORE non-risk but higher CORE risk scores, were on less medication and had a shorter time since first contact with services at baseline compared to those who remained in the study (section 4.2.2). Of those differences, a lower non-risk CORE score at baseline was associated with higher Quality of Life at follow up, while being on less medication at baseline was associated with lower Quality of Life at follow up. Also contradictorily, shorter length of contact with services at baseline was associated with more hospitalisation between baseline and follow up, while less medication at baseline was associated with less hospitalisation between baseline and follow up. The only non-contradictory difference was an association between less medication at baseline and higher Empowerment score at follow up (section 4.2.5). It is hard to say, therefore, if retention of this group would have had much of an impact on quantitative findings. However, the characteristics of this drop out group do reflect the qualitative observations made above on the timing of self care support: that a more well, more confident individual might feel that engaging in a project with people who seem less well is not useful for them. For these people there would be less incentive to remain in the research project.

*Self care and medication – a complex relationship*

Quantitative analysis also revealed a complex relationship between psychiatric medication and outcomes, relating to both how much medication people had been prescribed and whether or not they chose to take that medication. People who had been prescribed more medication had higher quality of life at follow up, while people who had been prescribed less medication were more empowered at follow up. People who had been prescribed atypical antipsychotic medication were also less satisfied with the self care project. People who chose to take psychiatric medication as prescribed were more empowered at follow up, while people who chose not to take medication as prescribed had higher mental health confidence at follow up. The weakest association with higher mental health confidence was among those people who chose to take their medication some of the time.

This complexity was reflected in qualitative data, with some people saying that taking psychiatric medication made them feel better, while for others the experience of taking medication was one of feeling less well. Similarly those people who decided to take their medication (who were more empowered at follow up) felt that medication formed part of their broader approach to self care, while those people who decided not to take their medication (and who had higher mental health confidence at follow up) conceived of self care as something that was achieved without medication.

The prominence of findings related to medication suggests that understanding the relationship between self care and medication is key to

the support of self care by the Mental Health Trust. This synthesis of qualitative and quantitative analysis indicates that the response by the Trust to the individual's decision whether or not to take medication is potentially either a barrier or facilitator of self care support. Some individuals are happy to incorporate medication into their personal approach to self care, while others might benefit from support from their Trust in their decision to come off medication in order to facilitate their personally preferred approach to self care. Of course the service user and clinician might not agree on a course of action. Rather this finding suggests that a joint approach to decision making around medication is intrinsic to supporting self care.

*Is self care support diagnosis specific?*

There were no statistically significant associations between diagnosis and outcome. London was the only mental health problem specific project: Personality Disorder. However, less than half of service user participants in London reported Personality Disorder as their primary diagnosis (a formal diagnosis was not needed to join the project). Effect sizes in changes in outcome – quality of life, empowerment and mental health confidence – were larger in London than the other sites (the last two being significant), and only London reported a significant within site decrease in psychiatric use of Accident and Emergency services. In the London qualitative interview data, issues around provision, access and appropriateness of Personality Disorder services were raised, as well as a specific understanding that self care was in part about reducing self harm. It is reasonable to conclude that self care support tailored for people with Personality Disorder can bring particular benefits to those people.

*Is self care support gender specific?*

There were no statistically significant associations between gender and outcomes. However, analysis of qualitative data by gender offered some evidence of gender specific experiences (section 4.4.6). Men were generally more confident than women with using public transport to travel to community based services. Given that community based settings were seen to support the development of non-mental health identities, this raises access issues, especially in geographically dispersed locations.

In addition, there was some indication that women might find sharing experiences about coping strategies difficult in group settings that were dominated by men, suggesting that some women might find gender specific support for self care useful.

*Is self care support culturally specific?*

As was shown above (section 4.2.2), 84% of the service user sample was White British, 12% White Other and 3% was from other, non White ethnic groups. Comparing sites, London had a more diverse sample with 63% of people classified as White British, 26% White Other and 3% from other ethnic groups, compared to West Yorkshire (86% White British; 12% White Other; 2% other ethnic groups) and Hampshire (100% White British). While this comparison did reflect differences between the populations of the areas

served by the Trusts (section 4.1), people from non White ethnic groups nonetheless remained under represented at all sites: 19% of people living in the area of the London site were from non White ethnic groups; 9% in West Yorkshire; 3% in Hampshire (with the largest group being Asian in each case). The lack of people from non White ethnic groups using the self care projects studied did not enable the team to explore the assertion (cited in section 1.2) that supporting self care provides an opportunity for community driven solutions for engaging people from different ethnic groups in appropriate and effective support for their mental health needs (Thomas et al, 2006). The biggest discrepancy between local population and people using the project was in London. Treatment seeking among people with Borderline Personality Disorder has been shown to be lower for people from Black and Asian ethnic groups than White ethnic groups (Coid et al 2009), while similar levels of under representation were found in an earlier study of eleven UK community based pilot projects for Personality Disorder, including the SUN project (Crawford et al 2007). It would seem that at all sites – and particularly with the London Personality Disorder project, where the local community was most ethnically diverse – initiatives supporting self care were failing to engage people from non White ethnic groups, although people from non British White ethnic groups (including people from Eastern Europe) were well presented in London and West Yorkshire.

*Who chooses to engage with self care projects?*

A higher quality of life at baseline was shown to be significantly related to a high level of engagement, or use of self care projects (as specifically defined for each case study project). Qualitative data from all sites exploring engagement with projects complemented the observation made above: that timing is a crucial aspect of support for self care, with people talking about the time having to be right in order to be ready, willing and/ or able to engage in support for self care. If the time was not right, some people went as far as describing the experience – for example, the requirement to make a personal plan – as stressful or even dangerous.

Age was also shown to be significantly related to engagement, with younger people less likely to choose to use their project more often. Qualitative data on engagement analysed by interviewees' age groups suggested that younger people felt they did not fit in with the older people attending their project, or that the project did not suit their needs. It is important to note that the youngest sample was from the London project, and that they were also the least well. This relationship between age and engaging could therefore be interpreted as further evidence of the need to time self care support well (i.e. that the age finding was confounded by the clinical characteristics of the London sample). However, older people in London also used their project significantly more than the younger people. On balance, therefore, it seems safe to suggest that in supporting self care Mental Health Trusts need to carefully consider projects that target younger people if they want them to remain engaged.

**Understandings of self care, expectations of self care support**

On the whole – where previous experiences of mental health services had not lowered expectations – service user and carer expectations for self care support from the Mental Health Trust were high. A role for the Trust was envisaged that involved providing the tools to self care, and being an enabler where there were challenges. Interview data indicated that, while some service user participants stated that they did not have a clear understanding of the concept of self care, many understood self care to be about looking after themselves generally (including their physical health and wellbeing), taking control of their own mental health and being more independent in their everyday lives, this last point also echoed by carers. On a practical level, that meant having strategies for coping that served both healthy living in the broadest sense, and anticipating and avoiding mental health crises. For London service users, that also meant having strategies for reducing self harm. There was an expectation, especially in London and Hampshire that projects supporting self care would provide service users with those coping strategies, and particularly the tools to recognise and reduce potential crises.

Accessing a strong social network was also part of service user understandings of self care. There was an expectation in all sites, among service users and carers, that the self care project would provide a stepping stone, enabling the process of broadening the individual's social network, helping people to overcome barriers – personal and social – to increased social contact, in the wider community beyond mental health services.

When discussing their experiences of the self care projects (section 4.3.4) some service users and carers spoke of their fears of being 'abandoned' by the Trust, perhaps at a time of unpredicted crisis, if they were seen as well enough to self care. Many service users wanted a mental health service that, while flexible, was formal, or clinical enough (as described in section 5.1.3 above), and carers understood that greater independence could only be achieved if a safety net was provided by the Mental Health Trust. There was therefore a clear expectation that self care support incorporated access to crisis support within the Trust's mainstream mental health service provision, however informal the self care project itself was.

#### *Carers and self care*

Throughout section 4.3 the views of carers were well represented in the qualitative analysis. The complexities of the role played by carers in the process of supporting self care emerge from this data. Service users acknowledged the support that carers give them, both to access the project initially (particularly with creative arts projects in community setting in West Yorkshire), and in their ongoing involvement: for example, in Hampshire where sharing WRAP plans with the carer was often mutually beneficial. However it was also noted that carers doing too much could undermine the taking of control by the service user that self care entails. Carers themselves were often very aware of the change in their role, as carer, that resulted from their caree's involvement in the self care project. They noted the service user's increased independence and the need for them to relinquish control, which could represent something of a challenge. On the

one hand, carers appreciated being able to resume, once again, a primary role as, for example, mother. On the other hand there were instances of the carer finding it hard to give up control and conflict occurring between carer and caree as they struggled with their changing relationship. Finally, while only a small proportion of our sample identified carers who also wanted to be interviewed, it has been noted (section 4.4.2) that complex changes in relationships with partners and parents who may have been playing an unacknowledged caring role also characterised the dynamic of starting to self care.

### **5.1.3 Self care staff: individuals and teams**

Box C of the theoretical framework sought to identify factors related to individual self care project staff members, and the staff team, that were potential barriers or facilitators to supporting self care. Data for this was wholly qualitative, generated through interviews with project staff at each site and reported largely in section 4.3.7 above.

It should be noted that none of the case study projects – and consequently none of the staff roles within those projects – were formally labelled as self care. However, staff largely shared understandings of self care with service users and carers; the issues of taking control and living independently noted in section 5.1.2 above. And staff at all sites - as well as service users when asked about their relationships with project staff - talked about the staff role in similar terms, and contrasted it with past experiences of working in, or using mainstream services in Mental Health Trusts. They spoke about a new, or change of role that was one of enabling participation in project and self care activity, and enabling the individual to use and develop their own resources, rather than providing support and care more directly. However they also spoke of a balancing act; of trying to be less formal, more relaxed and non-judgemental, without appearing to be too distant, uninterested or unable. This balancing act was reflected in the difficult calls project staff found themselves having to make, especially around deciding whether or not to step in with clinical support or to provide boundaries – especially where there were issues of risk, often related to the less formal nature of the project (e.g. open access) – while not wanting to disempower the individual through assuming control unnecessarily.

It was noted, by staff and service users, that a positive attitude to this new role, rather than a particular professional background, was a vital facilitator of good self care support practice. Many staff reported being highly motivated, and for seeking out their post because they were interested in the approach, in group work or in working in creative arts and mental health. Levels of staff satisfaction – and service user satisfaction with staff – were reported (qualitatively) as high. The training that staff reported as best equipping them for their role required them to personally experience the sorts of activities (personal planning, creative arts) that service users would be undertaking in the projects, including training which they did together with service users. Staff also reported feeling well supported in the

job in the immediate context of the self care team and through supervision, with some stating that they felt that the ethos of self care included staff.

However, staff felt less supported by their Trust at an organisational level, primarily around issues of job security related to funding. Self care projects were largely externally funded, or funded on an annual basis, so most staff were on rolling, one year contracts and felt obliged to at least consider moving back into mainstream posts.

Finally, service users were employed as staff in some capacity on all of the case study projects. People using the project attributed to service user staff members a great deal of credibility because of their shared experiences, and as role models they were facilitators of good self care. They were also well placed to negotiate some of the 'difficult calls' referred to above around deciding whether to manage risk within the resources of the self care project, or to call on the more clinical resources of mainstream Trust services. However, from all perspectives interviewees expressed anxieties about the mental health of service user staff. The organisational investment required to properly support the role was noted. The benefits to service user staff in terms of their own mental health and wellbeing were also acknowledged.

#### **5.1.4 Self care projects: structure, process and philosophy**

This component – Box D of the theoretical framework – was designed to explore which elements of projects supporting self care could be identified as barriers and/ or facilitators of self care support. Standardised measures were used to identify change in outcomes over time (section 4.2.4), while synthesis of quantitative and qualitative data (section 4.4) considered service user, carer and staff perspectives on those changes. Where these findings have relevance to the structure and approaches to providing the case study self care projects they will be summarised below. In addition, key findings from qualitative interviews that explore experiences of using and working in the case study projects will also be summarised here (section 4.3.6).

Across all three sites increases in quality of life, empowerment and mental health confidence were statistically significant (increases in empowerment and mental health confidence were significant within site in London, and mental health confidence within site in West Yorkshire). Noting that this significance is based on the combined, heterogeneous sample, it is important to further explore, through the qualitative data, the experiences of the specific populations. In West Yorkshire interviewees specifically linked their increased confidence to increased social contact they achieved through participating in creative arts projects, and their developing broader self identification with creative arts (a non-mental health identity). In London service users also attributed increased confidence to the reduced isolation they experienced through their involvement in the SUN project, while Hampshire service users felt empowered by the increased awareness of their own mental health issues that personal planning offered them.

Reduced psychiatric use of Accident and Emergency was significant across sites, and also within the London site. SUN project service users spoke of the benefits of being able to bring issues that might lead to crisis to the peer support group, and of feeling that they had good access to crisis services through the group.

These findings are further reflected in the complex, qualitative narrative of self care support articulated in section 4.3.4, summarised below.

*Real self referral*

Service users, echoed by carers and staff, described as empowering a genuine process of self referral to self care projects that were right for them, at the time they were right. But the benefits of self referral were jeopardised if the individual felt they were coerced, or not given a real option about attending, or if the opportunity to self referral was given without the support necessary to overcome personal challenges about attending a new project for the first time.

*Flexible, responsive and ongoing support – ‘but don’t abandon me’*

Service users wanted support for self care to be flexible, and that flexibility meant responding to the individual service user’s needs. For some people this was frequent contact, but for others this meant the ability to drop in and drop out of the service without fear of being discharged for not attending: to be in control of when and how the service was used. But service users qualified that they did not want a service that was so loosely structured that they did not have the confidence that it would be there to support them in a crisis, when they might need access to more clinical support.

*Routine and structure, without dependence*

Support for self care should provide routine and structure – ‘something to get up for’ – for those people who needed it, but there was a danger of people becoming too comfortable in an ongoing project and creating a new dependence on services.

*Peer support groups and how to survive them*

Peer support groups offered many facilitators of self care, enabling people not to feel alone, to gain insight into their own mental health and self care strategies through sharing experiences, and to expand and develop their social networks. However, there were anxieties around entering and remaining in a peer group, especially one where difficult issues were discussed, where there was an expectation that members would provide support for each other, and where there was open access and irregular attendance of groups. Some of the qualities of self care support identified as positive could also act as barriers to some people. This might result in high turnover in peer group type projects, but where people were supported to remain in the group there were rewards – increased confidence – to be gained from overcoming those challenges.

*Personal plans – ‘taking control of your mental health’*



Personal plans were a facilitator of self care, providing an active tool for achieving a key aspect of the service user defined understanding of self care articulated above: 'taking control of your own mental health'. Personal plans also provided a means to include family and partners – carers – in self care. However there were barriers too: the requirement for writing and paperwork presented a problem for some people; like talking in groups, producing crisis plans could oblige people to confront difficult issues (especially in London where plans were developed in the group); for some people (especially in Hampshire) once the stage of developing the plan was over, they felt the 'abandonment' reported above, without continued support to sustain their use of the plan.

*The productive project – developing 'well' identities*

Many service users spoke about their project as something they could identify with. Identifying with other people using the project on the basis of shared mental health issues could be a facilitator, but over-identification with mental ill health was for some a barrier. Producing a wellness plan (in Hampshire), or producing an art work (in West Yorkshire) as part of the project facilitated the development of new identification with a 'well self' that was not defined or limited by mental ill health.

### **5.1.5 Processes: engagement and relationships**

This component – Box E of the theoretical framework – sought to explore the extent to which two specific factors were associated with outcomes: experience of the therapeutic relationship between service users and staff; the level of service user engagement with the project. Relevant analysis of factors associated with outcomes (section 4.2.5) as well as qualitative analysis exploring service user and staff experiences of self care support (section 4.3.4) are summarised below.

#### **Relationships**

There is consistent evidence in psychotherapy research that the therapeutic alliance is the most robust predictor of treatment success and this has been evident across treatment modalities (e.g. Martin, Garske and Davis, 2000). Furthermore, research suggests that client ratings of the alliance are stronger predictors of treatment outcome than therapist ratings (Horvath and Symonds, 1991). However, our findings indicated that service user ratings of therapeutic relationship with the member of staff on the self care project that they had most contact with were *not* significantly related to any of the psychological or service use outcomes that we tested for (section 4.2.5).

This finding reflects qualitative data that indicates that, while service users and staff at all sites reported a different quality of relationship to that which they had previously encountered in mainstream mental health service provision – a quality of relationship that enables self care – strong positive identification by service users was with the service user group and with the project, rather than with individual staff members (section 4.3.4). This combination of quantitative and qualitative evidence suggests that a good

relationship with individual members of staff, as rated by the service user, is *not* an 'active ingredient' in the support of self care by the Mental Health NHS Trust. The SUN project staff refusal to complete the STAR (professional version) on the grounds that service user identification in the project was intended to be with the group, rather than with individual staff members (reported in 4.2.7 above), would appear to be vindicated by this finding. In addition, in the two sites where staff did rate their experiences of therapeutic relationship with service users, neither were staff ratings of relationship related to outcome, to service user engagement with the self care project or to service user ratings of the same relationships.

### **Engagement**

Quantitative analysis across study sites indicated that there was no significant relationship between the level of engagement with their self care project that individual opted for, and any outcomes measured. However, qualitative analysis of service user interviews strongly suggested that the ability to choose how much to engage – in terms of frequency, duration, and having the freedom to drop out of the project without fear of discharge and to resume contact when it suited the individual – was highly valued. Indeed service users attributed their improved sense of control over their mental health – a self care outcome – to having that degree of choice. These combined findings suggest that it is not the amount of support for self care that the individual receives that is important: that is to say, self care support cannot be 'dosed' like medication. Rather, it is the ability to choose the level and terms of engagement with self care support that is important. As was shown in section 4.2.3, analysis of the engagement data raised the possibility that continued use of the SUN Project came as a result of service users being able to use the project as and when they needed it (including being able to drop out for extended periods of time). Almost paradoxically, the Mental Health NHS Trust can facilitate support for self care not by *requiring* its service users to engage in that support, but by making the option to engage available, on the individual's own terms.

As has been discussed in section 5.1.2 above, levels of engagement have been shown to be linked to age and quality of life, and more broadly, to the idea of 'timing' support for self care well. This further suggests that the option to engage in self care support must be made available to the right people at the right time, reflecting their needs as an individual.

### **Process and the empirical framework for supporting self care**

Given that both qualitative and quantitative analysis has suggested these two particular factors are not associated with self care outcomes in a simplistic way, this box will not feature in the empirical framework for supporting self care. That is not to say that the processes of relationship and engagement are not important facilitators of self care support. Rather that staff roles and relationships in the self care project should play a qualitatively different role, enabling the development of a wider sense of identity and reducing dependence on mental health professionals and the Trust. And far from requiring a level of engagement in the project for it to be seen as a success, projects supporting self care should be structured in

such a way as to give the individual service user full control over the terms of that engagement. These facilitators of self care support are covered in boxes C and D of the empirical framework respectively.

### 5.1.6 Outcomes

While this was not an effectiveness study it is useful to reflect on the outcomes that were used and, given that the rationale for including these outcomes were primarily policy driven (to explore the extent to which a range of factors might be associated with change in a number of outcomes that self care policy required health service organisations to improve), to consider the relationship between self care support and outcomes.

Statistically significant changes were observed in Quality of Life, Empowerment, Mental Health Confidence and psychiatric use of A&E, and relationships were variously demonstrated between these outcomes – as well as satisfaction with the self care project – and medication and clinical severity. While this analysis was conducted on a combined, heterogeneous sample, subsequent qualitative analysis revealed in some depth how individual service users, carers and staff attributed an improved sense of empowerment and confidence to involvement with the project, and with specific qualities of the projects and the way they were provided. While quality of life was not specifically referred to in qualitative interviews, 'looking after yourself' (including physical health and healthy living in general), prevented crisis and reduced self harm (in London, where use of A&E attendance dropped significantly) were important. High levels of satisfaction with specific qualities of service delivery in the self care projects was widely expressed in qualitative interviews by service users, often in comparison with previous experiences of mental health services.

While it was noted that 'amount of engagement' with the project was not related to outcome – that self care support cannot be dosed – qualitative data again suggested that individuals associated outcome with the 'quality of engagement': primarily individual control over the terms of engagement. Therefore evidence suggests that quality of life, empowerment, mental health confidence and satisfaction with the service (and psychiatric use of A&E by a Personality Disorders population) are important self care outcomes that might usefully be included in any future controlled study of self care support.

It should be noted that study participants talked about self esteem and control as much as they talked about empowerment and confidence. It is therefore also likely that these are also important outcomes of self care support that could be tested in a future study. Expanded social networks were an important part both of service users' and carers' conceptualisations of self care that they expected projects to enable. Some measure of social networks might also be a useful addition to a future outcomes study. Interviewees also spoke about recovery as an outcome or product of self care (as though self care was part of a package that would deliver recovery). Currently there is no well validated self report measure of mental

health recovery, but this findings is useful in understanding the conceptual relationship between self care and recovery.

In addition, staff working in the self care projects reported, in qualitative interviews, high levels of satisfaction with their work, often in comparison to previous posts and ways of working in mainstream mental health service delivery.

The range of outcomes discussed above will be incorporated into the empirical framework for supporting self care.

## ***5.2 An empirical framework for supporting Self Care in Mental Health NHS Trusts***

As was impressed upon us at the feedback conferences, much of self care support is a double edged sword: get it right and challenges can be overcome and the individual flourish; get it wrong and the barriers appear and a culture of provided care prevails. Thus the findings summarised in the sections above are presented here – in figure 6 – as neither barriers nor facilitators. These are the issues that, our case studies have shown, the Mental Health Trust must respond to if it is to implement the cultural change – from ‘doing for’ to ‘doing with’ – envisaged in Department of Health Self Care policy.

It is of interest to compare this empirically derived framework with the theoretically driven framework (figure 1, section 3.2) that informed study design and data collection. The organisational factors facilitating support for self care (Box A), as indicated in the organisational literature, were largely supported by empirical data – for example, strong strategic alignment – while particular issues (risk, partnership across sector boundaries) were highlighted. Elucidation of Box B – Service Users & Carers: understandings and expectations of self care – offered only tentative findings on ‘who benefits’ at the level of demographic populations. Instead, the empirical evidence was all about the individual: an expectation that self care was about individual control and empowerment; experiential evidence that support for self care worked when the individual was ready for it, and had control over the timing for self care support. While our theoretical box C – focussing on staff supporting self care – had placed a certain emphasis on team and role structure, our empirical model emphasised instead the particular qualities of the self care support role, and suggested that a culture of supporting self care needs to run through the organisation for the role to be effective. Service users working as staff emerged as integral to the self care support team. Box D – exploring components of self care projects – was effective in mining our case studies, picking out from the broad sweep of factors listed in our theoretical model those specific elements that were supported in the data. Again, it was the particular qualities of, for example, self referral, peer support groups and personal planning that were articulated. Issues such as abandonment, dependence, control and wellness emerged from the data, grounding the theoretical model in lived experience. As described above, the process variables (box

B) that we had theorised would moderate self care outcomes did not operate in the way we had anticipated. Findings indicated that a different, more enabling quality of service user-staff relationship was actually integral to the whole notion of self care, rather than a simple 'confounder' of how well an individual might respond to a treatment. Similarly, levels of engagement with self care support seemed much less important than control over use of that support: again, this sense of control emerged as integral to self care, rather than a moderator of self care. Finally, our modelled set of outcomes was on the whole well supported empirically, in the qualitative as well as quantitative data sets. Improved individual sense of control emerged as a primary outcome of supporting self care. Expanded social networks for service users and high staff satisfaction had not been anticipated in our theoretical model.

Figure 6. Empirical framework for supporting Self Care in Mental Health NHS Trusts



### **5.3 Generalising across mental health care**

The findings and discussion above are derived from three case studies which, although representing a range of geographical, socio-demographic, Trust and service delivery environments, and a range of service users, remain three case studies. Given this variation, it is necessary to consider how these findings might be generalisable across mental health care. The comparative case study approach has been shown to be an effective tool in the study of policy implementation and organisation change in health service organisations (Ferlie et al 2005), enabling the identification of generic features of change as they are indicated across contrasting cases. Comparison between our case studies, in particular when taking differences between samples into consideration (section 4.2.2), provides insight into where the barriers and facilitators of supporting self care have generic importance. The final national mapping of support for self care in Mental Health NHS Trusts, in addition, provided an opportunity to consider how similar case study Trusts were to Mental Health Trusts nationally, on a range of dimensions, and therefore the extent which findings from case studies might reasonably be expected to reflect a wider picture of self care support (5.3.1).

At two of the case study sites – Hampshire and West Yorkshire – samples were similar on nearly all socio-demographic, mental health and service use characteristics (people in Hampshire had used services for longer, had more lifetime inpatient admissions and were more likely to receive support from a Community Psychiatric Nurse than those in West Yorkshire, probably explained by more of the Hampshire sample having been recruited from inpatient, rather than community populations). As such, the Hampshire and West Yorkshire samples were demographically similar in terms of age and gender to people using secondary mental health services nationally (non-admitted secondary mental health service users are more likely to be female and in the 36-54 age range: NHS 2008), while their patterns of service use can be described as broadly typical of people using Community Mental Health Teams in Trusts nationally. While the under representation of people from non White ethnic groups in the samples has been discussed above (5.1.2), as a consequence of this under representation it must be acknowledged that it is not possible to reflect here on potentially culturally specific issues of self care and its support.

In contrast, the London population – a diagnosis specific population (Personality Disorder) - was younger, more likely to live alone, less likely to be receiving Care Programme Approach from the Mental Health Trust, more likely to be seeing a Drug or Alcohol Counsellor (they had higher levels of harmful drug and alcohol use), more likely to use A&E for psychiatric reasons, less likely to receive support from a friend or family member, and had higher scores on CORE (in short, they were less well). However, in spite of this range of issues, the vast majority of the range of barriers and facilitators to supporting self care discussed in section 5.1 above applied

equally to this group. There were specific issues around the appropriate timing of self care support for people with Personality Disorder and challenges around their access to the SUN project from other Trust services, particular challenges and potentials to providing a peer support group for people with Personality Disorder, and a focus for some on self care to reduce self harm as well as to develop confidence and control. However, those core issues of timing, access and peer support remained the same and equally important for the London sample. This suggests that the range of barriers and facilitators to self care support identified here may well be common across mental health, but that within conditions there is need for specific research that identifies particular variations in the way, for example, self referral, peer group support and so on are implemented and supported, and how interventions are targeted to diagnosis specific populations.

### **5.3.1 Generalising to Mental Health Trusts nationally – national mapping of self care support**

It should be noted that, in exploring the extent to which our findings appear to generalise to Mental Health Trusts nationally, we are comparing online survey data from senior managers with a complex case study data set derived from standardised measures, and in depth structured and qualitative interviews with service users and carers, as well as senior managers and frontline staff in the case study Trusts. Similarities or differences may well therefore reflect the alignment of perspectives, and the comparison summarised below should be read with that proviso in mind.

Responses to the survey came from 50% of Mental Health NHS Trusts in England, from all ten Strategic Health Authorities and from respondents with a wide range of strategic and senior management roles. It is reasonable to claim that survey responses are broadly representative of senior NHS management of Mental Health services across England.

Our four case study Trusts were typical of the large majority of Trusts from which we received responses, in terms of size (medium to large), Foundation status (obtained or sought) and performance (good to excellent). None of our self care data comes from Trusts that would be described as atypical Mental Health Service organisations.

Our case study Trusts were also largely typical of Mental Health NHS Trusts nationally in terms of strategic implementation of self care policy. Most Trusts do not have a formal self care policy, with respondents reporting that self care is covered by a number of policies likely to include Recovery, Social Inclusion and Wellbeing. Similarly, most Trusts did not have a named self care lead, with responsibility falling across a number of roles, typically including leads for Recovery, Social Inclusion and Quality. Like our case study Trusts, respondents were reasonably likely, despite this lack of dedicated strategy and leadership, to state that staff training for self care was provided, and less likely to say that self care was covered by Trust Risk strategy and training.



Most of the features that were identified by a third or more respondents as being an important part of self care initiatives in their Trusts - group work; peer support networks; self referral process; formal referral from other Trust services; open access to initiative from outside of the Trust; development of personal plans; service users as members of staff; initiative is goal orientated – were also identified in the case studies as being barriers and facilitators of supporting self care in Mental Health Trusts. Implicit in this finding is the observation that many of the conclusions we have drawn above on those barriers and facilitators are relevant to large numbers of Trusts nationally. Only a small number of features - initiative is service user led; support for service users' informal carers – identified by a third of more respondents were NOT also identified in case studies as barriers and facilitators. This does not exclude the possibility that those features are barriers or facilitators; indeed, many carer interviewees spoke of the need for more support for carers as the caring relationship changed. Rather this indicates that the case studies did not generate data that could offer insight into those features in Trusts nationally.

Majority attitudes among survey respondents reflected case study findings that were indicative of concerns over: the short term nature of funding arrangements for self care projects; low awareness of the concept of self care support outside of those projects with a specific self care remit; concerns in London and Hampshire that coordination with other organisations were not as well developed as they might be (partnerships with voluntary sector agencies in the delivery of creative arts projects in West Yorkshire were an exception). The ambivalence expressed by respondents to other statements also reflected the range of opinions expressed by case study interviewees. In particular, discussions that took place between stakeholders at feedback conferences reflected a diversity of opinions on resistance to self care among both service users and staff, and the both positive and negative aspects of risk in supporting self care.

With the proviso expressed above – that comparison has been made between the views of senior managers and the findings of a complex case study data set – we feel that our findings are broadly generalisable to Mental Health NHS Trusts nationally on the grounds that:

- a. National coverage of the survey was good;
- b. Case study Trusts were typical Mental Health Trusts;
- c. The strategic implementation of self care policy in case study Trusts – that self care policy was largely implemented by default though a number of related, rather than dedicated strategic initiatives – was typical of Trusts nationally;
- d. Features of self care activity identified as barriers and facilitators to supporting self care in the case study Trusts were evident in many Trusts nationally;
- e. Key areas of concern that had been raised in case study Trusts about the implementation of support for self care were shared with Trusts nationally.

## **5.4 Generalising across health services**

Meetings were held between three of the four SDO funded self care projects – mental health; younger people; older people – four times over the lifetime of this study. The methodological similarities between the studies were noted, all employing a national mapping stage and detailed case studies. While no formal attempts were made to compare or synthesise findings, discussions between the teams did reveal a number of areas in which emerging findings overlapped:

(1) All studies offered insight into the way in which the organisational environment - issues of commissioning, the health and social care market place and partnership working between health, social care and third sector providers - impacted on the delivery of self care support, strongly suggesting that these environmental issues are core to the support of self care across health services;

(2) All teams felt that their studies would offer learning from positive experience on the ground that would inform the delivery of support for self care, while noting that conceptualisations of self care, and the key features of its support, do relate differently to different health and treatment dynamics within different health service areas, and so distinguish learning that is core from that which is condition specific;

(3) All studies raised questions about the extent to which evidence of good practice in self care support that was observed was driven by (a) policy and its communication downwards through the health service organisation, and/ or (b) bottom up initiatives originating from new patient/ practitioner partnerships, innovative teams and charismatic leaders;

(4) The importance of increased awareness of where, why and when supporting self care - as opposed to more conventional provision of treatment - actually reflected the preferences and choice of patients and service users (rather than fulfilling provider-side priorities) was indicated in all studies, suggesting that this is of core importance across health service areas;

(5) All studies collected evidence of provision of support for self care reflecting a change in the culture of service delivery, and in particular, changes in roles and relationships between health service practitioners and patients/ service users, and also between patients/ service users and their informal carers, partners and family members, again suggesting that these changes in roles and relationships are core to supporting self care across health services.

## **5.5 Reflections on the study design**

The funding brief (Appendix A) committed the team to critique the study design in the light of having undertaken the research. In addition, we felt it was important to reflect on the impact of the approach we had taken to the involvement of service users in the research process.

### 5.5.1 Limitations of the study

As we noted at the outset, the lack of a cohesive evidence base for supporting self care in mental health meant that an experimental study design was not possible. Having taken an observational approach, analysis of change in outcomes was exploratory in nature and was used in order to identify factors that might be moderators or mediators of change, rather than indicating the effectiveness of our case studies. Furthermore, we selected varied self care initiatives that served varied populations. This was in order that the research would identify a broad range of factors that might act as barriers or facilitators to supporting self care. However, given the heterogeneity of our samples, this approach does mitigate against generalising our findings to specific populations. Any findings, conclusions and recommendations should be read with this proviso in mind.

As such, this was a naturalistic study, with implementation of self care support initiatives determined by conditions that applied locally in each case study Trust. Study of the organisational environment in which self care was being supported was, of course, central to this project. This represented a strength of the study design, allowing us to mirror the organisational environment in which Trusts routinely deliver services and respond to policy. Nonetheless, the study design necessarily responded to this naturalistic context. In particular, recruitment was shaped by the pace of roll out, and the services to which self care was rolled out. This meant participants were recruited from two different Trusts in West Yorkshire, and that the sample included a number of inpatients in Hampshire. While heterogeneity within study sites provided an opportunity to identify barriers and facilitators that were common across broad populations at those two sites (in contrast to the more homogeneous London sample), this did impact on other analyses. For example, change in service use data was skewed by the inpatient participants in Hampshire, while the West Yorkshire data was an aggregate of smaller samples from two Trusts. In particular, reflections were made on the organisational context in West Yorkshire on the basis of more limited interview data from each Trust. On balance, however, the opportunity to study *in vivo* the implementation of support for self care outweighed these methodological limitations. Had we been able to establish more rigorous inclusion criteria and limited the heterogeneity of samples we would be less well placed to indicate how our findings might apply to routine practice.

A possible approach to exploring the impact of the naturalistic study setting on research findings would have been to have recruited an additional sample of people with similar mental health diagnoses and service use histories who did not receive support for self care, either because that support was not made available to them or because they chose not to become involved (the study was successful in retaining participants who chose to disengage with projects during the course of the study). Collecting quantitative data about those people would have told us if they differed at all from those who accessed self care support. With this data we could talk about our findings as generalisable across populations with more confidence. Collecting qualitative data from these people might have

identified why they chose not to become involved, or if they would have done if they had been given the opportunity. We did collect some data that indicated that referring staff might make decisions about who they thought should be enabled to 'self refer' to self care support (section 4.3.6), and it would have been informative to have explored this in more detail. In particular, it would have been extremely informative to collect data from people from non White ethnic groups in order to find out why they were not accessing the self care support we studied. Additionally, if we had selected projects that specifically targeted people from, for example, Black or Asian ethnic groups, we would have been able to explore the possibility that culturally specific support for self care offers an opportunity to provide accessible and engaging mental health services for people from non White ethnic groups.

In addition, because entry to self care projects was managed independently to the research (see 3.4.1 above), some participants had attended a small number of sessions (between one and three, in one case five) prior to interview. In answering qualitative questions about their expectations of the project some participants stated that they were 'thinking back' to before they first attended. This suggests the potential for either recall or social desirability bias that could extend to quantitative as well as qualitative data. However, in all cases the actual time elapsed between first attending the project and baseline interview was short (only in one case was it longer than two weeks) and so the impact of such bias is likely to be small.

The collection of a very large volume of qualitative interview data had both advantages and disadvantages, undoubtedly adding to the interview burden for participants. It has already been noted that the Locus of Control measure was dropped from the schedule because of that burden (section 3.4.1), yet sense of control emerged in the qualitative interviews as central to both understandings of self care (4.3.3) and self care outcomes (4.4.1). In addition, changes in relationships (and social networks more generally) also emerged as an important outcome (4.4.2) and might usefully have been measured. While the amount of qualitative data collected providing the opportunity for the very rich analysis and depth of insight presented above, the size of the task of organising that data, even with the assistance of NVivo, perhaps also inhibited the qualitative analysis. It is unusual to have a longitudinal qualitative data set of the sort collected here, with qualitative interviews at both baseline and follow up. However, because of the size of the analysis task and the time constraints placed on the study, analysis of change in experiences and attitudes as evidenced qualitatively was guided largely by the change in outcomes in the quantitative data set. While this data synthesis (section 4.4) is powerful and informs much of the subsequent discussion, further insight would have been offered if analysis of change had been allowed to emerge from the qualitative data. In retrospect all service user participants might have undertaken a lengthier quantitative interview, while a subsample of participants at each site attended a second, qualitative interview at both baseline and follow up. The team would then have had the resources to fully exploit a longitudinal qualitative data set.

### 5.5.2 Reflections on service user involvement and the collaborative approach

The collaborative approach described in section 1.4 above characterised the research project. Investigators, research assistants and advisors, identifying variously with personal experiences of mental health issues, as service users and carers, and as researchers and clinicians, brought these perspectives to data collection, analysis and to the collaborative direction of the project. This was no more evident than in the four meetings held over the lifetime of the project that brought the entire team and advisory group members together in London, Leeds, Southampton and Kingston respectively. In particular, at those meetings the team engaged collaboratively in the analysis of the qualitative data set, and in the interpretation of the full set of findings as the study progressed. The group stage of developing the qualitative analysis framework was described above (3.4.6), and sought to capture service user and carer, as well as academic and clinician, interpretations of the data in the developing framework. We felt as a team that we achieved this objective, and that a richer analysis emerged as a result. Findings focused on service user and carer views and experiences complemented those that reflected the priorities and concerns of clinicians and managers in the NHS. The recommendations made below will speak to policy makers, practitioners, service users and carers alike as a result.

However, these discussions were not without tensions as our different priorities were voiced. Differences in the way we interpreted the qualitative data were resolved productively through retaining the complexity of the qualitative analysis framework (4.3.1) and by coding interview data to a range of analytical nodes where different interpretations were possible, thereby ensuring that this complexity remained available when the analysis was written up. Members of the team who had personal experiences of mental health issues were particularly concerned that we did justice to the interview data – to participants' personal experiences and the contribution they had made to the project by agreeing to be interviewed – and this ensured that we did not apply an overly reductive approach to analysing the qualitative data set, in spite of its size.

There were different views about the emphasis placed on certain findings. In particular, the issue of the relationship between medication and support for self care encouraged a great deal of debate, with some members of the team (including, but not only, service users) feeling that the 'visibility' of medication in the findings was driven by the inclusion of structured questions about medication and the resulting statistical analysis. However other members of the team (including service users as well as clinicians) felt that the large volume of qualitative data about medication, and the usefulness of this qualitative data in explaining the complexities of the quantitative findings (section 4.4.5) indicated that service user participants were themselves concerned about the relationship between medication and their self care. We did not wholly resolve this issue as a team, and took the 'academic' approach of reporting the data and offering an interpretation that focussed on the complexity of the issue. This debate illustrated the

challenges and the productive potential of the collaborative approach that made this project so stimulating and rewarding for all those involved.

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## 6 Conclusions

In this project we set out to identify the barriers and facilitators to the provision of support for self care by Mental Health NHS Trusts. It has been shown above that it is not always helpful to differentiate between barriers and facilitators: many factors were both facilitator when put in place or when challenges were overcome, and barrier if neglected or 'not got right'. The emphasis in the recommendations that follow is therefore on guidance for Trusts, raising awareness of what they should put in place in order to support self care for the benefit of service users.

In addition it must be restated that none of our case study projects were specifically labelled as 'self care projects'. It was also observed that self care policy had a low profile in case study Trusts (and indeed in Mental Health Trusts nationally). However, we found that neither the lack of an explicit self care label, nor a high level of consciousness that 'we are doing self care' were a barrier to good 'support for self care' practice. Rather, support for self care comprised many distinct qualities of providing mental health care that, together, constituted a change in the culture of care. This remained the case even where some of those qualities of providing care were called, by the Trusts, recovery, social inclusion or something different again. The Department of Health has signalled its support for self care with the publication of 'Your Health, Your Way: a guide to long term conditions and self care' (DH 2009). The recommendations that follow will indicate that it is through enabling a genuine change in the culture of providing mental health care, from 'doing for' to 'doing with', that Mental Health NHS Trusts can best support self care.

### **Services supporting self care**

Two of the means of delivering support for self care advocated in the policy literature – peer support groups and personal plans – were strongly indicated as facilitators of self care when well supported. Service users developed strong positive identifications with projects supporting self care. However, attending peer support groups in particular, as well as completing and using personal plans, represented challenges for some service users, especially at the start of their involvement.

The research strongly indicated that service user control over when to access support for self care (self referral) and how to use that support (flexible, ongoing support) was fundamental to effective support for self care. A sense of being in control was also indicated as an important self care outcome. In addition, it was control over engagement in self care support, rather than amount of engagement that seemed to be important: support for self care cannot be 'dosed'. 'Timing' support for self care was also identified as crucial, and it was indicated that it should be the individual service user – rather than professional staff – who decides when the time is

right. Where a Trust is able to give up control over how support for self care is used, there seems to be potential to establish a 'virtuous circle' in which control over service use leads to improved control over the individual's mental health and wider life.

Data suggested there was no simple linear progression from provided care to supported self care, and neither can service users be 'discharged' to self care (indeed many service users experienced anxiety about being 'abandoned' by the Trust).

### **Self care and risk**

It was noted that engaging in self care often required the individual to confront difficult issues – for example, renegotiating difficult relationships – and that the individual might 'get worse before getting better' as a result: that self care involved a degree of 'positive' risk for both individual service users and the service provider. However, overcoming those difficult issues seemed to offer rewards in terms of improved self care outcomes (e.g. empowerment, quality of life).

The relationship between medication and support for self care was complex, but appeared to be important for service users, many of whom were prescribed medication by the same Trust that was supporting their self care. Some individuals were happy to incorporate medication into their self care, while others made a decision to come off medication. Others were still struggling with whether or not to take medication as prescribed.

### **Self care and the service user-staff relationship**

All projects were characterised by a change in the staff role – from provider to enabler – and a change in the service user-staff relationship. Relationships were less formal and non-judgemental of the service user. However, where relationships were perceived of as 'too relaxed' service users could lose confidence in the ability of the service to provide clinical support at times of crisis.

Employment of service users as staff on self care support projects offered clear benefits for service users, the service user employees themselves and their colleagues within the Mental Health Trust. However, the transactional costs of training and supporting service users and staff were not negligible.

### **Self care and social networks**

Carers were very positive about self care support and the benefits it offered both them and their carees. However, self care impacted on their relationships and this could be a source of conflict.

Social networks were strengthened through self care, especially where support was given in settings away from the Mental Health Trust and where new, non-mental health identities were nurtured: for example, with creative or vocational projects that had no explicit mental health label. Support for self care offered a 'stepping stone' into mainstream community participation, although making that step could be challenging if not well supported.



### **Self care and the Trust**

Trust staff working in self care support were often highly motivated, expressed high job satisfaction and felt well supported in their teams. They were also at risk of low morale if they felt that their work did not have a high priority in the Trust and that their job security was low.

Professional resistance to a cultural change to delivering services 'with' rather than 'for' service users was in evidence, but was not widespread. The lack of an organisation wide strategic approach, rather than deliberate resistance was most likely to act as a barrier to imbedding cultural change.

The sustainability of some innovative projects was best achieved by bringing them into the Trust as part of mainstream service provision. However, some of the most beneficial features of those projects could be lost through this mainstreaming process: for example, through adopting Trust record keeping or risk management procedures.

### **Self care and partnership working**

Where support for self care was provided outside of mainstream mental health services – for example, in the voluntary sector – there were potential advantages in terms of innovative and flexible ways of working that offered benefits to service users. However, these initiatives could also be vulnerable to loss of funding in a shifting health and social care market.

Support for self care was delivered in an ever changing health and social care, and policy environment. However, many of the qualities of self care described above aligned well with other policy initiatives (e.g. recovery) and social care priorities (e.g. personalisation), providing a strong rationale for Trusts to support those projects.

### **Self care policy implementation**

Communication with the other SDO self care research teams indicated that many features of self care support were common across health service areas, although with condition specific variations in the way that support was provided. However mental health was distinctive in that one of the key facilitators of supporting self care – giving control over use of self care support to service users – was also an important mental health outcome: an increased sense of control. Realising this 'virtuous circle' was not without its challenges for Trusts and for service users.

## ***6.1 Recommendations***

### **Services supporting self care**

- Mental Health Trusts should provide support for service users to become and remain involved in supported self care – including properly informed self referral – while taking care not to create new dependencies on mental health services;

- Mental Health Trusts should 'give up' control over deciding when support for self care - rather than directly provided care - is right for the individual. Service user control applies in both directions: moving from provided care to supported self care, and moving back from supported self care to crisis care;
- Mental Health Trusts should provide support for self care that complements, rather than replaces acute and crisis provision, ensuring that crisis support remains accessible to those who are engaged in self care, including community based activity outside of the Trust;

#### **Self care and risk**

- Mental Health Trusts should embrace and articulate positive, rather than protective risk, at the heart of self care strategy, where necessary making distinctions between acute care and self care in formal risk management policy and procedure;
- Mental Health Trusts should proactively adopt a joint service user-clinician approach to decision making around medication, including developing supported personal strategies for medication reduction as part of self care plans;

#### **Self care and the service user-staff relationship**

- Mental Health Trusts should provide dedicated training (co-facilitated by service users) to staff teams supporting self care in order to equip them to carry out this new role;
- Mental Health Trusts should invest time and resources in ensuring that appropriate contractual arrangements are developed and that service user employees are effectively managed and supported in their role;

#### **Self care and carers**

- Mental Health Trusts should support carers in their changing role, including reaching out, as part of self care strategy, to those parents, partners and family members who do not readily identify as carers;

#### **Self care and the Trust**

- Mental Health Trusts should demonstrate strategic support for self care in order to recruit and retain the best staff in self care support roles;

- Mental Health Trusts should enable self care projects to become agents for change by supporting their leaders, staff teams and service users to champion good practice in supporting self care, for example, by sharing their expertise in the roll out of self care training;

#### **Self care and partnership working**

- Mental Health Trusts should work closely with commissioners, local authorities and voluntary sector partners to ensure that the best projects are sustainably supported;
- Mental Health Trusts should consider carefully which projects are best supported from within the Trust and which will offer a better service if they remain outside of the Trust;
- Mental Health Trusts should work closely with social care and voluntary sector providers to support initiatives across sectors that deliver on self care objectives that complement the key performance indicators found in those parallel strategies. This approach will offer the delivery of self care support some resilience where provision might otherwise become fragmented;

#### **Self care policy implementation**

- Mental health specific guidelines for implementing support for self care should be developed, through collaboration between researchers, policy makers, service providers, service users and their carers.

## ***6.2 Future research***

The research raised, as well as answered questions. Where this was the case we make recommendations for future research:

- The study was indicative of a number of characteristics of supporting self care that might be associated with improvements in a range of outcomes. Formal, controlled intervention studies are necessary to determine the effectiveness of self care interventions such as those studied here. However it is important to note that these are complex interventions, and that detailed process evaluations should complement any randomised controlled trials.

- We noted the development of good 'support for self care' practice alongside (in spite of) the absence of well developed, organisation wide self care strategy. In order to facilitate the wider implementation of self care policy, research is needed to understand the extent to which innovation is driven by policy and its communication downwards through the health service organisation, and/ or bottom up initiatives originating from new service user-practitioner partnerships, innovative teams and charismatic leaders;
- The impact of changing staff roles and staff-service user relationships on the staff team needs further investigation in order that the Trust can provide better training, support and career development for its employees. In particular, the recruitment, training, support and integration of users of the Trust's services as employees on its clinical teams needs to be properly studied to ensure that the challenges for all involved are understood and the benefits realised;
- We noted the vulnerability of funding for self care initiatives. At the same time some interviewees expressed a belief that support for self care was being introduced by their Trusts as a means to save money. Research is needed to explore the cost effectiveness of supporting self care in order to better inform commissioning decisions around provision of self care support.
- Many people using the Mental Health Trust's services also have long term physical health issues. Mental Health service users identified their physical health as an important part of their self care. Research is needed to identify if, when and how support for self care for physical health issues is appropriately provided through the Mental Health Trust, and/ or how health service organisations should work together to provide a comprehensive self care support package;
- There is urgent need to carry out research that focuses on support for self care that specifically targets people from a range of ethnic groups. The potential exists for community driven solutions to improve access and appropriateness of mental health services, but generic support for self care, like

generic mainstream mental health care, is unlikely to engage people from non White ethnic groups by default;

- While many of the qualities of supporting self care identified by this research were core across mental health, the Personality Disorder case study suggested that variations might apply to supporting self care for specific mental health problems. Research should be undertaken to explore how support for self care might be best provided in other specialist settings;
- This project demonstrated how a complex model of service user involvement in research – many members of the team expressed multiple identities as researchers and clinicians, with personal experiences of mental health problems, and as mental health service users and carers – was productive of a rich analysis of data, informing findings that related to the priorities of NHS managers and professionals, service users and carers. Further research is needed of how this ‘mature’ approach to service user involvement in research impacts on the collaborative research process, shapes the findings that emerge and facilitates the mobilisation of research into practice in the health service organisation.

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# Appendix 1 Funding call from the National Institute for Health Research's Service Delivery and Organisation (SDO) Research and Development Programme

## **PROGRAMME OF RESEARCH ON SELF CARE SUPPORT**

### **Introduction**

The SDO Programme is inviting proposals to conduct research on self care support as part of its patient and carer centred services theme. Self care is increasingly perceived as central to developments in health and social care. The recent White Paper *Our Health, Our Care, Our Say* (DoH 2006) stresses the importance of self care and the role of the NHS in supporting it, the public health White Paper *Choosing Health* introduced health trainers and placed a greater emphasis on building skills of people for preventing ill health (DoH 2005a) and the Green Paper on Adult Social Services *Independence, Well-being and Choice* highlights the need to support people with long-term conditions to manage independently (DoH 2005b).

The SDO Programme wishes to commission one study that examines the role of health and social care commissioners in developing self care support in the NHS and social care services and up to five projects on supporting self care.

### **Background**

While there are a number of definitions of self care the Department of Health has defined it as:

"the care taken by individuals towards their own health and well being, and includes the care extended to their children, family, friends and others in neighbourhoods and local communities. Self care includes the actions individuals and carers take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social, emotional and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital". (DoH 2005a)

There is a growing recognition of the need to provide greater support to patients with long term and chronic health conditions and to help them take care of their conditions more effectively. The British household surveys of 2001 and 2002 and the health survey for England 2001 suggest that over 50% of the population have some form of chronic health problem. People with chronic disease are more likely to be users of the health system, accounting for some 80% of all GP consultations and 10% of inpatients account for 55% of in patient days (British household panel survey 2001). Older people are more likely to have multiple chronic problems and be intensive users of health care services and "...15% of under 5s and 20% of

the 5-15 age group are reported to have a long-term condition" (Wilson et al. 2005: 658). In addition, it is also estimated that as much as 40% of general practice consultations and 70% of A&E visits are for minor ailments that could be taken care of by people themselves (DoH 2005a). The benefits of supporting self care have been shown to be improved health outcomes, a better quality of life for those with long-term conditions, increased patient satisfaction and effective use of a huge resource to the NHS patients and the public (DH 2005a).

The Department of Health has been developing a stream of policy related work on self care for some years and self care is identified within a number of National Service Frameworks (eg. Diabetes NSF, Long Term Conditions NSF and the Children's NSF -

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCare>

[Topics/HealthAndSocialCareArticle/fs/en?CONTENT\\_ID=4070951&chk=W3ar/W](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCare/HealthAndSocialCareArticle/fs/en?CONTENT_ID=4070951&chk=W3ar/W)). The Department is keen to see research developed in this area building on existing work particularly relating to how the NHS supports self care (DoH 2004, 2005c, 2005d, 2005e). Initial programmes of work in the NHS include NHS Direct, the Expert Patients Programme, work on long term care and the establishment of the Working in Partnership Projects - the self care skills training for health care professionals project and the self care for people project (<http://www.wipp.nhs.uk/>).

There is widespread public demand for increasing support for self care, though many people already engage in self care (DoH 2004, 2005e). However, inter country comparisons suggest that the UK NHS is poor at providing support for self care and individuals require the confidence and knowledge to successfully embark on self care with different demographic groups, such as older people requiring more support than others (Ellins and Coulter 2005, Coulter 2006). Existing mechanisms for developing support for self care are through education and training and commissioning activities. To date there is little evidence to show that PCTs have utilised the flexibilities offered by primary care contracts to develop greater support for people with long term conditions. (Wilson et al 2005). In a recent survey PCTs did not have strategic approaches to support self care and a major area of work activity tended to be subsumed into a number of work streams with no co-ordination. Following their analysis of USA Managed Care organisations approaches to organising care for people with chronic conditions, Dixon et al. (2004: 225) concluded that "More evidence is needed on the best ways to identify high risk patients and the cost and effects of multifaceted management of high risk patients and disease specific management programmes for lower risk patients."

Research in Canada identified five categories of support: supporting the person, sharing knowledge, facilitating learning and personal development, helping the person build support networks and providing a supportive environment (Health Canada 1997). SDO is interested in supporting research which explores one or more of these areas. There is already a substantial literature on aspects of self care and there are a number of

projects aimed at supporting self care that have been supported by local PCTs and other agencies.

This call for research is part of a developing area of work and the SDO Programme has already commissioned related research including support for carers, access to care, change management and continuity of care. Some of the findings from these projects may be relevant to the current proposed areas of research. A scoping exercise on concordance, adherence and compliance in medicine taking has recently been completed which will also be relevant (Horne et al. 2006). We have also recently commissioned research on the contribution of nurses, midwives and health visitors to chronic disease management. Research commissioned by SDO on governance and incentives in health care organisations in the studying health care organisations programme may also be relevant. Information on these studies and copies of documents can be downloaded from the SDO Programme website  
<http://www.sdo.lshtm.ac.uk/commissionedprojects.htm>.

### **SDO current call for proposals**

The SDO Programme now wishes to commission a series of empirical studies to increase knowledge about the ways in which the NHS can support self care.

#### 1. The role of commissioning in self care – SC177 (up to two projects)

We wish to commission up to two studies that examine the role of health and social care commissioners in relation to self care. Recent changes to the GMS contract and Quality and Outcomes Framework provide financial incentives for primary care to support initiatives such as self care support interventions to reduce demand in primary care and the Department of Health is in further discussions with the BMA on focusing QOF more on supporting self care. In addition, the introduction of Practice Based Commissioning is seen by the government as a key tool in developing NHS approaches to supporting self care. To date, however, there is no evidence to demonstrate how commissioners are addressing self care nor how existing commissioners, the PCTs, are taking a whole systems approach to developing self care support Wilson et al (2005, DoH 2005d). Supporting self care also requires working with social care commissioners as services will need to be developed across the health and social care spectrum. There is, therefore, a need to examine the way in which health and social care commissioners can develop strategic commissioning approaches to self care that change professional practice and lead to increased support for self care, and improved outcomes for patients, users and carers.

Key questions are therefore:

- What are the roles of different health and social care commissioners?
- What are appropriate structures and mechanisms for supporting joint commissioning between health and social care agencies?

- How effective are the different contractual mechanisms (QOF, DES/MES, PMS etc) in incentivising health and social care agencies and professionals to develop strategies for supporting self care?
- What evidence is there to demonstrate the benefits of such commissioning mechanisms in terms of improved health outcomes, improved quality of life and increased satisfaction.?
- What are the costs and benefits for commissioners of increasing self care?

Up to two research projects may be commissioned on this topic. It is anticipated that the research will take between 2 and 3 years. Value for money will be a key consideration in commissioning the research.

## 2. Supporting self care – SC180 (up to five projects)

Two recent Department of Health reports (2004, 2005c) have highlighted the usefulness of support networks, education and skills training for enhancing self care among people (Wilson et al. 2005). In addition the National Primary Care Research and Development Centre has conducted a review of the Expert Patients Programme (Kennedy et al. 2005a, 2005b) and the Leeds Metropolitan University is currently evaluating the Working in Partnership self care projects in a number of Primary Care Trusts.

To build on this work SDO is considering funding up to five research studies of varying sizes that demonstrate how health and social care professionals can support people with long term conditions and chronic health problems. The SDO programme does not want to be prescriptive at this stage, given the range of possible approaches to supporting self care which might be examined. However, the programme is particularly interested in commissioning research on supporting self care which clearly relate to NHS and social care priorities and implementation of government policy and National Service Frameworks.

Applicants are free to propose any area of research relevant to this topic. However, research teams will need to demonstrate how their findings will have wide relevance to different groups of people and priority will be given to studies that address generic issues even though any particular research may be conducted with certain specific patient groups. Proposals should also be jointly made between researchers and service providers and/or users.

Key questions to be considered in proposed research projects may include some of the following:

- In what ways are health and social care professionals supporting self care locally in practice?
- What strategies are in place and how well are they functioning?
- What service delivery models are being utilised and how successful are these?
- How are the various self care support facilities integrated in the locality?

- What are the main barriers and facilitators for supporting successful self care initiatives?
- What are the main barriers to changing professional practice in this area?
- In what ways could health and social care professionals support patient self care better?
- What are the implications for patients and carers, health and social care professionals and the organisations they work in for changes in health care practice and increased patient self care?
- What is the evidence of benefits for patients and carers in terms of improved health outcomes, improved quality of life and increased satisfaction?

Up to five research projects could be commissioned on this topic varying between one and three years in length. Research teams need to demonstrate that proposed projects provide value for money and are achievable within their proposed budget and timescale.

### **Methods**

Applicants for each study specified above should provide a clear conceptual and theoretical grounding for the research.

Applicants should demonstrate that they have a research team in place with the appropriate range of research skills.

Indication should be provided about how they will work with the SDO Programme and relevant stakeholders to build in an active programme for disseminating their research findings in policy, practice and research contexts. The involvement of patients and carers in this area of research is of particular relevance and research teams will need to demonstrate how this will be achieved. Research that demonstrates how health inequalities are being addressed would be particularly welcome.

### **Outputs**

The principal output of each research project should be a detailed report. The report will need to include:

- A short and coherent executive summary of no more than three pages;
- A full account of the methods used in the research project, including a critical appraisal of these methods;
- Rigorous and detailed conclusions;
- A commentary that indicates how these findings relate to current policy and practice concerning self care, and the key lessons to be learned;

And where appropriate,

- An agenda that establishes the key areas for further research and the appropriate methods that should be used in this research.



Successful applicants may be required to present their completed work to the SDO Programme Board and to participate actively in SDO events related to the networks theme.

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## Appendix 2 Local self care mapping questionnaire

### SELF CARE ORGANISATIONAL CONTEXT QUESTIONNAIRE

#### STRATEGY AND PLANNING

Does the trust currently have a self care strategy in place?

Yes / No

If yes, please give details:

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Is the Trust currently developing a self care strategy?

Yes / No

If yes, please give details

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Does the Trust have other strategies in place that incorporate self care (or its related concepts, e.g. self management, self help, recovery, social inclusion, skills training etc)?

Yes / No

If yes, please give details:

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Are other strategies being developed within the Trust which incorporate self care (or its related concepts)?

Yes / No

If yes, please give details:

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Which of the Trust's following plans include self care?

5 year strategy Yes / No

Business plan Yes / No

Local Development Plan Yes / No

Other (please specify) Yes / No

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#### LEADERSHIP AND HIERARCHY

Does the Trust have a self care lead? (Or respective title)

Yes / No

Job title:

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Brief description of role:

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Is there anyone within the Trust whose role includes leadership of self care strategy or activity?

Job title:

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Brief description of role:

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Is self care on the agenda of any steering group or committee within the Trust?

Yes / No

If yes, please give details:

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**SELF CARE ACTIVITY**

Does the Trust currently have any of the following self care support projects/ initiatives in place?

Patient education/ self care skills training (e.g. Expert Patients Programme)	Yes / No
Health and social care information	Yes / No
Care planning approaches	Yes / No
Self diagnostic tools/ self monitoring devices	Yes / No
Peer support networks	Yes / No
Home adaptations	Yes / No
Community pharmacy scheme	Yes / No

Brief description of initiatives:

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Please list any that are currently being developed or planned:

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Are there any other self care projects/ initiatives in place that are Trust – initiated?

Yes / No

If yes, please give details:

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Does the Trust currently operate other self care projects or initiatives that are delivered in partnership with other organisations?

Yes / No

If yes, please give details:

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Does the Trust have other projects or initiatives in place that include self care in some way or its related concepts?

Yes / No

If yes, please give details and state whether these are Trust-initiated or partnership based:

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**SELF CARE TRAINING**

Does the Trust provide training for staff in supporting patients/service users with self care?

Yes / No

If yes, please give details:

Course name	Length	Content	Delivered by	Participating staff
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Does the Trust provide any other training that includes self care in some way or its related concepts?

Yes / No

If yes, please give details:

Course name	Length	Content	Delivered by	Participating staff

**RISK ASSESSMENT**

Does the trust risk assessment policy include self care in some way?

Yes / No

If yes, please give details:

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Does the Trust provide risk assessment training that includes self care?

Yes / No

If yes, please give details:

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Who participates in this training?

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Who delivers it?

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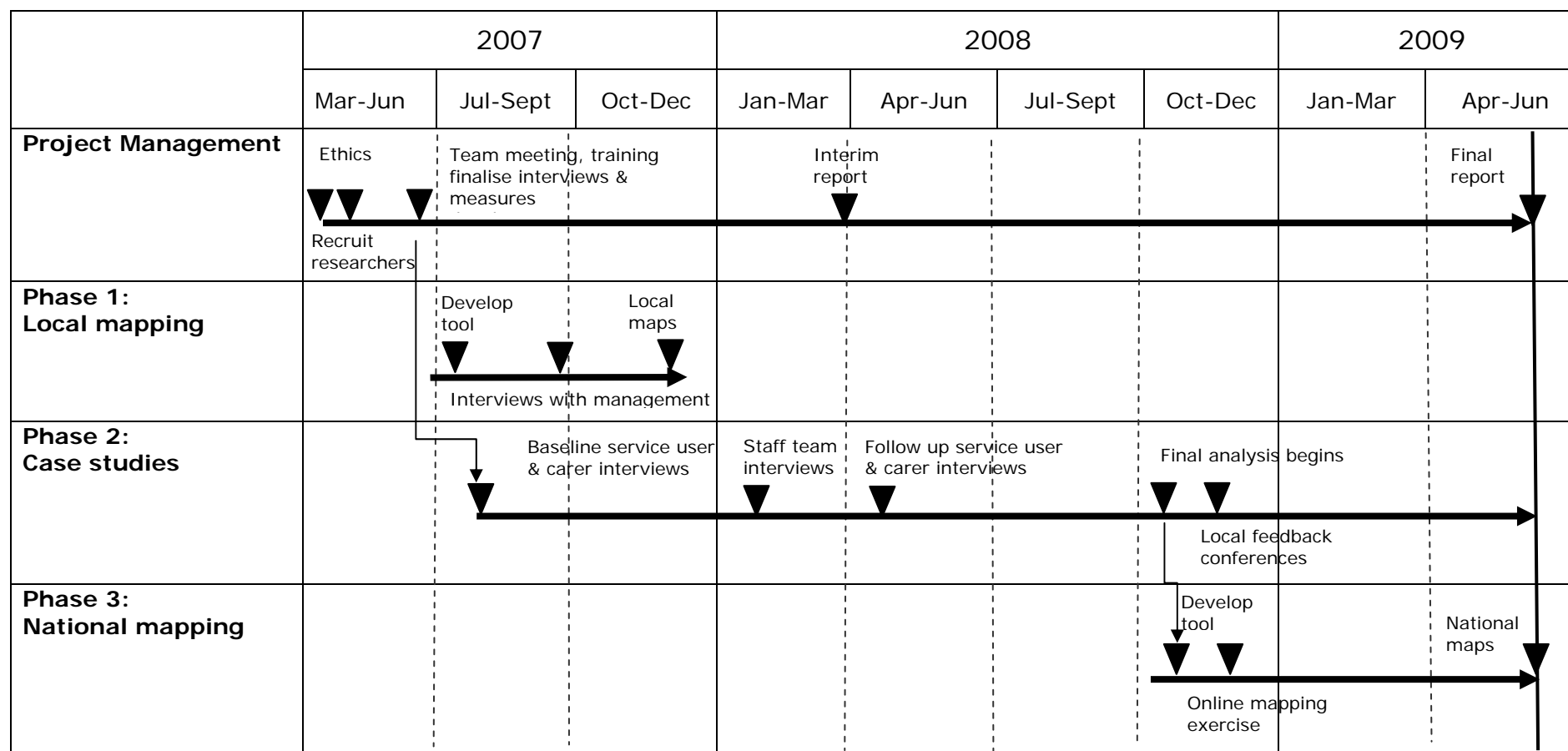
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END OF QUESTIONNAIRE

## Appendix 3 A timeline for the study, indicating how the case studies fit with both the local and national mapping exercises



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## Appendix 4 Client Socio-demographic and Service Receipt Inventory (CSSRI) - adapted version

### ***CLIENT SOCIODEMOGRAPHIC AND SERVICE RECEIPT INVENTORY: SELF CARE STUDY***

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#### ***1. SOCIODEMOGRAPHIC INFORMATION***

- 1.1 Date of birth                                    /       /
- 1.2 Sex
- 1- Female  
2 - Male
- 1.3 Marital status (*From a legal perspective*)
- 1 – Single/unmarried  
2 – Married/Civil Partnership  
3 – Living with partner  
4 – Separated  
5 – Divorced  
6 – Widow/widower  
9 - Not known
- 1.4 Number of dependent children
- 1.5 Ethnic group (*Refer to guidelines*)
- 1.6 Highest completed level of education
- 1 – Up to 16 years  
2 – GCSE/O-level  
3 – A-level/BTec/Highers  
4 – Degree  
5 – Postgraduate degree  
6 – Other \_\_\_\_\_  
9 – Not known

## 2. USUAL LIVING SITUATION

2.1 What is your usual/normal living situation now?

- 1 – Living alone (+/- children)
- 2 – Living with partner (+/- children)
- 3 – Living with parents
- 4 – Living with other relatives
- 5 – Living with others
- 9 – Not known

2.2 What kind of accommodation is it? (*Refer to guidelines*)

2.3 Have you lived anywhere else in the last 9 months? Yes / No / DK

**If yes:**

<i>Accommodation name</i>	<i>Accommodation type (Refer to guidelines)</i>	<i>Number of days in the last 9 months</i>

## 3. EMPLOYMENT

3.1 What is your current employment status?

- 1 – Employed full-time
- 2 – Employed part-time
- 3 – Employed on a supported scheme/permitted work
- 4 – Self-employed
- 5 – Student
- 6 – Retired
- 7 – Unemployed
- 8 – Other (please specify) \_\_\_\_\_

3.2 Do you receive any of the following benefits:

- |                             |               |
|-----------------------------|---------------|
| Jobseeker's Allowance       | Yes / No / DK |
| Income Support              | Yes / No / DK |
| Incapacity Benefit          | Yes / No / DK |
| Disability Living Allowance | Yes / No / DK |

Other (please specify) Yes / No / DK

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3.3 What is your current or most recent job? \_\_\_\_\_

Industry classification (*Refer to guidelines*)

3.4 Has your employment status changed in the last 9 months? Yes / No / DK  
If yes, please describe the changes that have taken place in the box below

3.5 How many days (if any) have you had to take off from working (including voluntary work) or studying in the last 9 months as a consequence of mental health problems?

#### **4. SERVICE RECEIPT**

4.1 How many times have you been admitted as a psychiatric hospital inpatient over the course of your life?

- 1 – Never
- 2 – 1-2 times
- 3 – 3-5 times
- 4 – 6-10 times
- 5 – 11+ times
- 9 – Unknown

4.2 How many years has it been since your first contact with mental health services?  
years

4.3 Do you receive support from a Mental Health Team? Yes / No / DK

**If yes:**

What type of Mental Health Team is it?

- 1 – Community Mental Health Team
- 2 – Assertive Outreach
- 3 – Early Intervention
- 4 – Other
- 9 – Unknown

Do you have a CPA? (Care Programme Approach) Yes / No / DK

Is it an Enhanced CPA? Yes / No / DK

4.4 In the last 9 months, what face-to-face contact have you had with these professionals for reasons relating to your mental health?

(*Note: only record one-to-one contacts here; see next questions for group activities, inpatient care and outpatient appointments*)

<i>Care provider</i>	Have you had contact?	<i>NHS/ Voluntary/ Private</i> 1 = NHS 2 = Voluntary 3 = Private	Usual location 1 = GP 2 = Community centre 3 = Hospital OPD 4 = Own home 5 = Other	No. of contacts in last 9 months	Average duration per contact (minutes)
A. General practitioner (GP)	Yes / No				
B. Psychiatrist	Yes / No				
C. Other doctor (mental health related)	Yes / No				
D. Psychologist	Yes / No				
E. Drug & alcohol advisor	Yes / No				
F. Other counsellor / therapist	Yes / No				
G. Social worker	Yes / No				
H. Community Psychiatric nurse	Yes / No				
I. Occupational Therapist	Yes / No				
J. Support worker	Yes / No				
K. Other (please specify) _____	Yes / No				

4.5 In the last 9 months, have you used any mental health day care services *over and above* the contacts identified above (e.g. group activities, attending a drop-in centre etc.)?

Yes / No / DK

**If yes:**

<i>Care provider</i>	Yes/ No	<i>NHS/ voluntary/ private</i> 1 = NHS 2 = Voluntary 3 = Private	Name of centre or facility	No. of attendances in last 9 months	Average duration of each contact (minutes)
A. Drug / alcohol service	Yes /				

	No				
B. Day care / day hospital	Yes / No				
C. Drop-in centre (incl. street agencies)	Yes / No				
D. Self help / support group (Excluding self care intervention under study)	Yes / No				
E. Education/training (as part of mental health support)	Yes / No				
F. Sheltered workshop	Yes / No				
G. Other day care activity provided by team (specify)	Yes / No				

4.6 In the last 9 months, have you been admitted as a psychiatric inpatient?  
(*Note: please include any secure hospital stays; includes current admission if applicable*)

Yes / No / DK

**If yes:**

<i>Admission</i>	<i>Hospital/facility name, and name of ward (or speciality)</i>	<i>Planned/ unplanned admission (1 = Planned, 2 = Unplanned)</i>	<i>Detained under MH Act?*</i>	<i>Total days</i>
1 <sup>st</sup> admission			Yes / No	
2 <sup>nd</sup> admission			Yes / No	
3 <sup>rd</sup> admission			Yes / No	
4 <sup>th</sup> admission			Yes / No	

\* Detained under Section 2, 3, 5/2 or 37 of the Mental Health Act

4.7 In the last 9 months, have you received any **unplanned** psychiatric outpatient services?

Yes / No / DK

**If yes:**

	<i>Number of attendances / days</i>
Psychiatric outpatient visit	

A&E for psychiatric emergency	
Crisis resolution/home treatment team	

4.8 In the last 9 months, have you received help from **friends, relatives or another care provider** on any of the following tasks, as a consequence of your mental health?

<i>Type of help</i>	<i>Circle</i>	<i>Funded or unfunded</i> <i>(1 = funded, 2 = unfunded)</i>	<i>Average number of hours help per week</i>
Child Care <i>(circle 'No' if you have no children)</i>	Yes / No		
Personal care <i>(e.g. washing, dressing etc.)</i>	Yes / No		
Help in/ around the house <i>(e.g., cooking, cleaning etc.)</i>	Yes / No		
Help outside the home <i>(e.g., shopping, transport etc.)</i>	Yes / No		
<i>Other _____</i>	Yes / No		

4.9 Please list below any medication prescribed for psychiatric symptoms over the last 9 months. This includes any medication which is prescribed for side effects caused by other medication, or for any mental health related issues.

<i>Name of drug</i>	<i>Depot</i>	<i>Type of drug(code)</i> <i>(Refer to guidelines)</i>	<i>For how long have you taken this drug?</i> <i>(months)</i>
1.	Yes / No		
2.	Yes / No		
3.	Yes / No		
4.	Yes / No		
5.	Yes / No		
6.	Yes / No		
7.	Yes / No		

4.10 Do you take this medication as prescribed?

- 1 – Yes
- 2 – Partially
- 3 – No



- 4.11 Do you drink excessively or have problems controlling your drinking?  
0 – No problem with controlled drinking  
1 – At risk from alcohol misuse or currently receiving help  
2 – Current drinking harmful or uncontrollable
- 4.12 Do you have problems with drug use?  
0 – No dependency or misuse of drugs  
1 – Receiving help for dependency or misuse of prescribed, non-prescribed or illegal drugs  
2 – Current use of prescribed, non-prescribed or illegal drugs, harmful or uncontrollable
- 4.13 How long has it been since you were first given a mental health diagnosis? \_\_\_\_\_ years
- 4.14 What is your current primary mental health diagnosis? \_\_\_\_\_  
(*Note: Record here interviewee's self-reported diagnosis*)

- 1 - Personality disorder (if so what type: \_\_\_\_\_ )  
2 – Schizophrenia/schizoaffective disorder  
3 – Bipolar disorder  
4 – Major anxiety/depressive disorder  
5 – Other  
9 – Unknown

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## Appendix 5 Service user baseline schedule

### Preamble to qualitative interview:

- *Thank you for agreeing to meet with me today and take part in this study.*
- *The first part of this interview is intended to be a conversation about your views on self care, and it will involve me asking you some questions*
- *There are no right or wrong answers to the questions; we are interested in your views.*
- *If there are any questions that you don't want to answer you do not have to and you do not have to give a reason as to why not.*
- *If you would like to stop the interview then you can do at any time and to do not have to give a reason for stopping.*
- *The discussion will be divided up into three sections.*
  - *In the first part, we will talk about your expectations of the project you are about to start.*
  - *In the second part we will focus on your own understanding and personal experiences of self care.*
  - *In the third part of the interview we will explore your previous experience of being supported in self care by mental health services.*
- *Finally, if you would like to have a break at any point during the interview then please let me know.*

### Expectations of self care support from mental health trusts

The reason you've been asked to take part in this interview is because you've been referred to the ..... project and we are interested to know both your expectations and your experience of it.

1. How did you come to be involved in the project?

**Is this part of a care plan?**

**Yes / No / DK**

What part do you feel you played in becoming involved?

Since you agreed to do this, has anything else changed in your care?

2. What are you hoping to get out of the project?

Which part(s) of the project are you most looking forward to?

Which part(s) are you least looking forward to?

What do you think will be the benefits of you taking part in this project?

When the project finishes, how do you think you will use the experience of it in the future?

3. Is there anything about the project that makes you anxious, nervous or worried?

*If yes: what is it and why?*

Is that a positive or a negative thing?

4. What role do you think the staff will play in supporting you to improve your own mental wellbeing in this project?

How is this different from what they usually do to support you with your mental health needs?

### Self care understandings

5. The ..... project could be described as a project that supports people with self care. What does the idea of self care mean to you?

*If the interviewee finds this difficult to answer:*

- Some people say that self care is the care that people take to look after their own health and well-being
- It could include those things that people do to maintain their mental and physical health
- Or the things people do to make sure their needs are met and work towards recovery

*If interviewee does not talk about self care in relation to mental health:*

- What do you understand of self care in relation to mental health?

6. What sort of things do you do in terms your self care?

How is that related to your mental health?

7. **a. Is there anyone close to you that supports you in caring for your own mental health?**

**Yes / No / DK**

Can you tell me about the support they give you?

- b. Do you have a wider circle of people you know who support you in caring for your mental health?**

**Yes / No / DK**

Can you tell me about the support they give you?

8. **Do you go/have you been to any other organisations or places that support you with self care for your mental health needs?**

**Yes / No / DK**

*If yes: can you tell me more about that?*

How does/did that support your self care?

**9. Do you think that mental health services should support people with self care generally?**

**Yes / No / DK**

*If yes:*

Why should they?

How should they?

*If interviewee finds this difficult to answer:*

How do you think mental health services could support you with self care?

*If no:*

Why shouldn't they?

Who should?

**10. Is there anything that you think would make it difficult for mental health trusts to support people to get involved in self care?**

Is there anything that would make it easier for them to do this?

Previous experiences of self care support from mental health trusts

**11. Have you ever received support for self care in the past by mental health services?**

**Yes / No / DK**

For example, with a similar project?

What did that involve?

How long were you involved for?

**12. Did you find it helpful?**

Do you think it had any impact on your life or your mental health?

Did anything change?

What did you like about this project?

What didn't you like about it?

Is there anything about it that could have been improved?

13. Were any other organisations involved?

For example, voluntary organisations

14. Are your expectations of the ..... project, are influenced in any way by any previous experience of self care?

If yes then how are they?

That is the end of my questions for this part of the interview.

- How do you think the interview went?
- What did the interview feel like to you?
- Was it what you expected?
- Is there anything that you hoped that we would ask but didn't?
- Was there anything that came up in the interview that you would like some support around from a member of staff?
- Is there anything else you would like to say?

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## Appendix 6 Service user follow up schedule

### **Preamble:**

Thank you for agreeing to meet up with me again for this research study. The last time we met we talked about your understandings, experiences and expectations of self care. This time I am interested to hear about your experiences with the WRAP project. It is intended to be a conversation about your experience of and views towards this project. There are no right or wrong answers to the questions; we are interested in your views. If you do not want to answer any of the questions you do not have to nor give me a reason as to why not. Also if you would like to have a break at any point of the conversation please let me know.

### **Self care experience**

**1. Please describe to me what it has been like taking part in the ..... project?**

***Questions specific to the individual project to be inserted here***

### **2. Broader questions to use if these ideas have not emerged already**

What did you like about the project?

What didn't you like about the project?

Were there any aspects of the project that were:

- particularly useful
- not very useful?

Is there anything that could have been differently? If 'yes' what and why?

What might have been done differently that might have helped you more?

What were the benefits for you of attending the project?

Were there any difficulties that arose as a result of attending the project?

What did you take from the project?

How have you used what you learnt or gained from the project?

### **3. Other questions about the self care project**

How would you compare your experience with this self care project to your previous experience or your previous contact with services (if any)?

What do you think are the main differences between the projects that made one approach more successful than the other?

Have your views of self care changed since attending the project? Why have they changed or not changed?

### **Experience of change**

Can you describe any changes or life events you have experienced over the course of the last nine months in each of the following areas?

- experience of symptoms;
- the way that you look after yourself ;
- the way in which you tackle problems;
- the way you think about yourself and your problems?
- your daily routine?
- Your relationships with others (family, friends, partner etc)?

For each of these areas please tell us:

1. How did you notice these changes?
2. How did you record these changes?
3. Did you feed them back to the project workers or your key worker?
4. Do you think these changes are because of taking part in the project or because of other events in your life?
5. Which of the changes in your life do you think are related to the project?
6. How do you think the project helped you through these changes?
7. Why do you think these changes have come about?

**Experience of other care**

1. Has the role of support workers (for example, your key worker)/care coordinator – not WRAP staff) changed during your time with the (*name of*) project? If it has, please tell us how that relationship has changed.
2. How do you now interact/engage with the service or organisation? How would you describe your relationship with the service or organisation?
3. Has the role of your main carer changed during your time with the (*name of*) project? If it has, please tell us how that relationship has changed.
4. Do you plan to stay with this project or get involved in any other projects in the future?



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## Appendix 7 Carer interview schedules

### Carer baseline interview

#### Introductions

Explain the study, check that the participant has read and understood at least part 1 of the information sheet

If happy to proceed, complete consent forms (2 copies)

Turn on digital recorder

Begin the qualitative interview

#### Preamble to qualitative interview:

- *Thank you for agreeing to meet with me today and take part in this study.*
- *The first part of this interview is intended to be a conversation about your views on self care, and it will involve me asking you some questions*
- *There are no right or wrong answers to the questions; we are interested in your views.*
- *If there are any questions that you don't want to answer you do not have to and you do not have to give a reason as to why not.*
- *If you would like to stop the interview then you can do at any time and to do not have to give a reason for stopping.*
- *The discussion will be divided up into three sections.*
  - *In the first part, we will talk about your expectations of the project your friend/relative/partner is about to start.*
  - *In the second part we will focus on your own understanding and experiences of self care from a carer perspective*
  - *In the third part of the interview we will explore your previous experience of caring for someone who is being supported in self care by mental health services.*
- *Finally, if you would like to have a break at any point during the interview then please let me know.*

#### Expectations of self care support from mental health trusts

The reason you've been asked to take part in this interview is because your friend/relative/partner has been referred to the ..... project and we are interested to know your expectations of it and what it might mean for you as a carer.

15. How did your friend/relative come to be involved in the project?

What part do you feel you played in you're friend/relative/partner becoming involved?

**Did anyone from the trust talk to you about your friend/relative/partner getting involved in the project?**

Yes / No /  
DK

**Have you had a formal carer's assessment?**

Yes / No / DK

***If yes: does this include self care in some way?***

Yes / No / DK

If so, how does it?

Since your friend/relative/partner agreed to do this, has anything changed in your role as a carer?

*If yes: How has it?*

16. What are you hoping to get out of the project as a carer?

What do you think will be the benefits might be for you?

What is it about the project that you are most looking forward to and why?

What is it about the project that you are least looking forward to and why?

When the project finishes, how do you think you will use the experience of the project in the future as a carer?

17. Is there anything about the project that makes you anxious, nervous or worried?

*If yes: what is it and why?*

Is that a positive or a negative thing?

18. What role do you think the staff will play in supporting your friend/relative/partner to improve their own mental wellbeing in this project?

How is this different from what they usually do to support your friend/relative/partner with their mental health needs?

Self care understandings

19. The ..... project could be described as a project that supports people with self care. What does the idea of self care mean to you?

*If the interviewee finds this difficult to answer:*

- Some people say that self care is the care that people take to look after their own health and well-being
- It could include those things that people do to maintain their mental and physical health
- Or the things people do to make sure their needs are met and work towards recovery

*If interviewee does not talk about self care in relation to mental health:*

What do you understand of self care in relation to mental health?

20. Is there anything that you do to support your friend/relative/partner to self care?

How is that related to their mental health?

**21. Do you receive *any* support to help your friend/relative/partner with their self care?**

**Yes / No / DK**

*If yes:* can you tell me more about that?

How does that affect your role as a carer?

*If no:* What support do you think you need?

**22. Do you think that mental health services should support people with self care generally?**

**Yes / No / DK**

*If yes:*

Why should they?

How should they?

*If interviewee finds this difficult to answer:*

How do you think mental health services could support your friend/relative/partner with self care?

*If no:*

Why shouldn't they?

Who should?

23. Is there anything that you think makes it difficult for mental health trusts to support people to get involved in self care?

Is there anything that makes it easier for them to do this?

Previous experiences

**24. Has your friend/relative/partner ever received support with self care in the past by mental health services?**

**Yes / No / DK**

For example, with a similar project?

What did that involve?

In what way were you involved?

How long were you involved for?

25. Did you find it helpful as a carer?

Do you think it had any impact on your friend/relative/partner's life or mental health?

Did anything change?

Do you think this affected your role as carer? How?

What did you like about this project?

What didn't you like about it?

26. Are your expectations of the ..... project influenced in any way by previous experience of being a carer for someone participating in a self care project?

If yes then how are they?

That is the end of my questions for this part of the interview.

- How do you think the interview went?
- How did it make you feel?
- Was it what you expected?
- Is there anything that you hoped that we would ask but didn't?
- Is there anything else you would like to say?

### **Carer follow up interview**

Introductions

Revisit purpose of the study, check that the participant understands and remind about consent form.

If happy to proceed, turn on digital recorder

Begin the qualitative interview

Preamble to qualitative interview:

- *Thank you for agreeing to meet up with me again for this research study.*
- *The last time we met we talked about your understandings, experiences and expectations of your relative/friend taking part in self care. This time I am interested to hear about what has happened since your relative/friend began taking part in the .....project.*
- *This is intended to be a conversation about both your experience of and your views towards this project.*
- *There are no right or wrong answers to the questions; we are simply interested in your views.*
- *If there are any questions that you don't want to answer you do not have to and you do not have to give a reason as to why not.*
- *If you would like to stop the interview then you can do at any time and do not have to give a reason for stopping.*
- *Also if you would like to have a break at any point of the conversation please let me know.*

### **Experience of the self care project**

1. Please describe, from your perspective, what it has been like for your friend/relative/partner to take part in the ..... project?

*Specific questions about the particular components of each case study to be developed at each site – will need more prompts e.g.*

- *What activities did they do?*
- *What did they enjoy doing/ least enjoy doing?*
- *What were the benefits of them taking part?*

2. What has been your experience as a carer since your friend/relative/partner took part in the self care project?

3. Did you have any interaction or communication with the project staff?

4. Were you given any information or support?

### **Experience of change**

5. Have you noticed any changes in your friend/relative/partner?

If yes, what changes have you noticed?

*If the interviewee finds this difficult to answer:*

*For example:*

- This might be in your relative/friends experience of symptoms;*
- In the way that your relative/friends cares for themselves;*
- Their relationships with others (friends, family, partner, professionals);*
- With their medication or other treatments*
- Their engagement with activities*
- The way in which they tackle problems*

- How did you notice these changes?

7. Apart from taking part in the ..... project what other things have happened to your friend/relative/partner over the last nine months?

*For example:*

- *Other changes in care,*
- *other life events (positive or negative)*
- *a new relationship or loss of a relationship, moving house, new job*

- How would you describe these changes?

8. Why do you think these changes have come about?

- Do you think the changes are because you relative/friend has taken part in the self care project or because of other events in their life?

9. How does this self care project compare to previous help they've received from services?

- What do you think were the main differences?

### **Experience of support/care**

10. Has your role as a supporter/carer changed during the last nine months?

*If yes,*

- How has your role changed?
- Do you think any of this change is because your friend/relative/partner has taken part in the self care project?

11. Has your understanding of self care changed?

That is the end of my questions for this part of the interview.

- How do you think the interview went?
- How did it make you feel?
- Was it what you expected?
- Is there anything that you hoped that we would ask but didn't?
- Is there anything else you would like to say?

---

## Appendix 8 Staff interview schedule

### Understanding self care in mental health trusts

Self care project staff/  
Staff dealing directly with service users

#### **Personal details**

Age

Gender

Ethnicity

Professional background/training

Summary of post-qualification training

What is your current job (title and short description)?

Do you work as part of a team? If yes, probe about size and make-up of the team.

#### **Understandings of self care (in general)**

*What about the ordering of the sections of the interview? Should this be the first section or should we start with the experience with the self care study?*

1. What does the idea of self care mean to you?
  
2. What would you say are the advantages of self care for
  - a) service users?
  - b) staff?
  - c) the service?

And the disadvantages or risks (for each of the groups)?

3. Do you think there is agreement on what self care entails among team members, managers, and/or other stakeholders?
  
4. How similar or different is self care to other ideas such as
  - a) self management?



- b) self help?
  - c) recovery?
5. To what extent do you think you support self care in your work with service users?

**Experience with the self care project**

4. Can you tell me about your involvement in the ..... project and how this came about?

Probes:

Voluntary or decision made by manager/other? If the decision was made by others, to what extent were you consulted about the introduction of the ..... project?

Length of time involved?

Main/sole responsibility or part of job?

Previous experience of self care work?

Can you describe what you do in the ..... project?

*Specific questions about the individual projects for each case study to be added in here?*

What specifically is your role?

How do you implement it in your service?

5. Have you undertaken any training or development specifically designed to support the introduction of the ..... project?

Probes:

External Conferences, short courses etc

Formal Training

Team meetings

Coaching/ mentoring

Supervision

In what ways has this training helped with the introduction of the ..... project?  
What has worked for you? What has not?

6. To what extent have you (or your team) been free to decide on how to implement the ..... project?

Probes:

Have standard procedures and practices been laid down?

If appropriate, has it involved changes in the way the team is organised?

What kind of support/guidance/supervision have you had in implementing these changes from

- a) your line manager?
- b) managers or staff from other departments, e.g. the project, human resources, training and development?
- c) any external agencies?
- d) any professional bodies to which you belong?

7. In what ways, if any, has your involvement with the ..... project changed your relationships with service users?

Probes:

Are service users more or less involved in deciding on aspects of their care?

Has it changed the extent to which you give advice to service users?

Do you find you are more or less able to develop a therapeutic relationship with service users?

Has it changed the length of time in which you maintain involvement with service users?

Do you respond any differently when there are risk issues for service users?

8. To what extent does working with the ..... project require change in the attitudes and values of professional groups working with patients and service users?

Probes:

In what way has your professional and other training supported your involvement in the ..... project?

In what ways has your professional and other training hindered your involvement in the ..... project?

9. What impact has being involved in the ..... project had on your work experience?

Probes:

Job satisfaction

Workload

Stress

Confidence

Professional status

Commitment to organisation

What impact has being involved in the ..... project had on your relationships with

- a) your team and colleagues?
- b) managers
- c) external agencies?
- d) user bodies?

Has it brought about changes in your role/way you do your job?

Probe differences in objectives, systems, procedures, cultures and values etc  
If part of role/job, how does it fit with the rest of your role?

Do you feel your involvement in the ..... project has any implications for your career development and progression?

10. What do you think has been the impact on the quality of care for service users?

Has the ..... project altered the definition of what constitutes good quality care?

11. What would you say are the advantages of the ..... project for

- d) service users
- e) staff
- f) the service

And the disadvantages or risks?

Did you undertake a systematic risk analysis before embarking on the project?

Probes:

How did you do it?

What measures did you take to deal with the findings (or the risks mentioned above, if they have not undertaken a systematic evaluation)

What have been the main barriers to the introduction of the ..... project?

How have you overcome them, what has helped facilitate it? Are there any issues that remain unresolved?

12. How do you see the future of the ..... project?

---

## Appendix 9 Referring staff interview schedule

### Understanding self care in mental health trusts

Staff referring service users to the self care projects

#### Personal details

Age

Gender

Ethnicity

Professional background/training

Summary of post-qualification training

What is your current job (title and short description)?

Do you work as part of a team? If yes, probe about size and make-up of the team.

#### Understandings of self care (in general)

*What about the ordering of the sections of the interview? Should this be the first section or should we start with the experience with the self care study?*

1. What does the idea of self care mean to you?
  
2. What would you say are the advantages of self care for
  - g) service users?
  - h) staff?
  - i) the service?

And the disadvantages or risks (for each of the groups)?

3. Do you think there is agreement on what self care entails among team members, managers, and/or other stakeholders?
  
4. How similar or different is self care to other ideas such as
  - a) self management?
  - b) self help?

- c) recovery?
5. To what extent do you think you support self care in your work with service users?

**Understanding of the self care project.**

6. What do you understand is the purpose of the ..... project?

Probes:

How well do you understand the .....project?

To what extent do you see it as a project that supports self care?

How well is the ..... project known about and advertised?

7. What is the process for service users to become involved with the ..... project?

Probes:

Is the ..... project open to all those who use your service? If not, how are service users selected to take part in the ..... project?

What role do you play in the referral process?

Are there clear referral guidelines for the project? If so, what are these?

What sort of service user would you refer to the .....project and why?

7. In what ways, if any, has the services' involvement with the ..... project changed your relationships with service users?

Probes:

Are service users more or less involved in deciding on aspects of their care?

Has it changed the extent to which you give advice to service users?

Do you find you are more or less able to develop a therapeutic relationship with service users?

Has it changed the length of time in which you maintain involvement with service users?

Do you respond any differently when there are risk issues for service users?

8. To what extent does working with the ..... project require change in the attitudes and values of professional groups working with patients and service users?

Probes:

In what way has your professional and other training supported your involvement in the ..... project?

In what ways has your professional and other training hindered your involvement in the ..... project?

9. What do you think has been the impact on the quality of care by the introduction of the ..... project for service users?

Has the ..... project altered the definition of what constitutes good quality care?

10. What would you say are the advantages of the ..... project for

- a) service users
- b) staff
- c) the service

and the disadvantages of the ..... project for

- a) service users
- b) staff
- c) the service

11. How do you see the future of the ..... project in your service?

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## Appendix 10 Organisational interview schedule

### CEO and Senior Managers interview schedule

#### **Information on respondent**

Age

Gender

Ethnicity

Professional background/training

Summary of post-qualification training

What is your current job (title and short description)?

Department

#### **Understanding of the concept of self care**

What do you understand by the term self care?

How is it different/ similar to other strategies such as self management, recovery, etc?

Does self care mean reducing direct contact with patient? Or does it enhance what the professional does?

Is an essential element training patients and promoting their skills to self manage? Or are set of instructions sufficient?

Does it mean a change in who has the final say in choice of treatments?

Does it mean shift in responsibility?

Range of dimensions - empowerment; control; choice;

Ask for examples from practice

#### **Information on Strategy and Context**

Can you describe the history of introduction of the [self care] project?

Have you had previous experience of introducing a similar initiative? If yes, please describe.

What was the rationale for introducing it in the first place - was it part of an overall strategy or an opportunistic response to a government of other initiative? Or was it was internal initiative i.e. a bottom up? If so, who proposed it (role dept etc)

**What are your main priorities over the next year/five years for your area of responsibility?**

E.g. Foundation status; will this involve a shift in resources – towards or away from self care?

Does the [self care] project fit into this strategy, if yes how?

How do you see it evolving in the future (probe whether it will be uniform practice or for a selected group of patients)?

**Are there any resource implications of introducing [the self care project]/self care?**

Please explain details i.e. more or less costly - why?

Are resources for the project ring fenced or do they have to compete with other resources within your area of responsibility?

If [the self care project] had not been funded by [funding body] would it have been something that you would want to fund?

**How does [the self care project] fit into the organisational structure now and in the future?**

Is it integrated into standard structures and processes or does it stand alone?

If alone –are there any plans to integrate it, merge with other r projects- or phase it out?

Is what the [self care] project is doing seen as central to the trust? And what about in your section/department?

Do you see it staying as it is with external funding or being mainstreamed?

**The Management of Change**

Has the introduction of the [self care] project entailed any major changes in policy and practice?

How have staff responded to these changes?

Does it entail differences in the way professionals work with each other, with patients?

How effective has the [self care] project been in disseminating ideas, practices and experience to your mainstream operations? Have there been any resistance to these ideas, practice and experiences?

**External relations**

Who are the main external agencies that you work with in patient care here? (E.g. PCTS, social services, housing; voluntary bodies)



How do the partnerships with the voluntary organisations in the [self care] project fit with the Trusts strategy for working with voluntary organisations?

Was there consultation with or involvement with external agencies in setting up the project.

Has the project entailed any changes in the way in which they work with you?

What has been their response and involvement?

### **Risk Management**

Are there any risks involved in the [self care] project? If so what-give examples

(Examples to suggest if need to: Good use of scarce resources?; what evidence base is there for spending resources on the [self care] project? Service users holding own records?; people working independently on [self care] project away from services?; limited monitoring of delivery of [self care] project?; service users training professionals in [self care] project?)

Did you undertake a systematic risk analysis before embarking on the project? How did you do it?

What measures did you take to deal with the findings (or the risks mentioned above, if they have not undertaken a systematic evaluation)

### **Closing questions**

#### **Advantages and Disadvantages**

Has the project had any impact on other parts of the organisation-in what way?

Summing up, what would you say are the advantages of self care for the Trust/your section/other stakeholders?

And the disadvantages?

#### **Barriers and Facilitators**

What have been the main barriers to the introduction of this change?

How have you overcome them, what has helped facilitate it? What issues remain unresolved?

#### **Final question**

If someone came and asked you about embarking on a similar programme, what would your advice be?

**Additional questions for the training and development manager (to be inserted during the interview)**

**Training strategy, policy and practice**

What do you think is the best way to train people?

How does training link to the strategy of the trust?

Who should take responsibility for staff training (e.g. does the concept of 'self care' extend to employees?)

**Self care training**

How does [self care] project fit with the overall training strategy?

(Probe: It could be argued that in the past many professional felt that their role was to provide care for people with mental health problems. In this context, how do you train professional to promote self care?)

What training approaches are used in the [self care] project?

Does training people in the [self care] project entail doing any thing differently?

Are any other measures in place to support the implementation of the [self care] project? (e.g. how is it linked to performance management, appraisals, re-fresher training)

---

## Appendix 11 Protocol for qualitative analysis

### **Self care in mental health Trusts: the qualitative analysis**

This document is our 'handbook' for the completion and writing up of the qualitative analysis for the self care study! There are three parts to what follows:

- (1) Details of the questions, or 'queries' we will ask of our data;
- (2) Instructions on how to carry out those queries using NVivo;
- (3) Guidelines and examples of how to write up queries so that they can become part of the final report.

While this document is based very much on the discussions we have had as a team over the lifetime of the project, it will necessarily feel a bit 'prescriptive' or mechanical in its approach. This is because our first task for the qualitative analysis is to ensure that we successfully incorporate the range and depth of qualitative data in the final report for SDO. While that might feel that we are not allowing space for the more creative and instinctive side of qualitative research, this will remain an important part of the process. In particular we need those of you who are closest to the data to be able to guide 'what goes in', especially where that does not fit with the process described below.

For example, section 1 below appears to predetermine what data will be used in what parts of the final report. This is not intended to be the case. We have done this to avoid duplicating analyses. There is no reason why analysis done for one section of the final report cannot be used in another section. Any member of the team can suggest the inclusion of particular themes or data in sections of the report as they are written up.

In addition, it will certainly be the case that the final report will not go into as much detail in some (all!) areas as we would like. This report will inevitably not do full justice to all the contributions of all the interviewees. To a certain extent, completion of the report is something we need to do to satisfy the conditions of the grant, and there will be many other outputs from the research where we can more fully use our qualitative data and where it will probably have more impact. We have already discussed the wide range of papers and articles we might write and there will be space in those to go into much more depth and use more of the qualitative data once the report is out of the way.

But in the meantime...

## (1) NVivo queries for qualitative analysis

Following discussion of the analysis process at the Kingston Self Care team meeting, it was agreed that four sets of NVivo queries should be run on the qualitative data set (comprising Service User baseline and follow up interviews, Staff interviews and Carer baseline and follow up interviews). These queries would inform the writing of two sections of the final report as follows:

Query set	Report section
Q1: Specified set of nodes containing data on expectations and experiences of self care, contrasted by site (Yorks, Hants, London) and by stakeholder group (Service Users, Carers, Staff)	4.3 Descriptive qualitative analysis of stakeholders' expectations and experiences of self care
Q2: Matrix queries largely of nodes containing Service User and Carer follow up data on 'change' using attributes derived from quantitative analysis	5.1 Data synthesis exploring the identification of 'barriers' and 'facilitators' of self care using the theoretical model
Q3: Specified set of nodes identified through the emerging themes explored at feedback conference, contrasted by site and stakeholder group	
Q4: Specified set of nodes that contain data that complements analysis of the organisational data set	

The queries to be run under each set are as follows:

### Q1 – expectations and experiences of self care

The following nodes should all be run as matrix queries against the Site (an attribute), Gender (an attribute) and Stakeholder (all type 1 Sets) in order to describe expectations and experiences of self care:

- Expectations of the Project (top level)
- End product
- Hopes and anxieties
- Practical expectations
- Unknown
- Experiences of Self Care (top level)
- Structure and focus of the self care project
- New roles and relationships
- Previous experiences of Self Care (top level)
- Coping, skills & strategies
- Carers
- Benefits for carer
- Carer concerns
- Information and support for carer

Partners  
Understandings of self care (top level)  
Dimension of self care  
Language  
Other related models  
Personal philosophies and attitudes to self care  
Personal qualities  
Unsure

Total of 22 queries run against the Site and Gender attributes, and Stakeholder sets.

## **Q2 – synthesis with quantitative analysis**

2.1 In order to explore the relationship between site and a range of outcomes indicated in the quantitative analysis, the following nodes should be run in matrix queries against the Site (an attribute):

Change (top level);  
Changes in care;  
Changes in experience of mental health;  
Changes in Self Care;  
Rationale for change;  
Progress and moving on;  
Crisis support;  
Interface with self care/ routine care.

2.2 In order to explore relationships between outcomes and other service user characteristics the following nodes should also been run in matrix queries against CORE (an attribute) and Age (an attribute):

Change (top level);  
Changes in care;  
Changes in experiences of mental health;  
Changes in Self Care;  
Rationale for change;  
Progress and moving on;  
Qualities of Self Care support.

2.3 In order to explore the relationship between engagement with self care and other factors, matrix queries should be run on:

The node Engagement & Commitment against Age (an attribute);  
The nodes Motivations and Biography against Engagement (an attribute).

2.4 In order to explore the relationship between outcomes and medication the following nodes should be run in matrix queries against Compliance (an attribute):

Change (top level);  
Changes in care;  
Changes in experiences of mental health;

Changes in Self Care;  
Rationale for change;  
Progress and moving on;  
A new 'medication' node created by using the key word 'medication'  
and capturing the whole paragraph in which the key word appears.

2.5 In order to explore the relationship between whether or not an individual is with a CMHT and links to other services matrix queries should be run on:

The nodes Interface with self care/ routine care and (Self) referral process against CMHT (an attribute).

This represents a total of 34 queries.

### **Q3 – emerging themes**

The following nodes should all be run as matrix queries against the Site (an attribute) and Stakeholder (all type 1 Sets) in order to explore the themes emerging at feedback conferences:

Barriers and facilitators  
Advantages & disadvantages of self care  
Implementation challenges  
Groups, social, talking  
Identity & acceptance  
Barriers to social support  
(Self) referral process  
Routine & structure  
Survival strategies  
Awareness & triggers  
Qualities of Self Care support  
Role of mental health services  
Patients as staff  
Relationships with self care project staff  
Indirect support  
Job and career  
Role of staff  
Supporting self care staff  
Training  
Creative input, choice and control  
Partnerships and inter-service relationships  
Social networks  
Service user organisations and networks  
Attitudes, values & personal challenges

Total of 24 queries run against the Site attribute and Stakeholder sets.

### **Q4 – organisational data**

The following nodes should be viewed and reports written:

Organisational context  
Environment  
Differing priorities

HR & occ health policy  
Risk and risk management

Total of five nodes to explore.

**Note:**

Inclusion of nodes in more than one query set has been kept to a minimum to ensure that writing of query reports is as efficient as possible (we should not use time writing the same query report twice!). However, there is no reason why individual query reports cannot be used to write more than one section of the final report. For example, we are very likely to borrow from the Q3 Emerging Themes query report Groups, Social, Talking to write the Service User section of the final report that describes Experiences and Expectations of Self Care, but we will not need to run and write up that query twice.

So, while you are running queries if you think there is vital data missing that is needed in your section of the report, make a note of it and we will find it later, rather than running duplicate queries.

**(2) Instructions on running NVivo queries**

Three ways of exploring the coded data will be used to address the four questions described above. We can use the term 'query' as a shortcut for all three:

- (i) Matrix queries for Q1, Q2 (except text search query 2.4) and Q3;
- (ii) Text search query for Q2.4;
- (iii) Simply viewing the nodes for Q4.

We should all know how to view a node so I'm not going to describe that. Instructions for Matrix queries are given below.

**Matrix Query**

The purpose of a matrix query is to find the data that is at the intersection of two project items e.g. a node and an attribute, like gender, or a node and a group of study participants (we've grouped ours into sets for this purpose). It is like a cross tab in quantitative data in that it shows what data is relevant to the two specified criteria.

To demonstrate the process of a Matrix Query the example will be used. This is one the queries under Q1 expectations and experiences of self care - End Product taking in turn Site (an attribute) and then Stakeholder (all type 1 sets). Running the query is in two parts, first *design* the query and then second *run* the query to view the results.

To design the query, first, select the queries area in the bottom left hand menu. Go to the New button at the top of left hand side of the screen and select new 'Matrix coding query in this folder...'.

You will get the Matrix Coding Query dialogue box pop up. First task is to Add to Project by checking the box in the top left hand corner of the dialogue box. This will prompt the part of the dialogue box where you have to name the query (the general tab). Please use the following convention for naming

## MX Q1 Site and End product

This shows it is a matrix query (MX), relevant to question 1 (Q1), looking at the Site attribute and the End product node.

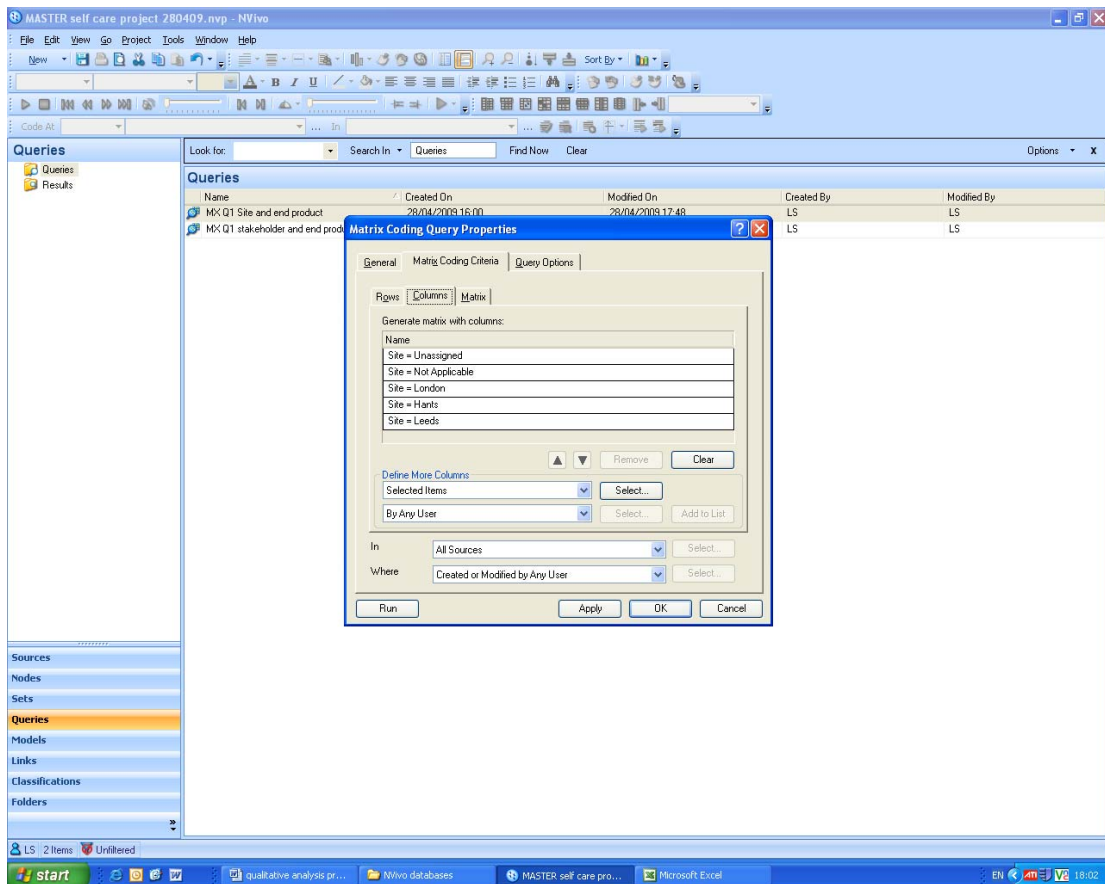
Next go to the 'Matrix Coding Criteria' tab. In this section we need to specify which project items need to go into the query. Here you will see another row of tabs (Row, Column and Matrix) underneath the main set of tabs. Start with the 'Row' tab. We will always put the node into the row of the matrix (the attribute (or sets) will go into the column). To select the row/node, go to the drop down menu and 'Select...' button underneath the 'Define more rows' subtitle. When you press the 'Select...' button you will get the usual 'Select Project Items' dialogue box. Here, go to the specific Tree Node that you are working with (make sure you highlight the Tree Node label in the left hand column, rather than tick the box). In this case we are interested in End Product so will check the box (make sure no other items are checked) and click OK.

**IMPORTANT:** when you are returned to the Matrix Coding Query dialogue box you must click the 'Add to List' button. You will then see the Tree Node appear in the 'Generate matrix with rows' area.

Next, we need to specify the columns for the matrix query – go along to this tab within the dialogue box. Again, to the 'Select...' button in the 'Define more columns' area. The usual 'Select Project Items' dialogue box appears again. Here you are going to the Attributes list (highlight the name rather than check the tick box) and select 'Site' by checking the box and click OK.

**IMPORTANT** – remember to click to 'Add to List' button – a list of the categories for the attribute Site will appear in the 'Generate matrix with Columns' area (see screen shot below)





Next move along to the 'Matrix' tab and make sure AND is selected in the 'Search criteria' options.

The final part of designing the query is to move along to the Query Options tab in the main tabs at the top of the dialogue box. In the Results option drop down list select the 'Create Results as New Matrix' option. Make sure 'Results' is in the Location option and the name you gave the query is automatically entered into the Name option. This will save the results of the query in the Results folder of the Queries area in the database. The design or writing part of the query will be saved in the queries folder.

At any point while you are designing the query you can press the 'OK' button and the query will be saved in the Queries folder (assuming you added to the project at the start of the process). Once you are satisfied with the query you can press 'Run' and the matrix will appear in the bottom half of the screen.

### ***Viewing the results of a matrix query***

The matrix query looks like a small table (see screen shot below). The numbers in the cells usually refers to the number of sources coded at this intersection (in this case End Product and each site). To view the text coded at each intersection double click in the relevant cell of the table and a further window will open with the coded text.

The screenshot shows the NVivo interface for a matrix query. The main window displays the following results table:

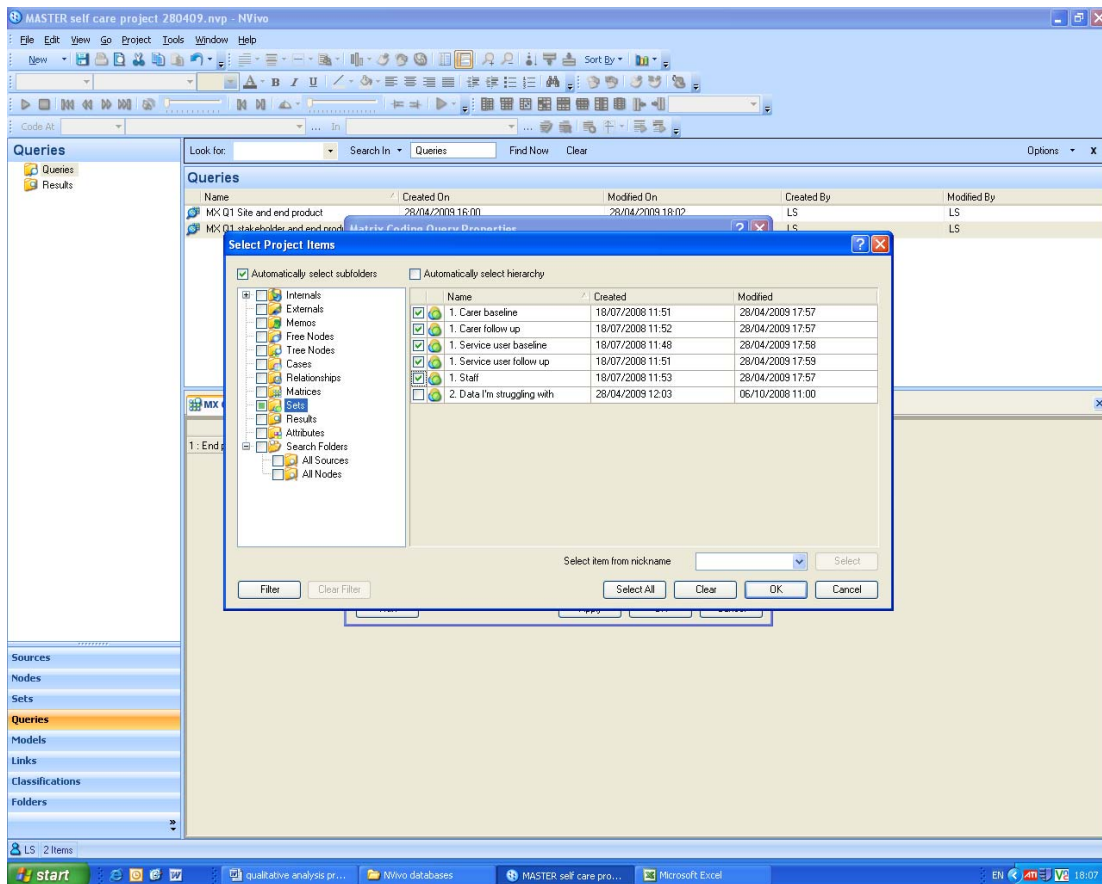
Name	Sources	References	Created On	Created By	Modified On	Modified By
MX Q1 Site and end product	173	499	28/04/2009 17:50	LS	28/04/2009 18:02	LS
MX Q1 stakeholder and end produ	91	288	28/04/2009 16:30	LS	28/04/2009 18:02	LS

Below this, a smaller window titled 'MX Q1 Site and en' shows a matrix query configuration with the following table:

	A: Site = Una...	B: Site = Not...	C: Site = Lon...	D: Site = Hants	E: Site = Leeds
1: End product	0	0	52	56	65

### ***Designing a Matrix Query using Sets (not an attribute)***

If you are running a matrix query that is using 'Stakeholder' (that is, staff, service user, or carer) as the criteria you do this by using the Sets option. Follow the process as above for specifying which node you are working with (remember the node goes into the row for this query and you must press the 'Add to Project' button!). When you move along to specify the columns again bring up the Select Project Item dialogue box and go into the Sets option. Here you will need to check the boxes for all the Type 1 sets (see previous guidelines for working in NVivo for a description of Sets). This is shown in the screen shot below.



Once you have pressed 'Add to List' these should then appear in the 'Generate matrix with Columns' area. Continue as before for completing the query and viewing the results.

### (3) Guidelines on writing up NVivo queries as a 'query report'

Once the query has been run it will produce output that contains all text coded against the node that has been extracted from the database. Each section of text will be identified by its source indicator.

Output from queries will, in many cases, be extensive. However, query reports need to be written up as succinctly as possible in order that they can form the basis of the final report without too much editing.

We have a very large number of nodes and so, except in the cases of certain nodes that are inclusive of a number of 'subthemes' – e.g. Groups, social, talking – nodes should be written up under a single heading, the node label.

Commentary should be kept to a minimum and should build on the node descriptor. Short additional commentary (limited to a sentence or two) should be used to indicate, for example, different perspectives on a theme (e.g. pros and cons of a particular aspect of self care) or to explain possible differences between sites or stakeholder groups.

Where the query also contains text from researchers' memos these can be used as part of the commentary.

The bulk of the query report should be quotation from interviews, referenced using the source indicator.

On the whole reports should be one or two pages long, including quotes, except in the case of very long or inclusive nodes. This won't feel long enough, but we have listed 85 potential queries above that will need to fit in about 20 pages of report! We have no choice but to be disciplined!!

While you may feel important data is being missed by this process, we can always return to the query if we want more data (*save all your queries!*) and we will certainly do that when we write up other outputs at a later date.

The structure of query reports will vary. Suggested formats are as follows:

*Q1 reports – expectations and experiences of Self Care*

These reports will have up to three main sections: Service Users; Staff; Carers. This is because these reports will be used in the part of the final report that describes the expectations and experiences of each stakeholder group.

Not all reports will need to have all three sections where the issue is not relevant to all stakeholder groups.

Each section should begin with one or two quotes that are indicative of views/ experiences that are shared across all three sites.

One or two quotes may then be used to indicate views/ experiences that are particular to individual sites (it is not necessary to find quotes for each site where there do not appear to be site specific issues).

There might also then be one or two quotes that illustrate views/ experiences that seem to be gender specific where this emerges as relevant.

*Q2 reports – synthesis with quantitative analysis*

These reports will be structured by attribute. That is, if the attribute has three categories (e.g. Site – Yorks, Hants, London; CORE – mild to moderate, moderately severe, severe) the report will have three sections.

These reports will comprise quotes that illustrate the **differences** between attributes, rather than looking for common views/ experiences. This is because these reports will be used to complement quantitative findings that indicate possible differences that we want to use the qualitative data to try and explain.

*Q3 reports – emerging themes*

These reports will be structured like the Q1 reports. The exception is that they can begin with an opening section that quotes views/ experiences that are common to all stakeholders at all sites if appropriate (i.e. where the emerging theme is widely held).

They will then have sections that illustrate views/ experiences that are particular to different sites and different stakeholder groups.

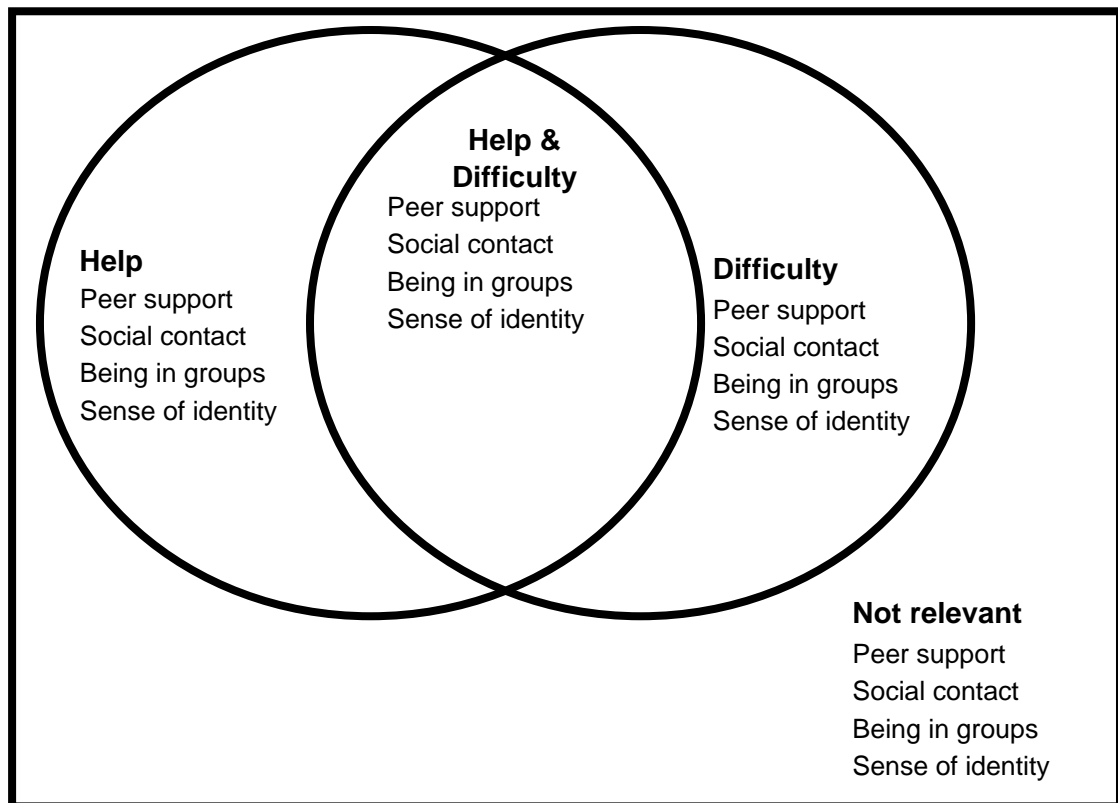
*Q4 reports – organisational data*

These reports will simply illustrate a range of views and experiences, taking care to cite the source reference in order to indicate site and stakeholder. This is because these reports will be used to complement the other organisational data.

---

## Appendix 12 Example theme Venn diagram

### (1) Groups, talking & social contact



## Appendix 13 Online survey mapping self care support at a national level

**Self Care in Mental Health**

**1. You and Your Trust**

CONFIDENTIAL

The survey is being conducted on a confidential basis. We will not identify you, or the Trust you work for, in any output derived from this survey.

\* Please enter your Unique Record Number (URN) from the email

\_\_\_\_\_

**1.1 In which NHS region is your Trust?**

East Midlands Strategic Health Authority

East Of England Strategic Health Authority

London Strategic Health Authority

North East Strategic Health Authority

North West Strategic Health Authority

South Central Strategic Health Authority

South East Coast Strategic Health Authority

South West Strategic Health Authority

West Midlands Strategic Health Authority

Yorkshire and The Humber Strategic Health Authority

**1.2 Total number of employees in the Trust?**

Up to 1000

1001-2000

2001-3000

More than 3000

**1.3 Trust status?**

Foundation status

Currently applying for foundation status

Not currently applying for foundation status

**1.4 Healthcare Commission Annual Health Check rating for 2007/ 2008?**

	Weak	Fair	Good	Excellent
Quality of services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use of resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**1.5 What is your current role in the Trust (e.g. Clinical Director, HR Director)?**

PLEASE SPECIFY

\_\_\_\_\_

**Self Care in Mental Health**

**2. Strategy and Planning**

In its policy implementation guidance (Self Care – A Real Choice 2005) the Department of Health defines Self Care as:

'...a part of daily living. It is the care taken by individuals towards their own health and well being ... the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.'

**2.1 Does the Trust currently have a formal Self Care strategy in place?**

Yes - GO TO QUESTION 2.3

No

Don't know

**2.2 If not, is support for Self Care covered in any of the following formal strategies?**

PLEASE CHECK ALL THAT APPLY

Recovery

Self Management

Social Inclusion

Wellbeing

Other Strategies (please specify below)

None of these

Names of Other Strategies (please specify)

\_\_\_\_\_

\_\_\_\_\_

**2.3 Are any of the following core elements of Self Care support covered by any of these strategies?**

PLEASE CHECK ALL THAT APPLY

	Self Care	Recovery	Self Management	Social Inclusion	Wellbeing	Other Strategy
Empowering people to manage their own condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Offering real choice over treatment options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improving access to information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Investment in training & developing skills for staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enhancing support for informal carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased collaboration between health, social care & the third sector	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Self Care in Mental Health**

**3. Leadership for Self Care**

**3.1 Does the Trust have a specifically named Self Care lead?**

Yes

No

Don't know

**Self Care in Mental Health**

**3.2 If not, is there anyone else within the Trust whose role would include leadership of Self Care strategy or activity?**  
**PLEASE CHECK ALL THAT APPLY**

Recovery lead

Self Management lead

Social Inclusion lead

Wellbeing lead

Clinical Director

Director for Patient Experience

Quality lead

Other roles (please specify below)

No

Names of other roles (please specify)



**Self Care in Mental Health**

**4. Self Care Training**

**4.1 Does the Trust provide specific training for staff in supporting patients/service users with Self Care?**

Yes

No

Don't know

**Self Care in Mental Health**

**4.2 If not, does the Trust provide training in another area that includes training for staff in supporting patients/service users with Self Care?**

**PLEASE CHECK ALL THAT APPLY**

Recovery

Self Management

Social Inclusion

Wellbeing

Other training (please specify below)

No

Names of other types of training (please specify)

**Self Care in Mental Health**

**5. Risk assessment**

**5.1 Does the Trust risk assessment policy cover aspects of Self Care?**

Yes  
 No - GO TO QUESTION 5.3  
 Don't know - GO TO QUESTION 5.3

**5.2 If Yes, which aspects of Self Care are covered in the Trust risk assessment policy?**  
**PLEASE CHECK ALL THAT APPLY**

Access to the service for people not currently using mental health services  
 Signposting into non-statutory community activities  
 Peer support (outside of Trust services)  
 Service user led activities  
 Patient records held by service users rather than the Trust  
 Service users employed as staff members

**5.3 Does the Trust provide risk assessment training that specifically includes aspects of Self Care?**

Yes  
 No  
 Don't know

**Self Care in Mental Health**

**6. Self Care Activity**

**6.1 Does the Trust currently provide or routinely refer service users to any projects or initiatives that offer the following support for Self Care?**

	Yes	No	Don't know
Appropriate and accessible advice and information (including multi-media information sources)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal care plans (in addition to Care Programme Approach)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self-diagnostic tools, self-monitoring devices and Self Care equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health education, for example through the Skilled for Health programme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self Care skills training, for example through the Expert Patients Programme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Multi-lingual Self Care facilities and information materials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Campaigns and training on lifestyle issues to change behaviours, promote good health and prevent ill health, for example by lay Self Care trainers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Utilising networks of peers with experience of acute or long-term conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Building social capital and Self Care support capacity in the community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participation of the public in the design and implementation of local programmes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education to change attitudes and behaviours of practitioners and public towards Self Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training of practitioners in when and how to use approaches to support Self Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Initiatives to develop partnerships between professionals and the public	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home adaptations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Pharmacy Scheme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Direct Payments/ Personal Budgets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Self Care in Mental Health**

6.2 Does the Trust currently provide or routinely refer service users to any other Self Care projects/initiatives in place that are not covered by the list above?

Yes  
 No  
 Don't know

If Yes, please name and briefly describe

**Self Care in Mental Health**

6.3 To the best of your knowledge, do any of the Self Care projects/initiatives you have indicated include any of the following features as an important part of the initiative?

PLEASE CHECK ALL THAT APPLY

Group work  
 One to one support provided by a member of staff  
 Peer support networks  
 Self referral process  
 Formal referral process from other Trust services  
 Open access to initiative from outside of the Trust  
 Development of personal plans  
 Service users as members of staff  
 Initiative is service user led  
 Initiative has its own dedicated staff team  
 Staff split their role on the initiative with other Trust duties  
 Trust risk management protocols apply to the initiative  
 Initiative has own risk management protocols  
 Trust patient record keeping systems apply  
 Initiative has own record keeping system  
 Service user access to the initiative is time limited  
 Initiative has no formal discharge process  
 Service users are able to 'dip in and out' of the initiative  
 Initiative links service users to activities outside of the Trust  
 Support for service users' informal carers (e.g. family, partner, friend)  
 Professional staff and service users share clinical decision making responsibility  
 Initiative is goal orientated (enables service users to pursue personal interests)

**Self Care in Mental Health**

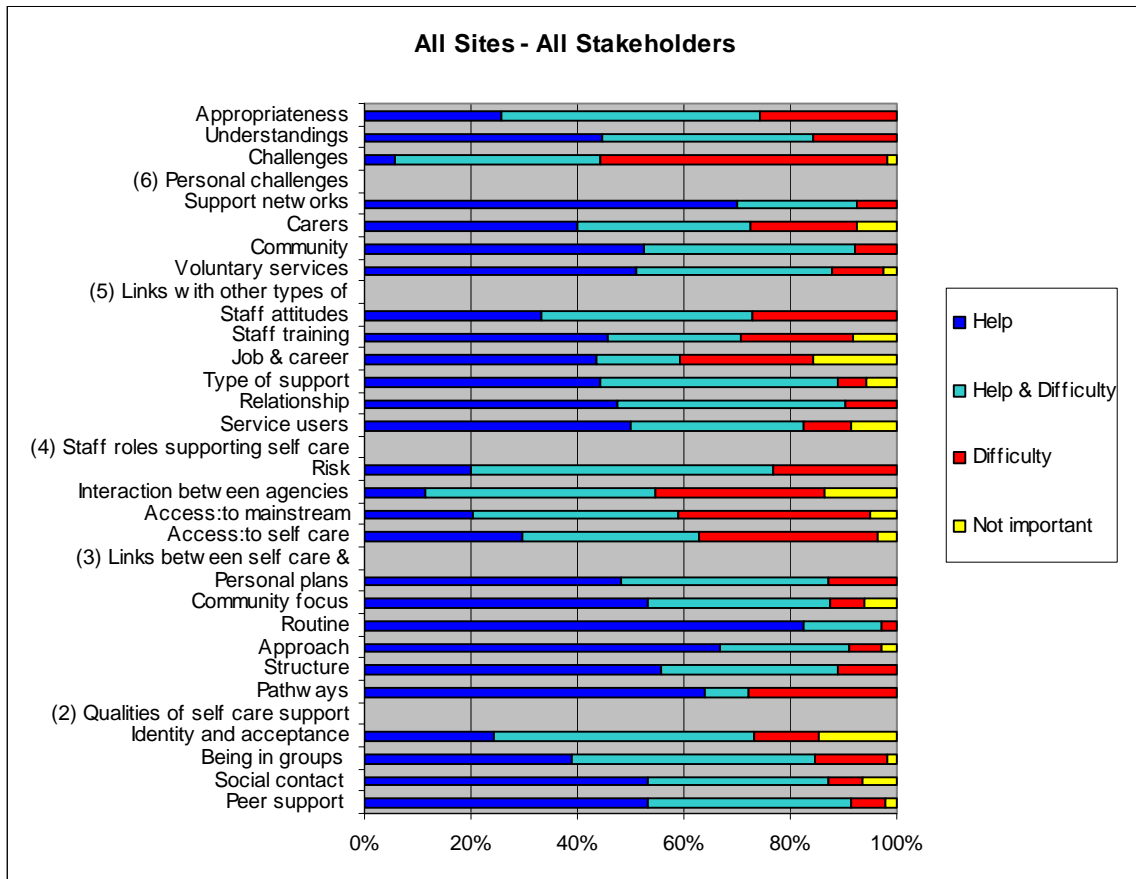
**6.4 Do any of these statements apply to any of the Self Care initiatives you have listed?**  
**PLEASE CHECK ALL THAT APPLY**

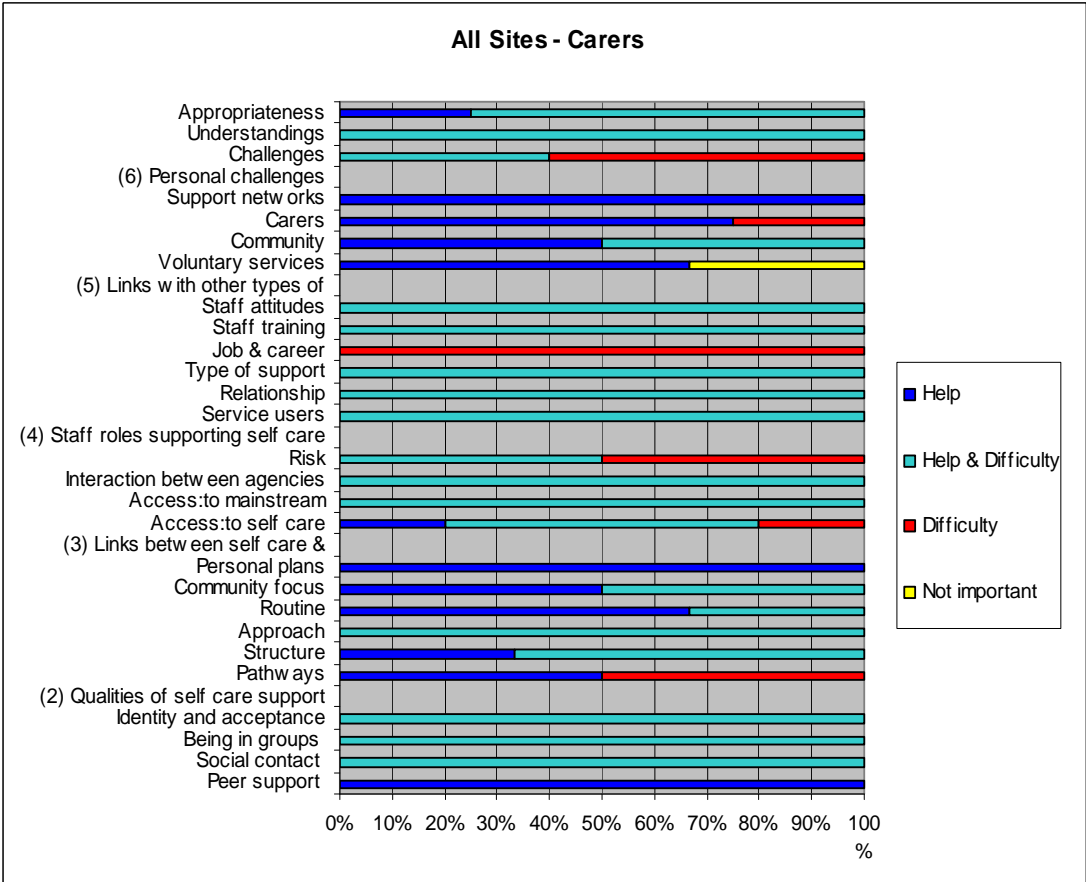
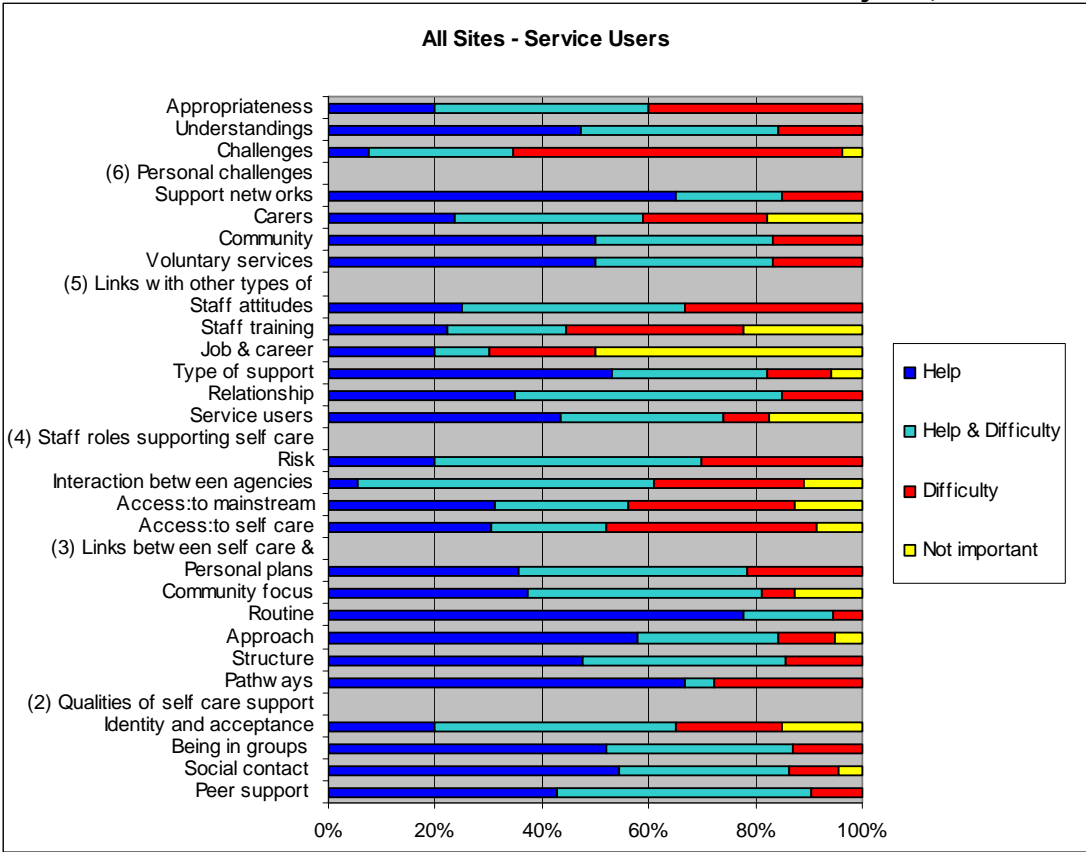
- Initiative is formally integrated into the mainstream service provision of the Trust
- Initiative is largely supported through the efforts of a local 'champion' or a single service manager
- Funding for the initiative is time limited
- Future funding for the initiative is uncertain
- The initiative is funded by the Trust
- The initiative is funded by the Local Authority
- The initiative is funded from external sources (e.g. national pilot or demonstration site)
- The initiative is wholly or in part delivered by social service (LA) providers
- The initiative is wholly or in part delivered by voluntary sector providers

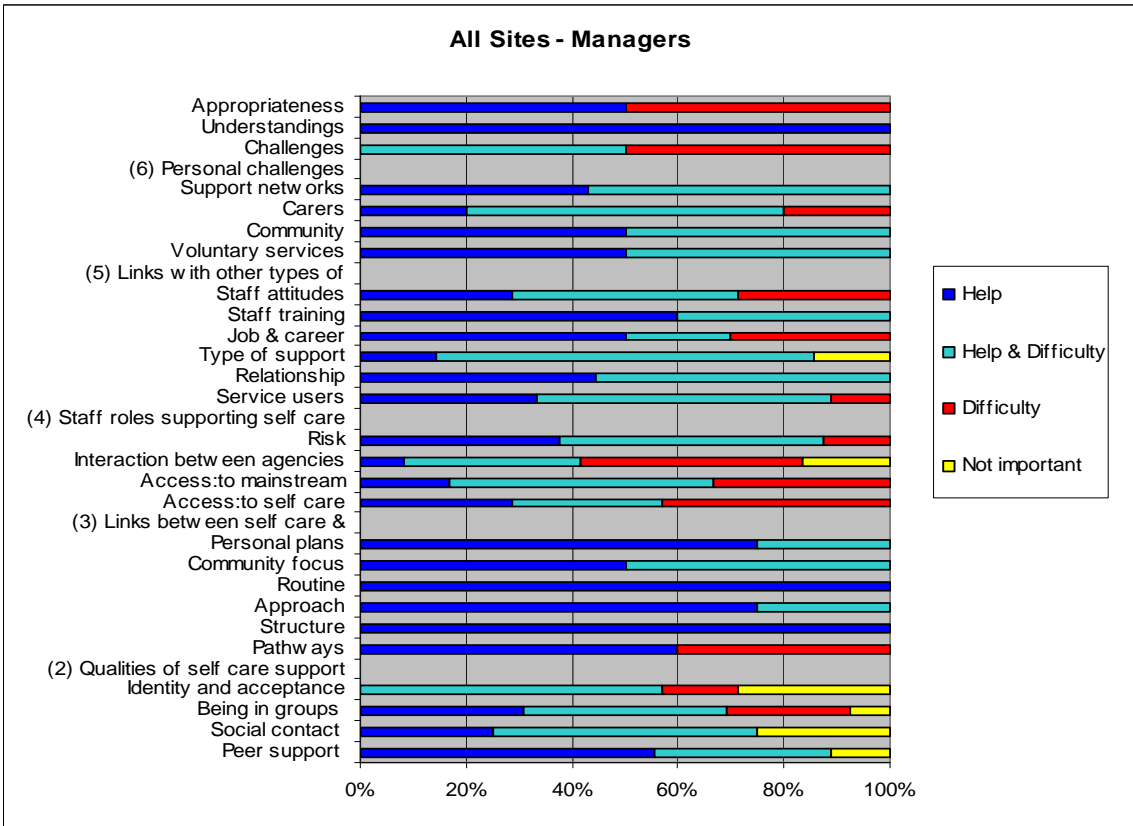
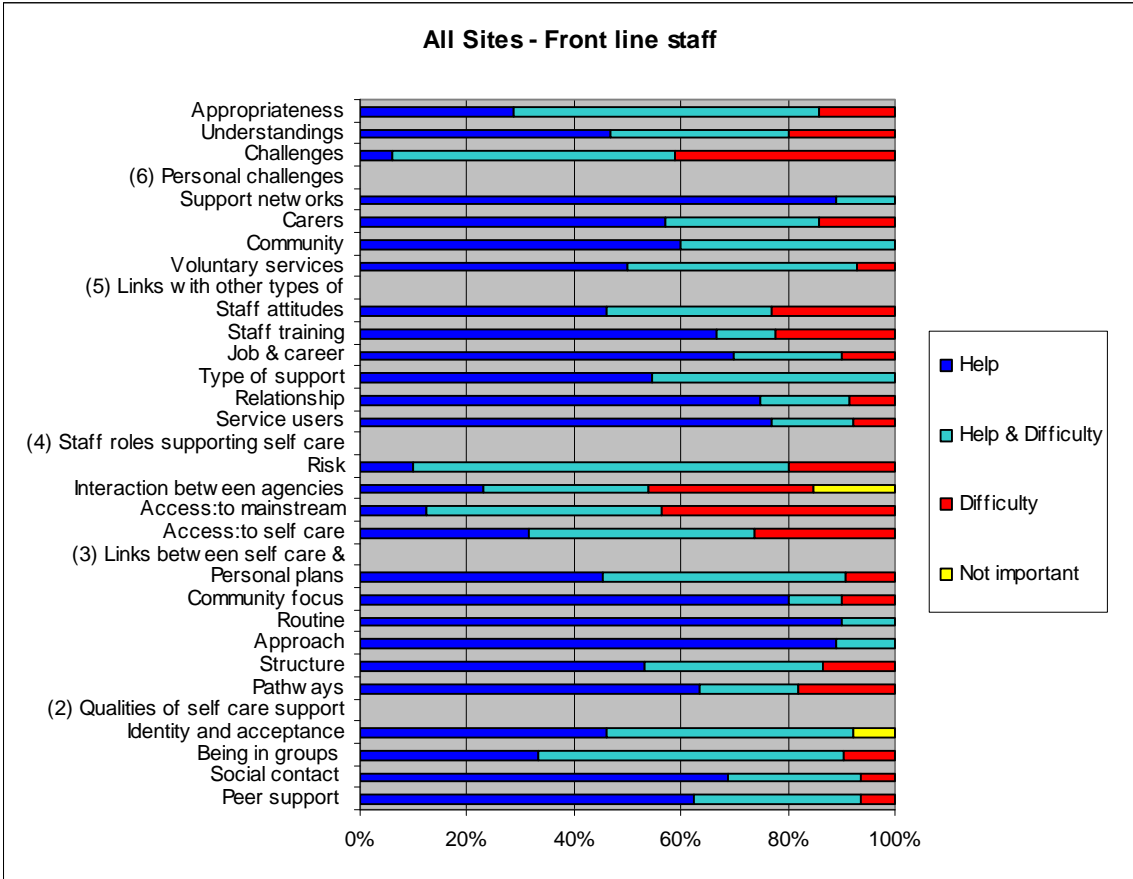
**6.5 To what extent do you agree or disagree with the following statements about the implementation of Self Care support in your Trust?**  
**PLEASE CHECK ONE BUTTON FOR EACH STATEMENT**

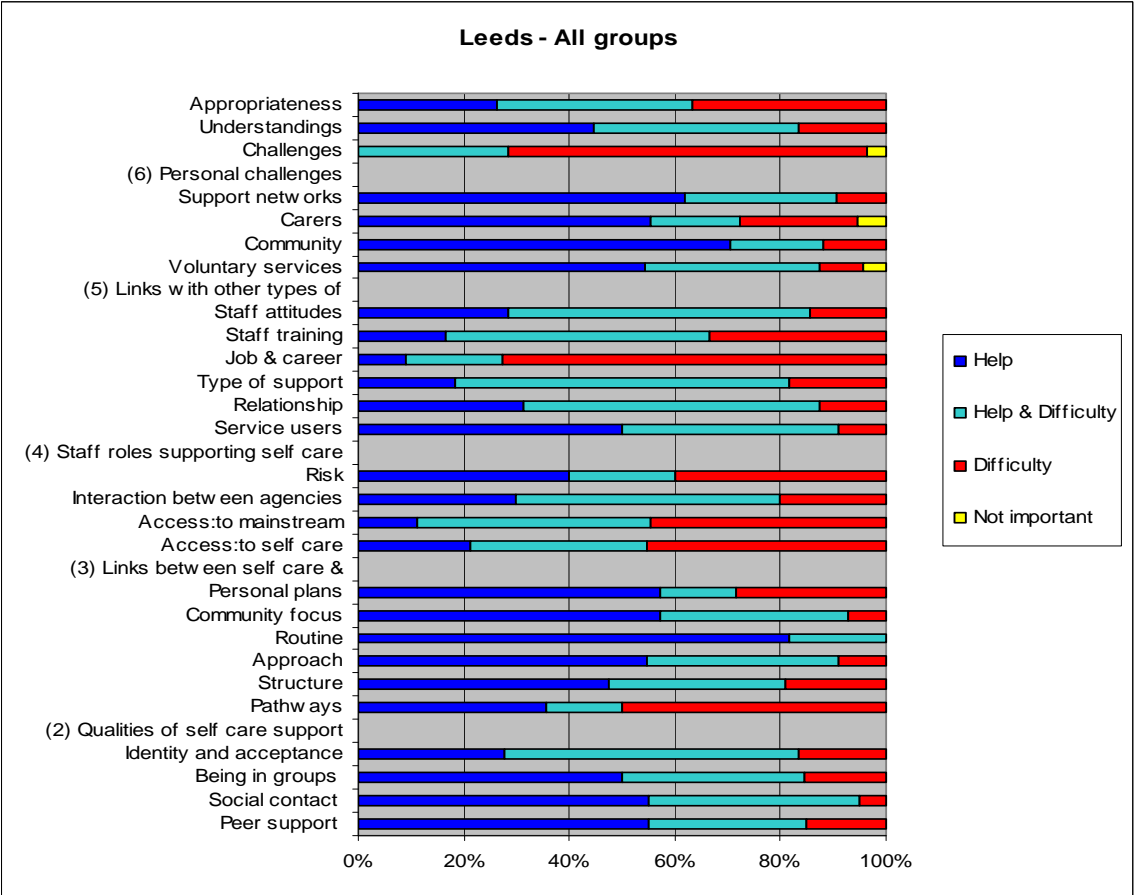
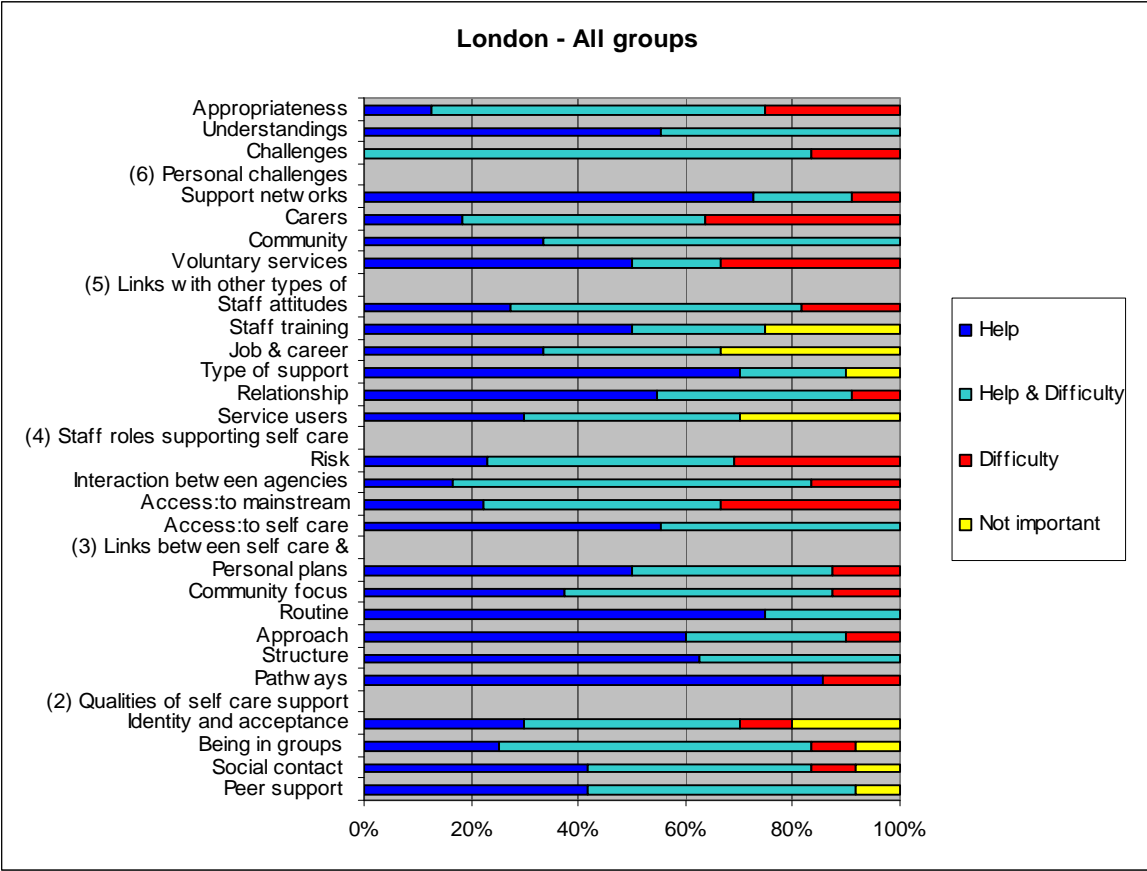
	Strongly disagree	Disagree	Neither	Agree	Strongly agree
a) Self Care support has lower funding priority than other service provision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Level of senior management 'buy in' to implementing Self Care policy is high	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Awareness of Self Care policy across the organisation is high	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Professional staff are resistant to change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) It is difficult to coordinate support for Self Care across organisational boundaries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) Service users are resistant to taking more responsibility for their own care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) There are high levels of staff expertise and/or experience in supporting Self Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Risks are identified in supporting Self Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Appendix 14 Ratings for each feedback conference themes by site and stakeholder

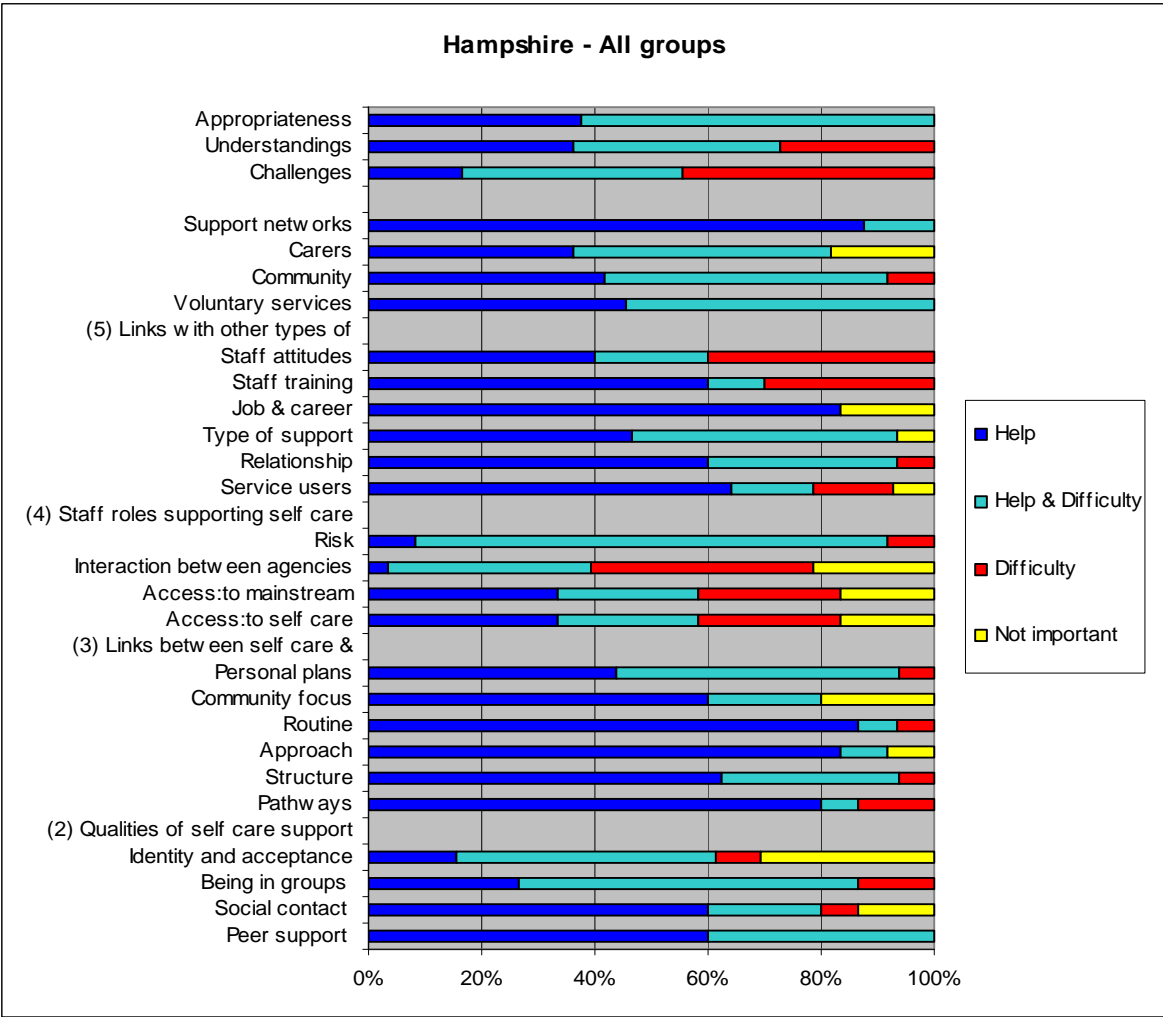












## Appendix 15 Full responses to the national mapping survey

### Self Care in Mental Health: Summary of Replies

**Table 1: You and Your Trust**

NHS Region	Self Care data		No Self Care data		Total cases	
	Number	%	Number	%	Number	%
East Midlands Strategic Health Authority	1	3	2	12	3	5
East Of England Strategic Health Authority	3	8	2	12	5	9
London Strategic Health Authority	8	20	0	0	8	14
North East Strategic Health Authority	2	5	1	6	3	5
North West Strategic Health Authority	2	5	3	18	5	9
South Central Strategic Health Authority	3	8	1	6	4	7
South East Coast Strategic Health Authority	3	8	0	0	3	5
South West Strategic Health Authority	7	18	1	6	8	14
West Midlands Strategic Health Authority	4	10	4	24	8	14
Yorkshire and The Humber Strategic Health Authority	6	15	3	18	9	16
Not answered	1	3	0	0	1	2
Total Cases	40	100	17	100	57	100
<b>Total number of employees</b>						
Up to 1000	1	3	1	6	2	4
1001 to 2000	6	15	4	24	10	18
2001 to 3000	17	43	6	35	23	40
More than 3000	13	33	6	35	19	33
Not answered	3	8	0	0	3	5
Total Cases	40	100	17	100	57	100
<b>Trust Status</b>						
Foundation status	22	55	9	53	31	54
Currently applying for foundation status	10	25	6	35	16	28
Not currently applying for foundation status	7	18	2	12	9	16
Not answered	1	3	0	0	1	2
Total Cases	40	100	17	100	57	100

Source: Self Care in Mental Health Survey, 2009

## Notes:

1. Responses are based on replies from 57 respondents from 44 trusts.
2. 11 respondents from 10 trusts did not answer the questions on Self Care.
3. One respondent from six of the trusts with two or more respondents did not answer the questions on Self Care.

**Table 2: Healthcare Commission Annual Health Check rating for 2007/2008**

Quality of Services	Self Care data		No Self Care data		Total cases		
	Number	%	Number	%	Number	%	
Weak	1	3	2	12	3	5	
Fair	3	8	2	12	5	9	
Good	12	30	4	24	16	28	
Excellent	22	55	7	41	29	51	
Not answered	2	5	2	12	4	7	
	Total Cases	40	100	17	100	57	100
<b>Use of Resources</b>							
Weak	1	3	1	6	2	4	
Fair	6	15	2	12	8	14	
Good	19	48	5	29	24	42	
Excellent	11	28	6	35	17	30	
Not answered	3	8	3	18	6	11	
	Total Cases	40	100	17	100	57	100

Source: *Self Care in Mental Health Survey, 2009*

**Table 3: Formal Self Care strategy in place**

	Number	%
Yes	4	10
No	31	78
Don't know	5	13
Total Cases	40	100

Source: *Self Care in Mental Health Survey, 2009*

## Notes:

1. Replies based on 40 respondents from 34 trusts.

**Table 4: Current role in Trust**

	<b>Self Care data</b>	<b>No Self Care data</b>
Assistant Director (Governance)		1
Associate Director - Adult Mental Health (WAMH, SMS, LD)	1	
Associate Director Mental Health		1
Associate Director of Nursing	1	
CE	1	
CEO	2	
Chief Executive	1	2
Clinical Services Manager, Adult Acute	1	
Deputy Director of Nursing		2
Director	1	
Director for Social Inclusion	1	
Director of Corporate Development		1
Director of Integrated Governance & Executive Nurse	1	
Director of Nursing	3	1
Director of Nursing and Education	1	
Director of Nursing and Professions	1	
Director of Operations	1	
Director of Operations and Workforce		1
Director Public Health		1
Exec Director	1	
Executive Director of Nursing and Operations	1	
General Manager	1	
Head of Nursing	1	
Head of practice governance	1	
Head of Service	1	
Interim Service Director	1	
Interim HR Director		1
Medical Director	5	2
Medical Director & Dir Strat & Business development	1	
Medical Director/Deputy chief executive	1	
MD for Finance and Business strategy/ Deputy CEO		1
Nurse Consultant - Rehabilitation and Recovery	1	
Nurse Director	1	
Nursing Director	1	
Operational Director		1
Operational Manager		1
Practice Development lead	1	
Professional Head of Nursing	1	

Project lead	1	
Research Nurse		1
Service Director	3	
Not answered	1	
Total case	40	17

Source: *Self Care in Mental Health Survey, 2009*

**Table 5: Self Care support covered by strategy for:**

	Number	%
Recovery	24	73
Self Management	6	18
Social Inclusion	18	55
Wellbeing	17	52
Other strategy	12	36
None of these	2	6
Total Cases	33	100

Source: *Self Care in Mental Health Survey, 2009*

Notes:

- 3 respondents did not answer this question.

**Table 6: Names of other strategies**

Care Programme Approach

Care programme approach people participation social inclusion carers strategy

CPA Strategy, general approach and philosophy of care delivery, carers strategy. We are developing a Recovery Strategy!

Enshrined in a number of Policies and procedures e.g. CPA, Advanced statements PSI strategy

Every Adult Matters Personalisation

Medication

Mental Health Promotion Strategy

Personalisation

Public Health strategy CPA policy

Recovery Co-ordination

Service delivery strategy

Service User Carer

Source: *Self Care in Mental Health Survey, 2009*

Notes:

- One respondent wrote: 'We have tried to embed self care principles and recovery within many of our strategies and policies. We try to think of it in a continuum rather than as a separate entity that requires a strategy.'

**Table 7: Core elements of Self Care support covered by:**

	Self Care		Recovery		Self Management		Social Inclusion		Wellbeing		Other strategy		Not answered		All	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Empowering people to manage their own condition	6	17	28	80	8	23	14	40	18	51	13	37	0	0	35	100
Offering real choice over treatment options	4	11	23	66	8	23	13	37	15	43	11	31	4	11	35	100
Improving access to information	3	9	18	51	9	26	12	34	15	43	16	46	4	11	35	100
Investment in training & developing skills for staff	5	14	19	54	6	17	12	34	14	40	15	43	3	9	35	100
Enhancing support for informal carers	5	14	16	46	4	11	10	29	14	40	20	57	5	14	35	100
Increased collaboration between health, social care & the third sector	4	11	18	51	6	17	16	46	14	40	16	46	4	11	35	100

Source: *Self Care in Mental Health Survey, 2009*

**Notes:**

- Five respondents did not answer this question.

**Table 8: Named Self Care lead**

	<b>Number</b>	<b>%</b>
Yes	5	13
No	27	68
Don't know	6	15
Not answered	2	5
Total Cases	40	100

---

*Source: Self Care in Mental Health Survey, 2009*

**Table 9: Self Care strategy led by:**

	<b>Number</b>	<b>%</b>
Recovery lead	15	47
Self Management lead	0	0
Social Inclusion lead	13	41
Wellbeing lead	7	22
Clinical Director	9	28
Director for Patient Experience	7	22
Quality lead	10	31
Other role	6	19
None of the above	2	6
Total cases	32	100

---

*Source: Self Care in Mental Health Survey, 2009*

**Notes:**

1. 3 respondents did not answer this question.

**Table 10: Names of other roles**

Care Programme Approach (CPA), Essence of Care Benchmark on Self -Care,

Head of social work

Patient experience team and manager Choosing health lead

People Participation Leads (3) occupational therapists

Professional leads, managers and clinicians

Staying Well Practitioners

---

*Source: Self Care in Mental Health Survey, 2009*

**Table 11: Provides specific training for staff**

	Number	%
Yes	24	60
No	8	20
Don't know	6	15
Not answered	2	5
Total Cases	40	100

---

Source: *Self Care in Mental Health Survey, 2009*

**Table 12: Other areas of training for staff**

	Number	%
Recovery	10	77
Self Management	1	8
Social Inclusion	7	54
Wellbeing	8	62
Other training	4	31
No training	0	0
Total cases	13	100

---

Source: *Self Care in Mental Health Survey, 2009*

Notes:

1. One respondent did not answer this question.

**Table 13: Names of other types of training**

Medication

Psychosocial interventions, medicines management

Personalisation

Self care for people with weight problems forms part of an intervention that we are developing as part of an NIHR programme grant

---

Source: *Self Care in Mental Health Survey, 2009*

Notes:

1. One respondent wrote: Not in older adults services



**Table 14: Risk assessment policy covers aspects of Self Care**

	<b>Number</b>	<b>%</b>
Yes	16	40
No	10	25
Don't know	10	25
Not answered	4	10
Total Cases	40	100

---

*Source: Self Care in Mental Health Survey, 2009*

**Table 15: Aspects of Self Care covered in risk assessment**

	<b>Number</b>	<b>%</b>
Access to the service for people not currently using mental health services	10	63
Signposting into non-statutory community activities	11	69
Peer support (outside of Trust services)	7	44
Service user led activities	7	44
Patient records held by service users rather than the Trust	4	25
Service users employed as staff members	6	38
Not answered	3	19
Total Cases	16	100

---

*Source: Self Care in Mental Health Survey, 2009*

**Table 16: Risk assessment training specifically covers aspects of Self Care**

	<b>Number</b>	<b>%</b>
Yes	18	45
No	8	20
Don't know	10	25
Not answered	4	10
Total Cases	40	100

---

*Source: Self Care in Mental Health Survey, 2009*

**Table 17: Refers to projects/initiatives offering support for Self Care**

	Yes		No		Don't know		Not answered		Total cases	
	Number	%	Number	%	Number	%	Number	%	Number	%
Appropriate and accessible advice and information	29	81	3	8	3	8	1	3	36	100
Personal care plans	25	69	6	17	5	14	0	0	36	100
Self-diagnostic tools, self monitoring devices	19	53	3	8	13	36	1	3	36	100
Health education	23	64	4	11	8	22	1	3	36	100
Self Care skills training	19	53	7	19	9	25	1	3	36	100
Multi-lingual Self Care facilities and information	15	42	11	31	9	25	1	3	36	100
Campaigns and training on lifestyle issues	28	78	5	14	3	8	0	0	36	100
Utilise networks of peers	22	61	8	22	5	14	1	3	36	100
Building social capital and support in the community	14	39	10	28	11	31	1	3	36	100
Public participation in design of local programmes	17	47	9	25	9	25	1	3	36	100
Education to change attitudes and behaviours	19	53	9	25	7	19	1	3	36	100
Training of practitioners	16	44	8	22	10	28	2	6	36	100
Initiatives to develop partnerships	23	64	5	14	7	19	1	3	36	100
Home adaptations	21	58	7	19	6	17	2	6	36	100
Community Pharmacy Scheme	18	50	11	31	5	14	2	6	36	100
Direct payments/personal budgets	26	72	6	17	3	8	1	3	36	100

Source: *Self Care in Mental Health Survey, 2009*

Notes:

1. Four respondents did not answer this question.

**Table 18: Provides/refers to other Self care projects/initiatives**

	Number	%
Yes	4	10
No	8	20
Don't know	22	55
Not answered	6	15
Total Cases	40	100

---

Source: *Self Care in Mental Health Survey, 2009*

**Table 19: Self Care projects/initiatives referred to:**

Florid.org.uk web site mentoring, volunteering  
 MIND and ReThink services  
 Vocational and community groups which facilitate self care.

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Source: *Self Care in Mental Health Survey, 2009*

**Table 20: Self Care projects/initiatives include:**

Features	Number	%
Group work	23	58
One to one support provided by a member of staff	25	63
Peer support networks	21	53
Self referral process	19	48
Formal referral process from other Trust services	13	33
Open access to initiative from outside of the Trust	13	33
Development of personal plans	23	58
Service users as members of staff	25	63
Initiative is service user led	16	40
Initiative has its own dedicated staff team	5	13
Staff split their role on the initiative with other Trust duties	9	23
Trust risk management protocols apply to the initiative	8	20
Initiative has own risk management protocols	3	8
Trust patient record keeping systems apply	10	25
Initiative has own record keeping system	6	15
Service user access to the initiative is time limited	2	5
Initiative has no formal discharge process	2	5
Service users are able to 'dip in and out' of the initiative	11	28
Initiative links service users to activities outside of the Trust	10	25

Support for service users' informal carers	17	43
Professional staff and service users share clinical decision making responsibility	12	30
Initiative is goal orientated (enables service users to pursue personal interests)	14	35
Not answered	11	28
Total Cases	40	100

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Source: *Self Care in Mental Health Survey, 2009*

**Table 21: Characteristics of Self Care projects/initiatives**

	Number	%
Initiative is formally integrated into the mainstream service provision of the Trust	14	35
Initiative is largely supported through the efforts of a local 'champion' or a single service manager	9	23
Funding for the initiative is time limited	1	3
Future funding for the initiative is uncertain	5	13
The initiative is funded by the Trust	15	38
The initiative is funded by the Local Authority	8	20
The initiative is funded from external sources	3	8
The initiative is wholly or in part delivered by social service (LA) providers	6	15
The initiative is wholly or in part delivered by voluntary sector providers	8	20
Not answered	16	40
Total Cases	40	100

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Source: *Self Care in Mental Health Survey, 2009*

**Table 22: Attitudes to implementation of Self Care support**

	<b>Disagree strongly</b>	<b>Disagree</b>	<b>Neither</b>
	%	%	%
Self Care support has lower funding priority than other service provision	0	15	33
Level of senior management 'buy in' to implementing Self Care policy is high	9	15	42
Awareness of Self Care policy across the organisation is high	25	25	16
Professional staff resistant to change	12	30	33
Difficult to coordinate support for Self Care across organisational boundaries	0	25	22
Service users resistant to taking more responsibility for own care	15	33	33
High levels of staff expertise/experience in supporting Self Care	0	27	36
Risks identified in supporting Self Care	6	27	33

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*Source: Self Care in Mental Health Survey, 2009*

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme, and managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO), based at the London School of Hygiene & Tropical Medicine.

The management of the SDO programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact [sdo@southampton.ac.uk](mailto:sdo@southampton.ac.uk).