

Optimising the cancer patient journey

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Abstract

This thesis describes the research undertaken by the author from the beginning of 2017 up until the end of 2021. The research started by investigating the support that community pharmacy teams can provide to patients who take oral anti-cancer therapy. This expanded into evaluating the experience of cancer patients at various points throughout their journey, hence the final research question overall is how to optimise the cancer patient journey. The research presented in this thesis provides new evidence to answer this question.

The thesis starts by introducing the reader to the journey of a cancer patient, what they may encounter and what it is like to live with and beyond cancer. The history of cancer policy is discussed including the impact this has had. The author's career history is provided. The first chapter finishes by explaining the structure of the thesis and the aims and objectives.

Chapter 2 is devoted to the methodology used throughout the work described in this thesis. The reasons why the methods were used is discussed as well as the philosophy surrounding them. Chapters 3 and 4 provide detail of the two themes that make up this thesis. Chapter 3 takes the reader through the research and studies that were undertaken to determine whether community pharmacists can support patients who take oral anticancer medication and what the model encompasses. Chapter 4 details the studies conducted to explore cancer patient experience which became heavily influenced by the effects of COVID-19.

The final chapter summarises the work undertaken to achieve the aim and objectives as set out in the first chapter. The thesis closes with a plan for the author's future research intentions.

Chapter 1 – Overview, context, aims and objectives

1.1 Introducing the journey of a cancer patient

Cancer is a disease resulting from the uncontrolled over proliferation of cells. It is a leading cause of death worldwide¹. The most common types of cancer in the UK and worldwide are breast cancer, lung cancer, colorectal cancer and prostate cancer^{1, 2}. In 2016-2018 these four cancers accounted for over half of all new cases of cancer in the UK². Cancer survival in the UK is improving however between 2010 and 2014 the UK observed the lowest 1-year survival worldwide for stomach, colon, rectal and lung cancer³. Australia, Canada, and Norway showed the highest 1-year survival for most cancers³. The UK has the lowest 5-year survival rates for cancer except for ovarian and oesophageal cancers compared with Australia, Canada, Denmark, Ireland, New Zealand, and Norway³. The UK therefore needs to catch up with the rest of the world in terms of survival rates.

The pathway which a cancer patient goes through, starting at diagnosis, is often referred to as a journey, with multiple ups and downs⁴. Some patients have many trips to their general practitioner (GP) and/or trips to their local accident and emergency department before receiving their diagnosis⁵. If a diagnosis is made by the GP in the UK then the GP will refer the patient to secondary care via the two week wait pathway⁶. The two week wait referral pathway is a cancer performance standard from NHS England and Improvement detailing that all patients who have suspected cancer should be seen by a specialist within two weeks^{6, 7}. After receiving a confirmed cancer diagnosis, the patient will then be sent for further investigations to determine the stage, spread, and best course for treatment⁸. Treatment will consist of radiotherapy, surgery or systemic anti-cancer therapy or a combination of these^{4, 8}. Patients may have several lines of therapy and depending on the type of cancer, they may end up in remission with possible subsequent relapse⁸. The prognosis for a patient depends on the cancer type itself, age of the patient, the stage at diagnosis, other co-morbidities the patient may have and the spread of the cancer among other determinants^{9, 10}. Those with a poor prognosis or who have incurable cancer will find themselves living with cancer, others may survive beyond cancer. The

experience patients have as they undertake their individual journeys will play an important role in their recovery and outcome¹¹. All cancer patients will spend much of their time in the community spending only small amounts of time in hospital for appointments and inpatient stays. Some may spend lengthened time in hospital as an inpatient, but they will remain in the community for the most part of their time living with cancer. Therefore, the significance of accessible care in the community is important as patients will be able to receive the care they need in the right place and at the right time.

1.2 Living longer with cancer

There are 2.5 million people living with cancer in the UK as of April 2016¹². The priority for the NHS is for cancer patients to not only live with cancer but to live well with cancer¹². The cancer charity Macmillan Cancer Support states that an individual is twice as likely to survive after a cancer diagnosis for at least 10 years than the same individual would have 40 years ago¹³. The charity recognises that once the initial acute treatment of cancer is completed, many patients have other unmet needs such as physical or emotional problems¹³. There are many different ways in which a patient's life can be affected by cancer and there is a call for an individualised approach. The 2015 Cancer Strategy for England stated that 83% of people were financially impacted by their cancer¹⁴. One of the recommendations from this strategy was to ensure that everyone with cancer has access to the recovery package¹⁴. The recovery package encompasses a holistic needs assessment, a cancer care review, a treatment summary and access to health and well-being support¹³. The holistic needs assessment should be conducted at diagnosis and then at different time points throughout the patient's care and is completed by the patient's hospital team. The cancer care review should be completed 6 months after diagnosis and should be completed by the GP¹⁴. The treatment summary should be completed after each treatment phase and a copy sent to the GP¹⁴. Health and well-being opportunities should be provided to the patient and their carer(s) throughout the patient's care and can consist of access to a Macmillan support worker, information online or written information, and health and well-being events. Since the introduction of the recovery package in 2014 it has now been revised and is known as personalised care and support planning (PCSP)¹³. It is

estimated that around 80% of cancer teams across England are offering personalised care and support planning¹⁵.

1.3 Cancer services in the UK

Cancer services in the UK are managed locally by cancer alliances. There are 21 cancer alliances in England¹⁵. Each cancer alliance brings together the cancer care providers within their region to improve outcomes locally¹⁵. They are responsible for ensuring the priorities for cancer set by NHS England and NHS Improvement are met¹⁵. Some cancer services are delivered by providers in primary care such as community pharmacies and GP surgeries. They are responsible for educating patients on how to prevent cancers, identifying, and referring possible cancers and supporting patients who have active cancer. It is the responsibility of a GP, should they suspect cancer in one of their patients, to refer the patient via a two week wait pathway to secondary care. If cancer is confirmed, the GP is responsible for providing on going care to the patient in relation to their cancer. A number of smaller general hospitals provide some cancer care. This includes cancers of low complexity. Specialist cancer hospitals provide care to patients of low complexity and high complexity. It is the patient's choice guided by the knowledge of the GP as to where the patient would like to be treated.

1.4 Detailed analysis of cancer strategic policy

There have been several policies for cancer over the last two decades, as shown in Table 1. Each policy has built on what the previous one had or had not achieved. These policies have spanned a few different governments. For example, the first cancer strategic policy, the NHS Cancer Plan (2000)¹⁶ contains a foreword from Alan Milburn, the Secretary of State for Health for Labour at the time. The policy entitled Improving Outcomes: a strategy for cancer (2011)¹⁷ contains a foreword from Andrew Lansley and Paul Burstow who represented Conservative and the Liberal Democrats respectively, during the Coalition Government. This shows how much impact the government has on shaping England's cancer strategy.

The changing government is not the only factor affecting cancer strategy. There has been a change in the incidence of cancer as well as survival. For example,

the NHS Cancer Plan (2000)¹⁶ notes within the executive summary that more than one in three people in England will develop cancer and one in four will die of cancer. The cancer risk has now increased to one in two people will be expected to be diagnosed with cancer². For people diagnosed with cancer in 2015 the one year survival is 11% higher than it was when the NHS Cancer Plan was published in 2000^{16, 18}.

The Five Year Forward View (2014)¹⁹ provided a strategy for not only cancer but the whole NHS. Following on from the Five Year Forward View (2014)¹⁹ the Independent Cancer Taskforce was established to deliver the objectives set over the next five years. The taskforce produced the cancer five year strategy and several documents following this to provide updates on progress^{14, 20-22}. The progress report (2017) for 2016-2017 highlights a number of improvements such as the establishment of 19 cancer alliances (which later became 21), the pilot of the faster diagnosis standard which has now been fully implemented and the new 'be clear on cancer' campaigns among many others²¹. The progress report also introduced the vanguards. The vanguards were three cancer alliances that were set up earlier than the others to test ways of working and new models of care which the later cancer alliances then learnt from²¹.

The NHS Long-Term Plan (2019)¹⁸ was the next significant paper to recognise the work that had been done and to set the ambitions and commitments for the next 10 years¹⁸. It is the responsibility of the NHS Cancer Programme to deliver the objectives for cancer in the Long-Term Plan. These objectives were developed from the work and recommendations from the Independent Cancer Taskforce²³.

A year later after the NHS Long-Term Plan (2019)¹⁸ was released COVID-19 hit, changing the future of the NHS. The government released Build Back Better: Our Plan for Health and Social Care (2022)²⁴. This strategy recognised the pressure that the NHS came under commending its efforts of continuing with cancer surgery and care²⁴. The government increased funding for elective recovery to support the restoration of cancer services²⁴. Where the other strategies built on from work from previous strategies, this strategy was focused purely on recovery from the effects of COVID-19.

The 10-year Cancer Plan is due to be published this year and it will focus on the positive effects the pandemic has had on cancer innovations and improvements, what additionally needs to be adopted and then looking beyond the Long-Term plan²⁵.

As the years pass more attention is given to preventing cancer and cancer screening in the new strategies that are released. This is likely because survival is improving, and more is known about risk factors for cancer and suitable methods to prevent it. This allows for community pharmacists to be highlighted as key members of the workforce for patient self-management and health checks¹⁸. The Cancer Reform Strategy (2007) recognises the importance of community pharmacists in smoking cessation²⁶. Attention to the experience of patients is provided early on but where initially it has a tokenistic feel, the importance of patient experience increases as more realisation of its impact on patient outcomes improves.

Table 1: Cancer strategic policies published from 2000 – present.

Title	Publication year	Summary of policy
NHS Cancer Plan ¹⁶	2000	The first national cancer programme for England. Details four aims; save more lives, ensure cancer patients receive the right support and care, reduce inequalities, and invest in the cancer workforce, research, and genetics.
Cancer Reform Strategy ²⁶	2007	Sets direction for cancer for the next five years detailing 10 areas of action related to improving cancer outcomes and delivery.
Improving Outcomes: a strategy for cancer ¹⁷	2011	Outcomes strategy to save an additional 5,000 lives every year by 2014/2015 with the view to reducing inequalities at the same time.

Five Year Forward View ¹⁹	2014	Aims to provide better prevention, faster diagnosis and better treatment, care, and aftercare.
Achieving world-class cancer outcomes - A strategy for England 2015-2020 ¹⁴	2015	Five-year strategy to deliver the vision in the Five Year Forward View. Six strategic priorities are identified.
Achieving World-Class Cancer Outcomes: Taking the strategy forward ²⁰	2016	An implementation plan to deliver the cancer strategy for England.
Achieving World-Class Cancer Outcomes: One Year On 2015-16 ²²	2016	Review of the first year of the cancer outcome strategy and highlighting areas to focus on.
Delivering World-Class Cancer Outcomes: Guidance for Cancer Alliances and the National Cancer Vanguard ²⁷	2016	Details guidance for cancer alliances and the national cancer vanguard to deliver the cancer strategy for England.
Achieving World-Class Cancer Outcomes: A strategy for England 2015-2020. Progress report 2016-2017 ²¹	2017	Review of the cancer strategy for England after the second year.
NHS Long Term Plan ¹⁸	2019	Sets out the commitment to improve cancer outcomes and services in England over the next 10 years specifically looking at improving quality of life outcomes, improving patient experience, and reducing variation and inequalities.
Build Back Better: Our Plan for Health and Social Care ²⁴	2022	Details the impact of COVID-19 on the NHS as well as what the NHS

		has achieved during this time and future plans for reform and funding.
10-Year Cancer Plan ²⁵	To be confirmed	Awaiting publication.

1.5 COVID and effect on cancer services – how covid affected and increased usage of oral anticancer therapy

COVID-19 had a profound impact on the care of cancer patients, the numbers of new diagnoses and the services that provide cancer care. There were significant reductions in urgent two week wait referrals which may lead to a future increase in late diagnoses and subsequent death²⁸. Both secondary care and primary care are still coping with significant backlogs of patients who have not been diagnosed or who are untreated²⁸. Another impact for diagnosis was the pause on cancer screening programmes²⁹. Macmillan, in their 'The Forgotten 'C'? The Impact of Covid-19 on cancer care', publication estimated there to be 50,000 missing diagnoses across the UK in 2020³⁰.

In terms of the impact of patients who currently had cancer, it was quickly realised that cancer patients were particularly at risk of COVID-19. This was because they may be receiving chemotherapy or radiotherapy, they may have recently undergone a bone marrow or stem cell transplant or due to the type of cancer they have a weakened immune system. The European Society of Medical Oncology produced guidelines on how to manage cancer patients during the pandemic³¹. One of the recommendations within this guideline was for patients who are currently receiving systemic treatment to consider switching temporarily to an oral anticancer therapy³¹. The same was recommended by the NHS in their 'clinical guide for the management of non-coronavirus patients requiring acute treatment: cancer'³². This approach occurred in many other parts of the world also, for example, the Netherlands, Germany, and Italy³³. In the UK at the hospital where the author was working at the time, the oncology pharmacy department set up a system to post the oral anticancer medication to the patient after the patient had had bloods taken locally and a virtual consultation with the hospital consultant. This removed the interaction between

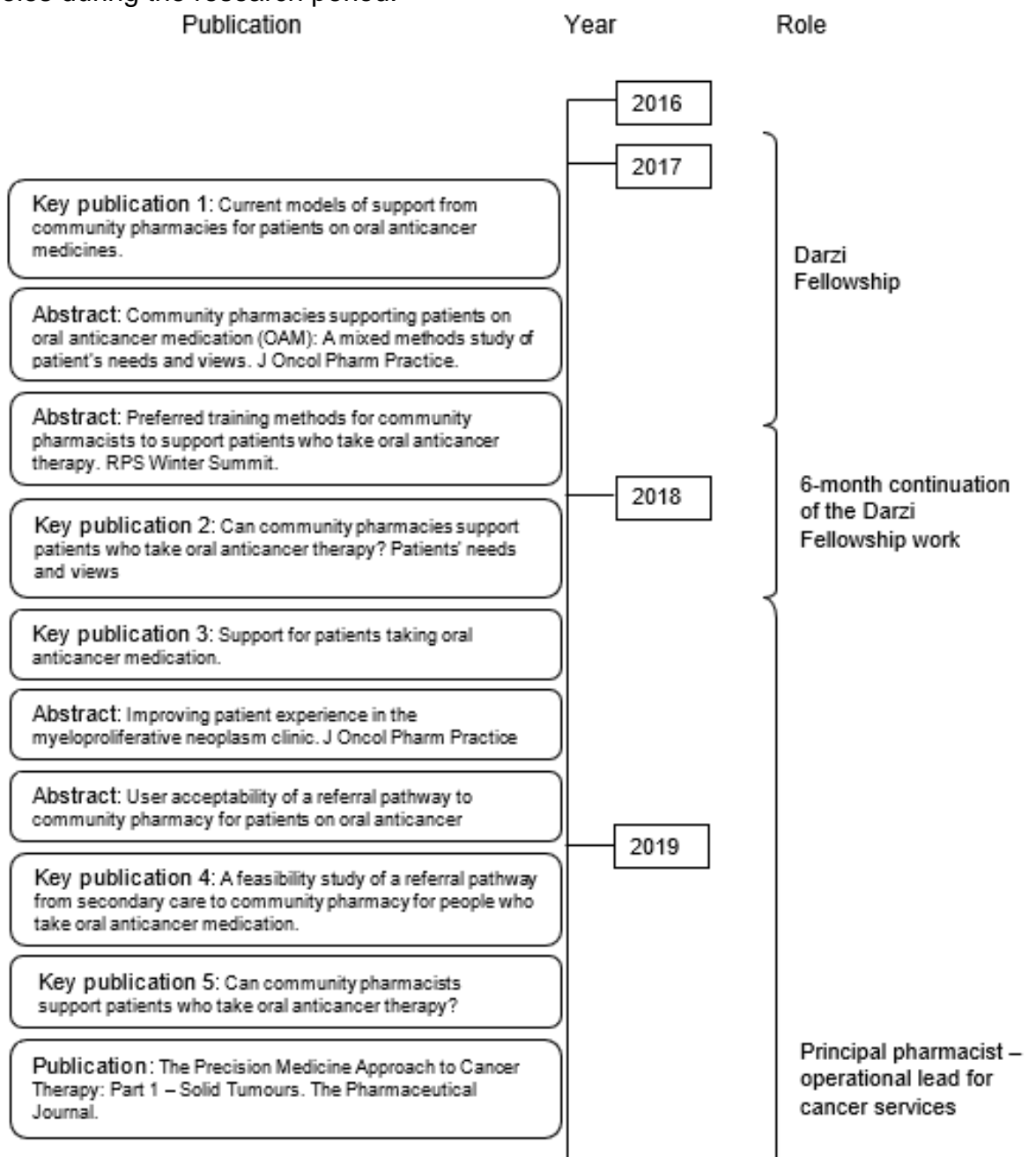
the patient and the hospital pharmacist thus reducing the opportunities for conversation around side effect management and interaction with other medicines. A safer solution could be to deliver to the local community pharmacist who upon suitable training could provide this essential dialogue with the patient when the patient comes to collect. This idea links to the first theme of the author's research.

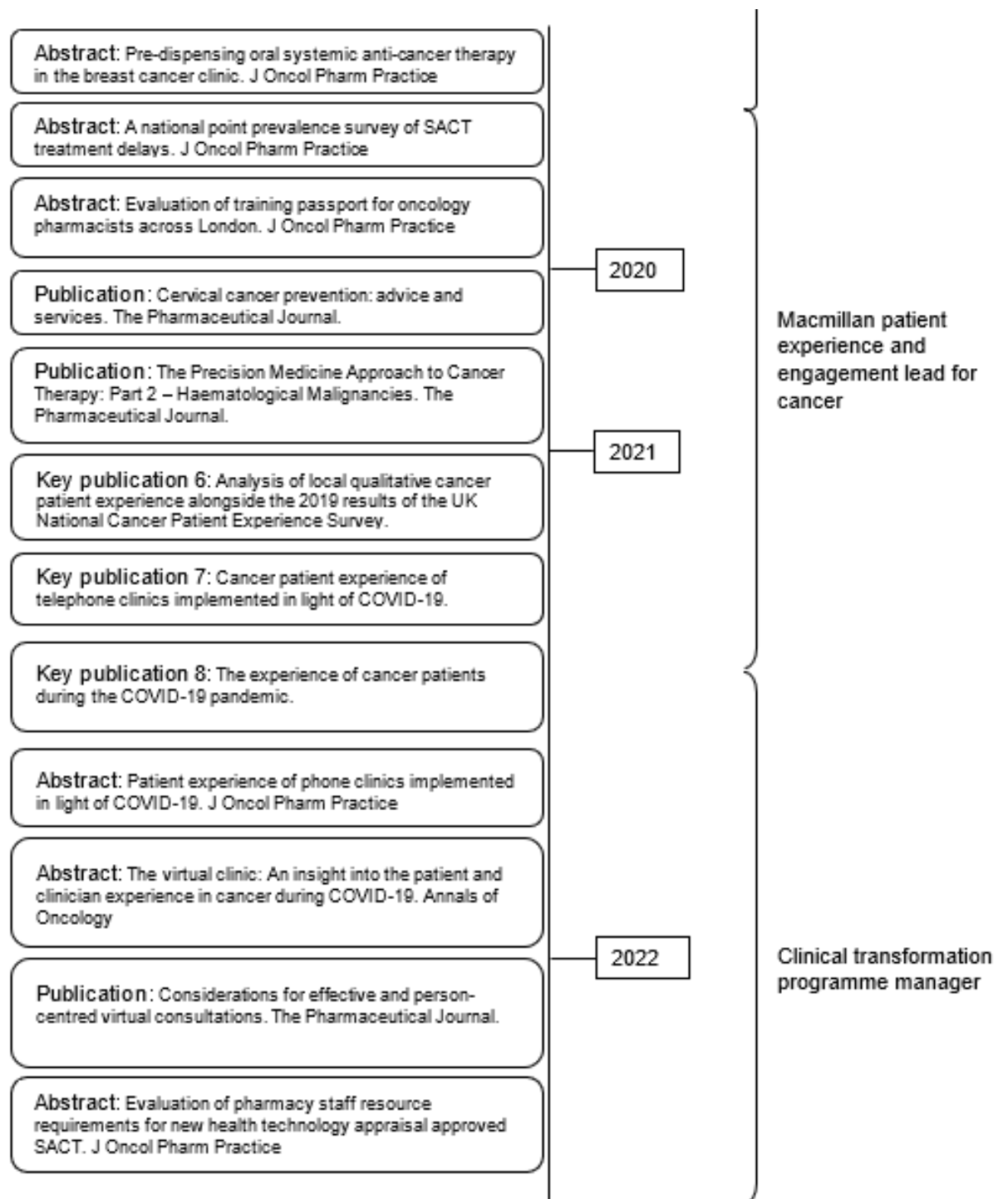
1.6 Career history

The author's career working in a hospital setting started in 2008. It wasn't until four years later that the author decided to specialise in cancer having completed the required pharmacy training. The first few years as a specialist cancer pharmacist were spent operationally acquiring skills and knowledge of the different aspects of the care of someone with cancer. The author spent one year as a highly specialist oncology pharmacist before starting a Darzi Fellowship. A Darzi Fellowship is a bespoke leadership programme that combines an academic qualification with the experience of undertaking a complex change initiative³⁴. The academic side taught the author different theories for managing change and dealing with wicked problems in a healthcare setting³⁴⁻³⁶. The complex change which the author focused on was scoping how community pharmacists could support patients who took oral anticancer therapy. This was the beginning of the author's research career and where the interest in research started (refer to figure 1). The author spent a significant amount of time and thought into the planning of the Darzi project. This led to the realisation that a review of the current literature surrounding the topic was essential. The author completed a literature review as a sole author and published this in 2017³⁷. By following the project plan the author completed the Darzi year with enough data for another two publications^{38, 39}. At this point the author had already decided that a PhD was something that was achievable with the support network that had built up over the year. The author applied to the Clinical Doctoral Research Fellowship (CDRF) commissioned by the National Institute for Health Research (NIHR)⁴⁰. At this point the project had gained traction and the author was able to secure 6 months of funding from Guy's and St Thomas' NHS Foundation Trust (GSTT) to continue the next step of the project whilst also working with a consultant haematologist on a quality

improvement project. During this time the author was unfortunately unsuccessful at securing the NIHR CDRF despite making it through to the interview round. However, the author was able to complete a feasibility study to test the model of care that community pharmacists could support patients who took oral anticancer therapy⁴¹. This provided the author with additional data to apply for the NIHR CDRF a second time round. Once again, the author was successful in application and was invited to interview but was not awarded the fellowship.

Figure 1: Timeline of key publications, abstracts, other publications and job roles during the research period.





The author took on a more senior position in the pharmacy oncology team at GSTT for 16 months covering maternity leave. At the end of this, there was not a role available, so the author left GSTT and started a new job as a Macmillan Patient Experience and Engagement Lead for Cancer and Barts Health NHS Trust. This role allowed for the flexibility to lead on innovative projects whilst incorporating research methods. The author has therefore continued to

undertake research and publish work under a new topic within the umbrella theme of optimising the cancer patient journey.

1.7 Structure and outline of the thesis

This thesis describes the author's contribution to research from 2017- present. Chapter 1 starts with an introduction of a journey that a typical patient with cancer might go through. This helps the reader to understand all the challenges, difficulties, and decisions that a cancer patient and their families or carers must face. The chapter then sets the scene for the two themes that make up the body of research. These are community pharmacists supporting patients with oral anticancer therapy and cancer patient experience. These themes contribute towards the research question of how to optimise the cancer patient journey. Chapter 1 explains the relevance of the research to ongoing national strategic health policy describing the significance of the work in relation to key papers such as the NHS Long-Term Plan¹⁸. The author's career history is included to provide the reader with an understanding of how the author's career shaped the research.

Chapter 2 provides an overview of the methods used and why they were chosen. The author has presented them in the sequence that they were used to display the learning and skills that were developed as the research progressed. This is important as more skilled methods could not have been conducted without first learning simpler methods.

Chapter 3 and chapter 4 are devoted to each subtheme. Within each there is a summarised literature review, a discussion as to how the articles fit within the umbrella theme and the area of research, outputs, and future plans for the research theme.

The main purpose of the final chapter is to provide a reflection of the work. This includes a self-critique looking at the barriers and the limitations but also looking forward to personal developments and future research ambitions. The chapter provides a summary of the achieved aims and objectives.

1.8 Aims and objectives of the PhD

1.8.1 Aim

The aim of this thesis is to describe the journey of research undertaken by the author and explain how the work has influenced national policy to optimise the cancer patient journey through community pharmacy support and improved experience of care.

1.8.2 Objectives

- Describe the author's contribution to research to support and provide evidence for the requirement of community pharmacy to support patients who take oral anticancer therapy.
- Describe the author's contribution to research for the importance of patient experience of cancer care and the development of cancer services.
- Provide evidence for the research skills acquired during the research period and how these skills will be further utilised by the author.
- Critique the research undertaken and evaluate its contribution to the topic area.
- Set a goal for future research and academic achievements.

Chapter 2 – Methodology

The understanding and concept of knowledge and how to gain knowledge are fundamentally required to answer the research question of how to optimise the cancer patient journey, which then within this thesis is broken down into the following two questions:

- 1) Can community pharmacists support patients who take oral anticancer therapy?
- 2) How can a cancer patient's experience be improved?

The study of knowledge or epistemology relates to not only 'what is knowledge?' but also 'how do we know something?'⁴². Pragmatism as a concept for research philosophy recognises the differing ways for interpreting the world and conducting research⁴³. As pragmatists believe that no single point of view can provide the entire answer, therefore, multiple methods or mixed methods are often used as the preferred approach^{44, 45}. The methods described in this chapter use a mixed methods approach as well as differing forms of data collection and analysis⁴⁴.

The author used both quantitative and qualitative methods for both themes that make up this research; community pharmacists supporting patients with oral anticancer therapy and cancer patient experience. This chapter explains the different methods used and the rationale for using them along with the methods used for data analysis. A section is included on co-production and patient involvement as this was fundamental to the author's work. The chapter finishes with a description of the publication strategy used to disseminate the work to the most appropriate audience with consideration to achieving the right level of impact. The author recommends referring back to figure 1 in chapter 1 as the methods within the different key publications are discussed.

2.1 Experience of research methodology prior to 2017

As with many healthcare professionals, audit and research is taught at a basic level at an undergraduate level. The author completed the final year dissertation on inhibitors of the eukaryotic translation initiation factor 4E (eIF4E) as anticancer agents. During the pre-registration and early years as a junior

pharmacist, audit and service evaluation work formed a significant part of continuing professional development and the author conducted several small audits and service evaluations. Four of these were accepted as poster presentations at conference level and one was accepted as an oral presentation⁴⁶⁻⁴⁹. Many of these pieces involved working with multi-disciplinary staff teaching the author the importance of collaborative work. The author was also presented with the opportunity of writing an educational article on lung cancer for a pharmacy magazine⁵⁰.

2.2 Research methodology used for this thesis

2.2.1 Medical Research Council (MRC) Framework

The area of research discussed within this thesis can be described as a wicked problem³⁵ that requires a complex intervention⁵¹. The MRC framework provided a suitable logical model to follow to ensure the research included the key elements of development and evaluation⁵¹. Figure 2 displays the framework that was utilised. Table 2 details which key publication links to which element of the framework. It is worth noting that the framework is not linear and development elements can be looked at again even after testing them in a feasibility study. Another point to note is that the MRC have updated the framework since the author utilised it, but the key components remain the same⁵².

Figure 2: The MRC Framework used by the author, 2008⁵¹

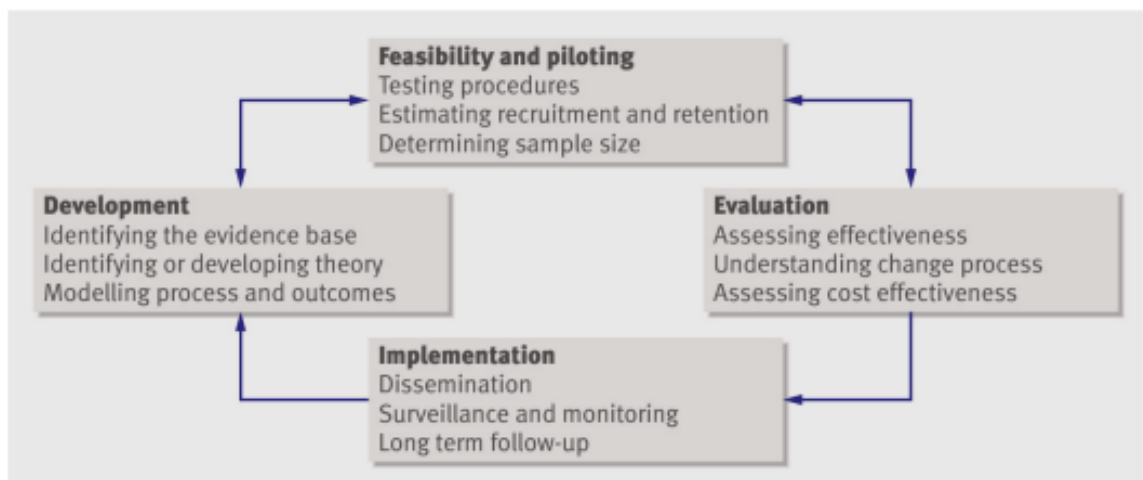


Table 2: Linking the key publications with the specific element of the MRC Framework, 2008⁵¹

Element of the MRC Framework	Publication
Development	Current models of support from community pharmacies for patients on oral anticancer medicines (key publication 1) ³⁷ .
	Can community pharmacies support patients who take oral anticancer therapy? Patients' needs and views (key publication 2) ³⁸ .
	Support for patients taking oral anticancer medication (key publication 3) ³⁹ .
Feasibility and planning	A feasibility study of a referral pathway from secondary care to community pharmacy for people who take oral anticancer medication (key publication 4) ⁴¹ .
Evaluation	Analysis of local qualitative cancer patient experience alongside the 2019 results of the UK National Cancer Patient Experience Survey (key publication 6) ⁵³ .
	Cancer patient experience of telephone clinics implemented in light of COVID-19 (key publication 7) ⁵⁴ .
	The experience of cancer patients during the COVID-19 pandemic (key publication 8) ⁵⁵ .
Implementation	Guidance on the oral anticancer medication (OAM) review service by community pharmacy and the oral anticancer medication (OAM) review both published within key publication 5 and on the BOPA website ^{56, 57} .

2.2.2 Comparison of chosen methods with other literature

Ultimately the research skills the author has gained through this body of work are largely self-taught with direction and guidance from key people. The two applications made to the NIHR CDRF taught the author the level of quality that

was required to conduct a PhD. As the research progressed, the dominant research method used was qualitative. It became apparent from the literature related to the topics and the nature of the topic itself, that this was the best approach as demonstrated by similar research: ⁵⁸⁻⁶¹ Ogunbayo et al (2017) and Yagasaki et al (2015) both used semi-structured interviews as their primary method of data collection when researching patient perspectives (Ogunbayo et al) and conflicts of receiving oral anticancer medications (Yagasaki et al)^{59, 61}. Kelly et al (2014) and Perepelkin et al (2011) had used telephone surveys to research patient attitudes (Kelly et al) and opinions of pharmacists (Perepelkin et al)^{58, 60}. Other articles that supported the use of qualitative as a chosen method included Gill et al who explored interviews versus focus groups⁶².

2.2.3 Literature review – key publication 1³⁷

A literature review was conducted at the beginning of the research under the theme of community pharmacists supporting patients taking oral anticancer therapy. The full research strategy is described in the published literature review – key publication 1³⁷. The author read through other published literature reviews and systematic reviews to understand the methodology and also the process of write-up⁶³. The author chose to complete a narrative literature review for key publication 1³⁷ rather than a systematic review as a summary of the topic was required rather than an answer to a specific question, the author at this point only had a limited understanding of the topic area and the literature available was limited⁶⁴. A narrative literature review was chosen as a summary of the body of literature was required to be able to draw conclusions and identify gaps. The author chose this over a scoping review as the author had selected a specific question whereas scoping reviews are conducted when the research question is more general. A limitation to the literature review was that the author only used two healthcare databases, Medline and Embase. For future literature reviews the author would consider using additional healthcare databases such as CINAHL⁶⁵, the Cochrane Library⁶⁶ and the TRIP Database⁶⁷ to provide a more comprehensive collection of published material to incorporate.

The purpose of the literature review (key publication 1³⁷) was to determine what models of care, whereby community pharmacists supported patients who take

oral anticancer therapy, already existed nationally and internationally. This learning could then be taken forward to develop a model across south east London to provide patients taking oral anticancer therapy with community support. A list of key recommendations was created which formed the basis of this model and is included in key publication 1³⁷.

Literature review skills were instrumental in the ongoing research planning, design, and evaluation of the remainder of the work detailed in this thesis.

2.2.4 Quantitative

The use of quantitative methods is seen as a post-positivism viewpoint or approach to gaining knowledge when used as the sole research method⁶⁸. The post-positivism view is one of traditional research requiring observation and measurement of an objective that truly exists⁴⁴. An important point to note is that post-positivists recognise that knowledge can be objective and do not require absolute certainty⁶⁹. This is different to positivists who believe that scientists should see the world as it really is⁶⁹.

Quantitative methods were used alongside qualitative methods in the author's research to gain data from a larger source through a mixed methods approach following the pragmatist approach⁷⁰⁻⁷². The author required rich data that qualitative methods would be able to provide and combined this with quantitative data collection through surveys⁷⁰. The mixed methods approach was introduced in 1959 by Campbell and Fisk who recognised that research methods do have limitations which could be neutralised by using other methods⁴⁴. A variety of different survey methods were used throughout the author's research demonstrating the new skills the author developed. Table 3 provides a summary of the different surveys and engagement methods that were utilised.

Table 3: Details of the survey methods used throughout the research.

Publication title	Publication year	Intended survey participants	Used in combination with	Methods of survey distribution

			qualitative methods or without	
Can community pharmacies support patients who take oral anticancer therapy? Patients' needs and views ³⁸ (Key publication 2).	2018	Patients who took oral anticancer medications treated at Guy's and St Thomas NHS Foundation Trust.	In combination with data collected through a focus group.	Paper surveys distributed in outpatient clinics by staff members.
Support for patients taking oral anticancer medication ³⁹ (Key publication 3).	2018	Community pharmacy staff in south east London.	In combination with data collected through a focus group.	Electronic survey emailed via the local pharmaceutical committee and made available via a web-based system.
Cancer patient experience of telephone clinics implemented in light of COVID-19 ⁵⁴ (Key publication 7).	2021	Cancer patients at Barts Health NHS Trust.	Combined with qualitative questions.	Data was collected via a telephone survey.
The experience of cancer patients during the COVID-19	2021	Cancer patients at Barts	Combined with qualitative questions.	Electronic survey distributed via text message.

pandemic ⁵⁵ (Key publication 8).		Health NHS Trust.		
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In the design of the surveys shown in table 3, the author reviewed questions in related literature to provide a draft questionnaire. For example articles on the attitudes and opinions of patients towards community pharmacy staff were utilised for key publication 3³⁹ in both the questionnaire design and focus group script design^{58, 60}. In all cases the questionnaire was reviewed by colleagues often in the form of a steering group along with cancer patients. Amendments were incorporated and then sent round for further review until no further comments were made. Many drafts of each questionnaire were produced, and the author took the learning into account when drafting a new questionnaire for the next study. This rigorous process was essential to ensure the validity of each questionnaire. In each case the validity of the questionnaire was tested by content and face validation⁷³. Content validity refers to the extent to which the topic is covered by the questions in the case of a questionnaire^{74, 75}. Face validity refers to whether the questionnaire is measuring what it appears to be measuring^{73, 75}. In many instances both open and closed questions were used resulting in an element of qualitative data analysis. In other instances, quantitative data was combined with a focus group and/or semi-structured interviews with participants.

As shown in table 3, surveys were conducted online or via paper or telephone. The author used a variety of methods for distributing the questionnaire:

1. Paper – key publication 2³⁸

Once produced as a word document, the questionnaire was printed. Staff working in the two outpatient floors of the Guy's Cancer Centre were tasked with handing the surveys out. As every patient who has an outpatient appointment has a weight taken, it was these staff who were deemed most appropriate to distribute the questionnaires. The staff member was given a list of possible oral anticancer medication and each time a patient was weighed they asked the patient if they were taking one or more of these medications. If the patient agreed, they would be

handed a survey to complete. Surveys were collated by the author at the end of each day over the specified data collection period.

2. Telephone – key publication 7⁵⁴

Once the questionnaire had been produced it was circulated to the staff who were conducting the telephone survey. Staff were trained on how to conduct the survey over telephone. A data collection spreadsheet with drop down selections was provided for the staff to complete as they spoke to the patient.

3. Electronic – key publications 3³⁹ and 8⁵⁵

Key publication 3³⁹ utilised Survey Monkey to produce an electronic survey. This was emailed to the local pharmaceutical committee who then emailed it to 133 community pharmacists in south east London. The questionnaire was also added as a link to PharmOutcomes® which is a system utilised by community pharmacists daily for capturing outcome data for their service.

For key publication 8⁵⁵, the author trialled a new method of distribution via text message. A questionnaire was designed using an electronic system called Civica®. This system is more versatile than Survey Monkey® allowing for a wider range of question styles. The author obtained a list of patient mobile numbers from the hospital business intelligence unit. As the hospital already send appointment details to patients via text message, the author utilised the same system to send out the survey link via text. This was made possible through the outpatient department. The author liaised with the hospital information governance team to confirm data governance standards would not be breached.

2.2.5 Qualitative

The philosophy of qualitative methodologies lends itself to the social constructivist view⁴⁴. Social constructivists believe that people look for an understanding of the world and express their experiences subjectively⁴⁴.

Qualitative methods were encouraged and initially supervised by a consultant cancer nurse who the author was working with at the time. During the Darzi

fellowship year (refer to figure 1) the author conducted four focus groups with cancer patients, community pharmacy and hospital staff contributing to key publications 2³⁸, 3³⁹ and 5⁵⁶.

The author initially observed a focus group a colleague was conducting and researched in the literature with regards to questioning techniques and how to conduct a focus group^{62, 76-78}. The author attended a qualitative data training session at the biomedical research department at Guy's Hospital. Each focus group had one or more facilitators present. A debrief was conducted with the facilitator(s) after each focus group.

Each focus group informed the next and the rationale for the order was carefully considered. It was felt that speaking to cancer patients (key publication 2³⁸) first would provide a certain aspect that would be beneficial to fully understand prior to speaking to the community pharmacy staff (key publication 3³⁹) and hospital staff (key publication 5)⁵⁶. Three semi-structured interviews were also undertaken with patients. The data that the cancer patients, community pharmacy staff and hospital staff provided was essential to formulating an appropriate model whereby secondary care could refer a patient to a community pharmacy using a closed system feedback loop. The purpose of the final focus group was to present the model back to the group to not only demonstrate that their comments had been actively utilised but also to gain their opinion to further refine the model. This method can be related to the nominal group technique whereby ideas were taken and clarified from the different groups. The participants were asked to select their preferred idea and then the participants were asked to provide feedback on the final suggested idea^{79, 80}. The strategy used for the focus groups also uses elements of co-production. This is described later in this chapter.

The author continued with qualitative data collection into the second theme of the research question of cancer patient experience. The author had planned to conduct seven focus groups with patients across the four main hospitals of Barts Health NHS Trust for key publication 6⁵³. The purpose of this was to determine the current experience adult and paediatric cancer patients were having to be able to develop an improvement plan. Only one focus group was

conducted as the pandemic of COVID-19 prevented patients from coming into the hospital unnecessarily. The author adapted the methodology and conducted semi-structured telephone interviews instead. This was successful and many of those patients and carers who were originally attending one of the focus groups were satisfied to have an interview over the phone instead. A disadvantage to this methodology was that the author had planned to hold three focus groups with parents and their children who had cancer. The semi-structured interviews meant that only the parents were interviewed as many of the children were too young to interview over the phone.

2.2.6 Quantitative versus qualitative

The author recognised the benefits of both quantitative and qualitative data collection methods including the disadvantages and differing philosophies of each as described earlier⁸¹.

Quantitative methods (a post-positivism philosophy) produce data that can be measured and statistically analysed to provide credible answers⁸². There are limitations to quantitative methods, for example, even with the most rigorously tested questionnaire some respondents may still misinterpret a question or deliberately provide an incorrect answer⁸². Quantitative data collection can oversimplify individual experience as respondents are often grouped into categories⁸³.

Qualitative methods (a social constructivist philosophy) for data collection provide holistic data and allows the researcher to ask layers of questions depending on what answers are given⁸². The data collected is dependent on the questions asked and on the level of experience of the qualitative facilitator.

The author has benefitted from conducting a questionnaire first to gain understanding of the subject from a broad range of people. Then to use this data to narrow down the subject and delve deeper into the answers using qualitative methods. This triangulation of data can be seen in key publications 2³⁸, 3³⁹ and 6⁵³. This is particularly helpful where the answers from a question in the questionnaire have only provided a high-level answer and more detail is required. For example, in key publication 2³⁸ the questionnaire found that only

8% of patients had visited their community pharmacy for a query related to their cancer or their oral anticancer medication. The focus group explored this, and it was realised this was because many patients didn't understand that community pharmacy staff can help them in this way and that patients need to be educated on the role of the pharmacist³⁸. Without the qualitative element the author would have little understanding of why patients were not attending their community pharmacy with these types of queries. Creswell et al (2009) explain that using a mixed method design in this way uses the strengths of both research methods (quantitative and qualitative) to provide the best understanding of the research question particularly when one method alone would be inadequate⁴⁴.

Morgan (1998) describes four different strategies for combining qualitative and quantitative research⁸⁴:

- Preliminary qualitative methods in a quantitative study.
- Preliminary quantitative methods in a qualitative study.
- Follow-up qualitative methods in a quantitative study.
- Follow-up quantitative methods in a qualitative study.

For the purposes of key publications 2³⁸, 3³⁹ and 6³⁸ the author can confirm that the strategy for these were preliminary quantitative methods in a qualitative study⁸⁴.

2.2.7 Feasibility study – Key publication 4⁴¹

Arain et al (2010) describe a feasibility study as a research study conducted prior to the main study⁸⁵. The purpose of completing a feasibility study is to identify several parameters which are required for the main study⁸⁵. The intervention for this feasibility study was a patient adherence check for oral anticancer therapy with a community pharmacist. Patient participants were provided with a self-assessment form for adherence by the hospital and were referred to a local community pharmacy. The community pharmacist was responsible for contacting the patient to arrange a suitable time for the patient to visit whereby the community pharmacist conducted a medication related consultation focusing on adherence using the self-assessment form as a guide.

For the purpose of key publication 4⁴¹ the feasibility study was conducted to determine the:

- Willingness of patients and community pharmacy staff to be recruited if the feasibility study were to be scaled up.
- Practicality of delivering the intervention in the proposed setting (south east London).
- Acceptability of the intervention to the users.
- Characteristics of the proposed outcome measure.
- Follow-up rates and response rates.
- Time needed to collect and analyse data⁸⁵.

No outcome measures can be analysed or reported from a feasibility study. It is to test the logistics in preparation for a larger study. This provides the outcome measures for the larger study with more credibility as learning from the feasibility study are incorporated. A feasibility study is different to a pilot as a pilot is considered a miniature version of the main study and the data collected can be analysed and set aside as an external pilot⁸⁵.

2.3 Chosen methods for data analysis

2.3.1 Descriptive statistics

Descriptive statistics was used for all quantitative data in the body of research described in this thesis. The author undertook training at the Biomedical Centre for Research at Guy's Hospital of more complex statistical methods but felt that descriptive statistics was sufficient for the purposes of this research. A number of the quantitative studies conducted had relatively small sample sizes⁸⁶⁻⁸⁸ and, in many cases, only a summary of the information was required to draw conclusions or to move onto qualitative data analysis⁸⁹. This applies to key publications 2³⁸, 3³⁹, 7⁵⁴ and 8⁵⁵.

2.3.2 Thematic analysis

The author attended training at the Biomedical Centre for Research at Guy's Hospital on qualitative data collection and analysis as well as engaging support from a consultant cancer research nurse who had co-facilitated the focus groups for key publications 2³⁸ and 3³⁹. There were a number of articles that

provided the author with a basic understanding of conducting thematic analysis^{59, 61, 77, 90-92}. For the qualitative data that was analysed using thematic analysis, another co-author to the publication reviewed the codes to reduce bias and assure credibility. This was completed for key publications 2³⁸, and 3³⁹. Another method for assuring credibility was the use of the Consolidated criteria for Reporting Qualitative research (COREQ) checklist⁹³. This was used to ensure the required aspects were considered prior to undertaking the study and then during write up of the publication.

After having used thematic analysis for key publications 2³⁸ and 3³⁹, the author wished to explore other methods for qualitative data analysis. When using thematic analysis, there is a lack of clear guidance to follow when undertaking this method^{94, 95}. This is described by Braun and Clarke (2006) who identify a gap in the literature of an adequate outline of the theory, application, and evaluation of thematic analysis⁹⁴. This is supported by Lorelli et al (2017) who identify that there is not enough literature to describe how to conduct rigorous and relevant thematic analysis⁹⁵. Braun and Clarke (2006) suggest that thematic analysis is a foundational method that all qualitative researchers should learn prior to undertaking more complex qualitative analysis methods⁹⁴.

The author used two different approaches to thematic analysis, inductive and deductive. The inductive approach which allows data to determine the themes was used for key publications 2³⁸, 3³⁹, 7⁵⁴ and 8⁵⁵. The deductive approach is used when there are preconceived themes based on theory or existing knowledge. This was used for key publication 6.

2.3.3 Framework matrix

When preparing for key publication 6⁵³, the author researched and read a number of articles for how to use the framework matrix method for qualitative data⁹⁶⁻⁹⁸. As key publication 6⁵³ looked at combining data from a national survey along with locally collected data it was felt that the thematic analysis method would not be suitable and that this was an opportunity to try another type of qualitative data analysis method. The framework approach has been shown to be beneficial for this type of analysis whereby there is cross-sectional descriptive data^{97, 99}. Other benefits to the framework approach are that it

displays transparency of the data and the process involved is more structured than thematic analysis^{97, 99}. Some concepts were the same as for thematic analysis such as recording of the interviews, transcription and then uploading of the transcription to the Nvivo® software. The main difference was that the themes used across the top of the matrix came from the National Cancer Patient Experience Survey (NCPES) questions. By listing the quotes within the matrix for each case according to the question the quote related to, the author was able to pull a theme together by reviewing the quotes to each question and understand the meanings within that theme or per case. The author found that when analysing using thematic analysis more re-reading of the same transcriptions was required to ensure accurate coding. This was not required with the framework matrix as the matrix provided a clear structure. The author found that it was efficient for the second author to review and discuss any amendments using the matrix. This qualitative data analysis method could benefit large data sets¹⁰⁰. The author would consider using this method for future qualitative data studies for the reasons described.

2.4 Data triangulation

Heale and Forbes (2013) described data triangulation in the use of research as 'the use of multiple theories, data sources, methods, or investigators within the study of a single phenomenon¹⁰¹. Using two or more methods of data collection, such as qualitative and quantitative data collection, can be described as triangulation^{101, 102}. Therefore, the author had previously used triangulation of data in the studies where qualitative and quantitative data collection had been used for the purpose of investigating one phenomenon (see table 2). The difference that key publication 6⁵⁵ brings is that the quantitative data collected was not collected by the author but was collected as part of a national project. The local qualitative data was collected by the author, but the criticism of triangulating that with outside data would be that the two different data sources may not be comparable and may have different weightings for the research question¹⁰¹. This was considered as a possible limitation to the study. The other consideration was regarding whether the data was convergent and led to the same conclusions, the data was complementary and may supplement each other but relate to different phenomena or be divergent to each other in that

they contradict each other^{44, 101}. The triangulation of the NCPES data and the locally collected qualitative data used in key publication 6⁵⁵ was described as divergent as the triangulation led to new and better explanations of the phenomenon under question which was cancer patient experience in this case¹⁰¹. The author felt the need to triangulate the data in this way as the NCPES only provides high level data. To be able to make significant changes to the experience of cancer patients locally it was essential for the author to delve into questions deeper hence the requirement of in-depth interviews. Chapter 4 describes this work in more detail.

2.5 Governance and ethics

The author used the Health Authority Research decision tool to determine whether NHS ethics approval was needed for any of the studies¹⁰³. Due to the fact that the studies did not demand a change to treatment, care, or services from accepted standards to the service users, there was no randomisation of participants, and the findings were not generalisable, none of the proposed studies needed NHS ethics approval. Key publication 1³⁷ was a literature review and the studies undertaken for each key publication 2-8^{38, 39, 41, 53-56} were defined as service evaluations. The publications were recorded on the hospital trust audit or clinical effective unit to allow the trust to acknowledge and monitor progress of the work. Governance was maintained through the collaborative working groups surrounding each study with reporting mechanisms in place at each trust the author was employed with at the time.

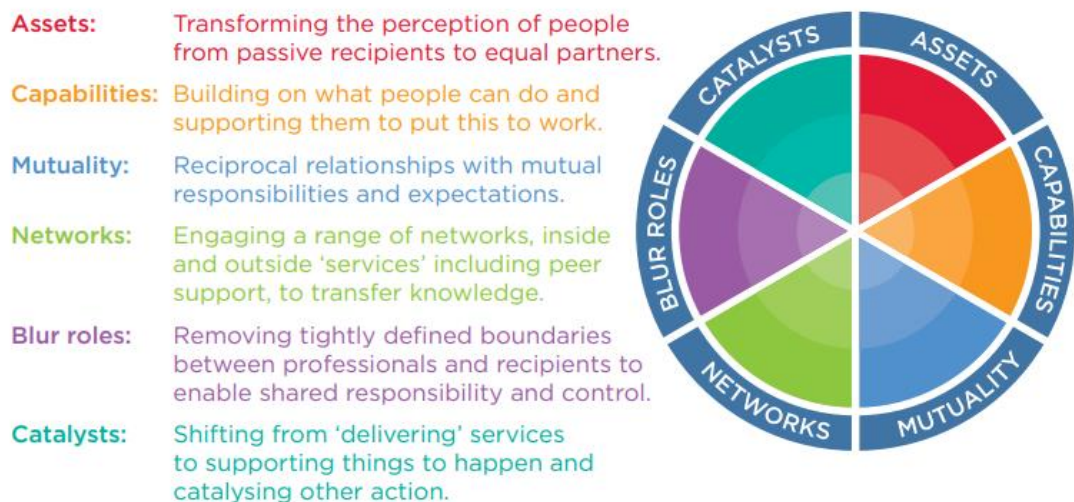
2.6 Co-production

Co-production can be related to the Greek physician Hippocrates who wrote "The physician must not only be prepared to do what is right himself, but also to make the patient, the attendants and externals cooperate"¹⁰⁴. Elinor Ostrom, who won the Nobel Prize for economics in 2009, first fully coined the term and embedded it in her work^{105, 106}. Ostrom worked at the Indiana University and with her team conducted her studies with the Chicago police in the 1970s^{105, 106}. Her work explored why there were certain aspects of policing that provided better services when the police worked with the public¹⁰⁵.

Currently there are a number of different methodologies to try to define co-production. McDougall (2012) describes a series of different frameworks from supplier-centred design all the way through to experience-led design¹⁰⁷. Two models of co-production that link with healthcare are the House of Care which explains the management of chronic health conditions with collaborative management to create personalised care planning and The Chronic Care Model which highlights the need for informed, activated patients to work with proactive professionals to give functional clinical outcomes¹⁰⁸.

The author has utilised the following model produced by Nef and Nesta for the co-production of the research topic as this model incorporated many aspects of those described above whilst presenting the term with a high level of clarification¹⁰⁹.

Figure 3: Model of co-production, developed by Nef and Nesta in the People Powered Health Co-production Catalogue (2012).



The author used this model when developing the steering group for theme 1 of the research, community pharmacists supporting patients who take oral anticancer therapy. This steering group brought together staff within secondary care, cancer patients, carers of cancer patients, and community pharmacists. The group brought together those people who individually had some skills and experience but collectively had the full set of skills and experience needed to progress the project. The steering group maintained a fluidity allowing for members to leave and new ones to join. This allowed for fresh ideas and

networks to form. Most of the steering group members had not worked in this way before and therefore there was a significant amount of individual and group learning. The steering group was in place for the duration of the Darzi Fellowship (October 2016 – August 2017) meeting every month.

This experience encouraged the author to carry on collaborative work in this way during work and in research. Some of the large-scale projects that the author has worked on at Barts Health NHS Trust have included collaboratively working across secondary care and primary care in a similar way to the Darzi steering group. The author has always advocated the requirement of patients and carers on such groups.

2.7 Patient and public involvement

The author advocates for patients and carers to be involved in research and any service improvements that directly or indirectly affects them. The components that make up figure 3 are relevant when working with patients and carers as it is to other stakeholders. Within the steering group developed for the Darzi Fellowship there was a total of 3 patients involved and 1 carer. All were involved in the design and implementation of the Darzi project of exploring how community pharmacists could support patients taking oral anticancer therapy. An example of when the patients made a difference occurred during a steering group meeting. It was noted that only 1 patient focus group attendee came from one of the two boroughs directly surrounding the hospital for key publication 2³⁸. After a discussion with a community pharmacist member of the steering group it was agreed, on suggestion by the patient, that the author would conduct semi-structured interviews with more patients to ensure the demographic of where patients were from was sufficiently representative of the population the Cancer Centre at Guy's Hospital served. This was taken on board and three semi-structured interviews took place. In order to gain further input from patients and carers the author took the project to the chemotherapy patient working group at Guy's Hospital and the south east London cancer research panel. Other examples of how patients and carers supported the work was through the design of the patient survey used for key publication 2³⁸ and they were involved

in designing posters and leaflets of the results to other patients at the Cancer Centre at Guy's Hospital.

In the role of Macmillan patient experience and engagement lead for cancer at Barts Health NHS Trust (refer to figure 1), the author had the flexibility to work with patients on several different projects, steering groups, and patient panels. Through this work, a cancer patient group organically developed. Some members of this group were invited to become members of the different cancer boards across the Trust thus having direct input into patient care. These patients designed and reviewed the interview guide developed for key publication 6⁵³, and key publication 7⁵⁴ and they designed, reviewed, and tested the text message survey for key publication 8⁵⁵.

The author utilised the NIHR Involve resources with regards to how to involve patients.¹¹⁰ This included payment for patients who were involved. The King's Fund produced a report entitled 'Patients as Partners'¹¹¹. This gives practical advice and tips about working with patients, particularly on how to find the right person.

A report which was published in 2019, during the span of the author's research, was the UK standards for public involvement¹¹². This report provides six standards to use as a framework for what good patient and public involvement looks like¹¹². The six standards are not too dissimilar to the six elements of the co-production model produced by Nef and Nesta (2012)¹⁰⁹ and include communications, governance, impact, support and learning, working together and inclusive opportunities¹¹². The main similarities include working together building mutually respectful relationships, building on the capabilities that patients already have and support them to learn new skills and engaging a wide network of patients to ensure opportunities are inclusively accessible^{109, 112}.

2.8 Publication strategy

The strategy for publication was a balance between publishing in peer reviewed, indexed journals, reaching academic readers, and peer reviewed, non-indexed professional journals to reach non-academic readers. Different platforms were used for maximum dissemination. These are described below.

2.8.1 Academic journals

In terms of finding the right journal, the author relied on the author's growing research network for support hence publications in the Journal of Oncology Pharmacy Practice (key publication 1³⁷, 7⁵⁴ and 8⁵⁵), the Cancer Nursing Practice (key publications 2³⁸ and 4⁴¹) and the International Journal of Pharmacy Practice (key publication 6⁵³). These were suggestions from the author's supervisor, the consultant cancer nurse who had co-facilitated the first focus groups and other contacts. A structured strategy was formalised when the author was developing the first application to the NIHR CDRF.

The author supported a previous student at Kingston University to write an article of the continuation of the research area of key publication 7⁵⁴. This has been submitted to the British Medical Journal Open.

2.8.2 Professional journals

Key publication 3³⁹ was published in a pharmacy professional journal. The Clinical Pharmacist, a peer reviewed journal from the Royal Pharmaceutical Society, was a sensible choice for this work as many community pharmacy professionals read this journal and therefore the exposure to the right target was likely to be larger.

2.8.3 Professional websites

Two supporting documents within the first theme were written in preparation for a pilot study to train community pharmacy staff on how to support patients who took oral anticancer therapy. One is a training programme¹¹³ for community pharmacists on how to support patients taking oral anticancer therapy and the other is a service specification¹¹⁴ for how to run a service that supports this patient group. After it became clear that the route of a PhD via the NIHR CDRF for this research topic was not going to be possible the author wanted to publish these two documents to allow others to utilise them. Both documents were published on the BOPA website⁵⁷ and communications were sent round to the members to highlight their presence.

2.8.4 Published books

Key publication 5⁵⁶ was requested by Lambert Academic Publishing from reading key publication 1³⁷. The book was written and published within the year as a resource for someone to continue or set up a similar model elsewhere.

Through BOPA, the author was invited to contribute and review sections of a book entitled 'Setting Up a Cancer Centre: A WHO–IAEA Framework' produced by the International Atomic Energy Agency and the World Health Organisation¹¹⁵. The topic areas the author contributed to were living with and beyond cancer and requirements of a pharmacy cancer team.

2.9 Summary of research skills learnt

This chapter has described the methodology used during the research undertaken. The author has learnt how to collect and analyse both quantitative and qualitative data as well as how to engage and work collaboratively with others including patients and carers. This journey has provided the author with a significant amount of learning some of which has been inspired and encouraged by key role models but other parts of which have been self-taught. For example, the author would not have had enough courage to conduct the first focus group without the encouragement and support of the consultant cancer nurse. The author learnt about thematic analysis from this person too. However, the author realised that analysing the qualitative data with a software such as Nvivo® was essential, therefore the author realised the gap in their knowledge and taught themselves how to use Nvivo®. The author's supervisor has played a significant part in the author's learning by guiding the author and introducing them to new concepts. The author has utilised these key people to help fill in the gaps of their knowledge as well as referring to and learning from relevant literature. By reading different published qualitative studies, not all relevant to the topic, the author was able to understand how to conduct and write up this type of research. The author's learning and ability to translate this learning into their working practice as well as utilise within research will continue.

Chapter 3 - Theme 1: Community pharmacy supporting patients taking oral anticancer medication

3.1 Introduction

Cancer treatments are increasingly being administered orally rather than intravenously¹¹⁶, and it has been estimated that 25% of antineoplastic drugs currently in development are oral medications^{117, 118}. Oral anticancer medication (OAM) requires the patient to self-manage their illness as the patient is responsible for taking the medication at home and reporting adverse effects¹¹⁹. This has led to concerns about adherence, toxicities, and interactions with other long-term condition medication^{120, 121}. Patients who receive OAM are often older, as more than 60% of cancers are diagnosed in older adults, have multiple comorbidities and consequently need more healthcare support¹²²⁻¹²⁴. According to Deery¹²⁵, patients on OAM need as much support as those receiving intravenous chemotherapy but do not receive the same level of support. Patients receiving chemotherapy intravenously will attend the hospital for their treatment and may have extra follow up blood tests on top of the clinic appointments they have. Patients taking oral anticancer medication will likely only be seen by a clinician when they attend their monthly clinic appointments and won't have the extra visits that patients receiving chemotherapy via other routes will have. A big impact that this lack of supervision can have is on adherence¹²⁶ as well as lack of reporting of toxicities. There is a recognition that effective systems need to be put in place for the safety and quality of care for patients taking oral anticancer medication¹²⁶.

Attitudes towards cancer are changing; cancer is being recognised as a chronic condition rather than a life-threatening disease¹²⁷. Many patients are living with advanced or metastatic cancer that although does not have a cure, these patients are surviving longer and living with their disease¹²⁸. Most oral anticancer medications are indicated for advanced or metastatic disease. Administration of OAM creates a shift from hospital to community-based care hence the increased use during the pandemic of COVID-19¹²⁹⁻¹³¹. COVID-19 has played a significant role in that more oral anticancer medications have been utilised during the pandemic to allow cancer patients access to anticancer care without attendance at a hospital as discussed in chapter 1¹²⁹⁻¹³¹. Potential

safety benefits of this include, patients no longer having to attend hospital so frequently, thereby reducing the risk of hospital acquired infections, and the reduced need for intravenous access, reducing the risk of life-threatening infections in an immune-compromised patient group¹¹⁶. This shift from hospital to home-based treatment is already a feature of the management of other disease conditions such as asthma and diabetes¹³². These conditions are now largely treated in the community, signalling the possibility of community-based treatment for cancer.

Community pharmacies are an excellent but relatively untapped source of expertise¹³³. Community pharmacy staff are likely to have increased numbers of encounters with cancer patients as more patients are treated with oral therapy¹³⁴. Many of these patients visit community pharmacies for health advice and for their regular medicines¹³⁵. Interactions between cancer patients and community pharmacists are often missed as community pharmacists are not confident when speaking to cancer patients and are inadequately trained. This corresponds with the survey results of Abbott et al, that showed only 9% (n=352) of community pharmacists felt comfortable educating patients on OAM¹¹⁶. With adequate training, community pharmacies could provide support to cancer patients through side effect management, identifying adherence problems, providing reassurance to the patient, relatives and/or their carers, checking for interactions with other medication, signposting and making referrals to the patient's hospital or to GPs^{39, 91, 136}.

3.2 Relevance to strategic health policy

At the time the author conducted the research, cross-sector working, community pharmacy involvement and providing specialist care closer to home had been documented in the following key policy documents: NHS Five Year Forward View (FYFV)¹⁹, Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020 and the two follow up reports^{14, 20, 22}. The sustainability and transformation plan (STP) for South East London, where the author was working at the time, detailed local implementation plans for the FYFV highlighting insufficient investment in community based services for either preventing illness or encouraging patients to manage their own health¹³⁷. At the

Royal Pharmaceutical Society's Innovators Forum (2016), the integration of pharmacists into new Vanguard care models was discussed¹³⁸. Within the Vanguard models there has been more focus on how hospital pharmacists can work closely with their community counterparts to provide specialist care in the community¹³⁸.

Since the author undertook the research in this area, more significant national strategic health policies have been produced. The most important of these is the NHS Long-Term Plan which was published in 2019¹⁸. The plan highlights the requirement for out-of-hospital care specifically recognising the valuable role community pharmacies can play with urgent care and promoting patient self-care and self-management¹⁸. The plan promises a more personalised approach to care. In relation to cancer care the plan discusses more tailored treatments¹⁸. Lastly the plan focuses on providing more digitally enabled primary and outpatient care thus providing patients with more convenient ways to access advice and care¹⁸. Therefore, a model whereby secondary care and community pharmacies could manage the care of cancer patients collaboratively using technology as an enabler, as discussed within this thesis, falls within the Long-Term Plan's ambitions.

STPs have since advanced into integrated care systems (ICS) to support the delivery of the Long-Term Plan bringing together primary, specialist, physical and mental health, and social care together¹³⁹. The ICSs were implemented in April 2021 and work as partnerships between NHS providers and commissioners within a geographical area¹⁴⁰. Primary care networks (PCNs) are part of the ICSs bringing together general practice and other community providers such as community pharmacies¹⁴¹. One of the purposes of developing the PCNs was to give primary care a louder voice when it comes to decisions about implementing the Long-Term Plan^{18, 142}. These networks will bring knowledge of their local populations' needs whilst strengthening not only the relationship between GP practices and community pharmacies but also the relationship with secondary care¹⁴².

A number of components of the Long-Term Plan have had good progress such as targeted health lung checks among others²⁵. The Department of Health and

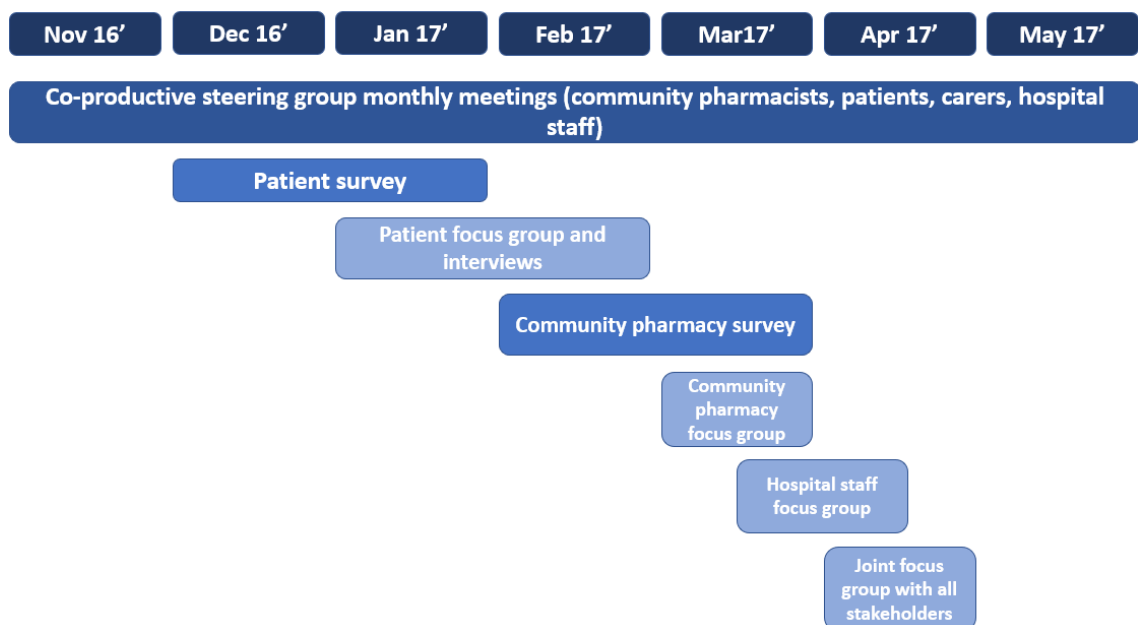
Social Care are now developing a 10-Year Cancer Plan²⁵. This will recognise what has already occurred, some of which will have been accelerated by the pandemic, what innovations and improvements still need to be done and then looking beyond the Long-Term Plan to what further developments will be required for cancer services (refer to table 1)²⁵.

Another significant paper written in 2020 by the Royal Pharmaceutical Society (RPS) specifically focuses on utilising community pharmacy teams to support cancer patients¹⁴³. This paper highlights the need for a wider acceptance of the role that community pharmacists can have when caring for cancer patients¹⁴³. The RPS recognises that community pharmacists are ideally placed to support patients taking oral anticancer therapy, that the community pharmacists should be supported by specialist hospital pharmacists and that a formal referral system would be the ideal method to identify patients in need¹⁴³.

3.3 Stakeholder strategy

The studies for the publications within this theme involved co-production and engagement with different stakeholders. Figure 4 details how and at what point these stakeholders were collaborated with.

Figure 4: Stakeholder co-production and engagement



3.4 Key publication 1: Current models of support from community pharmacies for patients on oral anticancer medicines

3.4.1 Rationale

Prior to initiating the research, the author was working as a highly specialist oncology pharmacist in a hospital and had a key role in supporting patients who took oral anticancer therapy. The author noticed the lack of support in the community for these patients and that patients were reliant on their monthly visit at the hospital for answers to questions related to side effects, interactions with other medications and other medication related queries. It was recognised that there was a gap in the literature with regards to community pharmacies supporting patients who take oral anticancer therapy. Researchers in the Canadian province of Newfoundland and Labrador had conducted a couple of studies^{116, 117}. These showed that a large number of community pharmacists did not have sufficient knowledge about oral anticancer medication and highlighted the need to urgently address the training and education requirements^{116, 117}. Hammond et al (2012) noted that Ireland was dispensing oral anticancer therapy, but this was largely deemed unsafe¹⁴⁴.

There was minimal literature with regards to community pharmacies supporting patients on oral anticancer therapy in the UK. This was therefore the rationale for why the author started with a literature review for key publication 1³⁷. The scoping literature review was intended to be wide to capture as much information on the topic nationally and internationally as possible. The literature review provided a significant amount of knowledge regarding models of care by community pharmacists that could be replicated in a cancer environment within a UK setting.

3.4.2 Contribution to research

Key publication 1³⁷ provides an in-depth overview about the current practice of community pharmacists supporting cancer patients who take oral anticancer therapy happening in the UK and across the world³⁷. As far as the author is aware this had not been conducted before. The publication pulls together best practice from the different models that are discussed creating a

recommendation list for a gold standard model of care whereby community pharmacists support patients who take oral anticancer medication. A key recommendation relates to the use of technology as a backbone to the model of care. Other recommendations include³⁷:

- Training for community pharmacy staff
- Access to chemotherapy protocols and treatment plans
- Communication between community and secondary care pharmacy teams
- Integrated working
- A key link person at the hospital
- An electronic referral system
- Patient consent
- Cancer targeted medicines use review
- Signposting information

3.4.3 Impact, citations, and outputs

After several accepted abstracts to the British Oncology Pharmacy Association (BOPA) annual conferences^{145, 146}, on the work completed, the author was invited to present at the 2018 BOPA Symposium. The presentation was titled: Ways to improve cancer care and patient outcomes through realising value through integrating community and hospital pharmacy. This was a well-attended session and created an engaging discussion post presentation.

As a result of this dissemination, the author was approached by Lambert Academic Publishing (LAP) to write a book around the subject of key publication 1³⁷. The author submitted an outline brief and LAP commissioned the book. Key publication 1 has had 5 citations¹⁴⁷.

3.5 Key publication 2: Can community pharmacies support patients who take oral anticancer therapy? Patients' needs and views

3.5.1 Study rationale

The rationale for conducting a qualitative study with cancer patients was to identify what support they required, whether they currently visit their community

pharmacy and what their perceptions of community pharmacy were. When developing and implementing a new service it is essential to speak to the users of that service as described in chapter 2 through co-production. Their views and opinions were collected through a survey and a focus group.

3.5.2 Contribution to research

Key publication 2³⁸ provided knowledge of what patients who are taking oral anticancer therapy need in terms of support and contact as well as what their opinions of speaking to community pharmacists about their cancer medication was³⁸. It was a mixed method approach with 142 respondents to the survey and five patients and one carer attending the focus group and a further three patients attending semi structured interviews. The data was analysed into three main themes with subthemes identified. The main areas of support that the patient identified were advice on side effect management, medication supply, supportive medication, and reassurance. The patients mainly perceived the role of the community pharmacist to be that of medication supply, advisors on medication and minor ailments. This suggests that patients are not fully aware of the wider support that community pharmacists can provide.

Even though this research was local to south east London, the learning can be utilised in other geographical areas, or the methods repeated to gain comparative data in other areas.

3.5.3 Impact, citations, and outputs

The publications for theme 1 have had numerous citations, the most significant of which being a white paper produced by the Royal Pharmaceutical Society¹⁴³. This paper is titled: Utilising community pharmacists to support people with cancer, and cites key publications 2, 4, and two supporting documents detailed in section 3.8^{38, 41, 113, 114}. This report has been highly distributed.

This publication is significant as it was the first phase of data collection from the stakeholders thus paving the way for key publications 3³⁹, 4⁴¹ and 5⁵⁶. This was also the first study that the author conducted using co-productive methods as discussed in chapter 2. Services that are co-produced have a higher likelihood of sustainability¹⁴⁸⁻¹⁵⁰.

Key publication 2³⁸ has had three citations in total¹⁴⁷. This study was also accepted as an abstract at the 2017 annual BOPA conference and the abstract published in the Journal of Oncology Pharmacy Practice¹⁴⁵.

3.6 Key publication 3: Support for patients taking oral anticancer medication

3.6.1 Study rationale

Key publication 3³⁹ describes a mixed method study consisting of a survey and a focus group with community pharmacy staff to identify if they currently saw cancer patients, if they felt confident and competent to speak to them about oral anticancer therapy and to establish what their training requirements were. This information was essential for the author to understand what the needs and requirements were of community pharmacy staff to be able to extend and implement a high-quality care service for patients taking oral anticancer therapy. For this service to be sustainable and safe, engaging and collaborating with community pharmacy staff, using the co-production method described in chapter 2, was a necessity.

3.6.2 Contribution to research

As stated, key publication 3³⁹ provides an understanding of whether community pharmacists currently see cancer patients as well as training requirements and most suited methods for training³⁹. Nearly 60% of community pharmacists who responded to the survey stated that they interacted with cancer patients.³⁹ This contradicted the comments from the focus group where community pharmacists stated they rarely saw cancer patients³⁹. The findings suggest that community pharmacists are keen to receive training to be able to support patients who take oral anticancer therapy more³⁹. The preferred methods for training were online packages, reading materials and evening meetings³⁹. The community pharmacists were keen to integrate with secondary care for the benefit of these patients³⁹.

There have been some studies which have looked at training requirements for community pharmacists for cancer but these studies have all collected the data through survey alone e.g. Abbott et al (2011)¹¹⁷, Abbott et al (2014)¹¹⁶

Charpentier et al (2012)¹⁵¹ and Mensah et al (2018)⁶³. The author used a combination of focus group and survey in a mixed method approach. The survey was conducted first providing a good understanding of the topic area. Similar questions were used in the focus group, but the author was able to probe deeper into the answers. This provided a more in-depth response to the research question compared with the findings in the literature described above.

3.6.3 Impact and outputs

Key publication 3³⁹ was published in a professional journal therefore it is difficult to evaluate the impact, but the publication would have reached all pharmacy staff who are members of the Royal Pharmaceutical Society as the journal is the official journal for the Society. An abstract was accepted at the Royal Pharmaceutical Society Winter Summit (2017) detailing the preferred training methods for community pharmacists¹⁵².

Key publications 1-3³⁷⁻³⁹ were used to support a funding application to Guy's and St Thomas' NHS Trust Charity. The application was successful, and the author was awarded £36,000. The competitive grant funded the second phase of this work providing remuneration to community pharmacists, for supporting patients taking oral anticancer therapy who were referred to them from secondary care, for the study described in key publication 4⁴¹.

3.7 Key publication 4: A feasibility study of a referral pathway from secondary care to community pharmacy for people who take oral anticancer medication

3.7.1 Study rationale

At this point in the research the author had collated information on the views from community pharmacy staff, patients, and hospital staff on a service whereby community pharmacists support patients taking oral anticancer therapy. The hospital staff data were published within key publication 5⁵⁶. The findings from this mixed method approach enabled the co-production of a model of care whereby community pharmacists supported patients taking oral anticancer therapy. The rationale for the feasibility study was to test the proposed model of care prior to conducting a formal pilot.

3.7.2 Contribution to research

The feasibility study is described fully in key publication 4⁴¹. This study describes the model of care for referring patients to primary care from secondary care and tests the key elements for this pathway. This article therefore provides new research into this topic area and paves the way for others to set up similar services. The key finding of this study was that a referral system whereby hospital staff could refer patients to community pharmacists was safe, feasible and acceptable to the users. The methods tested to determine adherence, drug-drug interaction incidence and user acceptability were appropriate for a larger scale study to take place.

3.7.3 Impact, citations, and outputs

Key publication 4⁴¹ has one other citation along with the white paper produced by the Royal Pharmaceutical Society^{143, 147}. The abstract for this study was accepted at the 2018 annual BOPA conference and published in the Journal of Oncology Pharmacy Practice¹⁴⁶.

3.8 Key publication 5: Can community pharmacists support patients who take oral anticancer therapy?

3.8.1 Rationale

The author was invited to write a book by the Lambert Academic Publishing (LAP) group on recognition of key publication 1³⁷. LAP tasked the author with writing a book on the same topic as key publication 1³⁷. The author utilised the opportunity to publish elements of the research related to community pharmacists supporting patients who took oral anticancer medication that had not been published elsewhere to produce key publication 5⁵⁶. The author wished to share the full body of research that had been undertaken as one piece to take the reader through the journey that the author had taken and to engage the reader to set up a similar model within their locality.

Within this publication two documents have been published as appendices:

- 1 Oral anticancer medication (OAM) review by community pharmacy training programme

2 Guidance on the oral anticancer medication (OAM) review service by community pharmacy

It was clear from the engagement work with community pharmacy staff that training was a big element for the proposed model to be sustainable. The training programme that was developed¹¹³ provides a clear series of activities for community pharmacy staff to undertake to increase their competence of supporting patients who take oral anticancer therapy. The Calderdale Framework was used in the development of the training programme¹⁵³. The Calderdale Framework is an evidenced transformative tool to support workforce development¹⁵⁴. All the resources listed within the training programme are readily available, but the training programme recommends which ones to use and for what purpose. The programme includes a variety of activities to suit different learning styles (table 4) and separates the resources into essential and desirable.

Table 4: Summary of the main training elements within the oral anticancer medication (OAM) review by community pharmacy training programme

Training element	Topics covered
Resources and reference materials	<ul style="list-style-type: none"> Basic introduction to cancer and chemotherapy Cancer prevention and screening Treatment types Managing side effects to treatment Living with and beyond cancer Palliative and end of life care
Evening educational sessions	<ul style="list-style-type: none"> Question and answer session on side effect management Consultation skills with a nurse Patient workshop with role play Adherence and referral pathway
Half-day visit to the cancer centre	<ul style="list-style-type: none"> Tour of the cancer centre Shadow oncology pharmacist in clinic Shadow clinical nurse specialist in clinic

	Debrief with questions and reflections
Assessment	Questionnaire assessment Objective structured clinical examination (OSCE)
Intervention fidelity	Audiotape 4 consultations within the first month and if deemed competent then audiotape 1 consultation a month for the remainder of a full year
Competencies	Competency standards for sign off

The guidance document¹¹⁴ that sits alongside the training programme is a service specification for how community pharmacies can set up the model of care. This document was endorsed by the Royal Pharmaceutical Society and provides a clear aim for the service along with conditions that need to be met and further specifications in order to run a safe service. The main rationale for this document was to provide community pharmacies and any potential commissioners with clarity of the model of care as well as providing standardisation for the service across multiple pharmacies. This is essential to ensure cancer patients receive the same level of care regardless of where they are being seen.

3.8.2 Contribution to research

The second chapter of the book provides the reader with an updated literature review. The updated literature is discussed in a different style from the original literature review of key publication 1 with new literature included³⁷. Chapter three and four are devoted to patient's needs and views and community pharmacists' view's respectively thus relating to key publication 2³⁸ and 3³⁹. Both chapters include data that were not published in the original publications as well as including related grey literature which was not discussed within the original publications. Chapter five describes the results of the hospital staff focus group which has not been published anywhere else as the sample size was too small. Therefore, the book provides a discussion from all of the stakeholders, patients, community pharmacists and hospital staff in one place which allows for comparison between the differing viewpoints. The final chapter

before the conclusion discusses the feasibility study which relates to key publication 4⁴¹. Again, this chapter discusses data that was not included in the original publication, but it also informs the reader about what a feasibility study is. Within the research world, there is significant confusion between a feasibility study and a pilot study⁸⁵. The chapter goes on to discuss how the feasibility study was conducted and what the learning points from it were. These topics are often not described in detail in academic research publications, but they are important areas to publish to add to the knowledge of how to conduct research. The book concludes with what further steps are required to convince commissioners and service providers that this support structure is essential.

Even though multiple training programmes are developed across all organisations in the UK to train staff, very few are published. The training programme¹¹³ was produced from the data collected in key publication 3³⁹ along with in house training, utilised for training hospital oncology pharmacists, from the hospital where the author was working,. The purpose of publishing the training programme onto the BOPA website was to ensure this resource was accessible to others.

As with the training programme, a service specification of the model of care to refer cancer patients from secondary care to primary care was published to add to the body of research specifics about what the model would look like in practice¹¹⁴.

3.8.3 Impact and outputs

This book has been available on Amazon UK® since 2019. A deputy chief pharmacist working for the National Cancer Control Programme (NCCP) has used the author's work, specifically the book, for her MSc titled: An Examination of the Views of Pharmacists, on ways to support the Safe and Effective Dispensing of Oral Anti-Cancer Medicines in Community Pharmacy, with a focus on Education and Training Programmes.

Both the training¹¹³ and guidance¹¹⁴ documents are available on the BOPA website for all members to view and utilise and were cited by the Royal

Pharmaceutical Society white paper¹⁴³. To date these documents have received 67 views from the BOPA website.

The author recently at the end of 2021, was invited to present at the Somerset, Wiltshire, Avon, and Gloucester (SWAG) Cancer Alliance as they wanted to utilise the author's learnings with a possibility of adopting the suggested model of care whereby community pharmacists support patients who take oral anticancer therapy. The author has remained in touch for advice and support to the team.

The author was invited to review a study protocol entitled 'Current management of adults receiving oral anti-cancer medications: A scoping review protocol' by the Health Research Board¹⁵⁵.

3.9 Future direction

The author believes that community pharmacists and staff within community pharmacies can provide the necessary support to patients who take oral anticancer therapy not only from the research the author has conducted but from other literature too. The methods used have been successful at obtaining the required data to answer the research questions within this theme. The author has used their learning throughout the first studies to further develop their skills and confidence which led onto the feasibility study (key publication 4)⁴¹. The author has developed as a researcher by creating opportunities for further research work such as presentations and abstracts at conference level, taking on the challenge of writing a book and the other outputs described in this chapter.

The author was unable to obtain further funding to take the feasibility study (key publication 4)⁴¹ onto a full pilot or randomised controlled trial but has continued the overarching topic of optimising the cancer patient journey by focusing on cancer patient experience.

In June of this year the government announced a new pilot scheme whereby community pharmacists will be able to refer patients for scans and checks for those showing symptoms or signs of cancer¹⁵⁶. This highlights the ever-

increasing profile that community pharmacists have with regards to caring for patients with suspected cancer.

Chapter 4 – Theme 2: Improving the experience of cancer patients within the hospital setting

4.1 Introduction and relevance to strategic health policy

The importance of patient experience in ongoing patient care and within the services that the NHS provides has had an increasingly raised profile over the last decade and more. Lord Darzi reported in the 2008 policy¹⁵⁷ from the Department of Health that the quality of patient experience should not only be measured, but that it should impact on how hospitals are funded¹⁵⁸. He recommended payment to hospitals on the quality of care to include patient experience¹⁵⁷. The report highlighted that progress with patient experience has been patchy and there needs to be a focus on empowering staff to provide a higher quality of patient experience¹⁵⁷.

Further evidence reports that improved patient experience leads to better health outcomes, a reduced cost of healthcare, improved patient control over their care, better staff/patient relationships and improved organisational reputation¹⁵⁸⁻¹⁶³. Patient experience has been described as one of the three pillars of healthcare including clinical effectiveness and patient safety with positive associations between each pillar^{159, 164}. The use of patient reported outcome measures (PROMS) and patient reported experience measures (PREMS) have been utilised for some time and can be used to explore the relationship between patient experience and the other two pillars or domains of healthcare^{164, 165}.

The benefits of patient experience are described in The Patient Experience Handbook produced by the NHS Institute for Innovation and Improvement¹¹. The National Institute for Health and Care Excellence in 2012 produced guidance titled; Patient experience in adult NHS services: improving the experience of care for people using adult NHS services¹⁵⁸. Both of these documents provide insight into how NHS providers can measure and utilise patient experience data.

The experience of patients is also highlighted throughout the NHS Long-Term Plan, eleven years after Lord Darzi's report¹⁸. These points relate to patient

choice, improved waiting times, and patient safety among others¹⁸. This shows that patient experience is increasingly important and is slowly being embedded within NHS priorities.

Most UK hospitals now actively measure and report patient experience¹⁶⁶. An increasing number of hospitals also employ staff specifically to focus on improving not only the experience of patients but also engaging patients to work with the trust to make improvements collaboratively. This links back to Lord Darzi's recommendation of staff empowerment.

Although data on patient experience is being collected, staff within hospitals are struggling to make use of that data and translate it into sustainable improvements^{166, 167}. In some instances it might be that the data collected is not reliable enough, there isn't the capacity to carry out the recommendations or enough data hasn't been collected in the first place^{168, 169}.

Even though none of the documents discussed so far are specific to cancer patients, the learnings and recommendations are transferable across all disease areas. Within cancer, most of the literature relating to patient experience discusses data collected from the National Cancer Patient Experience Survey (NCPES). This is a national survey commissioned by NHS England and NHS Improvement to monitor cancer care placing patient experience on par with clinical effectiveness.

Moreover, in response to the recommendations related to cancer in the NHS Long-Term Plan, NHS England and Improvement introduced a new survey called the national cancer quality-of-life survey¹⁷⁰. This is to introduce a quality-of-life metric to track and respond to the long-term impact of cancer¹⁷⁰. This survey was first released in October in 2021 so is very much in its infancy but will provide evidence for the need to continue the case for change.

There is little data published with regards to original research on cancer patient experience. What is available worldwide is limited by sample size and the numbers of cancer types studied^{171, 172}. Studies have shown that patient/carer involvement in decision making for their cancer treatment have shown to reduce decisional conflict, provide a greater satisfaction in their treatment and improve the patient's overall general well-being¹⁷³⁻¹⁷⁶.

The key publications described within this chapter show how the author's research is in line with current and previous national policy discussed above.

4.2 The National Cancer Patient Experience Survey (NCPES)

The National Cancer Patient Experience Survey (NCPES) was implemented in 2010 and is now on its eleventh iteration¹⁷⁷. The survey is commissioned by NHS England and is overseen by an advisory body¹⁷⁷. The NCPES is the first national cancer patient experience survey that has been undertaken of its kind¹⁷⁸. It provides NHS cancer patients across the UK an opportunity to feedback about the experience they have received for their cancer care. NHS trusts are provided with a trust level report of the survey which can be used to benchmark across other trusts and provides them with information on which areas their patients are having a good experience and which areas they need to improve on¹⁷⁷. The data is also broken down by cancer alliances and individual clinical commissioning groups¹⁷⁸.

The NCPES reports have provided evidence that the overall care of cancer patients varies across sociodemographic factors including ethnicity and geographical location¹⁷⁹⁻¹⁸¹.

Utilising the NCPES data alone is not enough to formulate an accurate action plan for improving cancer patient experience. Hospital trusts, cancer alliances and clinical commissioning groups need to be aware of the limitations of the NCPES when interpreting the data. Abel et al (2019) investigated the reliability of the NCPES¹⁸². They calculated the Spearman-Brown reliability of each individual score and considered values of <0.70 to represent low reliability and scores of ≥ 0.90 to represent high reliability¹⁸². They found that two thirds of the scores reported within the 2016 survey results did not meet reliability levels.¹⁸² They describe the key reasons for low reliability to be related to three key mechanisms. Individual hospitals with low sample sizes tended to have low reliability. Questions with limited variation between hospitals resulting in difficulties in distinguishing between hospitals performing at a similar level had low reliability. Lastly some questions across all hospitals have a small number of total respondents as they are only relevant to a small subset of patients¹⁸². Saunders et al (2016) show that higher response rates lead to higher

experience scores¹⁸³. Those questions that had a higher association between response rates and patient experience were those relating to administrative care processes¹⁸³. Saunders et al (2016) theorise that there may be multiple hospital-level factors that drive this¹⁸³. For example, hospitals with a dedicated patient experience strategy are likely to work harder to encourage more patients to return the survey¹⁸³. Those hospitals that have better administrative processes are likely to contain more accurate contact information for their patients thus facilitating better survey response¹⁸³. They also found that low-response rates were more likely to occur in hospitals in London and teaching hospitals^{180, 183}. Therefore, the author recommends triangulating data collected via the NCPES with other internal sources of data to provide a more accurate evidence for change. As far as the author is aware this has not been done before.

4.3 Key publication 6: Analysis of local qualitative cancer patient experience alongside the 2019 results of the UK National Cancer Patient Experience Survey

4.3.1 Study rationale

As previously described the NCPES provides NHS trusts with useful information about the experience of their cancer patients. The survey contains around 60 questions. A limitation in addition to those described in section 4.2 is that it can be difficult to drill down what specifically the trust needs to focus on particularly when the trust has multiple hospital sites and complex cancer pathways. For example, if the data showed that patients had a poor experience as an inpatient, it would be difficult to determine which hospital site or wards to start working with as the data is not provided at that level of granularity. The majority of the NCPES is presented as quantitative data. Although there are three questions that patients can answer qualitatively, often these answers are brief and provide little insight. The author therefore realised that it was essential to triangulate the NCPES data with locally collected data. This and other sources of internal data could then be used to develop an improvement plan for cancer patient experience and engagement for the trust. The method for this study was qualitative to provide deeper insight into what the patients from the trust were

truly feeling and experiencing and specific areas such as wards or departments could be identified to focus on initially.

4.3.2 Contribution to research

Key publication 6⁵³ analysed data collected via a focus group and semi-structured interviews with cancer patients and carers and triangulates this data with the results of the 2019 NCPES. Ten questions were picked from the 2019 NCPES and used to interview patients in north east London. The responses from the participants provided richer insights to the NCPES survey responses. In some instances, it was clear that the NCPES response was not reflective of the detailed response from speaking to a patient or carer. The author therefore recommends for all healthcare cancer providers to collect local data to use in collaboration with the NCPES when forming a strategy for improving cancer patient experience.

Key publication 6⁵³ is the first study to triangulate NCPES data with local qualitative data. It provides a model for other trusts to follow providing readers with information about how the NCPES data can be utilised to specifically relate to locally collected data and how the trust used this data. Secondly, it provides readers with details of how to triangulate data in this way introducing some to new methodology such as the framework matrix. Ideally this would encourage readers to conduct similar research within their own locality. Finally, it provides valuable information on the experience of cancer patients.

4.3.3 Impact, citations, and associated outputs

This publication was published in December of 2021 and currently has been cited in a systematic review¹⁸⁴. The next iteration of the NCPES is in progress and the results for 2021 are expected to be published in 2022. Therefore, it is likely that key publication 6⁵³ will receive more attention in the coming months as healthcare providers start researching how they can best utilise the data received.

The key output for the trust was the improvement plan for cancer patient experience and engagement. This included the need to investigate the

experience of patients with outpatient services as well as improvements in the provision of information and patient involvement.

4.4 Key publication 7: Cancer patient experience of telephone clinics implemented in light of COVID-19.

4.4.1 Study rationale

The COVID-19 pandemic required most healthcare organisations to rethink how they were going to deliver services in an environment where patients were not able to attend the hospital in person. It was highlighted very quickly that physical attendance at an outpatient appointment puts patients at significant risk of catching and spreading the virus¹⁸⁵. Therefore the introduction of virtual clinics was a method by which patients could still receive their care without attending the hospital¹⁸⁵⁻¹⁸⁸. At the NHS trust where the author worked, the uptake of virtual clinics, mainly in the form of telephone clinics, rapidly increased in all specialties including cancer. Therefore, the author identified a need to evaluate the patient experience within these clinics. This allowed the author to focus on outpatient services as suggested within key publication 6⁵³. The findings were disseminated to the cancer boards to allow for ongoing cycles of improvement.

The study was specifically designed to be completed within a short time period as staff resourcing during this time was an issue and the timely collection of the data to provide a snapshot of patient experience was key to allow for prompt improvements.

4.4.2 Contribution to research

The purpose of key publication 7⁵⁴ was to understand the experience cancer patients had of telephone clinics implemented in light of the pandemic. The study was conducted via telephone. The qualitative data were analysed and six themes (rushed, face to face, difficult to assess, communication, benefits, and compassionate care) with two subthemes (positive communication and barriers to communication) were identified. The majority (39/55) were either satisfied or very satisfied with their telephone consultation and 33 out of the 55 participants would like to continue with telephone clinics.

Prior to the pandemic there was a good amount of literature related to virtual clinics some of which related to cancer and the remainder had transferable learning¹⁸⁹⁻¹⁹⁵. What was lacking within the literature prior to the pandemic was how to rapidly implement and spread the usage of virtual clinics and what the experience was for patients on the receiving end. A number of key publications published after the pandemic focused on the implementation and spread but again very few focused on patient experience^{185, 186}. Therefore, key publication 7⁵⁴ not only contributes to this limited researched area by providing an insight into patient experience, but it also specifically focuses on cancer patients. This is key as a significant amount of discussion was had nationally about the impact the pandemic would have on cancer patient outcomes and waiting times^{28, 29, 196, 197}.

4.4.3 Impact, citations, and associated outputs

Currently this publication has received seven citations¹⁴⁷ and has resulted in three academic presentations all via invite to the author. The first was the Oncology Convention which was a virtual conference in March 2021. There were 51 viewers at the time the author presented. The presentation was uploaded for viewing post conference. The second presentation was a nursing webinar in July 2021. This was a similar presentation to the Oncology Convention. The final presentation was a BOPA research webinar. The author amended the presentation slightly to include a section at the beginning to explain the author's research career to date before then discussing the details of key publication 7⁵⁴.

A further output from this publication was the invitation to guest edit a research topic for the journal, *Frontiers in Rehabilitation Science*. This is in collaboration with the author's supervisor. The author and supervisor worked with the journal to identify the research topic of the Impact of COVID-19 on Cancer Care and Rehabilitation.

The author supervised an MPharm student for their final year dissertation to build on the results by completing in-depth interviews with patients and clinicians investigating their experience of virtual clinics. The findings of this work have been presented at the European Society for Medical Oncology

2021¹⁹⁸. The full manuscript is currently under peer review by the British Medical Journal Open. More recently the results and recommendations have been distilled into a learning publication in a pharmacy professional journal¹⁹⁹.

4.5 Key publication 8: The experience of cancer patients during the COVID-19 pandemic

4.5.1 Study rationale

This was a strategic piece of work to inform the cancer board of the trust how the pandemic affected cancer patients. Due to the effects the pandemic was having on cancer services, as described in chapter 1, the trust wanted to understand how these changes were affecting the experience of patients. The results of this study fed into the improvement plan for cancer patient engagement and experience. The cancer board recognised the work and the findings taking on board the impact the redeployment of clinical nurse specialists had on cancer patients.

4.5.2 Contribution to research

Key publication 8⁵⁵ included survey results from 82 respondents categorised into three themes, information provision and safety around COVID-19, impact on cancer care and feeling supported by staff. Patients felt safe coming into the hospitals and were satisfied with the amount of information they were given about protecting themselves against COVID-19⁵⁵. Most patients found that their overall care had not been impacted by the pandemic, but some had received delays⁵⁵. Inpatients felt that they were well supported during this time but would have liked more information about their ongoing treatment plan⁵⁵. Other patients stated that they were not informed about supportive services available to them and 25% of respondents found it difficult to contact their cancer nurse specialist⁵⁵.

This study was one of the first studies to be published on this specific topic. There were plenty of publications relating to waiting times for treatment and surgery which would have impacted on patient experience but nothing that specifically reviewed patient experience²⁰⁰⁻²⁰². Therefore, this publication

provided key insight directly from patients in north east London as to what their individual experience was.

4.5.3 Impact, citations, and associated outputs

This publication was published in December 2021 and therefore there are currently no citations or national impact as of yet. Within the trust where the author works, the data was presented at the cancer boards and circulated to the north east London Cancer Alliance and patient groups. The results were shared with individual cancer teams.

4.6 Future direction

The author has always used the opportunities within their working environment to conduct impactful research. During the time the research was conducted, the author was working as the Macmillan Patient Experience and Engagement Lead for Cancer for the trust. This was a two-year fixed term contract which has now ended. The author has remained within the same trust and is working within the strategy department transforming clinical services specifically within the outpatient setting. Therefore, the author is likely to continue to publish in the areas of virtual consultations, but additionally patient initiated follow up and the use of referral processes into secondary care from primary care.

Chapter 5 – Summary and conclusion

5.1 Summary

The title of this thesis is optimising the cancer patient journey. This research topic encompassed two themes: community pharmacists supporting patients who take oral anticancer therapy and cancer patient experience. Improving cancer patient experience optimises the cancer patient journey for all individuals and the utilisation of community pharmacists to support patients on oral anticancer therapy optimises a particular part of the journey for this cohort of patients.

The thesis contains 8 key publications, five of which relate to community pharmacists supporting patients who take oral anticancer therapy and three relate to cancer patient experience. Within this thesis the author provided an introduction to cancer including a description of the national cancer strategies and the impact COVID-19 has had on cancer patients and cancer services. An in-depth review of the methodology is discussed leading the reader onto the two themes in turn. Within each theme the key publications are discussed in detail including the impact and outputs.

5.2 Summary of achieved aims and objectives

5.2.1 Review of the aim

The aim:

- To describe the journey of research undertaken by the author and explain how the work has influenced national policy to optimise the cancer patient journey through community pharmacy support and improved experience of care.

This thesis described two themes, the first being how community pharmacy can support patients who take oral anticancer therapy and the second describing cancer patient experience. The author has taken the reader through the journey of the origins of the research, how the research was undertaken and then the results and findings. It is clear to see that the research has been influenced by the author's role but that the author created opportunities to be able to continue

the research. The journey described how the findings have been utilised to clinically impact cancer patient care.

The first theme significantly impacted national policy as a number of publications (key publications 2³⁸ and 4⁴¹ and the training programme and service specification published within key publication 5⁵⁶ and available through the BOPA website)⁵⁷ were cited within the Royal Pharmaceutical Society White paper¹⁴³.

5.2.2 Review of objective 1

Objective 1:

- Describe the author's contribution to research to support and provide evidence for the requirement of community pharmacy to support patients who take oral anticancer therapy.

Key publications 1-5^{37-39, 41, 56} and chapter 3 provide the evidence to fulfil this objective. Key publication 1³⁷, the literature review, was fundamental to achieving this objective as it provided the backbone for the rest of the research within this theme. Key publication 2³⁸ (cancer patient views and opinions), 3³⁹ (community pharmacy views and opinions), and 5⁵⁶ provided the data required to be able to complete the feasibility study in key publication 4⁴¹. Key publication 4⁴¹ showed a model whereby community pharmacists who supported patients taking oral anticancer medication could be achieved. Chapter 3 describes how these publications have contributed to the research topic.

5.2.3 Review of objective 2

Objective 2:

- Describe the author's contribution to research for the importance of patient experience to cancer care and the development of cancer services.

Key publications 6⁵³, 7⁵⁴ and 8⁵⁵ and chapter 4 provide the evidence to fulfil this objective. All three publications explored the experience that cancer patients were receiving at the time. Key publication 7⁵⁴ explores patient experience in relation to telephone clinics, key publication 6⁵³ provides more of an overview of

patient experience alongside the NCPES and key publication 8⁵⁵ looks at patient experience in light of the pandemic. Chapter 4 explains the rationale and impact that these articles have had thus achieving this objective.

5.2.4 Review of objective 3

Objective 3:

- Provide evidence for the research skills acquired during the research period and how these skills will be further utilised by the author.

The author has learnt a significant number of skills during this period of research. This can be seen throughout the thesis but is clearly shown in chapter 2 where the author fully explains the methodology including the reasons why those methodologies were chosen and the philosophy behind them. The author has discussed within this chapter (section 5.5.2 and 5.5.3) how they will use these skills going forward for further research.

5.2.5 Review of objective 4

Objective 4:

- Critique the research undertaken and evaluate its contribution to the topic area.

The thesis as a whole provides the evidence for this objective but also specifically section 5.3 of this chapter through assessment and discussion of the limitations of the publications.

5.2.6 Review of objective 5

Objective 5:

- Set a goal for future research and academic achievements.

This chapter (section 5.5.2 and 5.5.3) has explored the future research the author wishes to take forward as well as future academic achievements.

5.3 Reflections on methods and findings

The Medical Council Research Framework provided significant guidance for the author when planning the key stages of developing a complex intervention (key publications 1-3³⁷⁻³⁹) and conducting the feasibility study for key publication 4⁴¹.¹⁴⁶ Because the publications were sequential, this allowed the author to reflect on the learnings from one study before moving onto the next and thus selecting the most appropriate method to use. By the time the author had moved onto the second theme of cancer patient experience, the author was confident and competent in surveys, focus groups and semi-structured interviews. The author was therefore able to utilise these methods going forward but also develop the competence for other data collection methods such as the use of a survey via text message (key publication 8⁵⁵).

The author used a variety of different methods during the course of the research presented in this thesis. The author believed these were the correct methods to use for the data collection required. The author learnt and used methods for data collection and data analysis such as for the feasibility study (key publication 4⁴¹), the triangulation of different data sources (key publication 6⁵³) and the framework matrix (key publication 6⁵³) without formal training but utilised other literature sources for guidance. This provided the author with examples to refer to when using these methods for the first time and shows the determination of the author to continue to learn and grow as a researcher.

During this research the author determined the number of participants to interview for the qualitative data in terms of data saturation. This is defined by Glaser and Strauss (1967) as the point at which 'no additional data are being found whereby the researcher can develop properties of the category'²⁰³. The author has since read an article by Greg et al (2020) which describes an approach to estimating the sample size for qualitative data prior to data collection²⁰⁴. The approach uses three factors, the base size, the run length, and the new information threshold²⁰⁴. The base size refers to the information that has already been identified. The run length is the number of interviews in which new information is found. The new information threshold refers to the threshold of which the researcher will accept as data saturation. The author will

consider this method for estimating qualitative sample sizing for future qualitative research.

The author used their knowledge of the methods such as surveys and interviewing to provide leadership to others to conduct data collection as part of the research for this thesis. This was shown during key publication 7⁵⁴ where staff working in the Macmillan centres at the Trust were taught how to interview patients using a telephone survey over the phone. Another example was when the author supervised two MPharm students during their final year dissertation in which they carried out elements of the author's research. The author was able to pass on knowledge about conducting in-depth telephone interviews and how to produce a suitable survey to pharmacy professionals.

The findings from the second theme of cancer patient experience were fundamental to the author's role at the time. The author was in a strategic position to be able to utilise the data collected to make improvements. For example, key publication 6⁵³ was essential for the development of the improvement plan for cancer patient experience and engagement at the NHS trust the author was working at. This then led on to key improvements such as updating the trust patient facing website to include the information patients had requested. The findings from key publication 7⁵⁴ were fed back to the cancer board to highlight the need to improve virtual clinics during the pandemic and beyond. An example was the implementation of Attend Anywhere, a virtual conferencing tool, across each cancer specialty.

5.4 Limitations

5.4.1 Lack of relevant literature in the public domain

This limitation is mostly relevant for key publication 1³⁷. There are likely to be numerous models of care internationally and nationally whereby community pharmacies are supporting patients who take oral anticancer therapy, but they have not been published and are not available in the public domain.

With regards to relevance to the other key publications, there are likely to be many unpublished pieces of work that relate to community pharmacy supporting cancer patients and improving cancer patient experience. These pieces of work

would have provided the author with further evidence in support of the research for this thesis.

5.4.2 Low response rates and achieving data representative to the local population

Where there were small numbers of respondents to the surveys undertaken within this thesis this impacted on drawing firm conclusions. With small respondent sizes it was harder to review the data in terms of differing demographics. In some circumstances the data may not have been representative of the population of the area and would not have been comparable to other areas of London. Sample size calculations were not conducted for the surveys but because both hospitals, where the author completed the research, served large numbers of patients, the survey numbers were considered to be low.

Patients were handed the survey for key publication 2³⁸ by staff working within the cancer centre at the Trust where the patient was working and were left to complete the survey without assistance or guidance. Therefore, there could have been misinterpretation of the questions.

For key publication 8⁵⁵, the survey may have been too lengthy as a few respondents didn't finish the survey and stopped a few questions short of the end. Because this study was sent out as a link via text message to patients this would have excluded patients who do not have a phone, who do not have a smart phone or who are unfamiliar with completing surveys online. The author is aware that this contributes to the "digital divide" and will review other methods to ensure this patient group is not excluded from future surveys conducted by the author²⁰⁵.

One of the limitations of key publication 2³⁸ was that most of the patient participants in the focus group and semi-structured interviews were White British. This means that the data was skewed to this part of the population. Related literature recognises the challenge of engaging diverse subgroups²⁰⁶⁻²⁰⁸. The reasons discussed include language barriers, culture differences, fear

of being exploited and lack of researchers who are of minority ethnic groups²⁰⁶⁻²⁰⁸.

In relation to key publication 4⁴¹ the community pharmacists that took part were community pharmacists that the author had already engaged with. This would have had an impact on their overall belief and engagement with the study. It was difficult to understand whether patients with different cancers that were not represented in this study may be more or less inclined to engage with this service type in the future. The patients that took part in the study all lived relatively close to the community pharmacist in their area. For a larger study there maybe patients who live further away and therefore maybe less inclined to take part in this study type.

5.4.3 Limitations relating to qualitative data

For data that was collected by the author or another member of hospital staff via interviews, the patients may not have been solely honest compared to a feedback method that is anonymous. Validity in qualitative data relates to honesty. Validity can be ensured by triangulating data, allowing respondents to validate the transcripts, and comparing the data, treating it as a whole rather than individual elements²⁰⁹.

For key publication 6⁵³ because the NCPES data collection and the local data collection conducted by the author used different methods and criteria the data could not be compared as such but could be used collaboratively to identify areas for recommendation.

Not all of the qualitative data was transcribed verbatim. More insight would have been gained if the interviews had been recorded and transcribed verbatim allowing for thematic analysis (key publication 7⁵⁴).

5.4.4 Limitations specific to key publication 5- Can community pharmacists support patients who take oral anticancer therapy⁵⁶?

The limitation of key publication 5⁵⁶ was that it was self-edited as the publisher did not provide an editor. The author however utilised friends and family to review and edit the manuscript prior to submitting. Although the training programme for community pharmacists published within key publication 5⁵⁶

came from training resources already in use and available the training programme was not tested. Should the author have been successful with the application to the National Institute of Health Research Clinical Doctorate Research Fellowship (NIHR CDRF) the testing of the training programme would have made up part of this research.

5.4.5 Other barriers and limitations

A significant barrier to the first theme of community pharmacists supporting patients who take oral anticancer therapy was that funding to take the feasibility study onto the next step of conducting a randomised controlled trial was not achieved. The author applied to the National Institute of Health Research Clinical Doctorate Research Fellowship (NIHR CDRF) on two occasions, both of which did not progress past the interview stage. The author received a significant amount of learning from this process but was not able to progress the work any further. However, the author went on to continue the research topic of cancer patient experience.

If the author had been attached to a university or PhD programme the author would have had formal teaching and supervision throughout the data collection period. The author was able to gain some teaching, but the majority was self-directed learning. The author was fortunate that mentorship was identified via the trust the author was working at and via the British Oncology Pharmacy Association. The author also received a coach during the Darzi Fellowship.

5.5 Present and future work

5.5.1 Current practice or work

As described in chapter 1 and displayed in figure 1, the author has had a variety of differing roles during the period of research from 2017-2021. The author has moved out of a direct pharmacy role and into change leadership and transformational roles. The author is currently a programme manager for the clinical transformation team at Barts Health NHS Trust. The specific areas of work the author is leading on are implementing a new referral system for GPs to refer patients into secondary care and introducing teledermatology which currently is focusing on the dermatology cancer two week wait pathway. The

referral system, known as advice and guidance, is mandated by NHS England and NHS Improvement. The author is therefore continuing to work according to national policy. The teledermatology piece is looking to encourage GPs to attach macroscopic, close-up and dermatoscopic photos of a lesion to the two week wait referral form. These will then be reviewed by a dermatologist who will decide whether the lesion is malignant or not. This will help to reduce the number of patients with non-malignant skin issues being seen in the two week wait clinics. The author has utilised many of the analytical and research skills learnt from conducting this research during this role. These skills include co-production, descriptive statistics, and review of national policy. The author needs to work with a variety of people across north east London and descriptive statistics have been utilised when reporting key metrics. A final skill that the author regularly uses is working with patients and incorporating qualitative data into formal presentations and reports to NHSE/I and Trust boards.

5.5.2 Plans for future work

The author will proactively disseminate the work included in this thesis to reiterate the important work by speaking to the chair of the cancer board at the trust where the author works as well as the chair of the north east London cancer alliance. The author will share the work with other key members of the cancer alliance including the GP clinical leads for the surrounding boroughs and the commissioning leads. The author will contact NHS England and Improvement through the Experience of Care Lead and Lead for Cancer Improvement to highlight the work that has been conducted. Lastly, the author will contact the Chief Pharmaceutical Officer to provide on-going evidence that community pharmacists can support patients who take oral anticancer therapy.

The methods that the author will continue to use are surveys, focus groups and semi-structured interviews.

The author has plans to conduct qualitative research into the implementation of advice and guidance which the author is leading on in their current trust. This would involve researching the impact advice and guidance has had on patients and clinicians in primary and secondary care. This therefore leads onto a new area for research but still directly linking national policy into clinical practice.

This area involves the trending of key performance indicators and thus there will be a stronger element of quantitative data included in the author's future work.

In relation to the themes described within this thesis the author wishes to undertake a detailed review of the history of how the government has shaped the cancer strategy through the publication of the cancer policies over the last two decades (see chapter 1). The author has learnt the skills to be able to conduct this research through key publication 1³⁷ and the writing of this thesis.

Another area of research relating to the second theme of cancer patient experience is looking at comparing the new national Quality of Life survey with the longstanding National Cancer Patient Experience Survey. Key publication 6⁵³ has provided the author with the skills required to be able to conduct this piece of research.

5.5.3 Plans for personal development

The author will continue to focus research in areas relating to the area of work the author is currently involved with. The author will expand the journals that are chosen for publication. This is partly to gain experience working with less familiar journals but also because the nature of the research is likely to change with the role.

The author has enjoyed and learnt from taking on a supervisory role with MPharm students. This supervisory role will continue allowing the author to become competent with this.

As previously described the author is currently a co-editor for a research topic for a journal. This is ongoing personal development as this is a new experience for the author.

In relation to personal development for the author's career, the author would like to undertake the managing successful programmes (MSP) course and is considering completing a Master of Business Administration degree in the next 10 years. The MSP course would support the author's future research career by providing the author with knowledge of how to conduct and manage multiple streams or arms of research. Undertaking an MBA will encourage the author to

develop and drive a strategic approach for their research particularly in a changing environment.

5.6 Conclusion

This thesis clearly demonstrates the author's journey into an independent researcher leading, supervising, and supporting as an expert in this field of research creating opportunities for further impact and reach. The author's work has been cited several times including within a white paper by the Royal Pharmaceutical Society. This shows the ongoing growing impact the author's research has. The author is keen to continue the research journey completing their own research but also supervising and encouraging other pharmacists and pharmacy staff to undertake research of their own.

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Authorship statements

This section contains verification emails from colleagues who co-authored key publications with the author of this PhD thesis. The key publications are listed with the email request from the author of the thesis and the response from the co-author(s).

Key publication 2 - Support for patients taking oral anticancer medication

Hi,

I hope you are well. You co-authored an article with me in the Pharmaceutical Journal. This is the article for the community pharmacy focus group and survey. Are you happy with the following statement?

Support for patients taking oral anticancer medication

M. Dalby provided the conception and design of the work supported by C. Oakley. Data collection, analysis and interpretation were carried out by M. Dalby and C. Oakley. M. Dalby drafted the article with critical review and final approval for submission by C. Oakley.

Best wishes,

Mel

Hi Mel
I am happy with it
Bw Catherine

Key publication 3 - Can community pharmacies support patients who take oral anticancer therapy? Patients' needs and views

Dear Both,

As you know, I passed the viva for my PhD but there are a couple of minor amendments that I need to make to the thesis. One of these is including a statement regarding authorship of the publications included.

Both of you were co-authors for the following publication. Can you confirm if you are happy with the following statement of authorship?

Can community pharmacies support patients who take oral anticancer therapy? Patients' needs and views

M. Dalby provided the conception and design of the work supported by C. Oakley. Data collection, analysis and interpretation were carried out by M. Dalby, K. Kantilal and C. Oakley. M. Dalby drafted the article with critical review and final approval for submission by C. Oakley and K. Kantilal.

Many thanks,

Mel

Hi Mel

I'm fine with the wording.

Regards

Kumud

Hi Mel

I am also happy with the wording

Many congratulations Dr Dalby

All bw Catherine

Key publication 4 - Feasibility study of a referral pathway from secondary care to community pharmacy for people who take oral anticancer medication

Dear All,

I hope you are well. I recently passed the viva for my PhD by publication. There are a couple of minor amendments that I need to make to the thesis. One of these is including a statement regarding authorship of the publications included in the thesis.

All three of you were co-authors for the following publication. Can you confirm if you are happy with the following statement of authorship written under the title?

A feasibility study of a referral pathway from secondary care to community pharmacy for people who take oral anticancer medication

M. Dalby provided the conception and design of the work supported by S. El-Nabhani, R. Dhital and I. Norman. Data collection, analysis and interpretation were carried out by M. Dalby. M. Dalby drafted the article with critical review and final approval for submission by S. El-Nabhani, R. Dhital and I. Norman.

Many thanks,

Mel

Dear Mel

Many congratulations! And it is kind of you to remember my small contribution to the article.

I assume that the house style restricts the number of authors listed - so I am 'et al' ?

For correctness are you able to change my affiliation to 'Ian Norman, Emeritus Executive Dean, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London'.

Your authorship statement looks good to me.

All good wishes for the future - and thank you again.

Ian

Ian Norman

Professor of Mental Health & Emeritus Executive Dean|

Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care |

King's College London

Dear Melanie,

Good to hear from you and congratulations on your PhD. I agree with the statements regarding the study below.

Please let me know if you require further information.

Best wishes

Ranjita

Dr Ranjita Dhital MSc, PhD, MRPharmS, FHEA, FRSPH

Lecturer in Interdisciplinary Health Studies

Pharmacy Research UK Leverhulme Fellow *Architecture of Pharmacies*

UCL Arts and Sciences (UASc) Department

University College London

Key publication 6 - Analysis of local qualitative cancer patient experience alongside the 2019 results of the UK National Cancer Patient Experience Survey and key publication 7 - Cancer patient experience of telephone clinics implemented in light of COVID-19.

Dear Both,

As you know, I passed the viva for my PhD but there are a couple of minor amendments that I need to make to the thesis. One of these is including a statement regarding authorship of the publications included.

Both of you were co-authors for the following publications. Can you confirm if you are happy with the following statements of authorship written under the title of each?

Analysis of local qualitative cancer patient experience alongside the 2019 results of the UK National Cancer Patient Experience Survey

M. Dalby provided the conception and design of the work supported by S. El-Nabhani. Data collection, analysis and interpretation were carried out by M. Dalby. A. Hill reviewed and agreed the coding of the data. M. Dalby drafted the article with critical review and final approval for submission by both S. El-Nabhani and A. Hill.

Cancer patient experience of telephone clinics implemented in light of COVID-19.

M. Dalby provided the conception and design of the work. Data collection was carried out by members of staff led by M. Dalby. Analysis and interpretation were carried out by M. Dalby. M. Dalby drafted the article with critical review and final approval for submission by both S. El-Nabhani and A. Hill.

Many thanks,
Mel

Hi Mel

I am happy to confirm wording as you suggest below.

Kind Regards
Alison

Key publication 8 - The experience of cancer patients during the COVID-19 pandemic

Dear Nikant,

I hope you are well. As you know, I passed the viva for my PhD but there are a couple of minor amendments that I need to make to the thesis. One of these is including a statement regarding authorship of the publications included.

You were co-author for the following publication. Can you confirm if you are happy with the following statement of authorship written under the title?

The experience of cancer patients during the COVID-19 pandemic
M. Dalby provided the conception and design of the work. Data collection, analysis and interpretation were carried out by M. Dalby. M. Dalby drafted the article with critical review and final approval for submission by N. Ailawadi.

Many thanks,
Mel

Morning Mel,

Sounds fine to me – whatever you need to make it work for your submission.
Congrats again on your very proud achievement!

Regards,
Nikant

Nikant Ailawadi
Director of Insight
Barts Health NHS Trust