

What are the experiences of English NHS managers, clinicians, and patients of the National Cancer Waiting Times targets?

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## **Dedication**

I want to dedicate this piece of work to five amazing people who unfortunately died of cancer while I was writing it.

Four were healthcare professionals and colleagues whose dedication to their jobs was truly inspirational: Sean Vesey, Liz MacDonald, Julie Keenan and Sarah Lennon.

The fifth was my brilliant, annoying, big brother Al, whose reaction to this achievement would have been a shoulder shrug and “What took you so long?”

## Abstract

National cancer waiting times targets were introduced over 20 years ago in the NHS to ensure the delivery of timely diagnosis and access to treatment. Whilst the targets have been praised for improving waiting times and encouraging early diagnoses, they have been critiqued for distorting clinical priorities, creating cultures of cheating, eroding clinician autonomy, and neglecting certain patients. Yet, there is little empirical research exploring the impact of targets in practice.

Drawing upon semi-structured interviews with patients, clinicians, and managers (N=27) in Merseyside and Cheshire, I explore how the cancer targets affect their perceptions and experiences of delivering/receiving care, and how the targets are viewed as impacting upon patient pathways, service design, and practice. I found that patients are concerned about accessing secondary care and waiting to receive a diagnosis, yet they are less concerned about the time it takes to be treated (i.e., whether within a waiting time target) as long as they have a clear healthcare plan.

Managers and clinicians painted a complex picture. They believed that whilst open and reciprocal communication was essential to practice, there was more ambiguity and disagreement about whether patients should be informed about targets. The targets were identified as providing focus for individuals and organisations, yet managers highlight the constraints limited resources place on cancer services provision, and how challenges emerged when liaising with other Trusts. Moreover, clinicians and managers felt that targets created a two-tier system that prioritised some patients over others. Finally, clinicians dismissed the targets as under the remit of managers and not affecting their daily practice.

To conclude, I discuss the implications of my study and identify future directions for research. I consider the renewed interest in cancer waiting times following the COVID-19 pandemic and how the NHS can contribute to the recovery of cancer services.

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# Chapter 1: Introduction

## 1.1 Background

Cancer is one of the leading causes of mortality in the UK. The incidence of cancer continues to grow, with current research suggesting that someone in the UK is diagnosed with the disease every two minutes and half of the population born after 1960 will be diagnosed with cancer during their lifetime (Cancer Research UK 2021). Therefore, the NHS needs to be able to deliver timely, high-quality services to meet this demand. In addition, although survival rates have improved in recent years, in the UK, they are still behind comparable European countries (Cancer Research UK 2021). It is essential that patients have access to a prompt diagnosis and treatment to ensure the best prognosis for them.

Introduced in 2000, cancer waiting times targets are a national performance measure which set out minimum timeframes for stages in a patient's cancer pathway in NHS hospitals. Although the cancer waiting time targets are present across the whole of Great Britain, each country has its own rules, and so performance is not comparable between Scotland, Wales, Northern Ireland, and England. This thesis concerns the waiting times targets as they apply in English NHS hospitals. It presents an analysis of the impact these targets have on the care of cancer patients as perceived by three groups invested in delivery of excellent cancer care: NHS managers, clinicians, and patients.

Cancer Services in England are monitored by a series of waiting time targets which measure how long stages take between referral and first treatment, and then subsequent treatments. These targets are part of wider ranging changes in the NHS that started in the 1990s, introducing the ideas of new public management, internal markets, and pledges to reduce waiting times (Malin et al. 2002). Research by Spurgeon et al. (2000) found that waiting times varied substantially for patients according to tumour types and geography across England. The cancer targets aimed to standardise services to reduce inequalities, encourage earlier diagnosis and bring England's survival rates more in line with the rest of Europe. The targets were implemented in stages under the Cancer Plan 2000 (DoH 2000) and then underwent some revision in 2007 as part of the Cancer Reform Strategy (DoH 2007).

The targets were again reviewed in 2010 to determine if they were still fit for purpose or if any alterations were necessary. The advisory group who undertook the review decided that the targets would remain in their current form as the evidence they collected from patient groups and cancer charities unanimously agreed with NHS

managers and clinicians that targets are beneficial to patients, had driven service improvement and reduced patient anxiety (DoH 2011). Although the advisory group considered revising the targets to take account of differences in pathways by tumour site, they decided against this to avoid de-prioritising some patients. This review of the targets led to a report which concluded that the targets should be retained in their entirety in order to continue to “support clinical outcomes and patient benefits” (DoH 2011, p.16). In the review, the targets were considered to be aligned with the priorities of the Coalition government at that time, which was concentrating on “what really matters to patients”, as well as remaining clinically justified.

Interestingly, only four years later, in 2015, when the All-Party Parliamentary Group on Cancer set out its key priorities in cancer care over the next few years, targets were not considered to be part of the plan to improve outcomes. They are not mentioned once in the whole 25-page briefing (APPG 2015). The latest review, carried out in 2019, did recommend some changes to the reporting of the existing targets, if not to the times that they monitor. However, the implementation of these changes was delayed by the COVID-19 pandemic in 2020, although the Faster Diagnosis Standard (or 28-day target) was introduced, designed to measure how quickly patients are told whether or not they have cancer (NHS England 2018).

Although initially, Trusts across England were able to meet these standards, performance has been in gradual decline, with the 62-day target being missed since October–December 2013/14 (NHS Providers 2021). Furthermore, since March 2020, cancer services have had to develop new service models in response to the COVID-19 pandemic. National policy dictated that urgent cancer services should be protected from disruption. However, inevitably some patients have had to wait longer than usual for diagnostic tests and treatments (Macmillan 2020). Monitoring of the cancer waiting times has continued throughout the pandemic, and government guidelines have set out an expectation that normal waiting times resume and the backlog of waiting patients is cleared by March 2022 (NHS England 2021a).

## **1.2 What are the cancer targets?**

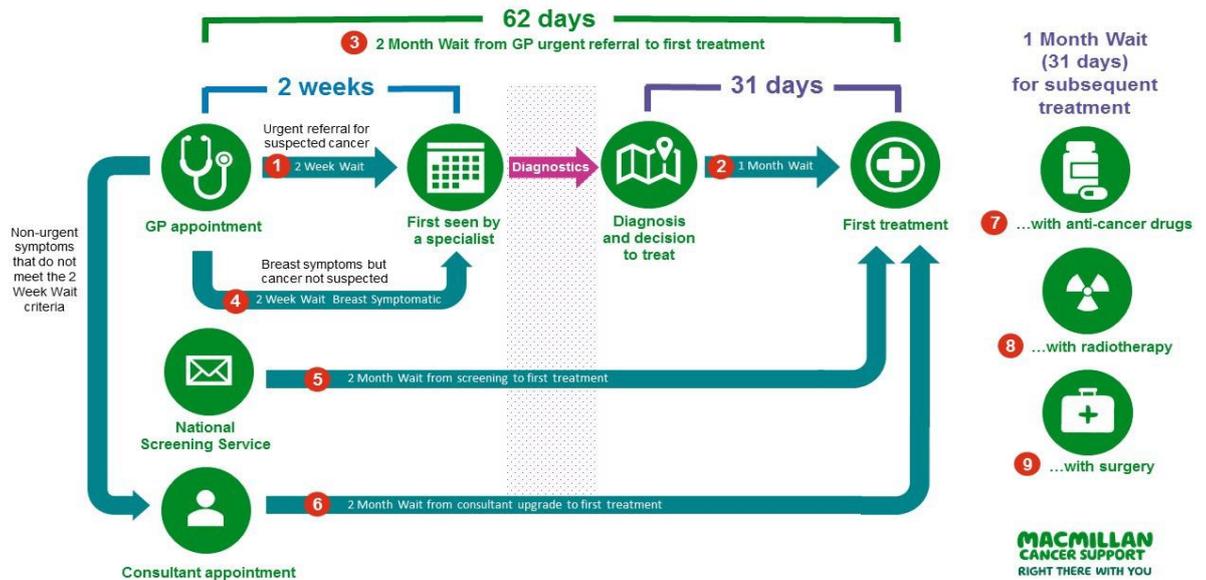
There are currently nine cancer waiting times targets, which measure the length of specific parts of a patient’s pathway. Each target has an operational standard, or threshold, which indicates the percentage of patients who must meet the target waiting time for a Trust to pass that target. Exceptions are made for clinically complex patients or those who chose not to attend within this time (by going on holiday, for example). The targets and operational standards are as follows:

**Table 1: The National Cancer Waiting Times Targets**

<b>Target</b>	<b>Operational standard</b>
14 days from receipt of an urgent suspected cancer referral by GP to first appointment with specialist (this may be a diagnostic test or scan if appropriate)	93%
28 days from receipt of referral to the date patient is informed of their diagnosis (cancer or benign) for patients for patients referred by GP or through the national screening programme	75%
31 days from the decision to treat to the start of first treatment for all cancers (irrespective of referral priority)	96%
31 days from decision to treat (or earliest clinically appropriate date) to subsequent treatment for surgery	94%
31 days from decision to treat (or earliest clinically appropriate date) to subsequent treatment for radiotherapy	94%
31 days from decision to treat (or earliest clinically appropriate date) to subsequent treatment for anti-cancer drug therapy, e.g., chemotherapy	98%
62 days from urgent suspected cancer by GP to start of first treatment	85%
62 days from urgent referral by an NHS Cancer Screening Programme (Bowel, breast, cervical) to start of first treatment	90%
62 days from a consultant's decision to upgrade the priority of a patient's referral from any other source to the start of first treatment	No standard set

In addition to these targets, there is a 14- and 28-day target for patients with non-suspicious breast cancer symptoms, and the 62-day target from referral to treatment is shortened to 31 days for paediatric, testicular and acute leukaemia cancer patients. The Macmillan diagram below (Billington 2019, reproduced with permission), although pre-dating the 28-day target, illustrates how the other targets all fit together as part of the patient's pathway from referral to treatment.

**Figure 1: The National Cancer Waiting Times Standards**



For most targets, a Trust's performance is the proportion of patients who meet the target as a percentage of the total patients in that month's cohort (e.g., the number of patients first seen within 14 days, the number of patients receiving treatment within 31 days of the date of decision to treat). However, calculating 62-day performance is far more complicated as all these targets can be shared across Trusts, depending on where patients are diagnosed and treated. Tertiary centres have no control over which day in a patient's pathway they receive a referral, so a system was developed whereby credit and breaches can be allocated to a Trust depending on the date of referral. Credit may be shared for patients transferred in a timely manner (day 38) or allocated in full to one trust or another, depending on how long the diagnostic and treatment parts of the pathway took.

Breaches of the target can also be shared between Trusts or reallocated to another Trust depending on how long the patient spends with each (there are six different scenarios with which each patient's pathway is compared with in order to decide how the allocation of credit/ breaches falls). Further complications arise when patients visit more than two Trusts, which is not uncommon for patients requiring specialist diagnostics not necessarily available to all Trusts. In summary, the system is designed to encourage timely pathways, with patients referred to tertiary centres on or before day 38 (NHS England 2016). However, the labyrinthine rules make monitoring this very arduous.

### **1.3 Aims and rationale for the study**

Having worked in a Cancer Services department since the advent of the cancer targets, I have participated in informal conversations which have revealed widely differing attitudes towards the cancer targets with managers, clinicians and patients. My literature review (chapter 2) identifies that the use of targets as performance indicators in healthcare is a contentious issue, not specific to cancer, with a spectrum of opinions on the positives and negatives for all three groups in my study. Although waiting times for patients (Neal et al. 2015), de-professionalisation of clinicians (Beecham, 2003) and manipulation of figures by managers (Seddon 2005) are just some relevant ideas discussed by healthcare commentators, the attitudes of frontline of staff and patients is an area which has not been explored in detail. In particular, there is very little research that considers the problems around operationalising these targets from the perspective of those who must implement them or that asks patients how relevant they think the targets are to their care.

A qualitative approach was taken to the study, with data collected through a series of semi-structured interviews with a purposive sample of patients, managers and clinicians (27 in total). Participants were recruited from NHS managers and clinicians across Merseyside and Cheshire whose work brings them into contact with the cancer targets and patients who have been treated for cancer in the last five years in the same area. The resulting data were analysed thematically and a picture developed of the experience of the cancer targets from the perspectives of patients, managers and clinicians.

The aim of my research is to gain a deeper understanding of how NHS managers, clinicians and patients experience cancer targets by considering their knowledge and beliefs about the targets. The three research questions were designed to explore how the clinicians, patients and managers experience how the targets work. Hospitals are vilified in the press and by cancer charities for their poor performance against these targets (Campbell 2014, Cancer Research UK 2015), so research providing a better understanding of why this – and whether the performance agenda of the NHS is in line with the clinical needs and personal desires of patients – is essential.

### **1.4 Structure of thesis**

This thesis is organised into seven chapters. This chapter has introduced the thesis and study in general terms. It has explained the context of the study, what the targets are and why I chose them as my research topic. Chapter two reviews the main themes and ideas around cancer targets and how they have been represented in the

literature. While clinical studies investigated the benefits of the links between the cancer targets and early diagnosis, the literature around the use of performance measures in healthcare is less positive, calling the system “targets and terror” (Bevan and Hood 2006). The literature review also found that the targets seldom make headlines unless they are being failed or because of a scandal (Donnelly 2009) and that information on patient attitudes is mostly limited to statements by charities (Cancer Research UK 2015). Lastly, the chapter considers some theoretical ideas with respect to managerialism and patient delays.

Chapter three presents the methods used to gather the data required to answer my research questions. The interview schedule is presented in this chapter, as well as a discussion around the ethics approval process, recruitment of participants and the approach taken to analysing the data. Chapters four, five and six report, primarily in the participants’ own words, the findings of the interviews. Chapter four, the first data chapter, considers the role that targets play in the cancer patient’s journey from the perspective of patients, managers and clinicians. It examines what is important to patients and the priorities that they place on accessing care, waiting times and good communication with their clinical team. Managers, too, thought good communication was essential, but not all agreed on whether the patients should be burdened with knowledge about the targets.

Despite this lack of knowledge about the targets displayed by the patients in chapter four, the next chapter (chapter 5) reveals the impact of the targets on the provision of cancer services and scrutinises the evidence for targets as a source of gaming and professional conduct. Cancer targets were both praised and critiqued. The targets provide focus for both individuals and organisations but also highlight resource constraints and are not considered to be an accurate measurement of the quality of cancer services. Clinicians and managers in the final data chapter (chapter 6) argue that the targets create a two-tier system, with some patients subject to monitoring and some patients not subject to such attention. The idea that the targets might be outdated when considered in the context of increasing patients’ co-morbidities and the availability of new diagnostic investigations is also examined.

The last chapter discusses the significance of the themes identified in my interviews and the implications of these findings in the context of the existing literature and also the future of waiting times for cancer patients in the English NHS. The study reveals a complex picture of my participants’ relationship with the cancer targets. The patients in my study were very concerned with the time they spent accessing their GP and

getting a referral into hospital, a part of their pathway not measured by any target. Once in secondary care, their concerns about the speed lasted until they were diagnosed and then became less important than having a plan for their care. Most knew little of the specifics around the different targets but agreed that they were a good idea in theory. For clinicians, the targets provoked a mixed response. Like the patients, they agreed that, in principle, they would lead to improvements but were generally dismissed as the concern of management, not the clinical teams. Clinicians were confident that they retained autonomy over their practice, and some questioned the value of a standardised system applied to many different diseases. Others overlooked this in favour of a system that ensures patients get the reassurance of a timely diagnosis and access to care. Managers explain how difficult it is to run target led services in practice. They acknowledge that the targets have led to a system whereby most people are treated in a prompt manner and organisations are focused on providing good care. However, to ensure that this happens, they have to manage with limited resources and sometimes a strained relationship with other Trusts, who may chase targets at the expense of patient experience.

Finally, in the concluding chapter, I consider the robustness of cancer services and how they coped under the unique challenges posed by the COVID-19 pandemic. I finish by considering what further avenues of research are suggested by the study.

## **Chapter 2. Literature review**

### **2.1 Chapter overview**

My research aims to gain a deeper understanding of how NHS managers, clinicians, and patients experience cancer targets by considering their knowledge and beliefs about the targets and how the targets impact patient pathways, service design, and practice. This chapter aims to explore themes and ideas identified in my reading. I have divided this into sections that address different aspects of the research and the different perspectives of the three groups involved. The basic aim is to gain an increased awareness of what research, if any, has been done in this area. I am interested in what the current literature can tell us about how targets can be used in healthcare to measure performance and what impact that has on frontline services and patients. This provides the context for my own study. Following an explanation of my search strategy, the chapter starts with a discussion about the use of performance indicators in healthcare, a topic that polarises opinion. Commentary on the use of cancer targets specifically was hard to find, so these sources predominantly refer to the use of targets generally, not just in the field of cancer. As my study investigates the views of clinicians, managers and patients, literature was examined that contained any of these. Opinions on the actual cancer targets tend to be limited to clinical studies and so are dealt with separately. Also discussed are some concepts and frameworks that I identified during my reading relevant to my study.

### **2.2 Key Sources**

In order to access materials, I carried out an NHS Evidence search of their databases, including EMBASE, CINAHL and PubMed, using the keywords "cancer targets", "62 day" "two-week wait", and "cancer plan" to get further information, which led to articles which also had useful bibliographies for identifying additional reading. The scope of the review included any papers published in English between 2000 (when the first targets were introduced) and 2020. A range of different study types were consulted. The purpose of this was to consider the topic from several angles, from clinical studies to patient questionnaires, with the aim of building as complete a picture as possible of the different aspects involved. Any article fitting this search criterion which may be related back to the main topic of the thesis, was considered for inclusion. Although my study is looking at targets in the English NHS, devolution in each country has taken a different approach to cancer targets, as there may still be something to learn from each other's approaches; evidence from all was reviewed.

### **2.3 Benefits of cancer targets**

The initial introduction of the two-week wait target, the first to be phased in nationally, led to a flurry of clinical audits, encouraged by the Department of Health (DoH 2000) to generate data on the target's efficacy regarding GP compliance with the guidelines and appropriateness of referrals. The Centre for Reviews and Dissemination undertook a systematic review of the audits in 2005, which contained an assessment of 241 clinical audits. The review found that the majority of included audits were poorly reported, with only 44% providing sufficient details of their methods to be reproducible. The targets were subject to some minor amendments after the Cancer Reform Strategy was published in 2007, so most of the literature found to be relevant for inclusion was published after this. Even then, the majority of the research studies concentrated on the two-week standard, with only Devbhandari et al. (2007), Ip, et al. (2012) and Raja et al. (2013) specifically considering the 62-day standard (the standard that has been given the most attention from the charities commentaries (Cancer Research UK 2015) and the one that Trusts are under the most pressure to meet).

Since their introduction in 2000, the NHS has continued to produce documents stressing the importance of the cancer targets. According to the Interim Management and Support Team in 2014, delivery against the targets for cancer is crucial to ensure quick reassurance of patients, speedy treatment and also to reduce late presentations and national variations (DoH 2014). There is an extensive number of clinical studies that support early diagnosis and improved survival, which is one of the key principles behind the introduction of waiting times targets. Issues identified in the literature that may prevent this from happening are examined by Austoker et al. (2009) and Mitchell et al. (2015), who discuss reasons for delays to diagnosis, identifying lack of symptom awareness and complexity of presentation of patients, respectively. Rubin et al.'s (2015) study on the referral practices of doctors in 8179 GP surgeries found that specific initiatives by cancer networks had a positive impact on referrals for suspected cancer. This included four quality improvement activities: clinical audits, significant event analysis, use of risk assessment, and the development of practice plans, all of which resulted in the more effective use of two-week wait referral by GPs. I found only one piece of research which directly asked the patient what they thought about their care on the two-week wait pathway, and this was an unpublished dissertation by MacDonald (2016). She found that patients admit that they did not know they were on a two-week pathway which could potentially mean they have cancer, which supports Rubin et al.'s (2015) theory that GPs not only need help knowing when to

use the referrals, but also in how to talk to the patients about the implications of being referred into the target system.

Related to this, Neal et al.'s (2015) systematic review examined whether increased time to diagnosis and treatment in symptomatic cancer is associated with poorer outcomes. They found that efforts to expedite the diagnosis are likely to result in improved survival, earlier stage diagnosis, and improved quality of life, although benefits vary between cancers. This ties in with work by Lyratzopoulos et al. (2015) about pre-and post- diagnostic intervals, which were found to vary greatly by cancer type. Discussing missed opportunities for diagnosis, the study supports the development and evaluation of public health interventions aimed at shortening patient intervals from presentation to diagnosis. In addition, McPhail et al. (2015) found that stage at diagnosis was the key predictor of overall cancer outcome. Further reductions in mortality may be more effectively achieved by diagnosing all cancers before they progress to stage 4, but for lung and ovarian cancer, there is also a need for a stage shift to earlier stages together with efforts to improve stage specific survival at all stages.

Specifically examining the effect of the two-week wait referral pathway on cancer survival, Møller et al. (2015) found that the use of the pathway by GPs showed reduced mortality. This study is valuable for its use of complete population data for England while controlling for GP practice and list size and patient population. Møller et al.'s findings assessed what proportion of the 215,284 diagnosed cancer patients in their study had resulted from an urgent referral by their GP. Practices with the highest referral and detections rates had lower mortality (47%) than those with the lowest rates of referral (53%). Their findings indicated that over the four year study period if all practices had behaved like those with the highest referral rates, 2400 fewer deaths would have occurred.

However, in 2011, only 54% of patients diagnosed with cancer were referred into hospitals on a two-week wait pathway, so a large number of patients are not covered by all the standards (Cancer Research UK, 2012). A more recent study by Di Girolamo et al. (2018) agreed that the targets encouraged timely treatment but also highlighted that not all patients are monitored under them. Their study of all adults diagnosed with colorectal, lung and ovarian cancer between 2009 and 2013 found that patients not on target pathways have much poorer survival. For those referred on a two-week wait pathway, these studies support the idea that the waiting times

targets are an important means of improving access to services and reducing times to diagnosis and treatment.

Considering all the targets (not just the two-week wait), Raja et al.'s (2013) study of haematology referrals thoroughly examines the pros and cons of the target referral system. Acknowledging the importance of rapid diagnosis, they note that effective systems are needed in order to achieve targets. Their study identifies where, for their patients, the delays in the lymphoma pathway are. Labelling these delays as clinically significant, they suggest practical solutions for these delays, indicating that they value the targets for their ability to speed up the diagnosis and improve their patients' outcomes.

#### **2.4 Performance measuring in healthcare**

Whilst these studies seem to confirm the benefits for patients of the waiting times targets, there is a diverse body of literature on the use of targets as performance indicators in the NHS, and the wider health care sector, which paint overall a more negative picture. For instance, the regimen introduced across the English NHS to reduce waiting times has been dubbed "targets and terror" (Bevan and Hood 2006, p.524). Although various analyses have concluded that targets improve performance, the costs of such measures are questioned (Bevan and Hood 2006; Propper et al. 2007). Bevan and Hood (2006 p.525) discussed the blame culture initiated by targets where managers cannot be seen to fail and focus on "hitting the target, but missing the point", while Hunter (2008) argues that targets distort priorities because practitioners manage to focus on what can be measured rather than what might be more important. Hood (2006) argues that crediting the targets with visible improvements in waiting times may be overly generous. For the period of time when the most improvements can be seen, the NHS also received a large injection of funds, which Hunter (2008) feels may have resulted in the improvements irrespective of the new performance management tools. He feels that targets have negative consequences for both clinicians and managers, leading to clinical detachment, falling staff morale and forcing unwanted change on managers. Meanwhile, in his debate on whether targets have done more harm than good in the NHS (2009), Gubb argues that targets do not tackle cultural or systemic failings in the NHS. Although they may appear to do good by reducing waiting times, inevitably, they focus on the "wrong" things. In response, Bevan (2009) states that the significant improvements in

performance outweigh concerns over dysfunctional consequences of target setting.<sup>1</sup> However, he identifies three types of gaming that need to be addressed: neglecting areas not measured by targets, lengthening waiting for follow-up patients, and manipulating data. He is not alone in identifying these problems. Blackman et al. (2006) discuss how an inquiry by the House of Commons Public Admin Select Committee (2003) found almost all their witnesses agreed in principle with targets, but even so expressed concerns around their operation in practice, stating they inspired cheating and put undue pressure on professionals.

Hunter (2008) also argued that too much energy was devoted to meeting targets rather than focusing on the core function of the NHS, which is to prevent and treat disease. Wilson et al. (2011) raise concerns that hospital-based cancer follow-up is being given decreasing priority, and capacity must be found to see initial referrals, which they describe as the unintended consequences of the targets. This study (Wilson et al. 2011) is one of a few pieces of research that asks patients to discuss their experiences of the cancer targets. Most patients were angry that their GPs did not refer them urgently, so there was a delay before they were first seen. In none of the subsequent discussions about further services or treatment do patients acknowledge or demonstrate awareness that they should be following a timed pathway.

Clinical opinion of the cancer targets can be seen in a series of (often disparaging) opinion pieces that appear in the form of editorials and letters in medical journals such as the *BMJ* (O'Reilly 2001; Gorard 2007; Levy 2007; Wishart and Britton 2007). Some of the articles offer alternatives or amendments to the targets that they feel would improve the system. In their review of the sustainability of cancer targets, Slade and Talbot (2007) recommended changes to targets rather than abandoning them altogether. They felt that to maintain buy-in from both clinicians and management, a move away from the "one size fits all" approach that fails to recognise the difficulties inherent in individual cancer pathways was necessary for future sustainability.

This is a criticism echoed by Hunter (2008), who also concludes that it would lead to more buy-in from managers and clinicians if targets were more realistic. Different

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<sup>1</sup> As the director of the office for information on healthcare performance which had a lead responsibility for the development of the star ratings stem for NHS organisations in England, his position is unsurprising.

cancer types require different investigations to diagnose, and some pathways are much more complex than others. For example, skin cancer generally can be diagnosed and treated in one visit with an excision biopsy, whilst a lung tumour may require a combination of x-rays, CT scans and biopsies to diagnose and then future scans and immunohistological staining to decide which treatment type would be most effective. The waiting times service review (DoH 2011) acknowledges these differences and even considers removing the target for prostate patients. However, it concludes that treating tumours differently might deprioritise some patients, that Trusts should monitor their own performance waiting times by tumour type, and that Trusts should accept that some cancer types would be more likely to breach their targets than others.

Other suggestions in the literature about possible amendments or alternatives that could lead to a more effective system include Glasby et al. (2006), who consider that one of the problems of a centrally dictated system is that there is no accountability to local communities who have different priorities. Seddon (2005), who fails to find any redeeming features in a target culture which he believes is dysfunctional and "fosters compliance rather than innovation" (p.191), also advocates local solutions. As an organisational psychologist, he suggests that those in frontline services should control the actions taken to improve performance. This echoes the sentiments of Griffiths (1983), who is regarded as the architect of managerialism in the NHS in the 1980s, who believed that doctors were the "natural managers". Dr Foster, an organisation which provides healthcare intelligence, discussed all the adverse consequences of targets with their expert panel of 25 people, which included one hospital consultant and one cancer manager (Shaw et al. 2015). They proposed an alternative system, which supports all these suggestions: performance measures that are outcome and patient rather than process-focused are clinically credible and based on local need. The charity MacMillan (2012) appear to agree with this sentiment. For them, it is more important that cancer services are designed around the needs of the patients.

I found only a small amount of research about what the patients and the public think and feel about the cancer targets. Initiatives to reduce waiting times for patients sound, in principle, like a good idea. However, if the press is to be believed, targets are one of the failings of the modern NHS. The Guardian (Campbell 2014) reported that NHS waiting times data are 'riddled with errors' according to a report from the audit office which questioned the accuracy of data for 18 weeks, which the reporter

suggests will deepen suspicions that hospitals are 'fiddling figures' so as not to breach targets. The Telegraph reported target cancer patients are prioritised over urgent A&E patients (Donnelly 2009) "so managers can meet government targets". This scandal is described as appalling doctors, patient groups and politicians who condemned it as a clear example of "how far the NHS target culture has gone in distorting clinical priorities" (Donnelly 2009). However, members of the same groups described targets as clinically justified outcome measures when consulted in the review of the targets the following year (DoH 2011). The negative ideas about targets were only further cemented in the minds of the public by the scandal at Colchester (Sturdy 2013), where it emerged that cancer waiting times were being misreported (although the enquiry later found this was due to ignorance rather than deliberate tampering). In addition, the Francis Report into the scandal at Mid-Staffordshire Trust was heavily critical of the target culture in the Trust, suggesting that staff were bullied into reporting inaccurate or adjusted data (Francis 2013).

Sensational headlines cannot be taken to be a true reflection of public opinion. Although limited, there is some evidence of patients being more positive towards the targets. The patient representative groups and charities who responded to the Review of the Waiting Times (DoH 2011) were positive about the targets, which they felt had raised standards of care. Interestingly, the Cancer Patient Experience Survey, which has been running since 2008 and is considered to be a good indication of what patients think about information provision, communication with clinic staff and general quality of service, does not consider the targets an important enough topic to include in the survey (Picker 2021). Although the targets are not specifically credited or cited, the results of the patients' satisfaction survey show increasing numbers of patients happy that they did not wait a long time to be seen at the hospital following a GP referral (Picker 2021).

Perhaps a better indication can be found in the literature produced by cancer charities as they represent patients. Some are generally positive about targets, as long as they are being met, while others reject them. One example is Kathleen Murphy of the Patients Association, who describes the "scandal of what pernicious targets are doing to patients" in the aforementioned Telegraph exposé (2009). Cancer Research UK produced a document in 2012 discussing the proposed reforms the NHS was to undertake. At this time, all the targets were being met nationally, including the 62-day referral to treatment target, and the document praises the ability of Trusts to meet the targets while dealing with increasing numbers of patient referrals and treating an

increasing number of patients. Their online blog reflects these positive ideas about how the targets should improve things, but the rhetoric becomes more hostile when hospitals fail to meet them. This it describes as "simply not good enough" and "it's about patients being let down" (Cancer Research UK 2015).

The charity stresses how important the 62-day wait is to ensure that patients are tested, diagnosed and treated quickly after seeing their GP with suspected cancer, stating "people want confidence that suspected cancer is taken seriously and is a priority for the NHS" (Cancer Research UK 2015). Their analysis of the data proves that 25% of patients are not just missing the target but waiting more than a month longer than 62 days. Waiting times, they claim, are a barometer for how well cancer services are doing. They clearly adhere to the view advocated by the Department of Health, whose briefing on delivering cancer waiting times states, "Achievement of the national cancer waiting times standards are considered by patients and the public to be an indicator of the quality of cancer diagnosis, treatment and care NHS organisations deliver" ((DoH 2014, page 5). However, a report by the Nuffield Trust (Dorning and Blunt, 2015) found that even the best performing hospitals are struggling to hit all the waiting times targets, which it attributes to widespread systemic problems, not managerial failings. This reinforces the importance of understanding how the key players involved in the targets feel in order to identify ways of improving services.

A further review of the cancer waiting times standards in 2019 has resulted in some key changes around how patients are reported. It includes different rules for the measurement of waiting times for some prostate and bladder patients. In addition, it sees the introduction of the Faster Diagnosis Standard, whereby patients will be expected to receive a diagnosis by day 28 in their pathway (NHS England 2019). Implementation of these new rules has been delayed by the COVID-19 pandemic, so it is not clear yet how successful or popular these amendments will be.

## **2.5 Relevant ideas and concepts**

In addition to the reading specifically about performance indicators and targets, I reviewed various texts on the sociology of medicine for ideas relevant to my study around waiting times, pathways and the organisation of these in the NHS.

Of particular interest is the wider context of performance management in the NHS and the challenges to medical dominance brought about by the rise of managerialism. The recommendations of the Griffiths Report in 1983 led to changes in the structure of the NHS, which ended clinical dominance through a shift in the balance of power with managers (Hood 1991). Nettleton (2006) and Clarke (2001) discuss Talcott

Parsons' ideas about patient-doctor relations and how the changing nature of these relations tie into Foucault's ideas about power and bureaucracy. From a practical perspective, this entailed an enhanced role for managers and the introduction of control measures to increase efficiency, accountability and transparency (Numerato 2011). Several elements of this influence can be seen in cancer care after the introduction of the Cancer Plan in 2000, with encouraged standardisation through the use of timed pathways designed to meet targets and enhanced referral guidelines (DoH, 2000). This blurring of professional jurisdictions did not affect everyone equally, with some professionals resisting (McGivern et al. 2015) and others taking up managerial positions as a means of reasserting their professional agency (Kirkpatrick et al., 2005; Waring and Currie, 2009), referred to by some as hybrid managers (McGivern et al. 2015).

As part of these changes, some commentators directly linked performance management to the de-professionalisation of clinicians. In an address to the British Medical Association in 2002, their chairman, Ian Bogle, claimed that target setting erodes clinical autonomy, with the suffocation of professional responsibility turning doctors into "bean counters" (Beecham, 2003). Furthermore, Smith (2008) claims that the target regime replaces the altruistic motivation of doctors with the mercenary intent of managers. Others also saw that the rise of the managers was at the expense of doctors (Clarke and Newman, 2006), with Payne (2006) depicting managers as causing conflict through their demands, whilst Koch (1991) was concerned about managers prioritising performance over quality of care.

While some frame this as a personal dispute between individual managers and clinicians (Scambler 2003) with their different priorities causing conflict, Numerato (2011) found that usually mediation and coexistence were the results. Kirkpatrick et al. (2005) also recognised that it was organisations that undermine the hierarchical control and autonomy of doctors in the NHS, so personal relationships between staff should not be affected.

Concurrent with the changing relationship within healthcare organisations was the rise of the evidence based practice movement. This was seen by some to challenge the autonomy of individual clinicians by encouraging the standardisation of practice based on research proven evidence of effectiveness (Parahoo 2006). A key stage was the foundation of NICE (The National Institute of Health Care and Excellence), whose referral guidelines form the basis for doctors of when to refer a patient to secondary care with a suspected cancer (NICE 2021). However, while some may

have been concerned that the evidence based movement promoted prescriptive guidelines that undermined clinicians' tacit clinical knowledge, Gabbay and le May (2004) found that clinicians relied instead on "mindlines" – tacit knowledge informed by their own and colleagues experience. The respondents in Langley et al.'s study (1998) used their discretion about following guidelines, describing them as an "ideal" which could be adjusted to suit circumstances.

While these changes purported to be in the best interest of patients, Williamson (2015) discusses how when doctors relinquish their clinical autonomy for performance management purposes, a patient's freedom to choose a particular course of action can be negatively affected. A system managed by guidelines and timed pathways potentially do not leave much room for patient choice. One of the important aspects of my study was did patients feel targets improved their waiting times? The cancer targets revolve around how long each patient has to wait for various steps in their pathway towards diagnosis and treatment, so I am interested in the impact patients felt they had on their receipt of timely care and their perceptions around how long was too long to wait for each step. This directed my reading towards some research around how time is perceived and specifically by patients who have cancer.

Adam (1995) describes how time may be experienced as having different tempi, with Schutz (2005) explaining that outer time (in society) has days with a definite length while inner time (experienced as personal and subjective) may standstill or rush forwards. Similarly, Braeden (1997) argues that cancer disrupts that ordinary continuity of our experience of time, with 'clock' time continuing, with no relation to 'self' time.

Rasmussen and Elverdam (2007) applied these ideas about time to cancer survivors in a study discussing how the receipt of a cancer diagnosis can disrupt patients' perceptions of time and by receiving a diagnosis that may shorten their life makes them more conscious of "time right now" (Rasmussen and Elverdam, 2007, p.614). Their research consisted of 9 weeks of participant observation followed by ethnographic interviews with 23 informants. They found that Schutz's (2005) idea that time can be taken for granted relevant to their findings, as some of the cancer patients in their study who post-diagnosis treat time as more valuable, especially if they feel their future may now be limited. Other patients that they talked to discussed the importance of quality time, where experience is more important than length. Although their study concentrates on people at a different stage in their cancer journey than my

own work, their findings explore how cancer survivors talk about, experience and manage time. Other studies have also shown that time has an important part to play in healthcare. Roth (1963) recognised that time is central to medicine, with many patients conceiving their illness as the time to diagnosis and treatment. He described how people divide time into purposeful units to help manage the uncertainty of illness.

Rogers and Elliot (1997) argue that patient perceptions are an important barometer of the effectiveness of services, and these ideas around how people perceive time influenced my interview questions to all the groups of participants around how long patients have to wait and also were a consideration when coding the data.

When reviewing my data for themes relevant to my research questions, it was important to consider the motivations of my participants. Several models can be used to explain people's behaviour, including how they come to define themselves as ill (Clarke 2001) and what motivates them to change their health behaviour (Nettleton 2006). Walter et al. (2012) explain how the use of a theoretical framework to study delays in cancer diagnoses provides a systematic approach that aids understanding and hypothesis generation. They undertook a systematic review of research that applied the Andersen Model of Total Patient Delay to cancer patients. Few studies fully used the model, and those that did were inconsistent in their definitions, thus making comparison between them difficult. However, Walter et al. (2012) found that the model defines a series of steps in appraisal, treatment, behaviour, where a delay may occur in a patient's pathway, and were able to ascribe delays to appraisal, illness, behaviour, scheduling or treatment. Molassiotis et al.'s 2010 study was one of those appraised by Walter et al. (2012), and they used Andersen's model to map a patient's change in health from initial onset of symptoms to diagnosis of cancer, identifying different types of delay involving both patient and system delays. Walter et al. suggest some refinements to the model with clearer definitions for the use in future studies to improve consistency. One important alteration is the addition of contributing factors to delay aside from patient related ones. Their version of the model includes healthcare provider, system delays and disease factors. Also, by changing the emphasis from "delay" and the negative connotations that come with that to "time interval," it gives a wider scope for consideration of the processes that occur at each stage in a patient journey. The stages of the model do not correspond directly with the stages of a patient pathway as measured by the cancer waiting times standards (although they align better following the introduction of the 28-day referral to diagnosis standard). However, it is useful when considering the different levels of importance

placed on each stage by my participants. One of the stages in a patient's pathway identified in "the Andersen model" and as described by Walter et al. (2012) was help-seeking. De Nooijer et al. (2001) examined this time period in cancer patients' pathways which occurs after the onset of symptoms while the patient needs to decide to seek help and then action that decision.

How patients react to symptoms and come to a decision to access help can be complex and due to a number of different reasons. De Nooijer et al. identify embarrassment at symptoms, and lack of recognition that their symptoms could be serious, among the reasons why patients delay taking action. They recommend that education and information around symptoms recognition would be useful. Embarrassment was also a key finding in Smith et al.'s (2005) ideas of help-seeking behaviour. They studied the effect of education around symptom recognition and the effect of gender on help-seeking behaviour, concluding that these factors need to be recognised when developing new strategies to encourage early diagnosis.

Research which considered how patients felt or behaved during the diagnostic or pre-treatment stages of their pathway, as defined by Andersen, is limited. My study will fill an important gap around how patients are and what they feel about the length of their cancer journey. While these models that seek to explain patient behaviour have influenced my approach, my study seeks to explore a diversity of experience outside of the confines of a specific model. While I don't intend to attempt to fit my findings into one of these models, these ideas have been extremely useful in identifying possible interpretations of the data I collected.

## **2.6 Chapter summary**

All Trusts in England must monitor their performance against measured timings of parts of a patient's cancer pathway, as dictated by the National Cancer Waiting Times Targets. This review has examined various aspects of how the targets work for cancer patients. The importance of initiating a pathway with the GP is clearly evidenced by the benefits of early diagnosis. Once the patient is in secondary care, the view of the targets sours and commentators highlight what they see as the multiple failings of using these performance indicators as a way to monitor and improve healthcare, chief of which is their insistence that hospitals cannot be trusted to put patient care above performance and so will subsequently cheat/fudge the numbers. These arguments are backed up to a limited extent by the scandals at Colchester and Mid-Staffordshire. Alternatives to the targets to benefit clinicians and patients have been posited, but the reviews of the waiting times insisted that they were still fit for purpose and they

remain in place, with only some minor changes, the most notable being the introduction of the new 28-day target.

Several theoretical concepts and ideas that may influence my approach have also been discussed where they were relevant to ideas around patients waiting, and delays and the impact of managerialism and potential conflict that it may cause between managers and clinicians have also been considered. Although there seems to be a large amount of literature with much to say about targets (even if not specifically the cancer targets), the benefits and drawbacks of applying them to healthcare, and what impact they will have on the three groups in my study, there is little direct evidence from doctors, managers, and patients. The research questions have been generated in response to this gap identified in the literature review:

1. How do clinicians think the targets affect their clinical practice?
2. What impact do managers feel the targets have on service provision?
3. What are patients' views on the cancer targets and their impact on their journey through care?

A comparison between these three groups provides insight into their knowledge and beliefs about the targets, including how they impact on patient pathways, service design and practice.

Chapter 3 outlines the methodology of the study.

## **Chapter 3. Research design and methods**

### **3.1 Chapter Overview**

According to Bowling (2014), the first stage in ensuring rigorous and accurate research is through detailed documentation of the research process. Therefore, this chapter sets out a description of the research methods used in the study, including why they were chosen and details about sampling, data collection and analysis. The ethical implications of the research were considered and how these were addressed, as well as details of my lengthy journey to achieve ethics approval.

As the central intention of the study was to develop a deeper understanding of how NHS managers, clinicians, and patients experience the National Cancer Waiting Times Targets in England, the first task was to select an approach that would give the best insight into their knowledge and beliefs about the targets. This would also determine the nature of the study, which would have important implications for the application for ethics approval as well as the results I was hoping to uncover. A cursory reading of the title might suggest it is a service review that is being undertaken to evaluate practice in the NHS. However, as an investigation of a social phenomenon and its effect on staff and patients, it is classed by Healthcare Quality Improvement Partnership to be a piece of research (HQIP 2011). The Health Research Authority decision tool also indicated that the study was research (HRA 2017), as opposed to a service review, as I maintain that the results will be transferable, reflecting the thoughts and opinions of people in other parts of England. The distinction is important to ensure that the appropriate clinical governance requirements are followed with regards to risk management and public protection (HQIP 2011). For my study, this meant submitting an application via IRAS (Integrated Research Application System) for ethical approval before further work could continue.

### **3.2 Study design and setting**

The research followed an interpretivist approach, with participants bringing meanings to the situations they found themselves in to make sense of the world (O'Donoghue 2006). A qualitative approach was appropriate because my intention was to develop ideas around waiting times for the groups based on their own accounts of their experience. I wanted an approach that would capture as full an understanding as possible of the participant's perceptions of their experiences and their reflections on the importance they attached to those experiences. Semi-structured interviews, which can pose open questions based on research aims, was an appropriate method for collecting the required data for this study. An interview study design allowed

individual engagement with each participant, making it easier for the patient cohort to discuss their feelings towards such a sensitive subject more openly. This may not be achieved through a questionnaire or focus group. As data collection occurred prior to the COVID-19 pandemic, interviews were conducted in person, which enabled me to create a relaxed environment and establish rapport with my participants. There has been some criticism of the dominance of interview studies used to examine patient experience (Atkinson and Silverman 1997). However, it has been recognised that interviews can be considered as a social encounter (Hammersley 2017), and as long as the resulting data is analysed in a robust fashion (Silverman 2016), they can still form a credible means of research.

The study design went through various iterations before I settled on this format. Initially, I had intended to focus only on cancer patients, comparing groups of patients with different types of cancer. Given the different pathophysiology of cancer types, the importance of time to diagnosis varies considerably. However, this leads to difficulties with recruitment as it was not always appropriate to interview patients whose cancer type had shorter survival times. Although, arguably, their experiences would have been significant, as the main group intended to benefit from the targets, it was not deemed to be appropriate to seek out considerably ill patients, potentially at the end of life, for this study. Instead, I set out to collect a diverse set of experiences that might produce some interesting contrasts.

There are benefits to introducing comparisons into the data collected as we understand a phenomenon that we are interested in better when we compare it with something else that is similar (Bryman 2012). This idea is seconded by Denzin and Lincoln (2000, p.1055), who state that "many social scientists now recognise that no picture is ever complete, that what is needed is many perspectives, many voices before we can achieve deeper understandings of social phenomena". I did not want to abandon the idea of gathering contrasting experiences, so I amended my question to include three separate groups of people. In addition to patients, my study includes managers who have to ensure services can deliver cancer targets and clinicians who have to practice within the targets and patients whose care has been delivered within the targets. Pope and Mays (2006) reiterate the benefits of multiple perspectives so that the viewpoint of one group is never presented as if it represents the sole truth about any situation. They also feel that collecting information from more than one group forms a useful method of triangulation which will improve the overall validity of the study.

### **3.2.1 Sample identification and recruitment**

#### **3.2.1.1 Eligibility Criteria**

The eligibility criteria were wide so that a diverse sample was recruited who could best answer the research questions. For the managers and clinicians, the main inclusion criterion was that they are NHS professionals whose work brings them into contact with the National Cancer Waiting Times standards. The inclusion criteria for patients were that they are adults (aged 18 and over) who have had a cancer diagnosis in an NHS hospital in England and be able to give consent to be interviewed. Recent research has revealed inequalities in age, gender, ethnicity and socio-economic grouping when it comes to participants in cancer research (McGrath-Lone et al. 2015). I felt that all members of these groups could give a valid insight into the topic, and a representative sample of these demographic groups will make the results more generalisable. Due to my own language skills, all the participants had to have a fluent level of English. This was to ensure a smooth interview and reassure me that they were able to understand the purpose of the study and give informed consent.

Given that cancer is, in some cases, a life-limiting illness, it is important that participants were fit enough to take part. Prior to being included in the study, all patients had completed their first round of treatment for a primary cancer. Having consulted with health care professionals, this timeframe was considered a suitable length of time for the participant to have adjusted from the emotional distress of the disease whilst not being too distant from the onset of the disease to prevent recollection of events.

#### **3.2.1.2 Participant population**

The study was conducted in the North West of England, with the majority of patient participants being recruited from one clinical site for practical reasons. I have an established network of health professions that I could call on to take part whilst undertaking the research around my full-time job.

#### **3.2.1.3 Sampling technique**

The sampling technique was a combination of convenience and purposive. It was important that certain people took part so that the information generated was useful, hence the eligibility criteria. However, I felt it was important that the participants in all groups felt that they were choosing to take part and that they are not being individually targeted. Study participants were recruited from events where I gave a 5-minute brief overview of my research and what I hope to find out, and how it can be used to help

others. Participants from the clinical and managerial groups were identified through networking at meetings of the Merseyside and Cheshire Clinical Network. I aimed to get a selection of new and experienced managers and clinicians from a variety of specialities. The participants in the patient group were identified through their attendance at public events for cancer patients run by the Trust where I work, which regularly attract several hundred patients and through their membership in cancer support groups. This removed the need to access confidential personal information about the patients in order to know whether they were eligible for the study. This method had the approval of the local prostate support group members, who were approached informally to discuss methods of identification of patients.

#### **3.2.1.4 Size of sample**

As the qualitative study is concerned with meaning, large numbers of participants in a sample were not necessary and sometimes impractical. The intention was to start with about 7 participants in each group, which it was felt would give a good representation of people's understanding. As the data collection progressed, the number of participants needed was reviewed. The sample of managers included representatives from primary and secondary, and tertiary centres, including some who had the dual role of lead cancer nurse and cancer manager. The clinicians' roles varied too from consultants, staff grade doctors and cancer specialist nurses. The patients were treated at four different Trusts and represented five different types of cancer (see appendix 5 for details of participants). This was a deliberate strategy to achieve as wide a range of data saturation as possible. In total, 27 participants were recruited: nine managers, nine clinicians and nine patients. Oppenheim (1992) suggests that there is no correct number of interviews, with quality more important than quantity, with Moule (2020) agreeing that the representative nature of the sample is more important than the size.

### **3.3 Instruments**

#### **3.3.1 Interview schedule**

The interview schedule varied slightly between each group of participants, consisting of 9 – 13 open-ended questions. It was designed to best explore each groups' experiences of the target system as "different social groups may experience the same event very differently depending on their shared norms and beliefs" (Avis 2005, p10). The schedule allowed for all the issues I felt to be important to be covered; it was also flexible enough to expand certain areas of interest that might occur during the interview process. Questions were informed by themes uncovered in the literature review. Patton wrote, "the primary aim of semi-structured interviews is to enable

participants to talk openly about their experiences in their own words" (2015), and the schedule was designed to be adaptable to ensure participant-led data collection. The focus of the interview schedule was, for all three groups, to enable participants to open up about their experiences and then use probes to gain elaboration, encourage the use of examples and clarify any incomplete information. Although Howitt (2010) cautions against the excessive use of probes lest they disrupt the flow of the interview, this clarification could be used to encourage deeper reflection on the more relevant issues raised by the respondents (Hutchinson and Skodel-Wilson 1992). It was important that the interviewees did not feel led by the questions, and they were jargon-free so that they were easy to understand. After several interviews, the schedule was reviewed to determine if any alterations were necessary following the conversations that had taken place. This iterative process was continued throughout the data collection period. A copy of the different interview schedules that are used with each group can be seen in Appendix 1.

### **3.3.2 Interview setting**

Finding a suitable location for the interviews was important. A clinical environment was not considered appropriate for the patient cohort as it was not considered an environment where they could easily relax. Patients were interviewed at the Macmillan events and at support group meetings. These venues have separate spaces for private conversations that are suitable for interviews to take place in. Although extreme care was taken not to upset any of the interviewees, on these occasions, they were able to access specialist nurse support afterwards should the interview raise any clinical questions. They were also invited to bring a companion with them for support if they wished. Managers and clinicians were interviewed on hospital premises, in their offices, as informal inquiries revealed that it was unlikely they would find time to talk otherwise.

### **3.3.3 Interview process**

Participants were welcomed to the interview and asked to confirm that they had received the information sheet (see appendices 2 and 3). A brief conversation was held about the intentions of the research. To maintain their autonomy, it was reiterated that the participants could withdraw at any point with no consequences for them. I provided the opportunity to ask any questions before obtaining written consent. Although following an interview schedule, patients were encouraged to discuss any topic they felt were important before moving on to the next question. The interviews started with an easy question to relax respondents and start them talking. Each

interview lasted about 45 minutes and was recorded on a hand-held digital recorder. This procedure was repeated for all participants, who were all interviewed by me.

### **3.3.4 Data coding and analysis processes**

In order to get closer to the data, I transcribed the complete texts of all the interviews from the audio recordings. I used thematic analysis as the qualitative tool to analyse and report on the patterns that I identified in my participants' responses. This fitted well with my interpretivist approach, which aims to make sense of the meaning that people bring to a phenomenon (Denzin and Lincoln 2011), in this case, what my participants made of the national cancer targets.

Polit and Beck (2014) describe thematic analysis as an inductive process that involves putting segments together into meaningful conceptual patterns, moving from broad themes into more specific ideas or codes. To achieve this, each interview transcript was read several times, looking for ideas that addressed the research questions.

Although the use of NVivo was considered, a manual approach was implemented, which involved going through each printed out transcript and making a note with a highlighter of the segments of text of interest and labelling them with a post-it note. This thorough approach was applied to the interviews of all the patients, managers and clinicians. Once this was completed, these codes were reviewed and grouped together, with the data collated into broader themes, both within the groups of participants and across them, to compare the different meanings that each group ascribed to the targets. While the process of actually undertaking the interviews and then their transcription had given me some prior knowledge of my participants' perspectives, it was this systematic analysis that completed my understanding of how they conceptualised and experienced the targets.

Using themes in the literature as a starting point for identifying similar ones in my interview transcripts, these findings were then written up in the following chapters. Each participant was given a pseudonym, and hospital names were changed to maintain anonymity. People who work in the NHS have a unique vocabulary that is comprised of abbreviations (many of which have several meanings, depending on context), terminology and local slang that can be impenetrable to the outsider. The language of cancer waiting times is a dialect of its own within this language (some key examples are explained in appendix 6).

Transcriptions of the interviews will be stored on the University of Cardiff's secure network in a section that only I have access to. Data will be retained following the university's data retention policy and destroyed after a mandated period of time.

### **3.4 Ethics**

I have been rigorous to ensure that the study is in line with relevant legislation and all ethical considerations have been undertaken before the commencement of the data collection phase. Gillam and Guillemin (2004) differentiate between two major dimensions of ethics in qualitative research: procedural ethics, which usually requires seeking approval from an ethics committee, and ethics in practice, which arise during the research process. They suggest that for many, the application to an ethics committee for approval is merely a formality, with applications carefully worded so as to receive approval. However, the other dimension includes practical issues which the researcher may encounter whilst undertaking research, giving them a moral duty towards the participants to look after their best interests. One of my major concerns with interviewing the cohort of participants who had had cancer was that I did not want to cause them any distress when they relived their memories of being diagnosed with cancer. However, a study by Montazeri et al. (1996) found that 96% of people did not mind being interviewed about their cancer. They found that there were four main themes around interviewing cancer patients: "the interview was not disturbing, they felt relaxed, and at ease, they liked to talk, and the interview was conversational" (p.447). By incorporating these aspects into the interview design and by making my intentions and the process explicit beforehand (including the opportunity to withdraw and not answer particular questions), I was confident that I had minimised the risk of harm to any of the patient cohort.

#### **3.4.1 Consent**

Blodgett et al. (2005) discuss how consent should not be regarded as a one-time event but rather an ongoing one that participants can withdraw from at any time. Participants may lack experience with research and therefore may not understand the issues, risks and benefits in the same light as the researcher. Therefore, it is the researcher's responsibility to commit to achieving ongoing consent whilst anticipating and addressing these concerns at the beginning of the process to help alleviate any mistrust and fears of research that the participants hold.

Informed consent was obtained prior to any participant undergoing any activities specifically for the purposes of the study (see Appendix 4 for a copy of the consent form). Consent was explained to the participants when they agreed to take part, and

they were offered to have it explained again at any time during the study. It was ensured that all participants understood the purpose of the research, their role and that they could withdraw at any time they may wish to with no penalties or effect on their future care or treatment. It was explained to patient participants that their cancer diagnosis was going to be discussed, which may be a distressing area of conversation for them. It was also explained to the participants how their data will be stored, used and how anonymised versions of their statements may be used in the completed work, which they would receive a copy of. Participants received a page of information about the study and were welcome to ask any questions. They were then asked to sign a consent form, which they were given a copy of for their records.

#### **3.4.2 Assessment and management of risk**

Wright and Flemons (2002) point out that the needs of the study must be secondary to the participant's needs. The risks associated with the study were considered for both the researcher and the participants. The locations chosen to undertake the interview mitigated any significant risk for the researcher. These were either be in NHS hospitals or for the patient interviews in a public venue with other people nearby. The primary concern for the patients who agreed to be interviewed was that discussions about their cancer might elicit distressing memories. Patients were reassured that they could terminate the conversations at any time, and there was specialist nursing staff available if they needed further reassurance.

#### **3.5 Research Ethics Committee (REC) and other Regulatory reviews**

It was determined after consultation with the university's ethics committee that an application would need to be made to the NHS ethics committee. To ensure that this could be done with the support of my workplace, an application for sponsorship by the NHS Trust where I work was completed. This included submitting a research protocol that was subject to both internal and external peer review approval before sponsorship was approved. An application was also submitted to the Cardiff University Research Governance Committee in line with their review process. An application was submitted to the UK Health Departments Research Ethics Service before the start of the study with full consideration of all the ethical implications. This was a lengthy process, with several resubmissions and clarifications required before they gave a favourable opinion for all documentation, including the consent forms, patient information and the study protocol. The following reference numbers were allocated to the study:

IRAS project ID: 23 27 02

HRA reference: 18/SC/0320

Sponsor reference: 1819-003

There is an increasingly critical narrative about the bureaucratic processes around gaining ethical approval for studies such as this one, which Haggerty describes as "a fetter on our knowledge production endeavours" (2004). Reed criticises a system she sees as irrelevant and inaccessible to health researchers (2007). Like her, I found the process of collating associated documents useful for refining my methods but struggled with the content and being able to relate some of the questions to my research.

### **3.6 Patient and Public Involvement**

Patient and Public Involvement in both clinical practice and research is currently advocated by the NHS (NHS 2005), as shown in the report "*Creating a user-led NHS*". It is suggested that including people in research regarding the services they use improves the relevance of research and increases the likelihood of successful implementation of research findings into clinical practice (Hanley et al. 2004). Patients were consulted during several stages of my research. The National Institute for Health Research considers public involvement in the development of research topics to be one of its key goals (NIHR 2012). My initial research idea was conceived following informal conversations with patients at support groups. Including service users from the beginning ensures that research outcomes will be meaningful and relevant to those living with the condition and using those services (Chalmers 1995). When these conversations were discussed further in my workplace, it became apparent that groups responded in different ways to the targets, and the research question was formed. The interview questions were developed with the desire to elicit rich data from all the participants. Patients were informally consulted about what questions might cause distress when discussing their cancer diagnosis and where they may be comfortable having these conversations. All participants received a summary of the results and will be offered a copy of the final thesis.

#### **3.6.1 The role of the researcher**

Hammersley and Atkinson (2007) discuss the importance of finding the correct role or position to research from, as each comes with different challenges. One of the fundamental principles about pursuing a professional doctorate is that the research is work-based to improve professional practice from a position where findings can influence change. This is inevitably going to be influenced to a degree by the preconceptions of the researcher. Moreover, cancer is in itself is a very emotive topic,

so I needed to carefully consider how I was going to position myself in the research. Arbor (2005) considers that by clearly identifying my position, I improve the credibility and reliability of my work. The key is to adopt a reflexive approach whereby I consider my position and how it may impact on my study (Delamont and Atkinson 1995). As Guillemin and Gillam noted, "a reflexive researcher is one who is aware of all these potential influences and is able to step back and take a critical look at his or her own role in the research process" (p.275, 2011).

There are advantages to being an insider researcher. As Coles says, "research may have a greater impact if someone who has intimate experience of the topic carries it out" (2015, p136). For me, this meant being able to research a real-world topic that I know impacts on thousands of patients in my hospital every year and hundreds of thousands nationally. I had easy access to participants to recruit for interviews. Although I was a novice interviewer, the locations and participants were reassuringly familiar – although Holloway and Wheeler (2013) warn that this can lead to biased observations. It was also important that I did not steer the interview conversations in a particular direction based on information that I already possessed, and I followed Adam's (2013) advice to make my role clear to participants. Several participants did attempt to involve me in the conversation, asking what I thought about a situation (see page 80), but I attempted to keep my interactions limited. I did not want to lose my critical and analytic perspective, so I tried to consider other potential threats to it which may occur. Hammersley and Atkinson (2007) discuss the familiarity problem when a researcher can become blinded to the obvious due to their closeness to the situation they are researching. Coughlan (2007) describes another data collection challenge that can happen when participants withhold knowledge because they presume it is something that the researcher already knows, which was another factor to be aware of while processing my data.

The iterative process of qualitative research, whereby one bit leads to another, lends itself to developing an awareness at the beginning of the research and continuing it through each stage. There are several methods, and the one that I chose to adopt was that of keeping a reflective journal. This was recommended to me in an early meeting with my supervisors, and I have found the process of documenting my thoughts about the decisions I have made has helped me acknowledge any preconceptions that I might have. By continuing throughout, this method identifies any issues as they arise as preconceptions are not linear. In Bolton's opinion (1999), reflective practice is more than just an examination of personal experience. To

achieve reflexivity is necessary to find strategies to question one's own actions, thoughts, feelings, values and identity. I think this will help me achieve research that is underpinned by knowledge rather than contaminated by my ideas.

### **3.7 Chapter summary**

This chapter details the physical processes undertaken to complete the study, including reflections on how and why this design was appropriate to answer the research questions. I consider my role as an insider researcher and explain the complex process of acquiring approval from the Health Research Authority to undertake the research. Careful consideration was made of who to include in the study, their recruitment, where to interview them, as well as the best questions to ask them to acquire the data needed to address my research questions. The following three chapters give me the opportunity to present the data that has been generated as a result of my interviews.

## **Chapter 4: Is what is measured, what matters? How important is the role of targets in the patient's journey?**

### **4.1 Chapter overview**

In this chapter, I examine how targets emerged in patients' accounts of their journey through the health care system and also the role that managers and clinicians attributed to the targets. Firstly, I discuss the elements that patients identified as important to their overall experience and where the targets fit into these expectations. For patients, this begins at their GP surgery, which is the first stage in their journey to get help. GPs act as gatekeepers into secondary care to access cancer diagnostics and treatment. Upon referral, in addition to timely progress on their journey to treatment, patients value information and a clear plan. The relationship discussed here between waiting times, and patient experience is complex. Targets are designed to speed up pathways, ensuring that patients have timely investigations and treatment. While all participants identify speed as important for a patient's mental health, as well as physical wellbeing, patients do not necessarily associate speed with targets. Patients in receipt of what they considered to be good care did not perceive their waiting to be longer than desired.

The second section considers the role the targets play in the patients' pathways from the managers' and clinicians' perspectives and what actual knowledge patients have of the targets. Again, this begins with the GPs who have the difficult role of deciding who to refer and when. Targets do not time this part of a patient's pathway, but patients wait for the GPs to take action on their behalf, which can depend on the level of experience the GP has identifying potential cancer symptoms. During this time, under the care of the GP, the exchange of information is crucial in how their patients go on to behave and engage with their investigations. For the GP, it is a delicate balance between making the patient overly anxious and ensuring that they understand the seriousness of their situation. The advantages and disadvantages of such knowledge are considered, which seems to divide opinions of those interviewed for reasons concerning the patients' health as well as those of service provision.

### **4.2 Negotiating access to GPs**

The patients' narratives began in primary care, where they discussed the reasons why they sought help from their GPs and the difficulties they faced accessing this help. The element of urgency is present at this time, with patients anxious for reassurance, even though this period of waiting is not measured by the targets. This time period can be crucial for patients with cancers as they need speedy access into

secondary care for diagnosis and treatment, which for the majority of them is achieved by a referral from their GP.

The first step is to gain access to their GP to discuss their concerns, but several barriers to achieving this were identified during my interviews. Several interviewees described shortages of appointments, with Yvonne, a service manager, summing up the situation by claiming that “*you have to be ill by appointment to see the GP now*”. The difficulties identified by Yvonne (of accessing GP services) are a result of complicated barriers which have been set up and need to be overcome before an appointment is allocated. Patients need to be able to access their GPs for further help, but at present, my study shows how these difficulties might deter people. In addition, several patients discussed elements of their encounters with GPs that they saw as reducing the quality of the meeting. This included not always seeing the doctor they wanted to, rules around what can be discussed in appointments, and physical discomfort at the surgery.

Janet's (patient) story, in particular, highlighted these issues with accessing her GP. An elderly patient with multiple medical problems, Janet complained about how at her GP's surgery, patients must wait several weeks for an appointment. Alternatively, there is a daily ration of urgent appointments provided on a first-come, first-serve basis. These are in high demand, so early attendance is required, which may disadvantage some patients. In addition, the quality of her encounter with the GP was adversely affected by external factors, namely, an unwelcoming physical environment and what she regarded as nosiness on the part of the surgery receptionist.

*It is horrendous at the surgery. There is no shelter. They won't open the doors. I was there one morning last winter, and it was absolutely freezing, and rain was pouring down, and one of the workers came, and they opened the door, and I said, "Can we come in?" and she said, "I can't let you in, it's health and safety." You have to go at ten past eight for them to open at half past eight. You have to be there if you want to be seen or for a chance to be seen on that day. Otherwise, you have to wait three to four weeks. Then when you get inside, they want to know what's wrong with you to see if you're sick enough to see the doctor! I always say it's my bowels. They never want to know any more details if you say that.*

It is easy to understand how patients who were not feeling well, especially those Janet's age, would find being made to wait in the rain and cold a deterrent to seeking their GP's advice. The unwelcoming tone of the encounter with the staff member who

denied Janet access may have undermined her confidence in the surgery as a place where she could seek help. Others, for example, those with childcare responsibilities, may find it difficult to wait around at that time in the morning. However, if you want to be seen on the day, these are the requirements expected of patients. Janet also did not want to discuss her problems with the receptionist at the surgery. It is a common approach adopted by GP surgeries to triage the urgency of patients' complaints, but many interviewees, like Janet, seemed to find it invasive. Janet has devised a method of getting around the policy. Playing on the assumed embarrassment around discussing bowel function, she uses this to dissuade further personal questions from a receptionist.

Nonetheless, her difficulties continue as Janet specifically wants an appointment with Dr J, but *"if I want to see him, it is three weeks [until an appointment is available]"*. If she wishes to maintain what she considers to be the continuity of care, Janet will have to wait to see her GP. Her familiarity with the doctor brought a sense of security and a feeling that the doctor knows her as a person and will be able to recognise if something has changed since her last visit. The desire for familiarity was evident in my conversations with other patients. In some cases, the patients think the relationship goes both ways, with patients caring about their GP and the GP caring for them. Another patient, Barbara, values the connection with her GP and likes to keep as up to date with events in his life, talking about her doctor like he is an old friend. She likes to receive news about his daughters and claims he is interested in her daughter, Elizabeth, who was under his care as a child.

*I like a chat with Dr Q. I've been seeing him for years. He always asks after our Elizabeth because I used to take her to see him. He has daughters too. It's not the same if you get a locum.*

Barbara views her GP appointment as a social opportunity to catch up with someone who knows her as well as offering a medical assessment, which is not possible if she sees a new doctor. She has a history with Dr Q of seeing him for several years, a personal connection that she does not feel with a locum GP who she does not know.

Another key factor that patients placed emphasis on was the length of time spent with their doctor. The patients I spoke to do not want to feel rushed in their consultation and to be able to talk through their problems. Hence, one of the biggest causes of discontent was the policy that has been adopted by several local GPs of only allowing patients to discuss one problem per consultation. A shortage of appointments has resulted in GPs needing to keep to their timetabled slots rigidly, which means patients

are only allowed one 'concern' per appointment. If you have a second 'problem', it is expected that you will make another appointment, which is not always possible if there is no availability.

David, who has a diagnosis of prostate cancer, explained that “*you can't go in with a menu of complaints, you get 10 minutes, so it's one problem only*”. Patients only have a brief opportunity to explain to their GP what their problem is, potentially risking a delay getting treatment for a more serious condition or for cancer patients getting a referral into secondary care.

#### **4.3 The Importance of speed**

Once their GP makes a suspected cancer referral, all stages of a patient's pathway are measured by the cancer targets. The targets are designed to ensure that patients progress smoothly through hospital systems to receive a timely diagnosis and treatment. My interviews revealed what importance the patients placed on the targets as a mechanism for speeding up their journey to treatment. One of the key benefits of the targets is reducing waiting time for patients, as long waits can be detrimental to their mental health. It was evident in the language used by patients describing how they waited for a diagnosis that waiting for any length of time was not a comfortable experience. Barbara, a patient with bowel cancer, explained how difficult it was for her to wait between each step in her pathway.

*I feel like I spend all the time between appointments holding my breath, waiting to find out what is going on.*

This illustrates how difficult it can be for patients to wait to find out what is wrong with them, how serious the diagnosis is, and what treatments they can have. In this respect, the patients benefit from the targets, which encourage care pathways that have maximum recommended timings between each step to ensure the mandated waiting times are met.

Clinicians recognise that reducing the length of time patients are waiting is the chief advantage of the target system. Considering the new 28-day referral to diagnosis standard, one clinician, Alexander, recognises the importance of fast-tracking anxious patients through the system to get a diagnosis, even if subsequently their treatment is not clinically urgent:

*If someone comes in with haematuria, it is quite scary for people, or if someone comes in with a testicular lump, it is scary for them. It is not*

*unreasonable to expect them to have a diagnosis in 4 weeks; treatment can go on forever after that.*

Alexander recognises that symptoms such as haematuria (blood in urine) or a testicular lump will naturally cause alarm in patients, so achieving a quick diagnosis for these people is very beneficial to alleviate their fear. It may be that the subsequent treatment for these conditions is not clinically urgent, but the patient can be reassured that the origin of their symptoms has been identified and their worries eased that they will be treated.

There was agreement from some of the patients that their concerns were lessened when their diagnostics and treatment progressed in what they saw as a timely manner. Henry (patient) explained how he was dealt with quickly at several points in his pathway, which he appreciated when he reflected on his experience.

*I got the biopsy on the day, which I wasn't sure about, but it was good for the doctor and for me. I needed to get it done. No one likes waiting, do they, when it comes to health matters?*

He recognises that the speed also fits with the doctor's plans and overcame his initial reluctance to go ahead with the biopsy as he knew he needed to have it done to get a diagnosis. He identifies what could be described as the key principle behind waiting times from a patient's perspective; no one wants to wait to find out what is causing their ill health. Any reservations Henry may have had about the speed of his pathway were gone by the time he had his diagnosis, and was having staging scans to determine what treatment was suitable:

*The doctor and the lead nurse said to me, "we'll be in touch later on today. You should get a phone call, and we're going to arrange a bone scan for you". So, I thought, well, good, obviously that is to check if there is any spread. So, I got a phone call that afternoon, and I was very impressed, and they arranged an appointment at Crosshill Royal to go off and have a bone scan. I was anxious to get the treatment started, and we did.*

Having received a diagnosis of cancer, the next step for Henry and his clinical team is to investigate if the cancer has spread outside of the organ of origin and around his body. This will determine both Henry's prognosis as well as what treatment options are available to him. He was clearly impressed that he had been called the same day to arrange his scan but also relieved that his care was moving quickly. It is important to him to get these answers so that he can start his treatment.

Another patient, Janet, was also impressed by the speed of her treatment, although she does associate this with good fortune. The surgeon called her shortly after her clinic appointment to offer her surgery within the week.

*I saw him, and I got a telephone call, and he could fit me in, and it was only five days, so I've had no hanging about. I've been very lucky. He said he had a quiet spot, and he could fit me in. It was so quick.*

Janet is grateful for having been operated on quickly and avoided having to "hang about" due to the surgeon's quiet spot. Other explanations for Janet's quick surgery could be attributed to clinical urgency or the targets, but Janet instead assumes she was just "lucky". The system worked without Janet's knowledge, ensuring her surgery happened when she needed it. While it is clear that patients appreciated timely care, they seemed to have their own ideas of what timely care was, which did not always correlate with the cancer targets. One theme that emerged was the emphasis patients placed on having a clear plan in place for their care. Trevor, one of the patients whose cancer was identified through the bowel screening programme, was given a very thorough explanation of what to expect. His briefing involved information on all aspects of his disease, as well as the processes around his treatment and when he was to expect it.

*I got a letter very quickly to go down to Sunnyside Health Centre to see a specialist nurse for an initial briefing with all the diagrams and the possibilities and the different ways in which cancer spreads and this that and the other and what the waiting times should be and what the process would be and where I would have the surgery which was here. It was very efficient and very effective, and very informative. She covered the waiting times in real detail: it was very reassuring to know that. When I left Sunnyside, I actually had a programme. I felt that I had a programme. I thought that was okay.*

Trevor felt reassured by receiving a detailed plan. His situation is exceptional in the amount and detail of information he received, but it is clear that the step-by-step explanation of his itinerary managed any anxiety he may have had about what was to come for treatment. He claims the waiting times were explained to him in detail. However, it appears Trevor misunderstood the information that the specialist nurse gave him as he continues his story detailing timings that did not fit within the 62-day treatment target for screening patients (the target which would apply to his care). He justified the time he waited for surgery by explaining several steps he went through, clearly feeling that these stages were scheduled appropriately and could not have

been done more quickly due to their complexity. He also says that if his cancer had been more advanced, he is sure he would have been treated faster, assuming his care was clinically prioritised.

*It was the end of June when I had my diagnosis confirmed at Everfield hospital, and I had my operation on the 21<sup>st</sup> October. In between times, there were phone calls, and I had to spend quite a lot of time, no not a lot of time; I had two or three meetings with the stoma nurses, so all that had to be fitted in. There were so many different processes to get all those people in a line in the right order. I thought it was quite good. So, it was way below the eighteen weeks; I don't know if that is the standard.*

*There was a lot to pack into eight weeks if you think about getting all those people in a row. That, for me, was fine. I can understand that my cancer being the way it was, there would be a lot of people far worse than I was. I can only imagine that had mine been a stage 3 or 4, I would have been in faster. I don't know how I would prioritise it. I can't imagine. But that was the process.*

Trevor's explanation illustrates how complicated diagnostic pathways can be leading up to treatment and how difficult it can be to fit all these steps into 62 days. For the surgery to progress smoothly, there are several steps that need to take place first, for example, the discussions with the stoma nurses. Despite this, he still trusts the system and imagines that it would have been faster were it clinically necessary. (In reality, the targets do not take clinical urgency into account.) The specific number of days do not seem to be as important to him as knowing he had a "programme" in advance with detailed steps, so he knew what to expect.

Trevor's experience mirrored several other patients whose reassurance over having a plan or timetable overrode any concerns about the length of time spent waiting for treatment. Mark describes how he found having a schedule of events with a clear explanation of his treatment timetable reassuring.

*Did I feel I waited too long? Not really, because it was explained to you. You are on some tablets for three months, and in that time, you'll see the oncologist, which I did, and they will tell you exactly what treatment you are going to get, which they did.*

Everything happened as Mark expected it to. He was reassured that, although waiting, there was a plan to follow. The rationale behind why he was on the tablets for a set period of time was explained. He was happy to comply, knowing he would

see an oncologist after three months. This then happened on time, as did his subsequent treatment, an order of events he was content with. Another patient, Henry, also revealed how he did not know what to expect, but once it was explained to him how a plan was in place, he was satisfied with what was happening.

*Of course, it was all new to me this, so I just went along. I was quite happy to just go along with whatever was agreed. But some short time afterwards, the bone scan came back negative, so that was a relief, and at a further appointment, they explained to me that we need to keep you on hormones to reduce your testosterone, and that's what happened. And they explained that to me, so I felt more comfortable with that because there was no delays. It was just this is the way we go.*

Here, Henry is describing one of the biggest worries for most patients. They do not know how the system works, so they rely on healthcare professionals to explain what is happening. Henry, like most non-clinicians, is happy to defer to his doctor's plan. Patients put their lives in the hands of the professionals trusting that they will do what is best for them. Henry's confidence in his medical team was justified when everything unfolded according to plan.

Every step occurred for these patients as they were told it would, which resulted in their satisfaction, irrespective of whether they met their targets or not. One of the managers, Frances, with a background in nursing, summed this up by pointing out that it is the quality of the contact during a patient's journey that they will recall, rather than the specific length of the journey:

*That is what they remember: the people who looked after them and the experience they had. That is what they remember, who helped them and the sort of information they had. That is the sort of stuff that sticks in their mind, not that they were treated on day 63.*

From my interviews, it seems that patients are far more likely to remember their care, a kind doctor or nurse, and how much they understood about what was happening to them. If they noticed that their treatment was delivered outside of target (day 63 on a 62-day pathway), it is unlikely to have made a big impression that this is their overriding memory of their experience. Treatment on day 63, as opposed to day 62, is not going to sour their experience. Frances illustrates this point with a recent example of a patient treated by her Trust who was extremely satisfied with the timeliness of his care despite breaching his targets:

*[Male patient] had a bowel cancer picked up by the screening programme, which he is very chuffed about because they caught it early and he has had surgery, and he hasn't got to have any other treatment. Now he actually breached the 62-day screening target, not by a huge amount, but the experience he thought was absolutely fantastic. He felt that everything happened really quickly, bang, bang, bang, one after another, got in really quick for surgery. So he did not meet that target, but he feels that everything was done really quickly, and he had a great experience.*

The patient participated in the national voluntary bowel screening programme, which resulted in his cancer being diagnosed in its early stages. The patient benefited from his proactive behaviour; getting a diagnosis before symptoms prompted him to seek help increasing his confidence in the NHS. His early diagnosis meant that he required no further treatment after his surgery, and although he did not meet the mandated waiting times from referral to treatment, he was still left with the impression that his care was timely.

Other experiences described by patients were also not specifically attributed to the waiting time targets. Most of the patients I spoke to only had positive experiences of their care, none of which seem to be predicated on meeting targets. Trevor was almost apologetic that he did not have a bad experience story to relate to me:

*If I had a bad experience, I would definitely tell you. I sound like an NHS advert. The experience was one I wouldn't volunteer for, but I would volunteer to be treated the way I was treated.*

Interestingly, even when an experience was discussed that was what one might consider to be a poor patient experience, the patients dismissed it as relatively unimportant. One patient, Stephen, described how his surgery was postponed twice because of different hospital errors, but this was not something that he appeared to be concerned or angry about.

*I spoke to the surgeon, Mr W, at Lakewood, and he arranged for the surgery at the end of August/ beginning of September. So, I went along and was told to be there for 11 am for the afternoon slot, so I was allowed an early breakfast at 6 am. On the day of the surgery, I had a phone call at quarter to 8 asking, "Where are you?" They had double booked my afternoon slot, so wanted me to go in the morning. "How long will it take you to get here?" So, I said one hour, but I've had food. They said they would phone me back. They did, and*

*the other guy hadn't eaten, so they did him. The next time I was prepped for surgery, there was another hiccup. They told me the robot had been misbehaving that morning in theatre, so we better not continue. So, I was sent home. Mr W phoned and apologised. He said I would be booked asap, in one to two weeks.*

Stephen was prepared for surgery, only for it to be cancelled on the day over an administration error about the timing of his operation. On the following occasion, a mechanical error with the robot which performs the procedure meant his surgery was cancelled for a second time. Both times, Stephen was swiftly reassured his treatment would go ahead soon. The surgeon himself rang and apologised the second time, which seemed to impress Stephen. He reports of his surgery "*I had the op, and all was well*". Perhaps because he could find no fault in his clinical care, administrative delays seemed of little importance. His opinion was shared by Henry, who also felt that small problems during his treatment were not important in the wider context of the quality of the care that he was receiving. He had asked for his appointments to be in the afternoon so that he could schedule his work around them and was very pleased that this had been arranged. This convenience outweighed the annoyance of a broken machine or delayed appointments. The supportive staff also helped ease the burden of his treatment. Henry said:

*Low and behold, when my appointments came through, they were all afternoon. Of course, the times varied, but I understood that, and there could be problems on the day with machines, there could be hiccups, you know, with machines, but all my appointments were there in the afternoon. I was really pleased if you can be pleased about that. It was going well for me in that respect, and it was a bit tiring and gruelling having to go there every day really and get yourself ready and drinking water and having your radiotherapy. They were super-efficient down there too. They couldn't do enough to put you at your ease because you are anxious about all this. The service was exemplary, and the care and I got through the 32 visits. The odd day one of the machines would break down so you would be there longer or whatever, but that's life, you know, things happen. Generally, you know, they would put you on the other machine and get you through the day, you'd get your treatment, you might be home a bit later, but got through that and come out the other side.*

Henry is determined to continue with his normal life as much as possible, going to work in spite of the need for "*tiring and gruelling*" treatment. The hospital recognised

this was important to him and scheduled his treatment so he could fit it in around his work. The efficiency and care of the staff helped him complete the exhausting regime of 32 visits. Henry accepted that sometimes treatment might run behind schedule, but he would be given it, if a little later than usual.

Once past the difficulties of getting to see their GP and being referred into hospital, the patients I spoke to seemed content with their care. When prompted, some patients had heard of the cancer targets, but they were by no means central to their personal stories about their cancer journey. Even those who described the importance of a rapid pathway did not associate this with the targets. Their focus is more on having a plan to follow, which helps them understand what is happening to them, rather than the targets and exact timing of events during their care.

#### **4.4 GPs as gatekeepers to secondary care**

The second half of this chapter begins by considering the difficult decisions that GPs have to make about referring a patient into secondary care on a suspected cancer referral. Starting with the patients at the beginning of the cancer pathway with the GP, a frequent complaint from the hospital managers was that GPs did not properly prepare their patients before referring them into secondary care. It then goes on to concentrate on the importance that my participants ascribed to the differing levels of knowledge patients had about the cancer targets.

GPs hold an important gatekeeping role; they decide which patients should be referred into secondary care (and when), instigating a suspected cancer pathway and its associated waiting time targets. In addition, they control how much information the patient is given about their subsequent journey. This can be difficult as an early referral may mean an early diagnosis with a more favourable prognosis but equally may unnecessarily alarm patients if the referral is premature. From the managers' perspective, the targets attached to suspicious cancer referrals mean that it is important that patients have enough understanding so that they engage with trusts and attend when required. Interviews revealed some interesting differences of opinion about the extent to which the waiting times targets should be explained to patients.

Having seen their GP, patients are reliant upon them to decide the most appropriate steps in their care. One concern raised was that patients wait too long to be referred, having to visit and revisit their GP before a referral is made to secondary care. Joan, a manager, explains how some patients have visited their GP several times before a referral is made to secondary care and that, during this period, they have been repeatedly reassured that if it is serious, they will be referred onto a specialist:

*What the hell has happened in primary care when they have been going back and forwards three or four times to a GP who says come back in 6 weeks, and I'll refer you if there is something to worry about?*

Once a referral to secondary care is made, all stages of a patient's pathway are measured, so the frustration for managers is that the targets put services under pressure to deliver speedy diagnoses for patients, but these patients may have been symptomatic while under that care of their GPs for some time already. During this time, they may have made multiple visits and been falsely reassured. However, it is not realistic to expect GPs to immediately refer every patient into secondary care. Such an activity is not always straightforward, and diagnoses often do not follow a linear sequence from presentation to definitive results. For instance, Mark (a prostate cancer patient) illustrates this when describing his experience:

*So I went back to the GP, and they said they had had the results, and there was an infection, and I was put on antibiotics, and he said, I'll take a PSA (prostate specific antigen) again now, and I'll do a rectal examination at some time later if it is still high, I'll let you know.*

Patients may get frustrated having to visit and revisit their GP with the same symptoms before a referral into secondary care is made. However, some conditions may be difficult to diagnose, and the GP may feel symptoms do not warrant a referral until other possibilities have been ruled out. In this example, Mark's problem (an infection causing a raised PSA) was identified and treated, but the GP still repeated his PSA and warned him he might need further investigations (the rectal examination) if his symptoms persisted. The GP recognised that Mark's raised PSA might not justify a referral into secondary care.

Another GP may have acted differently. Multiple factors influence referral rates. Research shows that referral decisions are informed by clinical considerations and the personal referral thresholds constructed by each GP based on their values, skills, and experience (Newton et al. 1991), and the managers in this study recognise this. Emma explains how this is a problem that affects local hospitals. With a high turnover even higher number of locums, the dynamic and extensive workforce results in a lack of standardisation of referrals in Cheshire and Merseyside:

*There are probably 2500 GPs across Cheshire and Merseyside. Each of them has differing levels of experience, differing levels of confidence, differing levels of knowledge and that results in differing thresholds of referrals.*

Each individual has different personal criteria for when they think a referral is required. While the pathway looks relatively straightforward, the evidence shows that complex and subtle judgements are involved. As well as a complex decision-making process in assessing the patient, there is an increasingly complex array of services and clinical pathways available to the GP to support the future management of the patient. This does not lend itself to GPs all acting in the same manner. Mike, a cancer clinician, explains how an ideal service should work to ensure cancer patients are seen swiftly and non-cancer patients are not alarmed unnecessarily with a referral to a cancer centre:

*Plan A is getting the patient to the cancer team and keep the non-cancer patients completely out of secondary care. So, you need to devise a gate that allows people who have got cancer; nearly everybody hasn't got cancer, that gate allows people with cancer through to the cancer team.*

Mike envisages a system whereby the correct patients, i.e., patients with cancer, are referred into the rapid access cancer service. Patients are referred as and when necessary, in a timely manner and to the most pertinent place. For the patients referred into secondary care, issues of communication arose around what their GP told the patients prior to their referral about what to expect. The GPs' dilemma is how much detail they should give the patient about their suspected cancer referral. Referring a patient on a suspected cancer pathway triggers the first measured waiting time target: from referral by GP to first appointment with a hospital specialist, the patient has to be seen within 14 days. The GP has a difficult balance of instilling a sense of urgency in the patient so that they make themselves available for further investigations without increasing any anxiety they may already feel about their illness and the potential for it to be something serious.

There were some very different ideas about how much the patients needed to know. Some felt it was not necessary to worry them. One manager, Emma, feels it puts undue pressure on patients who are already in a difficult situation, and the emphasis on patient care can be lost if targets are mentioned:

*I think GPs absolutely have to have the conversation with patients to say it is really important that you come in. We don't need to explicitly turn around to a patient and say, "look, we're being targeted on this, so you need to come in on time" because that makes it too impersonal and makes it sound like we don't care.*

Emma is clear that targets should not be discussed with patients due to the potential for putting the patient under additional stress. Urgency can be implied in other ways to convey the importance of attendance without resorting to specifics about days waiting. Discussing timings and targets with patients sends the wrong message to the patient about why we want them to attend.

Another manager Rebecca appears to agree with Emma that the GP should explain the importance of attendance at appointments. Still, actual descriptions of timings could have a detrimental effect if the patient cannot be accommodated in time. It is important to get patients on board with their treatment plan rather than clock-watching to measure how far apart each event is on their pathway. Rebecca said:

*I think the patients don't know about targets until they are potentially in the pathway. Once they are referred, the GP is supposed to talk to them about how important it is for them to make their appointments. Whether they specifically refer to a two-week target, I don't know. Actually, it is not very helpful for the patient to be that knowledgeable because if they are one of the unfortunate 5% who doesn't make the target, then they could become very focused on that, rather than getting on with their lives. You want to educate your patients about what your expectations are and what they should be achieving. You don't want them getting too hung up on things like that. It wouldn't make them more compliant. We need to say you have a cancer; let's get you onto a treatment plan, rather than we have a target to meet, so we need you to go to your appointments; the onus is on the benefit to your tick boxes rather than the patient.*

Rebecca feels that it is important that the patients do not feel that the process is target-centric rather than patient-centred. The focus of communication with patients should be around investigating their illness and the importance of getting treated. They should concern themselves with their wellbeing, not the hospital's targets. A fellow manager Cathy voices a similar opinion to Rebecca, but in stronger terms. Cathy explains that she believes that patients should not be aware of the targets. She describes a scenario where the patient feels that it is the target that has motivated the Trust rather than a desire for good patient care. She believes that nothing should challenge their faith in the hospital when patients are undergoing such stressful and potentially life-changing events:

*I don't think patients should ever be aware of whether we are targeted on this or not. I think cancer patients or patients who have a suspicion of cancer have*

*enough anxieties and a difficult enough journey, and I don't think they should ever be aware of all the work that happens or all the targets that happen because I think for me if I were a patient and I haven't gone through this journey myself, but I think if I was thinking the only reason the Trust wants to treat me as soon as possible was because of a target, that is quite an impersonal approach isn't it, so I don't think they should be aware of it at all.*

It is important to Rebecca that the patients are not aware of the targets at all for the patients to get through their difficult experience, thinking that the hospital cares about them as a person, not just targets that need to be hit. In direct contrast, a manager, Molly, feels that the GPs in her area do tell their patients, and it avoids confusion and uncertainty. Patients know what is happening and why it may be fast. They are also reassured that they will be seen quickly, and this understanding will encourage their compliance.

*I think targets have been dead helpful because they give GPs, and they give patients, and they give secondary care a clear route for that patient. I am worried that there is a risk of cancer. Therefore, I am really keen that we investigate at speed, and it is also easier to bring a patient on board with you if you can articulate a standard – "you will be seen within two weeks. I am referring you for that suspected cancer" so I think it helps bringing patients on board having targets. I think it is a clearer message to everybody.*

The advantages of the targets are that they set out a clear route into secondary care for the GP, who can be reassured that the patient can access speedy diagnostics. In addition, the patients are given expectations about how long they should wait to be seen, and the secondary care organisation has its performance expectations outlined too. Everyone knows what to expect.

In addition to seeming impersonal, the target system can be very confusing for patients. The cancer waiting times standards require activity wherever possible to be undertaken within rigid timescales, which in some cases may not be clinically necessary. Participants raised the concern that with standardised targets came standardised expectations. When patients are informed they are on a target pathway, and the importance of their attendance at appointments is impressed upon them, it can be strange if, for patients with some cancer types, the sense of urgency is diluted. Patients may be encouraged to attend for investigations, but once their diagnosis is confirmed, on the one hand, the targets require their pathways to maintain their momentum and for them to be treated swiftly. However, with some

cancers, they could wait for surgery with no detriment to their health. One manager, Joan, explains using prostate cancer as an example:

*All our patients get told they have cancer or not by day 28, but if they have prostate cancer and they want robotic surgery, they can then wait nine months to a year for the surgery.*

Joan's patients meet the target, which specifies that they must have a diagnosis by day 28 of their pathway. Patients on a suspected cancer pathway should be treated by day 62, which a patient knowledgeable about the targets may expect. However, some of the patients with prostate cancer are not clinically urgent and so can wait for surgery, and they may be confused if they are subsequently informed that this is the case when they are expecting to receive treatment within a specified timescale. Equally, if a patient misses their target deadlines, they may become even more anxious. Liz, a cancer specialist nurse, points out that patients will want an explanation if they do not meet the target, even if it is for unavoidable reasons.

*I don't think that it is helpful to give people days because you will be getting phone calls at 28 days. I think the delays that we've got are true delays, and it is not because anyone is lazy.*

If patients expect a diagnosis by day 28 in line with the target, they become more stressed if this does not happen. Informing patients about the targets as a means to reassure them that their care should follow a set timescale will not always work. As Liz highlights, this is not always the fault of the staff; sometimes, pathways are complex, and patients are delayed for unavoidable reasons, but this does not reassure patients if they believe that they should have been seen sooner. In contrast, a proponent of discussing the targets was Lyn, a clinician who explains how she thinks knowledge of the targets can be reassuring for patients. For her, the knowledge that the target patients have "an army of bureaucrats" watching their progress can be shared to help the patient recognise that their care is being directed and monitored to ensure it is as speedy as possible. She tells the patients this without mentioning her own less favourable opinion of the targets:

*I tell my patients when I meet them, I use the target and tell them the patient that we are legally being followed by a government target and they are on a pathway and that we actually. I don't tell them that I take it with a pinch of salt. But I do tell them that actually, we do have targets, and we have a big cancer services team of trackers, and if for any reason a patient hasn't had a*

*procedure, or result, or treatment, then we'll get a penalty. I use that to tell the patient, and that reassures them.*

Lyn does not expect the patients to know about the targets before she meets them, so she tells them herself. She may not feel that the targets are important to her, but she feels that by informing her patients about them, it will provide reassurance that they are being pushed through the system to get timely care.

The patients themselves had different levels of knowledge about the targets and how they were measured, but none seemed concerned with missing specific deadlines. Even those with little specific knowledge had heard of the targets and had some thoughts about what they mean, if not the specifics, about how they apply to their care. It seems that it is the idea that they are being monitored that provides reassurance rather than the specific timings. One patient, Stephen, expresses a popular opinion that the targets are good if they are met:

*I've heard about the targets – they're good as long as they are kept to. I was first seen in May and treated in September. I was also seen within a month of seeing my GP. Rushing is good, as is sooner treatment if there is capacity to do so. If you are diagnosed earlier, then it is easier to treat.*

At the time of the interview, he did seem to indicate that he felt that this was an acceptable period of time to wait. However, to meet the targets, he should have been seen and treated within the 14 and 62-day targets. Stephen understands that early diagnosis and treatment results in an optimal prognosis, so quick treatment is good if possible. Still, he did not recognise that his own care fell outside of optimal timing.

In contrast, cancer patient Henry was quite open in his lack of knowledge about the cancer targets and did not associate the speed of his treatment with them. But when questioned about specifics, Henry was very clear that he felt they were a positive influence on patient care:

*I do think [that they are a good idea]. Obviously, there is so much of it about cancer, now and it is a big thing in people's lives. They get diagnosed, and they want the treatment, the appointments for whatever type of cancers they've got, or whatever they are going through. It's only going to add to their woes if there are too many cancellations or if they are waiting too long.*

Henry recognises the prevalence of cancer in modern society and how important it is to people that they get fast treatment. In addition to a cancer diagnosis, patients do

not want to worry about when their treatment will be or have to wait too long for it. David, a patient, also said that he initially did not know why his GP had sent him to the hospital:

*I got a letter saying I had an appointment at the hospital. I didn't know what it was for, but I'm an obedient sort of chap, so I went along.*

David reveals that he was referred in without his knowledge, certainly not having had a chat with his GP about why. In spite of this, he followed instructions about where he was supposed to be and when. His apparent willingness to follow instructions means that his GP did not need to give him further information about why he was being referred to the hospital. David's experience was not an exception. Several managers felt it was common for patients to have no or little knowledge of the targets, like Rebecca, Emma and Cathy wished. However, there was evidence in patients' behaviour that they also had no idea that their GP thought they might have cancer. This, it was felt, led to difficulty instilling a sense of urgency when trying to get a patient to attend for appointments.

Here, the managers' concern with how much information has been shared with the patient is to do with the effect that having or not having this knowledge would have on the services provided. Yvonne, a manager, describes how, despite reassurances from the service commissioners, she does not believe patients have the system explained to them at the point of referral. For her, this is a problem around patient compliance, not about any negative effect it may have on the patient. Without knowing how serious their condition could potentially be, they may not appreciate the necessity of attending appointments, some of which may be at short notice. Yvonne, like most of the managers interviewed, felt that patients do not appreciate the potentially serious implications of a referral or the timescales attached to their future appointments, which the target must measure and report against:

*I don't think they know about them (the targets), and I don't think they are being counselled about why they are being referred in. I don't think they know or understand the speed that they could potentially go through the pathway or the importance of turning up for appointments.*

The concern that the service managers have is that patients will base their availability on convenience rather than urgency to reach a diagnosis if the importance of their referral is not explained to them. Without the information from the GP, patients may be confused or alarmed if they have not been properly prepared for what might

happen. It may be necessary for several diagnostics to occur quickly in order to meet the timed pathway and achieve an early diagnosis. It was felt by some managers that this behaviour was an exception, and frustration over why patients might not be attending led to Yvonne carrying out an audit in her hospital to assess the knowledge of the patient for why they are there:

*We did an audit of the patients coming through a clinic, and out of 40 patients, only one of those patients who were on a two-week rule said they knew they were coming for a cancer referral. So, there is clearly some miscommunication going on between GP and patient.*

Most of the patients who took part in Yvonne's audit were unaware that they had been referred urgently on a suspected cancer referral. It seems that GPs are not comfortable having a conversation with their patients about how their symptoms may indicate that they have cancer, and they need to have further tests to investigate. The patients' lack of understanding can also affect the administrative staff trying to make appointments for patients. It leads to difficult conversations for junior staff who have been told to book patients in as soon as possible because they may have cancer, but the patients do not know that yet. One of the managers, Yvonne, explains:

*The hotline staff in appointments are band 2s. They can't be expected to explain to a patient that their doctor thinks they may have cancer.*

Band 2s are the most junior administrative staff, and as such, the role does not include the responsibility of having a difficult conversation with patients. The GP should have had a conversation before referring the patient in, including information about what the patients should expect from the investigations they have been sent for. Increasingly, tumour sites follow NICE recommended pathways where the first appointment is an investigation. This can come as a shock to a patient not expecting it, especially if it involves having an invasive camera test<sup>2</sup>. Yvonne describes how patients who potentially have upper gastro-intestinal cancer go straight for an investigation that involves an examination of their throat using a camera:

*It is difficult with our Upper GI patients. They go straight to test, and our DNA [do not attend] rate is huge because people don't realise that they are going*

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<sup>2</sup> Investigations for gastro-intestinal cancers usually involve a test where a camera is inserted either down the throat or into the rectum. Many patients find this uncomfortable, embarrassing and invasive so it helps if they have been prepared for the possibility in advance.

*to get a camera shoved down their throat until they get the leaflet from endoscopy.*

She ascribes the high rate of patients who fail to turn up to their first appointment to worry about the test they are going to receive. Given the nature of these tests, particularly the uncomfortable ones involving cameras going into orifices, it is perhaps surprising that the patients received no notice before this occurred. In addition to discussions about what will happen at the first hospital appointment, it would be helpful if GPs also discussed how soon these appointments are likely to occur after the patient visits their GP. However, patients frequently fail to appreciate how *quickly* they are supposed to be seen. Another criticism of the GPs from managers was that they refer patients when they know patients will be unavailable within the next two weeks, thus making it impossible for the hospital to meet the two-week wait target<sup>3</sup>.

Patient unavailability is a significant annoyance for hospitals, especially when it seems that the patients may not be adequately prepared for their primary care physician's suspicions that they may have a life-limiting illness. The target threshold is designed for patient choice breaches, i.e., patients who cancel or are unavailable for their appointments. Still, referrals can be subject to seasonal fluctuations, making it difficult to accommodate these breaches and remain compliant against the 93% threshold level set for the standard.<sup>4</sup> Joan criticises the functionality of the two-week wait referrals, whereby the referral is made, and the clock starts, and it cannot be stopped until the patient is seen:

*You can't halt the pathway at all even if it is the patient's fault or GPs fault; you can't say let's just be sensible about this and say, let's call day one the day the patient is available to be seen rather than the day we can offer them.*

The measure of waiting time to first appointment is not stopped by inconveniences such as patient unavailability. Suppose a patient does not accept an appointment within the first 14 days, in that case, the hospital has to accept that breach as the time

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<sup>3</sup> Although a pause can be applied to the 14-day clock if a patient does not attend their first appointment, other delays to the patient attending the first appointment such as cancellations and unavailability cannot stop the clock. A 93% threshold has been set for the two week wait standard. In other words, up to 7% are expected to breach for unavoidable (from a trust's perspective) reasons e.g. holidays, cancellations etc.

<sup>4</sup> Referral rates are sensitive to many influences including celebrity diagnoses, soap opera story lines, public health campaigns and the weather.

is measured from referral until they attend, irrespective of patient availability. However, the patient needs not only to be free for their first appointment but for all potentially measured milestones on their pathways throughout the entirety of their care. This means being available for subsequent appointments so that their diagnostic journey is complete by day 28, and they can start their first definitive treatment within 62 days of referral by GP. One manager, Rebecca, discusses how this can be a problem during certain times of the year:

*The two week from GP for first appointment is quite tricky, especially during your traditional holiday periods. We don't want the GP to be sitting on appointments. We are potentially saying, "can you make sure the patient knows that we need them to be free for the next eight weeks?"*

Rebecca expresses this with a sense of resignation as she knows how difficult it can be to schedule a mutually agreeable appointment within 14 days.<sup>5</sup> The GP must impress upon the patient how important it is to make themselves available for the next 62 days if the hospital has any chance of meeting the 62-day target. Otherwise, patients will continue to be unavailable during holiday periods and will not prioritise their healthcare over other activities. Another manager, Judith, suggests that patients should be given a choice about whether they are fast-tracked, which might improve their willingness to attend when required.

*They should have a choice at the beginning of the pathway. Do you want to be fast? Do you want to go on this pathway?*

Such a decision would require a complete conversation with their GP about why they were being referred to secondary care. The patient could then decide if they were available for speedy investigations and if they were willing to fulfil the requirements of a cancer pathway.

Joan describes how patients will get a timely diagnosis, but patients may have to wait for treatment if clinically appropriate. While some patients may be confused by the seeming contradiction of fast diagnosis and slow treatment, others may find themselves being rushed through the system to meet the target when it is clinically

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<sup>5</sup> Technically the rules allow for a GP to defer making the referral until the patient is available (Cancer Waits, 2019). However, in reality few CCGs agree to this due to the fear that referral might get lost while still in primary care, while secondary care have mechanisms in place to track referrals, even if patients are initially unavailable.

unnecessary. Joan explains how patients may choose to wait if they knew that they could.

*You are pushing patients through a system which is too quick for them sometimes; you are forcing them into a treatment within 62 days when they might choose otherwise; if they had the real information of this could go along for a bit longer.*

Some discussion around future treatments may require considerable thought on the part of the patient to ensure that they make the correct choice for them. Speed was not a priority to all the patients. Some people simply feel too rushed if investigations are scheduled to happen very quickly and choose to delay their appointments for diagnostics and treatment.<sup>6</sup> One patient, Richard, recounted how he postponed his treatment because he felt it was too soon. He describes how he felt it might have been scheduled so quickly due to the targets, and although he was not told this outright, he felt under pressure to not delay his surgery any further:

*I was offered surgery in two weeks, but I had to put it back. It was too soon. I gave him a date I would be available the following Monday. I was surprised at the speed, to be honest. The speed was the hard part, to be honest. In the back of my mind, when I said can it be a month? I got the impression that it was outside of his targets. I got a feeling that it was a target, but it was never said straight. I knew it wasn't clinically urgent; the other consultant had said it wasn't. It was a little bit of a surprise.*

Interestingly, Richard was the only patient to connect the timeliness of his treatment to the targets directly, and his was a negative example. He was not prepared for the surgery to be scheduled so quickly, and, in his case, it was a large operation that has potentially several unpleasant side effects. He had to make arrangements around his work, so he delayed the surgery for both psychological and practical reasons.

#### **4.5 Chapter Summary**

Several factors shape cancer patient journeys. As well as meeting targets, there are other aspects to the care patients receive that are important to them. Barriers to this

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<sup>6</sup> Patients can “remove themselves from the cancer pathway” (NHS, 2020), but it is unusual for them to specifically ask for their waiting times clock to stop. Accordingly, timed pathways continue in spite of patient initiated delays and the hospital must report these as target breaches.

can be caused by difficulties accessing GPs and then convincing the GP that they need to be referred to secondary care. Once under secondary care, patients referred on a suspected cancer pathway are fast-tracked through the system. Most patients did not want to wait long periods of time between stages on their pathway and saw speed as a key indicator of their care quality. However, they appreciate having a clear plan, as it provides reassurance and a sense of control if their pathway is explained to them. The feelings of waiting for the next step in their pathway has been mitigated by receiving an explanation of exactly what that will entail and when it will be. It appears that cancer services have created timed pathways as a reaction to the targets, which have resulted in systems that better fulfil the majority of patient needs; not by ensuring treatment is before a specific day but by empowering patients by reassuring them that their care is progressing according to a plan.

Knowledge of the targets among patients was limited, and the managers debated the value of explaining them to the patients. There were advantages for the patient understanding how the system works for them and what they can expect, but also disadvantages of feeling their care is impersonal and possibly rushed. The managers, however, were also concerned about patient compliance and felt one benefit of giving patients information about the targets was that it encouraged attendance. The patients who did have some knowledge of targets demonstrated limited understanding of the complexities of the targets and specific timings but did feel that they play an important role in hospital cancer services.

In the next chapter, I examine some of the advantages and disadvantages that the cancer waiting time targets have on the provision of cancer services in hospitals.

## **Chapter 5: What have the targets ever done for us?**

### **5.1 Chapter overview**

This chapter examines how the cancer waiting time targets divide opinions amongst managers and clinicians involved in the provision of cancer services in hospitals tasked with diagnosing and treating cancer patients. Having considered if the targets are really necessary, I go on to illustrate how targets provide a focus for both staff and organisations to prioritise the needs of cancer patients. From here, I explore how participants question whether the mechanics of how targets are reported are fair or if they offer an accurate picture of how Trusts are performing.

Following this, the notion of 'gaming' targets is discussed, whereby hospital staff manipulate the way they monitor and report the targets in an attempt to improve their position. I establish the different areas of strained relationships that can be ascribed to the targets, both between managers and clinicians, but primarily between managers at different Trusts. The conflict is partly the result of the complicated system of monitoring referrals between Trusts, which has resulted in an additional level of bureaucracy. Participants question whether this is a fair use of administrative resources and whether these administrators would be better placed to undertake improvement projects. The chapter ends by considering how resource limitations, particularly in the NHS workforce, restrict the effectiveness of newly developed timed pathways and the ability to deliver cancer standards.

### **5.2 Are the targets necessary?**

The fundamental principle of the cancer waiting times standards is to ensure that cancer patients receive speedy access to diagnosis and treatment. This was recognised by all the groups I spoke with. However, the use of targets in healthcare can be very divisive, and some strong criticism emerged alongside discussions about their benefits. Although there were many suggestions for improvement or changes, it was overwhelmingly felt that they performed a necessary function. Only manager Cathy tentatively suggested that without the targets, patients would still get speedy treatment. She describes how clinicians would ensure patients were treated quickly to maximise their chances of a good outcome and positive experience rather than be driven to do this because of a target:

*I think if you are a clinician, you are concerned about outcomes, so you would treat a patient speedily if it will improve their outcomes and make sure they have a good experience, not because of a 62-day target.*

Despite Cathy's faith in the motivation of clinicians, until the targets were introduced, waiting times were overly long, and England's outcomes were poorer than equivalent countries in the rest of Europe. Targets have led to a demonstrable reduction in waiting times (Propper et al. 2009). Whatever their reservations may be about working with the cancer targets, several clinical staff made a compelling case for the need for targets to reduce waiting times by recounting anecdotes about the time before they were introduced. Tracy recalls how before targets, patients waited a long time. She credits the advent of targets as being responsible for hastening patients through the system and concludes that without targets, the situation for patients might be worse:

*If we didn't have targets, maybe it might not be better for patients. I remember a long time ago when there were no targets and patients used to wait forever. It helps them to get through the system. They get to be seen.*

Clinician Julie and Manager Frances supported this view, giving examples of waiting times for patients before the targets, stating how this would not be allowed to happen under the current target system. Julie uses the two-week wait target in her example, referring to how patients now have better access into appropriate outpatient clinics for rapid assessment of "red flag symptoms", i.e., those that can indicate cancer:

*Twenty years ago, before we had the target, patients with postmenopausal bleeding would be waiting six months to be seen in clinic. At least now, if they've got it, you know they will be seen in two weeks.*

Whereas pre-target, a patient may have had to wait to be seen, Trusts are now obliged to provide capacity so that at least 93% of patients referred with suspected cancer by their GP to secondary care do not wait longer than two weeks. From her previous role as a ward sister, Frances's example describes how patients who came in for surgery had frequently waited a significant length of time for their procedure. She feels that targets have now prevented that from happening.

*I was a ward sister on a surgical ward, so we would have our TCI [to come in] list every day, and we'd have probably every day an 18-month long waiter that was a 'do not cancel'. I mean, you don't get people waiting 18 months to be treated, so you know they [the targets] do have their place.*

Frances's view is that the 62-day target, which measures the time from referral to treatment, prevents patients from waiting a long time for treatment. Clinician Andrew sums this up, stating that there is now an impetus on organisations to encourage more timely pathways for patients compared with the situation previously. Trusts have

to keep track of their patients so that their care is not delayed. Ensuring each stage of their pathway is completed in a timely way, patients' cancer is diagnosed more quickly than before these monitoring mechanisms were introduced. Andrew claims:

*I think I am old enough to remember a time before the cancer standards came in. I think what the cancer standards probably have done is have put some impetus into the system to make sure that patients are on a managed pathway that has at least got some vague timings attached to them. I think they have probably overall improved the timeliness of cancer diagnosis since they were started.*

Andrew does go on to say that although initially successfully, it was perhaps time for a review.

*I do think they are probably outdated now, and they need to be reviewed and revised if possible.*

Thus, as a concept, clinicians and managers feel that targets are effective at helping patients move through the system but, as Andrew suggests, may now need to be reviewed. In addition to offering a focus for clinicians, the targets help by putting a spotlight onto certain patients for the non-clinical staff who support the provision of their care.

The targets ensure that Trusts are concentrating on providing timely services for their patients. It is one of their key purposes that patients receive high-quality, efficient care. To meet such deadlines, care pathways have to be carefully designed with the timings of each step planned. The timings bring structure to patient pathways and are intended to ensure that all organisations' focus is on their suspected cancer patients as a priority. Molly, a manager, welcomes how the targets aspire to fast track this urgent group of patients through hospital systems:

*Targets help people try to do their best for a particular group of patients, and it keeps organisation focus and attention on those patients.*

In her mind, the targets enable Trusts to identify patients with a high suspicion of cancer and help them access timely care. In addition to the targets having a positive influence by focusing on organisations' attention, there was evidence in my interviews that this influence extended to individuals who took the targets very seriously. Another manager, Judith, explains how she feels the targets are integral to the provision of a high standard of patient care, enabling patients to travel along their pathway through

diagnosis and treatment as smoothly and efficiently as possible. According to Judith, the targets have resulted in service reviews to create optimal care pathways for the cancer patient:

*Personally, I am committed and passionate about the targets and the waiting times and do think that patients deserve equality and that they should be treated fairly and as quickly as possible. I think that every day that patients are waiting is a day too long, everything should be a smooth line, and you know, as easy as possible. The targets have made us look at pathways, you know, look at the radiotherapy to treatment, look at the individual steps and how long it takes between each bit.*

The targets make managers like Judith consider ways to shorten these waits where possible. For Judith, it is additionally a question of equality so that all patients on a target pathway can expect to receive the same level of care. However, the targets are not always necessary to drive speed in pathways. A consistent theme that emerged from my data was managers and clinicians trying to empathise with the patients by imagining that it could be one of their families and how, if they were waiting for diagnostics or treatment, it would make them personally feel. Liz, a clinician, explains how she has chased a referral letter to another specialist for one of her patients so that she does not have to wait, an act Liz has performed for the patient, not as a response to pressure to meet a target.

*I've pushed for that lady to have a letter done this afternoon, and let's not just wait another week. I didn't even look at the targets. This was for the patient, that could be my mum.*

Liz's focus is on patient care, so the targets do not dictate her actions to speed up the patient's pathway. She imagines her own mum in the position of the patient, and that is what motivates her to act. Judith also explains how, in her opinion, by appreciating the patients' perspective or that of their family can lead to patient-focused care:

*I think we are doing the best we can for our patients, and we are very patient-focused, I would say. You have got to remember that every patient you come across, that could be your relative or something like that, so you want what is best for patients.*

This attitude results in patient needs becoming the top priority, treating them as you would your own family. While the targets may help some become clear about an organisation's aims, that of providing high quality and efficient care to patients, others

do not require the targets to direct them to do this. In addition to providing focus, so it is clear what an organisation wants to achieve, the targets provide a mechanism to measure how successful a Trust is at achieving these priorities. Some of my participants, however, do not feel that the targets were the best indicator of the quality of cancer care that their Trust provides.

### **5.3 Targets as an accurate illustration of performance**

The interviews generated much discussion around the topic of how accurately targets describe a Trust's performance, and the pessimistic attitudes expressed by my participants should be considered in the context of the ongoing national failure of the targets. While the existence of the targets may drive particular behaviour to improve patient care, when targets are not met, staff morale falls. The details of how the targets are reported at Trust level were questioned, whether the compliance thresholds are generous enough, as well as if they work as a benchmarking tool. Some participants touched on the controversial issues of whether the targets themselves encourage dishonesty in reporting. For instance, a nurse manager, Frances, expresses her frustration about the blame Trusts are receiving for failing what she sees as unmanageable targets. She makes the point that surely if everywhere is failing the targets, then the blame should not lie with individual Trusts, but with the targets themselves:

*I think we have to have a look at the fact that the cancer targets have not been met operationally for two years, possibly longer than that now, so is there something fundamentally unmanageable about that target? Probably, yes. I don't think we really understand what that is. We just get beaten with a big stick for not doing it, but nobody is doing it. Well, the odd one or two places are that have got one hospital and tertiary centres and really tiny places. There is something fundamentally unmanageable about this, and how do we need to change that. It would be completely different if we were failing as one Alliance or failing as a Trust, but everyone else is doing too.*

The targets have not been met nationally for the last two years<sup>7</sup>, then Frances sees this as a failing of the target themselves, and most Trusts, with some exceptions, cannot meet them. In addition to the challenge posed by the inability of Trusts to meet the targets, one of the managers, Rebecca, found fault with how performance results

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<sup>7</sup> Currently (2021) the 62 day target has been consistently missed at a national level since 2013/14 (NHS Providers, 2021)

are reported. Firstly, the targets are too general, and standardised reporting is not a good indicator of how Trusts as a whole are performing. Although Trusts can analyse data at a more granular level by tumour site (e.g. how many patients with breast cancer met the targets compared to how many with lung cancer), Trusts are publicly described as passing or failing a target by an overall percentage. By reporting performance as one combined cohort of patients, issues with individual tumour sites are hidden. Rebecca explains:

*Targets are done across all tumour groups, but if you actually deep dive into a tumour group, you might find that that tumour group is failing and is being propped up by another tumour group.*

If one tumour site is performing well, with all patients with one cancer type meeting their targets, it may mask problems in another site if overall combined performance is good. A Trust may be achieving 85% compliance against a target which would mean it is under less scrutiny than failing Trusts but still have significant problems in some areas. For example, a Trust can treat lots of patients with skin cancer, which is usually straightforward to diagnose and can be treated quickly and within target. They may also treat a patient with another type of cancer, for example, liver cancer, which may have taken several months to diagnose and so breaches the waiting times target. This could have been a complex case that required several extra diagnostic tests to make a diagnosis, or it may be that the case was mismanaged, and the patient faced avoidable delays. If, however, the overall performance for the Trust is compliant due to the large number of skin cases treated on time, the mistakes made in the liver case may go unnoticed. Performance is reported as a percentage of patients meeting the target. This means that the higher number of patients who meet the target, the more patients you can have who are not treated on time and still meet the compliance level required to pass the target. Indeed, as some participants identified, certain groups of patients may not be benefiting from the targets. For instance, one manager Molly suggests:

*Your performance changes but have experiences for individual patients changed? The performance measure doesn't give you that, have things got better for colorectal patients or are things steadily getting worse?*

Molly recognises that it can be challenging to determine from changes in percentages if circumstances are improving for individual patients. The method of reporting the targets means Trusts could be slow to identify problems in specific service areas. A further problem with reporting targets in this way does not make benchmarking

between Trusts easy. The performance figure is comprised of patients with different cancer types who may have visited several Trusts throughout their timed pathway. Trusts have different service profiles; while one Trust may only treat specific tumour sites, another may only provide diagnostics and another only tertiary treatment. Yet all these Trusts are measured against the same target, with the same threshold for success or failure. For example, my own Trust does some diagnostics for most tumour sites, but more complex investigations are sent to several other secondary Trusts in Merseyside and Cheshire. Treatment may then take place there, or the patient may be sent to the local oncology centre for chemotherapy or radiotherapy. Pathways with multiple stages across multiple Trusts can be lengthy, and it can be difficult to identify where any delays may have taken place. Molly explained it like this:

*Who are you actually measuring? At the moment, we are not measuring tumour specific performance, and that is a right tangle crossing organisations. So many specialities work across organisations that it becomes difficult. If someone is not meeting the target, you've got to be able to pin it somewhere; you can't pin it across multiple points. Tumour is complicated because it crosses multiple organisations: Trust is complicated because Trusts are not always in control of their own performance because it crosses organisations. Equally, Trusts do different tumours, so it is all about numerators and denominators depending on the speciality profile that you've got. Targets are general. What we should really be looking at is performance getting better or worse and using that as our yardstick to drive improvement activity. I look at different Trusts that have different speciality profiles, and we should be thinking, is head and neck [cancer] across Cheshire and Merseyside getting better or worse?*

When monthly performance is published for all Trusts by NHS England, it is not clear from the overall Trust results which aspects of a pathway are performing well or if some tumour sites are struggling more than others due to the complexities of treatment pathways. Molly considers the possibility of reporting by tumour or cancer site, but this would still result in the same issues as Trust level reporting, identifying at which Trust these problems in the pathway occur for complex diagnostic pathways across organisations. Given that, she is prepared to consider regional tumour specific performance as an indicator of quality and use that to drive service improvement activity across the whole area of Cheshire and Merseyside. Frances was also concerned about patients with multiple Trust pathways and how performance could

be measured accurately in these cases. As an alternative, she suggests CCGs (Clinical Commissioning Groups) measure their performance by monitoring all the waiting times of patients whose GPs fall under that CCG geographically.<sup>8</sup> It would also end one of the most confusing aspects of Trust reported performance whereby Trusts are given credit for half a patient while the other half goes to another Trust. Frances felt that if performance was measured by CCG rather than at Trust level, this would incentivise all the Trusts in a patient's pathway to move patients along as the CCG would be held accountable for any delays:

*Why don't we just measure performance by CCG because the patient is in just one place then? It is then for the CCG to do their RCA [route cause analysis] and then put pressure on whichever place caused them to fail. It is less complicated: there is none of this, half this and half that and the other.*

The CCG could do a route cause analysis (an examination of the timings between steps in the pathway) of patients who breach and hold the Trust responsible for their part in the pathway. Interestingly, Rebecca (one of the managers from the CCG) has a contrary opinion. She explains how this can also give a confusing picture in different ways due to the intricacies of how CCG performance is calculated. She explains how performance for her CCG includes patients that started at a variety of places, including outside of the area altogether. Like Molly, Rebecca is concerned that it is not always clear how certain tumour sites are performing if overall performance is all that is looked at. It is possible for tumour sites where patients meet targets to counterbalance badly performing ones and give the illusion that Trusts are performing better than they really are. Rebecca said:

*The way we have to report on them is that we report on how our commissioned provider is doing (in our case, Westfield Hospital), and we report on them at Westfield CCG level. At Westfield CCG level, we're looking at any patient that falls within a Westfield GP, but they could be diagnosed treated at a number of different places. A student in Oxford can fall under our figures, which is interesting if a patient decides to go across to Liverpool that falls under our CCG figures. Westfield hospital gets patients from Merseyside, Cheshire and North Wales, who have different performance targets, so we'll ignore the Welsh ones for now. It's quite a confusing reporting figure and what we can*

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<sup>8</sup> Clinical Commissioning groups commission services throughout the local community and some specialist services in Secondary Care.

*have is our main commissioned provider passing their performance targets because that's how their figures aggregate up, whereas we actually fail ours because they aggregate differently.*

Thus, reporting performance based on the patient's CCG of origin also would not provide an accurate picture of the quality of a Trust's cancer services. As Rebecca explains, her CCG's main service provider, Westfield hospital, is passing its targets. However, her CCG is failing due to the method used to aggregate the total, so for her, this figure is not the best indication of the state of local cancer services. She also comments that Westfield treats patients from Wales. This causes an interesting dilemma for Trusts as these patients are not subject to the same targets as English patients, and Trusts do not have to report how long these patients wait. There does not appear to be one particular way to calculate performance that gives a clear picture of how effective services are at providing for patients.

#### **5.4 Gaming the system**

Given the problems achieving success with the cancer targets and the complicated nature of calculating it accurately, I was interested in exploring with my participants if they had encountered any manipulation of Trusts' performance results. This "gaming" or "fiddling the figures", as one doctor, Alexander, described it, is thought to be an inherent problem in public services whose behaviour is regulated by targets (Bevan and Gubb 2009). This can take the form of perverse behaviour to meet the targets that is not in the best interest of the patient or, alternatively, deliberately misrecording information to hide how long patients have waited. Whilst no one was willing to admit to witnessing gaming directly to improve performance in secondary care; managers did feel that GPs were guilty of manipulating the system in their favour. The lack of capacity in routine clinics can cause problems for GPs wanting to refer their patients for a non-urgent specialist opinion. Joan explains how GPs will send in patients on a suspected cancer pathway if they think they will otherwise have to wait an unreasonable amount of time for an appointment:

*I've seen skin referrals that say I'm sending this on a two-week referral because I can't get them into an urgent pathway. We know it is not cancer, but we are sending them anyway.*

In her example, non-cancer skin referrals have to wait to be seen, whereas those sent in on a suspected cancer referral are guaranteed to be seen in two weeks. She expresses the concern that the GPs deliberately act to manipulate the system to shorten the waiting time for an appointment for their patients they know do not have

cancer but do not want to wait to be seen. Whilst this may be in the patient's best interest, it does build up resentment in secondary care, with another manager, Emma, explicitly accusing GPs of deliberately misusing and 'gaming the system'. This causes Emma frustration because of the resource implications when more and more people are referred in on a cancer pathway and subject to strict timings.

Although quick to point out faults in primary care, clinicians and managers were less willing to identify abuses caused by the target system in secondary care. It was primarily referred to jokingly as a way to deflect the negative attention of more senior managers away from failing performance. One clinician, Alexander, humorously implies that he does not need to concern himself with his patients' performance as it would be taken care of by the managers, who would ensure the numbers were favourable:

*I don't worry about our performance. I know the managers look after that [laughing], so our figures always look good.*

Alexander implies that he does not need to let targets dictate his actions as he assumes that the managers in his Trust will record patients as compliant. One of the managers, Molly, acknowledges that fraudulent reporting would be sensible as it would make her job more manageable:

*It might make more sense for us to fix figures. We'd certainly have less paperwork to do and less hassle from the execs!*

Manipulating the data resulting in improved performance would benefit Molly by decreasing her workload and meaning that there would be less explaining to do to the Trust executive team about why performance was poor. Another manager, Yvonne, points out that if gaming were happening, her Trust would not be failing the targets. Some reference was made to Trusts who consistently achieved 100% as fixing their performance as no one is that successful. However, manager Yvonne argues that this was too obvious and notes that if she were going to change performance, she would be smart enough to make it look realistic so it would not be questioned:

*If I were going to, we wouldn't be failing every month. Yes, you'd make it realistic, so you would fail occasionally but pass most of the time with just enough breaches not to look suspicious.*

Yvonne uses the fact that her Trust is currently failing to meet the targets as evidence that she is not misreporting data. She then explains that if she were to change data in her Trust's favour, she would only do it for some patients some of the time so that the results did not look artificial. In all these comments, 'gaming' does not seem to be a serious concern or considered to be a major failing of the target system, which was contrary to my findings in the literature review and will be considered further in the discussion chapter.

### **5.5 Targets as a source of professional conflict**

Although there were no outright allegations from my participants of specific Trusts gaming to improve their performance, there was a sense of competition between Trusts, which did border on professional conflict in some instances. My interviews revealed several areas where the targets and their management were responsible for strained relationships between different Trusts across Merseyside and Cheshire.

The primary area where the targets seem to provoke conflict was between managers across Trusts where there are shared care pathways due to the competitive reporting of targets at Trust level. Under the Cancer Waiting Times system, when patients move between several Trusts (something which is increasingly common with the development of specialist treatment centres), a complicated system of accountability occurs. Performance is calculated based on how many days a patient's care is attributable to each Trust. Originating Trusts share credit for treatment or breaches of the target with the treating Trusts. In contrast, the second Trust in a three Trust pathway where patients may spend considerable time undergoing diagnostics are not acknowledged. This has led to a situation where Trusts report 'half' patients. Prior to 2018, the national guidelines for the management of Cancer Waiting Times left the possibility open for local agreements for the reallocation of 'breaches' if one Trust was considered more to blame for a lengthy portion of a patient's pathway than another. These rules were welcomed by tertiary centres who have always been penalised by late referrals of patients whom they cannot treat in time, but a share of whose breach falls on their figures. However, these policies, which were supposed to redress the balance, were complex to administer and usually considered unfair by some of the providers involved. This can lead to accusations of aberrant behaviour, such as not reporting breaches or patient priorities being changed, i.e., a specialist centre might treat their 'own' patients before those referred to them.

From April 2019, a new national system of reallocation was introduced whereby one of "six scenarios" is applied, and the accountability of each Trust in the pathway is

calculated for every patient. This process is labour intensive as the IT systems responsible for recording this information both nationally and locally were slow to adapt to these new rules<sup>9</sup>. The switch to the new rules was in progress while I carried out my interviews, and it was clear that it was a major source of stress for the managers and a source of some inter-Trust conflict that would not be easy to resolve. For example, Joan, whose Trust provides the diagnostic portion of the pathway, views the focus on counting days negatively. She feels there is too much emphasis on referring within specified timescales which can lead to inter Trust rivalry and an obsession with who is responsible if a patient breaches their target. She feels it detracts from larger scale working across the Cancer Network to fix problems as each Trust looks inwards at their own issues:

*I think what has happened is that the targets were originally there to try and drive people to work together, whereas it has done the opposite. People are now working in silos thinking, "can I get my patient out by day 38? Can I get my patient treated in 24 days? Am I going to take a portion of this breach?" Rather than, you know what, we've got a problem getting this person from A to B because of A, B and C. Instead of fixing A, B and C, we'll just fix A and B and C aren't our problem, so we won't worry about that, and I do think that is what happens. I don't think we work as one team across multiple organisations and one pathway. It is how fast can you get them off your own pathway so that if anything happens, it is not your fault. I know that sounds dreadful, but I think most Trusts have got that mentality.*

Rather than create a system that helps patients, targets amount to a form of shifting blame. Joan sees the target system as one that shifts blame rather than help patients by forcing Trusts to compete rather than work together. Trusts are too busy counting how many days they have been responsible for a patient's care instead of taking a system-wide approach to any problems that may occur in a patient's pathway. If the secondary centre can refer to the tertiary centre before day 38, then they are not accountable for any delay that may subsequently occur. Equally, suppose a tertiary centre can treat the patient within 24 days of the transfer of care. In that case, they do not share the responsibility for any delays that happened

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<sup>9</sup> At the time of writing, the main computer system used to record and report performance across Merseyside and Cheshire – the Somerset Cancer Register – is still unable to apply these rules to calculate performance accurately.

before the patient was transferred. Participants suggested that each Trust is busy trying to improve their own performance, so has little interest in what problems may have arisen for the patient in other Trusts.

Rebecca, a manager, likens this problem to a hot potato whom no one wants to keep hold of, as everyone is keen to pass the patient, and with them the responsibility for the pathway, over to another Trust:

*They are like a hot potato as no one wants the patient. We're all trying to pass it on to someone else. It doesn't seem to be in the patient's best interest.*<sup>10</sup>

One manager, Frances, even goes as far as to suggest that tertiary centres may not prioritise patients that are not sent late, resulting in these patients waiting longer for treatment. She refers to the previous system whereby referrals should be done by day 42 to ensure a shared breach. Under the new rules, patients sent after day 38 can have their breach reallocated back in full to an originating provider. Frances thinks this behaviour is inconsistent and must be driven by the targets:

*We feel that the targets pit us against other hospitals. We've had ones that we've sent over on day 39, day 40, and they have come in on day 63, and you think, come on! You would have moved heaven and earth in the days when it was day 42. Part of Poppyfield's feedback, they give numbers of patients that they have saved, treated on day 61 or 62, less than 24 days. This is the thing, one thing that we are noticing, some of the bigger breaches that they were never going to get, referred on day 58 or whatever, they are managing to treat some of those patients within 7 or 14 days. We've had a few. We're still working stuff out manually, and you see they have it for 15 days. My argument would be if you can do it for these ones, why can't you do it for the ones sent on day 40?*

To Frances, it seems odd that patients can be treated within a week or two of their transfer in some cases, but for others, it takes longer. It seems convenient that the length of the patient's wait seems to depend on whether the tertiary centre can reallocate a breach or not. She goes on to voice the opinion that the new system while

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<sup>10</sup> Describing something as “a hot potato” can refer to it as a difficult or controversial subject that no one want to deal with and so passes to someone else, but in this context, Rebecca means the expression literally, that to avoid being burnt when holding a hot potato, it must be passed quickly to the next person to save one’s hands.

benefiting some Trusts (the tertiary centres), causes divisions with others, as well as being incredibly challenging to understand and implement. Like fellow manager Joan, she feels the targets discourage network-wide working:

*I think the reallocation policy removes the incentive to do the network-wide work. I can understand why the tertiary centres pushed and pushed and pushed for a reallocation policy, but you know what, all they are doing is organising treatment; I don't think they have any concept of what it is like to get patients through diagnostics. The other thing about the new breach reallocation policy is that they have just taken it too far. They have made it too complicated; why add all those extra bits into it? You know like if you send it on day 39 and Poppyfield treat it in time, they get all the credit. Why put that in? It makes it overly complicated to work out.*

For Frances and other managers working in secondary care organisations, the system has resulted in tension with tertiary care. In Frances's opinion, the complex and time-consuming part of the pathway for a patient is the diagnostics and staging investigations that are necessary before treatment. The tertiary centres only have to arrange to give the treatment. In addition to being able to apportion blame for breaches to secondary centres who refer late, tertiary centres also can claim credit for the patients who are referred late but are treated on time, with no credit showing on the secondary centre's performance, which makes performance complicated to calculate. Frances acknowledges that the tertiary centres had good cause to petition for the policy, and Judith, who works as a manager in a tertiary centre, highlights the problem from their perspective. If they receive patients late on in their timed pathway, her Trust does not have sufficient time to plan and provide treatment that meets the deadline. However, her Trust is still expected to be able to meet the same performance threshold as secondary care centres, even though patients may be referred to them already past breach date, which to her seems unfair. Judith says:

*We've got the problem of the late referrals into the Trust, but we've still got the same tolerance level as everybody else. We have 8 to 10 patients every month that don't meet the target, so all of this hard work that we are doing and patients still don't meet the targets.*

Every month, Judith's Trust receives referrals for patients who are already significantly advanced along their pathway. It is unavoidable that most of these patients will pass their 62-day target before their treatment starts. Under previous

rules, the tertiary centres would have to accept a portion of that breach on their performance figures which they felt was very unfair for something that they were not in a position to influence. In order for this complicated performance to be calculated, Trusts need to agree on what date (and therefore day in the pathway) patients are referred from one Trust to another. This has resulted in disagreements about when it is appropriate to transfer a patient's care, which has affected clinicians as well as managers.

For clinicians, it can be frustrating because some tertiary centres will not accept referrals until the secondary centre has finished its investigations. Clinician Mike describes how by following steps in a pathway consecutively rather than concurrently, his patients can experience delays. A tertiary centre may refuse to accept a patient when actually they could begin preparations for patients without all the results having to be ready. For example, some lung cancer patients can have a test for the presence of the EGFR (epidermal growth factor receptor) mutation on their biopsy sample, which will determine if specific targeted chemotherapy will be effective. Tertiary centres refuse to accept referrals of patients waiting for the results of this test, even though, as Mike argues, initial appointments with an oncologist could be planned while the results are pending:

*The guidance says you need all your markers before seeing an oncologist, but actually, easily ten days before you know it is adenocarcinoma and it is inoperable, the oncologist can start to plan for when that result is back. So the pathways, the way blame is attributed, blocks the pathway into blocks, and it stops completely that indigitation where two teams can be doing anything because you know where you are, you know where you need to go and therefore why don't you get the EGFR, the this and the that and start planning this now because we are still waiting on that. The pathways apportion blame and stop people working together because pathway B won't start until everybody in pathway A has completely finished. We're not going to see them as the guidance is, we can't without all these things, well actually you can plan nearly everything without all these things, and we need to interdigitate, work together.*

The tertiary centre in this example is concerned about the transfer of care date for the patient, which specifies how long they have to treat them. This means that rather than accept a referral and see the patient to begin to organise their treatment, they insist on waiting while test results are pending. This delay is attributed by Mike directly

to the targets, which in his view, prevent Trusts from working well together. His view of the targets is not altogether negative, though. In some cases, the targets are responsible for speeding up some aspects of care, even if they discourage affective inter-Trust working. Mike claims:

*Some aspects of the targets make you think about what you are doing, and if you're beaten with a stick because you're too slow, that's good, but some aspects of the thinking around the targets around provider A has x number of days to do this, and provider B has x number of days to do that could be a lot more interdigitation so if you're working well with your oncologist and say look this one is going to come your way. It is going to come your way in 10 days' time, you want to pick some of that baton up now, and you can start some of your processes off while I'm finishing mine and the pathway actively discourages that.*

By tying each Trust to a set number of days to complete their part of the pathway, Trusts compete rather than co-operate. Pathways become disjointed if clinicians cannot work together when organising a patient's care. For this to be true, it depends on clinicians allowing their actions to be dictated by the targets. The clinicians that I spoke to were aware of the targets but claimed that they did not let them dictate their activities or supersede their clinical autonomy. Angela notes how the administrative staff are concerned by the patient status, but it does not affect her actions as a clinician:

*Target patients are treated differently by non-clinical staff, not the clinical staff, as we just look at patients and we're, you know, we'll see within minutes of them being in the room, I'll ask their name, what their history is, what their symptoms are. I have no interest whether they are a target patient or not. It makes no difference at all. I will be guided by what the patient tells me, and if they have a normal endoscopy, and I feel they warrant further investigations, bloods, CT scans because I am concerned about their symptoms, they will get them urgently, target patient or not.*

Angela says that she treats all her patients equally and performs clinical duties unaffected by any targets that may be attached to a patient's pathway. Although her non-clinical colleagues may treat patients differently depending on their target status, she claims to look at what the patient needs when she decides how to prioritise their care. Generally, the clinicians interviewed were confident enough in their professional autonomy that they did not allow the targets or the managers to dictate their practice.

Alexander, a clinician, also explains that although pathways in his clinical speciality have been designed around meeting a timed pathway rather than clinically led, it is his decision ultimately how the patient progresses:

*It is not a protocol, it is a guideline, and within a guideline, you have room to manoeuvre. You still have autonomy. We are not pressured into following the guidelines. All these guidelines give you freedom to make your own decisions. You have to make the decision when you see the patient.*

For Alexander, the cancer waiting times guidelines may make recommendations about how he as a clinician behaves, but he has the autonomy to ignore them if clinically appropriate. Some clinicians put more credence in the value of the guidelines and were more inclined to go along with management interventions. Tracy recognised that she was being asked to do things a particular way because the service managers were following instructions too about what was best for the patient:

*Management pressurises us to meet targets because they are getting pressure from somewhere else. I wouldn't say it is unnecessary. I think those guidelines are there for some reason because they have been looked into, and they are there for patient safety and because the patients get treated quickly.*

Not all clinicians attributed the same level of importance to the targets. Some less experienced clinicians felt more obliged to pay attention to the targets and worry about the consequence if they are not met. Cancer Nurse Specialist Liz explains how, due to her experience, she is confident that her patients are getting timely care, but her colleague, who is relatively new to the job, worries about the target date attached to patients. Their database has a countdown that turns from green to red if a patient is past breach date, something which may not worry Liz but will be of concern to the administrative staff who monitor the Trust's compliance:

*I never felt that my patient had been compromised at any point by them [the targets]. I'm not asked to prioritise certain patients over others. I know that they are on a target pathway, but because of the nature of my patients, when I put the cancer register on, I glance at the green writing at the top and sometimes notice that the writing is in red, but I don't get too bothered. I take it with a pinch of salt. I have a new colleague who gets very twitched when she sees someone's breach date in red. My colleague thinks someone will shout at her or that it needs changing, but I worry about other things rather*

*than seeing a minus date in red. If my patient is ready for treatment, they will get treatment.*

Liz is aware from her database that a patient may be on a target pathway, but she is not concerned that they may be waiting (according to the target) longer than they should, as her patient cases can be complex. She is certain that they have received timely care, and there is nothing she can change to start their treatment any earlier. Liz mentions that her colleague thinks someone will shout at her if patients breach. She is referring to the dedicated administrative staff who are required to monitor patients' pathways in order for Trust to report their performance monthly.

### **5.6 Target monitoring requires increased bureaucracy**

Most Trusts now have teams of trackers whose primary responsibility is to ensure that patients on a cancer pathway pass through the system efficiently. These teams provide clear advantages for patients, namely, ensuring that diagnostics and treatments are scheduled promptly, and appointments are expedited if necessary. They are also well-positioned to highlight any bottlenecks in operational systems which may prevent this. However, questions arose over whether this was a good use of administration resources. Liz explains how she likes that the targets have created structures that act as a safety net for her patients. This reassures her that they cannot get lost in the system as someone will be monitoring where the patient is up to along their pathway and what is happening next to them. The trackers may call her and ask what that next step may be, which provides reassurance that she is doing all she can for her patients:

*I do quite like them [the targets] in a little bit of a way because I think the other thing is actually if nothing else, it can be a safety net. If you are a specialist nurse, it can be very difficult if you have got complex patients, a big list, then actually there is a little bit of a backup if someone is going, 'this patient has not had a biopsy', or 'what is going on?' So, sometimes when I do get these phone calls, I like to think that I am already on the ball and I can't have done anything any faster, but I do feel that it is a bit of a safety net, but whether that is a good use of resource using it as a safety net, I'm not sure.*

In her busy role as a specialist nurse, she can rely on the trackers to ensure that a patient's investigations and treatment proceed in a timely way. They may call her to check that everything is progressing according to plan for a patient, but she is confident that she can tell them that it is. However, she is not sure if this is the best use of administrative resources. Liz was not alone in questioning if this added

bureaucracy is a good use of resources. Fellow clinician Angela was quick to point out this safety net would not be necessary if systems were effective in the first instance:

*We're paying people to track patients when we should be sorting out our efficiency. If the system was slick, then the patient wouldn't need to be tracked.*

Angela points out that it seems absurd to pay people to do a job that would not need to exist if the systems were set up properly in the first place. With efficient systems, patients would not need to be tracked. Managers also acknowledged that while the targets speed up steps in a patient's pathway, an extra level of bureaucracy is now required to monitor and report them. One of them, Joan, expressed the opinion that resulting speed is not necessarily an indicator of a high-quality service:

*I think they could have easily gone by the wayside and spend weeks and weeks and weeks waiting to be seen, so I think they [the targets] did drive improvement when they first came in. I think now they just drive an industry of paper chasing, really, passing patients through the system, making sure that they get this, that and the other on time; I think they have driven speed, I'm not sure that they have driven quality.*

Joan feels that previously patients could potentially wait weeks to be seen, and the introduction of the targets has stopped that from happening. However, now they have created bureaucratic processes to ensure patients pass particular milestones on time without ensuring the quality of the experience.

Bureaucracy designed to improve efficiency in patient pathways can sometimes go too far in the other direction resulting in unhelpful resource-intensive inefficiencies. One patient, Mark, explained how his appointment time was changed, and he received another letter to inform him of this, even though it was only altered by 20 minutes. He felt that this second letter was redundant as he already expected to have to wait to be seen:

*I've got a dermatology appointment this afternoon. I got the letter, and it was ten minutes past two. I got another letter saying very sorry, we've had to alter your appointment to half-past two. Now to me, that was the waste of a letter because I'll be there anyway. I'll just sit. I thought it must be because they have to see people within such and such a time of them arriving. I mean. Twenty minutes. How silly. I expect to sit and wait for that time anyway. If you're seen within half an hour, you think that's all right.*

For Mark, this was an example of the excessive bureaucracy to be found in some services of the NHS. He would have been happy to sit in the waiting room and decided that this second appointment must have been the result of a target that dictates how long patients are allowed to wait. Several managers acknowledged that the targets placed an administrative burden on Trusts that some could not absorb easily. In some cases, staff are directed to prioritise the monitoring of targets for which the Trust receives the most attention, i.e., their 62-day target performance.<sup>11</sup> The less important targets may not be pursued to the same extent due to resource limitations. Judith, a manager, describes how the 31-day subsequent target is marginalised in her Trust. They do not have the staff necessary to monitor it effectively, especially as numbers of patients accessing the service have been going up:

*That's right, we do have a 31-day report for subsequents as well, but we've had staffing issues, and if you have staffing issues, that goes by the by. We really need to be tracking all the patients, but with the number of patients, it's just, you know, they are increasing exponentially.*

She acknowledges that ideally, all the patients need to be tracked against all the targets, but when there are staff shortages and a rising number of patients, it is not possible. Alternatively, manager Yvonne feels that it is not the number of patients that is the problem but the number of targets that need to be reported on. The addition of the 28-day target, with no extra resource in her Cancer Services department, is anticipated to cause problems in 2020:

*The impact of the 28-day target is massive. We've no extra resources or staff, so it will be a nightmare to manage.*

Introduced to try to reduce waiting times in the diagnostic phase, Yvonne anticipates the introduction of the new target will be difficult to manage within her existing team. Several people mentioned that it involved diverting resources from other, possibly more useful, activities by monitoring targets. Another manager, Cathy, was concerned that monitoring the new 28-day target may redirect the staff away from facilitating the smooth movement of patients along their pathways. By giving the

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<sup>11</sup> The 62-day standard is the only target that takes into account the whole patient pathway from referral to treatment and as such, is the most difficult to meet. Performance against this standard is often the focus of attention both internally and externally as an indication of how well a Trust's cancer services are performing.

trackers an extra target to monitor, they have less time to expedite appointments for patients:

*Flipping heck, hardly any of the pilot sites are achieving the 28 days, and there is a whole level of extra bureaucracy needed to measure it. Measuring it is taking people away from getting people through. The systems that have been put in place – the new Open Exeter<sup>12</sup>, do not focus on improving things. They should make work easier rather than harder.*

Cathy mentions feedback from the Trusts, which are currently piloting the 28-day target before it is rolled out everywhere. They have experienced difficulties meeting the new target and have found it labour intensive to monitor. Trackers who are pursuing information about 28 days may not have time to expedite appointments for other patients as they would normally. Cathy was not alone in her criticism of the national IT system for recording the targets, as its implementation has not been without its problems. Resource constraints frequently mean that managers get involved in the monitoring processes as well as their teams. Manager Judith expresses her fear that she probably could use her time more wisely, but unfortunately, it is necessary for her to check patients individually due to the new system's limitations:

*I like going through the pathways and checking every patient. We're doing what we are doing because we've got to do it. Could my time be better spent? Probably.*

The new online reporting system is very labour intensive and although Judith gains satisfaction from checking her teams' data is correct, it is taking her away from completing other work. All Trusts now have to do these checks if they want to ensure accurate reporting, and Frances concurs that the managers are spending their precious time undertaking administrative tasks that take them away from potentially more productive work that could benefit patients:

*This is one of the concerns, the more bureaucracy you have around meeting the targets, the less you are doing to meet them in the first place. Time could be spent doing service improvement is now going to be spent filling out a form*

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<sup>12</sup> Open Exeter was the national online portal for uploading data including cancer waiting times information. The cancer aspect was replaced in April 2018 by a new site run by NHS Digital called the Cancer Waiting Times Data Collection System.

*about why we didn't do service improvement. I think we are creating a big industry out of it.*

Frances is worried that opportunities for undertaking improvement projects are lost if all her time is spent on paperwork. Targets not met require administrative reviews, which take time away from preventing further patients from failing their targets. A picture of a complicated, interconnected system emerges from my interviews. The targets highlight inadequacies in services that require improvement projects to fix. However, the very process of monitoring and reporting the targets takes resources away from any improvement projects undertaken to create more efficient services (and to speed up pathways), which would result in more patients meeting the targets. The targets may create problems for the provision of services, but at the same time, they reveal resource shortages in those services, which are affecting the ability of Trusts to deliver them.

### **5.7 Targets as levers for change**

In addition to highlighting the resource constraints in systems, one of the benefits of the target system is that it gives each group an excuse to demand improvements until the timelines it imposes are met. One manager, Mary, admitted that the targets were aspirational, but their existence gave her the ability to ask her clinicians to work towards them:

*The benefits of having the targets in place would be that they are obviously aspirational targets, but it gives us the impetus to push clinicians and diagnostic services to move cancer patients through the system quicker to allow them to be treated in a more timely manner.*

Mary sees the length of the targets as arbitrary but observes that they can be used to encourage both clinicians and service providers towards improvements that speed up care. The targets can be used as a lever to move otherwise obstinate clinicians towards more effective ways of working. Emma, another manager, also claims that the clinicians she works with also feel that the targets can be used as a lever for change (even if their initial instinct is to distrust them):

*I was speaking to an oncologist the other day about the oesophagogastric pathway, and she was very passionate about the fact that the 62 days was a force for evil, but at the end of the day, it has given us the opportunity to bid for funding to drive improvements regardless of that, so it is actually a good thing too.*

The oncologist who spoke to Emma may dislike the 62-day target, but from a practical perspective, recognises that the need to meet the target can be used as an excuse when applying for money to make service improvements. While some clinicians recognise that they can use the targets to get more funding, others do not seem to take advantage of this opportunity. Patient Barbara also thinks that the targets could be used as a means to get extra resources from management. In her case, when her doctor told her that she would have to wait for her surgery, she thought he should be able to use her treatment deadline as leverage to get more operating sessions:

*The doctor said he would do me as soon as he could fit me in. If there are all these targets, then there shouldn't be any waiting at all. He should be able to tell his boss that to meet his targets, he needs extra time in theatre, but it doesn't seem to work like that.*

Barbara assumes that the need by the hospitals to meet targets means that there are no waiting lists for procedures and was surprised that her surgeon could not ask for more theatre sessions. This highlights how the targets can create but also reveal resource shortages in services that struggle to provide them to tight timescales.

### **5.8 Resource constraints**

Some participants feel that resources are being wasted redesigning pathways to meet waiting time targets when Trusts cannot meet them. One of the significant concerns raised by members of all three groups (particularly managers) who were interviewed was that the targets system puts pressure on a resource-strapped NHS. Shortfalls both in workforce and equipment are currently evident to many. This results in capacity constraints which in turn lead to difficulties in meeting performance targets. Targets encourage particular ways of working and service designs that are resource-intensive, requiring money to be spent on the administration systems needed to monitor and report them, and more importantly, the availability of a workforce to operationalise them.

Nurse manager Cathy identifies workforce shortages in nearly all the major support service areas that provide cancer care: diagnostics, radiology and endoscopy:

*It is frustrating that we have been continuing to fail cancer performance, and the resources that are going into trying to meet those targets are going into the wrong places, so we've got a lot of administration and work that we are trying to do around pathways to improve the waiting times and bring them back into performing when actually the fundamental resources underneath are*

*not there, and that's where the support should be. There have been problems around resources for diagnostics, radiology, endoscopy, whilst there are workstreams at NHS England are focusing on trying to radically reform and do things differently, I just don't feel that they are going to plug the gaps that we've got with people retiring, losing expertise, you know, people are moving out of the country to work.*

For Cathy, although additional administrative resources are being provided to monitor the targets, what is needed is investment in infrastructure to ensure that the fundamental diagnostic services can be delivered in spite of a rapidly diminishing workforce. Rebecca also highlights the existing workforce issues, which are national problems and are due to shortages in trained staff, resulting in capacity limitations in essential services:

*If you delve into the pathways and see where the problems are and the themes that come out around diagnostic capacity but then the underlying root cause of that are around the lack of radiologists, not just trained radiologists but around the whole area that we just haven't got the radiologists to train anyway. There is a new lot of pathways being developed at a regional level. They are putting a lot of pressure on radiology when really, they can't achieve those turnaround times, and there is no magic solution to them because they haven't got the staff. There aren't the staff out there to recruit, so I think that is really difficult. The targets highlight this is where your bottleneck is, but it does not provide any solutions. It is the same with biopsies, too – there is just not the staff to do them.*

Rebecca's analysis of her Trust's breaches has identified that a key issue is the lack of radiologists. These roles are key in providing the diagnostic pathway as shortages reduce the capacity for scans and lengthen the wait for results. The timed pathways designed to ensure rapid diagnostics and treatment for as many patients as possible are, in some cases, not feasible. They require increased staffing levels, and there is no additional staff available to recruit in an already overstretched and under-resourced NHS. The targets have helped Rebecca identify where the problems and delays are in the patient pathways but offer no solutions to fix them.

Joan offers a similar view. Her Trust has vacancies for key staff members without whose expertise she cannot run a timely diagnostic service for cancer patients, especially with increasing numbers of patients needing to be seen. However, she also acknowledges that removing the targets would not help as it would be likely that steps

would slow down for the patient. Equally, it is important to her that patients get a quality service, which is not always possible due to the constraints at her Trust:

*I think the challenge is that we haven't got the capacity: we have got those key skill-set shortages, so you are never going to be able to get things turned around in a timely manner. We alone have got five radiologist vacancies, and we had three pathologist vacancies up until last year, so how can you increase your referral rate by 20-30% and still expect a team that hasn't grown and has, in fact, depleted to keep up with the volume of work that is coming through? It is just simple pint doesn't fit in half-pint pot, isn't it? I completely get that you need to drive change, and you need to drive patients through the system quickly; you need to make sure there is quality associated with that, but how can you when you've got a national shortage of radiologists, pathologists, radiographers, CNSs [Cancer Nurse Specialists]. You have got these key skill sets that are missing, so there is only so much you can flog a dead horse, really. What we have got now is instead of, it is a difficult one because you know you relax a target and everyone's standards become relaxed, but if you keep your foot on the gas of the target, you are in a way driving Trusts to make sure that things happen for patients in a timely manner, but you know there is a whole industry around chasing referrals, counting the beans rather than what is the quality in this process.*

Joan is aware of the key problems in her Trust, which makes them unable to hit the Cancer Waiting Times targets: capacity constraints as a result of staff shortages against a background of increasing referrals and therefore patients in the system. While speedy care is important for patients, it is impossible to provide with such shortages. However, relaxing the targets is not the answer as without the pressure to meet the targets, services might become worse.

All three managers Joan, Rebecca and Cathy, identify deficiencies in the workforce, which cannot be fixed easily. The targets to them have become an almost impossible obstacle that cannot be met no matter what changes to services are implemented because the resources are just not available. The patients also demonstrated that they were aware of the pressures to deliver that the NHS is under. Henry effectively summed up the problem with his comments about the new 28-day target, which he feels will be good for patients, but difficult for hospitals to deliver:

*This new standard sounds good, but obviously, it puts pressures on health workers and GPs and everyone. It's got to be a good thing, I would have*

*thought. The NHS is short of funds, so that is obviously an issue. I hear that 1 in 2 people could have a cancer in their lifetime. That is staggering; that's 50% of the population, and the NHS, I think, needs all the support it can get. Funding is a big thing. You can't do anything without money. If you need more staff, more hospitals or facilities you need more money, simple as, you know.*

Henry recognised that with such a high incidence of cancer in the population, the NHS is going to be under significant pressure to deliver services. Although the new 28-day target will benefit patients, it will be impossible to deliver without giving the NHS more money and resource. Janet, a lung cancer survivor, questioned me about what happens when the demand for services increases past the level of supply. She then commented on the difficulty that arises getting a GP appointment and then in the surgery with the GP if there are no appointments available at local hospitals.

*Janet: What happens if you just have so many people that it can't be done?*

*Interviewer: They just wait.*

*Janet: But then you are not meeting your target. You can only do so much if you have got a lot of people going to the doctor. My wait was ok, but I would say that the GP service with what it is at the moment you can wait three weeks for an appointment. It's a major problem. You go, and they get on the computer, and they say, well, there is nowhere to fit you in at Trust A, there is no room at Trust B. I think that is really, really bad.*

Once informed that some patients may have to wait to be seen, Janet acknowledges the difficulties she assumes Trusts must face fitting patients in if demand exceeds capacity. She is concerned that patients may not be able to be seen at the hospital of their choice. The prevalence of this issue in the interviews shows how successful the target system is at shining a light on resourcing issues. By examining why patients are not meeting a target, shortages, as well as failings in an organisation, can be identified.

There was one dissenting voice amongst all the concerns that the lack of resources caused problems. One of the doctors, Andrew, believes that the problem is not that the resources are not available for patients to be treated in time. Rather, it is that pathway blockages have organisational origins:

*I think the cancer improvement work that we have done across Cheshire and Merseyside within the Cancer Alliance has demonstrated very clearly that the limitations on the pathways are often organisational rather than resource.*

It is interesting that Andrew is an outlier amongst those I interviewed, especially as everyone else was so insistent that it was a not insignificant problem. This then indicates that improvement projects that Frances mentions above having little time to undertake are of vital importance.

### **5.9 Chapter summary**

This chapter considers the effect that the national cancer targets have on the provision of cancer services in NHS hospitals and the ambiguous nature of the attitudes of my participants towards them. Most managers felt the targets are necessary to prevent excessive waiting times for patients but raise concerns about their accuracy as a means of judging the quality of services. Contrary to accusations in the literature, managers deny gaming the system to improve performance but admit to them being a source of conflict between Trust who are all trying to perform well. Clinicians do not concern themselves with the targets, which require increased numbers of administrators to monitor. The use of targets to motivate improvements and their role in highlighting resources limitations are also discussed. In all of these considerations, the targets are seen to influence how cancer services throughout the country are designed and provided to ensure patients receive timely care. Managers have mixed feelings and vacillate between declaring them a nuisance to lauding how they improve patient care. Indeed, they approach targets with ambivalence and ambiguity. The following chapter considers whether uniform targets work and if the targets have become outdated by developments in cancer care since their inception.

## **Chapter 6 Does one size fit all? The challenge of standardised cancer targets**

### **6.1 Chapter Overview**

This chapter examines one of the most significant drawbacks of the targets and an issue that causes considerable concern: inequality between patients who are referred as suspected cancer patients and therefore the primary 14, 28, 31, and 62-day targets that apply to them, and patients who have presented to secondary care through another route and are not subject to the same targets. The chapter ends by considering the idea that the targets may be outdated when considered in the context of increasing co-morbidities and new diagnostic tests.

### **6.2 Do uniform targets work?**

The ideas of inequality raised in my interviews came in two forms; the first that the targets themselves were an unfair way to measure progress against the many different forms of cancer, and the second that the targets divided healthcare into two levels, one for those who were on target pathways (who are all treated equally) and another for those who were not. Currently, the same targets apply to all types of cancer, with the exception of testicular, acute leukaemia and children's cancer, which are subject to the 14- and 28-days target but whose treatment must commence in 31 days rather than 62 days. These so-called "rare cancers" are considered high risk enough that they have to be treated in a tighter timescale. Apart from these rare cancers, all cancer types from skin to oesophagus are measured by the same waiting time targets. However, some Trusts differentiated between "true targets" – those referred on a suspected cancer pathway and those patients upgraded onto a 62-day pathway by a clinical team when a suspicion of cancer arises. As the latter do not fall into the same performance cohort as the 'classic' 62-day patient, their waiting times compliance does not benefit Trusts.

Several participants suggested that all tumours should have separate, distinct targets. Given that cancer progresses in different ways and at different speeds depending on what part of the body is affected, it does not make sense for it to be treated in a standardised way. One manager, Joan, points out how all cancers behave differently and progress and spread around the body in different ways. With some cancer types, it is more clinically urgent to treat than others. This leads Joan to question why treat patients the same when it comes to waiting times:

*I think they need to start looking at a target for each individual tumour group, different targets for each group because they all behave differently; they all metastasise differently; they all progress differently. You've two streams of patients, haven't you? You've got your low risks and your high risks. Your low-risk prostate patient can bumble along for years without any real progression of the disease, so why do they have to be treated within 62 days? What's the point?*

Joan's use of prostate cancer as an example was not an isolated incident. It was the most quoted example of why it does not make sense to have the same targets for a fast-growing, aggressive cancer and a low risk, slowly advancing one. Hospitals have to prioritise resources to ensure that patients who could potentially safely wait a bit longer for treatment are treated on time, resulting in some patients being rushed through the system unnecessarily.

One of the clinicians, Alexander, compares the different cancer types that he sees in his department, and how from a clinical perspective, each type could potentially have a different target and urgency, depending on how quickly they need to be treated. Giving examples of different waiting times for several different cancer types, he asks why one target should cover all these different diseases. He not only discusses the urological cancers that he works with, but he also uses breast cancer as an example where targets could benefit from being shorter than the 62-day standard. He also quotes the apparent disparity for testicular cancers, who are on a shorter 31-day pathway, in the process critiquing this standardisation of care for all patients. He also mentions how men with prostate cancer can wait for treatment and so he may breach his target without suffering any ill effects:

*Why can't they have separate [targets]? Urologists could say – kidney target is, let's say, six weeks, prostates 12 weeks, bladder it has to be six weeks, testicular it has to be four weeks. So you can have that. Why can't we have that? Why should it be one [target] fit all? You should have different targets for different cancer. A testicular cancer should be much shorter. A bladder cancer, in theory, should have a much shorter pathway than your prostate cancer. A radical prostatectomy, he can wait for another six months before he decides to go on and have something else. So essentially, he may breach, but he doesn't need to have anything done. Personally, if you want to have a target, you have to have a separate target for each cancer, and that is not just in urology. Somebody, say a female with breast cancer has to be done within*

*four weeks, and you have the same target. 62 days should not apply to prostate. For example, if it is going to be a testicular cancer, that 62 days is a nonsense. If they can get it for 31 days, then why can't they get it for others? Where do they get the 31 days from?*

Alexander, a clinician, then goes on to point out some clinically important conditions do not fit under the purview of cancer targets. Carcinomas in situ (CIS) and pre-invasive (pTa) cancers are not measurable under the Cancer Waiting Times standards. However, in the bladder, its treatment is arguably more urgent than muscle-invasive cancer. He explains:

*pTa bladders are not included, but CIS is the most aggressive cancer in the bladder. If I see a patient with CIS, he needs to have it treated more urgently than a G3. It was done by people who don't know anything about urology, the idiots.*

As a consequence of the targets not always making clinical sense, there is a fear amongst the managers that clinicians do not take the targets seriously. For Joan, more "intelligent" targets which took into account the differing severity and prognosis of cancer types would help with clinical engagement and would contribute to the smooth running of services:

*Clinical buy-in is really important, and if it made more clinical sense, you would get better engagement. I think recognising the disease trajectory in the targets would actually incentivise the teams that are looking after that patient group because it is something meaningful to them, you are taking account of the disease process, and you're acknowledging that you don't need to do all of these really quickly because this is a group that can wait for a few weeks or a few months, but actually, the groups that are really going to struggle and not benefit by waiting, they are just left by the wayside because there aren't many of them in number. It doesn't make sense to me to say that across the board, everybody should get the same target.*

The support of clinicians is really important, and Joan predicts that this could be achieved if the targets reflected the difference in cancers in different body parts. Less common cancers would not be neglected because they are few in number and do not have a significant impact on performance. Although the clinicians I interviewed did not think the target system was perfect and offered suggestions for improvement, only Alexander appeared to be disengaged from the process of meeting targets. He

suggested that the targets were not developed by informed people who cared about tumour specifics. Instead, he argued their development was driven by a political agenda and doctors were not consulted to ensure they made clinical sense.<sup>13</sup>

*It is because the people who made the decisions are purely political; to make sure they are doing something, it is a tick box. Nobody thought about it, and we were not given any information, and we were not asked. We were not included in these things. How can a physician make a decision on cancer of the prostate? How many urologists were involved in the drawing up of the guidelines, not a single one? It was one size fits all for all cancers.*

He clearly feels that he, and his colleagues, were excluded from the decision-making process around the development of the targets. Having a group of physicians who were not experts in all the areas when developing the guidelines has resulted in trying to fit all the cancer types into a standardised system that does not suit them all.

In addition to the clinical disparities identified by Alexander, another issue discussed by clinicians was the differences between the pathways for each cancer type and how each type are diagnosed and treated. This makes the standardised targets seem unfair towards the teams working with more complex tumours. Although specialist diagnostics are in the patient's best interest, they can slow down the diagnostic process. One such example is the haemato-oncology diagnostic service (HODS), which is a regional centrally run pathology service for the processing of haematology samples. It is considered to be the gold standard to use this laboratory for analysis. However, as a result, it is in considerable demand and processing specimens takes time. As Judith comments about their haemato-oncology (HO) service: "HO can't get anything done. We can't get anything through HODs in 28 days." In dermatology, for example, patients usually only require one biopsy to reach a diagnosis, then a further surgery if the tumour was not excised completely at the time of the biopsy. Tracy, a consultant dermatologist, recognised that cancers in her speciality were easier to diagnose than more complex tumour types:

*I think the system would work better if there were different targets for different sites. Skin is a much more easy procedure to follow, so obviously, there will*

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<sup>13</sup> This may not be an accurate description of how the targets were developed, but this clinician clearly believes it to be true.

*be variation across specialities. If we had the resources, then yes, we should have different targets.*

She feels that different targets for different cancer sites would be more effective. Her own area of expertise, skin cancer, has a less complicated pathway than others, so she sees that it is different from other cancer types when it comes to the targets. Tracy also appreciates that this may involve a resource implication if different targets for each tumour site were introduced. The managers echoed this concern that the targets disproportionately penalise certain cancer types. Judith sums up this issue succinctly:

*The straightforward pathways are doable, aren't they? It's the ones that need an extra test; you've got no chance then.*

Judith is dividing pathways into those that are straightforward where, for example, a cancer can be diagnosed on a simple biopsy and received treatment in a limited number of visits to hospital. This could easily be scheduled to meet the 14,28,31, and 62-day targets. Patients with cancers that are more complicated to diagnose that may require several, or repeat tests are not going to meet all, if any, of their mandated waiting times targets. Another manager, Molly, uses the lung cancer pathway to illustrate the point that complex pathways are physically hard to fit into 62 days due to the number of stages needed to reach a diagnosis and prepare a patient for treatment:

*With lung, there are so many diagnostics; it is hard to fit them into the pathway. The targets don't allow for the improvements in diagnostics; everyone has so many tests now. When you go looking for something, you find something else. The diagnostics allow you to look for more and more.*

It is both complex to diagnose, and improved diagnostics have lengthened patients' pathways. Molly points out that another consequence of improved diagnostics, as well as lengthened pathways, is the finding of unexpected additional illnesses and sometimes cancers. Some managers were also concerned that the 62-day target does not account for patients whose co-morbidities prolong their diagnostic pathway. Yvonne explains:

*The targets do not reflect the increasing complexity of the pathways and co-morbidities that patients come in with, and also with the improvements in diagnostics, they come in with something else and then that creates more of a headache if incidental findings or additional cancers are found.*

It was felt by several of the managers that since this introduction of the targets, patients seemed to have increasingly complex conditions in addition to their cancer. Rebecca also mentioned this problem, using lung cancer patients as an example as those who frequently present late and whose co-morbidities can prevent a smooth diagnostic pathway since they are not always fit for the investigations:

*The lung [cancer patient] is a really good example. They tend to come in at a late stage, are usually quite complex, have other health issues, which means that you cannot get them in for diagnostic tests straight away, so it is difficult.*

Patients who already have an advanced cancer, in addition to other serious health conditions, are frequently too poorly to attend for investigations which further delays their pathways. Aside from patients with low-risk prostate cancer who do not need to be treated in 62 days, there are some patients who have their symptoms monitored as it is impossible to determine at presentation whether they have cancer or not. They will be reviewed after a period of time and, depending on the findings at review, may undergo further investigations. Yvonne explains how this is what is clinically best for the patients; they remain on an active pathway:

*There are the patients who are sent away to come back in 3-6 months. It is clinically right to do that because if you don't, patients might have unnecessary treatment, radiotherapy, surgery, et cetera. We also have breast patients – we'll see you in 6-8 weeks to see if it has changed, but you can't take them off the pathway because they still haven't said yes or no to cancer. I don't think the threshold accounts for that.*

Clinicians claim that it is clinically the correct decision to monitor how these patients' symptoms progress over a period of time. However, the Cancer Waiting Times rules do not allow these patients to be removed from their timed pathways, as they have not yet received a definitive diagnosis. The threshold Yvonne refers to is the tolerance level linked to the targets, which allows them to have several patients who breach the target before it is failed. For the 62-day target, it is 15% of the total patients treated, so 85% have to meet the target for a Trust to be compliant. Previous iterations of the cancer waiting times rules allowed for pauses to be added to patient pathways, which meant patients with unavoidable delays in the journey for reasons of patients' choice, or clinical necessity would continue to be monitored against the targets, but a Trust would not be penalised. Andrew, a clinician, was one of several participants who lamented the removal of pauses from the guidance and felt there was a need to build

*"intelligent clock stops for the cancers that don't need to be on a 62-day standard"* into the waiting times.

Several potential solutions were offered to the problem of standardised targets. While some debated the need for individualising timings for tumour sites, it was recognised that this would not be an easy task. The difficulty with having tumour specific timed pathways, with different timings for each tumour site, would be deciding how long they should be. Judith agrees that they are not ideal in their current state and wonders how a decision around an exact time for each site would be reached:

*What about individual targets for different tumour groups? You'd have less kickback from the clinicians, prostate, for example, who are always going to be 'well it's not time-sensitive. But how do you put a time on it? One doesn't fit all, but it is almost at a patient level, isn't it?*

Individual targets may be a solution for different tumour groups. While it pleases the urologists who currently feel that their patients do not benefit from a rapid pathway, it may be difficult to establish just how long each group should be allowed. This is especially true when considering that each patient has their own set of individualised co-morbidities that may prolong their pathway or have a cancer that is complex to diagnose. In this case, it almost seems necessary to have patient level targets which, in practice, remain unobtainable.

Some participants also feel that if most cancer types are subject to the same targets, the patients may expect to all follow a common pathway with the same diagnostic and treatment milestones. As mentioned briefly in a previous chapter, there is a prospect of providing mixed messages about the urgency with which their cancer is treated. When patients are informed that they are on a target pathway, and the importance of their attendance at appointments is impressed upon them, it can be confusing if, for some tumours, the sense of urgency is diluted. Once again, using prostate cancer as an example, one of the clinical nurse specialists, Julie, explains how patients can expect to wait several extra months for treatment. It may not be clinically urgent to treat this cancer, but it can be difficult to explain this to a patient who is not only expecting to be treated by day 62 but has also just been given a diagnosis of cancer:

*It can be confusing for patients. We rush them through the system to get a diagnosis by day 28, but then we tell them that yes, they have got cancer, but*

*it is not that serious, and they can wait a few months to be treated. Never mind day 62, they hear the word cancer, and they want it sorted.*

Julie describes how patients will get a timely diagnosis, but prostate patients may wait for treatment. While some patients may be confused by the seeming contradiction of fast diagnosis and slow treatment, others may find themselves being rushed through the system to meet the target when it is clinically unnecessary. Julie fears that the existence of the targets may encourage Trusts to rush patients to treatment in order to meet an arbitrary deadline which might not be in their best interest. It is decisions about their care, irrespective of the target date that the Trust should start their treatment by.

Another related issue linked to the standardised timed pathway for all cancer types is the strain its puts on a hospital's capacity. Needing to process all the patients quickly can put pressure on certain services. It can also mean that the low risk, slower-growing cancers can take appointments or theatre spaces more usefully attributed to the higher risk patients, either in the same tumour site, as described by manager Joan:

*Then the ones who are high risk and you should be pushing through can't get a slot because all the low risks are going through.*

If all the patients referred in on an urgent pathway have to meet all the targets, then there may be patients fast-tracked unnecessarily, and other patients may be equally clinically urgent but are not fitted in. Joan was not alone in feeling that the targets may make decision-makers at Trust disregard the clinical needs of patients in favour of meeting the targets. Another manager, Rebecca, expresses concern that Trusts prioritise patients by target dates rather than by clinical necessity. She describes in more detail the problem when there are competing priorities for limited resources:

*The other thing is that the targets can actually make a little bit of a mockery of priority because some tumours groups are a higher priority than other ones. For example, prostate cancer isn't going to change quickly when some of the other cancer groups will change quickly but, because of the targets, you might be trying to get prostate patients in for diagnostics and treatment when in fact, there are more urgent patients for other tumour groups that you need to get in, but they haven't hit their critical target point. They take capacity from other, more clinically urgent ones. Prostate is a good example of that because they*

*are generally not a fast-growing tumour, but you have to do it because of the targets.*

In her example, the Trust may only have the capacity to provide so many diagnostic appointments or spaces for treatment. If these slots are taken by patients whose disease may be slow-growing but have targets attached to their care pathway, there may not be enough availability for other patients to be seen too. Joan vividly explains that for patients with particularly aggressive cancer types, such as pancreatic cancer, it can be detrimental to their health if a patient presents with advanced disease and then has to wait to be seen:

*What about the poor buggers who are coming through with pancreas cancer who are absolutely scrogged when you get them? By the time they get a slot to see anybody, they are even more scrogged, and then they are not fit enough for any treatment, so, you know, what about them? What about that patient group?*

Joan's colourful explanation depicts patients whose cancer is negatively affected by having to wait to be seen. These patients are at a disadvantage having to compete for appointment slots with patients with other cancers who are not as ill and whose disease will not advance as quickly while they wait. Hospitals have to juggle finite resources and limited capacity for investigations and treatments to ensure that patients are not penalised in the way Joan describes.

In addition to there being a two-tier system amongst cancer patients, depending on which target applies to each patient, clinician Tracy raised the concern that cancer patients are being prioritised over patients with non-malignant conditions. The targets result in cancer patients being placed ahead on waiting lists and forces patients with routine conditions to wait. Tracy points out that some of these benign conditions still need to be treated urgently, so clinically, they should be a priority:

*In a way, cancer targets are having a detrimental effect on other patients, though. The other patients are being left out. They were pushed out from their turn. We need to make it fairer for everybody. If everybody is on a pathway, then that will really stretch our resources. This is why we have so many follow-ups going up and up and up, and if someone has cancer, then we will put them over someone who does not have cancer, and so that is the way the routine ones do suffer. I have seen that in the past. Patients may have clinically urgent conditions, but because they are not cancer, they get pushed back.*

Tracy sees the negative effect that fast-tracking patients on a cancer pathway can unintentionally have on other patients. Cancer patients come first, which means other patients have to wait, including patients in the system requiring routine follow up. The system may compromise the health of a patient with a serious yet non-malignant condition as they are not subject to the same waiting time targets as the cancer patients.

This potential cause of unfair treatment was mentioned as a concern by several other managers and clinicians in addition to Tracy. One of the most challenging aspects of managing the targets is the feeling that they have created a two-tier system for cancer patients between those who are measured against the targets and those who are not. Several of my respondents commented on examples where this might be the case. Manager Molly points out that non-target patients are not watched as closely as they have no targets to meet:

*You've got to worry about the emergency presentation patients who just don't get that same level of support, really. There isn't a clear target associated with them.*

Patients who present through emergency departments usually have more advanced cancers, and their symptoms have driven them to seek urgent help. Whilst all patients are measured against the 31-day decision to treat to treatment targets for first and subsequent treatments, the main 14- and 62-day targets do not apply to their care.

Another manager, Judith, also discusses how Trusts are encouraged by the targets to move patients along their pathway, and some Trusts may treat non-targets patients differently. She describes patients who are not on a cancer pathway (RTT is a term for routine patients), who arrive at the treating Trust having been investigated and diagnosed routinely, on pathways that may have included lots of waiting to find out what results are. Even patients with benign results deserve to be told quickly, according to Judith:

*It seems to me targets do help because the other patients are perhaps not getting the push to come in to get their treatment within target. As a Trust, we do try to treat all patients the same. We do get lots of patients who come in on RTT pathways who come in very late in their pathways. It doesn't matter if you've got the diagnosis if you're waiting. If you've gone with a problem, it doesn't matter what it is; you know you should be treated as quickly as*

*possible. I know we are now looking at patients who have waited 52 weeks or more, and that to me is unbelievable.*

Judith sees targets as helping patients to access timely treatment, which they might not receive without this incentive. She goes on to describe how patients are referred to her Trust who are not on a cancer pathway but rather a routine one (which she refers to as RTT - referral to treatment), not subject to the cancer targets. As they are not on a targeted cancer pathway, they may have been in the hospital system for some time. It is difficult for her to understand how patients have been waiting so long for treatment – to her, even patients without cancer should not have to wait for treatment. Managers were not alone in their concern over the inequalities that targets created in the system. Theresa, a cancer specialist nurse, was very passionate about ensuring that all her cancer patients get the same service. All of her patients may have lung cancer, so no one patient should wait any longer than another:

*I think it is great for them [the target patients], but I also advocate for the other non-target patients who come through the system as upgrades or ward discharge patients, so to me, all the patients that come to my service potentially are lung cancer patients, and they go through the same process as anyone else. If an urgent appointment became available for a target and I had somebody else waiting, I don't see why somebody should take priority.*

As any of her patients may have cancer, Theresa has to be proactive in ensuring her patients not measured against target still get timely care. She feels that if a patient is waiting to be seen, their status (on a target pathway or not) should not matter. Some services reserve appointments specifically for target patients, but in this case, Theresa would give the most urgent patients that appointment, irrespective of target status. It becomes particularly difficult when clinicians are asked to prioritise their patients based on their target status. One clinician, Mike, initially claimed that all patients are treated the same, irrespective of whether they are being measured against a target. The system at his Trust ensures equality, and no favouritism is shown to any patient:

*The key is it doesn't matter if you are a pathway patient or not; all our patients are treated the same. On our timings dashboard that we put through the system, all our patients are treated equally. I've seen no evidence that there is prejudice for patients not on a target pathway.*

Mike thinks all the patients at his Trust are treated equally and monitored through the hospital system in the same way on a dashboard. However, he then goes on to admit that if clinically urgency for the patients is the same, he will prioritise the pathway patients:

*I get the odd mental dilemma because we've got two patients who come in together, or we are doing a repeat test on a patient who is day 25 of a pathway or a new referral who needs an EBUS [endobronchial ultrasound]; I'll pick the patient furthest along the pathway. If they are both completely equal, I will pick the pathway patient, but if one is a bit frailer, I'll pick them first. It goes first on clinical urgency.*

Although he primarily considers the clinical urgency of patients when listing patients for procedures, he does consider their position on the pathway – is it a new referral or a patient requiring a repeat test, checking to see which is furthest along their pathway and nearest to the treatment target. Yvonne argues that as a manager, the solution to this is to ignore any target timings attributed to the patients and track their progress all in the same way. This involves clinicians' upgrading' patients onto a 62-day pathway at any point before the decision to treat. This then provides the solution where all the patients are tracked and expedited by administrative staff in the same way. "We don't differentiate between 62 and upgrades – we just track from top to bottom."

However, Joan, a fellow manager, worries that not only does this create work for the trackers following and chasing pathways, but the true targets will still be the main priority:

*Targets are prioritised, and that is a sad fact of life. We encourage all our consultants to upgrade wherever possible, so if they do see somebody who is not coming through a two-week pathway, we are getting more than ever, but that is a load of work as well. Once they are upgraded, we do track them, so they sort of get some attention on them to make sure they get treated really quickly.*

This quote illustrates the complicated system created by the different targets. Upgrading patients creates work, but it will help the patients receive more attention when scheduling their care, if not the same amount as two-week wait patients. Joan admits consultants are encouraged to upgrade, but it is not mandatory, so presumably, some patients are not upgraded onto a 62-day pathway. This seems to

create another layer in the target hierarchy; the true targets, the upgrades and those who are not upgraded.

### **6.3 Has the system outgrown the targets?**

Although the targets have been reviewed and adapted several times since their inception, there was still concern that they were out of date (the most recent changes introduced in 2020 came into effect after my interviews). For instance, participants often identified how targets did not consider the increasing numbers of complex patients (due to their multiple co-morbidities) or complex pathways (due to technological developments in diagnostics). Nurse-manager Cathy explained how poorly patients are not always able to follow a streamlined pathway:

*We have so many patients on our PTL [patient tracking list]<sup>14</sup> with cardiac and respiratory problems: there are just so many of them that are unwell in between investigations. Unwell generally and unfit so that we can't get on. We used to have them, I'm sure, but I don't know if you have seen an increase in those patients?*

Once a patient is referred to secondary care on a suspected cancer pathway, their target clock is started. The 62-day clock continues, with a few exceptions<sup>15</sup>, until a patient is treated. Patients with co-morbidities make it difficult to complete diagnostics and commence treatment as their other illnesses frequently slow down or prevent investigations from going ahead. Cathy believes that there are more patients now than when the targets were initially introduced who have a pre-existing condition, and this is slowing down their care. The targets have not evolved to reflect this wider social change. Another area where they have not kept up with changes over time is in the area of diagnostics. Manager Yvonne reflects how advances in the investigations that are available to diagnose patients extend the length of pathways, making it more difficult than ever to meet targets:

*The targets do not reflect the increasing complexity of the pathway, and with the improvements in diagnostics that creates more of a headache, for*

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<sup>14</sup> The PTL is used to keep track of where patients are up to in the system and how far they are along their pathways.

<sup>15</sup> The clock can be paused for specific circumstances, including for patients who require treatment of another clinically urgent condition before their cancer treatment and patients who are unavailable to start treatment at a particular time.

*example, with lung [cancer], there are now so many diagnostics, it is hard to fit them into the pathways.*

Yvonne mentions developments in investigations for patients on the lung cancer pathway. Patients may now receive PET scans and EBUS as routine diagnostics and genetic testing to identify specific tumour types for targeted therapies, all of which are difficult to schedule in 62 days. Specialist Nurse Theresa comments that managers may suggest seeing patients sooner, but for her, it is all about what the patient needs. Sometimes having an appointment moved forward to be seen more quickly is not appropriate (although it may move the patient along their pathway more quickly):

*You go with clinical priority and urgency, but you are fighting management about when you can fit them in. We have an extra clinic on Wednesday, so we thought to move some of the Friday patients, but we have a young man on and if we move his appointment by two days, he is going to think, "Oh my God, I'm dying!" So, it is the psychological impact. It's not all about dates and targets. It is the person as a whole, and this young man is quite an anxious person anyway, and there is stuff going on for him, so things like that do matter. So, sometimes you leave it as it is.*

Theresa provides an example of one of the perverse incentives created by the target system, whereby seeing a patient earlier may not be in their best interest. By moving an appointment by a mere two days, the patient reacts with shock imagining that the news he will receive must be very bad if it is so time sensitive.

#### **6.4 Chapter summary**

This chapter considers whether the targets create inequality in cancer services with different priorities for those on a pathway subject to the targets and therefore fast tracked, and those who are not. My participants debated the question of whether, given that all cancers progress differently, there should be distinct expectations attached to how long it takes to diagnose and treat them. This argument seems to be increasingly relevant given the introduction of more complex but time-consuming diagnostic investigations and higher numbers of patients with complex needs. The system prioritises patients who are on a target pathway, irrespective of clinical urgency and potentially at the expense of other non-target patients. Clinical engagement is vital to making the system work and would be more likely if the system reflected their clinical priorities. Additionally, patient flow would improve if patients were listed for procedures by clinical priority, not just according to the number of days they have waited and how they were referred into a Trust. Ultimately, both managers

and clinicians try to ensure that managing patients using targets does not interfere with their clinical urgency but have to work in a system that can make that difficult.

In the next chapter, I discuss the findings from my data and draw conclusions from my research.

## **Chapter 7 Discussion**

### **7.1 Chapter overview**

In this study, I examined how clinicians, patients and managers felt they were affected by the national cancer targets. Drawing on qualitative interviews, I explored the different views and experiences of each group, together with how their interaction with one another shaped the clinical encounter and, ultimately, the cancer journey. The data reveal a complex picture, with themes emerging which contribute to answers for all three central research questions (repeated below) and offering a new perspective on our understanding of the cancer targets.

Patients revealed how despite limited knowledge of how the targets actually work, waiting for a diagnosis played an important part of their experience. Interestingly, they placed a similar importance on the practicalities of accessing their GP, persuading them to refer them into secondary care, as much as the timings of the events in their cancer journey. Managers and clinicians raised some of the key criticisms of target-led healthcare that are reflected in the literature (Hood 1991, Hunter 2008). For clinicians, this meant addressing the concerns that the targets were not clinically meaningful. Additionally, the clinicians discuss whether the implementation of targets has undermined their professional autonomy by dictating their actions. Discussions with managers revealed their ambiguous relationship with the targets. While they recognised that they brought benefits to the patients by reducing waiting times and focussing attention on their needs, for example, they were also frustrated by the operational constraints that the targets bring and without necessarily being a good indicator of a service of quality. In what follows, I discuss each of the three research questions and reflect on the major themes from the research.

### **7.2 What are patients' views on the cancer targets and their impact on their journey through care?**

Key findings of my study address the gap in the literature around patient views and experience of targets. Patient representative groups were involved in the consultation when the targets were reviewed in 2010 (DOH 2011), and similar to my participants, felt they were generally a good idea. Given how integral targets are to the cancer care that patients receive, it is important to understand how patients feel about them and the impact they have on a patient's care – yet little research has explored this. If targets are to be patient-centred, they need to measure things that are important to patients. The patients who I spoke to discussed how their experience was affected by more than just how many days they waited. In what follows, I discuss how patients

negotiate access to their GP, patients feeling about the speed of their pathways, what the patients know about the targets and the effect the targets may have on patient autonomy.

### **7.2.1 Accessing the GP**

When patients were asked to talk about their experiences of being diagnosed with cancer, almost all of them started their stories with their decision to go to the GP or with the screening service, prior to their referral into secondary care, a time period not measured by the targets (but reflected in Andersen et al.'s (1995) modelling of a patient's journey). Studies acknowledge that this time period can be a key determinate of patient outcomes (Richards 2009; Caswell et al. 2017), but much of the literature concentrates on reasons patients may delay this contact, primarily revolving around fear or simply a lack of recognition of the severity of certain symptoms (Neal and Allgar 2005, Austoker et al. 2009, Mitchell et al. 2015). In my study the patients' concern was more to do with practical issues around the quality of their encounter at the GP surgery and whether their specific needs were addressed. The barriers they encountered included having difficulty getting appointments, especially with a named doctor, the length and limits on what they could discuss in their consultations, and the physical discomfort of the surgeries. The efficiency strategies that have been introduced by some surgeries are not satisfying for patients with complex needs or who have multiple symptoms. It is possible that GPs will miss key red flags that should trigger a referral into secondary care, or patients may pick a symptom to discuss, thereby overlooking a more serious complaint. Patients need to be reassured that they have had a comprehensive review of all their symptoms and will be referred on if necessary. This is an area for further research as early diagnosis initiatives concentrate on getting patients to act (Rubin et al. 2015), but these will fail if patients' faith in the ability to access a suitable service from their GP has been eroded. A more holistic approach is needed whereby GPs are encouraged to reduce barriers that prevent patients from attending their surgeries.

This waiting period has become more important during the COVID-19 pandemic as restricted access to GPs has resulted in a reduction of urgent cancer referrals. This could be due to many reasons, such as patients being anxious about leaving the house, GPs not undertaking in-person appointments, and confusing a new cough with a mild form of COVID-19 rather than a symptom of lung cancer. Whatever the reason, data from NHS England show that the number of urgent GP referrals for cancer dropped by 60% in April 2020 compared with the same month the previous year (NHS

England 2020). This may seem tangential to my research questions as a non-targeted period of time. However, it is important because we learn something of how to make patient experience better and potentially speed up referrals resulting in earlier diagnoses. To patients, their journey does not fall into conveniently timed periods that can be measured in days, so when asked about their experiences, they start at what *they* see as the beginning, not the beginning as measured by the targets.

The advantage of targets for patients is clear: they outline a clear route into secondary care for suspected cancer patients to follow. However, the literature concentrates on the impact for patients of delayed referrals, but also the difficulties that GPs face making the decision to refer given how few cancers most see in their career. The clinicians in my study complained of high levels of inappropriate referrals, so it would be interesting if further research could be conducted with GPs around their role as the gatekeepers to secondary care and their motivation to refer patients on a suspected cancer pathway.

### **7.2.2 Do waiting times matter to patients?**

My study makes some key contributions in relation to patients' perspectives on the timing of their pathway. One of the interesting findings was that although the cancer targets are concerned with how long patients wait, some of the patients did not always prioritise speed when it came to their care. They ascribe importance to different elements of their pathway, depending on what stage they are at. It seems that while the time to diagnosis was still a concern, once these patients were told they had cancer, timings (and by association the targets) were secondary to the security they derived from having a clearly explained management plan for their care. Those who had been given explicit expectations about the events of their cancer journey placed this as equally important, and sometimes more important, as the speed of their journey when describing their experiences.

Once over the "scanxiety" (Bauml et al. 2016) of waiting for results and a diagnosis, waiting for treatment seemed to be less important. Although research by the King's Fund (2018) has found that long waiting times are one of the reasons that patients are dissatisfied with their care, the patients I spoke to had difficulty articulating what they meant by 'timely care', and their definition did not seem to coincide with the targets. For them, speed is not necessarily synonymous with quality. Unless there is an exceptional wait, the patients in my study were more likely to remember good care and kindness than how long they waited for something. Of the patients that I interviewed, none were unhappy about how long they waited, even those who gave

descriptions of waiting (unbeknownst to them) months over target. One finding not articulated elsewhere in the literature was the idea that patients might find that events on a pathway subject to targets move too quickly. Only one of the patients expressed this, but a manager also mentioned that patients may feel pressure if rushed through the system. It is an important consideration that the targets have the potential to push patients faster than they would like.

Patients describing luck as being responsible for a quick surgery, and their calm acceptance of cancelled operations, are examples of how timings did not seem to be the patients' top priority. Furthermore, some clinicians underplayed the urgency of the pathways (especially in urology), no doubt reducing any concerns patients may have had over meeting treatment targets.

The NHS Plan in 2000 declared a "war on waiting", and performance indicators were introduced into several different areas of health care to reduce the time patients had to wait for essential services (DoH 2000). Once referred into secondary care, the length of time each step takes for every patient is measured by a target. This becomes the area in which the targets have one of the biggest impacts for the patients. Several authors, including Neal et al. (2015), McPhail et al. (2015) and Møller et al. (2015), agreed that measuring and shortening the time patients wait for treatment is very important to encourage early diagnosis and reduce the psychological stress of waiting. This mirrors the opinions of my clinical and managerial participants, who felt that time was the most important factor to a patient in their cancer journey.

While managers tend to divide the timings of patient journeys according to the targets (time to first appointment, time to communication of diagnosis, etc), patients see them in more basic terms of onset of symptoms, accessing help, time to diagnosis and treatment, which corresponds to the stages of the Andersen model (Andersen et al, 1995). Clinicians have an even more complex idea of how the pathway works from diagnosis to staging, and treatment planning through to subsequent treatment. These different perspectives make it difficult to consistently apply the model to a study whose participants hold these different definitions and priorities. However, it was a useful starting point when considering how patients' view the steps in their cancer journey. The new 28-day target will address the diagnostic phase so that patients receive their diagnosis quicker. Monitoring against this target had not yet started when I conducted my interviews, but when asked, participants expressed support of it. As a now live target, research can explore how effective this is at allaying patients' fears, which from my findings it seems its effectiveness is vital.

An interesting area of the literature examined concepts around the understanding of time itself, which has implications for policy makers when the targets are next reviewed. One explanation could be around the way the different groups I spoke to perceive the passing of time. As Jones (2001, p.150) says, “clock time is taken for granted” as the dominant time- frame in Western health care, whereas Adam (1995) proposes in her research that, contrary to accepted Western concepts around time, it moves at different speeds for different people depending on the circumstance that they find themselves in.

Targets are set in linear time, or clock time, as managers attempt to organise patient pathways against 14, 28 and 62 days. From my conversations with clinicians and patients, it is possible that they do not necessarily experience time this way, but rather according to personal subjective time. This might explain how new patients experiencing the fear of the unknown, while undergoing diagnostics, become less concerned with timings to treatment if they have a plan and the hope that accompanies it. Likewise, this was also evident when a clinician, Alexander, talked about how long patients were waiting, and he repeatedly underestimated the time that they had been waiting for tests.

Other explorations of time in the literature found that once patients receive a diagnosis of cancer which makes them feel their future is uncertain, time becomes a more valuable commodity (Braeden 1997, Schutz 2005). Braeden found that “cancer disrupts the ordinary continuity of our experience of time” (1997, p.978). As such, it is measured by quality not quantity, with patients conscious of time *right now*. For the dying patients in Braeden’s study, time changes from being measured by the individual in years to a time where the quality of lived events becomes more important. The patients in my study, although cancer survivors, still live with the threat that the disease may return, and as such measure their time waiting for treatment as more valuable when they feel in control and have a plan for the treatment. This has implications for the future of the targets, in particular the 28-day faster diagnosis standard, as from a patient’s perspective this is the time period that patients are most concerned with. The need to meet the 62-day target will not seem as important to patients. Deery (2008) also found in their study with health professionals that when time is pressured, the administrative and technical aspects of care get prioritised above the nurturing relationship. Given that the patients in my study revealed that they appreciated good experiences over time, it may be time to rethink the importance placed on some of the cancer waiting time targets.

### 7.2.3 Communication around how the targets work and patient autonomy

My work offers a unique perspective from patients of their knowledge of the target system. Trusts need to work with GPs to ensure that they are fulfilling their obligations, properly educating the patients about the reasons for their referral. Patients need to appreciate the importance of attending not just their first appointment within 14 days but any following investigations in a timely manner.

The patients in my study were generally unaware of the targets system and certainly the specific timing associated with each target. MacMillan, paraphrasing the NICE guidelines (2015), recommends that GPs ensure patients have appropriate and understandable information about their upcoming appointments, including “why they have been referred, what it means and what they have to do” (Macmillan 2016, p8). A recent study by Jefferson et al. (2019) discussed the use of a patient leaflet to encourage attendance at two-week wait appointments but found that only some GPs used it. Their findings mirror my own: the GP has a difficult balance of instilling a sense of urgency in the patient so that they make themselves available for further investigations, without increasing any anxiety they may already feel about their illness and the potential for it to be something serious. There was frequent frustration at patients who disrupt their own pathways by cancelling appointments or simply not turning up for them. If patients understand the timed pathway and the events in it, they can decide for themselves if they wish to proceed. Patients are not forced to attend and frequently choose not to, much to the frustration of staff trying to schedule their care.<sup>16</sup> The guidelines that accompany the cancer waiting times do allow patients to “remove themselves from the pathway”, although it does not specify the circumstances under which patients may be assumed to have done so. It is left up to a Trust’s discretion to develop an access policy that fairly takes into account patient wishes whilst at the same time encourages attendance at these important appointments (NHS 2020).

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<sup>16</sup> It is difficult to determine exact numbers, as these data are not routinely collected for cancer referrals. However, for general hospital referral from GPs in the period Jan-Mar 2020 (the latest available at time of writing), 1% of total referrals did not attend their first appointment and a further 9% went on to fail to attend subsequent appointments. (NHS England, 2021b)

Better communication with patients was regarded as a way to get patients more engaged in their care and less likely to cancel appointments. There was considerable discussion around what patients need to know about the target system. There was consensus among my participants that preparing patients to manage their expectations around how long they would have to wait and as a tool to provide reassurance about what to expect was a good idea. However, it was the specifics around the timings measured by the targets that some people doubted the value of sharing. McPherson et al. (2001) discussed in detail and with no real solution what information patients should be given about their disease as everyone processes a cancer diagnosis differently. Further research could investigate methods of encouraging patients to attend and subsequently comply with the timings of the targets.

It is important that patients retain agency over their care. A balance needs to be struck between the target system, which emphasises the need for patients to be fast-tracked through specific timed pathways and the NHS ethos of empowered patients who choose what happens to them, where and when. The NHS Improvement Plan (DoH 2004) describes “a personal health service for every patient”, which seems to contradict standardised pathways with patients encouraged to comply with dictated timings. Williamson (2015) linked changes associated with managerialism, evidence based medicine and performance management with a reduction in freedom of choice for patients. While my managers expressed frustration when patients cancelled appointments, there is also concern from Joan who felt that patients could be pushed too quickly and Richard who was not ready for his surgery.

Trusts need to be able to assure patients that their services are designed with the patients at their heart, rather than around the requirements of the targets, but equally explain how the targets provide a framework for the provision of timely care, giving them explicit expectations about how their pathway is going to progress.

### **7.3 How do clinicians think the targets affect their clinical practice?**

Conversations with clinicians were centred around the research question, *how do clinicians think the targets affect their clinical practice?* The main theme that emerged in discussions with clinicians around the cancer waiting times targets was that they felt they were not clinically led or clinically meaningful. This led to them seeing patients in their cancer clinics who had been inappropriately referred, but more importantly, as the targets are not tumour specific, this was seen as undermining their clinical worth. The standardisation of the targets, which means that almost all cancer

types are subject to the same timings, does not account for complexities in diagnostic pathways or tumour biology, which results in some cancers growing and spreading faster than others. While a standardised target is obviously easier to administer, especially desirable in a system already considered to be overly bureaucratic, both clinicians and managers have concerns about the implications for patient care if they continue to be monitored in this way.

Similar arguments were presented in 2010 when the cancer targets were reviewed by the Department of Health to determine if they were still fit for purpose. The review asked the question, should specific cancer types be excluded from the standards? Although finding that some cancers were more clinically urgent than others and that some pathways were more complex than others, ultimately, the outcome was to retain all the targets in their current form. Other research that raises similar ramifications of monitoring the majority of tumour sites against the same target includes Ip et al. (2012), who found that it would be fairer and more effective to have smarter targets that focused on the performance of individual tumours. It is clear that this aspect of the target system has led to several problems in the management of cancer services, which were highlighted by my study participants but have also been recognised in the literature as a national problem (Seddon 2005, Hunter 2008, Gubb 2007). Slade and Talbot (2007) found that it would be necessary to move away from standardised targets if clinical engagement was to be maximised. Clinical engagement is an important pre-requisite to enable the effective implementation of targeted services.

When previous reviews of the cancer waiting times standards have been undertaken (DoH 2011), the targets were being consistently met at a national level. It could be argued that this contributed to the decision not to amend them. However, following a further review in 2019 and a consultation that included both managers and clinicians (DoH 2019a), new guidelines have been published. These recent amendments came into effect in July 2020 following five years at least when the primary target of 62 days has been repeatedly failed. The changes made should have a positive impact on the performance of most Trusts and, although not addressing all the longstanding concerns about the clinical appropriateness of the targets, there were several key alterations around how prostate and bladder patients are monitored (while other tumours continue to be monitored in a standardised way) (NHS 2020).

### **7.3.1 Targets as a threat to clinical autonomy**

My study offers a new perspective on the role of targets in the deprofessionalisation of clinicians. The clinicians I spoke to were not threatened by the targets and did not

feel that they dictated their clinical practices to a detrimental extent. They were aware of the expectations that targets placed upon their activities. Tracy described pressure to meet targets from management, and Theresa mentions fighting management over when to see patients. Despite this, relations between clinicians and managers had not been eroded. Rather, they implied that their interactions with management were generally positive (with jokes in one case about how the managers help circumvent the targets if necessary) and, when appropriate, they felt free to ignore the targets in favour of their sense of appropriate patient care.

This seems very different from the picture painted in the literature of a power struggle between resentful doctors who felt deskilled by the increasing bureaucratic processes and managers who embody all the negative aspects of performance management (Edwards 2003; McCann 2015). The strained relationship between hospital teams and management was a common theme (Clarke and Newman 2006; Bevan and Hood 2006; Payne 2006; Smith 2009).

However, clinicians in my study discuss how they have found strategies to negotiate the protocols and target systems of care, using a combination of implicit knowledge learnt over time and guidelines to dictate their actions. Similar to Greenhalgh and Papoutsis (2018), who found there to be a mismatch between the “patient in the guideline” and the “patient in the bed”, clinicians often follow their own instincts honed through experience when it comes to planning a patient’s care (Gabbay and le May 2004). This avoids the situation described by Freidson (2012, p 212) whereby professionals become “merely technical experts” without the autonomy to make their own decisions about patient care.

Furthermore, the participants in my study illustrate the evolution of the clinical profession, as several were “hybrid” managers (Scambler 2003) who have a clinical background but now hold positions in management. Elsewhere in my study, managers explain the importance of having co-operation of the clinical teams when operationalising the targets. The reactions of clinicians to targets have implications for policy makers going forward if new targets are going to be successfully implemented.

#### **7.4 What impact do managers feel the targets have on service provision?**

My study also explored the question, *what impact do managers feel the targets have on service provision?* As a group, managers are a relatively untapped resource in

research around the cancer waiting times. From the unique position of trying to operationalise targets in the daily running of their Trusts, their opinions revealed both positive and negative aspects of the target system. Having established that the managers felt the targets were necessary, I discussed the issue of how targets can provide a focus for both an organisation and individual staff. Despite the problems that the targets cause for the managers when running their services, they still felt that they were necessary. My participants identified several features familiar from the literature, including how targets necessitate more bureaucracy and resources and can distort priorities. Still, they did not find them a sufficient deterrent to suggest abandoning the targets because of them as generally they ensure patients receive a timely service.

The managers explain how the targets provide a valuable focus for organisations, similar to Smith's (2009) ideas about targets used in other areas of health care. However, my findings went further with managers explaining how the targets also focus the work of individual staff when developing services.

Seddon (2005) argues the opposite, namely, that targets in healthcare remove people's sense of purpose. While clinical teams devote their work to ensuring patient care is a priority, it can be difficult for managers to view their work the same way. Rather than de-personalising a patient's care, I found that the targets can help managers and administrators to empathise with individuals, comparing them to family members and ensuring their care occurs in a timely manner. These ideas around quantifying organisational goals and targets providing motivation for managers are fundamental to the origins of targets and one of the reasons that charities and patient groups champion them (Locke and Latham 1990; Verbeeten 2008). While others also feel that this focus is not necessarily a good thing, leading to organisations focussing on arbitrary waiting times or on part of the pathway at the expense of another (Gubb 2007; Bevan and Gubb 2009; Smith 2009), for the managers, the targets may have caused frustrations, but they did put a spotlight on cancer patients. They felt that the targets led to the adoption of best practice and new ideas and resulted in pathways of care that were dynamic and provided up-to-date care with organisations constantly trying to deliver more efficient care. This is an important lesson for policy makers, that those responsible for implementing the targets believe they are making a difference for cancer patients.

One area that managers were particularly concerned about was the lack of resources available to them to run services that would comply with the demands of the targets.

While some blamed the targets for these shortages, others recognised that the existence of the targets merely highlighted areas of concern. This is especially true in the workforce, which nationally needs urgent attention and potentially, without this spotlight being placed upon them, could have continued unnoticed with waiting times increasing to compensate for shortages. It is perhaps a missed opportunity that this was mostly viewed in a negative light, rather than as a means to request more resources at Trust, CCG and national level. While the managers mentioned how they used the targets as a lever to encourage certain behaviours from their clinicians locally, there was no discussion about Trusts using the need to meet targets to demand additional resources. For those who have to implement them, targets might become more palatable if they came with an implementation package to ease pressure on a Trust's resources. The regional Cancer Alliances get funding to support the improvement of performance against the targets, but the lack of discussion of this indicates that its impact is not always felt to be significant at a local level. There was particular concern around the monitoring and implementation of the new 28-day faster diagnosis standard, which was felt by all to be a timely addition to the targets, but resource shortages could cause difficulties come implementation.

Where the use of targets could be seen to benefit patients, they were lauded, but as a tool for monitoring Trust's performance, they were not as well-received by the managers in my study, a view that was previously undocumented. The target system was not viewed by the managers as the best means of demonstrating the quality of a Trust's service. As the targets only measure waiting times, the Trusts fall into the trap described by Ritzer (2004), whereby they are not judged by how well they deal with complex cases; rather, they are assessed on how many standard cases they can get through the system in a set timescale. In addition, it was felt by managers in this study that the targets were outdated, given changes in pathways due to increasingly complicated investigations and patients' more challenging medical needs, resulting in difficulties hitting the 62-day target.

A common assumption in the literature is that managers would be tempted to 'game' the system in order to rectify their poor performance (Seddon 2005; Bevan and Hood 2006; Hunter 2008). This was validated with the publication of the Francis Inquiry into the failings in the care at Mid Staffordshire NHS Trust. The report published in 2013 found that some junior administrative staff in cancer services were so worried about their managers' response to failing the cancer targets that they amended data to hide the problem (Francis 2013). Staff fabricating or being misleading with data to

make performance appear better than it actually is is just one way identified that targets could be 'cheated' (Bevan, 2006). Participants in Hood's (2006) study consider this as acceptable gaming (separate from outright falsification, which is unacceptable). It is also described more kindly as "creative compliance" (Commission for Health Improvement, 2003) or as an example of "street level bureaucracy" where the managers develop a means of working around the targets (McCann et al. 2015). There is a tension between introducing new targets and increasing the bureaucracy and administrative teams to report information. The more bureaucratic the processes become, the less Trusts are encouraged to accurately record and report.

However, the idea of adjusting the figures in their favour is dismissed by all I spoke to, and as one participant points out, it would make her life much easier if her Trust passed all its targets as there would be a lot less paperwork to complete. Managers considered the possibility that gaming might go on by GPs or in other Trusts but not in their own. The level of concern around this topic from my participants, including a comment from one that it might not be possible to meet the targets at all in their current form (in addition to the published data showing that all the local trusts, like most, are struggling to consistently meet their targets), gives credence to their claims that they are not fraudulently submitting data.

Further frustrations were voiced by both clinicians and managers around the two-tier system that the targets create, with some patients subject to their timings and others not, depending on how they present. By avoiding the scrutiny placed on patients subject to targets, patients may have to wait much longer for their treatment. Another area where the system was seen in a negative light was the impact of the cancer targets on relationships across organisations. Rather than the competing demands of targets versus patient care (McCann 2015), the source of conflict was between managerial colleagues across Trusts where patient care was shared. This new finding illustrates how the targets have created a system that encourages debates over the transfer of care of patients, which as a consequence places strain on collegial working and can actually slow down the patient's journey. More patients on shared pathways breach, which reflects the difficulty in co-ordinating care between providers. The more Trusts are having difficulties meeting targets; the more animosity is generated between Trusts passing patients between them. Participants working at tertiary centres were particularly disgruntled when patients came to them late in their pathways, giving them little notice to arrange care on time. This abated slightly with the 2018 amendment to cancer waiting times guidance which enables them to

reallocate the breach back to the referring provider based on the date of transfer of care. However, subsequently, this led to discontent with the secondary referring trusts, who could not agree on transfer dates with tertiary care.

Previous research has concentrated on the clinical implications of the targets for patients or how they impact on patient experience, not the challenges to the operational teams who have to make the targets work. Whereas in separate works Seddon, (2005), Hunter, (2006), and Bevan and Gubb, (2009), amongst others, criticise the use of targets, my interviews contextualise these ideas so that it is possible to differentiate between failings of targets and potential problems in their application. For example, targets cannot cover all patients or scenarios, which is a failing of the system which impacts all Trusts, as opposed to their fallibility if they are misreported, which would be down to individual application.

### **7.5 Limitations of the study**

The primary strength of the study is that it is the first study that explores how patients, managers and clinicians experience the cancer targets. The rich data that has been produced illustrates the problem from three contrasting perspectives in an attempt to gain as complete a picture as possible. The participants in the clinician and manager groups came from a wide range of Trusts, experiences and job roles, while the patient sample included people who were treated at four different Trusts and covering a variety of cancer types. Evidence from patient voices was lacking in previous research with regards to their experience of the cancer targets, and although there was ample criticism of how managers dealt with performance indicators in health care, there was little from the managers themselves. My study fills an important gap in the literature, highlighting the priorities that each group interviewed has in regard to the cancer waiting time targets. My study uses verbatim quotes from my participants, which illustrates the link between my interpretation and the original data, and overall validity is improved by comparisons between more than one data source and the thematic analysis involved coding until data saturation occurred and no new themes were identified.

However, there were a number of limitations with this study. The setting was based on the experience of the targets in the English NHS. Waiting times targets exist as performance indicators across the whole of the United Kingdom, but they are all measured in a slightly different way. Although I am confident that the responses from my participants are transferrable to a wider area outside of Merseyside and Cheshire,

fundamental differences in how the target systems work in Wales, Scotland and Ireland means that my results may not apply outside of England. Further research should address the differences in the systems across borders.

Although the sample produced relevant data to enable the identification of key themes, arguably, the patient sample could have been more diverse. Research by McGrath-Lone et al. (2015) recognises that certain groups are underrepresented in cancer research, and this group was the hardest to recruit as it was important to consider if taking part would cause distress. Additionally, my sample of participants may have influenced these results. As patients who have recovered from cancer, their perspective on the length of time to treatment may differ from that of a terminally ill person. However, further research could address these gaps by approaching patients with other cancer types or different prognoses

## **7.6 Wider implications**

The NHS is a dynamic and ever-changing landscape, and within it, the target rules are under continuous review. Since beginning this piece of research, several developments have occurred with regards to the cancer waiting times targets. The commencement of a new period of the pathway to be measured in the 28-day standard was one of the most significant, and the intention to introduce it was announced in time for me to amend my interview questions to include the initial impressions of my participants had about it. The 28-day target measures the time between GP referral and the patient being informed of their diagnosis. This will address some of the concerns of achieving a faster diagnosis and was initially intended to replace the two-week wait target. It will also benefit patients who do not have cancer, who currently may wait a considerable time to be told of a benign diagnosis.

Subsequently, after several different rumours and proposals around amended various aspects of how the traditional 62-day target works, the new rules (so-called “version11”) came into effect in July 2020 (slightly delayed from their initial start date of April 2020, due in part to COVID-19) (NHS 2020). The amendments to the guidelines saw changes to how the targets are measured in some cases (primarily around prostate and bladder cancers, altering the clock stop points in these cancers’ pathways). These seek to appease both the clinical and managerial teams and address some of the issues that have been identified in my study. Future research could be undertaken to assess the success of these changes, especially if they resulted in more engagement with the targets by clinicians.

### 7.6.1 Cancer Services provision during the Covid-19 pandemic

Performance compliance is important to management teams because it is an indication that services are running smoothly and the patients in their care are passing through the system in an efficient manner. It is clear that the cancer waiting times influence daily practices within the cancer services departments and cancer clinics in Trusts. The maintenance of the cancer waiting times during the COVID-19 pandemic has kept Trusts' focus on cancer.

However, current cancer services provision has, like most non-virus-related activity, been severely impacted by COVID-19 and the pressure the pandemic has placed on health care services. As previously mentioned, concerned patients unable to attend their GP surgeries or too worried to come into hospitals on account of possibly catching the virus resulted in a dramatic reduction in urgent suspected cancer referrals into Trusts. Furthermore, several things resulted in changes to the usual processes in secondary care, including controversial instructions from the Department of Health at the outset of the first wave around prioritising access to certain cancer treatments (NHS 2020b)<sup>17</sup> and an inability for surgeons to be able to access theatres due to them having been repurposed as intensive care wards.

Although much has been made of cancer diagnoses being missed and treatments cancelled (Cancer Research 2021; Macmillan 2021), for many Trusts, cancer services departments have continued to monitor patients and endeavour to ensure they receive a swift diagnosis and treatment. In Cheshire and Merseyside, many Trusts chose to severely reduce the services offered and, in some cases, cease their provision altogether. Actions like this have led to the NHS being accused by some of delaying diagnoses and vital treatments, which could lead to anywhere between 3,300 and 60,000 excess deaths (Maringe et al. 2020). Just as services were being restored in early Autumn, the country and especially the North West experienced a severe increase in COVID-19 cases, and Trusts had to reconsider how to deal with their cancer cases during a second wave. The data around these delayed patients has come under intense scrutiny, especially the so-called 'harm reviews, which have always been undertaken for all patients whose wait exceeds 104 days. Harm reviews

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<sup>17</sup> NHS, March 2020, Extract from *Clinical guide for the management of cancer patients during the coronavirus pandemic*, p.5, "It is suggested that clinicians begin to categorise patients into priority groups 1-6. If services are disrupted, patients can be prioritised for treatment accordingly."

ascertain if the patients' delay starting treatment has had a negative impact on their health. Although currently only recorded at a local level, this data, if collated, could provide a vital contribution to the debate around how the targets improve patients' longevity. With respect to COVID-19, Trusts across Merseyside and Cheshire have been advised not to restrict access to diagnostics and treatments for cancer patients as far as possible. Even if cases of COVID-19 once again fall, leaving services able to resume, increased hygiene precautions reduce the number of patients able to be seen, diagnosed and treated. Patients can no longer sit in waiting rooms, and diagnostic and treatment areas have to be deep cleaned between each patient, while clinicians don even more protective clothing than usual. Recent guidance on recovery of services post-pandemic requires Trusts to be working towards compliance with the cancer waiting times standard by March 2022 (NHS 2021a). Research has already begun into several aspects of the impact of COVID-19 on the detection and management of cancer (Morris et al. 2021). However, the role that the targets played in the maintenance and recovery of cancer services during the pandemic will provide a rich source of data for future researchers.

## **7.7 Conclusion**

Since the introduction of the cancer waiting times targets in England, it is generally accepted that waiting times for patients have been reduced. Optimal pathways of care have led to increased standardisation and reduced the postcode lottery previously found to be affecting the care on offer. However, improved outcomes are more difficult to assess.

This study recruited managers, clinicians and patients to discuss their experience of the cancer waiting times targets. The research questions were as follows:

1. How do clinicians think the targets affect their clinical practice?
2. What impact do managers feel the targets have on service provision?
3. What are patients' views on the cancer targets and their impact on their journey through care?

Each group has explained how their experience of the receipt or provision of cancer services has been impacted upon by the existence of the targets. The study addresses a gap in the literature by capturing patient views and experiences of targets, as well as synthesising and contrasting the different perspectives of my participants on how the targets work.

For patients, the existence of targets shapes patient experiences, even with patients being unaware of them, and they explained how speed should not replace well communicated and planned cancer care.

Clinicians demonstrated how patient care was their top priority, and targets did not interfere with their ability to strive to provide top quality care. Managers were frustrated by the limitations that the targets place on how they provide their services but also acknowledged the benefits they clearly bring to patient care. When asked if the targets are the best way of monitoring cancer care in England, participants felt that the system was far from perfect, but no alternatives were suggested. The latest review of the system (at the time of writing) may have re-vamped how the targets work, but due to the COVID-19 pandemic, responses to the new guidelines have been muted. It remains to be seen how the new guidelines will be received and what impact they will have on the design of cancer services and clinical practice in the future.

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## **Appendix 1: Interview Schedule**

- The interviewees will have had the consent form and information sheet.
- General introduction
- Easy background/ warm-up question to relax interviewee to start
- Questions, topics to cover, probes for more information
- Adapt if necessary after several interviews

### **Patients**

My name is Heather Wright, and I am the data and performance manager at Southport & Ormskirk NHS Trust. I'm undertaking some research about the national cancer targets for my doctoral thesis.

I would like to ask you some questions about when you were diagnosed with cancer to find out how you feel about your experience. I hope that by understanding the process from your point of view, I will be able to assess how well the system is working and what changes could be made to make it better for patients in the future.

The interview should take about 30 minutes. Are you okay for it to be taped? I want to remind you that your responses are confidential and will not be shared with the clinical team who are looking after you. You should feel that you can be honest about your experiences without any concern that it will affect any future treatment you may need. We can stop at any time if you become uncomfortable.

1. Tell me how you came to be diagnosed.
2. Can you tell me more about how long you waited for each step – between tests, appointments?
3. Did you have any of your tests or appointment rescheduled at short notice? Was this a good thing, or did it worry you?
4. My research is about the cancer targets that set out how long you should wait for a different part of your care. Do you know about these targets?
5. Do you think these targets are a good idea?
6. Did your GP tell you that you might have cancer when he referred you into the hospital?
7. Did you cancel any appointments during your care? Why?

8. In 2020, a new target is being introduced, which means everyone should have a diagnosis within a month of seeing their GP. What are your thoughts about this?
9. Can you think of any time when you may not want to have your care quickly?

### **Managers**

My name is Heather Wright, and I am the data and performance manager at Southport & Ormskirk NHS Trust. I'm undertaking some research about the national cancer targets for my doctoral thesis.

I'm interested in your thoughts about the targets and how you feel they influence your service and patient care. I'm interested in your thoughts about how well they work and what if any improvements could be made to either how we deliver the targets or the targets themselves.

The interview should take about 30 minutes. Are you okay for it to be taped? We can stop at any time if you become uncomfortable.

1. Tell me about your job role in cancer services
2. What benefits do you feel the targets bring to the patients?
3. Can you think of any examples where the targets did not improve things?
4. And any specific examples where they did make a difference?
5. Do the targets help to drive service improvement?
6. Do you find patients frequently chose to breach their targets? Do you think this is because they don't know about them? Should suspensions for patient choice be reintroduced?
7. How do you ensure that all patients' waiting times are monitored, given that not all are measured against all the targets?
8. Are the performance thresholds realistic?
9. Should specific cancer types be excluded?
10. How have the cancer targets impacted on the organisation of cancer services?
11. What impact is the introduction of the 28-day target going to have?

## **Clinicians**

My name is Heather Wright, and I am the data and performance manager at Southport & Ormskirk NHS Trust. I'm undertaking some research about the national cancer targets for my doctoral thesis.

I'm interested in your thoughts about the targets and how you feel they may influence or interfere with your clinical practice and patient care. I'm interested in your thoughts about how well they work and what if any improvements could be made to either how we deliver the targets or the targets themselves.

The interview should take about 30 minutes. Are you okay for it to be taped? We can stop at any time if you become uncomfortable.

1. Can you tell me about what work you do with cancer patients?
2. How do you feel about the cancer targets?
3. Are you aware that patients are on a target pathway when you see them?
4. Does it influence how they are treated?
5. Do you feel pressure from management to meet targets/change practice,/reprioritise patients?
6. Are you confident that you know how all the different cancer targets work?
7. Do you feel the Trust expects you to prioritise targets over patient care?
8. How do the targets help the patients?
9. Are the targets clinically justified?
10. Is it reasonable to have the same targets for all cancers?
11. Do you think the patients appreciate that the targets are helping them?
12. What improvements do you think could be made to the target system?
13. Has the need to meet targets resulted in any improvements in the service provided?

## **Appendix 2: Participant Information Sheet: Patients**

**Research project:** What are the experiences of English NHS managers, clinicians, and patients of the National Cancer Waiting Times targets?

### **Participant Information Sheet (Patients)**

**Chief investigator:** Heather Wright

You are being invited to take part in a doctoral research study that has been approved by the National Research Ethics Committee. This information sheet outlines the purpose of the research project and provides a description of your involvement and rights as a participant.

**Some questions you may have for me:**

#### **What and who is being researched?**

I am interested in finding out what you know about the National Cancer Waiting Times Targets. These specify that you are entitled to receive your cancer care within set timescales to ensure that you have a quick, efficient and effective pathway through your cancer journey. You may feel that your diagnosis and treatment could not have been any quicker, and the fact that the hospitals are monitored against these targets hugely benefited you. Alternatively, you may not have realised that they even exist or feel you waited too long. There are no right or wrong answers!

As part of the research, I will also be talking to the doctors who manage cancer patients care and the managers who organise it to see what they think about the targets.

#### **Who are you, and why are you doing this research?**

I am an experienced NHS Manager working in Cancer Services. This research is being undertaken as part of my doctoral thesis project. The aim is to produce practical research which results in positive improvements in my workplace and potentially other NHS hospitals.

#### **Why have I been chosen to take part?**

You have been chosen to take part because you have recently received a diagnosis of cancer in a local hospital. I am interested in finding out how the cancer targets have affected your journey as a cancer patient. I believe you can help me by telling me what you know about them and how you think they may have improved or changed

the care you received. This knowledge will be used to inform discussion about how services can be redesigned to make things better for patients in the future.

### **Do I have to take part?**

Your participation in this research is entirely voluntary, and you do not need to decide today whether or not you will participate in the research. The choice you make will have no bearing on any future care or treatment you may need to receive.

### **How are you doing the research?**

If you agree to take part, I would like you to agree to be interviewed, which would be audiotaped with myself. We will meet here at the support group / next health and wellbeing event. The interview will last for no longer than an hour and will only need to take place once.

### **Are there any disadvantages to taking part?**

Talking about your cancer diagnosis can be difficult. It is very important that no one experiences any distress as a result of taking part in this research. If you do not wish to answer any of the questions during the interview, you may say so, and we will move onto the next question. You will be asked to share your thoughts on your journey through the health care system, and if you think this may upset you, you can stop at any time.

If you have been affected by any part of the discussion, there will be a cancer nurse specialist available to talk to you about your experience. If you feel upset after you leave the interview, you will be given a contact number to ring to arrange further clinical input.

### **What will happen to the information?**

The information recorded is confidential. It will be transcribed for analysis purposes after the interview, but no one else will have access to the information documented during your interview. The results will be written up into a thesis, and although quotes from the interviews may be used, they will be fully anonymised, and no one will be able to identify the source of the information. Each participant will be given a summary of the results, with the option of receiving a copy of the completed thesis if they wish.

The study has been reviewed by the Hampshire A Research Ethics Committee.

Southport & Ormskirk NHS Trust is the sponsor for this study based in England. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Southport & Ormskirk NHS Trust will keep identifiable information about you for five years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information by contacting Heather Wright on 01704 704788 or at [heatherwright2@nhs.net](mailto:heatherwright2@nhs.net)

### **Appendix 3: Participant Information Sheet – Staff**

**Research project:** What are the experiences of English NHS managers, clinicians, and patients of the National Cancer Waiting Times targets?

#### **Participant Information Sheet (Staff)**

**Chief investigator:** Heather Wright

You are being invited to take part in a doctoral research study that has been approved by the National Research Ethics Committee. This information sheet outlines the purpose of the research project and provides a description of your involvement and rights as a participant.

**Some questions you may have for me:**

#### **What and who is being researched?**

I am interested in finding out what you know about the National Cancer Waiting Times Targets. These specify that patients are entitled to receive their cancer care within set timescales to ensure that they have a quick, efficient and effective pathway through their cancer journey. You may feel that patients' diagnosis and treatment could not be and do not need to be any quicker, and the fact that the hospitals are monitored against these targets hugely disrupt your working practice. You may feel that they are an effective way of ensuring patients get the best possible care in the shortest timescales. There are no right or wrong answers!

As part of the research, I will also be talking to the patients who have been managed on these pathways to see what they think about the targets.

#### **Who are you, and why are you doing this research?**

I am an experienced NHS Manager working in Cancer Services. This research is being undertaken as part of my doctoral thesis project. The aim is to produce practical research which results in positive improvements in my workplace and potentially other NHS hospitals.

#### **Why have I been chosen to take part?**

You have been chosen to take part because you are known to work in a speciality which deals with the cancer targets on a daily basis, and I am interested in how you feel this affects the service you provide to all patients, not just the ones with cancer. I believe you can help me by telling me what you know about them and how you think they may have improved or changed the care you give. This knowledge will be used

to inform discussion about how services can be redesigned to make things better for everyone in the future.

### **Do I have to take part?**

Your participation in this research is entirely voluntary, and you do not need to decide today whether or not you will participate in the research.

### **How are you doing the research?**

If you agree to take part, I would like you to agree to be interviewed, which would be audiotaped with me. We will meet in your office or another location in your Trust at a time that is convenient to you.

### **What if I am worried about any aspect of the research?**

If you do not wish to answer any of the questions during the interview, you may say so, and we will move on to the next question. You can stop the interview at any time.

### **What will happen to the information?**

The information recorded is confidential. It will be transcribed for analysis purposes after the interview, but no one else will have access to the information documented during your interview. The results will be written up into a thesis, and although quotes from the interviews may be used, they will be fully anonymised, and no one will be able to identify the source of the information. Each participant will be given a summary of the results, with the option of receiving a copy of the completed thesis if they wish.

This study has been reviewed by the Hampshire A Research Ethics Committee.

Southport & Ormskirk NHS Trust is the sponsor for this study based in England. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Southport & Ormskirk NHS Trust will keep identifiable information about you for five years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information by contacting Heather Wright on 01704 704788 or at [heatherwright2@nhs.net](mailto:heatherwright2@nhs.net)

#### Appendix 4: Consent form

Research project: What are the experiences of English NHS managers, clinicians, and patients of the National Cancer Waiting Times targets?

#### Participant Interview Consent Form

Chief investigator: Heather Wright

Participant id number \_\_\_\_\_

Please initial boxes

1. I confirm that I have read and understood the information sheet date 01 September, (version 1) about this research project. I have had the opportunity to ask questions, and these have been answered satisfactorily.
2. I understand that my participation in an interview is voluntary and I am free to withdraw at any time without giving a reason.
3. I agree to the interview being audio-recorded, transcribed and both the recordings and transcription will be securely stored in accordance with the Data Protection Act 1998.
4. I understand that I will not be identified in any way in the analysis and reporting of results. I understand that even if I withdraw from the study, information already collected about me may be included in the final study analysis after being anonymised.
5. I understand that everything I say will be treated confidentially and only used for research purposes, in accordance with the General Data Protection Regulation.
6. I agree that quotes from the interview can be used anonymously in any publication of the research findings.
7. I agree to take part in the research study.

Name of participant: \_\_\_\_\_ Date: \_\_\_\_\_ Signature \_\_\_\_\_

Name of researcher: \_\_\_\_\_ Date: \_\_\_\_\_ Signature \_\_\_\_\_

1 copy for participant; 1 copy for  
researcher

## Appendix 5: Study participants

<p><b>Patients</b>  Mark  Trevor  Henry  Barbara  Janet  Stephen  David  Richard  Maurice</p>	Prostate cancer/ Skin Cancer Bowel cancer Prostate cancer Bowel cancer Lung cancer/ Gynaecology cancer Prostate cancer Prostate cancer Prostate cancer Prostate cancer
<p><b>Clinicians</b>  Alexander  Mike  Liz  Lyn  Andrew  Tracy  Theresa  Julie  Angela</p>	Surgeon Physician Clinical Nurse Specialist Clinical Nurse Specialist Surgeon Surgeon Clinical Nurse Specialist Clinical Nurse Specialist Clinical Nurse Specialist
<p><b>Managers</b>  Frances  Yvonne  Joan  Emma  Rebecca  Cathy  Mary  Judith  Molly</p>	Lead Cancer Nurse/ Cancer Manager Cancer Manager, Acute Trust Cancer Manager, Acute Trust Cancer Improvement Project Manager Cancer Lead CCG Lead Cancer Nurse/ Cancer Manager Cancer Manager, Acute Trust Cancer Manager, Tertiary Centre Cancer Lead CCG

## Appendix 6: Terminology and Abbreviations

This list is by no means exhaustive but attempts to explain the most important examples.

CNS	Clinical or Cancer Nurse Specialist
CWT	Cancer Waiting Times
RCA	Root Cause Analysis – an in-depth investigation into why a patient breached
PTL	Patient Tracking List – a list of all the current patients in the system
TCI	To Come In
DNA	Did Not Attend
CT Scan	Computerized tomography – produce detailed images of inside the body
CCG	Clinical Commissioning Group – NHS bodies which commission primary and some secondary care services.
Scrogged	Local slang referring to a very poorly patient who is unlikely to survive
Red flag symptom	Symptoms identified by NICE as possibly indicating the presence of cancer. Patients with these symptoms should be referred on a TWW referral
TWW	Two week wait, also called 14 day or 2-week wait
Band 2s	Staff are banded (and paid) according to several factors including whether they have to talk to patients about difficult topics. 2 is the lowest band.
RTT	Referral to Treatment – a term used to describe routine patients on an 18-week pathway (i.e. not on a suspected cancer pathway)
Tumour site	Cancers tend to be treated based on their location in the body. This refers to the site of the main tumour, e.g. breast, or lung. A patient with a primary cancer in their lung may be referred to as a lung patient, under the lung team.
EBUS	Endobronchial ultrasound – a diagnostic test for lung cancer
PET	Positronic Emission Tomography - An imaging test that uses radiotracers to identify potential areas of cancerous activity in the body.