NATASHA L. ELMORE, DANIELA RODRIGUEZ-RINCON, CATHERINE A. LICHTEN, ADAM BERTSCHER, JON SUSSEX

# Decision-making for investment in early diagnosis interventions for cancer

An interview-based study for Cancer Research UK

For more information on this publication, visit www.rand.org/t/RR4362

Published by the RAND Corporation, Santa Monica, Calif., and Cambridge, UK

© Copyright 2020 RAND Corporation

**RAND**® is a registered trademark.

RAND Europe is a not-for-profit organisation whose mission is to help improve policy and decision making through research and analysis. RAND's publications do not necessarily reflect the opinions of its research clients and sponsors.

## Limited Print and Electronic Distribution Rights

This document and trademark(s) contained herein are protected by law. This representation of RAND intellectual property is provided for noncommercial use only. Unauthorized posting of this publication online is prohibited. Permission is given to duplicate this document for personal use only, as long as it is unaltered and complete. Permission is required from RAND to reproduce, or reuse in another form, any of its research documents for commercial use. For information on reprint and linking permissions, please visit www.rand.org/pubs/permissions.

### Support RAND
Make a tax-deductible charitable contribution at
www.rand.org/giving/contribute

www.rand.org
www.rand.org/randeurope

# Preface

This report written for Cancer Research UK's Policy and Information Directorate presents an overview of findings about how decisions are made about investments in early diagnosis interventions for cancer in the National Health Service (NHS) in England and Health and Social Care (HSC) in Northern Ireland. The study consisted of interviews with stakeholders in England and Northern Ireland and a workshop with representatives of Cancer Research UK. The study was conducted between April and November 2019.

In this report, we introduce the context for early cancer diagnosis decisions in England and Northern Ireland (Chapter 1); present an overview of the methods used (Chapter 2); describe findings for England (Chapters 3 and 4) and Northern Ireland (Chapter 5); and reflect on what can be concluded from those findings, with a focus on implications for Cancer Research UK's activities (Chapter 6).

RAND Europe is a not-for-profit policy research organisation that helps to improve policy- and decision-making in the public interest through research and analysis. RAND Europe's clients include European governments, institutions, Non-Governmental Organisations and firms with a need for rigorous, independent, multidisciplinary analysis. This document has been peer reviewed in accordance with RAND Europe's quality assurance standards.

For more information about RAND Europe or this document, please contact:

Jon Sussex
RAND Europe
Westbrook Centre
Milton Road
Cambridge CB4 1YG
United Kingdom
Tel. +44 (1223) 353 329
jsussex@randeurope.org

# Summary

Cancer survival is lower and mortality rates are higher in the United Kingdom (UK) than in some other high-income countries. An important way to improve cancer survival in the UK is to increase the proportion of cases that are diagnosed early, as patients diagnosed at stages I and II have the best chance of successful treatment and long-term survival. In March 2019, Cancer Research UK awarded a grant to RAND Europe to undertake a piece of research with the purpose of helping Cancer Research UK's Early Diagnosis programme to better understand how commissioners of healthcare services and Cancer Alliances make decisions about early diagnosis interventions at a local level, with a particular focus on England and Northern Ireland. In 2019, the decision-making landscape in England was shaped by the new NHS Long Term Plan and the Implementation Framework that goes with it; meanwhile in Northern Ireland a new cancer strategy was under active development (Department of Health NI 2019a).

Cancer Alliances were introduced by NHS England to improve the diagnosis and treatment and care of cancer patients. Improving early diagnosis and reducing the burden of late-stage disease are crucially important for improving cancer survival. Cancer Alliances operate by bringing together a range of clinicians and managers who work together to identify need at a local level, and transform care through a number of transformation projects. There are 20 Cancer Alliances in England in total, although at the time of conducting this research there were 19 in existence, each holding responsibility for transformation of cancer services in their 'patch' (NHS England 2018).

In this study, we gathered evidence through more than 30 interviews with stakeholders at Cancer Alliances and national bodies in England, and from six interviewees from national bodies and at local level in Northern Ireland. Three sets of interviews were conducted: two sets with stakeholders in England –before and after the publication of the NHS Long Term Plan Implementation Framework in late June 2019 – and one set with stakeholders in Northern Ireland in the autumn of 2019.

The main findings in England were that:

- Many investments in early diagnosis are in effect centrally prioritised. The national priorities are supported locally. There are differing views about the extent of local discretion to invest in interventions other than those that are in line with the national priorities.

- The Long Term Plan Implementation Framework was largely well received by Cancer Alliances, but lacks operational detail.

- There is concern among Cancer Alliances about how to achieve the national target for 2028 of 75 per cent of cancer diagnoses being at stage I or II.

- Most Cancer Alliances report using evidence to some degree to support their decision-making. This includes referring directly to existing evidence and data from Public Health England (PHE) and the Cancer Alliance Data, Evidence and Analysis Service (CADEAS); seeking evidence-based guidance from stakeholders; and gathering evidence if it is not already available.

- Data analytical capacity varies considerably across Cancer Alliances.

- More data – by tumour site if possible – for local areas would be welcomed by Cancer Alliances in order to tailor interventions to their population, especially about:

  o Public awareness interventions;

  o Rarer cancers; and

  o Emergency presentation.

- Ideas for how Cancer Research UK might continue to support Cancer Alliances with improving early diagnosis included:

  o Shaping national guidance and influencing policymakers;

  o Providing information/analyses;

  o Providing, or helping Cancer Alliances to develop, data-analytic capacity;

  o Facilitating more primary care involvement in Cancer Alliances;

  o Assisting with horizon-scanning for innovations;

  o Linking researchers and innovators to NHS commissioners and providers of cancer services; and

  o Better coverage of the National Cancer Diagnosis Audit (NCDA).[1]

- Cancer Research UK is perceived by most interviewees as a highly influential and credible organisation.

Principal findings relating to Northern Ireland were that:

- Useful sources of evidence as reported by interviewees included:

  o National Institute for Health and Care Excellence (NICE) guidance and recommendations;

  o Local research evidence;

  o Reports from Cancer Research UK, Macmillan and other charities;

  o Cancer Patient Experience Survey;

---

[1] The National Cancer Diagnosis Audit is a partnership involving support and input from: the Royal College of GPs, Macmillan Cancer Support, Public Health England (specifically the National Cancer Registration and Analysis Service), NHS England and NHS National Services Scotland. It is operationally managed by Cancer Research UK (Cancer Research UK 2019b).

- o Northern Ireland Cancer Network (NICaN) registry; and
- o Population statistics.

- Routine annual provision of cancer pathways data and analysis, similar to that provided by PHE and CADEAS in England, was advocated in order to support decision-making for early diagnosis, as well as cancer services more widely in Northern Ireland.

- As in England, Cancer Research UK was perceived by interviewees in Northern Ireland as a highly influential and credible organisation.

The desire for more and better evidence to steer decision-making in the National Health Service (NHS) and Health and Social Care (HSC) about investments in early cancer diagnosis was universal among the people we interviewed. The NHS Long Term Plan (LTP) and its Implementation Framework in England have created further pressure within the NHS to improve early diagnosis, and have focused attention on achieving a national target of 75 per cent of cancer diagnoses to be at stage I or II by 2028. The development of a new cancer strategy for Northern Ireland can be expected to have a similar focus and therefore increase the pressure on healthcare services to deliver improvements in early diagnosis. There is no lack of demand for help from Cancer Research UK.

# Table of contents

# Figures

# Tables

# Abbreviations

| | |
|---|---|
| AI | Artificial intelligence |
| BSO | Health and Social Care Business Services Organisation (Northern Ireland) |
| CA | Cancer Alliance |
| CADEAS | Cancer Alliance Data, Evidence and Analysis Service |
| CCG | Clinical Commissioning Group |
| DoH | Department of Health (Northern Ireland) |
| DHSC | Department of Health and Social Care (England) |
| PHE | Public Health England |
| FIT | Faecal Immunochemical Test |
| GDPR | General Data Protection Regulations |
| GP | General Practitioner |
| HPV | Human Papillomavirus |
| HSC | Health and Social Care |
| HSCB | Health and Social Care Board |
| ICS | Integrated Care System |
| LCG | Local Commissioning Group |
| LTP | NHS Long Term Plan |
| LTPIF | NHS Long Term Plan Implementation Framework |
| NCDA | National Cancer Diagnosis Audit |
| NCRAS | National Cancer Registration and Analysis Service |
| NGO | Non-Governmental Organisation |
| NHS | National Health Service |
| NI | Northern Ireland |
| NICaN | Northern Ireland Cancer Registry Network |

| | |
|---|---|
| NICE | National Institute for Health and Care Excellence |
| PCN | Primary Care Network |
| PHA | Public Health Agency (Northern Ireland) |
| QALY | Quality-adjusted life year |
| STP | Sustainability and Transformation Partnership |
| UK | United Kingdom |

# Acknowledgements

# 1. Introduction

Cancer net survival[2] and the rate of decrease in mortality are both lower in the UK than other countries that have high-quality cancer registries and universal access to – and comparable expenditure on – healthcare (Arnold et al. 2019). An important way to improve cancer survival in the UK is to increase the proportion of cases that are diagnosed early, as patients diagnosed at stages I and II have a better chance of successful treatment and long-term survival. Achieving earlier diagnosis remains one of Cancer Research UK's priorities, and is a key component of realising the ambition of three-quarters of people with cancer surviving the disease by 2034 (Cancer research UK 2018b).

In 2019 the cancer strategy in England was shaped by both the NHS Long Term Plan (LTP) (NHS 2019a), and the Implementation Framework (LTPIF) (NHS 2019b) that goes with it. In Northern Ireland a new cancer strategy has been under active development (Department of Health NI 2019a).

The NHS England Long Term Plan (LTP) sets early diagnosis at the heart of its cancer priorities, with a focus on interventions that are aimed at improving:

- Public awareness and recognition of symptoms;

- Screening, and the capacity for screening;

- Access to primary care and waiting times, which are affected by capacity;

- GP preparedness to investigate and refer;

- GP direct access to diagnostic services; and

- Diagnostic capacity (staff, equipment) and waiting times.

Effectively, all such interventions to improve early diagnosis require some commitment of resources, at least in the short term, even if they lead to more efficient healthcare in the longer term. Consequently, decisions have to be taken at the local level in the NHS about whether and which investments in early cancer diagnosis are to be made, in the context of all the other demands on funds that there are.

Many factors may influence these local decisions, including the population's healthcare needs, the current configuration of services and the availability of funds, national strategies and guidance. A particular focus of this study is the availability of evidence about the effectiveness and costs of the different interventions that may support early diagnosis of cancer locally, and the availability of data to facilitate the use of those

---

[2] Net survival represents the net effect of a cancer diagnosis: the chances of surviving assuming that cancer is the only possible cause of death.

interventions. Tools to translate such evidence and data into the local circumstances of a decision-maker, and other decision aids (such as prioritisation tools using multi-criteria decision-analysis methods), have the potential to greatly facilitate appropriate and prompt decisions. Relevant tools and data about cancer and the NHS in England include:

- Public Health England's (PHE) 'Return on Investment Tool: Colorectal Cancer' (Public Health England 2016), populated with baseline data for each Clinical Commissioning Group (CCG) in England.

- National Cancer Registration and Analysis Service (NCRAS – now part of PHE) data (Public Health England 2019), including Cancer Services Fingertips data at GP practice and CCG level, and resources such as factsheets.

- The Cancer Alliance Data, Evidence and Analysis Service's (CADEAS – a partnership between NHS England and Public Health England) data (Public Health England 2010), which is specifically aimed at Cancer Alliances and draws on NCRAS data and methods.

The LTP states prominently that 'by 2028 the Plan commits to dramatically improving cancer survival, partly by increasing the proportion of cancers diagnosed early, from a half to three quarters.' In support of this commitment the LTP describes specific actions that the NHS in England is to implement:

- modernise the Bowel Cancer Screening Programme to detect more cancers earlier;

- implement Human Papillomavirus (HPV) primary screening for cervical cancer across England by 2020; and

- extend the lung health checks that 'have already produced strong results in Liverpool and Manchester' (NHS 2019a).

The responsibility for commissioning the majority of health services in the NHS in England lies with 195 CCGs. However, they do not commission cancer services. NHS England is responsible for commissioning cancer services and does so through 19 Cancer Alliances.[3]

Cancer Alliances were introduced by NHS England to improve the diagnosis, treatment and care of cancer patients. Alliances operate by bringing together a range of clinicians and managers who work together to identify need at a local level and transform care through a number of transformation projects in their 'patch' (NHS England 2018).

In Northern Ireland, the development of a new national cancer strategy was announced in March 2019 by the Department of Health (DoH) 'to identify new ways of working to secure further advances across cancer care' (DoH 2019a). However, the importance of evidence-based, informed decision-making around early diagnosis policy and practice is just as applicable.

In March 2019 Cancer Research UK awarded a grant to RAND Europe to undertake the research reported here. The purpose was to improve Cancer Research UK's Early Diagnosis programme's understanding of

---

[3] There were 19 Cancer Alliances when the research was conducted but the number has increased to 20 at the time of writing.

how it might most usefully help to fill gaps in supporting local decisions to implement early diagnosis measures, with a particular focus on England and Northern Ireland.

The first phase of the research was undertaken from May to August 2019 to investigate local decision-making around early diagnosis interventions in the NHS in England – and national support for that decision-making – in the context of the LTP. The Long Term Plan Implementation Framework (LTPIF) was then published by NHS England in late June 2019, providing further information to guide local NHS planning, prioritisation and implementation in England, including some further information about funding arrangements in support of LTP implementation (NHS 2019b). A second phase of research was then conducted, informed by the findings of the first phase of the study. Undertaken between September and November 2019, this second phase involved interviews with stakeholders in England to evaluate reactions to the LTPIF at the local level within the NHS. In parallel with this work, we conducted interviews with key stakeholders in Northern Ireland to obtain views on the decision-making process for the early diagnosis of cancer and the development of the Northern Ireland national cancer strategy. Our research in Northern Ireland was conducted mainly with stakeholders at the national level, plus one interview at an HSC Trust.

In the following chapters we first describe our research methods (Chapter 2), and our findings with respect to England (in Chapters 3 and 4) and Northern Ireland (in Chapter 5). Chapter 6 concludes with reflections on the overall picture of supporting decision-making for investment in early diagnosis interventions for cancer in England and Northern Ireland.

# 2. Methods

We gathered evidence for this study through interviews with stakeholders in England and Northern Ireland, and a workshop with the Cancer Research UK Steering Group (for an overview of our approach, see Figure 1). In this chapter, we describe how each study component was designed and conducted, and how the data we gathered were analysed and brought together. We began with the first set of interviews at Cancer Alliance and national levels in England, and the large majority of the interviews were completed before the workshop, which took place in late June. One remaining interview at national level was completed in early August. After the workshop, and based on discussions there with Cancer Research UK, a second set of interviews with representatives of Cancer Alliances in England were conducted between September to November 2019, in parallel with a set of interviews in Northern Ireland. The numbers of interviewees and workshop participants are provided in Table 1.

### Figure 1. Overview of approach
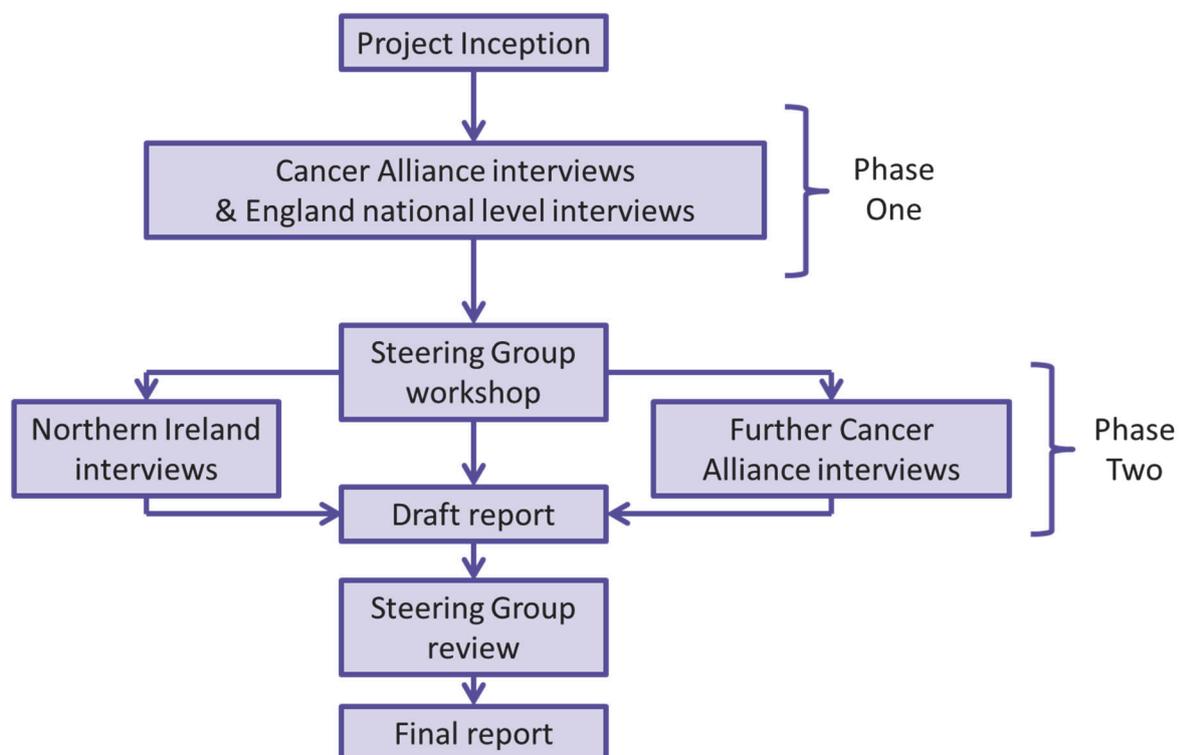
Table 1. Interview and workshop details

| Method | Stakeholder group | Number of interviewees and organisations | Date(s) |
|---|---|---|---|
| Interviews in England – Phase one* | Cancer Alliances | 15 interviewees representing 11 Cancer Alliances | 9 May 2019 – 26 June 2019 |
| Interviews in England – Phase one | Representatives of national organisations and initiatives | 1 interviewee from each of:<br>• NHS England<br>• PHE<br>• CADEAS<br>• NCRAS | 7 June 2019 – 6 August 2019 |
| Workshop | Cancer Research UK representatives | 7 participants from Cancer Research UK | 24 June 2019 |
| Interviews in England – Phase two* | Cancer Alliances | 15 interviewees representing 12 Cancer Alliances | 12 September 2019 – 13 November 2019 |
| Interviews in Northern Ireland | Health and Social Care in Northern Ireland (HSCNI) | 6 interviewees representing:<br>• Department of Health Northern Ireland<br>• Health and Social Care Board (HSCB)<br>• a Health and Social Care Trust<br>• HSC Business Services Organisation (BSO) | 5 September 2019 – 3 October 2019 |

*Nine people were interviewed across both Phase one and Phase two, giving a total of 30 Cancer Alliance interviews, with 21 different individuals, representing 14 different Cancer Alliances.

## 2.1.    Phase one interviews – in England at local and national levels

Our research team sought to interview respondents from all 19 Cancer Alliances existing at the time of the study, and from national-level key informants at NHS England and PHE, including NCRAS and CADEAS. The interviews covered:

• How decisions are made locally about investment in early diagnosis of cancer.

• The evidence and tools used to support local decision-making.

• Reflections on the Transformation Funding process by which Cancer Alliances receive funds to develop cancer services, including early diagnosis.

• The resources or support that would be most useful in enabling early-diagnosis decision-making.

We identified the leadership of each Cancer Alliance through a combination of online searches and from Cancer Research UK's network of contacts with CCGs. We then agreed – in discussion with Cancer Research UK staff – the initial interviewees to approach at each Cancer Alliance and at national-level organisations.

### 2.1.1.    Interviews in England – Cancer Alliances (Round one)

In the first phase of interviews with stakeholders in England, 15 individuals – representing 11 Cancer Alliances – were interviewed. All interviews were conducted by telephone and lasted approximately 45 minutes. Interviews were audio-recorded, subject to the consent of the interviewee, and the answers to all questions were noted during the interview itself. The audio-recording enabled us to check the detail of the interview responses and select direct quotes after the interviews. The interviews were semi-structured to facilitate data extraction, analysis and comparison between sites. All interviews were conducted under the principle of informed consent and in line with General Data Protection Regulations (GDPR), and specific quotes were not linked to individuals or organisations without interviewee permission. During each interview, there was opportunity for open discussion to ensure that interviewees had the chance to emphasise what was of importance to them, and to go into more detail where appropriate. A similar yet separate interview protocol was developed for Cancer Alliances (see Annex A) and national-level key informants (see Annex B) respectively. The initial draft protocols were discussed with the Steering Group during the project inception period, and revised accordingly before being used.

Interviewees were invited to participate in the study via email. If the initial invitee declined to participate in the study, we asked them to recommend who else we should interview. After the initial invitation email, up to three follow-up emails were sent if necessary.

For the Cancer Alliance interviews, 33 invitations were sent to potential participants. To promote positive responses from Cancer Alliances, a letter of recommendation from Cancer Research UK accompanied the email invitations. Of the 33 individuals invited to participate, 15 were interviewed (45 per cent response rate), between them covering 11 of the 19 Cancer Alliances. Three of the other invitees declined to be interviewed (9 per cent) and 15 (45 per cent) either did not respond to the initial requests or did not respond to interview scheduling emails.[4]

### 2.1.2.    Interviews in England – national-level representatives

Alongside the local-level interviews with Cancer Alliance representatives described above, we also conducted interviews with four national-level key informants (representing NHS England, PHE, CADEAS and NCRAS). The methods used were identical to those described above in section 2.1.1.

## 2.2.    Workshop

When the first set of interviews was largely complete, a workshop was held on 24 June 2019 at Cancer Research UK's offices in London to provide the project Steering Group and additional colleagues at Cancer Research UK with an opportunity to reflect on the initial findings, consider the implications of our initial analysis of the interview findings, and plan the next steps of the project in the light of health service developments.

The workshop discussions led to a decision by Cancer Research UK to adopt a dual focus for the remainder of the research: (1) to undertake further interviews with Cancer Alliances in England in order to gauge how

---

[4] Percentage figures are subject to rounding and therefore may not total 100 per cent.

the LTPIF was influencing their decision-making around early diagnosis; and (2) to conduct interviews with stakeholders in Northern Ireland in order to gain a better understanding of how decisions for investment in early diagnosis of cancer are made there, in the light of the development of the cancer strategy for Northern Ireland.

## 2.3. Phase two interviews: in England at local level and in Northern Ireland

Using the same approach as described above for Phase one interviews, all Phase two interviews – including those conducted with interviewees from Northern Ireland – were conducted by telephone and lasted approximately 45 minutes. Interviews were audio-recorded, subject to the consent of the interviewee, and the answers to all questions were noted. Interviews were conducted with two stakeholder groups: Cancer Alliance representatives in England, and local and national-level stakeholders in Northern Ireland as set out below.

### 2.3.1. Interviews in England – Cancer Alliances (further interviews)

A total of 43 interview invitations were sent out and we secured an interview with 15 of those (35 per cent), representing 12 Cancer Alliances. A total of ten potential participants declined or did not offer an interview date (23 per cent); but six of those who declined made a recommendation we speak to someone else. Of the people we contacted, 18 did not respond at all (42 per cent).

Of the 15 interviews secured and completed, nine had been participants in Phase one interviews and six participants were new to the study, i.e. they had not been interviewed in Phase one. The nine for whom this was a second interview within the study were asked questions solely related to the LTPIF, which had been published by NHS England in late June 2019 (see Annex C). The six first-time interviewees were asked the Phase one questions as well as the questions related to the LTPIF (see Annex D). Thus all 15 of the Phase two respondents were asked about their views on the impact of the LTPIF in relation to decision-making for investing in early diagnosis, covering:

- Reactions to the LTPIF in terms of work around early diagnosis of cancer.

- Whether/how the LTPIF was affecting decisions and planning about investment in early diagnosis of cancer.

- Specifically, whether/how the new funding arrangements described in the LTPIF might affect such decisions.

- The resources or support that would be most useful in enabling early-diagnosis decision-making.

### 2.3.2. Interviews in Northern Ireland

Interviews were conducted on the telephone and lasted up to 45 minutes, as described for Phase two interviews above. The Northern Ireland interview protocol (Annex E) was developed and agreed with the project Steering Group. The interview questions covered:

- How decisions are made in Northern Ireland about investment in early diagnosis of cancer;

- The evidence and tools used to support that decision-making; and

- The resources or support that would be most useful in enabling early diagnosis decision-making.

We approached a total of 13 potential participants from key stakeholders and received an initially positive response from 10 (77 per cent), after one email invitation and two email reminders. However, four of these individuals did not offer an interview date when requested. Our final sample consisted of interviews with six key stakeholders (46 per cent), who represented: a Health and Social Care Trust; the Health and Social Care Board (HSCB); the Department of Health in Northern Ireland (DoH); and the Health and Social Care Business Services Organisation (BSO). Of the remaining people contacted, two people declined to be interviewed (15 per cent) and one person (8 per cent) did not respond.

## 2.4. Analysis

We conducted a detailed qualitative analysis of the views and experiences provided through each set of interviews. We adopted a framework analysis approach, in which we mapped the information collected against the key study questions. We used Microsoft Excel spreadsheets to extract information from interview notes and record interviewees' answers against study questions and themes. This allowed us to chart all the evidence collected relating to one particular issue or question of interest and thereby fully address that issue. At an internal workshop the research team reviewed, compared and collated the evidence from the individual interviews, and reached an agreed understanding of the ranges of views presented, and any common views where they existed. Through this process we also identified any overall themes that emerged from the interviews.

Findings from a preliminary analysis of the Phase one interviews in England informed the design and content of the 24 June workshop, at which those preliminary findings were discussed and compared with the experience of the Cancer Research UK Early Diagnosis team and other Cancer Research UK colleagues. These findings helped to inform the ongoing approach and focus on particular stakeholder groups for the remainder of the study.

Adopting the same approach described above, we subsequently conducted separate, detailed qualitative analysis of data collected as part of the Phase two interviews. Data from the second round of interviews in England were analysed separately from data collected from the interviews with key stakeholders in Northern Ireland.

# 3. Decision-making on investment in early diagnosis interventions in England

Released a few months before the Phase one interviews were conducted, the NHS England Long Term Plan (NHS 2019a) outlines a programme of NHS service and outcome improvements for the next ten years. The LTP highlights better early diagnosis of cancer as an area of work to deliver 'world-class care for major health problems'. At the time of the Phase one interviews, NHS England had not yet published the Long Term Plan Implementation Framework (LTPIF) (NHS 2019b). Released in late June 2019, the LTPIF provides further details of the approach that Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) are asked to take to create five-year strategic plans for their respective areas of England. The Cancer Transformation Fund process for allocating funding to Cancer Alliances for financial year 2019/20 had been completed in the months immediately prior to the Phase one interviews, and had taken a different approach to that of funding rounds in previous years, as we discuss further.

This chapter presents the findings from the first Phase of interviews with representatives from the Cancer Alliances and national-level key informants at NHS England, PHE, NCRAS and CADEAS, in the context described above.

In the Phase two interviews we spoke to six Cancer Alliance representatives with whom we had not spoken in Phase one, and took the opportunity to include in these six interviews the same questions that we had asked of Cancer Alliance representatives in Phase one. In this section, we report the combined findings from the answers to those questions. Table 2 below outlines the numbers of interviewees whose views are included in the analysis in this chapter. Interviewees who also participated in Phase two of the study are identifiable with a number '2' in brackets after their interview identifier code.

Table 2. Numbers of interviewees included in analysis described in Chapter 3

| Interview type | Interviewees | Alliances |
|---|---|---|
| Phase one interviews at Cancer Alliances | 15 | 11 |
| Cancer Alliance interviews applicable from Phase two[5] | 4 | 3 |
| National-level key stakeholders | 4 | n/a |
| Total number of interviews included in Chapter 3 analysis | 23 | 14 |

## 3.1.  How decisions are made regarding resource investment in early diagnosis

**Key findings:**
- Many investments are in effect centrally prioritised.
- Cancer Alliances support those national priorities.
- There are differing views across Cancer Alliances on the extent of their discretion.
- Cancer Alliances involve CCGs, Local Authorities, GPs and cancer service providers in local decision-making.

### 3.1.1.  Cancer Alliances welcomed the national cancer strategy for England

Most interviewees were familiar with the national cancer strategy for England (Independent Cancer Taskforce 2015), and described it as providing instruction to the Cancer Alliances on the areas for investment, including improvement in early diagnosis (INT01, INT02, INT06, INT08, INT09, INT12, INT13, INT14, INT15, INT23(2)). Interviewees generally agreed with the importance of the national priorities and were willing to design work plans based around them. A representative from NHS England confirmed that the LTP built upon the Independent Cancer Taskforce strategy for 2015–2020 that was published in 2015 (Independent Cancer Taskforce 2015) (INTN02). This interviewee emphasised that the cancer sector, when consulted in the autumn preceding publication of the LTP, clearly indicated that the Plan should continue to build on areas that were a focus in the strategy so that progress could be sustained and delivered in those areas (INTN02).

There were varied perceptions as to the level of discretion Cancer Alliances have in shaping a work plan for their region around the national priorities. Although three interviewees felt that the guidance provided by NHS England was very prescriptive (INT01, INT02, INT12), most felt there was some degree of flexibility

---

[5] Where a Phase two interviewee was from a Cancer Alliance from which we had not had an interviewee in Phase one, we asked them the Phase one questions as well as the Phase two questions. Their answers to the Phase one questions are included in the analysis presented in Chapter 3. This was the case for four Phase two interviewees, who were from three Cancer Alliances not represented among Phase one respondents.

to be guided by local needs and resource availability (INT03, INT06, INT08, INT09, INT10, INT11, INT13, INT14, INT15). Interviewees who considered there was some flexibility for Cancer Alliances in decision-making regarding resource investment explained that NHS England provides a national framework for the Alliances' work plans (INT06, INT09, INT14, INT23(2)). However, they reported that delivery of the work plan and activities designed within the focus areas were guided by local priorities (INT06, INT09, INT14, INT23(2)). As one representative of a Cancer Alliance said:

> It is the Cancer Alliances that are aware of pressure points, such as waiting times and performance. (INT09)

Other interviewees commented that decisions on resource allocation within their Cancer Alliances were based on the success an activity had in the previous year (INT03) or on the ability of the STP to carry out the activity (INT08, INT15).

### 3.1.2. Cancer Alliances work collaboratively and strategically

Overall, most interviewees viewed the role of Cancer Alliances as a strategic one, convening key stakeholders to develop a local plan based around national priorities. Stakeholders include CCGs, public health teams, Local Authorities, GPs, Regional Cancer Boards and NHS Trusts (INT01; INT02; INT03; INT04; INT06; INT14; INT07; INT09; INT12; INT13). As one interviewee put it, Cancer Alliances 'engage with everybody and anybody they feel they need to engage with' (INT08). All of the Cancer Alliance interviewees indicated that their Alliance involves a range of stakeholders in decision-making. However, the reported extent of that involvement varied between Cancer Alliances both in terms of who was involved and how much involvement took place. For example, a representative from one of the Cancer Alliances said that decision-making at local level was mainly done by the Executive and Clinical Leads of the Alliance, and representatives from CCGs (INT05). Interviewees from five different Alliances commented that they organised workshops and meetings with representatives from CCGs, senior management, public health teams and local authorities to identify areas of work (INT03, INT06, INT10, INT11, INT14, INT21(2), INT22(2)). Two interviewees mentioned that Cancer Alliances contact stakeholders to identify key interventions that will contribute to them meeting the national targets, then review the proposals and map them onto the national priorities (INT13, INT23(2)).

## 3.2.    The use of evidence and tools in decision-making

**Key findings:**
- Most Cancer Alliances report using evidence to some degree to support their decision-making.
- This includes referring directly to existing evidence; seeking evidence-based guidance from stakeholders; and gathering evidence if it is not already available.
- CADEAS data were referred to several times, and CADEAS has a work programme to develop more support for Cancer Alliances.
- Other evidence sources cited as being used were data on waiting times, outcomes and public awareness; National Institute for Health and Care Excellence (NICE) guidelines and other best practice information; PHE's Cancer Services Fingertips tool; academic literature; and reports from Cancer Research UK and Macmillan Cancer Support.
- Awareness and use of the PHE Return on Investment tool for colorectal cancer was patchy.
- Data-analytical capacity varies considerably across Cancer Alliances.
- Some interviewees said lack of evidence has not proved to be an obstacle to decision-making around early diagnosis.
- But more data, by tumour site if possible, for local areas would be welcome, especially about:
  - Public awareness interventions;
  - Rarer cancers; and
  - Emergency presentation.

### 3.2.1.    The use of evidence and approaches taken by Cancer Alliances in decision-making for early diagnosis varies considerably

According to a representative from NHS England, in developing the cancer priorities in the LTP, the organisation consulted stakeholders in the sector and made use of evidence on cancer incidence and the effectiveness of interventions (INTN02). Stakeholders engaged included charities, patient groups and Royal Colleges. Other sources of evidence included data from NCRAS (run by PHE), CADEAS (a partnership between NHS England and PHE), the National Cancer Patient Experience Survey,[6] as well as academic literature.

Overall, across the 14 Cancer Alliances' representatives interviewed, we found that the reported use of evidence and specific tools to support decision-making varied considerably. The majority reported using evidence to some degree. Some interviewees said they relied heavily on evidence and used a variety of sources to support their decision-making, 'using whatever reputable data was available' (INT20(2)). A representative from one of the Cancer Alliances commented that they 'look at everything they consider useful', such as CADEAS data, waiting times, National Institute for Health and Care Excellence (NICE) guidelines,[7] best-practice evidence, and studies from Cancer Research UK and Macmillan Cancer Support

---

[6] National Cancer Patient Experience Survey (2019). The National Cancer Patient Experience Survey data is an annual survey that has been conducted by the Picker Institute since 2010 on behalf of NHS England, the results of which are publicly available online.

[7] For National Institute for Health and Care Excellence guidelines, see NICE (2020).

(INT08). Other interviewees described referring to evaluation reports by Cancer Research UK, information on population awareness, outcomes data and published journal articles (INT03, INT12, INT07, INT08). Two interviewees reported using local evidence and knowledge to support decision-making (INT07, INT20(2)), and another interviewee reported having pathway groups as part of their Cancer Alliance, which represent the main pathways of interest and a research group to help translate research into practice (INT23(2)). In contrast, another interviewee felt that the translation of research into practice was an area that needed to be improved (INT22(2)). Representatives from one Cancer Alliance and from NCRAS felt that the time lags before data become available could sometimes hinder decision-making, as data are usually one or two years out of date by the time of publication (INT10, INT11, INTN04). Two Cancer Alliances also said they used PHE's Cancer Services Fingertips tool[8] (INT06, INT07, INT14).

In contrast to the approaches described by interviewees above, representatives from one Alliance said they undertook 'deep dives' into what they considered to be the biggest issues in their region (INT06, INT14). They also took the view that 'pioneers build evidence', explaining that they sought to gather evidence they needed if it was not readily available (INT06, INT14). For example, they had recently developed an outcomes dashboard for their population and conducted a review on inequality in access to healthcare (INT06, INT14). Four interviewees said their search for evidence depended on the intervention being considered and that they mainly focused on engaging with stakeholders who could provide insights and interpretation of the data available (INT01, INT02, INT05, INT09). A representative from one Alliance stated that they referred to evidence on a 'quick and dirty' basis and focused mainly on national studies (INT04). Representatives from two Alliances reported that they did not use any specific evidence in their decision-making process (INT01, INT02). One of them explained that the Cancer Alliances did not have the time to gather evidence, and so relied on engagement with PHE staff or local authorities for the necessary information (INT01). Similarly, another interviewee reported that, when looking at the effectiveness of screening programmes, they would engage with colleagues from PHE who focus on screening and could provide them with evidence to support – or not – the implementation of an intervention focused on screening (INT05).

### 3.2.2. Cancer Alliances reported a need for more evidence

Some interviewees felt there was a lack of standardised evidence to support their decision-making (INT03, INT05). One interviewee noted that 'there is not necessarily lack of data but rather of conglomerate data' (INT07), which we understood to mean that more 'joined-up' data are required. Another interviewee mentioned that the evidence available was not easily accessible but that, 'they knew where to look' (INT03). The interviewees at CADEAS and NCRAS (INTN03, INTN04) considered that while there is good availability of data analyst resource in some Cancer Alliances, others suffer from much poorer access to data analysts: 'some organisations have their own analyst staff, others do not' (INT04). This view was shared by an interviewee at a Cancer Alliance, who said that although the evidence was available, there was little capacity within their Alliance to analyse it and determine what it means at a regional level (INT09).

---

[8] The Cancer Services Fingertips is a tool that contains data gathered by NCRAS on cancer services at GP and CCG level. This data is intended to be used by commissioners and health professionals when assessing the impact of cancer on their local population and in their decision-making process on cancer services (Public Health England 2019).

Two interviewees felt that lack of evidence was mainly a problem in the area of public awareness, and particularly a lack of evidence on the effectiveness of interventions to build public awareness (INT03, INT05). Other areas where more evidence at local level was mentioned as being desirable were for rarer cancers (INT03), and more detailed data on emergency presentation, vague symptoms and asymptomatic patients; as well as on cancer stage (INT08, INT15, INT023(2)). However, three interviewees emphasised the need for all evidence to be able to demonstrate value for money when making a case for funding to NHS England (INT20(2), INT21(2)); or, as one interviewee put it: 'more bang for our buck' (INT23(2)). However, these data should be interpreted with caution – these interviews were conducted following the publication of the LTPIF, so it is possible that interviewees' responses will have been influenced by this knowledge.

The interviewee from NHS England indicated that Cancer Alliances are expected to take account of local circumstances in planning their activities, suggesting they would draw on quantitative data from CADEAS and their own working knowledge gained from day-to-day interactions with local providers, commissioners and others (INTN02). This interviewee said there was not a lack of cancer data available, but was not sure whether it was being used or whether some relevant data were being underused (INTN02). They also raised a question about whether there may be some duplication of effort, with multiple analysts looking at data on operational performance, and insufficient attention being paid to delving more deeply into data that could help explain the factors behind stronger or weaker performance (INTN02).

### 3.2.3. Views on CADEAS data and services

CADEAS was set up by NHS England and PHE to support Cancer Alliances with data and analysis specific to their particular regions. Many, though not all, of the interviewees from Cancer Alliances reported either using or being aware of CADEAS data. Interviewees from seven Cancer Alliances specifically said that they found CADEAS data to be useful, as it allowed them to benchmark performance in their region against other parts of the country and to identify gaps at a regional level (INT03, INT05, INT09, INT13, INT23(2), INT20(2), INT22(2)). However, there were mixed views on the timeliness of the data available on CADEAS. One interviewee said that the information was not timely (INT13), in contrast to another who mentioned that CADEAS provided pre-published data, which helped to make it more timely (INT03). Another interviewee found the main limitation of CADEAS to be that it does not offer bespoke support, but recognised that CADEAS was fairly new (established during 2017/18) and that it may take time to identify support needs (INT09).

The CADEAS representative we interviewed drew our attention to the CADEAS Work Programme 2019/20 document (CADEAS 2019), which refers to CADEAS receiving favourable feedback on its provision of evidence to support the implementation of the new faecal immunochemical test (FIT) to screen for colorectal cancer; and on its engagement in general with Cancer Alliances. Areas to consider for improvement in support to Cancer Alliances, and relevant to early diagnosis, as stated by CADEAS in the Work Programme document are:

- 'More tumour site breakdowns of data to support work such as implementation of best practice timed pathways.'

- 'Time series/dynamic reports rather than just snapshots/static reports and more tools to enable Cancer Alliances to interrogate data.'

- A 'catalogue of all [CADEAS] products in one place and a guide on how to use products.'

- 'Capacity for bespoke reporting and statistical advice.'

Our CADEAS interviewee reported that in deciding on where to put its efforts into supporting the Cancer Alliances, CADEAS consults the national workstream leads in the National Cancer Programme, and also consults all of the Cancer Alliances, via four regional workshops (INTN03). The same interviewee stated that CADEAS is keen to support local evaluations and strengthen local analytic capabilities, and is planning to design and commission a national evaluation of targeted lung health checks, and commission an external evaluation of Rapid Diagnostic Centres. As stated in the CADEAS Work Programme 2019/20, CADEAS understands that the Cancer Alliances want more information on screening uptake, including analysis by level of population deprivation and by ethnicity, to help them to better target their screening efforts (CADEAS 2019).

### 3.2.4. Views on PHE's Return on Investment Tool: Colorectal Cancer

Cancer Research UK highlighted the PHE Return on Investment Tool: Colorectal Cancer, as an example resource to inform the use of early diagnosis interventions (Public Health England 2016). The tool uses CCG-level data and looks at impact on patient outcome and costs over ten years, and hence the cost per quality-adjusted life year (QALY) gained as the result of an intervention. The tool was developed to help local commissioners understand the cost-effectiveness of interventions and inform decisions for prevention, screening and early diagnosis of colorectal cancer.

Only one interviewee at a Cancer Alliance reported specifically that they had used PHE's Return on Investment Tool for colorectal cancer. This interviewee said they had used the tool for their colorectal cancer programme and that it had helped them develop their bid for Transformation Funds (INT13). Another interviewee reported that return on investment tools generally are very helpful (INT20(2)), but this was not specific to the PHE's tool. Other available tools include those published by NICE for use in decision-making for interventions in tobacco, alcohol and obesity (Cancer Research UK 2016a). Representatives from one of the Alliances said they did not use the PHE ROI tool as they would expect NHS England to have done so when deciding on the priority areas they should focus on (INT06, INT14). Other interviewees at Cancer Alliances had either not heard of the tool or were unsure whether it had been used in their Alliance. In this context it should be noted that none of our interviewees at Cancer Alliances were data analysts. Rather, all were senior managers and/or clinicians.

Patchy awareness of the Return on Investment tool at Cancer Alliances was confirmed by our PHE interviewee, who said that when PHE (with CADEAS) had recently sought feedback about the tool from Cancer Alliances, they had found that quite a few Cancer Alliances had not previously been aware of the tool (INTN01), so asking for feedback had at least raised awareness. The national level interviewee reported that some Cancer Alliances who had not previously been aware of the Return on Investment tool had tried similar modelling themselves. Among those Cancer Alliances who were aware of the tool, some said they found it helpful for planning future demand and capacity, and would like similar tools for other types of

cancer. Others wanted the tool to be based on more up-to-date data (it is based on data from around 2013) and some had reported that they found the tool complicated and time consuming to use (INTN01).

## 3.3.    Views on the updated Transformation Fund Process for 2019/20

**Key findings:**
- The process by which Cancer Alliances obtain Transformation Funds was changed for 2019/20. Rather than bidding on the basis of proposals and past performance, as in previous years, Alliances were allocated 'fair shares' for 2019/20, but were then required to explain how those funds would be used to address national priorities.
- Overall, the new Transformation Fund process is preferred to the previous approach.
- The main advantages of the new process are cited as:
    - Certainty of funding, which helps with planning and staff retention; and
    - Fairness across Cancer Alliances.
- Disadvantages of the new process are cited as:
    - Reduced scope for local discretion and local innovation; and
    - The short time for submitting plans to NHS England.
- Both the previous and the new process suffer from:
    - A lack of sustained (>1 year) funding, which creates a barrier to staff recruitment and retention;
    - Absence of funds for capital investment (e.g. in facilities and equipment).

Each year since 2016, NHS England has provided a Cancer Transformation Fund in addition to the funding already received by providers of cancer services. The Transformation Fund helps Cancer Alliances to make the major changes needed to achieve earlier cancer diagnosis, as well as for projects linked to living with and beyond cancer. Interviewees explained that prior to 2019/20, funding for the Cancer Alliances had been performance-based and funds were awarded following a bidding process (INT02, INT03, INT09, INT10, INT11, INT13). Consequently some Alliances had not received the funding they had hoped for, while others did. Thus the Cancer Alliances had been responsible for identifying and determining their priorities (INT01, INT05), without an indication of the total budget they would receive (INT05). One interviewee defined this process as 'distracting' and 'hand to mouth' (INT04).

However, for 2019/20 NHS England changed the mechanism for Transformation Funding allocation to the Cancer Alliances. In the new mechanism, Transformation Funds for financial year 2019/20 are allocated on a 'fair shares' basis, with additional funding made available to the ten Alliances that host projects as part of the National Targeted Lung Health Checks Programme[9] (NHS England 2019b). Interviewees commented that the main change was the fact that Transformation Funding for 2019/20 was population-based rather than performance-based, as it had been in previous years. The new approach, which guarantees some Transformation Funding for all Alliances, was felt to be fairer (INT01, INT02, INT03, INT04,

---

[9] The NHS Targeted Lung Health Check Programme is a pilot programme being trialled in some parts of England from Autumn 2019, in which eligible patients who are considered at high-risk of developing lung cancer are offered Low Dose Computed Tomography (CT) scans to diagnose lung cancer at an earlier stage (Cancer Research UK 2019a).

INT05, INT06, INT08, INT09, INT10, INT11, INT13, INT14, INT15). Under the 2019/20 approach, the Cancer Alliances were asked to complete a form indicating their proposed activities for each area of focus identified by NHS England (INT02, INT05, INT06, INT08, INT14, INT15, INT23(2)), rather than bidding competitively to fund particular initiatives.

Overall, the new process was preferred to its predecessor by all Cancer Alliance interviewees, although both pros and cons were identified, as presented in the following sections of the report.

### 3.3.1.  Benefits of the new funding process

Interviewees identified two main benefits of the new funding mechanism. The first benefit relates to the change to population-based funding rather than performance-based funding, which all interviewees viewed as an improvement on the previous system. Some interviewees explained that this new approach ensured equitable funding across the country (INT01, INT06, INT07, INT14), which helps to standardise cancer care and service quality (INT07). The NHS England representative we interviewed also commented that the updated approach is fairer and better supports efforts to tackle health inequalities because funding can be adjusted according to the level of deprivation in an area (INTN02). Cancer Alliance interviewees also commented that the Alliances were informed in advance that they would be receiving the money, which enabled them to plan activities and secure staff (INT02, INT03, INT04, INT05, INT10, INT11).

The second benefit relates to the existence of areas of focus identified at a national level. Interviewees felt that the provision of national priority areas by NHS England ensured that all Cancer Alliances address the same problems (INT01, INT05, INT07, INT23(2)). One interviewee mentioned that it ensured new diagnostic tests were introduced in all regions (INT01). Additionally, one interviewee commented that having a fixed budget and priorities determined at national level made conversations with stakeholders easier (INT05). Another interviewee was also clear that there were positives to the new process:

> …it's transparent…it meant people think, [it] force[d] people to work together. (INT07).

### 3.3.2.  Challenges of the new funding process

Interviewees also identified some challenges with the new funding mechanism. Although interviewees considered that having population-based and annual funding was an improvement, they felt it still did not address the bigger issue that tackling cancer requires long-term investment (INT01, INT06, INT07, INT13, INT14, INT22(2), INT023(2)). Interviewees reported that short-term contracts hinder staff recruitment and retention, and that annual contracts are insufficiently long to address this issue; rather multi-year funding is needed (INT02, INT07, INT09, INT13, INT23(2)). One interviewee reported,

> ...the way of working has made it incredibly difficult for planning, particularly for certain projects where you really need to be able to plan on a longer term scale. (INT03)

Another interviewee commented that on occasion they had hired people for the longer term (i.e. not on short-term contracts) to improve staff retention, at their organisation's own financial risk (INT04). However, they perceived that this was not a viable option for smaller or less well-resourced Alliances (INT04).

Interviewees also reported that the template provided for the Cancer Alliances' proposal on activities was restrictive and could be clearer (INT03, INT06, INT14, INT20). Some interviewees commented that their

proposals had undergone several iterations between NHS England and the Cancer Alliance before being finalised, a process that they found frustrating and that led to delays in receiving the funds (INT02, INT08, INT09, INT10). Additionally, some interviewees commented that they were asked to set aside funding for Rapid Diagnostics Centres, but had received no further instruction on what this meant (INT05, INT06, INT13, INT14, INT22(2)).

Some interviewees felt that a great deal of work had gone into proposals that Cancer Alliances had developed in anticipation of the Transformation Funding bid process. However, these proposals did not always align with the priorities included in the funding call, and could not be included due to there being no scope for proposing additional activities. One interviewee felt that it would be useful to share information related to these projects with other Cancer Alliances:

> I would be quite keen to understand…what happens with those projects and if there are any plans to secure funding, how successful is it and really having a better understanding of what happens if the Alliances don't have enough money to do necessary projects. (INT12)

As discussed above, most interviewees felt there was limited flexibility in the new process. One interviewee suggested that a way to introduce more flexibility would be to allow 10 per cent of the budget to be allocated for local discretionary innovation (INT01). Another interviewee reported frustrations with the lack of flexibility related to innovations, but also recognised that some Alliances may find it difficult to deliver on these areas (INT23(2)). However, given this interviewee was interviewed as part of Phase two, their response may have been influenced by the release of the LTPIF. Other interviewees felt that some important areas of focus were missed in the new process, such as primary care (INT03, INT12):

> …primary care is really key to early diagnosis. (INT03)

The representative from NHS England acknowledged that while the new approach brought greater funding certainty it also left less room for creativity and new ideas (INTN02). According to the NHS England interviewee, a stream of innovation funding – still under development – will be made available to Cancer Alliances to enable them to develop and trial innovative approaches (INTN02). This innovation funding stream would help to address the challenge that creativity and innovation may be stifled by there being less flexibility in the new Cancer Alliance funding process.

Another challenge associated with the new Transformation Fund mechanism was the short turnaround time expected. Interviewees commented that the Cancer Alliances were given little time to prepare and submit their responses (INT05, INT08, INT13, INT15, INT20(2), INT21(2)). For example, one interviewee reported that:

> We had a three-week window to pull together this bid, which wasn't very well timed…around the Christmas period; we had a lot of people that were off on leave. (INT03)

One interviewee said that they were lucky to have already engaged with their stakeholders and were therefore able to produce a proposal in a short period of time (INT13). Another reported having to create a plan in the short term and then add detail from stakeholders afterwards (INT20(2)).

The last challenge identified by interviewees was a lack of capital funding in the Transformation Funds. This was considered a negative feature of both the previous and current cancer Transformation Funds. Interviewees commented there was no funding allocated to pay for buildings or scanners, which are

important for delivery of cancer diagnostics and care (INT06, INT07, INT12, INT13, INT14). For example, one interviewee said that there was no funding available to build rooms and buy equipment for people to perform endoscopies:

> If we want to improve diagnostics you could train more staff…but you couldn't buy or set up a new room to do [bowel endo]scopes. So that's probably an example of sustainability; if you could have spent more money on an additional room to do bowel [endo]scopes we could have solved that in the long term, but the money was specifically, 'no you can't have any capital costs'. (INT02)

The interviewee from NHS England understood that Cancer Alliances may have had difficulty recruiting or retaining staff because funding allocations were made on a 12-month basis, making long-term planning difficult (INTN02). The NHS England representative we interviewed explained that the LTPIF, which was due to be published shortly after the interview and came out in late June 2019 (NHS 2019b), was intended to address this by setting out funding available for cancer for the next four years. The published framework sets out indicative funding allocations to support LTP commitments (distributed on both a general 'fair shares' basis and on a targeted basis for specific investments) over the five-year period 2019/20 to 2023/24.

## 3.4. What additional support, evidence or tools would be helpful to support Cancer Alliances' decision-making about early diagnosis?

**Key findings:**
- Continued improvement to data access and more help with analysis of data could support local evidence-based decision-making.
- Ideas for how Cancer Research UK might support Cancer Alliances with improving early diagnosis included:
  - Shaping national guidance and influencing policymakers;
  - Providing information/analyses;
  - Providing, or helping Cancer Alliances to develop, data analytic capacity;
  - Facilitating more primary care involvement in Cancer Alliances;
  - Assisting with horizon-scanning for innovations; and
  - Linking researchers and innovators to NHS commissioners and providers of cancer services.
- Cancer Research UK is perceived as a highly influential and credible organisation.

A number of interviewees felt that data were not always as accessible to Cancer Alliances as they could be, because of the way they were presented and/or because the Alliances may lack resources to analyse them (INT10, INT11, INT12). Further, the time at which data were released was not always aligned to when Cancer Alliances made key decisions relating to funding and planning (INT12, INT13). Improving the graphical representation of these data and the timeliness of their release was cited by some Cancer Alliance representatives as being important for improving evidence-based decision-making (INT10, INT11), with one interviewee giving CADEAS as a specific example of these issues (INT10).

As discussed in section 3.3.2, interviewees felt that the ability to plan in the long term, particularly with respect to staffing sustainability, was difficult under the current system of Transformation Funding. A

number of interviewees felt that Cancer Research UK had the potential to influence changes relating to provision of longer term or multi-year funding for Cancer Alliances (INT10, INT11, INT03).

The most common suggestions from Cancer Alliance interviewees were in relation to Cancer Research UK providing information, further analyses of existing data or tools. Specific suggestions included:

- Developing return on investment tools (INT03).

- Health-economic analyses of particular interventions (INT04).

- Information to better understand the impact of interventions (INT05, INT13).

- Providing data and analyses presented by Cancer Alliance regional population and by tumour site (INT07, INT12, INTN04).

- Providing data related to emergency presentation of cancer patients and staging to better understand the stage of cancer presentation (INT08, INT15).

- Improving data linkages – for example, with national audit data – to help further improve decision-making of Cancer Alliances (INT09) and linking primary and secondary care data more generally (INT10, INT11).

- Given some Cancer Alliances lack access to data analysts, it would be useful if Cancer Research UK could undertake and disseminate more analyses for them (INTN04).

Cancer Research UK was also seen to play a useful role in helping individuals to network and build relationships across cancer care and in cancer research and innovation. Some interviewees suggested that Cancer Research UK could help support the strengthening of relationships between researchers and innovators in the field and the Cancer Alliances, in order to ensure that Cancer Alliances have the best available data (INT01, INT06, INT14). According to one interviewee, previous events organised by Cancer Research UK – such as speed-dating events between primary care physicians and secondary care multidisciplinary teams (Clayton & McNulty 2018) as a method to strengthen connections – were received extremely positively, and future similar events would be very welcomed (INT11).

The prospect of Cancer Research UK helping to support cancer innovation that NHS England would like to prioritise and encourage, was also raised by the interviewee from NHS England. They suggested that organisations such as Cancer Research UK could help NHS England to identify promising research and innovation developments, which NHS England could then support through testing within the NHS, possibly with Cancer Alliances (INTN02).

Linked to the fact that involvement of primary care in early diagnosis was not made a priority in the 2019/20 Transformation Funding process, a few interviewees suggested that Cancer Research UK could help to 'fill the gap in primary care' by providing or improving support in the early diagnosis of cancer (INT08, INT09, INT15). There were no specific suggestions as to what this support for primary care might look like. However, existing Cancer Research UK-funded GP Facilitators were seen as useful by several interviewees (INT04, INT06, INT14, INT08, INT15). A few interviewees simply suggested that Cancer Research UK could help to communicate (e.g. via email alerts) the availability of new or forthcoming tools (INT09, INT10, INT11).

The representative from NHS England commented that Cancer Research UK has made, and continues to make, valuable contributions to the NHS England National Cancer Programme (INTN02). These contributions come through Cancer Research UK being represented on the National Cancer Board, which reports to NHS England, and also participating in NHS England's data advisory group, charity forum and Rapid Diagnostic Centres development group. One specific example cited was work done to address the challenge that some overarching performance metrics (related to patient experience and survival, for example) had a one- to two-year lag. The interviewee explained that Cancer Research UK had helpfully led work into the metrics that NHS England could use as more timely leading indicators (INTN02).

The interviewee from CADEAS (INTN03) suggested that Cancer Research UK could work with CADEAS even more than they already do, in order to share knowledge and evidence on best practice around early diagnosis, to share their own experiences of setting up and undertaking local evaluations (e.g. ACE) and of how to get evidence/information used by Cancer Alliances and local systems, and by helping Cancer Alliances to develop their analytical capabilities.

Cancer Research UK was recognised as a highly influential and credible organisation by most interviewees. They reinforced the importance and value of Cancer Research UK continuing to use its profile to positively influence key people, including government, policymakers generally and NHS England, in order to shape national guidance and the cancer policy agenda. As one Cancer Alliance interviewee stated:

> If national guidance tells you, you have to do things, I find the CCGs and the Trusts do it. (INT02)

# 4. Reactions to the Long Term Plan Implementation Framework and impact on local decision-making on investment in early diagnosis interventions in England

The findings described in this chapter are based on analysis of a second phase of interviews with Cancer Alliances that occurred between September and November 2019, following the publication of the LTPIF (in late June 2019) and as decided at the late June workshop. Table 3 summarises the Phase two interviews. Four of the Phase two interviews were conducted with representatives of three Cancer Alliances we had not been able to obtain an interview with in Phase one. The remainder of the Phase two interviews were in effect following up interviews from Phase one. As outlined in Chapter 2, the focus of Phase two interviews was on the impact of the LTPIF with respect to decisions around commissioning interventions to improve the early diagnosis of cancer.

Table 3. Interviewees included in the analysis described in Chapter 4

| Interview type | Interviewees | Alliances |
|---|:---:|:---:|
| Number of new participants to the study | 4 | 3 |
| Number of follow-up interviews | 11 | 9 |
| Total number of interviews included in analysis | 15 | 12 |

## 4.1.    Views on the NHS Long Term Plan Implementation Framework

**Key findings:**
- The LTPIF was largely well-received and considered clear by Cancer Alliances.
- The five-year funding commitment was welcomed by most Cancer Alliances.
- Most Alliances thought the framework was sufficiently flexible, although some felt it did not provide sufficient detail to deliver at a local level.
- The 75 per cent target of all cancers being diagnosed at Stage I or II was of concern to most Cancer Alliances, as to how this would be achieved.
- The indicative/targeted funding approach did not elicit strong views from participants as there remained uncertainty as to how the targeted funding would be allocated to Cancer Alliances.
- The longer term funding commitment was welcomed with respect to helping to address problems with long-term planning and staff recruitment and retention.
- Most Cancer Alliances felt their plans for improving early diagnosis aligned with those published in the Implementation Framework.
- Working with Primary Care Networks was mostly considered easy to implement, but with recognition that they were not yet fully established.
- Implementation of genomics into early diagnosis plans was usually considered harder because it was not under the control of Cancer Alliances.

Overall the LTPIF was well-received by Cancer Alliance representatives we spoke to in Phase two of the study. Many interviewees felt the content was not unexpected; there were 'no surprises' when the LTPIF was released (INT06). It was perceived as being clear with regards to cancer and most Cancer Alliances also welcomed the commitment to a five-year funding plan as opposed to annual funding (INT08, INT16). However, it was recognised that there was a gap between the existing knowledge base and the LTP ambition, which created uncertainty amongst some interviewees as to how targets could be met (INT20, INT21, INT06, INT13).

### 4.1.1.    Local implementation of the LTPIF: flexibility, clarity and implementability

In terms of the perceived flexibility of how Cancer Alliances are able to spend their allocated funds, most interviewees agreed that the LTPIF allowed for some flexibility for Cancer Alliances (INT04, INT08, INT17, INT18, INT23, INT22, INT19, INT21, INT13): it was flexible 'to a point' (INT04). For example, one interviewee stated:

> …there is a bit of freedom on how you enact the recommendations. (INT17)

Some interviewees viewed the LTPIF as more of a high-level document (INT03) in which the details were left to Cancer Alliances to establish; referring to the framework as a 'strategic' (INT18, INT21) or 'summary' document (INT16, INT08). In contrast to this, one interviewee felt they would have preferred to be given clearer instruction as to how to allocate their Cancer Alliance funds rather than deciding for themselves (INT23), and another felt that the LTPIF was 'quite muddled' (INT14) with regard to operationalisation. There was concern that the local-level knowledge required to implement and deliver the framework may be partly lacking (INT06, INT20, INT21). Further, and similar to findings from Phase one, two interviewees considered the absence of capital funding to accompany the LTPIF as a barrier to implementing measures to achieve the LTP targets (INT02, INT14).

Some interviewees expressed particular anxieties with regard to meeting the target of 75 per cent of all cancers being diagnosed in stage I or II by 2028, set out in the LTP (INT04, INT18, INT23, INT22, INT19, INT06, INT14). A few referred to the 'waterfall' diagram provided to them by Cancer Research UK – which illustrates how various improvements in early diagnosis might be expected to close the gap between current performance and the 75 per cent target (see under "How do we achieve early diagnosis?" at: https://www.cancerresearchuk.org/health-professional/diagnosis/early-diagnosis-initiative) – as being very helpful to catalyse thinking in relation to this (INT03, INT04, INT19, INT06). Some interviewees expressed the view that the 75 per cent target is 'optimistic' (INT18) or 'ambitious' (INT14) given the current interventions available, and they were unsure how Cancer Alliances would meet the target. One interviewee felt that the evidence to support the ambitions in the LTPIF at a local level was not yet available, so it was not possible to provide an estimate of when they might be achieved (INT13).

## Impact on Cancer Alliances' existing early diagnosis plans

It was recognised by interviewees that Cancer Alliances' plans need to align with the LTPIF. One participant felt that the Framework helps to provide structure to the Cancer Alliance's planning with regard to early diagnosis and helps to 'calibrate our efforts' (INT04). Most interviewees, although not all, felt that they and their Cancer Alliances were familiar with the national priorities and that their existing plans for improving early diagnosis aligned fairly well with the LTPIF (INT03, INT17, INT23, INT22, INT19, INT21); indeed one interviewee reported: 'They completely align' (INT23). Another said the Cancer Alliance was already doing what the LTPIF said anyway, and there would be 'no change due to the LTP Implementation Framework' (INT19). However, in contrast, some interviewees felt that more could be done to enable Alliances to be more innovative – 'Alliances aren't being given much scope to be innovative' (INT20) – and wanted more innovation funding than was being made available (INT23).

## Perceived difficulty of implementing the LTPIF

Participants were asked about which aspects of implementing the LTPIF appeared most or least straightforward. Overall, participants felt the Framework was all achievable but – as already mentioned – lacked detail of how to succeed at a local level, particularly in relation to the 75 per cent stage I/II diagnosis target (INT04, INT23, INT13). One interviewee referred to the LTPIF as providing 'the golden thread all the way through' (INT22). However, having sufficient capacity within the Alliances to achieve the LTP was cited as a challenge by one participant (INT02).

Interviewees were specifically asked about coping with two potentially major changes to the NHS landscape: the new national genomic medicine service, which Cancer Alliances are expected to work with, and about engagement with Primary Care Networks (PCNs).[10] The implementation of genomics in early cancer diagnosis was usually considered more difficult by participants, reportedly because its implementation is not confined to Cancer Alliances alone and is therefore 'out of our control' (INT14, INT19, INT13). One

---

[10] As part of the LTP, general practices were instructed to work together as part of a network, covering an average of 30,000 to 50,000 patients, in order to provide more sustainable primary care services in terms of both structure and funding. All practices were required to be in Primary Care Networks from 1 July 2019 (NHS 2019a).

participant reported specific difficulties with agreement of payment tariffs and terms (INT19) in relation to implementation of genomic diagnostic services.

Most participants felt uncertain about how easy or difficult working with PCNs would be, because 'they are fledgling concepts' (INT20) and are:

> …still working out how things are working, so it isn't yet embedded into practice. (INT03)

In contrast, one interviewee reflected positively and thought that working with primary care would be relatively easy because 'they want to improve' (INT02).

A small number of participants felt that everything was challenging (INT08, INT16).

## 4.1.2.  Views on the hybrid funding approach: indicative and targeted funding

Interviewees did not appear to offer strong views on the hybrid funding approach described in the LTPIF, namely the combination of indicative funding, which is population-based, and targeted funding, which is dependent on specific streams and investments. Cancer Alliances reported that they felt the indicative funding stream was clear and it was helpful to have a commitment from the Department of Health and Social Care (DHSC) to five years of funding, although a degree of scepticism was expressed by some participants in terms of how the process might work in practice, as the funding was still not guaranteed, merely promised (INT04, INT19).

Similarly, uncertainty was highlighted several times by a number of interviewees in relation to the targeted funding stream, as it was not clear at the time of interview how these funds would be allocated. Some participants were concerned about whether allocation would be based on performance in relation to specific targets (INT03, INT04, INT06), and one felt that 'having the different funding streams makes [planning] difficult' (INT20).

Several interviewees felt that the indicative longer term funding made planning easier and thought that this *should be* beneficial to enable funding of longer projects (INT03, INT17, INT23, INT20, INT22, INT06, INT13) – with the previous annual funding it had not always been possible to determine the full effects of an intervention before the funding ceased (INT08, INT03). Three interviewees indicated that they did not believe the new funding approach described in the LTPIF would alleviate the annual funding problem in its entirety because whilst there was a commitment to five years of funding, this would still only be distributed on an annual basis (INT02, INT18).

Most interviewees were positive about the impact of the LTPIF and its funding arrangements on staff recruitment and retention, but were cautious about the extent of this. Interviewees used language such as 'hopefully' (INT03, INT20) and 'to an extent' (INT08) when asked whether they felt the LTPIF would have an impact on the previously identified problem of lack of continuity of funding and its negative effect on the retention of staff. However, a minority of interviewees indicated that the LTPIF would have little or no impact on this issue, as any impact would only be felt with respect to longer projects (INT02, INT03), and Cancer Alliances would still only be able to offer fixed-term contracts to recruits (INT18).

## 4.1.3.  Timescale for submission of plans

The call for Cancer Alliances to submit their strategic plans in response to the LTPIF opened in late June 2019, with a submission deadline of November 2019. Findings from our Phase one interviews with Cancer

Alliances had indicated that the timescale allocated for submitting plans for Transformation funding was often challenging. Interviewees in Phase two gave mixed responses to whether the allocated time was appropriate for submission of plans in relation to the LTPIF. Several interviewees reported they did feel they had enough time (INT04, INT17, INT19, INT22, INT23, INT21). This appeared to be largely dependent on how far their Alliance's plans had already been developed prior to this, and whether those plans were already aligned with the LTPIF priorities (INT23, INT21). A number of other interviewees reported that they did not feel they had sufficient time, citing practical issues relating to collating views and opinions of key stakeholders (INT03, INT06, INT14, INT18, INT13), and that crucial information needed for developing plans was not always released in a timely way or aligned to the submission deadline (INT06, INT20, INT13). One interviewee acknowledged 'timescales are always an issue' (INT13).

## 4.2.  The use of evidence and tools to support decision-making in the light of the LTPIF

**Key findings:**
- Cancer Alliances cited Cancer Research UK's 'waterfall' diagram as being useful for focusing thinking about meeting the LTPIF target of 75 per cent stage I/II cancer diagnosis.
- Interviewees emphasised the importance of evidence of good value for money.
- The CADEAS Early Diagnosis Projection tool was widely used but with limitations related to timing of release and data quality.
- Suggestions for additional useful evidence or tools included:
  - Data on Cancer Alliance performance at stage I and II cancer diagnosis;
  - More timely release of data; and
  - Better coverage of the National Cancer Diagnosis Audit (NCDA).

Cancer Alliance representatives provided a range of responses when asked to identify tools they found useful in the decision-making process, including the National Cancer Diagnosis Audit (NCDA), return on investment tools, evaluations, cancer pathways and benchmarking data. However, as mentioned earlier, of particular note was Cancer Research UK's 'waterfall' diagram (https://www.cancerresearchuk.org/health-professional/diagnosis/early-diagnosis-initiative), which was referred to multiple times as being a useful tool for focusing thinking about planning to meet the 75 per cent target in the LTPIF (INT03, INT04, INT06, INT19, INT13, INT14).

A number of interviewees emphasised the importance of demonstrating good value for money when deciding what to invest in (INT06, INT014, INT20):

> The emphasis is on cost-effectiveness and value for money…we can only improve efficiency of existing services rather than invest in something new or we would need to provide a very strong case for doing so. (INT20)

In regard to the LTPIF target of 75 per cent of cancers being diagnosed at stage I and II, several interviewees mentioned that better diagnostics data on the performance of individual Cancer Alliances – and CCGs within them – for diagnoses at these stages would be very helpful (INT02, INT06, INT21). Similarly, a

number of interviewees highlighted the need for more timely data (INT08) and more complete coverage, for example, by the NCDA (INT19).

Interviewees were specifically asked about their awareness and experience of the CADEAS Early Diagnosis Projection Tool, which was released after the Phase one interviews, with the expectation that Alliances should use the tool to support their thinking about local needs, plans and any future funding requests. The tool aims to support Cancer Alliances in exploring their current and historical early diagnosis data in more detail (including tumour specific data), and in drawing comparisons with other areas. The tool then supports future projections by asking the Alliances to use assumptions estimating the impact of different interventions on their early diagnosis rate. The majority of Cancer Alliance representatives we spoke to reported that they were aware of the tool, but their direct experience of it varied. Most participants reported that it was useful and one participant stated it was 'brilliant' (INT23), but several had not used it directly, with the implication being that it was not part of their role, or they had dedicated analysts within the Alliance who would have used it instead. One participant reported that whilst the tool was helpful, it was delivered too late to be helpful for their submission for funding (INT06), and another felt that there had been some issues with it that led to CADEAS amending the baseline 'because there had been some data quirks' (INT13). Participants did not report any specific questions that they wanted to ask CADEAS about the tool, although some participants mentioned they had raised issues previously and these had been largely dealt with satisfactorily by CADEAS (INT06, INT20, INT23). Most participants who were aware of the tool reported that it was easy to use, but one interviewee felt that CADEAS should have provided the cancer trajectories for Cancer Alliances, rather than Alliances having to produce them (INT13).

## 4.3.    Innovations in early diagnosis in the context of the LTPIF

**Key findings:**
- Nearly all interviewees were aware of the additional innovation funding due to be available from NHS England, but knew little about how it would be obtained.
- Identified opportunities for innovations in early diagnosis of cancer in the future included:
    - The use of artificial intelligence;
    - Expansion of Rapid Diagnostic Centres;
    - Genomic testing in early diagnosis;
    - Risk stratification; and
    - Engaging more with academic research.
- If decisions that were not aligned with national priorities were made at all, these would be based on local experience and expertise, using any available funds after national priorities had been met.

### 4.3.1.    Views on the proposed innovation funding

Nearly all interviewees were aware of the additional innovation funding that was soon to be available through NHS England, but most also reported at the time of the interview that they knew very little about it. Only one interviewee reported not being aware of the additional funding opportunity (INT21). The lack of specific knowledge of how the funding stream would be accessible meant that it could not yet be considered as part of their early diagnosis strategy. Some interviewees reported that they had repeatedly

requested more information from NHS England about how funds would be allocated, but had so far received little-to-no information in response.

### 4.3.2. What are the main opportunities for innovation in early diagnosis?

Improving methods of diagnosis was crucial to one participant (INT21) and mentioned by multiple others. A number of participants explicitly mentioned the use of artificial intelligence (AI) as a developing area, but one which could be used more innovatively in early diagnosis (INT21, INT03, INT18, INT17); machine learning was similarly mentioned (INT20). Specific examples of how AI could be used in the early diagnosis context related to helping to reduce the impact of the current shortage of radiologists by using AI in radiology reporting (INT21), or for diagnostic chest x-rays or patients identified as being high risk (INT17). Rapid Diagnostic Centres – a national initiative – were also highlighted as an opportunity for innovation in early diagnosis, expanding current piloting work and helping to meet the 28-day faster diagnosis target to be introduced in April 2020 (NHS England 2019a). A number of other suggestions were also made, including:

- Genomic testing in early diagnosis (INT04, INT08, INT16, INT13);

- Risk stratification to enable better targeted screening (INT18, INT23); and

- Engaging with academic research and innovation sooner (INT14, INT22, INT13).

Two interviewees made suggestions to improve access to diagnosis for patients in rural areas or other relatively under-served populations (INT19, INT21), but were not specific in how this could be achieved through innovative design.

### 4.3.3. Decision-making process with regards to early diagnosis innovations not linked to national priorities?

When asked about how they would make decisions relating to early cancer diagnosis that were not linked to national priorities, participants provided a range of responses. Two interviewees commented that they probably would not make such decisions (INT22, INT13). A number of other interviewees suggested that they would work with their Cancer Alliance Board and clinical teams – implying that such decisions would be made in the same way as those that were linked to national priorities (INT04, INT16, INT17, INT19) – and they would base their decisions on local enthusiasm, expertise and experience in relation to the proposed intervention (INT21). Another interviewee reported that decisions would be made based on the funds available after other priorities had been met (INT08).

## 4.4. What additional support, evidence or tools would be helpful to support Cancer Alliances make decisions about early diagnosis in the light of the release of the NHS Long Term Plan Implementation Framework?

---

**Key findings:**

- Cancer Research UK is perceived by most interviewees as a highly influential and respected organisation.
- Ideas for how Cancer Research UK might support Cancer Alliances to improve early diagnosis included:
  - Shaping national guidance and influencing policymakers;
  - Continuing to provide resources, such as Cancer Research UK facilitators;
  - Providing information/analyses, such as evaluations on specific interventions;
  - Providing, or helping Cancer Alliances to develop, data analytic capacity;
  - Translating research and innovations into practice; and
  - Providing Cancer Alliances with information on how Cancer Research UK might help them.

---

Overall, the suggestions made by Cancer Alliance representatives after the release of the LTPIF were not substantively dissimilar to those made before the Framework was released. Similar to the findings in Phase one interviews, participants reported that Cancer Research UK is considered a highly influential and respected organisation, and as such could play a significant role in helping to set national priorities through identification of priority areas at a national as well as local level. Linked to this, horizon-scanning, lobbying and providing information to help guide national areas for prioritisation were also suggested areas for support (INT02, INT03, INT04, INT20, INT06, INT17).

More analysis and analytical capacity at a local level would be welcomed by some Cancer Alliances (INT04, INT19). Aligned with previous points, some interviewees felt that Cancer Research UK could assist with the provision of more timely data (INT08), enabling the translation of research into practice more quickly (INT02, INT23), more resources such as data and facilitation (INT21, INT22, INT13), and evaluative information on different interventions to assist decision-making on what to invest in (INT18, INT23). One participant felt that Cancer Research UK had a significant role to play through continuing to share evidence and data, and could perhaps increase their presence at national or regional events with Cancer Alliances (INT13).

Two participants felt that it would be useful for Cancer Research UK to be explicit about what they were able to offer Cancer Alliances (INT08, INT16).

# 5. Decision-making on investment in early diagnosis interventions for cancer in Northern Ireland in the context of the development of a new cancer strategy

At the time the research was conducted, a new cancer strategy was under development in Northern Ireland. Cancer Research UK was interested to understand how decisions are made with regards to early diagnosis interventions, and how this could be best supported. The analysis in this section is based on interviews with six respondents representing: the Department of Health in Northern Ireland (DoH), the Health and Social Care Board (HSCB), one Health and Social Care Trust (HSC Trust) and the HSC Business Services Organisation (BSO) (see Table 4).

Table 4. Interviewees in Northern Ireland

| Representation | Number of interviewees |
| --- | --- |
| Department of Health Northern Ireland (DoH) | 1 |
| Health and Social Care Board (HSCB) | 2 |
| HSC Business Services Organisation (BSO) | 2 |
| Health and Social Care Trust (HSC Trust) | 1 |

At the time the interviews were conducted (between September and November 2019), all interviewees were aware that a new cancer strategy for Northern Ireland was in preparation, but had not yet been published.

## 5.1. How are decisions around cancer interventions made?

**Key findings:**
- The Northern Ireland Cancer Network (NICaN) plays a critical role in decision-making around early diagnosis – and cancer services more generally in Health and Social Care (HSC) – in Northern Ireland.
- Decisions are influenced by evidence from, and activity in, NHS England, NHS Scotland and NHS Wales.

The main organisations involved in decision-making around investment in early diagnosis of cancer (as identified through interview findings) are shown in Figure 2. The decision-making process was described

as being 'more driven from the ground up than the top down' by one interviewee (INT102). The DoH sets the initial wider budget for spend on healthcare – including cancer (INT101, INT102, INT104) – and the HSCB is then responsible for commissioning services, including for screening, diagnosis and treatment of cancer. The Public Health Agency (PHA) provides advice to the HSCB with respect to cancer screening.

**Figure 2. Overview of decision-making process for investment in early diagnosis in Northern Ireland**
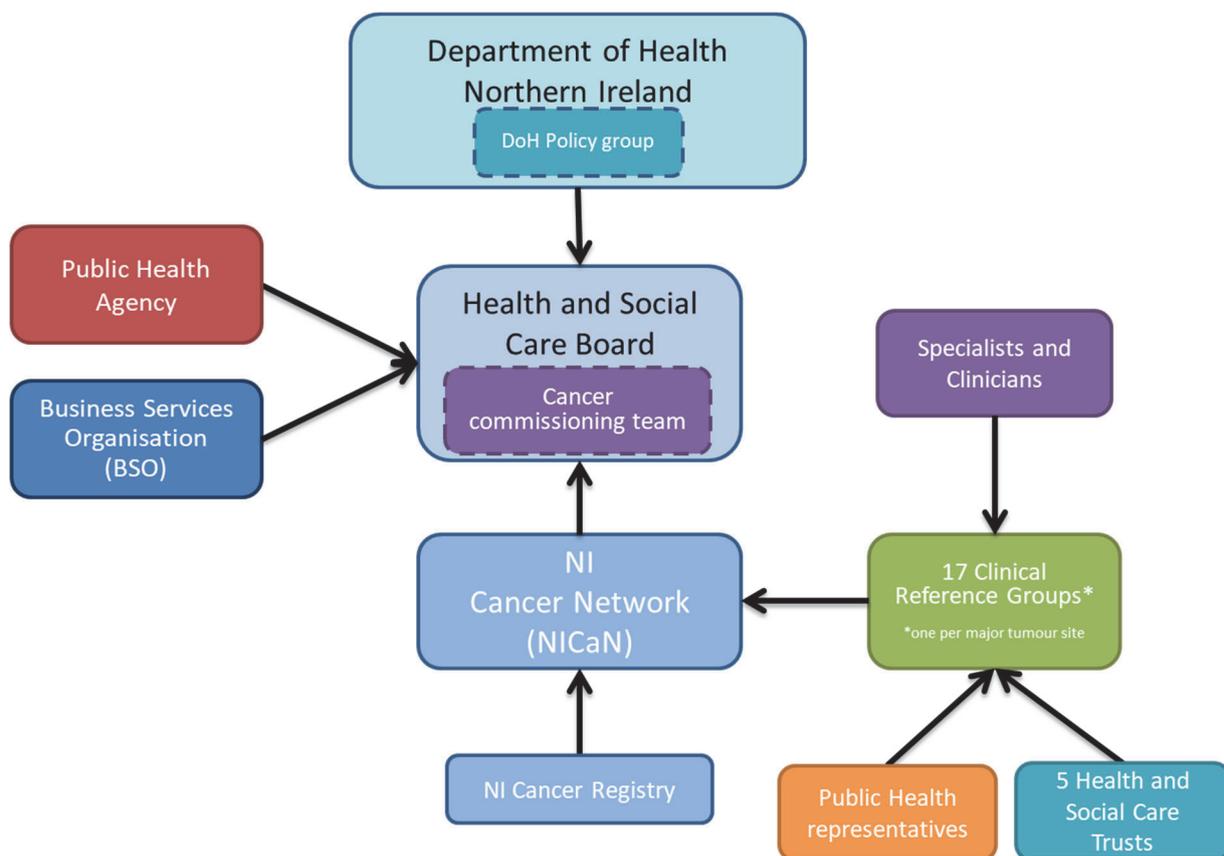


Similarly to Cancer Alliances in England, there was reported to be limited scope for HSC Trusts to invest in early diagnosis innovations at their own initiative, and they are required to wait for an invitation to make a submission for a case for change (INT102). However, prioritisation was reported to be very much a collaborative process, with several organisations and groups involved. A critical player in the prioritisation process, as highlighted by interviewees, is the Northern Ireland Cancer Network (NICaN), which is funded by the HSCB. NICaN brings together patients, healthcare professionals and managers from HSC Trusts to share best practice. Clinical expertise is provided to NICaN by 17 clinical reference groups (each of which covers either a major cancer site or a cross-cutting subject, such as systemic anti-cancer therapy). NICaN then provides information and advice to the Cancer Commissioning team within the HSCB. The final decision about funding prioritisation remains with the DoH. A 2016 report for Cancer Research UK noted that Northern Ireland's relatively small size allows members of the cancer community to interact and build relationships (Cancer Research UK 2016b).

Two interviewees reported that prioritisation is heavily influenced by what NHS England, NHS Scotland and NHS Wales are doing in relation to early cancer diagnosis interventions (INT102, INT103) and by evidence produced there.

## 5.2. What evidence is used to support decision-making for early diagnosis in Northern Ireland?

> **Key findings:**
> - Useful sources of evidence to stakeholders interviewed in Northern Ireland to support decision-making included:
>   - NICE guidance and recommendations;
>   - Local research evidence;
>   - Reports from Cancer Research UK, Macmillan and other charities;
>   - Cancer Patient Experience Survey;
>   - NICaN; and
>   - Population statistics.

A range of different sources were cited by the interviewees as being used for evidence to aid decision-making in early diagnosis. In particular, NICE guidelines and recommendations were cited as being very important as they already have a strong evidence base (INT102, INT101, INT103, INT104) and therefore are considered a reliable source for guiding decision-making. One interviewee stated explicitly that this was because NICE guidance has 'already been through a robust process' (INT102). Some interviewees referred to tools that have been developed by NICE – specifically, a template for costing the implementation of NICE's guideline on recognising and referring suspected cases of cancer (NICE 2015) (INT103, INT104). Local research evidence was also highlighted as being important (INT102).

Similar to what was reported in interviews in England, Cancer Research UK is highlighted as being a very credible source of information, and reports from them – and other cancer charities such as Macmillan – are described by two participants as being useful (INT101, INT102).

Interviewees were specifically asked about the utility of a number of sources of evidence, including:

- DoH diagnostic service reports (Department of Health NI 2019b);

- Population statistics and census data (NISRA 2019);

- Cancer Patient Experience Survey data (Quality Health 2019); and

- Northern Ireland Cancer Registry (Queen's University Belfast 2019).

Interviewees reported that the majority of these sources were useful. Specifically, the DoH diagnostic service reports were considered 'very useful' by two of the interviewees (INT101, INT102) – as were the Cancer Patient Experience Survey data (INT101, INT102). Interviewees also reported that the population statistics data are used to guide decision-making (INT101, INT102), as are data from the Northern Ireland Cancer Registry, run by Queen's University Belfast (INT102). One interviewee highlighted a new report on pathways to cancer diagnosis and their impact on outcomes, not yet published at the time of the interview,

that was expected to support decision-making for early diagnosis, as well as cancer services more widely (INT101). This report by the HSC Business Services Organisation (BSO) and Queen's University Belfast – with support from the HSCB and DoH information staff – drew on Cancer Registry and other data, and was published in January 2020 (HSC BSO and Queen's University Belfast 2020).

In contrast, the majority of interviewees reported that the National Census data were not used (INT101, INT102, INT103), with one participant (INT103) citing that, because it is only updated every ten years, the data were too out-of-date to be of use (the last census survey was completed in 2011).

In half of the interviews, participants emphasised the necessity of using evidence in their decision-making and ensuring that decisions are always evidence-based (INT101, INT102, INT104). One participant suggested that no decision would be made for or against an intervention without strong evidence to support it (INT102), although another interviewee speculated that some decisions may need to be made without the strong evidence to support it (INT101). A lack of evidence was not cited by any of the interviewees as a cause for decisions to be hindered, although some interviewees felt that more population-level data (INT104) and data on cancer recurrence (INT105) would be valuable.

## 5.3.    What new early diagnosis interventions are being considered?

> **Key findings:**
> - While there were no commonly proposed areas for future research, routine annual provision of data – similar to that provided by PHE and CADEAS in England – was advocated.

Current areas of investment include faecal immunochemical test (FIT) screening, primary HPV screening, and immunohistochemistry screening for Lynch Syndrome[11] in people with colorectal cancer (as recommended by NICE in February 2017 (NICE 2017a)) (INT103, INT104). Lynch Syndrome had not been mentioned in any of the interviews in England. One interviewee reported that although genomic medicine is a major area for research at present, currently it is used more in treatment than prevention (INT102).

One interviewee reported on the even greater need in Northern Ireland than the rest of the UK for improving public awareness, early detection and diagnosis of cancer as '[patient] outcomes in Northern Ireland are not as good as the rest of the UK.' This interviewee specifically articulated the need to invest more in lung-health checks and bowel endoscopies; in the latter case because, they said, more colorectal cancers are diagnosed through routine endoscopies than via the 'red flag' symptom process. But there is a substantial waiting list in Northern Ireland, leading to unacceptable delays in diagnosis (INT102). The need to ensure that people with high-risk factors are followed up appropriately was highlighted as a priority area by another interviewee (INT104).

An interviewee from the BSO expressed the hope that in future an appropriate HSC organisation (be it the Cancer Registry, DoH, BSO, PHA or a collaboration of partners) would be in the position to make cancer

---

[11] Lynch Syndrome is an inherited condition caused by genetic changes in some genes. Lynch syndrome is associated with a higher risk of developing certain types of cancers, including colorectal cancer (NICE 2017b).

routes-to-diagnosis activity – and related data – available annually for HSC staff. This was based on the experience of producing, on a one-off basis, the pathways report referred to earlier (INT102). They hoped to see continuation of the pathways-to-diagnosis project to tackle the information gap in Northern Ireland, filling a similar role to that of PHE and CADEAS with respect to cancer pathways data and analysis in England. To do so would fill 'a big information gap in Northern Ireland' (INT102) and support decision-making for early diagnosis, as well as cancer services more widely, in Northern Ireland.

## 5.4. What additional support, evidence or tools would be helpful to support decisions about early diagnosis in Northern Ireland?

**Key findings:**
- Work by Cancer Research UK was praised, including the 2019 workforce report, and benchmarking information.
- Interviewees gave few specific suggestions for how Cancer Research UK could help further.
- Cancer Research UK was perceived by interviewees in Northern Ireland as a highly influential and credible organisation.

Nearly all interviewees praised and valued the work of Cancer Research UK, with one interviewee stating that Cancer Research UK has 'their finger on the pulse' and that their ability to 'hold the mirror up' and share what is taking place in the wider UK is invaluable (INT102). In particular, a number of interviewees cited Cancer Research UK's work on the cancer workforce in Northern Ireland (Cancer Research UK 2019c) as being particularly helpful (INT101, INT103, INT104); provision of benchmarking information was considered very useful too (INT101, INT102, INT104).

Similar to the findings from the interviewees in England, Cancer Research UK is highly respected by interviewees in Northern Ireland and is considered very credible with decision makers.

# 6.  Concluding remarks

This report presents the findings from an interview-based study aimed at helping Cancer Research UK's Early Diagnosis programme to understand how decisions about early diagnosis interventions are made locally, how effective available resources are and what additional support would be most useful in England and Northern Ireland. Our findings are drawn from detailed analysis of more than 30 interviews with Cancer Alliance and national-level staff in England – including interviewees from 14 (74 per cent) of the 19 Alliances – plus 6 interviewees in Northern Ireland.

The study has a number of strengths: we secured a good representation of English Cancer Alliances and spoke to a number of key stakeholders in England at national level, giving us a broad range of views and observing a number of clear themes emerging from the interviews. Using an interview approach has meant we have obtained rich data.

The study also has limitations that should be acknowledged when interpreting our findings. Firstly, the sample size of interviewees representing Northern Ireland is small. Despite best efforts, we were unable to secure interviews with a number of contacts, particularly at local level, which means the views reported here may be biased towards a national perception.

Secondly, the release of the LTPIF may have influenced participants' responses and views in a different way to those interviewed in Phase one (which occurred prior to the release of the LTPIF). Whilst we have incorporated new Cancer Alliance representatives that were interviewed during Phase two into the Phase one analyses, and we note that responses did not differ substantively between Phase one and Phase two interviewees, the results should be interpreted with caution.

Thirdly, there may be a degree of self-selection bias across our sample. Potential participants who were approached but either declined to participate or did not respond, might have held different views to those who did reply to our questions.

Among those we interviewed both in England and Northern Ireland, while views on many questions varied, a balance between pragmatism and a desire for a robust evidence base on which to build decision-making was evident generally. In England, investments to improve early diagnosis are being made in all Cancer Alliances. The 75 per cent target for diagnosis at Stages I and II by 2028 – as set out in the LTP – has both focused planned service investments and generated a desire for evidence on how best to achieve that level of improvement in practice. In Northern Ireland, the process of developing a new cancer strategy is focusing attention on how to improve cancer survival, and has stimulated new data analysis on pathways to cancer diagnosis and treatment.

As well as the kinds of data and evidence available, local decision-making around early diagnosis is affected by factors including underlying population health needs relative to the resources available, the public's level of awareness of cancer, current performance on uptake of diagnostic and screening services, and the availability of data analytic resource locally – but evidence is nevertheless plainly important.

There was no consensus around the best way for Cancer Research UK to provide such support in future, but there was a large number of varied suggestions, as set out in this report. We heard requests for more granular and timely data from some Cancer Alliances, and a desire in Northern Ireland for routine provision of data corresponding to that which PHE and CADEAS provide to Cancer Alliances in England. Those Cancer Alliances with in-house analytical capacity focused on the provision of data, while those less well-equipped with such capacity sought help with analysis as well as with the data itself.

The desire for more and better evidence to steer decision-making in the NHS and HSC about investments in early cancer diagnosis was universal among the people we interviewed. CADEAS has been seen as a positive step towards meeting these needs. Suggestions for supporting investment decisions around early diagnosis included: more access to analysis, more locally specific data by tumour site, additional return on investment tools, and more intervention-specific analysis of impacts and health economics. Primary care has not been made a priority in the 2019/20 Transformation Funding process, but is still seen as a key component of early diagnosis. Continued efforts to support recognition and referral in primary care would be welcomed.

Cancer Research UK is widely seen, both at local and national organisations in England and Northern Ireland, as a highly influential and credible source of information, including about early diagnosis and ways of improving it. The people we interviewed reinforced the desirability of Cancer Research UK continuing to make use of its reputation and resources to support moves to improve early diagnosis.

# References

Arnold, Melina, Mark J. Rutherford, Aude Bardot, Jacques Ferlay, Therese M.L. Andersson, Tor Åge Myklebust, Hanna Tervonen, Vicky Thursfield, David Ransom & Lorraine Shack. 2019. 'Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study.' *The Lancet Oncology* 20(11): 1493–505.

CADEAS. 2019. 'CADEAS Work Programme 2019/20.' April 2019. As of 15 November 2019:
http://www.ncin.org.uk/view?rid=3967

Cancer Research UK. 2016a. 'Return on Investment (RoI) Tools.' As of 28 November 2019:
https://www.cancerresearchuk.org/health-professional/learning-and-support/planners-and-commissioners/return-on-investment-roi-tools

———. 2016b. 'Where Next For Cancer Services In Northern Ireland? An Evaluation Of Priorities To Improve Patient Care.' As of 21 November 2019:
https://www.cancerresearchuk.org/sites/default/files/cancer_services_in_ni_full_report.pdf

———. 2018a. 'Securing A Cancer Workforce For The Best Outcomes: The Future Demand For Cancer Workforce In England – November 2018.' As of 15 November 2019:
https://www.cancerresearchuk.org/sites/default/files/securing_a_cancer_workforce_for_the_best_outcomes_november_2018_full_report.pdf

———. 2018b. 'Why is early diagnosis important?' As of 21 November 2019:
https://www.cancerresearchuk.org/about-cancer/cancer-symptoms/why-is-early-diagnosis-important

———. 2018c. 'Worldwide cancer mortality statistics.' As of 21 November 2019:
https://www.cancerresearchuk.org/health-professional/cancer-statistics/worldwide-cancer/mortality

———. 2019a. 'Lung Health Checks.' As of 15 November 2019:
https://www.cancerresearchuk.org/about-cancer/lung-cancer/getting-diagnosed/lung-health-checks

———. 2019b. 'National Cancer Diagnosis Audit Overview.' As of 18 November 2019:
https://www.cancerresearchuk.org/health-professional/diagnosis/national-cancer-diagnosis-audit/ncda-overview

———. 2019c. 'Cancer Research UK Policy Paper: The Diagnostic Workforce in Northern Ireland.' As of 14 January 2020:
https://www.cancerresearchuk.org/sites/default/files/cruk_ni_diagnostic_workforce_paper_july_2019_0.pdf

Clayton, C. & S. McNulty. 2018. 'Supporting primary & secondary care communication: A speed dating approach.' cancerresearchuk.org. As of 15 November 2019:
https://www.cancerresearchuk.org/sites/default/files/8._speed_dating_sm.pdf

Department of Health NI. 2019a. 'Department announces way forward on a new cancer strategy.' As of 21 November 2019:
https://www.health-ni.gov.uk/news/department-announces-way-forward-new-cancer-strategy

———. 2019b. 'Diagnostic waiting times.' Department of Health NI. As of 18 November 2019: https://www.health-ni.gov.uk/articles/diagnostic-waiting-times

HSC Business Services Organisation and Queen's University Belfast. 2020. 'Pathways to a cancer diagnosis: monitoring variation in the patient journey across Northern Ireland 2012 to 2016.' HSC Business Services Organisation. As of 9 February 2020: http://www.hscbusiness.hscni.net/pdf/Routes%20to%20Diagnosis%20Report%20-%20Main%20Report%20Jan%202020.pdf

Incisive Health. 2014. 'Saving lives, averting costs: An analysis of the financial implications of achieving earlier diagnosis of colorectal, lung and ovarian cancer.' September 2014. As of 15 November 2019: https://www.cancerresearchuk.org/sites/default/files/saving_lives_averting_costs.pdf

Independent Cancer Taskforce. 2015. 'Achieving World-Class Cancer Outcomes A Strategy For England 2015–2020.' As of 15 January 2020: https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

National Cancer Patient Experience Survey. 2019. 'Welcome to the National Cancer Patient Experience Survey.' As of 15 November 2019: https://www.ncpes.co.uk/

NHS. 2019a. 'The NHS Long Term Plan.' As of 15 November 2019: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

———. 2019b. 'NHS Long Term Plan Implementation Framework.' As of 15 November 2019: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/06/long-term-plan-implementation-framework-v1.pdf

NHS England. 2018. 'Cancer Alliances – Improving care locally.' As of 28 November 2019: https://www.england.nhs.uk/cancer/improve/cancer-alliances-improving-care-locally/

———. 2019a. 'Diagnosing cancer earlier and faster.' As of 15 November 2019: https://www.england.nhs.uk/cancer/early-diagnosis/

———. 2019b. 'Funding and support for Cancer Alliances.' As of 15 November 2019: https://www.england.nhs.uk/cancer/improve/cancer-alliances-improving-care-locally/nhs-england-support-and-funding-for-cancer-alliances/

NICE. 2015. 'Costing statement: Suspected cancer. Implementing the NICE guideline on suspected cancer: recognition and referral (NG12).' As of 15 November 2019: https://www.nice.org.uk/guidance/ng12/resources/costing-statement-pdf-74145421

———. 2017a. 'Molecular testing strategies for Lynch syndrome in people with colorectal cancer.' As of 15 November 2019: https://www.nice.org.uk/guidance/dg27/informationforpublic

———. 2017b. 'Molecular testing strategies for Lynch syndrome in people with colorectal cancer: Information for the public.' As of 15 November 2019: https://www.nice.org.uk/guidance/dg27/informationforpublic

———. 2020. 'National Institute for Health and Care Excellence.' As of 22 January 2020: https://www.nice.org.uk

NISRA. 2019. 'Health and Social Care Statistics.' As of 18 November 2019: https://www.nisra.gov.uk/statistics/health-and-social-care/health-and-social-care-statistics

Public Health England. 2010. 'The Cancer Alliance Data, Evidence and Analysis Service (CADEAS).' As of 15 November 2019: http://www.ncin.org.uk/local_cancer_intelligence/cadeas

———. 2016. 'Return on investment tool: colorectal cancer.' As of 20 January 2020: https://www.gov.uk/government/publications/return-on-investment-tool-colorectal-cancer

———. 2019. 'Public Health Profiles: Cancer Services.' As of 15 November 2019: https://fingertips.phe.org.uk/profile/cancerservices

Quality Health. 2019. 'Northern Ireland Cancer Patient Experience Survey.' As of 9 February 2020: http://www.hscboard.hscni.net/download/PUBLICATIONS/PERSONAL%20PUBLIC%20INVOLVEMENT/Northern-Ireland-Cancer-Patient-Experience-Survey-2018.pdf

Queen's University Belfast. 2019. 'N. Ireland Cancer Registry.' As of 18 November 2019: https://www.qub.ac.uk/research-centres/nicr/AboutUs/international-links/

# Annex A. Protocol for Cancer Alliance interviews in Phase one

Cancer Research UK Early Cancer Diagnosis Interview protocol: Representatives of Cancer Alliances

### Preamble

RAND Europe has been commissioned by Cancer Research UK to improve understanding of how commissioners of healthcare services and Cancer Alliances make decisions at a local level about early diagnosis interventions for cancer. The study will not only explore how these decisions are made, but also the evidence and tools that are used to support those decisions, how effective these resources are and what new updates, evidence and tools would be most useful in this space.

The findings from the study will help to inform Cancer Research UK's work on improving early cancer diagnosis locally, and thereby improving cancer outcomes.

*Verify whether the interviewee has read, completed and returned the consent form and whether they consent to audio recording.*

*[Switch on recorder]*

*As a reminder: in any written documents from this interview, we will only use anonymous quotes and will not introduce any information in the quotes that would make the interviewee identifiable.*

### Questions:

*The decision-making process*

1. In this interview, we'll be focusing on investing in interventions for early diagnosis of cancer. But to start, thinking more broadly across the full remit of the Cancer Alliances, how are decisions made about what the Alliances invest their resources in?

Now focusing on interventions for early diagnosis:

2. What is the role of the Cancer Alliance in decisions about whether to invest in early diagnosis interventions in your region and who else is involved in those decisions?

3. How are decisions made in your Cancer Alliance about investing in interventions for early diagnosis? *Probe:*

   o Who is involved in making the decisions?

   o What is your role in the decision-making process?

4.  What types of evidence are used to inform decisions made in your Cancer Alliance about investing in interventions for early diagnosis?

    o   Are there any specific tools or resources that are particularly useful (or not useful) to help in the decision-making process? *Do not prompt with examples at this stage.*

5.  Has a lack of evidence or suitable tools hindered or prevented you from making decisions about interventions in early diagnosis?

*Thinking about a specific example: the Transformation Funding round in March 2019*

6.  We are aware that all Cancer Alliances were asked in March to submit information about how they would spend their allocated Transformation Funding. Could you talk me through the process for deciding how those funds would be spent?

7.  What were the pros and cons, in your view, of the process used by NHS England for allocating this round of Transformation Funding?

    o   As compared to previous years?

    o   Was there anything your Alliance would have liked to do with this funding but could not due to limitations in how the funds could be spent?

8.  What evidence, tools or resources were used to inform or aid the decision-making in this case? *Probe:*

    o   What was helpful about it/them?

    o   Were there any problems with it/them?

    o   *Prompt with specific examples:*

        -   Information from CADEAS (The Cancer Alliance Data, Evidence and Analysis Service).
        -   PHE's Return on Investment tool [Developed in response to the limitations of Cancer Research UK's report 'Saving lives, averting costs' as the model for that was deemed not robust enough for local level use, but the PHE tool has the limitation that there was limited support available for its use once it was developed.]

*Future development of toolkits/resources*

9.  What other early diagnosis interventions is your Cancer Alliance currently considering, or likely to consider in the next 1–2 years?

10. If you could ask Cancer Research UK for support (other than financial) for one thing to help you improve early diagnosis of cancer in your region, what would it be?

    o   Specifically, would any other evidence or tools be of help for those decisions or other future decisions in this area? *Possible areas to probe for more detail:*
        -   <u>What</u> would it look like? How would it measure outcomes and impact?
        -   <u>How</u> would it help?
        -   <u>Who</u> would you expect to be involved in developing it?
        -   <u>What</u> factors would you consider in deciding whether it is useful and reliable (or not)?
        -   <u>What</u> would be the best way to let you know that a new toolkit/resource is available?

*Close interview*

11. Is there anyone else you think we should talk to, either in your Cancer Alliance area or in another organisation? *[Internal note: at one or more of the CCGs or Local Authorities?]*

12. Did you have anything else to add?


*Thank participant for taking part.*

# Annex B. Protocol for national level key informant interviews in England

**Cancer Research UK Early Cancer Diagnosis Interview protocol: Representatives of NHS England and Public Health England**

### Preamble

RAND Europe has been commissioned by Cancer Research UK to improve understanding of how decisions are made about investment in early diagnosis interventions for cancer. The study not only explores how these decisions are made, but also how they may be supported, including the evidence and tools that are used to support those decisions, how effective these resources are and what new or updated evidence and tools would be most useful in this space.

The findings from the study will help to inform Cancer Research UK's work on improving early cancer diagnosis locally, and thereby improving cancer outcomes.

*Verify whether the interviewee has read, completed and returned the consent form and whether they consent to audio recording.*

*As a reminder: in any outputs drawing on this interview, we will only use direct quotes with the interviewee's permission but we cannot guarantee anonymity as we are only conducting a small number of interviews at national bodies and the information provided in these interviews may in effect make the interviewee identifiable. Before proceeding, confirm that the interviewee is happy to continue on this basis.*

*[Switch on recorder]*

### Questions:

*The decision-making process*

1. In this interview, we'll be focusing on investing in interventions for early diagnosis of cancer. But to start, thinking more broadly across the full remit of NHS England/PHE with respect to cancer, how are decisions made about what the NHS (and local government, for public health activities) invest their resources in?

Now focusing on interventions for early diagnosis:

2. What is the role of your organisation in decisions about whether to invest in early diagnosis interventions in England and who else is involved in those decisions?

3. How are decisions made in your organisation about investing in interventions for early diagnosis? *Probe:*

    o Who is involved in making the decisions?

  o What is your role in the decision-making process?

4. What types of evidence are used to inform decisions made in your organisation about investing in interventions for early diagnosis?

  o Are there any specific tools or resources that are particularly useful (or not useful) to help in the decision-making process? *Do not prompt with examples at this stage.*

5. What types of evidence, tools and resources are, to your knowledge, available to and used by Cancer Alliances and other local organisations involved in decisions about interventions for early diagnosis?

6. Has a lack of evidence or suitable tools hindered or prevented you from making decisions about interventions in early diagnosis?

7. In your view, has a lack of evidence or suitable tools hindered or prevented Cancer Alliances and other local organisations from making decisions about interventions in early diagnosis?

*Thinking about a specific example: the Transformation Funding round in March 2019*

8. *[Q for NHS England but not PHE]* We are aware that all Cancer Alliances were asked in March to submit information to NHS England about how they would spend their allocated Transformation Funding. Could you describe the extent to which national bodies (NHS England, Department of Health and Social Care, NICE, PHE) prescribed how those funds would be spent, and the extent to which Cancer Alliances retained discretion over how those funds would be spent?

9. *[Q for NHS England but not PHE]* Could you talk me through how NHS England carried out its part in the process for deciding how those funds would be spent?

10. *[Q for NHS England but not PHE]* What were the pros and cons, in your view, of the process used by NHS England for allocating this round of Transformation Funding as compared to the process in previous years?

11. *[Q for NHS England but not PHE]* What evidence, tools or resources were used by NHS England to inform or aid the decision-making in this case?
*Probe:*

  o What was helpful about it/them?

  o Were there any problems with it/them?

  o *Prompt with specific examples:*

    - Information from CADEAS (The Cancer Alliance Data, Evidence and Analysis Service).

    - PHE's Return on Investment tool [Developed in response to the limitations of Cancer Research UK's report 'Saving lives, averting costs' as the model for that was deemed not robust enough for local level use, but the PHE tool has the limitation that there was limited support available for its use once it was developed.]

*Thinking about evidence and toolkits/resources specifically*

12. *[Q for PHE but not NHS England]* What evidence, tools or resources have been provided by PHE to NHS England, Cancer Alliances and others in the last three years to support decisions about investment in early diagnosis?

*Future development of evidence and toolkits/resources*

13. What other early diagnosis interventions is your organisation currently considering, or likely to consider in the next 1–2 years?

14. If you could ask Cancer Research UK for support (other than financial) for one thing to help you improve early diagnosis of cancer nationally and/or locally, what would it be?

   o Specifically, would any other evidence or tools be of help to support decisions about investment in early diagnosis interventions or other future decisions in this area? *Possible areas to probe for more detail:*
      - <u>What</u> would it look like? How would it measure outcomes and impact?
      - <u>How</u> would it help?
      - <u>Who </u>would you expect to be involved in developing it?
      - <u>What </u>factors would you consider in deciding whether it is useful and reliable (or not)?
      - <u>What</u> would be the best way to let you know that a new toolkit/resource is available?

*Close interview*

15. Did you have anything else to add?

*Thank participant for taking part.*

# Annex C. Protocol for follow-up interviews with Cancer Alliances

**Cancer Research UK Early Cancer Diagnosis Interview protocol: Representatives of Cancer Alliances**

### Preamble

Thank you for agreeing to participate in a follow up interview for the project commissioned by Cancer Research UK to improve understanding of how commissioners of healthcare services and Cancer Alliances make decisions at a local level about early diagnosis interventions for cancer. In the first round of interviews, we gained valuable insight into how these decisions are made, as well as the evidence and tools used to support those decisions, how effective these resources are and what new updates, evidence and tools would be most useful in this space. Following the release of the NHS Long Term Plan Implementation Framework, Cancer Research UK is keen for us to explore with you how the Cancer Alliances view the Framework and how it is likely to affect your current and future activities.

The findings from the study will inform Cancer Research UK's work supporting the NHS to improve early cancer diagnosis locally, and thereby improve cancer outcomes.

*Verify whether the interviewee has read, completed and returned the consent form and whether they consent to audio recording. Reassure the interviewee that we will not be asking for a third interview.*

*[Switch on recorder]*

*As a reminder: in any written documents from this interview, we will only use anonymous quotes and will not introduce any information in the quotes that would make the interviewee identifiable.*

### Questions:

1. Since we last spoke, the NHS released the Long Term Plan Implementation Framework, which has implications for early cancer diagnosis. So we wanted to speak with you again to understand how it might affect decision-making related to early diagnosis in cancer. Before we discuss some specific points, are there any general comments you would like to make about the Implementation Framework?

2. Does the Implementation Framework provide sufficient clarity on how NHS England expects the Cancer Alliances to implement national priorities and the expected roles of the different structures (i.e. Primary Care Networks, Cancer Alliances) in improving early cancer diagnosis?

3. How does the LTP Implementation Framework affect the early diagnosis planning work carried out by your CA to date? How do the activities under the Implementation Framework align with the activities you were planning related to early diagnosis?

4. Does the Long Term Plan Implementation Framework allow enough flexibility for Cancer Alliances to decide what to invest in with regards early diagnosis of cancer?

5. What aspects of the Framework are easiest/hardest to implement in your Alliance? *Probe:*
    o New national genomic medicine service, which Cancer Alliances are expected to work with
    o Engagement with primary care networks

6. In the Implementation Framework, funding will be distributed through two streams: indicative funding (which will be population based) and targeted funding (which will depend on specific schemes and investments). How will this approach affect how you make decisions about interventions for early diagnosis of cancer?
    o What resources and tools would you find useful to support those decisions?
    o Is there any way Cancer Research UK could help support you in those decisions?

7. Another challenge identified by some Cancer Alliances we spoke to was that receiving funding annually, with different priorities each year, meant it was difficult to build on what was done from one year to the next. In your opinion, does the Implementation Framework help alleviate or otherwise affect this problem?

8. One concern that was raised by some Cancer Alliances we spoke to earlier was that they found the time they had to provide information on how they would use Transformation Funding was too short. The NHS Long Term Plan Implementation Framework was released in June 2019 with a deadline for strategic plans to be submitted in November 2019. In your opinion, does the June release of the Implementation Framework provide sufficient time to deliver a five-year strategic plan by November 2019?

9. Another challenge associated with the annual funding was that it is more difficult to retain staff and plan staffing. In your view, does the longer term outlook of the Implementation Framework mitigate this issue?

10. CADEAS is developing an early diagnosis (ED) projection tool to support Cancer Alliances in exploring their current and historical early diagnosis data in more detail (including tumour specific data) and draw comparisons with other areas. The tool then supports future projections by asking the Alliances to use assumptions estimating the impact of different interventions on their early diagnosis rate.
    o Are you familiar with this tool? Do you have any general comments on it?
    o Do you/have you had questions about it for CADEAS?
    o Do you feel you have the expertise to use it? What support do you need?

11. The Implementation Framework discussed the importance of research and innovation, and describes plans to further encourage innovation and the adoption of innovations. Where do you think the main opportunities are for innovation related to early diagnosis of cancer?

12. There may be additional innovation funding being introduced by NHS England for Cancer Alliances, and the LTP implementation framework talks about working with Cancer Alliances to test and roll out innovations. Is this something you are aware of and thinking about in your Alliance?

     o   How would you make decisions on whether to help test or develop innovations that are not directly related to national priorities?

13. Any final comments on how Cancer Research UK could support Cancer Alliances and decision-making around early diagnosis of cancer, in light of the Implementation Framework?

*Close interview*

14.  Is there anyone else you think we should talk to, either in your Cancer Alliance area or in another organisation? *[Internal note: at one or more of the CCGs or Local Authorities?]*

15.  Did you have anything else to add?

*Thank participant for taking part.*

# Annex D. Protocol for Phase two Cancer Alliances (new respondents)

**Cancer Research UK Early Cancer Diagnosis Interview protocol: Representatives of Cancer Alliances**

### Preamble

RAND Europe has been commissioned by Cancer Research UK to improve understanding of how commissioners of healthcare services and Cancer Alliances make decisions at a local level about early diagnosis interventions for cancer. In the first round of interviews, we gained valuable insight into how these decisions are made, as well as the evidence and tools used to support those decisions, how effective these resources are and what new updates, evidence and tools would be most useful in this space. Following the release of the NHS Long Term Plan Implementation Framework, Cancer Research UK is keen for us to explore with you how the Cancer Alliances view the Framework and how it is likely to affect your current and future activities.

The findings from the study will help to inform Cancer Research UK's work on improving early cancer diagnosis locally, and thereby improving cancer outcomes.

*Verify whether the interviewee has read, completed and returned the consent form and whether they consent to audio recording.*

*[Switch on recorder]*

*As a reminder: in any written documents from this interview, we will only use anonymous quotes and will not introduce any information in the quotes that would make the interviewee identifiable.*

### Questions:

*The decision-making process*

1. In this interview, we'll be focusing on investing in interventions for early diagnosis of cancer. But to start, thinking more broadly across the full remit of the Cancer Alliances, how are decisions made about what the Alliances invest their resources in?

Now focusing on interventions for early diagnosis:

2. What is the role of the Cancer Alliance in decisions about whether to invest in early diagnosis interventions in your region and who else is involved in those decisions?

3. How are decisions made in your Cancer Alliance about investing in interventions for early diagnosis? *Probe:*

- o  Who is involved in making the decisions?

- o  What is your role in the decision-making process?

4.  What types of evidence are used to inform decisions made in your Cancer Alliance about investing in interventions for early diagnosis?

- o  Are there any specific tools or resources that are particularly useful (or not useful) to help in the decision-making process? *Prompt with specific examples:*

    - Information from CADEAS (The Cancer Alliance Data, Evidence and Analysis Service).
    - PHE's Return on Investment tool [Developed in response to the limitations of Cancer Research UK's report 'Saving lives, averting costs' as the model for that was deemed not robust enough for local level use, but the PHE tool has the limitation that there was limited support available for its use once it was developed.]

5.  Has a lack of evidence or suitable tools hindered or prevented you from making decisions about interventions in early diagnosis?

**We know things have changed since the last round of transformation funding in March 2019 and we want to also discuss that, but first would like to discuss how it went the first time. So, thinking about a specific example – the Transformation Funding round in March 2019:**

6.  We are aware that all Cancer Alliances were asked in March to submit information about how they would spend their allocated Transformation Funding. Could you talk me through the process for deciding how those funds would be spent?

- o  What were the pros and cons, in your view, of this process?

**The NHS released the Long Term Plan Implementation Framework in June 2019, which has implications for early cancer diagnosis. So we wanted to speak with you to understand how it might affect decision-making related to early diagnosis in cancer.**

7.  Before we discuss some specific points, are there any general comments you would like to make about the Implementation Framework?

8.  Does the Implementation Framework provide sufficient clarity on how NHS England expects the Cancer Alliances to implement national priorities and the expected roles of the different structures (i.e. Primary Care Networks, Cancer Alliances) in improving early cancer diagnosis?

9.  Does the Long Term Plan Implementation Framework allow enough flexibility for Cancer Alliances to decide what to invest in with regards early diagnosis of cancer?

10. What aspects of the Framework are easiest/hardest to implement in your Alliance? *Probe:*
- o  New national genomic medicine service, which Cancer Alliances are expected to work with
- o  Engagement with primary care networks

11. In the Implementation Framework, funding will be distributed through two streams: indicative funding (which will be population based) and targeted funding (which will depend on specific schemes and investments).

   o How will this approach affect how you make decisions about interventions for early diagnosis of cancer?

   o What resources and tools would you find useful to support those decisions?

   o Is there any way Cancer Research UK could help support you in those decisions?

12. Another challenge identified by some Cancer Alliances we have already spoken to was that receiving funding annually, with different priorities each year, meant it was difficult to build on what was done from one year to the next. In your opinion, does the Implementation Framework help alleviate or otherwise affect this problem?

13. One concern that was raised by some Cancer Alliances we spoke to earlier was that they found the time they had to provide information on how they would use Transformation Funding was too short. The NHS Long Term Plan Implementation Framework was released in June 2019 with a deadline for strategic plans to be submitted in November 2019. In your opinion, does the June release of the Implementation Framework provide sufficient time to deliver a five-year strategic plan by November 2019?

14. Another challenge associated with the annual funding was that it is more difficult to retain staff and plan staffing. In your view, does the longer-term outlook of the Implementation Framework mitigate this issue?

*Future developments*

15. CADEAS is developing an early diagnosis (ED) projection tool to support Cancer Alliances in exploring their current and historical early diagnosis data in more detail (including tumour specific data) and draw comparisons with other areas. The tool then supports future projections by asking the Alliances to use assumptions estimating the impact of different interventions on their early diagnosis rate.

   o Are you familiar with this tool? Do you have any general comments on it?

   o Do you/have you had questions about it for CADEAS?

   o Do you feel you have the expertise to use it? What support do you need?

16. What other early diagnosis interventions is your Cancer Alliance currently considering, or likely to consider in the next 1–2 years?

17. How does the LTP Implementation Framework affect the early diagnosis planning work carried out by your CA to date? How do the activities under the Implementation Framework align with the activities you were planning related to early diagnosis?

18. The Implementation Framework discussed the importance of research and innovation, and describes plans to further encourage innovation and the adoption of innovations. Where do you think the main opportunities are for innovation related to early diagnosis of cancer?

19. There may be additional innovation funding being introduced by NHS England for Cancer Alliances, and the LTP implementation framework talks about working with Cancer Alliances to test and roll out innovations. Is this something you are aware of and thinking about in your Alliance?

    o   How would you make decisions on whether to help test or develop innovations that are not directly related to national priorities?

20. If you could ask Cancer Research UK for support (other than financial) for one thing to help you improve early diagnosis of cancer in your region, what would it be?

*Close interview*

21. Is there anyone else you think we should talk to, either in your Cancer Alliance area or in another organisation? *[Internal note: at one or more of the CCGs or Local Authorities?]*

22. Did you have anything else to add?

*Thank participant for taking part.*

# Annex E. Protocol for Northern Ireland interviews

### Preamble

RAND Europe has been commissioned by Cancer Research UK to improve understanding of how decisions are made about early diagnosis interventions for cancer – at a local level and a higher level. The study will not only explore how these decisions are made, but also the evidence and tools that are used to support those decisions, how effective these resources are and what new updates, evidence and tools would be most useful in this space.

The findings from the study will help to inform Cancer Research UK's work on improving early cancer diagnosis locally, and thereby improving cancer outcomes. The work will also help Cancer Research UK provide useful inputs to the development of the cancer strategy in Northern Ireland.

*Verify whether the interviewee has read, completed and returned the consent form and whether they consent to audio recording.*

*[Switch on recorder]*

*As a reminder: in any written documents from this interview, we will only use anonymous quotes and will not introduce any information in the quotes that would make the interviewee identifiable.*

### Proposed Questions:

*The decision-making process*

1.  In this interview, we'll be focusing on investing in interventions for early diagnosis of cancer. But to start, thinking more broadly across the full remit of the Department/HSCB/networks/Trusts *[identify appropriate option for each interviewee]*, how are decisions made about what to invest resources in?

Now focusing on interventions for early diagnosis:

2.  What is the role of the DHNI/HSCB/Network/Trust (identify appropriate option for each interviewee) in decisions about whether to invest in early diagnosis interventions, and who else is involved in those decisions?

    *Clarification questions for different interviewees:*

    - HSCB/Clinical networks: Query whether diagnostics falls within the remit of cancer commissioning or regular commissioning.
    - Clinical networks: What is the input of the network in the interpretation of commissioning direction (or indeed into what the direction should be – advance planning).

3. How are decisions made in Northern Ireland about investing in interventions for early diagnosis? *Probe:*

   o Who is involved in making the decisions?

   o What is your role in the decision-making process?

4. What types of evidence are used to inform decisions about investing in interventions for early diagnosis?

   o Are there any specific tools or resources that are particularly useful (or not useful) to help in the decision-making process? *Do not prompt with examples initially.*

   o We are aware of a few potentially relevant data sources. If I go through them, could you tell me whether you think they are useful or not and how much they are actually used to your knowledge?

      - Department of health diagnostic services reports on wait times;

      - HSC population statistics;

      - National census data; and

      - Cancer Patient experience data.

   o Do you think there are any other relevant sources of data that may be used when decisions are being made about early diagnosis interventions?

5. Has a lack of evidence or suitable tools hindered or prevented you from making decisions about interventions in early diagnosis?

## Thinking about the new cancer strategy currently under development in Northern Ireland (announced in March 2019):

6. If the result was a block of funding to improve cancer services and outcomes, how would you determine:
   o How much of that funding to allocate to improving early diagnosis? And
   o Which early diagnosis interventions to support?

7. What evidence, tools or resources would you use to inform or aid your decision-making, in particular for decisions related to interventions for early diagnosis of cancer?

8. As part of the strategy development process, Cancer Research UK representative Margaret Carr has been asked to chair the Diagnosis and Screening subgroup. In your view, are there specific issues related to early diagnosis that this subgroup should be focusing on? Please explain.

## Future development of toolkits/resources and Cancer Research UK support:

9. What early diagnosis interventions is the DHNI/HSCB/networks/Trusts *[identify appropriate option for each interviewee]* currently considering, or likely to consider in the next 1–2 years?

10. If you could ask Cancer Research UK for support (other than financial) for one thing to help you improve early diagnosis of cancer in Northern Ireland, what would it be?

    o Specifically, would any other evidence, data or tools be of help for those decisions or other future decisions in this area? *Possible areas to probe for more detail:*
       ▪ What would it look like? How would it measure outcomes and impact?
       ▪ How would it help?

- Who would you expect to be involved in developing it?
- What factors would you consider in deciding whether it is useful and reliable (or not)?

## *Closing*

11. Could you recommend who else we could speak with? We are hoping to speak with representatives from the Department of Health, the HSCB, Clinical Networks, and Trusts and/or Local Commissioning Groups. Any suggestions are helpful, but in particular, it would be helpful if you could suggest contacts at Trusts or Local Commissioning Groups (LCGs). Essentially we are interested in speaking to anyone who is part of decision-making processes with regards to interventions for early diagnosis of cancer in Northern Ireland.

   o Note from Cancer Research UK: They may recommend not speaking to the LCGs, but rather to relevant people in each Trust who manage service planning and presumably also interpret any new commissioning direction. In terms of early diagnosis of cancer, are these the people who plan diagnostics (given it's not all cancer related)? Into which area of the Trust management do they report, e.g. service improvement?

12. Anything else to add?

Thank you for your time.