September 2015

Evaluation of the electronic Holistic Needs Assessment (eHNA)

Final evaluation report
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1 Executive summary

Ipsos MORI was commissioned in 2013 to undertake a process and impact evaluation of the electronic holistic needs assessment (eHNA) project run by Macmillan Cancer Support and initially piloted in 2012. This executive summary details the key findings and conclusions from the evaluation of the ongoing eHNA prototyping phase covering the time period of January 2013 until 30th June 2015. It also provides considerations and recommendations for the future delivery of the eHNA.

Evaluation scope and method

Macmillan is prototyping an electronic version of the holistic needs assessment (the eHNA) and care plan, which previously was only completed verbally or on paper. This assessment is designed to capture any physical, emotional, spiritual, practical or social needs of individuals living with and beyond cancer.

The evaluation scope included conducting a process evaluation investigating how the eHNA project was being implemented by Macmillan and by each of the prototyping sites; an outcomes, impact and cost-effectiveness evaluation assessing the impacts of electronic assessments and care plans on people living with and beyond cancer, healthcare professionals, the healthcare economy and Macmillan, and an options appraisal to inform the decision on the future of the software platform underpinning the project.

The evaluation methodology involved a pre-and-post intervention design. A logic model for the project was designed in collaboration with Macmillan which articulated how the eHNA project was intended to deliver a range of outcomes and impacts. This project logic model formed the analytical framework for the evaluation.

The research methods employed to collect evidence to inform the evaluation included:

- Comparing baseline data on completion of paper HNAs at sites with data on completion of electronic assessments, alongside other monitoring data including care plan completion;
- Before and after comparison of views and behaviours of healthcare professionals (via an online survey pre and post, 127 responses compared with 180 at follow up);
- Before and after experiences of people living with and beyond cancer (via 482 paper surveys before and 250 telephone interviews after, in addition to 30 qualitative interviews);
• Longitudinal case studies at the prototyping site level which involved 77 qualitative interviews with a range of healthcare professionals, and other staff at the sites (including those with responsibility for IT and information governance); and

• Interviews with Macmillan staff and external stakeholders including representatives from NHS England and other bodies involved in the provision of cancer services.

**Overview of delivery 2013-2015**

The evaluation has shown that the eHNA project has made significant progress over the course of 2013-2015, with the number of sites enrolled and the number of assessments increasing substantially. Macmillan has been able to secure economies of scale in the cost of the project as it has expanded. The cost to Macmillan of each completed electronic assessment and care plan has decreased over time as the volume has increased and, as the numbers increase further, these costs will continue to fall.

**Inputs**

The total cost of the eHNA project to Macmillan by the end of Q1 2015 is £1,838,700. The greatest spend within this is on the set-up, licensing, hosting and software development costs associated with the eHNA platform (accounting for 52% of the costs).

The costs can be apportioned into those concerning site set-up (this includes capital expenditure on tablets and the initial development of the eHNA platform); site maintenance (covering software licensing and other ongoing support provided to sites); and service development (covering activities which develop the eHNA project such as the Learn and Share events and marketing materials). Site maintenance accounts for the greatest proportion of costs (45%), followed by service development (31%) and then site set-up (25%).

The total set-up cost per site is £6,900 based on the 65 sites live or in the process of being set up by the end of Q1 2015. Macmillan has secured economies of scale in the cost of maintaining live sites as the eHNA project has expanded. The maintenance costs per site per quarter was £10,300 when there were four sites live in wave one. This has fallen significantly to a cost of £2,100 to maintain each site per quarter as of the end of Q1 2015.

The cost to Macmillan of each completed electronic assessment and care plan has decreased over time as the volume of completes has gone up. Across the duration of the pilot in 2012, the cost per electronic assessment and care plan were £173 and £284 respectively (considering costs once sites are live and thus excluding set-up and service development costs).
These have fallen to a cost per electronic assessment of £48 and £67 per care plan over the duration of 2014.

This cost analysis is based on the grant money spent, rather than allocated, to sites. Only a fraction of the grant money available to sites has been spent by them to date (20%).

**Delivery activities at prototyping sites**

As of 30th June 2015, 48 sites were live with the eHNA project. A further 17 sites were currently in ‘testing’ mode and 13 sites had submitted an Expression of Interest (EOI). It is likely that a total of 67-68 sites will continue till the end of the prototyping phase as new sites come on board whilst some are suspended given their persistently low volume of electronic assessments and care plans.

The electronic assessment is most commonly completed close to diagnosis (in 40% of cases). Electronic assessments are completed in a variety of settings though most frequently in hospital waiting rooms prior to consultation and in private consultation rooms. Sites have embedded the eHNA project in a variety of ways, helping to accommodate it within different working practices.

As of 30th June 2015, 17,265 electronic assessments had been completed; 72% of these had been converted into a care plan. There is significant variation in the number of electronic assessments and care plans being conducted by sites, with some performing comparatively well/less well given their size and length of time as a prototyping site. Some sites are performing well but only in a small number of tumour groups. Guy’s and St Thomas’ continues to be an outlier, responsible for conducting nearly a quarter of all the electronic assessments done to date. This reflects the volume of individuals cared for at this site, its length of involvement (since March 2012) and that it has rolled out the eHNA project to every tumour group.

Where care plans are not created, the primary reason is a lack of time. This may mean healthcare professionals prioritise writing care plans for individuals known to have complex needs. Indeed, some healthcare professionals say care plans are not created if individuals have low-level, or no, concerns. Further, a quarter of individuals who complete an electronic assessment go on to decline a copy of their care plan (24%). Healthcare professionals suggest this happens when individuals have low-level, if any, concerns and/or when individuals feel their concerns were addressed by the discussion alone.

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1 This metric has been recorded since September 2014.
The baseline data show that, on average, 23.7 assessments were being carried out on paper per site per month prior to the eHNA roll-out². This has risen marginally to 25.4 electronic assessments per site per month when looking at the past six months of activity for the 30 sites which have been live for at least a year.

The conversion rate of assessment into care plan has dramatically increased since the advent of the eHNA project. Prior to the introduction of electronic assessments, baseline data show that 52% of paper assessments resulted in a care plan. As aforementioned, this has risen to 72% of electronic assessments resulting in care plans.

**Macmillan delivery activities**

Macmillan is fully committed to the continued development of the eHNA. The internal focus is now on how best to roll it out when the prototyping phase ends in summer 2016 rather than questioning whether to do so or not. Macmillan is therefore currently working out what ‘business as usual’ will look like. Accordingly there are a number of priority areas Macmillan will be focusing on over the coming year. The primary focus will be deciding the most appropriate provider to supply the software underpinning the eHNA delivery.

Macmillan will also be working to ‘future proof’ the eHNA – this will involve the development of an ‘at home’ version of the electronic assessment; testing of the eHNA in community settings; developing the automatic upload of assessment results and care plans into the Electronic Patient Record (EPR); and working with sites to expand the eHNA into a wider array of tumour sites. Crucially, Macmillan will be focusing on embedding the Recovery Package into mainstream commissioning; aided by its endorsement in both the NHS Five Year Forward View, and the Independent Cancer Taskforce’s July 2015 report.

The future delivery of the eHNA may be impacted by the imminent release of Macmillan’s Corporate Strategy. It is expected this strategy will positively influence the eHNA delivery but the full content remains unknown at present.

**Delivery lessons**

An interim evaluation report was submitted in June 2015 which focused on identifying the main barriers and enablers to successful implementation of the eHNA project at site level. The key findings from this report were:

- There are a number of external drivers which encourage the adoption of the eHNA project. These include the need to audit holistic needs

² Based on the 42 sites which submitted usable baseline data. See appendix for caveats around data interpretation.
assessments and care planning; a drive to improve quality and performance metrics to which the eHNA can contribute; the push to paperless working by 2018; and the potential benefit of the aggregate data. These drivers incentivise sites to work beyond any challenges they may face.

- Within sites, there are a number of factors which enable successful implementation. These include a willingness to change current working practices (for example, by employing more administrative staff); and having an embedded practice of using paper HNAs prior to the eHNA roll-out.

- Sites are working to overcome a number of barriers to implementation; the most significant of which is time constraints (associated with staff capacity issues, heavy workloads and competing priorities). Sites that have successfully overcome this challenge are those that have been willing to make structural changes to how clinics are run in order to better accommodate the eHNA project (such as introducing specific eHNA clinics).

- Some sites are facing a lack of senior management involvement in the eHNA project and resistance from healthcare professionals to changes in their working practices. Additionally an absence of mandatory targets and funding from commissioners for the eHNA project (and HNAs more widely) can mean the project does not receive due attention from staff internally. Overcoming these challenges requires securing senior management buy-in to the project early in the enrolment process and continual enthusiasm from champions of the project to counterbalance any negativity encountered.

- There are not always the available opportunities to administer electronic assessments and care plans and this can limit the project’s roll-out. This most commonly results from healthcare professionals having too high a case load. A lack of available clinical space in which to conduct the assessment and discussion can also be a limiting factor which sites are working to overcome.

- Many of these barriers to implementation also apply to paper assessments and care planning, with the exception of IT challenges presented by the eHNA project. The most severe of these has been the poor WiFi availability, although this appears to be diminishing in significance as the prevalence of wireless networking across the NHS becomes more commonplace. Information governance barriers are also lessening. This has been largely driven by Macmillan resolving contract issues and ensuring good quality advice and support on the matter.
Medium term outcomes and impact

Significant progress has been made on a number of the intended medium term outcomes and impacts of the eHNA project for people living with and beyond cancer, though more limited progress has been made on those relating to healthcare professionals, the wider healthcare economy, and Macmillan. However, the activities that Macmillan is currently undertaking (or is planning to undertake) will move them further towards achieving these. As such, if the outcomes and impacts of the eHNA continue to deepen and expand, its cost-effectiveness will increase further. While there remain a number of challenges and risks to the project at site level, these will continue to diminish as NHS working practices develop.

Intended medium term outcomes and impacts for people living with and beyond cancer

As the eHNA project stands at present, the evidence from this evaluation shows that it is fulfilling a number of the stated ambitions, namely “patients feel better supported”, “patients feel their holistic needs are being met” and they experience “improved quality of life”. The aim of individuals affected by cancer being able to “complete the electronic assessment in an environment of their own choice” will soon be achieved through the creation of the ‘at home’ assessment.

The remaining intended medium term outcomes and impacts for individuals living with and beyond cancer are not yet being realised, though progression is being made towards them:

- Conducting electronic assessments is not yet “routine” but it is becoming more commonplace as sites find ways to embed the project. Time presents one of the greatest barriers to implementing the eHNA project. Overcoming this barrier requires a change in the way clinics and resourcing are structured. Alternatively, the benefits of the eHNA project need to be significant and visible enough that healthcare professionals and senior members of staff are willing to work through any implementation challenges faced.

- It is not yet possible for individuals to “complete the electronic assessment with any service provider along the care pathway” (such as with GPs, in hospices and other community and social care settings). Progress has however been made towards achieving this ambition with the creation of the ‘at home’ version of the electronic assessment and with an increasing number of sites testing the eHNA project in the community setting.

- Macmillan cannot fully achieve the ambition of “all eligible individuals complete an electronic assessment” as healthcare professionals exercise discretion over who counts as ‘eligible’ and individuals choose
to decline the assessment. Instead, Macmillan should strive to ensure all eligible individuals are given the option of completing an electronic assessment and make an informed choice about whether to or not.

- There is a limit to which the ambition of “actions are taken as a result of having a care plan” will be met. Not all electronic assessments are converted into care plans, not all care plans are shared with individuals, and it is not uncommon for individuals who have completed an electronic assessment to decline a copy of their care plan. These factors all limit the extent to which actions are taken as a result of the care plan. Additionally where actions are taken following the assessment process, many believe these would happen irrespective of a care plan being created – greater importance lies in the discussion individuals have with their healthcare professional.

**Intended medium term outcomes and impacts for healthcare professionals**

The ambition of healthcare professionals having “greater confidence to deliver holistic needs assessments and care planning” is being achieved. The remaining two ambitions for healthcare professionals are being partially met at this stage in the prototyping phase:

- There are instances where the eHNA project is thought to “increase the productivity of healthcare professionals” – these all relate to activities outside the direct administration of electronic assessments and care plans. But, if healthcare professionals are used to conducting holistic needs assessments verbally or not at all, then the eHNA project represents a significant demand that diminishes the time they have available to complete alternative tasks. In some instances, the same sentiment is expressed by healthcare professionals who are already administering assessments on paper as the electronic version appears to result in a more thorough assessment of individuals’ concerns, thereby taking up more time.

- The eHNA project has had little impact on “recognition of the value of holistic needs assessments and care planning”, but simply because this process was already highly valued prior to the project’s roll-out. That said, healthcare professionals are able to name a number of benefits of holistic needs assessments and care plans; particularly so if done electronically.

**Intended medium term outcomes and impacts for the healthcare economy**

At this point, the eHNA project is not achieving the ambition of “service planning and commissioning taking better account of individuals’ needs” based on the aggregate data. The preceding stage to this intended impact is the outcome that “aggregate assessment data is used to shape local
decisions” – an outcome which is being partially met at present. Currently the aggregate data is being used more for the purposes of performance monitoring and information gathering rather than informing service planning and commissioning. However, there are some examples where the aggregate data has been used to pursue the latter goal and sites are increasingly looking to their growing pool of aggregate data to do so.

Once Macmillan establishes a means through which individuals affected by cancer can complete the electronic assessment away from the clinical setting then the ambition for healthcare professionals “to monitor patients’ needs remotely” will be possible.

Macmillan hopes that healthcare professionals will have “improved access to continual records of patients’ progress” as a result of the eHNA project. Underlying this premise is the desire for electronic assessments and care plans to be administered by any service provider at any point (or multiple points) along the care pathway and for these to be shared. The sharing of electronic assessment results and care plans has increased since the advent of the eHNA project, though it remains inconsistently done. It is hoped the sharing process within sites will be facilitated by the automatic upload of results and care plans to the EPR though it does not naturally follow that other professionals will view the assessment results and care plans made available to them. The ability for assessment results and care plans to be shared between healthcare professionals in different care settings will be facilitated by the push for, “all patient and care records to be digital, real-time and interoperable by 2020” as set out by the National Information Board.

**Intended medium term outcomes and impacts for Macmillan**

Macmillan is not yet achieving the intended aim of having “ongoing and personalised relationships with its customers”. This will no longer be achieved through the CRM database, but it is hoped this ambition will be realised through alternative means such as through the Recovery Package and through the possible development of an online HNA assessment which can be completed on the Macmillan website.

There are some examples evident of “increased patient and professional engagement with Macmillan” as a result of the eHNA project though this intended outcome is difficult to fully substantiate and these examples are not widespread at present.

The extent to which Macmillan “has an improved ability to influence regionally and nationally” as a result of the eHNA project is uncertain. Macmillan’s influence is likely to grow if Macmillan succeeds in getting the Recovery Package more widely commissioned. The likelihood of doing this will be aided by more closely aligning the Recovery Package to broader CCG programmes concerning other long-term conditions.
Recommendations

The key focus over the next year for Macmillan will be establishing a ‘business as usual’ model which will ensure the sustainability of the eHNA beyond the end of the prototyping phase. The next six months will be critical for Macmillan in determining which provider to commission as the supplier of the software underpinning the eHNA data platform. This decision will fundamentally shape how the project is run in future and Macmillan’s role in it. Choosing the most appropriate supplier, and establishing a strong working partnership with them, will be critical to the project’s success.

Recommendations for the coming year

A number of recommendations for the coming year are evident following completion of the evaluation:

- **Continue with current and planned initiatives**: There are no workstreams (either planned or currently underway) which the evaluation suggests should not be pursued. Of particular importance will be the establishment, following current testing, of an eHNA version to be completed by individuals at home.

- **Ensure minimal disruption in the move to a ‘business as usual’ model**: It is important for Macmillan to maintain close contact with sites to ensure momentum behind the eHNA is not lost. Contact with sites should be maintained, and any disruption in administration kept to a minimum, during any transition period into ‘business as usual’.

- **Share case studies**: Prototyping sites have implemented the eHNA project in a myriad of ways to best suit their current clinical practices and the needs of individuals affected by cancer. Arrangements have been more (and less) successful. Sites are still looking to Macmillan as the main conduit to help them learn of how their peers are implementing the project and overcoming the barriers they themselves face.

- **Share key evaluation findings with sites**: There are a number of evaluation findings which should alleviate concerns held by some healthcare professionals and these should therefore be shared (such as the vast majority of healthcare professionals saying that ‘more often than not’ they are able to help individuals with the concerns they raise).

- **Train healthcare professionals on how best to communicate the purpose and value of electronic assessments and care plans**: The explanations given to individuals affected by cancer as to why they should complete the electronic assessment are variable and, at times, inadequate. Macmillan has a role in training healthcare professionals in the best practice for communicating the purpose and value of the electronic assessment, recognising that the assessment is sometimes
introduced by volunteers. Providing guidance on this issue will also help to standardise how the electronic assessment is broached. Similarly, further training for healthcare professionals is warranted to help them better elucidate the value of care plans so individuals affected by cancer take greater consideration of them.

- **Provide healthcare professionals with guidance on eligibility:**
  Macmillan should look to develop more definite guidelines around who is considered eligible for an electronic assessment. Similarly, Macmillan should provide advice on how best to handle more challenging scenarios within which to present the eHNA (for example when individuals are receiving palliative care or are showing signs of distress, or when there are physical, mental or language barriers to completion).

- **Strengthen the value of the aggregate data:** The aggregate data is one of the central distinguishing features of electronic assessments and care plans compared to paper alternatives. Macmillan needs to be confident that the aggregate data generated through the eHNA project is representative of the concerns held by individuals with a cancer diagnosis nationally if it hopes to influence commissioning and service delivery. Achieving this will involve Macmillan working with sites to expand the tumour groups in which electronic assessments and care plans are created. Similarly, Macmillan should assist sites to administer electronic assessments and care plans across the pathway so that the aggregate data better reflects the variable nature of issues which arise as individual progress through their pathway. At present, if an individual completes multiple electronic assessments, their concerns are recorded in the eHNA datastore as unlinked, separate entries. Storing the data in this way may lead to the demand for particular services being over-represented and Macmillan may wish to consider a means through which to record data at the person- not assessment-level.

- **Consider the value of care plans:** The primary benefits of the eHNA for individuals affected by cancer appear to be secured through the discussion they have with their healthcare professional, with the care plan being of less importance (and for many having low salience). The care plan appears to have greater value to healthcare professionals given it is a way to evidence that the assessment has taken place and is as a reminder of individuals’ concerns. Macmillan may wish to examine if there are certain types of individuals who benefit more from their care plan (for example by assessing this in relation to Patient Activation Measures) and to consider the value of care plans to healthcare professionals in light of wider policy initiatives which may warrant their continued use. Going forward it is recognised that the care plan is now referred to as the care and support plan to better reflect its purpose.
• **Investigate further:** Macmillan may wish to investigate the profile of individuals who choose to decline the electronic assessment to see how much of a limiting factor this might be on getting aggregate data that is representative of the wider population of individuals living with and beyond cancer. Additionally, Macmillan may wish to map the usage of Macmillan services in local areas against what is known about electronic assessment and care plan completion in that area. This will help Macmillan better understand what uptake the eHNA project is having on engagement with Macmillan services.

**Recommendations for beyond the prototyping phase**

As Macmillan moves beyond the end of the prototyping phase, there are a number of recommendations to consider:

• **Re-evaluate the timeframes for the intended impacts of the eHNA:**
  The potential scale of the eHNA, and the wider contextual developments which have taken place, were not known to Macmillan at the start of the pilot and subsequent prototyping phase. As such, many of the intended impacts for the eHNA project as documented in Macmillan’s logic model were ambitious beyond the timeframes associated with the prototyping phase. It is a slow process for electronic assessments and care plans to become routine practice and thus other benefits (such as increased staff productivity) are not realised in the immediacy.

• **Provide continued support for wider enablers of the eHNA:**
  Macmillan has a role to play in supporting wider agendas which will positively impact on the eHNA. For instance, some of the IT barriers facing the project are slowly being overcome naturally as NHS trusts are increasingly installing WiFi and using tablets for purposes beyond the eHNA project. Furthermore, the eHNA will be enabled by a wider cultural shift towards the self-management and personalisation agenda.

• **Enrol sites in geographical clusters:** Once the prototyping phase is complete, Macmillan should give consideration to enrolling sites in geographical clusters (across different parts of the care pathway, both in and outside the acute setting). This will facilitate the exchange of ideas and experiences locally between sites who provide care and support across the whole patient pathway. It will also result in a larger pool of aggregate data within localities which will provide greater meaning to its analysis in that geographical area.

• **Explore the possibility of more localised administration and support:**
  Providing more localised support for geographically clustered sites could represent a more sustainable arrangement for Macmillan moving forwards. However, management of the eHNA should not become so localised that it is fractured and a collective understanding of the eHNA
is lost. Macmillan should therefore consider how best to provide administration and support at a local level, potentially making use of its regional structure.

- **Advise sites to secure protected time**: Sites are more likely to successfully implement the eHNA project if they have a project lead with dedicated time to embed it. Ideally sites should be advised that dedicated time should be carved out of lead individuals’ roles.

- **Establish more formal commissioning arrangements**: Alongside embedding the Recovery Package into mainstream NHS commissioning, Macmillan should consider encouraging the establishment of tariffs for the completion of assessments, care and support planning.

- **Consider how best to align the Recovery Package**: Macmillan needs to give consideration of how to align the Recovery Package into broader CCG programmes. Linking more closely to other long-term conditions may create a tension for Macmillan though there is a role for Macmillan to be the vanguard for assessing holistic needs as part of the self-management and personalisation agenda, leading the way based on the vast experience it has amassed.
Introduction
2 Introduction

Ipsos MORI was commissioned to undertake a process and impact evaluation of the electronic holistic needs assessment project run by Macmillan Cancer Support. This report concludes the evaluation; focusing predominantly on the extent to which the intended medium term outcomes and impacts for the project have been achieved thus far. The evaluation covers the period from the launch of the eHNA prototyping phase in January 2013 until 30th June 2015.

2.1 The eHNA

Macmillan is currently in the process of prototyping an electronic version of the holistic needs assessment (the eHNA), which previously was only completed verbally or on paper. This assessment is designed to capture any physical, emotional, spiritual, practical or social needs of individuals living with and beyond cancer. Macmillan has primarily been prototyping the eHNA project in NHS trusts; seeking to understand the scalability of the eHNA tool. There have been three waves of enrolment to the project though this progressed to be an ongoing, rather than staged, process from mid-2014 onwards. This follows a pilot of the eHNA project, held in 2012 as a proof of concept, and evaluated by Ipsos MORI.

As the project currently stands, individuals living with and beyond cancer complete a questionnaire about their holistic needs using a touch-screen tablet. Completion of the assessment in this way generates a pool of electronically stored data and a partially-populated care plan which are made available for the healthcare professional to view (and in the case of care plans, to edit). Following completion of the electronic assessment, individuals living with and beyond cancer should have a discussion of their assessment results with a healthcare professional who completes the care plan summarising the discussion and agreed actions.

The ambition is for care plans to be ‘owned’ by individuals living with and beyond cancer as a tool to assist them with self-management. The care plan can be downloaded by the healthcare professional as a PDF, RTF or TIFF file which may then be shared with the individual affected by cancer electronically or as a hard copy, and saved in a shared file location for other healthcare professionals to view. The way in which electronic assessments and care plans are administered is different in each site participating in the prototyping phase (as explored throughout this report).

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A key component of the eHNA is the eHNA datastore – a system management and reporting tool which facilitates the analysis of aggregate data.

The web-based platform underpinning the eHNA has been developed by HealthUnlocked, a web-based software design company, in conjunction with Macmillan.

Macmillan’s vision for the eHNA project is, for everyone living with cancer to have a tailored care plan that addresses their emotional, physical, spiritual, social and practical needs. The strategic rationale for the eHNA project, and the logic model underpinning it, are examined further in chapter 3.

2.2 Evaluation objectives

The evaluation objectives broadly fall into four areas:

- **Process evaluation**: this involved a detailed examination of process issues, looking in particular at barriers that limit the extent to which the full benefits of the eHNA project can be realised. This was reported upon in June 2015.

- **Impact evaluation**: assessing the impacts of electronic assessments and care plans on people living with and beyond cancer, healthcare professionals, the health economy and Macmillan.

- **Cost-effectiveness analysis**: capturing and quantifying the costs and benefits associated with the eHNA project to generate a thorough assessment of its effectiveness.

- **Options appraisal**: an options appraisal workshop, run in October 2013, assisted Macmillan in considering available options for the future of the software platform which underpins the eHNA project.

A number of reports have been issued as part of the ongoing evaluation; upon which this report builds.

2.3 Evaluation methodology

This section of the report gives a brief overview of the methodology employed. Greater detail can be found in the appendix to this report.

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5 Inception report, April 2013; Baseline report, July 2013; Interim 1, April 2014; Experience of people living with and beyond cancer, October 2014; Process Evaluation, June 2015.
2.3.1 Inception and familiarisation

The evaluation study began with an inception and familiarisation stage, designed to ensure a thorough understanding of the intervention and gain insight into perspectives on the eHNA project within Macmillan. This phase comprised:

- **Familiarisation interviews:** Depth interviews were conducted with six internal stakeholders involved in the design and delivery of the eHNA project.

- **Document review:** An understanding of Macmillan’s underlying logic model was furthered through a review of internal and external documents including policy descriptions and guidance for applicant sites.

As part of this familiarisation phase, the logic model underpinning the eHNA project was refined. This phase of the evaluation was concluded with an Inception Report (April 2013) which set out the scope of the evaluation research and the proposed methodology to meet Macmillan’s requirements.

Following the inception and familiarisation phase, a pre- and post-intervention methodology was employed to evaluate the eHNA project, as discussed below.

2.3.2 Pre-intervention data

Pre-intervention data was collected to provide a picture of holistic needs assessments and care planning prior to the introduction of the eHNA project. Baseline data was collected with the following groups:

- **Prototyping sites:** Sites were asked to submit a minimum of two months baseline data documenting their current level of paper HNA administration prior to enrolment in the eHNA project. A total of 42 sites submitted usable baseline data.

- **Healthcare professionals:** An online survey was conducted with 127 healthcare professionals prior to sites’ enrolment in the eHNA project to understand current use of verbal and paper HNAs.

- **Case studies:** 12 case study sites were followed longitudinally over the course of the evaluation through regular depth interviews with key healthcare professionals. Eight sites were selected from waves 1 and 2 of enrolment, four sites were selected from wave 3. The initial interviews took place prior to sites’ enrolment on the project.

- **People living with and beyond cancer:** 482 individuals completed a paper survey across 17 sites which were, at that stage, not participating in the eHNA project. This covered both counterfactual
scenarios of individuals receiving a paper HNA and individuals having an informal verbal assessment.

### 2.3.3 Post-intervention data

This data is analysed alongside the following post-intervention evidence:

- **Prototyping sites**: The aggregate, anonymised data recorded from electronic assessments and care plans provides (in the eHNA datastore) a comparison to the baseline data submitted by sites. Sites were also asked to submit follow-up data not captured through the eHNA datastore (such as the number of individuals to decline an electronic assessment). A total of 30 sites submitted follow-up data.

- **Healthcare professionals**: 180 healthcare professionals involved in the administration of the eHNA project were surveyed online in a repeat of the baseline survey.

- **Case studies**: In-depth qualitative evidence for the evaluation has been sought from multiple individuals at regular intervals with the case study sites. The eight case studies enrolled in waves 1 and 2 of the evaluation have fed into the evaluation four times (including at baseline\(^6\)). The four wave 3 case studies have contributed their experiences through the qualitative work three times (once as a baseline and twice since).

For the June 2015 Process Evaluation report, the remit of the case study research was broadened to include the views of Macmillan Development Managers (MDMs), and individuals working in IT and information governance at site level. Steering group meetings were attended (where running) to add an observational element to the research. For the final wave of case study research, the project leads of an additional 10 sites were interviewed. Over the duration of the evaluation, 77 interviews were completed with individuals in relation to the case study sites.

- **People living with and beyond cancer**: 250 telephone interviews were conducted with individuals known to have completed an electronic assessment and who consented to be contacted as part of the evaluation. The telephone interviews were staggered across the duration of the evaluation such that 10–11 people were interviewed each month. Of those surveyed, 211 recalled completing the electronic assessment.

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\(^6\) Excluding East Kent and Barking, Havering and Redbridge which withdrew from the eHNA project.
This quantitative data was supplemented with 30 qualitative depth interviews with individuals known to have completed an electronic assessment. Initially these interviews were completed over the phone, though the 18 most recent interviews were completed face-to-face to allow for the use of a visual prompt to aid recall of care plans.

- **Stakeholder interviews**: For the final wave of research, eight stakeholder interviews were completed with individuals internal and external to Macmillan. These sourced the views of a number of individuals including those working at NHS England and other bodies involved in the provision of cancer services.

### 2.3.4 The evaluation case studies

The main 12 evaluation case study sites were selected to provide a range of implementation environments; thus they include sites of different sizes, based in diverse geographies. Case study sites were also selected on the basis of how well they scored against Macmillan’s application criteria to be a prototype site and how easily the eHNA team, in its experience with other sites, felt they would be able to implement and embed the eHNA; sites were selected to represent a range of application scores.

The additional 10 case study sites interviewed for the final report were selected as they represented an implementation experience that was of particular interest to Macmillan.

### 2.3.5 Cost-effectiveness analysis

One of the original objectives of the evaluation was to provide a cost-effectiveness analysis of the eHNA project. Data on the costs and benefits of the project have been systematically collected through the evaluation (as originally set out in the Inception Report).

There is no known metric in wider literature with which to quantify the benefit of completing a holistic needs assessment. This limitation means it is not possible to conduct a full cost-effectiveness assessment of the eHNA project. Instead, as agreed with Macmillan, an assessment of the costs and benefits of the eHNA project is provided through a qualitative narrative, supplemented by the quantitative data collected as part of the evaluation.

### 2.3.6 The options appraisal

The options appraisal workshop assisted Macmillan in considering options for the future of the software platform which underpins the eHNA.

The workshop was attended by 12 individuals, both internal and external to Macmillan, who had intimate knowledge of the eHNA project and/or had purchase over the future direction of the project. In the course of the
options appraisal workshop, a long-list of potential options open to Macmillan, and the decision criteria against which they should be evaluated, was agreed. Each option was initially appraised against its ability to meet Macmillan’s core objectives for the eHNA project. Any options which failed to meet these core objectives were eliminated as viable options for Macmillan. The remaining options were then discussed in turn to see the extent to which they met the other decision criteria listed.

Following the appraisal process, re-tendering the third party software provider contract was the preferred option for the future delivery of the eHNA software platform, which Macmillan has since gone on to do. The result of this tendering process is not yet know.

2.4 Limitations of the evidence

A number of potential methodological limitations have been borne in mind when drawing conclusions from the evaluation. The most significant of these are referenced below (and throughout the report as required). Other considerations about the evidence collected are documented in the appendix.

- **Inaccurate baseline and follow-up data submitted by sites**: Some of the data sites were asked to submit may have been challenging to supply (such as the number of individuals considered eligible for a holistic needs assessment) and this may have affected the quality of data provided by sites. In some cases the data supplied by sites was incomplete.

- **Skewed sample of individuals living with and beyond cancer collected post-intervention**: Only individuals who had successfully completed the electronic assessment on a tablet were surveyed quantitatively (as completion of the assessment was the means by which individuals gave permission to be contacted in relation to the evaluation). This may have excluded the views of individuals who struggled to complete the assessment electronically. Efforts were made to understand how commonly individuals were unable or unwilling to complete the assessment electronically through other strands of the evaluation.

- **Different sample profiles for pre- and post-intervention surveys with individuals affected by cancer**: All individuals living with and beyond cancer surveyed as part of the post-intervention stage had completed an electronic assessment within the past two months. This was done to boost recall of the electronic assessment and care plan. It was not possible to control the sample of individuals surveyed at the pre-intervention stage and thus there are some differences in the sample profile between these two groups. The pre- and post-intervention samples have been weighted to ensure
they both have the same demographic profile and there is an equal proportion currently receiving treatment for their cancer. However, differences remain, with the post-intervention sample more likely to have received their cancer diagnosis recently and to recall completing their holistic needs assessments more recently. Where the effect of this may be pronounced on the data analysis, this has been flagged in the report.

- **Small base sizes:** In some instances, relatively small base sizes limit the reliability of inferences drawn from the data. These small base sizes have arisen through the natural fall-out of events (such as a low recall of care plans among individuals who have completed an electronic assessment). Findings in relation to small base sizes have been interpreted cautiously and flagged throughout the report.

### 2.5 Interpretation of the findings

Throughout the report, sample sizes below 100 respondents have been flagged.

Where it is stated that one result is significantly different from another result, this has been tested at the 95 per cent level.

### 2.6 Structure of this report

The remainder of this report is structured as follows:

- **Chapter 3 Strategic rationale:** provides the strategic context of the eHNA along with a discussion of the logic model.

- **Chapter 4 Project overview:** examines the inputs, activities and outputs associated with the project.

- **Chapter 5 Embedding and administering electronic assessments and care plans:** provides a broad overview of the administration of the eHNA project.

- **Chapter 6 Medium term outcomes and impacts for people living with and beyond cancer:** reviews the extent to which the eHNA project has successfully met the medium term outcomes and impacts envisaged for people living with and beyond cancer.

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7 This significance test assesses how accurate the reported value is. A significance test at the 95 per cent confidence level means that, in the instance of this data being collected repeatedly in the same way, in 95 out of 100 times the reported value would fall into the relevant confidence interval (the upper and lower limit of the possible true value).
• **Chapter 7 Medium term outcomes and impacts for healthcare professionals**: analyses the medium term outcomes and impacts for healthcare professionals.

• **Chapter 8 Medium term outcomes and impacts for the healthcare economy**: reviews the medium term outcomes and impacts for the wider healthcare economy.

• **Chapter 9 Medium term outcomes and impacts for Macmillan**: assesses the achievement of intended medium term outcomes and impacts for Macmillan.

• **Chapter 10 Cost-effectiveness of the eHNA**: gives an overview of the costs and benefits of the eHNA project to Macmillan and also at site level.

• **Chapter 11 Conclusions and recommendations**: this section sets out the main conclusions from the evaluation and what these mean for the future of the project.
Strategic rationale
3 Strategic rationale

This chapter sets out the strategic rationale for the eHNA, giving consideration to the wider policy context, before discussing Macmillan’s logic model which underpins the project and its evaluation.

3.1 Policy context and strategic rationale

As growing numbers of people are diagnosed with cancer and survival rates increase, more people are living with and beyond cancer in the UK. In 2015, 2.5 million people in the UK are living with cancer and this number is expected to rise to 4 million by 2030. By 2016 more than 1,000 people will be diagnosed with cancer each day in the UK and by 2020, almost half of the UK population (47%) will get cancer at some point in their lives. While survivorship varies with the type of cancer, survival rates for all cancers have increased considerably since the 1970s so the numbers of people living beyond cancer, and needing support, are also growing.

There is a need for person-centred care throughout the cancer journey which responds to and respects the preferences, needs and values of individuals. The support people need to live with and beyond cancer are more complex than their medical requirements and include addressing physical, practical, emotional and relationship concerns, and meeting lifestyle and information needs. As a means to identify complex needs and plan to address them, a HNA can be an important part of a package of interventions to support individuals living with and beyond cancer.

The National Cancer Survivorship Initiative (NCSI) launched in 2007 with the main aim of developing services to support and enable cancer survivors to

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live as healthy and as good a quality of life for as long as possible"\textsuperscript{13}. The NCSI was a partnership between the Department of Health (DH) and Macmillan, supported by NHS Improvement. In 2010, the NCSI undertook testing of assessment and care planning, with various benefits of conducting HNAs identified by both clinicians and individuals affected by cancer\textsuperscript{14}. However, there were also some perceived drawbacks. The 2010 research showed that assessment and care planning as it stood was administered inconsistently within healthcare settings, leading to inadequate support for some individuals affected by cancer. Paper HNAs also made it difficult for healthcare professionals working across different disciplines to easily share completed assessments and care plans.

The use of an electronic system for completing HNAs was seen as a potential solution to these problems. The NCSI undertook an initial exploration of using touch-screen tablets as part of the assessment process\textsuperscript{15}. In June 2010 the NCSI published a vision paper, ‘Electronic Solutions and Touch-Screen Computers for Assessments and Care Planning’ which specified the high-level requirements for the adoption of touch-screen data capture in cancer treatment\textsuperscript{16}. Soon afterwards, the NCSI commissioned the Yorkshire Centre for Health Informatics to produce a specification for the procurement of a pilot project before any nationwide initiative. The resulting Output-Based Specification produced by the Centre defined a core set of information system requirements to allow for a pilot of the HNA to be carried out using an electronic format\textsuperscript{17}. It was within this context that Macmillan, working as part of the NCSI, piloted the eHNA project in four test sites in 2012; an evaluation of which was undertaken by Ipsos MORI\textsuperscript{18}. These four pilot sites form ‘wave 1’ of the prototyping phase of the eHNA project. Evaluation findings from the eHNA pilot found the electronic assessment promised several potential opportunities for improvement over paper HNAs. Macmillan took the decision to fund further testing of the eHNA project in a prototyping phase designed to take place from early 2013 until mid-2015.

Prior to closing in March 2013, the NCSI released, ‘Living with and beyond cancer: taking action to improve outcomes’, which sought to provide evidence as a foundation for action. Its recommendations included the

\textsuperscript{14} Tribal/NHS Improvement and Macmillan Cancer Support (2010), ‘Assessment and Care Planning: Final Report’
\textsuperscript{16} National Cancer Survivorship Initiative (2010), ‘Electronic Solutions and Touch-Screen Computers for Assessments and Care Planning’
\textsuperscript{17} Yorkshire Centre for Health Informatics and National Cancer Survivorship Initiative (2011), ‘Electronic & Touch-Screen Systems Project Output Based Specification’
introduction of a set of interventions known collectively as the Recovery Package, and offering all patients an HNA was suggested as one way that the messages of the report could ‘be translated into action’. Macmillan subsequently took this concept of the Recovery Package forward; identifying it as a key set of interventions to better support self-management and improve the outcomes of individuals living with and beyond cancer.

Building on the NCSI, the Living With and Beyond Cancer Programme (LWBC) – a two year partnership between NHS England and Macmillan – was established in June 2014. The LWBC seeks to entrench key NCSI recommendations into mainstream NHS commissioning and service provision. Importantly, the LWBC includes ensuring all patients have access to the Recovery Package, comprising a holistic needs assessment, treatment summary, cancer care review and a health and wellbeing event (as depicted in figure 3.1).

**Figure 3.1 — The Recovery Package**

The Recovery Package was endorsed as part of the NHS Five Year Forward View whereby the NHS is committed to, ‘ensuring care is coordinated between primary and acute care, so that patients are assessed and care


planned appropriately\textsuperscript{22}. Additionally the importance of the Recovery Package has been reiterated in the Independent Cancer Taskforce’s July 2015 report \textit{(Achieving world-class cancer outcomes: A strategy for England 2015-2020)} which calls for ‘transformation in support for people living with and beyond cancer’ as a strategic priority\textsuperscript{23}. As part of this goal, the report states that ‘every person with cancer should have access to elements of the Recovery Package by 2020\textsuperscript{24}. In addition to this, the Taskforce recommends that NHS England, working with NICE, should develop a guideline by mid-2016 for, ‘a minimum service specification, building on the Recovery Package, thereafter to be commissioned locally for all patients, together with a suite of metrics to monitor performance’.

Additionally, the Independent Cancer Taskforce are calling for, ‘greater strategic coherence in commissioning’. The current arrangement of local and specialist commissioning is thought to be complex and limits efforts to design services with the ‘whole person’ in mind. The Taskforce calls for NHS England to set out clear expectations for the commissioning of cancer services by the end of 2015. The Taskforce has proposed a commissioning model which would see more treatment commissioned above CCG level than done presently, though their suggested approach is that services to support individuals living with and beyond cancer continue to be commissioned at the CCG level with support from Health and Wellbeing Boards\textsuperscript{25}.

\subsection*{3.2 The eHNA project logic model}

As depicted in Macmillan’s logic model, the eHNA project is expected to achieve impact through the following steps:

- \textit{Inputs}: Macmillan have committed a certain level of investment in the eHNA project which includes grant money awarded to successful applicant sites to spend on hardware or resourcing required as part of the project. Over the course of the prototyping phase, Macmillan has worked closely with their third party software provider on the platform which underpins the eHNA. Macmillan has also secured the input of external stakeholder organisations to increase the sustainability of the eHNA, including the Health and


- **Activities:** There are a number of activities undertaken by the eHNA project team (as discussed further in section 4.2). Crucially the team have been responsible for recruiting new sites and setting them up on the project, providing sufficient training and support for them to do so. Work has been ongoing to improve the functionality of the software platform underpinning the eHNA.

- **Outputs:** The primary outputs of the eHNA project are the number of sites enrolled, and the completed number of electronic assessments and care plans (as discussed in section 4.3).

- **Outcomes and impacts:** Macmillan has a number of intended outcomes and impacts for the eHNA project. The June 2015 Process Evaluation report discussed the extent to which the short and medium term outcomes were being met. This final report therefore examines the extent to which the medium term outcomes and impacts are being achieved to date; structured around the four key groups as follows:
  
  - **Individuals living with and beyond cancer:** “All eligible cancer patients have an eHNA”; “patients are able to complete the eHNA in an environment of their choice”; “actions are taken as a result of having a care plan”; “eHNAs are administered by any service provider along the care pathway”; “conducting eHNAs is routine”; “patients feel better supported”; “patients feel their holistic needs are being met”; and “improved quality of life for patients”.

  - **Healthcare professionals:** “Increased confidence to deliver holistic care planning”; “increased productivity”; and “greater recognition of the value of assessments and care planning”.

  - **The healthcare economy:** “Aggregate data is used to shape local decisions”; “improved access to continual record of patients progress”; “healthcare professionals are able to monitor patients’ needs remotely”; and “service planning/commissioning takes better account of patients’ needs based on available data”.

  - **Macmillan:** “Increased patient and professional engagement with Macmillan”; “Macmillan has ongoing personalised relationships with its customers”; and “Macmillan has an improved ability to influence regionally and nationally”.


A number of these intended outcomes and impacts are longer-term propositions which Macmillan recognises the evaluation will not be able to fully assess. Where this is the case, the progression towards these goals is discussed in this report.

The logic model as discussed is shown below.

**Figure 3.2 – The eHNA project logic model**

**Rationale**
In December 2007 the Cancer Reform Strategy highlighted the need to improve the experience of care and support for patients throughout the whole of their cancer care pathway. Patchy, paper-based and inconsistent assessment and planning services can lead to subjective assessments of patient needs and varied patient experiences. The initial pilot of the eHNA showed that an electronic assessment tool could potentially improve volume and consistency of assessments.

**Inputs**
- Recruitment of NHS Trusts
- Tablet purchase/repair
- Software updates
- Training sessions with Trusts
- Trusts’ IT systems configured
- Trusts’ time
- London Cancer Alliance time
- Software: license, development and platform hosting
- Hardware: purchase and repair
- Macmillan PM
- eHNA data linked to CRM

**Activities**
- eHNA rolled out to non-Trust settings
- Completed eHNAs
- Completed care plans
- eHNA data linked to CRM

**Outputs**
- Published assessment data
- Patients contacted by Macmillan
- Patients have a greater number of interactions with Macmillan
- Assessment data and care plans linked to EPR
- Completed care plans

**Short Term Outcomes**
- Increased delivery of assessment and care planning
- eHNA completion is perceived to be easy by patients
- The assessment and care plan perceived as useful by patients
- Provision of more appropriate care at the right time for patients
- Administration of eHNA perceived to be easy by health professionals
- Aggregate assessment data produced

**Medium Term Outcomes**
- Increased confidence amongst health professionals to deliver holistic care planning
- Improved access to continual record of patients progress
- Health professionals able to monitor patients needs remotely
- Aggregate assessment data used to shape local decisions

**Impacts**
- Conducting eHNAs is routine
- Patients feel better supported
- Patients feel their holistic needs are being met
- Improved quality of life for patients
- Increased productivity for health professionals
- Greater recognition of value of assessments and care planning amongst health professionals
- Service planning/commissioning takes better account of patients’ need based on available data
- Macmillan has ongoing and personalised relationship with its customers
- Macmillan has improved ability to influence regionally and nationally

**Wider benefits:**
- Increased use of the eHNA across other long term conditions
- Improved use of technology across cancer services and more widely in health and social care
- Increased recognition of cancer survivorship and need for services across the survivorship pathway
- Improved recognition of Macmillan as a leader in holistic needs assessment and care planning
- More informed cancer patients with improved ability to self-manage
- Culture shift within the NHS towards the integration of data and care provision

By 2030 all people affected by cancer are able to say: ‘I understand so I make good decisions’, ‘I get the treatment and care which are best for my cancer and my life’, ‘those around me are well supported’, ‘I am treated with dignity and respect’, ‘I know what I can do to help myself and who else can help me’, ‘I can enjoy life’, ‘I feel part of a community and inspired to give something back’, ‘I want to die well’.
Project overview
4 Project overview

This chapter provides an overview of the eHNA project; looking specifically at the inputs (in terms of direct and indirect costs) to the project, the activities undertaken and planned by Macmillan, and what the project has achieved in terms of outputs.

4.1 Inputs to the eHNA project

This section first looks at the financial and time requirements of the eHNA project for Macmillan, before giving consideration to the inputs required at site level. Whilst this section of the report focuses on the costs of the eHNA project, subsequent chapters examine the various benefits associated with it from the perspective of individuals affected by cancer, healthcare professionals, the healthcare economy and Macmillan. An overview of the costs and benefits of the eHNA project is provided in Chapter 10.

4.1.1 Inputs for Macmillan

Macmillan is securing economies of scale in the cost of the eHNA project as it continues to expand.

Macmillan has provided information on the direct and indirect costs associated with the eHNA project. This chapter provides an analysis of this information; updating that previously undertaken in April 2014 as part of the first interim evaluation report.

At present, Macmillan offers each site a grant of up to £11,000 to assist them in the implementation of the eHNA project; the amount offered to each site has changed over the duration of the prototyping phase. Of the £722,700 grant money made available to sites in total, only a fraction has been spent (£141,000 equivalent to 20%). Any grant money which is unspent by sites does not return to the eHNA project budget but is released back into Macmillan funding streams. The analysis of the cost data documented in this section is calculated on the basis of the grant money actually spent by sites to date as opposed to the full grant allocated to them.

It is estimated that by the end of Q1 2015, the eHNA project has cost Macmillan £1,838,700 including the indirect costs associated with staff time. Of this, the most significant cost to date has been expenditures on the set-up, licensing, hosting and software development costs associated with the eHNA platform, with payments made to the third party software provider totalling £961,200 (52%). Macmillan’s ongoing staffing costs (£418,000,
equivalent to 23% of the total project cost and capital expenditures\(^26\) (£287,700, equivalent to 16%) have also been significant. It is also estimated that there have been one-off staffing costs to Macmillan in the order of £48,800 (three per cent) covering time from the marketing team and the use of external legal support.

The eHNA project costs can be apportioned into the following categories:

- **Site set-up costs**: investments made in sites to enable them to go live with the eHNA project, such as capital expenditures on tablets and the initial investment made in developing the eHNA platform.

- **Site maintenance costs**: software licensing and other on-going support provided by Macmillan at the site level.

- **Service development costs**: this covers a broad range of activities which are not focused at the individual site level but which all pertain to the wider development of the eHNA project. This therefore covers activities such as the Learn and Share events, creation of marketing materials and user guides, ad-hoc improvements to the software functionality, the evaluation and future planning of the project.

Ongoing and one-off staff time has been split across the three categories above to broadly reflect how time is spent by different individuals in the eHNA project team. These calculations have accounted for the differences in tasks undertaken according to job roles (such as more junior staff spending a greater proportion of their time on site maintenance compared to senior colleagues who work more on service development). The cost analysis also considers how the proportion of staff time spent on these activities has changed over the course of the prototyping phase and more sites have enrolled onto the project.

Site maintenance costs account for 45% of the total eHNA project cost (£819,600) with the bulk being the ongoing monthly license fee for the eHNA software platform. Service development accounts for 31% of the total costs (£566,400) with the majority of this cost being staff time. The site set-up costs contribute least to the total costs, accounting for 25% (£452,700).

The total set-up cost per site is £6,900 based on the 65 sites live or in the process of being set-up by the end of Q1 2015. Macmillan has secured economies of scale in the cost of maintaining live sites as the eHNA project has expanded. For example, when there were four sites live in wave 1, the average maintenance cost per site per quarter was £10,300. This has fallen

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\(^{26}\) Included under ‘capital expenditure’ are the costs of tablets previously provided to sites by Macmillan though this is no longer the case, hosting of the Learn and Share events, travel to sites, grant money provided to pilot sites.
significantly to a cost of £2,100 to maintain each site per quarter as of Q1 2015.

The cost to Macmillan of each completed electronic assessment and care plan has decreased over time as the volume of completes has gone up. Across the duration of 2012, the cost per electronic assessment and care plan were £173 and £284 respectively (considering costs once sites are live and thus excluding set-up and service development costs). These have fallen to a cost per electronic assessment of £48 and £67 per care plan over the duration of 2014. It is expected that, as the number of electronic assessments and care plans continues to rise and fewer sites go live with the project, these costs will continue to fall.

Table 4.1 – Costs of the eHNA project by Q1 2015 end

<table>
<thead>
<tr>
<th>Costs to Macmillan</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Third Party Software Provider</td>
<td>c.£961,200</td>
</tr>
<tr>
<td>Ongoing staffing costs</td>
<td>c.£418,000</td>
</tr>
<tr>
<td>Capital expenditure</td>
<td>c.£287,700</td>
</tr>
<tr>
<td>One-off staffing costs</td>
<td>c.£48,800</td>
</tr>
<tr>
<td>Other (e.g. marketing and evaluation)</td>
<td>c.£123,000</td>
</tr>
<tr>
<td>Total</td>
<td>c.£1,838,700</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Set-up costs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total set-up costs</td>
<td>c.£452,700</td>
</tr>
<tr>
<td>Total set-up cost per site</td>
<td>c.£6,900</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Maintenance costs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total maintenance costs</td>
<td>c.£819,600</td>
</tr>
<tr>
<td>Total maintenance cost per site per quarter</td>
<td>c.£2,100</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Service development costs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>c.£566,400</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Costs per electronic assessment and care plan</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost per electronic assessment in 2014 (minus set-up/service development costs)</td>
<td>c.£48</td>
</tr>
<tr>
<td>Cost per care plan in 2014 (minus set-up/service development costs)</td>
<td>c.£67</td>
</tr>
</tbody>
</table>

Source: Costs supplied by Macmillan
4.1.2 Inputs at site level

There is a great variety in the costs incurred at site level depending on factors such as the size of the trust and the extent to which the eHNA project is rolled-out internally within sites. The average direct cost incurred is well within the allocated grant money provided by Macmillan.

Sites were asked to supply data on the direct costs they have incurred as a result of being part of the eHNA project. 18 sites submitted usable data concerning direct costs. Across these 18 sites, the average spend on the eHNA project is £5,123. This covers the cost of tablets purchased for use in the project, tablet covers and locks, the cost of repair/maintenance of tablets, the cost of accessing WiFi and any other costs incurred in the project. It assumes that sites have supplied cost data on the basis of outgoings incurred – irrespective of the grant funding provided by Macmillan which should adequately cover these costs.

Many of the direct costs are one-off costs (such as the purchase of tablets) though access to WiFi can be an ongoing cost incurred. This average cost calculation above accounts for access to WiFi for one year only.

As would be expected, the greatest direct cost at site level is that spent on tablets. Thus sites with a low overall spend are likely to be sites where few tablets have been purchased – either because they are already available within the site, or because they are small or have initially begun the eHNA project in a handful of tumour groups. The minimum direct cost spent by any site was £122. This site did not include any costs for the purchase of tablets, covers or locks. The maximum cost spent by any site was £9,996, most likely reflecting its size. The 18 sites from which the average direct cost is taken comprise mainly medium acute trusts (nine fall into this classification).

Sites were also asked to submit data on ongoing staff costs. They did this by listing each staff member involved in the eHNA project on an ongoing basis, providing their job title and an approximate proportion of time that individual spent on the project. Nine sites submitted usable data in this regard. Using known pay rates for professions in the NHS (and taking the middle spine point for each), an approximate cost of staff time was secured for each site (see appendix for full details of the calculations undertaken). Doing so showed that sites spend £16,380 on average per year on ongoing staffing costs as part of the eHNA project. This assumes sites have provided data for each staff member involved in the eHNA project though this may not always be the case.

The minimum cost of ongoing staff time in relation to the eHNA project is £5,320 whilst the maximum is £29,620. Again this is dictated by the size of the trust and the extent to which the eHNA project is being used across different tumour sites and clinics.
This data should be interpreted highly cautiously due to the limited number of sites upon which the analysis is based, and the potentially poor quality of data supplied by sites. These cost calculations should instead be used to provide an indication of the possible scale of direct and indirect costs incurred through the eHNA project. The assumptions underpinning these calculations are documented in the appendix.

4.2 Macmillan activities

Section 3.2 gave a broad overview of the activities undertaken by Macmillan as part of the eHNA project. This section of the report looks in more detail at activities undertaken by Macmillan—initially looking retrospectively before considering the activities Macmillan will undertake in the remaining duration of the prototyping phase.

4.2.1 Past activities

The scale and length of the prototyping phase have departed from Macmillan’s original ambitions as the importance of the project has grown internally. The project has benefitted from a number of amendments to the administration of it.

Over the duration of the prototyping phase, the eHNA project has evolved. An overview of the key changes is provided below:

- The significance of the eHNA project has grown within Macmillan. It is now considered one of Macmillan’s core programmes due to its potential impact on the lives of people living with and beyond cancer. Accordingly, the focus of the evaluation has shifted away from understanding whether the eHNA project should be further rolled-out, to assessing how the wider roll-out should be carried out to maximum effect.

- The original ambition was for 50 sites to be enrolled in the eHNA project as part of the prototyping phase which was due to end in June 2015, with an additional 50 sites to be enrolled following completion of the evaluation. The prototyping phase was extended by a year (originally due to run from January 2013 until June 2015, now due to end in June 2016) to allow for a greater number of sites to be involved.

- From mid-2014, Macmillan introduced a number of more stringent pre-requisites for applicant sites. These included having WiFi already accessible, and proof that sites were actively undertaking paper assessment and care planning already. Doing so benefitted the project as potential delivery issues could be identified earlier in the process of enrolment.
• Prior to mid-2014, Macmillan purchased the tablets required by each site for use in the eHNA project. This process was amended so that sites are now expected to purchase their own hardware from the grant money provided by Macmillan. The purpose of this was a reduction in the administrative time required of Macmillan, and the removal of any ambiguity over tablet ownership.

• Macmillan revised the contract between itself and test sites to reflect legal advice confirming Macmillan’s role as a ‘data controller in common’. This revision also allowed elements of the 2013/14 NHS Standard Contract to be taken into account, alongside feedback provided directly from sites. The eHNA project team report that this reissued contract has lessened the volume of queries they get in relation to information governance and results in an easier and less time-consuming contract signing process.

• Over the duration of the prototyping phase, Macmillan has introduced a number of means through which it communicates regularly with test sites; these run alongside forms of ad-hoc communication and include the eight-weekly newsletter, progress reports and the Learn and Share events.

4.2.2 Current and future activities

Now that it is coming to the end of the prototyping phase, there are a number of priority areas for Macmillan to concentrate on over the coming year. The primary focus will be defining a ‘business as usual model’, working with commissioners to establish the Recovery Package in their intentions and supporting sites to further embed the eHNA in a wider profile of tumour groups.

Macmillan is currently working out what ‘business as usual’ looks like once the prototyping phase ends in summer 2016. A crucial decision for Macmillan in the coming months will be deciding which provider to work with to supply the software underpinning the eHNA data platform. This decision will dictate the future direction of the project and Macmillan’s involvement in it.

Macmillan is presently waiting for the release of their Corporate Strategy, following a review of their overarching strategy and sub-strategies. This report will present Macmillan’s view on what its workforce needs to look like in 2030 to meet the needs of individuals living with and beyond cancer. It is known that the Recovery Package is a key priority area for Macmillan though some of the content of the strategy is still unknown and may impact on the eHNA project team’s work going forward.

The next year will prove key for Macmillan to get the Recovery Package into mainstream NHS commissioning. The recent release of the Independent Taskforce on Cancer’s report, ‘Achieving world-class cancer outcomes: A
strategy for England 2015-2020', will assist in this with its endorsement of the Recovery Package. However, the long-term sustainability of the eHNA relies on it being a service sought by CCGs. One external stakeholder talked of sites partaking in the eHNA prototyping phase as being 'enlightened' for seeing the potential benefits of it but that not all trusts are of the same thinking. For these trusts, a more formal commissioning arrangement may be needed to secure their involvement.

External stakeholders also pointed to the need for a wider perspective beyond cancer to ensure a sustainable commissioning arrangement of the eHNA and Recovery Package. It is unclear what this might look like in the future, through it is recognised that commissioners are likely to see cancer within the broader classification of long-term conditions.

There are a number of workstreams which Macmillan will progress to further embed and 'future proof' the eHNA. This includes the creation and piloting (which is already underway) of an electronic assessment that can be completed by individuals living with and beyond cancer in their own homes. It is envisaged that, in due course, individuals will be able to complete the electronic assessment securely on a PC, laptop, tablet or mobile. This will meet the demand for an 'at home' form of assessment completion which is being articulated by healthcare professionals. This is also crucial to facilitate movement of the eHNA into other parts of the care pathway – for example it will negate the issue of GP surgeries traditionally having poor access to WiFi.

A number of sites based in the community are due to go live with the eHNA project imminently. These will present opportunities for Macmillan to deepen its understanding of how the eHNA can become established in parts of the care pathway outside of the acute setting.

Macmillan will continue to work closely with the existing prototyping sites. Until the prototyping phase comes to an end, the eHNA project team will be focusing their efforts on spreading the use of electronic assessments and care plans internally within sites. It is important for electronic assessments and care plans to be completed in a breadth of tumour groups as part of ensuring its sustainability. Additionally the team will be working with sites to encourage them to make greater use of the aggregate data generated by the project to ultimately better inform service delivery.

IT modifications will continue to be made as part of the ‘future-proofing’ of the eHNA. A particular focus will be to enable the automatic upload of assessment data and care plans into the Electronic Patient Record (EPR). This is presently only achievable at Guy’s and St Thomas’ though there are plans for this to be expanded. It is envisaged that sites will need to develop their own mechanisms to map the exported PDF files of assessment results and care plans to the correct patient and event type within their own EPR systems.
Further work is ongoing to increase the extent to which sites can ‘self-serve’. For example, changes have been made to the functionality of the software underpinning the eHNA such that sites are now able to delete their own test assessments and care plans.

It is likely that the way tumour groups are presently coded will be changed to match ICD10 classifications. Similarly, changes will be made to other data codes (such as gender) so the aggregate data generated through the eHNA matches the language used more widely within the NHS. The eHNA project team will also be looking to translate the wording of the electronic assessment into languages other than English and Welsh as part of the drive to increase its accessibility.

Where sites already have established systems for the collection of HNA data, Macmillan is exploring the possibility of allowing them to use their own front-end for the assessment and care planning process whilst ensuring the anonymised data generated can still be submitted to the eHNA datastore. This will allow sites to use tailored front-end systems whilst ensuring the value of the aggregate dataset is maintained and enhanced as it continues to develop in both breadth and depth.

### 4.3 Outputs of the eHNA project

This section of the report looks at the outputs which have been secured through the eHNA project.

*It is likely that a total of 67-68 sites will continue until the end of the prototyping phase. Some sites will not have the opportunity to enrol in the project despite showing a desire to do so.*

As of the 30th June 2015, 48 sites were live with the eHNA project. A further 17 sites were in ‘testing’ mode. Figure 4.1 shows when the 48 sites went live with the project.

**Figure 4.1 — Number of sites live with the eHNA project**
Presently 13 sites have submitted an EOI and these are awaiting a decision from Macmillan. It is expected the total number of sites that will continue until the end of the prototyping phase will reach 67-68 as some new sites come on board (from those which have submitted an EOI) whilst others are removed. Macmillan has become increasingly vigilant about the trajectory of electronic assessment and care planning at the individual site level. A small number of sites have therefore been suspended from the project given their persistently low volume of electronic assessments and care plans.

4.3.1 Electronic assessment and care planning numbers

There is a huge variety in the volume of electronic assessments and care plans completed between sites. The conversion rate of assessments into care plans has steadily increased over the duration of the prototyping phase.

As of 30th June 2015, 17,265 electronic assessments had been completed27. Table 4.2 below illustrates the variety in the number of assessments being completed by individual sites. A quarter of all these assessments were completed by Guy’s and St Thomas’ (23%) which continues to be an ‘outlier’ in terms of completing a significantly greater number of electronic assessments and care plans compared with other sites involved in the prototyping phase. This is, in part, due to the length of time that Guy’s and St Thomas’ has been involved in the eHNA project. It, along with St Helens and Knowsley and North Bristol, has been testing the eHNA since March 2012 as an original pilot site. These three sites are all within the top seven in terms of the completed numbers of electronic assessments and care plans. Guy’s and St Thomas’ success is also due, in part, to the high volume of individuals cared for, and because electronic assessments are being completed in all tumour groups.

Some sites are doing considerably less well despite being enrolled in the project over a year ago as part of wave 2 (thus going live between July 2013 and March 2014). This reflects a number of barriers which sites have faced in the implementation of the project (to be discussed later in this report). Further, some sites are doing well in terms of embedding the eHNA project but they are only doing so in a small number of tumour groups and hence they appear to be conducting comparatively few electronic assessments and care plans compared to others.

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27 This figure is taken from the eHNA datastore and covers all sites that have been involved in the eHNA project up until and including 30th June 2015.
Table 4.2 – Completed electronic assessments and care plans (among 48 sites live at 30th June 2015)

<table>
<thead>
<tr>
<th>Case studies: blue=w1, green=w2, yellow=w3, purple=additional, white=not a case study</th>
<th>No of assessments</th>
<th>No of care plans</th>
<th>Conversion rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guy’s and St Thomas’ (w1)</td>
<td>4,009</td>
<td>3,355</td>
<td>84%</td>
</tr>
<tr>
<td>St Helens and Knowsley (w1)</td>
<td>1,080</td>
<td>1,006</td>
<td>93%</td>
</tr>
<tr>
<td>University Hospitals Coventry &amp; Warwickshire (w2)</td>
<td>831</td>
<td>703</td>
<td>85%</td>
</tr>
<tr>
<td>King’s College Hospital (w2)</td>
<td>786</td>
<td>606</td>
<td>77%</td>
</tr>
<tr>
<td>Dorset County Hospital (w2)</td>
<td>568</td>
<td>184</td>
<td>32%</td>
</tr>
<tr>
<td>Plymouth Hospitals (w2)</td>
<td>526</td>
<td>454</td>
<td>86%</td>
</tr>
<tr>
<td>North Bristol (w1)</td>
<td>502</td>
<td>385</td>
<td>77%</td>
</tr>
<tr>
<td>Oxford University Hospital (w3+)</td>
<td>447</td>
<td>380</td>
<td>85%</td>
</tr>
<tr>
<td>Uni Hospitals of North Midlands (Royal Stoke) (w2)</td>
<td>408</td>
<td>189</td>
<td>46%</td>
</tr>
<tr>
<td>Southend University Hospital (w2)</td>
<td>400</td>
<td>240</td>
<td>60%</td>
</tr>
<tr>
<td>Luton and Dunstable University Hospital (w3+)</td>
<td>388</td>
<td>309</td>
<td>80%</td>
</tr>
<tr>
<td>St George’s Healthcare (w2)</td>
<td>384</td>
<td>221</td>
<td>58%</td>
</tr>
<tr>
<td>Velindre (w2)</td>
<td>321</td>
<td>255</td>
<td>79%</td>
</tr>
<tr>
<td>Gateshead Health (w2)</td>
<td>302</td>
<td>286</td>
<td>95%</td>
</tr>
<tr>
<td>Queen Alexandra Hospital, Portsmouth (w2)</td>
<td>302</td>
<td>177</td>
<td>59%</td>
</tr>
<tr>
<td>Royal Berkshire (w3+)</td>
<td>299</td>
<td>97</td>
<td>32%</td>
</tr>
<tr>
<td>United Lincolnshire Hospitals (w3+)</td>
<td>293</td>
<td>188</td>
<td>64%</td>
</tr>
<tr>
<td>Taunton and Somerset (w2)</td>
<td>278</td>
<td>241</td>
<td>87%</td>
</tr>
<tr>
<td>Poole Hospital (w3+)</td>
<td>254</td>
<td>210</td>
<td>83%</td>
</tr>
<tr>
<td>Barts Health (w3+)</td>
<td>252</td>
<td>215</td>
<td>85%</td>
</tr>
<tr>
<td>Whittington Hospital (w3+)</td>
<td>228</td>
<td>204</td>
<td>89%</td>
</tr>
<tr>
<td>NHS Ayrshire and Arran (w3+)</td>
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<td>221</td>
<td>98%</td>
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<td>Great Western Hospitals (w2)</td>
<td>218</td>
<td>175</td>
<td>80%</td>
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<tr>
<td>Cambridge University Hospitals (w2)</td>
<td>208</td>
<td>183</td>
<td>88%</td>
</tr>
<tr>
<td>Brighton and Sussex University Hospitals (w2)</td>
<td>204</td>
<td>106</td>
<td>52%</td>
</tr>
<tr>
<td>Lewisham Hospital (w2)</td>
<td>197</td>
<td>171</td>
<td>87%</td>
</tr>
<tr>
<td>Uni Hospitals of North Midlands (County) (w2)</td>
<td>187</td>
<td>168</td>
<td>90%</td>
</tr>
<tr>
<td>The Princess Alexandra Hospital (w2)</td>
<td>170</td>
<td>108</td>
<td>64%</td>
</tr>
<tr>
<td>The Royal Marsden (w2)</td>
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<td>99%</td>
</tr>
<tr>
<td>The Royal Brompton and Harefield (w2)</td>
<td>162</td>
<td>131</td>
<td>81%</td>
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<tr>
<td>Nottingham University Hospitals (w3+)</td>
<td>153</td>
<td>70</td>
<td>46%</td>
</tr>
<tr>
<td>Homerton University Hospital (w3+)</td>
<td>121</td>
<td>89</td>
<td>74%</td>
</tr>
<tr>
<td>Royal Wolverhampton Hospitals (w3+)</td>
<td>114</td>
<td>105</td>
<td>92%</td>
</tr>
<tr>
<td>Western Sussex Hospitals (Worthing) (w3+)</td>
<td>98</td>
<td>91</td>
<td>93%</td>
</tr>
<tr>
<td>Salisbury (w3+)</td>
<td>86</td>
<td>81</td>
<td>94%</td>
</tr>
</tbody>
</table>

28 Note: only nine additional case study sites are shown here as the tenth is still presently in testing mode.
Pennine Acute Hospitals (w3+)
Harrogate District Hospital (w3+)
BUPA Cromwell Hospitals (w2)
West Suffolk (w2)
Pennine Care NHFT (w2)
Ipswich Hospital (w3+)
Northern Lincolnshire and Goole (w2)
University Hospital Southampton (w2)
University Hospitals of Morecambe Bay (w3+)
Basildon and Thurrock University Hospitals (w3+)
Northampton General Hospital (w3+)
North West London Hospitals (w2)
Central Manchester University Hospitals (w3+)

<table>
<thead>
<tr>
<th>Hospital</th>
<th>84</th>
<th>68</th>
<th>81%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pennine Acute Hospitals</td>
<td>79</td>
<td>69</td>
<td>87%</td>
</tr>
<tr>
<td>Harrogate District Hospital</td>
<td>65</td>
<td>64</td>
<td>98%</td>
</tr>
<tr>
<td>BUPA Cromwell Hospitals</td>
<td>65</td>
<td>8</td>
<td>12%</td>
</tr>
<tr>
<td>Pennine Care NHFT</td>
<td>49</td>
<td>26</td>
<td>53%</td>
</tr>
<tr>
<td>Ipswich Hospital</td>
<td>43</td>
<td>37</td>
<td>86%</td>
</tr>
<tr>
<td>Northern Lincolnshire and Goole</td>
<td>40</td>
<td>14</td>
<td>35%</td>
</tr>
<tr>
<td>University Hospital Southampton</td>
<td>38</td>
<td>24</td>
<td>63%</td>
</tr>
<tr>
<td>University Hospitals of Morecambe Bay</td>
<td>26</td>
<td>23</td>
<td>88%</td>
</tr>
<tr>
<td>Basildon and Thurrock University Hospitals</td>
<td>25</td>
<td>21</td>
<td>84%</td>
</tr>
<tr>
<td>Northampton General Hospital</td>
<td>24</td>
<td>15</td>
<td>63%</td>
</tr>
<tr>
<td>North West London Hospitals</td>
<td>23</td>
<td>12</td>
<td>52%</td>
</tr>
<tr>
<td>Central Manchester University Hospitals</td>
<td>6</td>
<td>3</td>
<td>50%</td>
</tr>
</tbody>
</table>

The care plan conversion rate has fluctuated over time, though there has been an upward trajectory over the duration of the prototyping phase. Of all electronic assessments completed by 30th June 2015 (including sites no longer live or not yet live), 72% were converted into a care plan. In the most recent month of June 2015, 81% of all electronic assessments were converted into care plans.

**Figure 4.2 – Care plan conversion rate**

![Graph showing care plan conversion rate]

Base All assessments and care plans completed as per the eHNA database

### 4.3.2 Current activity levels in comparison to the baseline

A **marginal increase in the average number of assessments being completed per site per month is evident following the introduction of the eHNA project. The proportion of assessments which result in a care plan has increased dramatically.**

Sites were asked to complete a minimum of two months’ worth of baseline data which captured the extent to which paper assessments and care plans were being carried out prior to the roll-out of the eHNA project. In total, 42
sites submitted usable data. The baseline data show that, on average, 23.7 assessments were being completed on paper per site per month prior to the eHNA roll-out.

Of the 48 sites currently live with the eHNA project, an average of 17.2 electronic assessments are completed per site per month (based on all the assessments they have completed since they went live). This rises to 25.4 electronic assessments per site per month when looking just at the past six months for the 30 sites which have been live for 1+ years. This latter figure provides an estimation of the number of electronic assessments being completed per site per month once sites have had time for the eHNA project to embed, and thus this represents a marginal increase in the volume of assessments being completed following the eHNA roll-out.

It is however recognised that there are limitations to comparing the baseline data with current assessment figures in this way. The 42 sites which provided baseline data are not matched to the sites from which current data is drawn. For example, the original pilot sites (which include Guy’s and St Thomas’) did not supply baseline data as they enrolled in the project prior to the evaluation beginning. Similarly, some of the sites which submitted baseline data are no longer involved in the eHNA project (such as Barking, Havering and Redbridge). It also does not account for the differences in tumour groups submitting baseline data versus the tumour groups where electronic assessments are presently being conducted.

There are 13 sites where we have comparable baseline and current data (matched by tumour group). Looking just at these sites provides a better ‘like for like’ comparison of before and after the eHNA project was introduced\(^29\). Prior to the eHNA roll-out, in these 13 sites, the average number of paper assessments being completed per site per month was 14.5. This compares with an average of 8.6 electronic assessments being completed per site per month since the eHNA project was introduced. Whilst these figures provide a more direct comparison, these 13 sites could be considered less successful pioneers of the eHNA project given none of them have expanded the eHNA project beyond the tumour sites where paper assessments were originally being conducted. Thus these figures may not be a fair reflection of the success of the eHNA project.

From the baseline data submitted by 42 sites, it is apparent that 52% of paper assessments resulted in a care plan. This has increased dramatically with the advent of the eHNA project as (based on the 48 sites live with the project) 77% of all electronic assessments completed have resulted in a care plan.

\(^{29}\) Note, the tumour groups where electronic assessments and care plans are currently being completed was determined by data held on the eHNA datastore which lists the number of care plans completed according to tumour type in the past six months. It is not possible to analyse this data according to the number of electronic assessments being completed. If electronic assessments are not being converted into care plans in any tumour groups then this analysis assumes electronic assessments are not being conducted in that location at all.
care plan. This rises to a conversion rate of 82% when looking just at the past six months for the 30 sites which have been live for 1+ years.
Embedding and administering electronic assessments and care plans
5 Embedding and administering electronic assessments and care plans

This chapter provides a broad overview of how electronic assessments and care plans are being embedded and administered at site level. It summarises information previously reported in the June 2015 Process Evaluation report.

5.1 Embedding the eHNA

Initially this chapter will explore how the eHNA is being embedded – giving consideration to the drivers and enablers of implementation before considering the barriers faced in establishing the project.

5.1.1 Drivers of implementation

*External drivers to encourage adoption of the eHNA include a need to audit holistic needs assessments and care planning; the drive to improve quality and performance metrics; the push towards paperless working; and the potential benefits of the aggregate data.*

There are a number of external drivers which incentivise sites to work beyond the barriers they face in implementing the eHNA project. Some sites are hopeful that conducting holistic needs assessments and care plans will contribute to better Cancer Patient Experience Scores through improvements made in the support provided to individuals living with and beyond cancer. The eHNA affords these sites a means through which to introduce assessment and care planning more formally.

Similarly, there is increasingly a need to evidence that holistic needs assessments and care plans are being completed and the electronic version greatly assists in this.

The push for paperless working by 2018[^32] is another externality that favours the adoption of the eHNA over previous paper systems in place.

The potential application of the aggregate data generated through the eHNA is highly valued – sites are keen to make use of this data to better improve their service delivery. Being able to show the power of the

aggregate data generated by the eHNA has encouraged sites to work beyond the challenges they may have faced. The aggregate data and its current and potential use is discussed more fully in section 8.1.

5.1.2 Enablers of implementation

*Delivery of the eHNA is most likely to succeed where changes are made to current working practices, requiring the support of both frontline and senior staff.*

Sites have shown it is possible to embed the eHNA into existing clinical structures but this process has been greatly facilitated in sites that have been able to make structural changes to pre-existing working practices. This has involved establishing ‘protected time’ to administer electronic assessments and care plans or introducing specific eHNA clinics. This has meant the project can become a manageable practice rather than an additional burden to already heavy workloads.

*"CNS time needs to be released from competing demands and there needs to be dedicated eHNA clinics incorporated into pathways... The eHNA project has acted as a catalyst for us to look at our pathways." (healthcare professional)*

The structural changes can also apply to staffing levels and composition, not just clinical scheduling. For one site, as Band 6 and 7 members of staff leave the trust, a greater number of Cancer Support Workers will be recruited to free-up the time of CNSs which will help them to complete electronic assessments and care plans.

Making these structural changes can be challenging if the eHNA project does not have full support from frontline staff and more senior personnel. As identified by Macmillan and communicated to sites, securing early buy-in to the eHNA project from the beginning is key to successfully embedding it.

*"There are politics around this at the moment... does this sit alongside existing practice or do we need to undertake a much larger review of the role of our CNSs in order to accommodate the resource in terms of the eHNA clinic time that is required?" (healthcare professional)*

*“Senior management have embraced the programme and have put forward the programme as a ‘non-negotiable’ process that must be adopted.” (healthcare professional)*

The success of the project can rely quite heavily on the enthusiasm and dedication of staff members involved in its roll-out. These are individuals who are prepared to work through the barriers and challenges they face because they believe in the fundamental premise of the eHNA.
"It's been worth it. I always have a smile on my face about the eHNA because, you know what, I am still a passionate believer in it." (Healthcare professional)

Some sites have employed the use of trained volunteers to lessen the demands placed on healthcare professionals' time. In these instances, volunteers are there to hand out tablets, explain the purpose of the assessment and aid in its completion if required. Other sites have had (or are in the process of recruiting) dedicated personnel to work solely or predominantly on embedding the eHNA and wider Recovery Package. This has helped immensely as project leads often have multiple work-streams or are practising clinicians themselves, meaning they have limited time to develop the project.

There is a growing use of WiFi and tablets across the NHS which is benefitting the eHNA project. Some sites no longer need to use their Macmillan grant to establish WiFi or purchase tablets and instead can invest in employing individuals specifically dedicated to embedding the eHNA project and wider Recovery Package as described above.

Sites that have firmly established paper assessments and care planning are more likely to succeed in successfully implementing the eHNA as they have often worked through some of the difficulties of incorporating the practice into daily work. Macmillan recognised this early in the prototyping phase and made it a pre-requisite for sites’ involvement in the eHNA project.

5.1.3 Barriers to implementation

Just over a quarter of all healthcare professionals say they have found it very/fairly easy to carry out electronic assessments and care plans over the past few months (28%). However, half of all healthcare professionals say it has been very or fairly difficult (48%). There are common implementation barriers faced across sites as discussed below.

*Time: Heavy workloads, poor staff capacity and competing priorities all represent significant challenges to sites.*

A perceived lack of time in which to administer electronic assessments and care plans has represented a significant challenge to establishing the eHNA in some sites. Making structural changes to how clinics are run (as mentioned earlier) has helped some sites overcome this as a barrier. However, some sites have been significantly hampered by staff capacity issues. Where skeleton teams are in place (due to sick leave, holiday absence or unfilled posts) the pressures on remaining staff members mean the eHNA project cannot be prioritised.

"At the moment we are in limbo, we've tried looking every which way on how we can concentrate our efforts in one area but we keep coming up against the same stumbling block which is that..."
at the end of the day it’s the CNS that has got to oversee the care plan even if we have someone at a lower banding to initiate it."
(healthcare professional)

"There is still opposition in places... It is perceived by members of the team to be a very resource intensive task." (healthcare professional)

"Some tumour sites don’t have the physical resources to even think about it (the eHNA)." (healthcare professional)

Some sites have slowed in their progression of the eHNA project due to other significant competing priorities. Examples of such issues include hospital mergers, and the need to address poor performance metrics such as waiting times. It is important for Macmillan to keep in close contact with these sites to ensure momentum behind the project is not lost.

Staff support: Securing early buy-in from a broad range of internal personnel is crucial, though some individuals are simply less open to the prospect of change.

As previously discussed, having senior management buy-in to the eHNA project is critical to its success – this support also extends to non-clinical functions including IT and information governance. The use of regular steering groups is important to maintain a focus on the project and its implementation.

The success of the project does rely somewhat on the personalities of individuals involved. Some are whole-heartedly committed to the eHNA project meaning its success can rely heavily on these individuals continuing to boost their colleagues’ morale levels.

Resistance to the eHNA project tends to be expressed when individuals cannot see how to incorporate it into existing structures and they are hesitant about changes being made to their working practices. In a few cases, vocal staff members can be quite disruptive to the progression of the project. Some healthcare professionals interviewed talked about the need for wider cultural change; acknowledging that not all staff members were fully behind the survivorship agenda given it is a departure from what they have known and practised previously. Exploring individuals’ concerns from their perspective rather than working to set a pro forma of issues to discuss can require a skill-set that may be new to some healthcare professionals.

"The challenge at present is it’s a big change in the way of working for our practitioners. We are redefining the relationship between patients and clinicians from one where our clinicians provide and carry our patients through pathways to one where we actually facilitate and encourage patients to take control of
their own conditions. That has been a difficult pill to swallow for numerous members of team here.” (healthcare professional)

In a few instances, healthcare professionals administering electronic assessments and care plans have revealed a lack of confidence in dealing with issues raised by people completing the assessment. This is discussed further in section 7.2.

Available opportunities: There are instances where it is not possible, or appropriate, to administer the electronic assessment and care plan, and in some instances individuals themselves decline to do so.

In some sites, the high volume of individuals living with and beyond cancer seen means healthcare professionals have limited time to spend with each person and thus completing the electronic assessment and care plan can be challenging. At the opposite end of the spectrum, some sites (and clinics) have limited opportunities to conduct electronic assessments and care plans since they see a low volume of individuals living with and beyond cancer (for example healthcare professionals working in the community setting as part of Pennine Care see approximately 4-10 individuals a week).

The volume of electronic assessments and care plans is also affected by the perceived eligibility of people to complete an assessment. This is discussed in greater detail in section 6.1.1, but it is apparent that healthcare professionals exercise discretion about who is considered eligible for an electronic assessment and care plan based on their physical and mental state leading them to conclude that sometimes it is not appropriate to ask individuals to complete the electronic assessment.

An issue for some sites is the availability of suitable clinic space in which to administer electronic assessments. Sites have had to think creatively about how to overcome these challenges – in some instances it has simply been a case of trialling individuals completing the electronic assessment in clinic waiting rooms. This has helped some healthcare professionals get over their initial concern that people would be unhappy to complete the assessment in a public place.

Quantitatively, time constraints are the greatest perceived challenge to embedding holistic needs assessments and care planning.

When looking quantitatively at the perceived barriers of implementing holistic needs assessments and care planning (non-specific to the eHNA project), issues of time limitations dominate. Over half of healthcare professionals say having too many patients is a significant barrier (58%), as is short appointment times (51%) and general time constraints (19%). The lack of suitable rooms and IT facilities also present challenges (51% and 37% respectively).
Figure 5.1 — Barriers to implementing holistic needs assessments and care planning in general

Q23. What barriers, if any, do you face in implementing Holistic Needs Assessments and care planning? Your answer should refer to Holistic Needs Assessments and care planning in general whether they are completed on paper, verbally or electronically. Please select all that apply.

Prior to the roll-out of the eHNA, healthcare professionals are less likely to cite ‘too many patients’ as an issue (46% mention this compared to 58% following the eHNA roll-out). Similarly they are less likely to mention general ‘time constraints’ (only four per cent mention this compared with 19% following the eHNA roll-out). Instead, healthcare professionals more commonly mention that they have had insufficient training on conducting assessments and care plans (17% versus five per cent following the eHNA roll-out); inadequate training (nine per cent versus three per cent); and that they lack confidence to conduct assessments and care planning (14% versus five per cent).

One particular barrier which seems to have lessened in its severity is information governance. At one stage this represented a significant barrier to implementation with sites expressing concern over data flows, data security/access, the involvement of the third party software provider and Macmillan’s role in the project. These concerns lessened once Macmillan issued the revised contract and once the eHNA project team secured a better grasp of the issues at hand and how to communicate with sites about them.

Lack of targets: An absence of targets and funding from commissioners led some to believe that the eHNA project is not receiving due attention from staff internally.

Some healthcare professionals interviewed felt that mandatory or enforced targets would mean greater weight was given to establishing the eHNA project. Similarly, they felt that financial incentives put in place through commissioning arrangements would encourage greater adoption of the tool.

"We are not getting any funding from the commissioners to enable, or financial incentives to encourage, it to take place and..."
that's the major problem. If commissioners were to say we're going to give you x amount of pounds and this is something that you've got to do then I'd expect there to be a change of heart."

(healthcare professional)

In North Bristol, the tariff paid by commissioners for completing electronic assessments and care plans has contributed to securing more administrative support, freeing up nurses so they can allocate more of their time towards assessments and care planning.

However, one site with experience of trying to meet targets set for holistic needs assessments and care planning warned of targets overshadowing what should be the primary driving force behind the eHNA project – that of improved care for individuals living with and beyond cancer.

*IT issues: Many barriers to implementation also apply to establishing paper assessments and care plans; the exception to this are the IT challenges specific to the eHNA.*

The barriers previously discussed (grouped into challenges pertaining to time, staff support, available opportunities, and a lack of targets) can all apply to the implementation of paper assessments and care planning. Though these may be exacerbated by the introduction of electronic alternatives, the only set of barriers which are specific to the eHNA are those pertaining to IT issues.

As shown in figure 5.2, when asked specifically to name barriers faced in implementing the eHNA project (as opposed to holistic needs assessments and care plans more generally), the top six issues raised by healthcare professionals all focus on IT. Most commonly healthcare professionals mention poor WiFi availability as a barrier (44%) though they also mention general IT issues (30%); a lack of printers, tablets and desktop computers (26%, 22% and 20% respectively); and poorly functioning tablets (18%).

As the use of WiFi and tablets become more commonplace in healthcare settings, it is hoped that some of these IT issues will lessen.
Figure 5.2 — Barriers to the implementation of electronic holistic needs assessments

Q27. Thinking specifically about electronic Holistic Needs Assessments, what barriers, if any, have you faced in the implementation of the eHNA project? Please select all that apply

- Poor WiFi availability in clinics: 44%
- General IT issues: 30%
- Lack of printers: 26%
- Lack of tablets: 22%
- Lack of desktop computers: 20%
- Tablets do not function properly: 18%
- Preference for paper assessments among patients: 16%
- Preference for paper assessments among staff: 15%
- Lack of time: 12%
- Not enough training available for staff: 8%
- Inadequate training for staff: 6%
- Senior staff not supportive of the eHNA project: 5%
- Issues with information governance: 4%
- Lack of space/room/clinic available: 4%
- Under resourced/short staffed: 3%
- Administration/ care plan creation: 3%
- Haven’t used it yet: 3%
- Other: 1%
- Don’t know: 1%
- None: 1%

Base: Post-intervention healthcare professionals: All participants (180)

In the qualitative interviews with healthcare professionals it emerged that some members of staff lack conviction in their technical capabilities and this can limit their use of electronic assessments and care plans.

"Using an electronic tool certainly caused apprehension amongst several stakeholder groups, a lot of that has been overcome as a result of internal learn and share, and one to one, training events." (healthcare professional)

For other members of staff, poor previous experiences where they have failed to successfully complete the electronic assessment hinders their enthusiasm to try again. Most of these ‘failures’ have stemmed from weak WiFi connections which prevent the completed assessment from being submitted.

“Sometimes we have to hover in the corridor (to access the WiFi).” (healthcare professional)

A lack of available hardware can at times present difficulties. This may be because there is a limited number of tablets available within clinics and/or a lack of computers on which to view assessment results and write up care plans. Sites are beginning to complete care plans on tablets; helping to overcome this challenge.

5.2 Administering electronic assessments

Brief consideration is given here as to how sites are actually administering electronic assessments. More detail is provided in the June 2015 Process Evaluation report.
Completion of electronic assessments and care plans happens most commonly close to diagnosis.

Macmillan (building on work done with the NCSI) recommends holistic needs assessments are done at key transition points in the care pathway – as near to diagnosis as possible, at the end of treatment, and subsequently if health or circumstances change. According to the eHNA datastore, electronic assessments are most commonly completed when individuals are newly diagnosed (accounting for 40% of assessments).

**Figure 5.3 — Pathway stage at time of electronic assessment completion**

Base: All electronic assessments completed as of 30th June 2015. Note “End of treatment” added to Pathway Stage in January 2014. Source: eHNA datastore

The majority of individuals living with and beyond cancer surveyed who recall completing an assessment believed they had completed one electronic assessment (85%) though one in ten thought that had completed two (10%) and five per cent believed they had completed three or more.

**Electronic assessments are being completed in a variety of settings though mainly in hospital waiting rooms prior to consultations or in private consultation rooms.**

Most people who recall completing an electronic assessment did so in a hospital waiting room before their appointment (44%). One in five did so in a private consulting room before their hospital appointment (23%), while 18% did so in a private consulting room during their appointment.

The healthcare professionals surveyed are most likely to say that individuals complete the electronic assessment in a private consulting room during their hospital appointment (35%) though it is also common for patients to complete the assessment in the waiting room prior to their appointment (27%).
Sites have embedded the eHNA project in a variety of ways; helping to ensure its sustainability within working practices.

A fairly common process for administering the electronic assessment and care plan is for individuals to complete the assessment prior to an appointment which is specifically set-up to discuss the assessment results. The care plan is then typically written up by the healthcare professional and posted to the individual living with cancer. However, the diversity of how sites work has resulted in a wide variety of practices being undertaken; some of which are referred to below. Other examples of how electronic assessments and care plans are administered can be found in the June 2015 Process Evaluation report.

- Coventry and Warwickshire (Head and Neck) – individuals are seen in one hour appointment slots approximately one week following diagnosis. The individual completes the electronic assessment and discusses their results for approximately 30 minutes with a CNS. They then go to meet with a dietician or speech therapist for the remaining 30 minutes, during which the CNS completes their care plan.

- Velindre (Sarcoma) – for this particular tumour group, the trust serves a wide geographical area and thus wants to limit the need for individuals to travel to the site unnecessarily. They therefore post a paper assessment to individuals; the answers of which are entered by a member of staff onto the tablet upon receipt. In dedicated eHNA clinics, individuals who have completed an assessment are called to discuss their concerns, following which a care plan is created for them.

- Pennine Care – given they are a community based team, healthcare professionals at this site are looking to administer electronic assessments and care plans at health and wellbeing events (as well as in other settings). This will involve a number of appointments being available on the day of the event in which to complete the electronic assessment and care plan.

5.3 Administering electronic care plans

As discussed previously, not all electronic assessments result in a care plan. This section of the report briefly considers the reasons why assessments may not be converted into care plans. Again, more detail can be found in the June 2015 Process Evaluation report.
A lack of time is the most common reason for care plans not being created or being delayed in their creation. A lack of available computers and low-level concerns raised through the assessment are other reasons commonly provided.

Through the case study interviews, a number of reasons have been identified as to why not all electronic assessments result in a care plan:

- **Care plans are not created (or there is a delay in their creation) due to time limitations and/or a lack of available computers.** This is the main barrier to care plan completion. Healthcare professionals acknowledged that, against best wishes, care plans could often be delayed (or not written) due to the time pressures they are under. A shortage of computers can present another barrier to completion. According to the survey of healthcare professionals, roughly one-fifth of care plans are written during the consultation (17%), a similar proportion are written immediately after the consultation (23%) but the bulk of care plans are written later on (52%).

- **Care plans are not created when individuals have low-level concerns.** Healthcare professionals may choose not to create a care plan if few, or low level, concerns are raised by the individual living with and beyond cancer. Equally, given the time constraints they face, healthcare professionals may choose to prioritise the care plans of individuals with complex needs meaning those with less complex needs do not get a care plan.

- **Care plans are written on paper instead of completed electronically.** Whilst rare, there were some mentions in the case study interviews of care plans being written up on paper despite the assessment being completed electronically. This reflects the lack of available computers and sometimes other technical issues which mean it is easier to complete the care plan in hard copy.

- **Individuals do not wish for their discussion to be documented in a care plan.** Rarely, when the subject matter of the assessment and subsequent discussion are highly sensitive or personal, individuals ask for their concerns not to be documented in a care plan. The occurrence of this is thought to be very low.

A hard copy care plan is often shared with individuals though it is not uncommon for individuals to decline it.

In September 2014 it became possible for healthcare professionals to record if individuals’ care plans were shared with them or not. This data has revealed that, in the main, care plans are shared with the individuals who completed the electronic assessment (in 62% of cases) and this is done primarily in hard copy as opposed to by email (60% versus two per cent).
In a quarter of all cases, individuals choose to decline a copy of their care plan (24%). Healthcare professionals suppose this happens when individuals have low-level, if any, concerns and/or when individuals feel their concerns were addressed by the discussion alone. This is discussed in greater detail in section 6.1.3.

**Table 5.1 – Care plan outcomes**

<table>
<thead>
<tr>
<th>% of care plans</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared with patient on paper</td>
</tr>
<tr>
<td>Declined by patient</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Shared with patient by email</td>
</tr>
</tbody>
</table>

Source: eHNA datastore  
Base: 2,731 care plan outcomes recorded
Medium term outcomes and impact on people living with and beyond cancer
6 Medium term outcomes and impact on people living with and beyond cancer

This chapter focuses specifically on the medium term outcomes and impacts of the eHNA project on people living with and beyond cancer. The findings build upon those previously reported as part of the October 2014 evaluation report.

6.1 Extent of assessment and care planning

As documented in the logic model, it is hoped that the eHNA project will result in an increased delivery of assessment and care planning: that “all eligible individuals complete an electronic assessment and care plan”, and that “conducting electronic assessments and care plans is routine”.

6.1.1 Eligibility

One-fifth of individuals living with and beyond cancer presently have an electronic assessment in the prototyping sites. Paper assessments are still done though considerably less so than prior to the eHNA roll-out, whilst verbal assessments continue to be done to the same degree.

Before the eHNA project, healthcare professionals were conducting either a verbal or paper assessment with an average of 46% of individuals. This proportion rises (non-significantly) following the introduction of the eHNA project such that, on average, 52% of individuals complete a holistic needs assessment (whether this is verbal, on paper or electronic). It should be noted that the average number of assessments completed in the last month is marginally less at the post-intervention stage. This may reflect a difference in the number of individuals eligible to complete an assessment, or natural variation in the sample of healthcare professionals surveyed before and after.

Since the advent of the eHNA project, the proportion of assessments being completed verbally has not changed – just under a quarter of individuals receive a holistic needs assessment of this type (23%). The proportion of paper assessments has declined such that now eight per cent of individuals living with and beyond cancer receive a paper assessment compared to 23% prior to the eHNA roll-out. And, on average, 21% of individuals living with and beyond cancer have an electronic assessment.
Table 6.1 — Proportion of individuals completing a verbal, paper or electronic assessment

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average number of assessments completed last month per healthcare professional (Q6a)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal</td>
<td>8.2 (49% of assessments)</td>
<td>6.4 (44% of assessments)</td>
</tr>
<tr>
<td>Paper</td>
<td>8.5 (51% of assessments)</td>
<td>2.2 (15% of assessments)</td>
</tr>
<tr>
<td>Electronic</td>
<td>0.0 (0% of assessments)</td>
<td>6.0 (41% of assessments)</td>
</tr>
<tr>
<td><strong>Average proportion of individuals who completed an assessment with (whether verbal, paper or electronic) (Q7a)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>46%</td>
<td>52%</td>
</tr>
<tr>
<td><strong>Average proportion of individuals completing an assessment by assessment type (calculation)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal</td>
<td>23% (=49 x 0.46)</td>
<td>23% (=44 x 0.52)</td>
</tr>
<tr>
<td>Paper</td>
<td>23% (=51 x 0.46)</td>
<td>8% (=15 x 0.52)</td>
</tr>
<tr>
<td>Electronic</td>
<td>N/A</td>
<td>21% (=41 x 0.52)</td>
</tr>
</tbody>
</table>

Source: Surveys of healthcare professionals
Base: 94 (pre) and 145 (post) healthcare professionals who complete holistic needs assessments

Whilst in theory all individuals are eligible to complete an electronic assessment, there are a number of instances when healthcare professionals exercise discretion about who should complete it.

The case study interviews revealed the ambiguity of who counts as ‘eligible’. The overarching response from healthcare professionals is that anyone is eligible so long as they have a cancer diagnosis and are in the care pathway. However, healthcare professionals exercise discretion about who is suitable to complete an electronic assessment and there are a number of groupings where greater consideration will be given to the appropriateness of asking them to complete an electronic assessment:

- Individuals who are very frail or unwell.
- Those with learning difficulties.
- Those receiving palliative care or with a particularly limited life expectancy.
- Individuals admitted as emergency cases.
• Individuals described as being 'not eligible on that day' given they show particular signs of distress. On these occasions, it is said that the process of assessment and care planning would disrupt the natural flow of conversation and detract from the individuals’ immediate concerns and desire to talk.

In some instances, language barriers have been cited as a challenge to administering electronic assessments, although on-site translators and family members have helped here.

6.1.2 Representativeness

*Individuals with an electronic care plan are more likely to be younger and female compared to the known profile of individuals with cancer across the UK – this may reflect the tumour sites where electronic assessments are presently being completed.*

The demographic profile of individuals who have had an electronic care plan31 created differs somewhat from the known profile of individuals with a cancer diagnosis across the UK. Those with an electronic care plan tend to be younger (with a greater proportion in the 25-64 age bracket and lower proportion aged 75+). Differences are also apparent in gender as individuals with an electronic care plan are more likely to be female whilst cancer diagnoses across the UK are more evenly split between the genders.

It is worth noting that the profile of individuals who complete an electronic assessment may differ from that of individuals with an electronic care plan given not all electronic assessments are converted into care plans. It is also worth noting that the number of care plans does not necessarily correspond to the number of individuals since some people may have more than one care plan (although the occurrence of this is low).

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31 This data, as reported on the eHNA datastore, is available only for care plans and not electronic assessments completed.
A number of factors are likely to contribute to the differences seen in demographic profiles. A key consideration is which tumour sites electronic assessments are presently being completed in. Table 6.2 below shows the most common cancers for which care plans are being created. The four cancers of breast, lung, prostate and bowel account for 53% of all cancers diagnosed in the UK, with breast cancer being the most common and these four cancers account for 42% of the care plans written to date. This suggests the profile of cancer types for those with an electronic care plan does not accurately reflect the profile of cancer diagnoses across the UK. This is particularly the case for breast cancer in women with the proportion of care plans created for this tumour group being considerably higher than the proportion of breast cancer diagnoses across the UK (26% vs. 15%). Given this tumour group is most prominent in women, this may explain the skew towards females in the care plans created.

By working with sites to spread use of the eHNA tool internally, the breadth of tumour groups involved should better reflect the national picture of cancer diagnoses. This will be important in ensuring the aggregate data generated through the project accurately reflects the concerns of the wider population of people affected by cancer.

Table 6.2 – The most common tumour groups to administer electronic care plans

<table>
<thead>
<tr>
<th>Tumour Type</th>
<th>Number of care plans</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer in women</td>
<td>3023</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>967</td>
</tr>
<tr>
<td>Colon and rectal cancer</td>
<td>823</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>706</td>
</tr>
<tr>
<td>Head &amp; neck cancers</td>
<td>627</td>
</tr>
<tr>
<td>Melanoma</td>
<td>488</td>
</tr>
<tr>
<td>Ovarian cancer</td>
<td>451</td>
</tr>
<tr>
<td>Womb (endometrial) cancer</td>
<td>432</td>
</tr>
<tr>
<td>Lymphoma, non-Hodgkin</td>
<td>417</td>
</tr>
<tr>
<td>Oesophageal (gullet) cancer</td>
<td>333</td>
</tr>
</tbody>
</table>

Source: eHNA datastore
Base: 11,789 care plans produced by 30th June 2015

The younger age profile of individuals with an electronic care plan compared to cancer diagnoses across the UK may reflect who is being asked, and who is able, to complete the assessment.

Some healthcare professionals interviewed expressed concerns that older people or those less technology-literate would struggle to complete the assessment electronically. These views tend to dissipate once electronic assessments become more established in sites. Sites that have been running with the eHNA project for longer comment that age is not a barrier to assessment completion. Section 6.1.4 below explores further how easy/difficult individuals find completing the assessment on a tablet.

"Age hasn’t been an issue, in fact they quite like it." (healthcare professional)

In general, it was felt that healthcare professionals are doing their best to administer electronic assessments and care plans with as many patients as possible but that there are a number of barriers (as discussed in section 5.1.3) which limit the numbers they are able to complete.

"They are trying to capture as many patients as they can, I don’t think they are picking or choosing their patients." (healthcare professional)
It is possible that the age/gender profile of individuals completing the electronic assessment differs from the known profile of cancer diagnoses as a result of who declines to complete the assessment—this is explored below.

### 6.1.3 Declining the electronic assessment

Some individuals **decline to complete the electronic assessment**—typically **because they do not feel it is necessary or they have limited time available**.

Some individuals decline to complete the electronic assessment; the exact proportion that do so is hard to ascertain. The baseline and follow-up data submitted by sites provides (where possible) the number of individuals considered eligible to complete an assessment and the number of individuals who choose to decline an assessment\(^ {33} \).

Only four per cent of individuals decline an electronic assessment, as a proportion of those deemed eligible to complete it. The comparative figure for the decline of paper assessments is three per cent. What is not recorded however, is the volume of individuals who are **offered** an assessment. The actual proportion of individuals who decline an assessment is likely to be higher than this given not all individuals considered eligible for an assessment are offered the chance to complete one due to time pressures and other limiting factors discussed elsewhere in this report.

What remains unknown is the profile of people who choose to decline the assessment. It could be supposed that particular age groups or genders may be more prone to decline the electronic assessment. This may be important if it limits the representativeness of the aggregate data.

Individuals mainly choose to decline the electronic assessment if they ‘feel fine’ and cannot see the benefit of completing it. Those with particularly robust support networks may also cite this as a reason for declining the assessment. Some individuals will choose to decline because they want to limit the time they spend at hospital or they have limited time available. Only in rare circumstances do individuals decline because they are unwilling or unable to complete the assessment on a tablet. According to the survey of healthcare professionals, an average of 14% of individuals offered the electronic assessment have declined to complete it or been unable to complete it.

"**It’s not the electronic or iPad that puts people off cos they get help with that if they need it, I think it’s just the faffing around with it really.**" (healthcare professional)

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\(^ {33} \) This is provided per cancer clinic per month.
It should be noted that there will always be people who choose to decline the assessment. This means Macmillan’s ambition for all individuals living with and beyond cancer to have an electronic assessment cannot be fully achieved. Macmillan can instead focus on ensuring all individuals living with and beyond cancer are offered an electronic assessment and make an informed decision about whether to complete it or not. Section 6.4 looks further at the extent to which individuals are presently receiving an adequate explanation of the electronic assessment process and purpose.

6.1.4 Ease of completion

_The vast majority of people feel the electronic assessment is easy to complete on a handheld tablet._

Individuals are very positive about the ease of completing the electronic assessment on a handheld tablet. More than eight in ten (82%) say completing the electronic assessment was very easy, with a further 14% saying it was fairly easy. Only two per cent of individuals say they found it very/fairly difficult to complete the assessment electronically.

*Figure 6.2 — Ease of completing the assessment electronically*

![Graph showing ease of completing the assessment electronically](image)

Whilst the quantitative results are very encouraging, it is worth reiterating that only individuals who were successfully able to complete the assessment electronically subsequently went on to complete the survey. The extent to which individuals struggled to complete the assessment electronically was therefore probed in the qualitative interviews with individuals living with and beyond cancer and also with healthcare professionals. Broadly, these individuals echoed that the electronic assessment was felt to be intuitive.

"_She went through the first couple of questions with me but I was fine because I use them (tablets) all the time._" (individual living with and beyond cancer)
A handful of people living with cancer who were interviewed qualitatively commented on their need for help in completing the assessment electronically. For one individual this was due to a fear of ‘losing’ the information by accidentally doing something wrong. For another, his partner was better placed to complete the assessment (in consultation with him) as English was not his first language. The use of volunteers in some sites has been useful in overcoming difficulties such as these.

"It’s not the norm for patients to experience difficulties. For those that do experience problems, a lot of patients come with family members. Once set-up with a little explanation and guidance then the patients don’t seem to struggle." (healthcare professional)

Age does appear to affect how easy individuals perceive it is to complete the assessment electronically, though the differences are marginal. Those aged below 55 are more likely to say the assessment was very easy to complete, compared to those aged 55 and above (88% vs. 79%). Those in the older age bracket are more likely to say they found the assessment fairly easy to complete (15% vs. 11%). Note, these differences are not considered statistically significant due to the relatively small base sizes34.

The majority of those who completed the assessment electronically would prefer to do so again rather than complete it on paper or they remain ambivalent either way.

Individuals who have completed an assessment electronically are broadly happy about completing the assessment electronically again. Just over half of those who recall completing an electronic assessment showed a strong preference for completing assessments on a tablet (56%). A third indicated they had no strong preference either way (32%), while 10% showed a strong preference to answer the assessment on paper.

No distinct differences were evident in preference according to age bands.

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34 68 individuals aged under 55, and 141 aged 55+, recall completing the electronic assessment.
### Figure 6.3 — Preferred mode of assessment completion among individuals living with and beyond cancer

Q19. I am going to read out two statements representing either ends of a scale from 1 to 10, where statement A=1 and statement B=10. Please select a number between 1 and 10 to show where your view fits on this scale.

#### A
- I would prefer to complete the Holistic Needs Assessment on a paper questionnaire: 1-4
  - 10%
  - 5-6: 32%

#### B
- I would prefer to complete the Holistic Needs Assessment electronically on a handheld tablet: 7-10
  - 56%

Don’t know: 2%

Base: Individuals living with and beyond cancer who recall completing an electronic assessment (211)

### 6.2 Completion settings

There is demand among healthcare professionals (though less so among individuals living with and beyond cancer) for people to complete the electronic assessment at home.

Macmillan would like for individuals to be able "to complete the electronic assessment in an environment of their choice" and "with any service provider along the care pathway" (such as with GPs, in hospices and other community and social care settings).

As part of these longer-term ambitions, Macmillan is presently working to establish a way in which the electronic assessment can be completed by individuals in their own home. This move will be welcomed by many of the healthcare professionals interviewed who are keen to see greater flexibility in where individuals complete the assessment.

At present, just one per cent of electronic assessments are completed at home on average (according to the survey of healthcare professionals). This compares to nine per cent of paper assessments being completed at home prior to the eHNA roll-out. The healthcare professionals keen to see electronic assessments completed at home reported that this would afford individuals greater privacy and time in which to complete the assessment, and it would limit individuals having to travel into hospital unnecessarily. As consultations increasingly take place over the phone or via Skype in the future due to high volumes of people to care for and clinical pressures, having an electronic version that people can complete at home will grow in importance. Some healthcare professionals talked about benefitting from the ‘at-home’ completion allowing them to conduct the electronic assessment at a more appropriate time for the individual rather than when they happened to see people as part of scheduled clinics.
“We want to be able to say to patients, ‘complete this tonight and we'll call you tomorrow’. We see people so infrequently nowadays apart from when going through treatment, we don’t want to do (the electronic assessment) on the ‘breaking bad news day’ because they are tired out.” (healthcare professional)

Whilst there is support for ‘at-home’ completion among healthcare professionals, individuals living with and beyond cancer do not have the same demand. When presented with the option of completing the assessment at home or in a hospital/clinical setting, individuals who recall completing an electronic assessment are either undecided either way (40% expressing no real preference) or would prefer to do so in a hospital/clinical setting (48%). Only one in ten show a preference to complete the assessment at home (nine per cent). This is not to suggest individuals would be averse to completing the assessment at home, but rather they are probably most comfortable with the idea of completing the assessment in the way in which they have previously done so.

Figure 6.4 – Preferred setting for assessment completion among individuals living with and beyond cancer

Q20. I am going to read out two statements representing either ends of a scale from 1 to 10, where statement A=1 and statement B=10. Please select a number between 1 and 10 to show where your view fits on this scale

<table>
<thead>
<tr>
<th>Setting</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>A: I would prefer to complete the Holistic Needs Assessment at home: 1-4</td>
<td>9%</td>
</tr>
<tr>
<td>5-6</td>
<td>40%</td>
</tr>
<tr>
<td>B: I would prefer to complete the Holistic Needs Assessment in a hospital/clinic setting: 7-10</td>
<td>48%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2%</td>
</tr>
</tbody>
</table>

The electronic assessment

The development of an electronic assessment which can be completed at home will be essential to facilitating another of Macmillan’s key objectives – that of the electronic assessment being done at any stage of the cancer pathway. If individuals are able to complete the electronic assessment more flexibly in terms of location and device (i.e. using a PC, laptop, tablet or mobile), it is supposed that other providers along the care pathway will not face the potential IT challenges of assessment completion on site.

This intended objective is a longer-term ambition for Macmillan which is not presently being realised. Greater sharing of assessment results and care plans between healthcare professionals will be needed to ensure that individuals’ concerns and actions can follow them through their care pathway rather than unconnected assessments being completed at various
points without due consideration for what has gone before. The sharing of assessment results and care plans between healthcare professionals is discussed in section 8.2 of this report.

6.3 Holistic needs and support

One of the ultimate drivers behind the eHNA project is the intended ability to provide individuals with care and support that is delivered appropriately (at the right time, from the right people, in the right setting), that individuals are "better supported/support is personalised" and "individuals have their holistic needs met". This section of the report examines the extent to which these intended impacts are presently being realised.

Most people feel they receive support for their cancer at the right time (particularly those who recall completing an electronic assessment).

The majority of people surveyed agree they have received support at the right time – irrespective of whether they recall completing an electronic assessment, paper assessment or no assessment.

However, individuals who recall completing an electronic assessment are particularly likely to agree they have received support at the right time. Eight in ten strongly agree that support for their cancer has been delivered at the right time (81%) – higher than the proportion who recall completing a paper assessment (70%) and those who do not recall completing an assessment (69%). Whilst these differences are not considered statistically significant, when taken in consideration of other findings they are encouraging.

It is important to consider the different sample profiles of individuals who recall completing an electronic assessment versus the two counterfactual scenarios. Individuals are more likely to strongly agree they received support for their cancer at the right time if they were diagnosed more recently (77% of those diagnosed in the past six months strongly agree compared to 70% of those diagnosed longer ago). Individuals are also more positive the older they get (76% of those aged 55 and over strongly agree compared to 65% of those under the age of 55)35.

The individuals surveyed who recall completing the electronic assessment tend to have had their cancer diagnosed more recently than those who recall completing the paper assessment or no assessment. Additionally the age profile of those who recall completing an electronic assessment is slightly older than for the two counterfactual scenarios. These natural differences in sample profiles may be influencing the results such that those who recall completing an electronic assessment are more positive towards the support they have received.

35 Please note that the sub-group differences for age and recency of cancer diagnosis includes both individuals who recall an electronic assessment and those who recall a paper assessment. Looking at the data in this way allows for larger sample sizes to be analysed.
Table 6.3 – Receiving cancer support at the right time

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Tend to agree</th>
<th>Neither agree nor disagree</th>
<th>Tend to disagree</th>
<th>Strongly disagree</th>
<th>NA/ Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recall electronic assessment (Base: 211)</td>
<td>81%</td>
<td>13%</td>
<td>1%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Recall paper assessment (Base: 67*)</td>
<td>70%</td>
<td>26%</td>
<td>3%</td>
<td>1%</td>
<td>-</td>
</tr>
<tr>
<td>Do not recall assessment (Base: 376)</td>
<td>69%</td>
<td>20%</td>
<td>5%</td>
<td>3%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Source: Surveys of individuals living with and beyond cancer
Base: As shown in table. * indicates small base size

In the qualitative interviews, individuals reflected upon what could be considered the ‘right time’ to receive support. In doing so they tended to focus on the timing of the electronic assessment rather than any subsequent forms of support. It was generally felt that the ‘right time’ was highly dependent on the individuals’ circumstances and preferences; making it challenging to time the electronic assessment for maximum impact.

"The eHNA was at the right time for me but maybe if you were someone who needed more support maybe earlier would have been better." (individual living with and beyond cancer who completed the electronic assessment 12 weeks after treatment)

It was easier for individuals living with and beyond cancer to identify instances when they felt the electronic assessment was not ideally timed. Too close to diagnosis and individuals are likely to be ‘in shock’, while just before treatment individuals are likely to be distracted. Some examples of these instances were apparent in the qualitative interviews. One individual completed the electronic assessment in the appointment immediately following her diagnosis; at this stage she felt very distracted by the recent news. Another completed the electronic assessment the day before surgery which again led her to feel distracted from the assessment and subsequent discussion. A third individual (who talked of being a very nervous patient) was asked to complete the electronic assessment during her first chemotherapy session and found this to be very poor timing; adding to her stress.
"My head was full of all the consultant stuff (following my diagnosis), it's all fresh in my mind, and I'm thinking how am I dealing with it and what's going to happen." (individual living with and beyond cancer)

"Given my surgery, at the time this (the electronic assessment) went away and didn’t get thought about properly." (individual living with and beyond cancer)

"I couldn’t think deeply about these things at that time (during my first chemotherapy treatment). I think it would have been helpful to do it at a time when I was not so stressed out... it just added to my stress levels." (individual living with and beyond cancer)

Whilst there are instances of when the electronic assessment could be better timed, it is recognised that healthcare professionals can be limited in the opportunities they have to see individuals in clinic (and thus administer electronic assessments). This lends support to the ongoing development of an electronic assessment which can be completed at home.

Most people living with a cancer diagnosis feel the support they receive is from the right people and in the right settings (particularly so for those who recall completing an electronic assessment).

Of those who recall completing the electronic assessment, the majority strongly agree they have received support for their cancer from the right people and in the right setting (82% and 84% respectively). This is significantly more than those who do not recall having an assessment (73% strongly agree they have received support from the right people, and 67% in the right setting), and marginally more than those who recall completing a paper assessment.

As discussed previously, age appears to affect how people respond, with older individuals more positive about the support they have received. People aged 55 and over are more likely to strongly agree they have received support from the right people and in the right setting (79% and 76% respectively) compared to those under the age of 55 (70% and 67% respectively). This may be contributing to the more positive scores of individuals who recall completing an electronic assessment given the age profile of this group is slightly older than for the two counterfactual scenarios\(^\text{36}\).

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\(^{36}\) Please note that the sub-group differences for age includes both individuals who recall an electronic assessment and those who recall a paper assessment. Looking at the data in this way allows for larger sample sizes to be analysed.
## Table 6.4 — Receiving cancer support from the right people and in the right setting

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Tend to agree</th>
<th>Neither agree nor disagree</th>
<th>Tend to disagree</th>
<th>Strongly disagree</th>
<th>NA/Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recall electronic assessment (Base: 211)</td>
<td>82%</td>
<td>12%</td>
<td>2%</td>
<td>1%</td>
<td>2%</td>
</tr>
<tr>
<td>Recall paper assessment (Base: 62*)</td>
<td>78%</td>
<td>20%</td>
<td>1%</td>
<td>-</td>
<td>2%</td>
</tr>
<tr>
<td>Do not recall assessment (Base: 365)</td>
<td>73%</td>
<td>18%</td>
<td>6%</td>
<td>2%</td>
<td>1%</td>
</tr>
</tbody>
</table>

Q3b: To what extent do you agree or disagree that you have received support for your cancer... From the right people?

| Recall electronic assessment (Base: 211) | 84% | 11% | 1% | 1% | 2% | 1% |
| Recall paper assessment (Base: 61*) | 69% | 25% | 5% | - | 2% | - |
| Do not recall assessment (Base: 361) | 67% | 22% | 6% | 2% | 1% | 1% |

Q3c: To what extent do you agree or disagree that you have received support for your cancer... In the right setting?

Source: Survey of individuals living with and beyond cancer
Base: As shown in table. * indicates small base size

### 6.3.1 Receiving personalised care

*The vast majority of people living with cancer believe their care has been personalised to their needs irrespective of whether they recall completing an electronic assessment, a paper alternative or no formal assessment.*

A high proportion of people living with and beyond cancer believe the care they have received has been personalised to their needs – this is irrespective of whether they have completed the electronic assessment, a paper alternative, or had no formal assessment.

For those who recall completing an electronic assessment, just under three-quarters say their care has been personalised a great deal (72%) and a further 17% say it has been personalised a fair amount. The proportion of individuals who recall completing a paper assessment saying their care has been personalised a great deal/fair amount is higher than for those
completing an electronic assessment (97% vs. 89%). However, due to the small base size of individuals who recall completing the paper assessment (n=68), this finding should be interpreted cautiously.

Figure 6.5 — Receiving personalised care

In the qualitative interviews with individuals living with and beyond cancer, there was little spontaneous talk of cancer support being personalised to their needs. Instead they talked more about the healthcare professional with whom they discussed their assessment results. Where healthcare professionals showed particular kindness or empathy, this was positively remarked upon with individuals recognising that who they discuss the assessment results with had a large effect on how positively they felt about it.

6.3.2 Meeting holistic needs

Holistic needs are better met for people who recall completing an electronic assessment.

In general, the holistic needs of individuals living with and beyond cancer are being well met, particularly for those who recall completing an electronic assessment. As shown in table 6.5, people who have completed an electronic assessment are more likely to say their needs (physical, emotional/mental, practical and social) are being met completely compared to those who recall completing a paper assessment or no assessment. The only exception to this is spiritual/religious needs where a high proportion of people claim this is not applicable to them.

As seen previously, the recency of diagnosis may be affecting results since those diagnosed within the past six months are more likely to say their needs are being completely met compared to those diagnosed longer ago. As discussed elsewhere, the sample of individuals who recall completing an electronic assessment are more likely to have been diagnosed within the past six months compared to individuals who recall completing a paper
assessment. Additionally, the results may reflect another recency bias since a far greater proportion of people who recall completing an electronic assessment did so in the past month (70%) compared to those who recall completing the paper assessment (34% based on 63 people) – see the appendix for more detail.
Table 6.5 – Extent to which holistic needs are being met

<table>
<thead>
<tr>
<th>Question</th>
<th>Completely</th>
<th>Somewhat</th>
<th>Hardly</th>
<th>Not at all</th>
<th>NA / Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>at all</td>
<td>all</td>
<td></td>
</tr>
<tr>
<td>Q7a: To what extent, if at all, do you feel that your needs are being met... Physical?</td>
<td>74%</td>
<td>16%</td>
<td>2%</td>
<td>3%</td>
<td>6%</td>
</tr>
<tr>
<td>Recall electronic assessment (211)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall paper assessment (64*)</td>
<td>54%</td>
<td>40%</td>
<td>-</td>
<td>1%</td>
<td>5%</td>
</tr>
<tr>
<td>Do not recall assessment (363)</td>
<td>56%</td>
<td>26%</td>
<td>4%</td>
<td>3%</td>
<td>10%</td>
</tr>
<tr>
<td>Q7b: To what extent, if at all, do you feel that your needs are being met... Emotional/mental?</td>
<td>70%</td>
<td>16%</td>
<td>1%</td>
<td>4%</td>
<td>7%</td>
</tr>
<tr>
<td>Recall electronic assessment (211)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall paper assessment (60*)</td>
<td>32%</td>
<td>46%</td>
<td>8%</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>Do not recall assessment (347)</td>
<td>38%</td>
<td>29%</td>
<td>7%</td>
<td>5%</td>
<td>20%</td>
</tr>
<tr>
<td>Q7c: To what extent, if at all, do you feel that your needs are being met... Spiritual/religious?</td>
<td>18%</td>
<td>3%</td>
<td>1%</td>
<td>2%</td>
<td>75%</td>
</tr>
<tr>
<td>Recall electronic assessment (211)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall paper assessment (49*)</td>
<td>35%</td>
<td>16%</td>
<td>2%</td>
<td>8%</td>
<td>39%</td>
</tr>
<tr>
<td>Do not recall assessment (320)</td>
<td>20%</td>
<td>9%</td>
<td>3%</td>
<td>10%</td>
<td>55%</td>
</tr>
<tr>
<td>Q7d: To what extent, if at all, do you feel that your needs are being met... Practical?</td>
<td>74%</td>
<td>12%</td>
<td>3%</td>
<td>2%</td>
<td>9%</td>
</tr>
<tr>
<td>Recall electronic assessment (211)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall paper assessment (59*)</td>
<td>49%</td>
<td>39%</td>
<td>3%</td>
<td>-</td>
<td>8%</td>
</tr>
<tr>
<td>Do not recall assessment (337)</td>
<td>41%</td>
<td>22%</td>
<td>4%</td>
<td>6%</td>
<td>25%</td>
</tr>
<tr>
<td>Q7e: To what extent, if at all, do you feel that your needs are being met... Social?</td>
<td>72%</td>
<td>13%</td>
<td>3%</td>
<td>3%</td>
<td>10%</td>
</tr>
<tr>
<td>Recall electronic assessment (211)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall paper assessment (58*)</td>
<td>42%</td>
<td>37%</td>
<td>1%</td>
<td>8%</td>
<td>12%</td>
</tr>
<tr>
<td>Do not recall assessment (333)</td>
<td>33%</td>
<td>20%</td>
<td>6%</td>
<td>7%</td>
<td>33%</td>
</tr>
</tbody>
</table>

Source: Surveys of individuals living with and beyond cancer. Table does not show ‘prefer not to say’
Base: As shown in table. * indicates small base size
6.4 Quality of life

A crucial impact of the eHNA project for Macmillan is that individuals living with and beyond cancer experience "improved quality of life" as a result of their electronic assessments and care plans. This section of the report explores this premise and also gives consideration to some of the direct welfare/leisure costs of the eHNA project to individuals living with and beyond cancer.

6.4.1 Perceived benefits of electronic assessments and care plans

*Individuals can name a number of benefits of completing the electronic assessment, most notably a reduction in their worries and feeling encouraged to speak about issues they otherwise would not have.*

The most prominent benefits of completing the electronic assessment to individuals who recall doing so are the discussion leading them to feel less worried (mentioned by 56%) and bringing up concerns they might not have done otherwise (51%).

Other benefits individuals associate with completing the electronic assessment include giving them confidence to discuss concerns they might have been embarrassed to bring up (37%), receiving help for the issues they were concerned about (34%) and finding the discussion with their healthcare professional to be more focused as a result of the assessment (34%).

As shown in figure 6.6, electronic assessments appear to provide greater benefit to individuals compared to paper alternatives. Whilst these results are very encouraging, it should be remembered that those who recall completing the electronic assessment will have completed it far more recently than the group of people surveyed who recall completing the paper assessment (again please refer to the appendix). A recency bias may be in play such that people who have completed an assessment in the more recent past are better able to articulate how the assessment has benefited them.
Many of these findings were substantiated through the qualitative interviews with individuals who had completed an electronic assessment. Individuals talked of the assessment prompting them to consider issues they may not have thought of previously, or may not have considered raising with their nurse. For some, the assessment lowered the threshold to talk about particular concerns.

“It was something on the questionnaire that I might not have thought was in her (nurse) sphere really without the questionnaire.” (individual living with and beyond cancer)

Individuals were grateful for the opportunity to talk about non-physical issues.

“I remember it being quite interesting because it covered a lot of things I didn’t think we would talk about — emotional as well as physical needs really.” (individual living with and beyond cancer)

“The financial side of it, I remember it was lovely, very caring I thought oh good somebody’s on my side here.” (individual living with and beyond cancer)

Benefits of the electronic assessment extend to family members as well. In one of the qualitative interviews, a daughter talked of her gratitude that the assessment process allowed her to better understand what her father was going through. The assessment and discussion can also directly benefit family members if they are given information or signposted to services which help them as a carer or individual closely affected by cancer.

“Dad is not a talker so it was nice to understand his feelings... The assessment would be good for Dad to repeat, to get it off his
chest... it would be ‘cleansing’.” (daughter of individual living with and beyond cancer)

“There’s a patient I did one with a few weeks ago and his biggest concern was the effect that his diagnosis was having on his family. He used it to start off a conversation with his daughters. It sort of prompted them to talk to each other and you know, get lots of things sorted out about wills and what his wishes were for his funeral.” (healthcare professional)

For some individuals, seeing the list of potential symptoms as part of the assessment could be daunting (and in this instance it is important for healthcare professionals to provide reassurance that not all symptoms listed are inevitable), whilst others found the list to provide reassurance that they were not the only person to have felt such a way.

"It made me think about what I was going through really... It made me think ‘oh that’s normal!’.” (individual living with and beyond cancer)

Whilst the assessment content was broadly very well received, one participant felt the assessment questions were focused on the ‘major’ cancers and did not adequately account for all of the issues they were having as a result of their skin cancer. This issue has also been raised by healthcare professionals working within specialist gynaecology teams who say the assessment tool does not adequately cover concerns over fertility. This suggests that some degree of tailoring to specific cancers would be welcome in the future.

As recorded on the eHNA datastore, the most prevalent concerns listed in electronic assessments are tiredness/fatigue (mentioned in 40% of all care plans) and worries/anxieties (mentioned in 34%). Other common concerns (though not to the same degree) include sleep issues (27%), relationships with partners/children (27%), and pain (24%). Information needs predominantly concern diet and nutrition (mentioned in 12% of care plans) and exercise (11%). See the appendix for more detail on the concerns and information needs most commonly listed in care plans.

Assessments are in the main perceived to be useful.

Most people living with and beyond cancer find the holistic needs assessment useful (irrespective of whether they completed it electronically or on paper). Four in ten say the electronic assessment was very useful (37%) with a further 29% saying it was fairly useful. This compares (non-significantly) with 33% and 42% of those who completed the assessment on paper.
While the total proportion describing the assessment as useful is greater amongst those completing the paper assessment, those completing it electronically are more likely to describe it as being very useful.

**Figure 6.7 — Perceived usefulness of assessments**

| Q16. To what extent, if at all, did you find the Holistic Needs Assessment useful? |
|---------------------------------|-----------------|-----------------|----------------|----------------|----------------|
| Very useful                     | Fairly useful   | Not very useful | Not at all useful | Don’t know     |
| Recall paper assessment         | 33%             | 42%             | 19%             | 16%            |
| Recall electronic assessment    | 37%             | 29%             | 7%              | 23%            | 4%             |

Base: Individuals living with and beyond cancer who recall paper assessment (61), recall electronic assessment (211)

The electronic assessment and care plan can lack relevance to individuals who ‘feel fine’ and have low-level, if any, concerns.

Three in ten say they found the electronic assessment not very/not at all useful (30%). From the qualitative interviews, it is likely that individuals say the assessment is not useful when it comes at a time of irrelevance. Individuals talk of ‘feeling fine’ and having no concerns they wish to discuss.

“It didn’t really apply to me... I’m not in need of additional support.” (individual living with and beyond cancer)

Some individuals still agree to complete the electronic assessment even though they do not believe they require additional support. In seven per cent of electronic assessments, no concerns are listed (as documented on the eHNA datastore). Individuals in this position did not mind completing the electronic assessment, and it certainly did not detract from the care they were receiving, they simply felt there was little to gain given they had low-level, or non-existent, concerns.

The perceived usefulness of the electronic assessment is shaped by its introduction. Current explanations of the assessment could be improved to give greater significance to it.

Individuals appear to receive hugely varied, and at times, patchy explanations of the electronic assessment from healthcare professionals. Examples given range from fairly simplistic explanations (‘to see how things are’, ‘to get some feedback’, ‘to understand how you are feeling’, ‘to look at what your needs might be’) to those where the purpose is obscured.
somewhat (‘it will help others’, ‘because the nurse seemed particularly keen to have my results electronically’, ‘the hospital were trialling it and did I mind completing it?’).

"The nurse just gave it to me and said could I complete this form?" (individual living with and beyond cancer)

“She said Macmillan wanted to embark on a survey of people that have been through some form of cancer treatment would I mind answering questions?” (individual living with and beyond cancer)

Despite these sometimes rather patchy explanations, individuals rarely questioned the purpose of the electronic assessment and did not ask for further information about it. There was a sense from the individuals interviewed that they had been asked to fill in multiple forms over the course of their cancer pathway and thus were agreeable to another request.

"I had no real explanation of what it was... you do what you are told and you trust in the process; they've never asked me to do anything that wasn't worth doing.” (individual living with and beyond cancer)

Whilst individuals tended to be willing to complete the assessment, it is possible that greater gravitas and significance would be given to the assessment if it was introduced with a better explanation of its purpose.

6.4.2 Welfare/leisure costs

The welfare/leisure costs lost to completion of the holistic needs assessment are broadly similar whether the assessment is completed electronically or on paper.

Individuals, if completing the electronic assessment in a hospital/clinic setting, are likely to experience some loss of leisure time due to the time they spend travelling to/from the appointment, waiting to see the doctor and so on.

As would be expected, the time spent travelling to their appointment and waiting to see the doctor/nurse is very similar for those that recall completing an electronic assessment versus those that recall completing a paper version.

Findings from the surveys of individuals living with and beyond cancer suggests that people spend less time filling in the assessment, and more time discussing the results, compared to those completing a paper assessment. Individuals who recall completing an assessment say on
average it takes 14.4 minutes to complete on paper compared to 11.2 minutes to complete electronically. Individuals then go on to say it takes an average of 28.4 minutes to discuss their assessment results (if they completed it electronically) compared to 24.6 minutes if they completed it on paper. Due to the small base size of individuals who recall completing a paper assessment (see table 6.6), these findings should be interpreted cautiously.

Overall, combining the different stages shown below in table 6.6, the welfare/leisure cost is broadly similar for those who complete the assessment electronically compared to those who do so on paper. It is also worth noting that in most cases, these time costs are not solely attributed to the assessment and care planning process. Only seven per cent of those who completed their electronic assessment in a hospital waiting room or private consultation room say they attended hospital specifically for the assessment and had no other appointments that day (for those that recall their paper assessment the equivalent figure is 18% though this is based on only 38 respondents and is therefore indicative only).

**Table 6.6 – Average time to complete various stages of holistic needs assessments**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Recall paper assessment</th>
<th>Recall electronic assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travelling to the appointment</td>
<td>36.5 min (base 55*)</td>
<td>37.8 min (base 210)</td>
</tr>
<tr>
<td>Filing in the assessment</td>
<td>14.4 min (base 55*)</td>
<td>11.2 min (base 208)</td>
</tr>
<tr>
<td>Waiting to see the doctor or nurse</td>
<td>29.4 min (base 53*)</td>
<td>29.7 min (base 195)</td>
</tr>
<tr>
<td>Talking to the doctor/nurse about the assessment and your response</td>
<td>24.6 min (base 53*)</td>
<td>28.4 min (base 183)</td>
</tr>
</tbody>
</table>

Source: Surveys of individuals living with and beyond cancer
Base: As shown in table. * indicates small base size

### 6.5 Actions taken

A key outcome of the eHNA project for Macmillan is that "**actions are taken as a result of having a care plan**". This is explored in depth below—first examining the types of actions listed in care plans and how often these are followed through, before looking more broadly at how well care plans are

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37 The average time taken to complete the electronic assessment from start to finish as recorded on the e-HNA datastore is 6.2 minutes (discussed in section 7.1.1).
recalled among recipients and what this means for their perceived usefulness.

6.5.1 Actions listed in care plans

‘Discussed concern, general advice given’ and ‘information given’ are the most common actions listed in care plans.

The most common action listed on care plans is that concerns were discussed and ‘general advice given’, mentioned in two-fifths of all care plans created (40%). ‘Information given’ is the second most commonly mentioned action though this is far less prevalent (15%).

Table 6.7 – 10 most common actions listed in care plans

<table>
<thead>
<tr>
<th>Action</th>
<th>Number of care plans listed in</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussed concern, general advice given</td>
<td>5103</td>
</tr>
<tr>
<td>Information given</td>
<td>1961</td>
</tr>
<tr>
<td>Medication reviewed</td>
<td>479</td>
</tr>
<tr>
<td>Dietitian referral</td>
<td>459</td>
</tr>
<tr>
<td>Advised to see GP</td>
<td>407</td>
</tr>
<tr>
<td>Patient did not want to explore this concern at this time</td>
<td>374</td>
</tr>
<tr>
<td>Counselling referral</td>
<td>367</td>
</tr>
<tr>
<td>Short term follow up by CNS</td>
<td>328</td>
</tr>
<tr>
<td>Advised to contact welfare or benefits advisor</td>
<td>308</td>
</tr>
<tr>
<td>Advised to increase physical activity levels</td>
<td>288</td>
</tr>
</tbody>
</table>

Source: eHNA datastore
Base: 12,904 care plans completed by 30th June 2015

These findings are corroborated by findings from the post-intervention survey with healthcare professionals. This shows the most common actions following completion of the electronic assessment is for there to be a discussion, for advice (both verbal and written) to be given and for individuals to be signposted or referred to relevant services. Far less common is for individuals to be given further appointments, be prescribed medication or referred on for further treatment.
Q11. In your experience, which of the following typically happens after the patient has completed the electronic Holistic Needs Assessment? Please include all actions whether or not an electronic care plan is completed. Please select all that apply.

- Concerns are discussed as part of the appointment: 89%
- They are given verbal advice: 88%
- They are signposted to relevant services: 84%
- They are given written information: 83%
- They are referred to relevant services: 81%
- They are given a further appointment: 30%
- They are prescribed medication: 26%
- They are referred for further treatment: 18%
- Responses sent to a colleague for them to complete care plan: 12%
- Other: 9%
- Don’t know: 1%

Base: Post-intervention healthcare professionals: All those who complete eHNAs or are project leads (157)

The average number of actions listed per care plan is 2.0 (as of 30th June 2015 and according to the eHNA datastore). This compares to an average of 3.3 actions per care plan according to the baseline data\(^{38}\). There does appear to be a slow drop-off in the average number of actions per care plan as shown below:

- **July – December 2013**: Average number of actions per care plan 2.8
- **January – June 2014**: 2.5
- **July – December 2014**: 2.0
- **January – June 2015**: 1.5

This may be explained by the smaller number of care plans completed during July – December 2013 (328) compared with January – June 2015 (5,440) with the latter representing a more stable average result. However, even when looking just at January – June 2015, the average number of actions listed per care plan declines each month from 2.1 in January to 1.0 in June.

The types of actions listed in care plans remain consistent with the 10 most commonly listed actions remaining the same when comparing electronic assessments completed across all sites from the first six months of 2014 with the first six months of 2015.

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\(^{38}\) Based on 42 sites which submitted usable baseline data.
6.5.2 Actions taken as a result of care plans

*Actions listed in care plans are not consistently followed-up. Actions may happen irrespective of the care plan and many concerns raised do not require specific actions to be documented.*

Results in table 6.8 below show the number of individuals completing the action listed in their care plan. Due to the small number of individuals surveyed who could recall their care plan, and the content of it, these findings should be considered indicative only.

In the main, if individuals were given leaflets or suggested sources of information, they went on the read the content advised (happening in 30 of 38 cases). Roughly half of individuals given general advice followed this (18 of 32 cases) though this is a fairly unspecific action and it cannot be said to what extent general advice was heeded or not.

For more specific actions (such as having a follow-up appointment or a physical activity assessment), the adherence to what was written in the care plan is variable. Though these results can only be interpreted cautiously, it is clear that not all actions listed in care plans are followed-up.

**Table 6.8 — Actions followed up from care plan**

<table>
<thead>
<tr>
<th>Action</th>
<th>Number that took action listed in care plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>I read the leaflets given to me/ I followed up the information sources suggested to me</td>
<td>30 of 38* (79%)</td>
</tr>
<tr>
<td>I followed the general advice I received</td>
<td>18 of 32* (56%)</td>
</tr>
<tr>
<td>I arranged my follow-up appointments/ I attended my follow-up appointments</td>
<td>10 of 16* (63%)</td>
</tr>
<tr>
<td>I had a physical activity assessment</td>
<td>2 of 14* (14%)</td>
</tr>
<tr>
<td>My medication was changed/renewed</td>
<td>4 of 8* (50%)</td>
</tr>
<tr>
<td>I arranged my referral appointments/ I attended my referral appointment</td>
<td>2 of 7* (29%)</td>
</tr>
<tr>
<td>I was discharged</td>
<td>2 of 3* (67%)</td>
</tr>
</tbody>
</table>

Source: Survey of individuals living with and beyond cancer  
Base: As shown in table. * indicates small base size

Where possible, the actions listed in individuals’ care plans were discussed as part of the qualitative interviews. Some examples of actions listed were that advice was provided to individuals about putting on weight and
sleeping better. These general advisory 'actions' are likely to have happened irrespective of the care plan (and potentially the electronic assessment and discussion). The actions which can be more directly tied to the electronic assessment and care plan are where individuals have been signposted or referred to specific services which they would not have known about if they had not gone through the assessment process. For example, one individual was referred to a Fresh Start course for weight loss. Another was prompted to approach Help the Aged to install mobility aids in their house. And one individual spoke with a Macmillan benefits advisor following the concerns she raised about her financial entitlements.

However, for these examples, the care plan was not instrumental in the actions being completed; instead it was the discussion with the healthcare professional following completion of the electronic assessment which raised awareness of support services available to them.

"I had all the answers I needed in that session." (Individual living with and beyond cancer)

It is worth noting that, in some instances, individuals will have very few actions listed on their care plan (given their low level or limited concerns), and that some actions listed are not all that 'actionable'. For example, one individual interviewed qualitatively produced a care plan which included actions of 'discussed good sleep hygiene', 'have treatment as soon as possible', 'assess concerns about the wound post-survey' and 'keep taking Gaviscon for indigestion'. Another had actions to 'get a date for surgery', 'increase medication from GP', and 'information given'. Many of these actions are seen as things which would happen irrespective of the formal electronic assessment and care planning process.

6.5.3 Recall of care plans

There is a low salience of care plans among individuals living with and beyond cancer.

A quarter of individuals who recall their electronic assessment say they remember a care plan being created for them (25%). Of course, not all of these individuals will have had a care plan created for them. The recall figure rises marginally to 28% of individuals where is it known that a care plan was 'created', 'saved' or 'unlocked' for them. For the 21 individuals for whom it is known their care plan was shared in hard copy or by email, three can recall the document. Of the 18 individuals interviewed qualitatively (for whom it was known a care plan had been created), eight could recall the document.
Table 6.9 — Recall of care plans

<table>
<thead>
<tr>
<th></th>
<th>Recall electronic assessment (211)</th>
<th>Recall paper assessment (57*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, definitely</td>
<td>24%</td>
<td>26%</td>
</tr>
<tr>
<td>Yes, I think so</td>
<td>1%</td>
<td>23%</td>
</tr>
<tr>
<td>No</td>
<td>71%</td>
<td>35%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>4%</td>
<td>16%</td>
</tr>
</tbody>
</table>

Source: Surveys of individuals living with and beyond cancer
Base: As shown in table. * indicates small base size

There are a number of possible explanations for the low recall of care plans among individuals living with and beyond cancer:

- **Care plans are not created:** this happens in approximately 21% cases on average (over the past six months). The reasons why are discussed in section 5.3.

- **Care plans are not shared with individuals:** care plans are shared in 62% of cases once they are written (see section 5.3). This also accounts for the fact that some patients choose to decline a copy of their care plan.

- **There is a delay in receipt of care plans:** there is often a delay in when care plans are written due to competing time pressures and it is possible that individuals were surveyed or interviewed prior to having received their care plan.

- **Individuals have poor recall of the care plan:** It was clear from the qualitative interviews with individuals known to have had a care plan created for them, that there was general confusion about what the care plan was, and where it might be if they had received a copy. Individuals talked of being given a lot of hard copy documentation in relation to their cancer; of which the care plan was just one piece.

“**Yes I did think she did print it off – it might be here still around the house somewhere...I never looked at it again...I think it’s because I thought I was getting better.”** (Individual living with and beyond cancer)

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39 Individuals were asked if they recalled their doctor/nurse creating a care plan; described as “a document that lists your concerns and has a written plan of action to help you”.

40 The maximum amount of time between electronic assessment completion and individuals being surveyed or interviewed was two months.
"I've got so many bits of paper, there is paper all over the house." (individual living with and beyond cancer)

"Your head's in bits and you're given so many leaflets, I might have been given one [care plan]." (individual living with and beyond cancer)

Individuals have most commonly filed the care plan away (in 36 of 55 cases equivalent to 68%) or shown it to family/friends (in 31 of 55 cases, 58%). Only in a handful of instances have individuals taken the care plan to appointments at the hospital, or shown it to other healthcare professionals.

6.5.4 Reviewing care plans

Care plans are reviewed or monitored in the minority of instances.

Three in ten individuals who remember getting a care plan following their electronic assessment say they were asked to bring their care plan to their next appointment (29%, based on 55 individuals). This reflects findings from the post-intervention survey with healthcare professionals whereby three in ten say care plans are reviewed at individuals' next routine appointment (27%).

Over half of individuals living with and beyond cancer say there are no plans in place to review their care plan (53% based on 55 people who recall their care plan after completing an electronic assessment). This is slightly higher than the proportion of healthcare professionals who say care plans are not reviewed (41%). There are other instances in which care plans may be reviewed by healthcare professionals – these include reviewing the care plan over the phone with individuals, reviewing it on admission/on the ward, or reviewing it at a MDT meeting.

Individuals interviewed qualitatively very rarely expected to see their care plan reviewed or monitored in any way. However, one individual expressed disappointment that she felt her care plan would exist in ‘isolation’ and would not be followed-up by a healthcare professional.

“When I go to have chemo, this [the care plan] won't be in anyone's mind, it will just be my document... it's not useful just to me as I know those things. I'd like somebody else to take notice of them. I get the feeling this document is not looked at by anyone else... there should be some follow-up somewhere on it, it just seems to be a document in isolation. The idea is very good but it's just not seen through.” (individual living with and beyond cancer)
6.5.5 Perceived usefulness of care plans

The care plan is of greater use to some individuals – particularly as a memory aid though, for some, the document makes little difference to how well supported they feel.

Of the individuals who recall receiving a care plan from their electronic assessment, nearly all thought that the care plan had been useful. Half said the plan was very useful (52%), with a further 28% saying it was fairly useful (note this is based on 55 individuals). Just under one in five said it was not very/not at all useful (19%). Only 27 individuals recall receiving a care plan after their paper assessment – a similar proportion found the care plan to be useful.

From the qualitative interviews (both with individuals living with cancer and with healthcare professionals), it was evident that the care plan could be useful for some people, but not all.

For those that thought the care plan was (or could be) a useful document, this was principally as a memory aid. They felt individuals living with cancer are often presented with a wealth of information when they are already quite overwhelmed and thus the care plan can act as a useful documentation of their discussion with the healthcare professional.

"One thing that I have found out since is the treatment for breast cancer affects your memory. I spoke to someone about it because I kept forgetting things and they said it's one of the side effects. They call it ‘chemo brain’, a bit like ‘baby brain’." (individual living with and beyond cancer)

"It was helpful to have in one place, to remember what I said." (individual living with and beyond cancer)
When looking back through their old care plan, some individuals talked positively about being able to observe the differences in their symptoms and concerns between then and now. This process of review was also mentioned as a potential benefit by other individuals who could not recall their own care plan – believing there to be value in identifying how thoughts and beliefs change over the cancer pathway. However, there is little sense from either the qualitative interviews or the quantitative survey that care plans are presently being used in this way.

The care plan was also mentioned by a few individuals living with and beyond cancer as a potential aid for family members – helping them to better understand what the individual living with cancer was feeling and experiencing.

Individuals gave a number of reasons why the care plan was less useful to them personally. For individuals with low level (if any) concerns, the care plan was not needed. Similarly, if individuals felt they had a good support network (whether this was from friends, family or their nurse) then the care plan was less relevant to them.

"I understand the purpose of it (the care plan) and appreciate the point of it... but it doesn't apply to me." (Individual living with and beyond cancer)

"I didn't need much, I have a lot of family support and I've got the nurses' numbers so could turn to them if I needed." (Individual living with and beyond cancer)

Some of the individuals interviewed felt the care plan was soon irrelevant as their condition changed. One lady in particular was averse to referring back to the care plan as she felt that would limit her ability to 'move on'.

"I want to move on from it, I don't want to keep looking back and dwelling on stuff I'm trying to remain really positive, just get on with it." (Individual living with and beyond cancer)

The care plan may offer more value to the healthcare professional administering it compared to the individual who completed the electronic assessment.

Some of the healthcare professionals interviewed qualitatively acknowledged that sometimes the care plan could be more useful to them than it was to the individual living with and beyond cancer. The care plan provides evidence that a holistic needs assessment has been completed. It also acts as a memory aid to professionals – with it summarising where an individual is in terms of the support they require and what advice/actions they have already been recommended.

Some patients decline a copy of their care plan as they feel it’s not necessary and are happy to just discuss any concerns raised in the eHNA.

Healthcare professional
"I think sometimes we probably put the value of it to the patient as much higher than it actually is because so many of them go, 'oh yeah thanks' and never look at it again... As long as those referrals are being made and they are getting the help and things they are, then they don't really look at it. From the nursing point of view, if we are going to assess something we need to show we have actioned it." (healthcare professional)

There was some suggestion among healthcare professionals interviewed qualitatively that more training was required to give healthcare professionals the tools to adequately explain the purpose of the care plan to individuals who have completed an assessment so that they take due consideration of it.

“One disappointing thing is patients don’t always fully understand the value of the care plan so you see quite a lot of patients declining a copy of it... There is probably a training need in terms of understanding the benefit of the patient owning the document and owning the process end to end...It’s the skill in which the conversation between the patient and clinician is managed in terms of how the care plan is sold to patients.” (healthcare professional)
Key benefits of the eHNA for individuals living with and beyond cancer

- Individuals who recall completing an electronic assessment are more likely than those who recall a paper assessment or no assessment to say they have received support for their cancer at the right time; from the right people; and in the right setting (though it is important to note the natural variation in sample profiles that may be affecting these results as previously discussed).

- Those who recall completing an electronic assessment say their holistic needs are being better met compared to those who recall a paper assessment or no assessment.

- Individuals can name a number of benefits of completing the electronic assessment, most notably feeling less worried (mentioned by 56%), and being encouraged to bring up concerns they might not have done otherwise (51%). Individuals who recall completing an electronic assessment are better able to articulate how the process benefitted them compared to those that recall completing a paper assessment (though this may reflect a recency bias in when the assessment was done, as previously discussed).

- Other benefits named by individuals include the electronic assessment giving them confidence to discuss concerns they may have been embarrassed to mention (37%), receiving help for issues they were concerned about (34%) and finding the discussion with their healthcare professional more focused as a result of the assessment (34%).

- Qualitatively, individuals feel better supported as a result of the electronic assessments.
Medium term outcomes and impact on healthcare professionals
7 Medium term outcomes and impact on healthcare professionals

The following chapter examines the extent to which Macmillan’s intended medium term outcomes and impacts of the eHNA project on healthcare professionals are being realised at present.

7.1 Productivity

Macmillan would like to see “increased productivity for healthcare professionals” as a result of the eHNA project. There are principally three ways in which the productivity of healthcare professionals could be boosted by the eHNA project. Time savings mean healthcare professionals can:

- Conduct more electronic assessments and care plans compared to verbal or paper alternatives.
- Complete electronic assessments and care plans to a higher quality, and in greater depth, than done previously.
- Spend longer on other activities unrelated to assessment and care planning.

The fundamental premise behind these different scenarios is that the eHNA saves healthcare professionals time in comparison with pre-existing working patterns.

7.1.1 Time spent doing assessments and care plans

*It appears that healthcare professionals spend marginally more time supporting individuals to complete the assessment when it is electronic as opposed to paper, though this support is not always provided by the member of staff who goes on to discuss the concerns raised.*

On average, healthcare professionals say they spend around ten minutes supporting individuals to complete the assessment (whether it is on paper or electronic). The average time spent supporting individuals to complete the paper assessment is 11.3 minutes – this is marginally higher (though not significantly) than the 10.4 minutes spent supporting people complete the electronic version. However, it does appear that more varied answers were given by healthcare professionals regarding the length of time spent supporting individuals to complete the assessment – when comparing median values the time spent for paper assessments is 6.1 minutes; lower than the median 8.6 minutes reported for electronic assessments. As
previously mentioned, it is known from the eHNA datastore that the average
time taken to complete the electronic assessment from start to finish (so
excluding any time required for explanation or demonstration) is 6.2
minutes.

Based on the qualitative interviews with healthcare professionals, it is more
plausible that it takes longer to support individuals to complete the
electronic assessment as opposed to the paper version given greater
guidance may be needed on how to use the tablet. It is worth noting that
the support given to individuals to assist in the completion of their
assessment is sometimes done by volunteers or a staff member who will not
go on to discuss the results with them.

*It is thought that healthcare professionals spend longer discussing
individuals’ concerns following an electronic assessment as opposed to
a paper one, though any differences are likely to be marginal.*

Healthcare professionals say an average of 22.0 minutes is spent
discussing the concerns of individuals following a paper assessment. This
rises marginally (though non-significantly) to 24.1 minutes following an
electronic assessment. The same pattern emerges when looking at median
times.

This pattern is substantiated by the survey of individuals living with and
beyond cancer, with marginally longer being spent discussing concerns
following an electronic assessment (28.4 minutes on average) compared to
after a paper assessment (24.6 minutes based on 53 respondents). Again a
similar pattern is observed when studying the median values.

*It takes healthcare professionals longer to complete electronic care
plans compared to paper alternatives.*

The data is more conclusive when comparing the length of time taken to
complete care plans following paper and electronic assessments.
Healthcare professionals believe it takes on average 10.6 minutes to
complete a care plan following a paper assessment (6.5 minutes median).
This rises to an average of 15.2 minutes to complete the care plan following
an electronic assessment (9.9 minutes median); this rise is considered
statistically significant. Reasons why electronic care plans may take longer
to complete are discussed below in section 7.1.2.

As discussed in earlier sections of this report, the proportion of individuals
living with and beyond cancer who are completing a holistic needs
assessment has increased (though non-significantly) since the advent of the
eHNA. Similarly, there has been a marginal increase in the average number
of electronic assessments done per site per month in sites that have been
up and running with the project for a year or more. This means that
healthcare professionals are not only taking longer to complete electronic
assessments and care plans but that they are doing more of them.
7.1.2 Additional time required by electronic assessments and care plans

If a healthcare professional is not used to administering paper holistic needs assessments then the eHNA project constitutes a loss of productivity for them.

Healthcare professionals are more likely to perceive the eHNA project as time-demanding if they are not used to conducting paper assessments before the eHNA project is introduced.

Related to this, some healthcare professionals feel that the more formalised process of electronic assessments and care planning means they are dealing with a greater volume of concerns from individuals; which places greater demands on their time. This is particularly evident if healthcare professionals are used to conducting assessments verbally but it also appears to be the case when comparing electronic assessments with paper alternatives. As discussed previously, the average number of concerns raised per electronic assessments is currently 6.9 – higher than the average of 4.3 recorded in the baseline data\(^41\). This could reflect a different profile of individuals completing electronic assessments compared with paper versions (with the former having more complex needs) but a more likely explanation is that the electronic assessment shows each possible concern on a separate screen meaning people score concerns individually. Healthcare professionals remarked that individuals would often only give one score for their overall level of concern when completing the paper assessment – misinterpreting how the form should be completed. Indeed over half of healthcare professionals say a key benefit of the eHNA project is that people now score their concerns individually rather than providing an overall score (54% - see section 7.3 below).

Given the greater number of concerns to be discussed following electronic assessments, this may explain why electronic care plans take longer on average to complete compared with paper alternatives. Healthcare professionals also talked about it taking time to create care plans that were individualised and appropriate for each person living with and beyond cancer. Having said this, there was also an appreciation that, though care plans might take longer on average to complete, their automatic generation and inclusion of drop-down boxes in electronic care plans helped save professionals time when writing them up.

Some healthcare professionals felt the eHNA project was an added demand on their time given its duplication with other systems already used. This was particularly evident in instances where sites or tumour groups used the Somerset Cancer Register – in one site a tumour group is refusing

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\(^{41}\) Based on the 42 sites which submitted usable baseline data.
to take part in the eHNA prototype given their pre-existing use of the Register.

"The data cannot be moved into Somerset so it makes extra work for CNSs because they are doing that data input twice... that's a big bugbear. If the eHNA talked to other systems it would be so much easier and there would be more of an uptake." (healthcare professional)

7.1.3 Time saved with electronic assessments and care plans

The healthcare professionals interviewed could name a number of ways in which the eHNA project helped them be more productive – these were always in relation to activities outside of the direct administration of assessments and care plans.

One of the most significant productivity gains is the ability to analyse the volume of assessments and care plans electronically rather than manually. Some healthcare professionals interviewed talked of cumbersome, or highly inaccurate, systems previously used to generate reports on assessment and care planning activity.

"The ability to pull off the care plan reports has made a huge difference to me in populating my monthly reports." (healthcare professional)

If should be noted that this is not a benefit afforded to all healthcare professionals as some made limited attempts to analyse the volume of assessments and care plans being completed when on paper.

Healthcare professionals also talked of time being saved by accessing care plans electronically rather than having to search for hard copy versions.

One site mentioned they find referrals much easier now they are doing electronic assessments and care plans – this is principally because it is possible for healthcare professionals to request individuals are called by Macmillan to help assist with the concerns they have raised.

In another site the eHNA project is allowing healthcare professionals to make better use of their time. In this instance, CNSs will view completed electronic assessment results before calling individuals to discuss their concerns. Efforts are better targeted such that more time is spent with individuals known to have a large number, or more severe, concerns and less time is spent with individuals known to be relatively untroubled.

Some healthcare professionals believe they are getting a reduction in inquiry phone calls from individuals living with and beyond cancer because their concerns are being addressed earlier in the care pathway. They did
however acknowledge that this particular productivity gain is difficult to evidence.

"In theory it will save time... there is a reduction in the crisis management activity that takes place in the pathway in terms of needs being identified much earlier on. The problem is, at the national level, evidence is poor so that has given us a bit of a challenge." (healthcare professional)

It is worth noting that even if the eHNA project were to save healthcare professionals time in comparison with verbal or paper alternatives, time pressures (as described in section 5.1.3) will always remain a challenge given there will always be a push to increase the proportion of individuals being offered an electronic assessment.

7.2 Confidence in delivering holistic needs assessments and care planning

It is important to Macmillan that healthcare professionals experience “increased confidence to deliver holistic care planning” as a result of the eHNA project.

Healthcare professionals show greater confidence in delivering holistic needs assessments and care plans (particularly so for the latter) following the introduction of the eHNA project.

Healthcare professionals express a fairly high level of confidence in administering holistic needs assessment both before and after the introduction of the eHNA project. However, the proportion of healthcare professionals who say they are very confident in their abilities is higher following the advent of the eHNA project (45% compared with 36% pre-intervention). Though this difference is not considered statistically significant it shows the positive direction that confidence levels are moving in since the introduction of electronic assessments.

A more pronounced picture is evident for healthcare professionals’ confidence in using electronic care plans. Confidence levels rise (this time statistically significantly) from 25% saying they are very confident using care plans prior to the introduction of the eHNA project, to 37% post-intervention.
Figure 7.1 – Confidence in conducting assessments and care planning


<table>
<thead>
<tr>
<th>Confidence in using (electronic) assessments</th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very confident</td>
<td>36%</td>
<td>45%</td>
</tr>
<tr>
<td>Fairly confident</td>
<td>51%</td>
<td>48%</td>
</tr>
<tr>
<td>Not very confident</td>
<td>6%</td>
<td>12%</td>
</tr>
<tr>
<td>Not at all confident</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Not relevant/don't know</td>
<td>1%</td>
<td>9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Confidence in using (electronic) care plans</th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very confident</td>
<td>25%</td>
<td>37%</td>
</tr>
<tr>
<td>Fairly confident</td>
<td>38%</td>
<td>48%</td>
</tr>
<tr>
<td>Not very confident</td>
<td>12%</td>
<td>9%</td>
</tr>
<tr>
<td>Not at all confident</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Not relevant/don't know</td>
<td>17%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Any concerns healthcare professionals may have about being unable to deal with the issues raised by individuals are generally unfounded and tend to dissipate once the eHNA project is up and running.

In a few instances, healthcare professionals administering electronic assessments and care plans have revealed a lack of confidence in dealing with issues raised by people completing the assessment. This stems from concerns about their own ability to successfully handle what arises from the assessment, or a concern that the support services individuals may require are not available (such as there being limited psychological support services).

“CNs will do their best to help the patient but sometimes they get to the point where they don’t know where they can go with this anymore. They signpost patients as best as they can but I know they often feel that they haven’t completed this satisfactorily. We don’t have a clinical psychologist which is a bit of an issue and is an unmet need. If we had this resource it would make a difference.” (healthcare professional)

One case study site talked of healthcare professionals sometimes not knowing where to signpost individuals to in the local vicinity. This particular site has tasked a non-clinical member of staff to scope what support services are available in the local area which will aid healthcare professionals in their discussion of assessment results.

Whilst some healthcare professionals expressed concerns about their ability (or that of their colleagues) to adequately meet the needs of individuals completing the assessment, the vast majority of healthcare professionals say that ’more often than not’ they are able to help individuals with the concerns they raise during the assessment and care planning process.
(70%). A further 17% say they are 'always' able to do so, with only small proportions saying they can help 'about half the time' (nine per cent) or 'less often than not' (three per cent).

7.3 Recognition of value

As a result of the eHNA project, Macmillan hope healthcare professionals have a "greater recognition of the value of assessments and care planning". This section of the report examines the extent to which this intended impact is presently being realised. It first looks at the overarching value healthcare professionals place in the assessment and care planning process before examining the benefits of the eHNA project as seen from the perspective of healthcare professionals.

7.3.1 The value of assessments and care planning

The eHNA project appears to have little impact on the extent to which healthcare professionals think there is value in holistic needs assessments and care planning since this was already highly valued prior to the roll-out.

The vast majority of healthcare professionals say that holistic needs assessments and care planning are important to the care of individuals living with and beyond cancer. The proportion who thinks this does not differ before and after the introduction of the eHNA project (95% and 92% respectively).

Figure 7.2 – The value of assessments and care planning

Q21. Thinking about a typical cancer patient, how important do you feel Holistic Needs Assessments and care planning is to the overall care of that patient? Please select one

7.3.2 Benefits of electronic assessments and care planning

There are a number of benefits afforded by the use of holistic needs assessments and care planning in general – principally the improved ability for healthcare professionals to meet the needs of the individuals they care for.
Healthcare professionals name a number of benefits of holistic needs assessments and care planning in general. They most commonly say that the assessment and care planning process (irrespective of how it is done) allows them to signpost individuals to relevant services and support (88% mention this). They also believe the process of needs assessments and care planning allows them to address individuals’ needs that would have otherwise remained unknown (82%) and that it contributes to patient centred care (81%).

Figure 7.3 – The benefits of holistic needs assessments and care planning in general

Q22. In your view, what are the benefits, if any, of Holistic Needs Assessments and care planning? Please select all that apply

- Signposts patients to relevant services/support: 88%
- Addresses patients’ needs that would otherwise remain unknown: 62%
- Contributes to patient centred care: 81%
- Contributes to patient wellbeing/quality of life: 77%
- Supports patient self-management: 77%
- Provides structure to discussions with patients: 74%
- Assists in service planning: 50%
- Other: 2%
- Don’t know: 3%

Base: Post-intervention healthcare professionals: All participants (180)

The qualitative interviews with healthcare professionals reiterated many of the benefits shown in figure 7.3 above. The process means healthcare professionals do not impose their own agenda on individuals living with and beyond cancer but they view concerns from the perspective of people they support. Healthcare professionals talked about having better therapeutic relationships with the individuals they care for as a result of the assessment and care planning process.

"From a patient quality point of view it tends to bring out more things than what patients would have mentioned before. When people are upset they only tend to talk about what they need to talk about whereas when you put a structure to it they sometimes bring out things they haven’t thought to mention so that’s really good.” (healthcare professional)

Completing assessments and care plans electronically affords a number of additional benefits to healthcare professionals.

The most prominent benefit of completing assessments and care plans electronically is the ability to evidence that they are being carried out (mentioned by 65% of healthcare professionals).
"The eHNA has formalised the process. Everyone says they do it (holistic needs assessments and care plans) but in the past it has been very difficult to monitor how it’s been done. Now you can evidence what you are doing." (healthcare professional)

Other benefits of the electronic completion include the move towards a paperless system (62%), it avoids illegible handwriting (62%) and the care plan is automatically generated (58%).

Figure 7.4 – The benefits of administering electronic assessments electronically

As discussed earlier in section 7.1.3, the use of electronic assessments and care plans can save healthcare professionals time for example by enabling the better targeting of efforts, and reducing the crisis management required down the line.

On balance, healthcare professionals exhibit a preference to complete holistic needs assessments and care plans electronically as opposed to on paper.

The majority of healthcare professionals say they prefer to complete holistic needs assessments and care plans electronically (65%). Some professionals remain ambivalent showing no real preference to complete it electronically or on paper (16%). Only a small proportion say they prefer to complete the assessment and care plan on paper (16%).
Figure 7.5 – Preferred mode of assessment completion among healthcare professionals

Q25: I am going to read out two statements representing either ends of a scale from 1 to 10, where statement A=1 and statement B=10. Please select a number between 1 and 10 to show where your view fits on this scale.

A. I prefer to administer Holistic Needs Assessments and care plans on paper: 1-4
- 16%
- 16%
- 5-6
- 16%

B. I prefer to administer Holistic Needs Assessments and care plans electronically: 7-10
- 65%

Don’t know
- 3%

Base: Final intervention healthcare professionals: All those who complete eHNAs (145)

Key benefits of the eHNA for healthcare professionals

- Healthcare professionals have greater confidence to deliver electronic holistic needs assessments and care plans (particularly the latter) compared to paper alternatives.

- The assessment and care planning process (irrespective of how it is done) allows healthcare professionals to signpost individuals to relevant services and support (88% mention this); means they can address individuals’ needs that would have otherwise remained unknown (82%); and contributes to patient centred care (81%).

- The most prominent benefits specifically of the electronic assessment as opposed to paper or verbal alternatives are that it provides an audit trail (65% mention this); it is a paperless system (62%); avoids illegible handwriting (62%) and the care plan is automatically generated (58%).

- Qualitatively, healthcare professionals say they are better able to meet the needs of those they care for, with them establishing better therapeutic relationships as a result of the electronic assessment process.

- There are some examples of increased productivity as a result of the eHNA (in relation to activities outside the direct administration of assessments and care plans).
Medium term outcomes and impact on the healthcare economy
8 Medium term outcomes and impact on the healthcare economy

In this section consideration is given to the extent to which the eHNA project is presently meeting the intended medium term outcomes and impacts for the wider healthcare economy.

8.1 Service planning and commissioning

The eHNA project is designed to primarily impact on the lives of people affected by cancer in two ways; by improving the support provided to individuals directly as a result of the concerns they raise through the process; and more widely by ensuring the services commissioned and provided in local areas are better targeted towards the needs of the population affected by cancer. This section of the report looks at the extent to which the eHNA project is impacting on wider service planning and commissioning.

Macmillan’s specific intended medium term outcomes and impacts as documented in the logic model are for “aggregate assessment data to be used to shape local decisions” and that “service planning/commissioning takes better account of patient needs”.

The aggregate data is a key reason for pursuing the eHNA project and sites are beginning to use it – primarily for monitoring and information gathering but increasingly to support wider service development.

There is widespread enthusiasm among healthcare professionals regarding the potential use of aggregate data. In many cases, this was one of the driving forces behind enrolling in the eHNA project and continues to help maintain momentum in the face of implementation challenges. However, use of the aggregate data (at all or to its full potential) is not yet widespread.

Of the healthcare professionals surveyed, a third have looked at the aggregate data themselves (35%) and a further 20% believe a colleague has done so. Project leads are much more likely to have looked at the data themselves (63% say they have done so compared to 22% of other staff).

Individuals are very positive about the usefulness of the data. Nearly all consider the data to be useful (91%) with 44% saying it is very useful.

42 Note this is based on responses from 58 project leads and thus should be interpreted cautiously.
Figure 8.1 — Perceived usefulness of the aggregate data

Q30 How useful, if at all, is the aggregate data produced from the electronic Holistic Needs Assessments?

For the individuals who look at the aggregate data, they tend to do so infrequently. Healthcare professionals interviewed as part of the case studies talked of looking at the data ‘periodically’, ‘every 6-8 weeks’, ‘2-3 months ago’.

For those that have not looked at the data, or do so rarely, time pressures and capacity issues were the main reason for this. In some cases, there is a paucity of data for sites from which to draw meaning and this limits the usefulness of the data at present.

Currently, the aggregate data tends to generate discussion rather than initiate action. The most common outcome following a review of the aggregate data is for it to be discussed with colleagues (49%), discussed with service providers (19%) and discussed with someone from Macmillan (11%). However, sites are beginning to use the data to shape service provision and roughly one in ten say they have made changes to the information they provide, or the services they provide, to individuals affected by cancer. A further one in ten say they have conducted training with staff as a result of the aggregate data.
Figure 8.2 – Actions taken as a result of the aggregate data

Q31. What, if anything, have you or others in your trust done with the aggregate data produced by the electronic Holistic Needs Assessments? Please select all that apply.

- Discussed it with colleagues: 49%
- Discussed it with service providers: 19%
- Discussed it with someone from Macmillan: 11%
- Made changes to the information provided to patients: 11%
- Made changes to services provided to patients: 9%
- Conducted more training with staff: 7%
- Conducted more training with patients: 7%
- Other: 11%
- Nothing as of yet: 31%

Base: Post-intervention healthcare professionals. All those who say they or someone else has looked at the aggregate data from the eHNAs, excluding those who say 'don’t know' (75)

8.1.1 Performance monitoring/intelligence gathering

The case study interviews provided a number of examples of how the aggregate data is being used for the purposes of performance monitoring and intelligence gathering; these are discussed below.

Most commonly the aggregate data is reviewed (typically by the project lead) to check how the eHNA project is progressing – which tumour groups are conducting electronic assessments and how well they are doing this. In some instances, this permits project leads to chase up particular tumour groups or members of staff to check on why progress is not as expected.

"It’s hard to measure a CNS's performance so it’s something that is really useful to see how many eHNAs have been completed. From a quality side it’s really useful to make sure all patients have been offered an eHNA in the trust." (healthcare professional)

As well as performance managing internally within sites, some project leads use the aggregate data to provide feedback to senior members of staff on how well the eHNA project is embedding and to provide an update on progression. A handful of project leads have used the aggregate data to evidence the capacity issues faced by particular nursing teams.

Where sites have targets to meet regarding the extent of holistic needs assessments and care planning, the aggregate data permits them to run reports far more easily than previously possible. The data is sometimes reported upon in annual reports.

Staff interviewed as part of the case studies also talked about using the aggregate data to look at the greatest concerns held by the people they care for. This has been a source of discussion among colleagues – particularly when the concerns documented are not what nurses would necessarily expect. One case study site talked about expecting to see fears...
about treatment and depression as predominant concerns among pre-
treatment individuals. Instead they were surprised to learn of the high
information needs around exercise and diet of the individuals they were
caring for. Being able to counter healthcare professionals' presuppositions
has been helpful in some sites as a way to drill home the importance of the
eHNA.

Some sites have used the aggregate data in presentations they have given
about the eHNA project—either internally, to other sites, or to networks
within which they work.

8.1.2 Shaping service provision

Assessing the needs of individuals affected by cancer requires
arrangements to be in place to meet these needs. Making sure service
delivery develops alongside the eHNA project is therefore crucial. Whilst the
aggregate data is more commonly used for performance monitoring and
intelligence gathering, there are examples evident of how the data is being
used more specifically to shape service provision.

Some sites have reconsidered the information they provide to individuals
living with and beyond cancer. For example, one site has provided more
leaflets in their waiting rooms about managing finances after recognising
this was more of an issue for people affected by cancer than previously
thought. Another site based an information day around the most common
concerns raised by individuals living with and beyond cancer. Another site
set-up a project called 'Anxiety Management' to help individuals manage
their anxiety—highlighted as being a common concern through the
aggregate dataset.

Other sites have used the aggregate data to push for better service
delivery. One has recently appointed a new counsellor to provide support to
the family and friends of individuals living with and beyond cancer after
realising this was an unmet need. Similarly, one site has put forward the
case for a clinical physiologist after recognising greater support was
needed in this area.

One site has decided to set-up a post-treatment eHNA clinic to mirror their
current pre-treatment clinic as they recognised the concerns being raised
by individuals living with and beyond cancer were long-term and required
ongoing support.

"Doing the eHNA has pushed the development of the clinic... We
felt the concerns coming up were longer-term or ones that
needed to be re-addressed in a formal setting again, with lots of
patients saying they feel on their own after treatment so that's
where we have slotted in post-treatment appointment."
(healthcare professional)
A quarter of healthcare professionals surveyed say they are using the aggregate data to support wider planning in their trust (26%). This has increased from 16% prior to the eHNA project roll-out when trusts were collating information collected through paper assessments.

Where sites are not presently using the aggregate data to inform service delivery, they could recognise the potential of doing so.

“We haven’t used it yet to go to commissioners to say ’XXX is needed’ but we can clearly see what the top concerns are for patients and that will help plan for the future”. (healthcare professional)

8.1.3 Future use of the aggregate data

_The value of the aggregate data could be enhanced if some modifications were made to how it is collected and analysed._

As the number of completed electronic assessments and care plans grows, the value of the aggregate data is becoming increasingly apparent. Macmillan is undertaking internal analysis of the data and there is a lot of heightened interest (both internally and externally) in it.

Within Macmillan there are hopes of being able to overlay the aggregate data generated through the eHNA project with other cancer intelligence data. This could, for example, involve mapping the concerns held by people living with and beyond cancer onto geographic boundaries or known metrics on other health outcomes. This would require modifications to how the data is collected at present. For example, it may require postcode data to be collected, and informed consent to be given by individuals which would permit more extensive data analysis.

The hope is for the aggregate dataset to be driving changes in service provision which, in part, will be achieved through shaping commissioners’ decisions. At present there are some limitations in the aggregate data which could limit how receptive commissioners are to it. The data is not yet reflective of the age, gender and tumour group profile of the wider UK population affected by cancer. It is therefore important for Macmillan to work with sites to broaden the profile of tumour groups involved and the individuals completing electronic assessments. As the number of electronic assessments and care plans grows, Macmillan and others will be better able to cut the data according to different characteristics they would like to analyse by.

At present, individuals can complete multiple electronic assessments and be counted numerous times within the dataset. This may come under scrutiny as commissioners and service providers increasingly demand to know the concerns at a person, rather than an assessment, level. There are
challenges to this since it would require a departure from the anonymity of the data as it is currently collected.

8.2 Continual care

Macmillan hopes the eHNA project will mean "healthcare professionals are able to monitor patients' needs remotely", and there will be "improved access to continual records of patients' progress". This section of the report examines to what extent these intended impacts are presently being met.

The desired impact for health professionals to be able to monitor individuals’ needs remotely is being partially met at present. This will be achieved imminently once Macmillan establishes a means through which the electronic assessment can be completed by individuals in their home and in other locations away from the clinical setting.

Underlying the objective for improved access to continual records is the desire for electronic assessments and care plans to be administered by any service provider along the care pathway. For this to be achieved, there needs to be an ethos of sharing assessment results and care plans between healthcare professionals and a means through which to do so.

The sharing of assessment results and care plans between healthcare professionals is greater following the introduction of the eHNA project. However, the lack of automatic upload into the EPR and incompatible IT systems between sites can limit the extent to which assessment results and care plans are shared.

On average, half of all care plans produced following an electronic assessment are shared with other healthcare professionals (50%). This is much higher than care plans produced following paper assessments – of which 39% on average are shared with other healthcare professionals. Whilst this is encouraging, it is not known what constitutes ‘sharing’ in this context. It may be that the healthcare professionals surveyed believe a care plan to be ‘shared’ if it is saved in a file location accessible to other healthcare professionals even though the care plan may not be read by others.

When considering the sharing of assessment results and care plans between healthcare professionals, there are three distinct levels – sharing within teams; sharing outside of teams but within sites; and sharing with healthcare professionals outside of sites. The case study interviews gave the sense that the frequency of sharing follows this same order with results and care plans most commonly shared within teams.

A third of healthcare professionals surveyed say that individuals’ care plans are saved in the EPR. Some sites do not save care plans in the EPR but save a hard copy in individuals’ records (mentioned by 36% of healthcare
professionals surveyed post-intervention) or save an electronic copy in a shared file location (20%). The demand to automatically save assessment results and care plans in the EPR is high among the case study sites. It is hoped that by doing so, staff efficiency will greatly improve, as will the care provided to individuals affected by cancer.

Until the automatic upload into the EPR is more widespread, sites have adopted 'workarounds' to enable results and care plans to be shared internally. This most commonly is a manual process whereby care plans are saved onto secure servers before being uploaded into their EPR system. Healthcare professionals interviewed admitted this could be a 'laborious' process that inevitably led to delays in care plans being uploaded to EPRs.

“Care plans are stored in a secure drive so they can at some point be downloaded and shared, but at the moment it’s not automatic. I can do a manual upload but I haven’t had time to do this so we have around 100 care plans sitting in a folder waiting to be uploaded.” (healthcare professional)

Where care plans are saved on secure hard drives and not uploaded to EPRs, this can mean they are inaccessible to different teams internally thus limiting the extent to which care plans are shared.

Whilst healthcare professionals talked of ways in which they attempted to share assessment results and care plans, they admitted they were uncertain of the extent to which these documents were actually reviewed by professionals not involved in their original creation. One healthcare professional talked of viewing old care plans if she took over the care of an individual affected by cancer from a colleague, but these examples were few. It is therefore worth bearing in mind that, even if assessment results and care plans are shared between healthcare professionals, this does not mean they will be viewed by multiple professionals.

Sharing more widely outside of sites can be a challenge due to the different information management systems used (and is dependent on local Data Sharing Agreements). One site talked of the particular cancer datastore they used being inaccessible to healthcare professionals outside of their trust. This is a real challenge for the eHNA project given there is an ambition for electronic assessments to be done at any stage along the cancer pathway and it may be hard to provide joined-up care if the results of previous assessments are not easily accessible to all healthcare professionals.

It is particularly important for assessment results and care plans to be easily shared with GPs if, at some stage, there are ambitions for electronic assessments to be conducted at Cancer Care Reviews. At present, a third of healthcare professionals surveyed post-intervention say that care plans are typically shared with GPs (36%). Often this is a hard copy in the post.
One site have established a system whereby they save care plans as RTF files which are copied and pasted into a clinical reporting system that generates a letter that is automatically emailed to the relevant GP.

Care plans are also sent with referrals (12% of healthcare professionals say this typically happens) and shared with individuals’ specialists/oncologists (11%).

"If we have a psychology referral we'll send it to the psychologists too. They find it really helpful to have in writing what plan has been discussed with patients and what problems were raised, so they can get a feel for the levels of distress the patient might be experiencing." (healthcare professional)

Figure 8.3 — What typically happens to care plans once created

Key benefits of the eHNA for the healthcare economy

- The aggregate data generated by the eHNA is thought to be useful by 91% of healthcare professionals who say they, or a colleague, have looked at it.

- Sites are beginning to use the aggregate data— particularly so for the purpose of performance monitoring and intelligence gathering, but increasingly to shape service provision.

- Care plans are more commonly shared between healthcare professionals following electronic assessment completion compared to paper alternatives (typically shared in 50% of cases compared to 39%).
Medium term outcomes and impact on Macmillan
9 Medium term outcomes and impact on Macmillan

In this chapter, consideration is given to how the eHNA project has impacted Macmillan; looking at the extent to which Macmillan has better engaged with individuals affected by cancer and healthcare professionals as a result of the project, and the regional and national influence exerted by Macmillan.

9.1 Engagement with people living with and beyond cancer

A key objective of the eHNA project for Macmillan is to have greater engagement with people living with and beyond cancer. It is hoped this can be achieved through "increased patient engagement with Macmillan" and that "Macmillan has ongoing and personalised relationships with its customers".

9.1.1 Increased engagement with individuals living with and beyond cancer

The eHNA project is strongly associated with Macmillan by those who have completed an electronic assessment. Of the 71 people who knew the electronic assessment was affiliated to a particular charity, 93% knew Macmillan was behind it.

*Engagement with Macmillan appears to be higher among those who recall completing an electronic assessment compared with those that recall a paper alternative. However, this may not be causal, and there are no clear patterns in how this engagement occurs.*

The most likely sources of help for people living with a cancer diagnosis (irrespective of whether they have completed the assessment electronically, on paper or not at all) are doctors/nurses in hospital, friends and family, and Macmillan.

However, people who recall completing an electronic assessment appear more engaged with Macmillan. Seven in ten would turn to Macmillan if they wanted help in dealing with issues related to their cancer diagnosis (70%), compared with 51% of those who recall completing a paper assessment\(^3\) and 56% of those who do not recall having completed an assessment. However, it is difficult to prove this is a causal link. Indeed, there is no clear

\(^3\) Based on 68 people
pattern in how individuals engage with Macmillan differently depending on whether they have completed an electronic or paper assessment.

Individuals who recall completing an electronic assessment say they are more likely to have read Macmillan literature (66% have done this compared to 45% of individuals who recall completing a paper assessment\(^{44}\)); been seen by a Macmillan cancer nurse (55% vs. 46%); and donated to/or fundraised for Macmillan in the past (56% vs. 25%). In contrast, those who recall completing a paper assessment are more likely to have visited a Macmillan information centre (28% vs. 14% of those who recall completing an electronic assessment); and talked to a Macmillan adviser (28% vs. 13%).

This data suggests there is no particular effect of the eHNA project on the ways in which individuals engage with Macmillan. Macmillan may wish to investigate this further by looking to map the usage of local Macmillan products and services against what is known about electronic assessments and care plans being done in that area.

### 9.1.2 Ongoing and personalised relationships with individuals living with and beyond cancer

**Securing ongoing and personalised relationships with individuals affected by cancer will no longer be secured through the CRM database but may develop through alternative means.**

When Macmillan originally devised the eHNA project logic model they believed that ongoing and personalised relationships with individuals affected by cancer could be achieved through linking assessment data (following individuals’ consent) to the Client Relationship Manager (CRM) database. As the project has evolved and developed there has been some departure from this original ambition.

Due to a number of factors including delays to the CRM programme, it was agreed that the proof of concept would take place as a phased process. A pilot of this phased process is almost concluded, with individuals providing consent to be contacted by Macmillan’s Support Line (MSL) to hear more about the support Macmillan can provide and, only then, being asked to consent for their information to be entered into the CRM database. Early findings from this pilot suggest that there is a low volume of requests to be contacted by the MSL (and therefore limited numbers of individuals being entered into the CRM database).

It seems that the development of ongoing, personalised relationships with individuals living with cancer may now come through the establishment of

\(^{44}\) Based on 69 people
the Recovery Package rather than through linking assessment data with the Macmillan CRM database as originally envisaged.

Another possible way in which Macmillan could develop personalised relationships with those affected by cancer is presently in very early discussions. This would see a future scenario whereby individuals affected by cancer can complete a version of the assessment on Macmillan’s website which would automatically signpost individuals to local (Macmillan) resources and support services in relation to the concerns they have expressed.

Given the future will see considerably more recovery and longer-term care provided out of the acute setting, Macmillan will continue to invest in supporting self-management as much as possible. Allowing individuals to independently complete an electronic assessment through a secure website would aid this ambition to enable better self-management for those living with and beyond cancer. The qualitative interviews with people affected by cancer revealed a number of instances where individuals expressed surprise to learn of the services available to support them in their local area.

9.2 Professional engagement

*There are some examples of increased professional engagement with Macmillan as a result of the eHNA project.*

It is hoped that there will be *“increased professional engagement with Macmillan” as a result of the eHNA project.* Most of the healthcare professionals registered to administer electronic assessments and care plans are not Macmillan professionals – this suggests Macmillan is engaging a wider array of healthcare professionals although it is not possible to ascertain what involvement these professionals had with Macmillan prior to the introduction of the eHNA project and how this has changed as a result. Anecdotally a handful of healthcare professionals in prototyping sites talked of referring to Macmillan services more than previously and of working more closely with their Macmillan Information Centre. In one site, individuals often refer on to the Macmillan Information Centre if they are unsure of where else to signpost individuals.

"I think we probably promote the Macmillan helpline a little more... I possibly know more about Macmillan services but not consciously – it’s in your head more, being at the [Learn and Share] events so you just kind of pick things up." (healthcare professional)

"We have used the (eHNA) project to pull together what was happening in isolation so we are working more closely with the Macmillan Information Centre and are not reinventing the wheel"
(in terms of available services to signpost patients to)."
(healthcare professional)

9.3 Regional and national influence

Macmillan will best be able to exert regional and national influence through the commissioning of the Recovery Package. This will be facilitated through aligning the Recovery Package more closely to other long-term conditions.

Through the eHNA project, Macmillan hopes to have an "improved ability to influence regionally and nationally". Principally this can be achieved through the Recovery Package being commissioned and through using the aggregate data to exert influence on services provided to meet the needs of individuals affected by cancer. This section of the report briefly discusses the commissioning intentions of CCGs based on discussions with external stakeholders. It is recognised that there are other pieces of work and workstreams that explore commissioning of the Recovery Package in far greater detail but it is referenced here to ensure the evaluation results are understood in the round.

In the main, CCGs are aware of the Recovery Package (and therefore the eHNA) and there are a number of barriers and enablers to the Recovery Package being commissioned. An ongoing challenge for CCGs is the competing priorities they must address and the limited budget they have to do so. There tends to be a greater focus placed on the early diagnosis of cancer as opposed to helping individuals live with and beyond it. External stakeholders talked of the need to make commissioning as cost-effective as possible which may involve aligning the Recovery Package to other conditions, as discussed below.

"In a very cash strapped environment, we need to make commissioning as manageable and sustainable and as cost-effective as possible... We need to hook this (the Recovery Package) onto as many things as possible to get it commissioned and delivered." - external stakeholder

The commissioning process may be made more challenging for Macmillan given the huge local variation in the priorities of CCGs and the structure of commissioning. Knowing who commissions what may present a challenge to getting the Recovery Package embedded.

However, there are a number of supporting factors which, if harnessed by Macmillan, may encourage the Recovery Package to be more widely commissioned (and thus enable Macmillan to exert greater influence regionally and nationally). It is believed that CCG commissioning intentions often include cancer as part of long-term conditions. External stakeholders believe that better aligning and integrating the Recovery Package into
broader CCG programmes around long-term conditions will increase the sustainability of it.

Organisations affiliated with other health conditions are looking to develop similar products to the eHNA tool. This puts Macmillan in the position of having significant experience relative to others. In the future Macmillan may wish to work closely with other long-term conditions to move towards a more collaborative approach to holistic needs assessments and care planning. For example, the future could see individuals with multiple diseases having one care plan which has been amalgamated from separate holistic needs assessments for cancer and for other conditions. This is a long-term vision but one which Macmillan should consider now to make the most of the 'head-start' it has.

“There are many other conditions where they are now pushing for HNAs and individual needs based care plans – there is a real synergy with what is happening in the world generally.” (external stakeholder)

In terms of using the aggregate data to exert influence regionally and nationally, the data is presently being used more commonly at the local level. This may change as the volume of aggregate data grows and enables more sophisticated analysis to be undertaken by Macmillan at the regional and national level.

Key benefits of the eHNA for Macmillan

- The eHNA is strongly associated with Macmillan by those who have completed an electronic assessment (with 93% correctly associating the assessment with Macmillan).

- There are some anecdotal examples of healthcare professionals having greater engagement with Macmillan through referring to Macmillan services, and working with their Macmillan Information Centre, more than they have done previously.

- Macmillan has significant experience relative to other organisations that are looking to create tools similar to the eHNA for other health conditions. Macmillan can therefore act as a system leader in this respect.
Cost-effectiveness of the eHNA
10 Cost-effectiveness of the eHNA

Throughout the report, the costs associated with the eHNA project and the various benefits secured in return have been documented. This chapter brings together these findings to provide an overview of the cost-effectiveness of the eHNA.

As discussed in section 2.3, a full cost-effectiveness assessment was not possible due to the lack of a known metric within the wider literature with which to quantify the benefit of completing a holistic needs assessment. Instead, a qualitative assessment of the costs and benefits has been undertaken, supplemented by the quantitative data collected as part of the evaluation. When interpreting the data, the caveats made clear throughout the report, and specifically in section 2.4, should be borne in mind.

10.1.1 Costs and benefits to Macmillan

The benefits of the eHNA (documented throughout the report) have been assessed as benefits directly to Macmillan, and those which primarily benefit individuals affected by cancer, healthcare professionals and the wider healthcare economy. Of course the benefits of the eHNA for these latter three groups should be recognised as indirect benefits for Macmillan, to be offset against the overall cost Macmillan has invested.

As discussed in section 4.1, it is estimated that the eHNA project has cost Macmillan £1,838,700 (by the end of Q1 2015). The most significant cost to date has been expenditures to the third party software provider for the set-up, licensing, hosting and software development associated with the eHNA platform. The current third party software supplier was commissioned though an open and competitive procurement process but there may be opportunities for greater value to be secured through the re-tendering of the software provider contract, given the increased scale of the eHNA.

A large number of benefits have been secured through the eHNA project. Principally, the eHNA project has resulted in the completion of 17,265 electronic assessments (by the end of June 2015), of which 72% have been converted into care plans. Since the introduction of the eHNA project, there has been a marginal increase in the average number of assessments being completed per site per month, though the proportion of assessments which result in a care plan has increased dramatically compared to the conversion rate of paper assessments.

Crucially for Macmillan, individuals living with and beyond cancer are positively benefitting from the eHNA. They are more likely to say they have received support at the right time, from the right people and in the right
setting, and to say their holistic needs are being met than individuals who recall completing a paper (or no) assessment. Individuals living with and beyond cancer can name a host of other benefits of the eHNA such as it making them feel less worried (mentioned by 56%), and it encouraging them to bring up concerns they otherwise would not have (51%). These benefits could also be achieved through completing paper assessments and care plans; however, indications are that the eHNA will result in a greater proportion of individuals having their holistic needs assessed. And, the care of individuals affected by cancer will improve indirectly once service planning and commissioning takes better account of the aggregate data generated by the eHNA – a benefit which is unique and cannot be achieved to the same degree through the use of a paper alternative.

At site level, healthcare professionals are able to name a number of benefits of the eHNA (as discussed below) which are positive developments for Macmillan. Indeed, there is some evidence (though limited at present) to show increased engagement of healthcare professionals with Macmillan.

Through the eHNA project, Macmillan has amassed significant experience regarding holistic assessments and care plans relative to organisations looking to develop similar tools for other health conditions. This is a key direct benefit from the project; giving Macmillan the position of system leader with respect to holistic needs assessments and care planning.

10.1.2 Costs and benefits at site level

As discussed in section 4.1, the average spend on direct costs of the eHNA project is £5,123 per site (based on 18 sites). This covers costs such as the purchase of tablets, and the access of WiFi. Sites spend, on average, £16,380 per year per site on ongoing staffing costs associated with the eHNA project (based on nine sites). These average costs hide a great deal of variation in the direct and ongoing staff costs of the eHNA at site level and hence should only be used to provide an indication of the possible scale of investment required. Lower costs are associated with smaller sites or fewer tumour groups; pre-existing WiFi and an established use of tablets prior to the introduction of the eHNA.

Many of the benefits mentioned in the section above apply at site level also, of which the most relevant are those for healthcare professionals. The eHNA project has resulted in increased confidence among healthcare professionals to administer holistic needs assessments and, in particular, care plans. Healthcare professionals believe the assessment process means they are able to signpost individuals to relevant services and support (mentioned by 88%), they can address individuals' needs that would otherwise remain unknown (92%) and that it contributes to patient centred care (81%). Many of these benefits could be secured through the use of paper assessments however, it is clear there are benefits which are unique to the eHNA and which cannot be secured through alternative
means. These include the eHNA providing an audit trail of assessment and care planning (mentioned by 65% of healthcare professionals), it being a paperless system (62%), it avoiding illegible handwriting (62%) and the care plan being automatically generated (58%). Care plans are more commonly shared since the advent of the eHNA project (happening on average in 50% of cases compared to 39% for paper assessments) though these instances of ‘sharing’ may include saving the care plan in a file location accessible to other healthcare professionals and not necessarily that the care plans are read by others.

Electronic assessments and care plans, are thought to take marginally longer to administer compared to paper alternatives; particularly so in the case of the latter. As discussed in section 7.1.2, the primary reason for this is thought to be that individuals score each of their concerns individually through the eHNA rather than providing an overall score as they are more likely to do when completing a paper assessment, leading to a more thorough assessment of their concerns. That said, healthcare professionals can provide examples of increased productivity as a result of the eHNA – always in relation to activities outside the direct administration of assessments and care plans such as the ability to analyse the volume of assessments and care plans electronically rather than manually.

Indeed, the aggregate data is considered another key benefit of the eHNA with the vast majority of healthcare professionals finding it useful (92%). Sites are beginning to use the aggregate data – primarily for performance monitoring and intelligence gathering, but increasingly to shape service provision.

10.1.3 Overview of the cost-effectiveness of the eHNA

The evaluation has shown that the eHNA project has made significant progress over the course of the evaluation, with the number of sites enrolled and the number of assessments increasing substantially. Macmillan has been able to secure economies of scale in the cost of the project as it has expanded. The cost to Macmillan of each completed electronic assessment and care plan has decreased over time as the volume has increased and as the number increases further these costs will continue to fall. At the same time, significant progress has been made on a number of the intended outcomes and impacts of the eHNA for people living with and beyond cancer, though more limited progress has been made on those relating to health professionals, the wider healthcare economy, and Macmillan (as summarised in the subsequent chapter). However, the activities that Macmillan is currently undertaking (or is planning to undertake) will move them further towards achieving these intended outcomes and impacts. As such, if the outcomes and impacts of the eHNA continue to deepen and expand, its cost-effectiveness will increase further. While there remain a number of challenges and risks to the project at site level, these will continue to diminish as NHS working practices develop.
Table 10.1 – Summary of the costs and benefits of the eHNA project

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Macmillan</strong></td>
<td>No significant welfare/leisure cost observed.</td>
</tr>
<tr>
<td>The healthcare economy</td>
<td>At site level, the average direct cost of the eHNA project is £5,123 with average ongoing staffing costs per year of £16,380.</td>
</tr>
<tr>
<td>Healthcare professionals</td>
<td>Electronic assessments and (in particular) care plans are thought to take marginally longer to administer compared to paper alternatives.</td>
</tr>
<tr>
<td>People living with and beyond cancer</td>
<td>No significant costs observed at this stage.</td>
</tr>
<tr>
<td>17,265 electronic assessments completed as of 30th June 2015.</td>
<td>Direct and indirect costs of £1,838,700 by end of Q1 2015.</td>
</tr>
<tr>
<td>Individuals more likely to say they have received support for their cancer at the right time; from the right people; in the right setting; and to say their holistic needs are being met if they recall completing an electronic assessment compared to those who recall a paper (or no) assessment.</td>
<td>Increased engagement with individuals living with and beyond cancer and healthcare professionals is starting to become apparent.</td>
</tr>
<tr>
<td>Increased confidence to deliver holistic needs assessments and care plans (22 percentage point increase in confidence to deliver care plans).</td>
<td>Macmillan has amassed significant experience relative to other organisations looking to develop similar tools to the eHNA but for other health conditions, meaning Macmillan can act as a system leader in this respect.</td>
</tr>
<tr>
<td>The assessment and care planning process (non-specific to the eHNA) means professionals can signpost individuals to relevant services and support (88% mention this); address individuals' needs that would have remained unknown (82%); and it contributes to patient centred care (81%).</td>
<td></td>
</tr>
<tr>
<td>Benefits of the eHNA specifically are that it provides an audit trail of assessments and care planning (65%); it is a paperless system (62%); avoids illegible handwriting (62%) and the care plan is automatically generated (58%). Qualitatively, healthcare professionals are better able to meet the needs of those they care for.</td>
<td></td>
</tr>
<tr>
<td>The assessment and care planning process (non-specific to the eHNA) means professionals can signpost individuals to relevant services and support (88% mention this); address individuals' needs that would have remained unknown (82%); and it contributes to patient centred care (81%).</td>
<td></td>
</tr>
<tr>
<td>Qualitatively, individuals feel better supported.</td>
<td></td>
</tr>
<tr>
<td>Aggregate data considered useful by 92% of healthcare professionals.</td>
<td></td>
</tr>
<tr>
<td>Sites beginning to use the aggregate data – particularly for performance monitoring and intelligence gathering, but increasingly to shape service provision.</td>
<td></td>
</tr>
<tr>
<td>Care plans more commonly shared between healthcare professionals (typically shared in 50% of cases compared to 30% for paper assessments)</td>
<td></td>
</tr>
</tbody>
</table>
Conclusions and recommendations
11 Conclusions and recommendations

This final chapter concludes the report, providing a summary of how well Macmillan’s intended medium term outcomes and impacts for the eHNA project are presently being met. It then goes on to discuss the implications the evaluation has for the coming year and beyond, leading to a number of recommendations for Macmillan’s consideration.

11.1 Progress on intended medium term outcomes and impacts

11.1.1 Intended medium term outcomes and impacts for people living with and beyond cancer

As the eHNA project stands at present, the evidence from this evaluation shows that it is fulfilling a number of the stated ambitions, namely “patients feel better supported”, “patients feel their holistic needs are being met” and they experience “improved quality of life”. The aim of individuals affected by cancer being able to “complete the electronic assessment in an environment of their own choice” will soon be achieved through the creation of the ‘at home’ assessment.

The remaining intended medium term outcomes and impacts for individuals living with and beyond cancer are not yet being realised, though progression is being made towards them:

- Conducting electronic assessments is not yet “routine” but it is becoming more commonplace as sites find ways to embed the project. Time presents one of the greatest barriers to implementing the eHNA. Overcoming this barrier requires a change in the way clinics and resourcing are structured. Alternatively, the benefits of the eHNA need to be significant and visible enough that healthcare professionals and senior members of staff are willing to work through any implementation challenges faced.

- It is not yet possible for individuals to “complete the electronic assessment with any service provider along the care pathway”. Progress has however been made towards achieving this ambition with the creation of the ‘at home’ version of the electronic assessment and with an increasing number of sites testing the eHNA project in the community setting.

- Macmillan cannot fully achieve the ambition of “all eligible individuals complete an electronic assessment” as healthcare professionals exercise discretion over who counts as ‘eligible’ and
individuals choose to decline the assessment. Instead, Macmillan should strive to ensure all eligible individuals are given the option of completing an electronic assessment and make an informed choice about whether to or not.

- There is a limit to which the ambition of “actions are taken as a result of having a care plan” will be met. Not all electronic assessments are converted into care plans, not all care plans are shared with individuals, and it is not uncommon for individuals who have completed an electronic assessment to decline a copy of their care plan. These factors all limit the extent to which actions are taken as a result of the care plan. Additionally, where actions are taken following the assessment process, many believe these would happen irrespective of a care plan being created – greater importance lies in the discussion individuals have with their healthcare professional.

11.1.2 Intended medium term outcomes and impacts for healthcare professionals

The ambition of healthcare professionals having “greater confidence to deliver holistic needs assessments and care planning” is being achieved. The remaining two ambitions for healthcare professionals are being partially met at this stage in the prototyping phase:

- There are instances where the eHNA project is thought to “increase the productivity of healthcare professionals” – these all relate to activities outside the direct administration of electronic assessments and care plans. But, if healthcare professionals are used to conducting holistic needs assessments verbally or not at all, then the eHNA represents a significant demand that diminishes the time they have available to complete alternative tasks. In some instances, the same sentiment is expressed by healthcare professionals who are already administering assessments on paper as the electronic version appears to result in a more thorough assessment of individuals’ concerns, thereby taking up more time.

- The eHNA project has had little impact on “recognition of the value of holistic needs assessments and care planning”, but simply because this process was already highly valued prior to the project’s roll-out. That said, healthcare professionals are able to name a number of benefits of holistic needs assessments and care plans; particularly so if done electronically.

11.1.3 Intended medium term outcomes and impacts for the healthcare economy

At this point, the eHNA project is not achieving the ambition of “service planning and commissioning taking better account of individuals’ needs”
based on the aggregate data. The preceding stage to this intended impact is the outcome that “aggregate assessment data is used to shape local decisions” – an outcome which is being partially met at present. Currently the aggregate data is being used more for the purposes of performance monitoring and information gathering rather than informing service planning and commissioning. However, there are some examples where the aggregate data has been used to pursue the latter goal and sites are increasingly looking to their growing pool of aggregate data to do so.

Once Macmillan establishes a means through which individuals affected by cancer can complete the electronic assessment away from the clinical setting (initially through the ‘at home’ assessment) then the ambition for healthcare professionals “to monitor patients’ needs remotely” will be possible.

Macmillan hopes that healthcare professionals will have “improved access to continual records of patients’ progress” as a result of the eHNA project. Underlying this premise is the desire for electronic assessments and care plans to be administered by any service provider at any point (or multiple points) along the care pathway and for these to be shared. The sharing of electronic assessment results and care plans has increased since the advent of the eHNA project, though it remains inconsistently done. It is hoped the sharing process within sites will be facilitated by the automatic upload of results and care plans to the EPR though it does not naturally follow that other professionals will view the assessment results and care plans made available to them. The ability for assessment results and care plans to be shared between healthcare professionals in different care settings will be facilitated by the push for, “all patient and care records to be digital, real-time and interoperable by 2020” as set out by the National Information Board.

11.1.4 Intended medium term outcomes and impacts for Macmillan

Macmillan is not yet achieving the intended aim of having “ongoing and personalised relationships with its customers”. This will no longer be achieved through the CRM database, but it is hoped this ambition will be realised through alternative means such as through the Recovery Package and through the possible development of an online HNA assessment which can be completed independently on Macmillan’s website.

There are some examples evident of “increased patient and professional engagement with Macmillan” as a result of the eHNA project though this intended outcome is difficult to fully substantiate and these examples are not widespread at present.

The extent to which Macmillan “has an improved ability to influence regionally and nationally” as a result of the eHNA project is uncertain. Macmillan’s influence is likely to grow if Macmillan succeeds in getting the
Recovery Package more widely commissioned. The likelihood of doing this will be aided by more closely aligning the Recovery Package to broader CCG programmes concerning other long-term conditions.

### 11.2 Recommendations

The key focus over the next year for Macmillan will be establishing a ‘business as usual’ model which will ensure the sustainability of the eHNA beyond the end of the prototyping phase. The next six months will be critical for Macmillan in determining which provider to commission as the supplier of the software underpinning the eHNA data platform. This decision will fundamentally shape how the project is run in future and Macmillan’s role in it. Choosing the most appropriate supplier, and establishing a strong working partnership with them, will be critical to the project’s success.

#### 11.2.1 Recommendations for the coming year

A number of recommendations for the coming year are evident following completion of the evaluation:

- **Continue with current and planned initiatives:** Macmillan is progressing a number of workstreams, looking to further embed and ‘future-proof’ the eHNA. There are no workstreams (either planned or already underway) which the evaluation suggests should not be pursued. Of particular significance will be the establishment of an eHNA version to be completed by individuals in their homes as this will provide greater flexibility to healthcare professionals in their administration of electronic assessments and care plans, and will progress a number of Macmillan’s intended outcomes and impacts for the project.

- **Ensure minimal disruption in the move to a ‘business as usual’ model:** Where sites have competing priorities or heavy time demands, their contact with Macmillan can lessen. It has been important for Macmillan to maintain close contact in these instances to ensure momentum behind the eHNA is not lost. There is a risk in moving to the ‘business as usual’ model, and potentially a change in the software provider, that delivery of the eHNA is disrupted. This disruption needs to be kept to a minimum, and contact with sites maintained over any transition period, so the administration of the project remains unaffected.

- **Share case studies:** Prototyping sites have implemented the eHNA project in a myriad of ways to best suit their current clinical practices and the needs of individuals affected by cancer. Arrangements have been more (and less) successful. Sites are still looking to Macmillan as the main conduit to help them learn of how
their peers are implementing the project and overcoming the barriers they themselves face.

Macmillan also has a critical role in sharing case study examples of how the eHNA has benefitted prototyping sites to provide inspiration and help maintain momentum in sites where the implementation process is proving more challenging. Similarly, providing examples of how sites are harnessing the power of their aggregate data should provide some inspiration for how sites might use theirs.

- **Share key evaluation findings with sites:** The evaluation findings should help alleviate some of the concerns held by healthcare professionals about the eHNA and what it means for them and the individuals they care for. For example, the evaluation shows the vast majority of individuals find the electronic assessment easy to complete; individuals commonly complete the electronic assessment in waiting rooms negating the need for private consultation rooms; and the vast majority of healthcare professionals say that ‘more often than not’ they are able to help individuals with the concerns they raise during the assessment and care planning process.

- **Train healthcare professionals on how to best communicate the purpose and value of electronic assessments and care plans:** The explanations given to individuals affected by cancer as to why they should complete the electronic assessment are variable and, at times, inadequate. The evaluation suggests that individuals affected by cancer are more likely to take notice of an explanation of the eHNA provided by a healthcare professional than they are a leaflet with an explanation.

Macmillan therefore has a role in training healthcare professionals in the best practice for communicating the purpose and value of the electronic assessment, recognising that the assessment is sometimes introduced by volunteers. Providing guidance on this issue will also help to standardise how the electronic assessment is broached.

Further training for healthcare professionals is also warranted on how best to communicate the purpose and value of care plans to individuals who have completed an electronic assessment. The purpose of such training would be to better enable healthcare professionals to elucidate the value of care plans so that individuals take greater consideration of them.

- **Provide healthcare professionals with guidance on eligibility:** There are varying definitions held by healthcare professionals of
who is considered eligible for an electronic assessment (or indeed a paper alternative). Macmillan should look to develop more definite guidelines around eligibility criteria. In addition, Macmillan may be able to help increase the volume of individuals offered an electronic assessment (even if they choose to decline it) by advising healthcare professionals on how best to handle more challenging scenarios such as when individuals are receiving palliative care or are showing signs of distress, or when there are physical, mental or language barriers to completion.

- **Strengthen the value of the aggregate data**: The aggregate data is one of the central distinguishing features of electronic assessments and care plans compared to paper alternatives. It is also the means through which care for individuals living with and beyond cancer can be transformed by shaping the planning and commissioning of local services. Macmillan needs to work with sites to encourage their use of the aggregate data – as aforementioned, part of this will be through providing examples of where the data has been successfully utilised by their peers.

Macmillan also needs to consider how the aggregate data can be harnessed at a regional and national level for the purposes of influencing commissioning and service delivery. When looking at the data in this way, Macmillan needs to be confident that the aggregate data is representative of the concerns held by individuals living with and beyond cancer across England or within specific regions. There is a role for Macmillan to work with sites currently (and soon to be) live to expand the tumour sites in which electronic assessments and care plans are created. This will better reflect the profile of cancer diagnoses more widely across the country and could therefore help in making the age and gender profile of those who have completed an electronic assessment more reflective of the wider population with a cancer diagnosis.

Similarly, Macmillan has a role in influencing sites to administer electronic assessments and care plans across the pathway. This will help ensure the concerns captured through the aggregate data reflect the variable nature of issues which arise as individuals progress through their pathway.

Finally, in relation to the aggregate data, Macmillan may want to consider how best to control for individuals completing multiple electronic assessments. At present the aggregate data is assessment-level rather than person-level. This could lead to the scenario where the potential demand for particular support services is over-represented.
• **Consider the value of care plans:** The evaluation has shown that whilst there are some individuals affected by cancer who make use of their care plan, the document has made little difference to how many of them have felt, with there being low salience of the document. The primary benefits of the eHNA for individuals affected by cancer appear to be secured through the discussion they have with their healthcare professional as part of the process. This raises a question as to whether care plans are vital to the process. That said, the care plan does appear to have greater value to healthcare professionals as a means to evidence that the assessment has taken place and as a reminder of individuals’ needs and the support/advice provided to them.

There may be value for Macmillan in examining further which individuals affected by cancer stand to gain more (and less) from the care plan, for example, by assessing this in relation to Patient Activation Measures. However, the evaluation findings are fairly conclusive with regards to the view of individuals living with and beyond cancer and Macmillan may stand to gain more by investigating the issue further with healthcare professionals and considering it in light of wider policy initiatives which may warrant the continued use of care plans.

Going forward it is recognised that the care plan is now referred to as the care and support plan to better reflect its purpose.

• **Investigate further:** Macmillan may wish to investigate the profile of individuals who choose to decline the electronic assessment to see how much of a limiting factor this might be on getting aggregate data that is representative of the wider population of individuals living with and beyond cancer.

Additionally Macmillan may wish to map the usage of Macmillan services in local areas against what is known about electronic assessment and care plan completion in that area. This will help Macmillan better understand what uptake the eHNA project is having on engagement with its services.

### 11.2.2 Recommendations for beyond the prototyping phase

As Macmillan moves beyond the end of the prototyping phase, there are a number of recommendations to consider:

• **Re-evaluate the timeframes for the intended impacts of the eHNA:** The potential scale of the eHNA was not known to Macmillan at the start of the pilot and subsequent prototyping phase. Nor was it known how the wider context would develop and, for example, how the aggregate data generated by the eHNA would become
such a crucial benefit and driving force behind it. Macmillan’s logic model was created without this knowledge and thus, retrospectively, the intended impacts within it were ambitious beyond the timeframes associated with the prototyping phase. At the site level, it takes time for the eHNA project to be embedded. Indeed, even if particular tumour groups normalise electronic assessments and care plans, there are typically other tumour groups within the same site that are yet to begin. It is a slow process for electronic assessments and care plans to become routine practice and thus other benefits (such as increased staff productivity) are not realised in the immediacy. Macmillan should therefore re-assess the timeframes originally devised for realisation of the intended impacts of the eHNA.

- **Provide continued support for wider enablers of the eHNA:** A number of changes in wider policy and NHS working practices are taking place which will benefit the eHNA. Some of the IT barriers facing the eHNA are slowly being overcome naturally as NHS trusts are increasingly installing WiFi and using tablets for purposes beyond the eHNA. Furthermore, delivery of the eHNA will be enabled by a wider cultural shift towards the self-management and personalisation agenda. This cultural shift is likely to happen very slowly, and much of this movement is outside the control of Macmillan, but a future scenario could see individuals affected by cancer placing pressure on those who care for them to address their holistic needs in a formalised way. Similarly, there are some healthcare professionals who are reticent to endorse the self-management agenda. This may evolve as a long-term cultural shift occurs in how individuals affected by cancer are best supported. Macmillan – as a wider organisation outside of the eHNA project team – has a role to play in supporting the development of these agendas.

- **Enrol sites in geographical clusters:** Once the prototyping phase is complete, Macmillan should give consideration to the geographical location of new sites to be enrolled. Sites would ideally enrol in geographical clusters (across different parts of the care pathway, both in and outside the acute setting). This will facilitate the exchange of ideas and experiences locally between sites, and will result in a larger pool of aggregate data in certain localities which will give greater meaning to its analysis for sites in that area.

- **Explore the possibility of more localised administration and support:** One possible scenario for consideration in deciding the future ‘business as usual’ model for the eHNA is for more localised support to be provided to geographically clustered sites. This could represent a more sustainable arrangement for Macmillan as
opposed to having a centralised team with growing responsibilities. Having local oversight will facilitate the process of sharing between neighbouring sites; ensure local knowledge (such as that of commissioning arrangements) is better harnessed; and help Macmillan to maintain momentum behind the eHNA. That said, the management of the eHNA should not become so localised that it is fractured and a collective understanding of the eHNA is lost. Macmillan should therefore consider how it can best provide administration and support at a local level, potentially making use of its regional structure.

- **Advise sites to secure protected time:** Sites are more likely to successfully implement the eHNA project if they have a project lead with dedicated time to embed it, or if they have dedicated personnel to work solely or predominantly on it. Ideally sites should be advised that dedicated time should be carved out of lead individuals’ roles. Doing this will increase the chances of a successful roll-out but will also necessitate the involvement of senior staff (known to be another positive contributor to successful implementation).

  Should Macmillan have the purchase to do so, it would be wise to recommend that newly recruited CNSs have electronic assessment and care planning written into their job roles. This is part of ‘normalising’ the eHNA and making it part of sites’ business as usual.

- **Establish more formal commissioning arrangements:** The coming year will prove key for Macmillan to embed the Recovery Package into mainstream NHS commissioning. Linked to this is the potential benefit of establishing tariffs for the completion of assessments and care plans as seen in one particular case study. In this example the tariff paid by commissioners has contributed to securing more administrative support, freeing up nurses so they can allocate more of their time towards assessments and care planning.

- **Consider how best to align the Recovery Package:** Macmillan needs to give consideration of how to align the Recovery Package into broader CCG programmes. Linking more closely to other long-term conditions may create a tension for Macmillan though there is a role for Macmillan to be the vanguard for assessing holistic needs as part of the self-management and personalisation agenda, leading the way based on the vast experience it has amassed.
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