A 2018 survey of Dietitians, Occupational Therapists, Physiotherapists and Speech & Language Therapists.
We are grateful that this work has been informed and supported by:
## Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Foreword</td>
</tr>
<tr>
<td>8</td>
<td>Executive Summary</td>
</tr>
<tr>
<td>12</td>
<td>Introduction</td>
</tr>
<tr>
<td>14</td>
<td>Background</td>
</tr>
<tr>
<td>16</td>
<td>Methodology</td>
</tr>
<tr>
<td>18</td>
<td>Main findings</td>
</tr>
<tr>
<td>52</td>
<td>Conclusions and recommendations</td>
</tr>
<tr>
<td>54</td>
<td>Appendix A</td>
</tr>
<tr>
<td></td>
<td>Survey questions</td>
</tr>
<tr>
<td>56</td>
<td>Appendix B</td>
</tr>
<tr>
<td></td>
<td>Sampling and response rates</td>
</tr>
<tr>
<td>58</td>
<td>Appendix C</td>
</tr>
<tr>
<td></td>
<td>Health and Care Professions Council registrants by UK country</td>
</tr>
<tr>
<td>59</td>
<td>Acknowledgements</td>
</tr>
<tr>
<td>60</td>
<td>References</td>
</tr>
</tbody>
</table>
I am delighted to provide you with the findings from the first UK wide survey of Allied Health professionals (AHPs). This survey data, covering dietitians, occupational therapists, physiotherapists and speech and language therapists, provides a unique insight into the roles and contribution of AHPs in supporting people living with cancer.

AHPs bring many benefits to patient care throughout and beyond the patient cancer journey. They help to optimise the experience for people living with cancer including:

- Signposting and making referrals to other healthcare professionals. This is crucial in supporting and guiding people living with cancer to be able to access the most appropriate support and expertise to meet their needs at different times and help navigate people through their journey.

- Supporting people with commonly presenting side effects and rehabilitation needs.

- Delivering treatment plans.

- Supporting families and carers.

- Delivering specialist interventions for patients with advanced diseases, complex palliative and end of life care.

- Advising on self-management.

- Delivering interventions to support emotional, practical and financial needs and those with functional and cognitive impairment.

This report demonstrates the importance of these professions in supporting people living with cancer and the breadth of the contributions they make to increasing quality of life and independence. Alongside this we provide case studies of work already underway, which demonstrate the role and value of AHP interventions in the care of people living with cancer.

The survey indicated that AHPs are focussing on supporting people during treatment, those with advanced cancer and at end of life. Interventions provided by AHPs have a considerable impact across the whole patient journey from diagnosis, through active treatment, living with and beyond cancer, through to palliative and end of life care. Only between 3–14% of respondents indicated involvement with people living with cancer in advance of treatment. Evidence shows that early intervention by way of prehabilitation is important in improving outcomes for patients with AHPs having a substantial role to play at this time as part of the wider multiprofessional team. This could represent missed opportunities to support people living with cancer, improve quality of life and potentially ease pressure on the overworked system elsewhere.
The population of people living with cancer is set to increase from 2.5 million in 2015 to 4 million by 2030. This rise is largely as a result of people living longer after treatment for cancer, some of whom will have multiple clinical conditions. The care for these people is inevitably more complex and rehabilitation becomes increasingly important to people living with cancer.

Our survey results are encouraging in that they highlight the important contribution of the AHP workforce in supporting people living with cancer across many different tumour types, with many different symptoms and interventions to deliver positive outcomes.

AHPs reported seeing patients across many different sectors and settings. These include:

- hospital,
- community clinics,
- GP surgeries,
- care homes and
- patients own homes.

AHPs show capability\textsuperscript{1,2} working across organisations to support patients and have an important role in supporting people living with cancer to navigate the system.

AHPs identified supporting people with a wide range of symptoms and consequences of treatment. These include:

- breathlessness,
- pain,
- fatigue,
- mobility,
- nutrition,
- swallowing problems (dysphagia) and
- communication.

AHPs have the capability, skills and knowledge to address identified unmet needs reported by people living with cancer including fatigue, pain and support with activities of daily living.

It is very encouraging that between 75% and 91% of respondents who had a sizeable cancer workload had had learning and development in cancer care in the past 5 years. However only between 28% and 37% of respondents who did not report a sizeable cancer workload reported receiving learning and development in cancer care in the past 5 years. It may be that although this group do not report a sizeable cancer caseload they may see people living with cancer at certain times in their roles. It is important that AHPs have a level of awareness and knowledge of how to support people living with cancer. This learning and development contributes to helping ensure that AHPs deliver high quality care for patients to achieve the best outcomes based on individual need.

The AHP workforce survey cannot definitively tell us whether we have sufficient AHPs to support people living with cancer. The majority (between 63% and 75% of respondents) felt more AHPs were needed to support people living with cancer with only between 14% and 22% reporting they felt there were the right number of AHPs.

This report clearly illustrates the substantial contribution of AHPs in cancer care, at a time when there are extensive workforce challenges across the healthcare workforce. Macmillan Cancer Support has identified AHPs as a prioritised group with which to engage.

This report will be of interest to commissioners, service providers and those involved in workforce planning to ensure the contribution of AHPs is well understood and considered when transforming and developing services for people living with cancer.
Allied Health Professionals (AHPs) provide a significant breadth of support for patients, from diagnosis throughout and beyond cancer treatment and in palliative and end of life care.

**AHPs...**
- ...make referrals and signpost to other services
- ...support those with commonly presenting side effects & rehabilitation needs
- ...deliver specialist interventions and treatment plans
- ...advise on self-management

**The cancer journey**
- Patient diagnosed with cancer but not yet started treatment.
- Patient currently undergoing cancer treatment.
- Patient currently undergoing cancer treatment.
- Treatment complete and patient is living with long term effects of cancer treatment.
- Patient is at end of life because of their cancer and has less than a year to live.

**Only 3–14% of AHP patients are seen pre-treatment.** There is opportunity to encourage early intervention through prehabilitation to improve patient outcomes.
Main cancer types seen by AHPs

- Breast
- Upper Gastrointestinal
- Lung
- Colorectal
- Head and Neck

What patient needs do AHPs commonly address?

Important unmet needs addressed by all AHPs include:
1. Feeling exhausted/fatigued
2. Pain/discomfort
3. Practical tasks at home
4. Appearance

Needs commonly addressed by each profession include:

- **Speech and Language Therapist**
  - "I have problems with dysphagia"

- **Dietitian**
  - "I have concerns related to nutritional status/dietary advice/malnourishment"

- **Occupational Therapist**
  - "I have concerns related to mobility and loss of function"

- **Physiotherapist**
  - "I have concerns related to mobility and loss of function"
Executive Summary

What did we do?

Macmillan commissioned this Allied Health Professional (AHP) workforce survey to better understand the roles of AHPs in supporting people living with cancer.

This is the first UK wide AHP workforce survey focussed on AHPs work with people living with cancer. There were 1774 respondents to the survey.

The survey focussed on four allied health professions. These were dietitians, occupational therapists, physiotherapists and speech and language therapists. Macmillan chose to focus on these four professions as they were felt to be the main AHP groups supporting people living with cancer.

The report findings can be used alongside other evidence to help improve workforce planning. The report includes information on:

• Age, location and pay grades of respondents
• Types of organisations where AHPs are employed
• Setting in which AHPs see patients
• How AHPs support people living with cancer and the types of interventions provided
• Learning and development of the allied health professions included in the survey
• Perceptions of workload

What did we find?

The contribution of AHPs in supporting people living with cancer

Allied Health Professionals (AHPs):

• provide a breadth of support for patients throughout and beyond treatment and in palliative and end of life care.
• have extensive skills, knowledge and expertise to provide interventions to patients following holistic needs assessments (HNA).
• are key members of the multidisciplinary cancer team and form a vital part of a skill mix approach to workforce planning.
• are able to be flexible with the interventions offered to deliver successful outcomes and support many of the strategic aims to transform cancer care and to improve quality of life.
• are key to supporting people living with cancer across different tumour sites to improve their independence and quality of life.
• address unmet needs such as; fatigue and energy management, pain, mobility, nutrition, communication and swallowing difficulties, and everyday life activities.

Respondents reporting having a sizeable cancer workload

545 respondents out of 1774 reported having a sizeable cancer workload.5
Stages that AHPs see people living with cancer
Between 3% and 14% of AHP respondents’ current cancer workload are those patients that have been diagnosed with cancer but not yet started treatment. There are many opportunities for AHPs to be more engaged and support patients at this time with prehabilitation to improve outcomes during and after treatment as highlighted in the recent Macmillan prehabilitation evidence and insight report.6

For the majority of the four professions surveyed (dietitians, physiotherapists and speech and language therapists) patients were seen predominantly when they were undergoing treatment. Speech and language therapists reported the largest percentage of patients seen once initial treatment was complete (patient is living with long term effects of cancer treatment). Occupational therapists reported that the majority of their patients had advanced cancer and/or were at end of life with less than a year to live.

The recently updated cancer rehabilitation pathways7 describe the contribution and importance of the interventions that AHPs can provide from diagnosis through to end of life care.

Interventions provided by AHPs can have a significant impact across the whole patient journey from diagnosis, through active treatment, living with and beyond cancer, through to palliative and end of life care.

Most common cancer types seen by AHPs
Across the four AHPs a range of tumour types were reported as being seen including brain and central nervous system, breast, colorectal, lung, head and neck and upper gastrointestinal cancer.

Where AHPs are employed
The majority were employed by NHS provider organisations. 4% of dietitians, 5% of speech and language therapists, 13% of physiotherapists and 21% of occupational therapists reported working for other employers including local authorities, hospices, voluntary sector, charity, University, GP practices and private companies.

Settings in which AHPs work
The largest proportion of patients are seen by AHPs in hospital settings. Patients were also seen in their own homes, care homes, hospices, GP surgeries or as part of a private practice.

Learning and development
Between 75% and 91% of respondents who had a sizeable cancer workload8 had had formal training in cancer in the past 5 years. 1229 respondents out of the total 1774 respondents did not report a significant cancer workload. Out of those without a significant cancer workload 28% of dietitians, 31% of occupational therapists, 34% of physiotherapist and 37% of speech and language therapists reported having formal training in cancer in the past 5 years.
What does this mean for the future?

The recommendations from this work are set out below which should be considered as part of the future planning of services for people living with cancer.

1. AHPs should be integral to the development and transformation of services for people living with cancer.

   The findings from the survey read alongside the cancer rehabilitation pathways\(^9\) provide important information to aide decision making when transforming cancer services. AHPs are involved in a wide range of interventions to support people living with cancer. These should be considered when transforming cancer care to ensure AHP input is included at all stages of the development, design and delivery of services.

2. Early intervention has been shown to have a substantial impact on people living with cancer to help achieve the best outcome for patients including improving quality of life, proactive management of symptoms and the consequences of treatment.\(^10\) AHPs have an important role in early intervention and should be encouraged to lead service transformation in cancer care to support early intervention with people living with cancer in advance of treatment whether surgery and/or chemotherapy and/or radiotherapy.

3. AHPs can provide a wide range of interventions identified as part of Holistic Needs Assessment which can have positive outcomes for patients. AHPs should be included as key members of the cancer multidisciplinary teams, they have a key role in managing complex needs and form a vital part of a skill mix approach to workforce planning.

4. Macmillan has identified AHPs as a prioritised group with which to engage as part of its workforce engagement model. AHPs should continue to have access to formal training to support their professional development in order to provide high quality care for people living with cancer which can be informed by the Macmillan AHP competence framework.
Introduction

Macmillan commissioned this Allied Health Professional (AHP) workforce survey to better understand the role of AHPs in people living with cancer.

This is the first UK wide AHP workforce survey focussed on AHPs working with people living with cancer.

Macmillan chose to focus on dietitians, occupational therapists, physiotherapists and speech and language therapists as they were felt to be the principal AHP groups supporting people living with cancer. It is fully recognised that there are other allied health professions that have roles in supporting people living with cancer including art, music and drama therapists, paramedics, podiatrists, prosthetists and orthotists and radiographers (diagnostic and therapeutic) however these were out of the scope of this work.

The last workforce modelling of the AHP workforce working in cancer care was undertaken in 2012 by the National Cancer Action Team (NCAT) and Mouchel Management Consulting Limited. This was limited to the then cancer networks across England. There has been no information collected about the AHP workforce working with people living with cancer at a national level since this time. This AHP workforce survey provides us with contemporary data about the AHP workforce supporting people living with cancer.

The AHP survey asked for information about:

- staff members’ age, gender, employer
- sector and setting in which they work
- role, banding, job title and description of their role
- the proportion of time they spend with people living with cancer at what stages in the pathway
- the tumour types with which they come into contact
- concerns and symptoms addressed, and interventions undertaken with people living with cancer.

It is anticipated that this report will help emphasise the importance of AHPs in supporting people living with cancer and support national, regional and local decision making about workforce, and ensure that AHPs are considered when reviewing and planning services for people living with cancer.
The role and contribution of each profession in people living with cancer can be summarised as below.

- Dietitians specialise in the nutritional assessment of people living with cancer, which together with other clinical information is used to provide dietary treatment. Malnutrition is the single most common secondary diagnosis in patients with cancer. Dietitians advise on achieving optimal nutritional status, improve nutrition throughout the cancer patient’s journey and minimise discomfort through appropriate nutritional support.

- Occupational therapists assist the patient and carers to maintain their maximum level of function and independence. They are involved with the care of patients who have problems with functional ability, fatigue, stress or physical discomfort as a result of cancer and symptom management as well as having a pivotal role in vocational rehabilitation.

- Physiotherapists help maximise the patient’s potential in terms of functional ability and independence as well as gain relief from distressing symptoms such as breathlessness and incontinence. The physiotherapist will provide a range of therapies for physical disability and pain.

- Speech and language therapists specialise in the diagnosis and treatment of patients who have speech, language and or swallowing problems as a result of cancer. They are also involved in the teaching of alternative methods of communication and symptom management and support those with altered body image.

Macmillan would welcome the opportunity to work with partners to address specific challenges, with the aim of ensuring everyone living with cancer has the best possible outcomes and experience of care through access to AHPs.
Background

It was acknowledged in Macmillan’s recent Thinking Differently report14 that AHPs play a critical role in supporting people affected by cancer and very often provide specialised support. The AHP workforce are important to consider in developing the workforce to support people living with cancer as part of a skill mix approach.

A cultural shift in the UK in how people with cancer are supported and empowered is required to enable person-centred care.

A great deal of work has been undertaken to understand the workforce and how personalised, tailored support and care planning can be delivered to reflect what people want in their care journey and what knowledge and skills are required. AHPs play a fundamental role in the provision of active and enabling care whether in hospital, primary care, community, hospice or in people’s homes and there is an increasing need to help people take real control of their condition.

Depending on need people living with cancer should have access to AHPs. People who have a cancer diagnosis, their carers and families need support and guidance to help them through what can be a traumatic period of their lives. AHPs are well placed to support people living with cancer to maintain independence.

A modern healthcare system needs to support people to live their lives, fulfil their maximum potential and optimise their contribution to family life, their community and society as a whole. Rehabilitation can help to achieve this by focusing on the impact that the health condition, development difficulty or disability has on a person’s life, rather than simply focussing on their diagnosis. It involves working in partnership with the person and those important to them so that they can maximise their independence and have choice and control over their lives and links very much to personalisation of a person’s care.15

A strong body of evidence already exists which demonstrates the value of rehabilitation for people living with cancer. Evidence has been reviewed which illustrates the important role that AHPs play in leading and supporting good quality rehabilitation and meeting the needs of people living with cancer.16,17,18,19,20

It is increasingly acknowledged that effective rehabilitation delivers better outcomes and improved quality of life. It has the potential to reduce health inequalities and make significant costs savings across the health and care system.21

Rehabilitation is a central element of cancer care. It enables patients to make the most of their lives by maximising the outcomes of their treatment and minimising the symptoms and consequences of treatment such as fatigue, pain, breathlessness and lymphoedema. The need for rehabilitation starts from the point of diagnosis by helping patients prepare for treatment, known as prehabilitation. It can help patients get well and stay well and addresses the practical problems caused by disease and treatment, helps patients become as independent as possible and minimise the impact on carers, family and support services.
It is suggested this report is used by commissioners, service providers and those planning the workforce alongside the following which provide further background as to the roles and contributions of AHPs in cancer care:


Methodology

When was the fieldwork?
The survey (Appendix A) was developed in collaboration with Quality Health and administered by Research Now. The online survey was live between 30th November 2017 and 15th January 2018.

How was the survey disseminated?
Macmillan worked with the professional body for each profession to disseminate the survey to their members. Each professional body helped to disseminate the survey in different ways:

• British Dietetic Association: Email with non-response followed up.
• Royal College of Occupational Therapists: Single email & social media.
• Chartered Society of Physiotherapy: Message board & social media
• Royal College of Speech and Language Therapists: Single email & social media.

Who took part?
All AHPs who were members of their respective professional body were invited to take part in the survey individually.

The total number of 1774 responses were received split by the different professions as follows:

• Dietitians: 646 (Response rate 9%)
• Occupational Therapists: 480 (Response rate 2%)
• Physiotherapists: 401 (Response rate 1%)
• Speech and Language Therapists: 247 (Response rate 2%)

For more information on dissemination and response rates for each professional body, please see the Appendix.

How should the results be interpreted?
The survey results should be treated as indicative rather than representative of the population as a whole for the following reasons:

• The sample sizes achieved for each AHP profession are not large enough to enable survey results to be generalised to the overall population for that profession as the margin of error would be too great.
• Respondents to the survey were self-selecting: all who met the inclusion criteria were invited to take part and there were no quotas applied. AHPs with a sizeable cancer workload may have been more likely to see the survey as relevant, due to the survey being co-branded with both the logo of the relevant professional body and that of Macmillan. As there is currently no reliable data on the characteristics of AHPs who work with cancer it was not possible to explore this potential response bias further or to correct for it.

Results are reported at the aggregate level for the UK only as the base size for the individual countries within each profession are too low to report. For example, in Scotland, only 32 Speech and Language Therapists took part in the survey, while for Northern Ireland there were less than 50 respondents across all four AHP professions.
# Main findings

<table>
<thead>
<tr>
<th>Theme</th>
<th>Headline findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>The average age of respondents was 42 years old.</td>
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<tr>
<td><strong>Length of time working as an AHP</strong></td>
<td>The majority of respondents reported working 10 years or more with around one in 10 looking to retire in the next 5 years.</td>
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<tr>
<td><strong>Country where respondents undertake the majority of their work</strong></td>
<td>The majority of respondents undertake their work in England.</td>
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<tr>
<td><strong>Working hours</strong></td>
<td>Between 7% and 13% of respondents reported working 20% more than their contracted hours.</td>
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<tr>
<td><strong>Respondents reporting having a sizeable cancer workload</strong></td>
<td>545 respondents out of 1774 reported having a sizeable cancer workload. These respondents were then asked further questions about their role with people living with cancer.</td>
</tr>
<tr>
<td><strong>Where AHPs are employed</strong></td>
<td>The majority were employed by NHS provider organisations. Only 4% of dietitians, 5% of speech and language therapists, 13% of physiotherapists and 21% of occupational therapists reported working for other employers including local authorities, hospices, voluntary sector, charity, University, GP practices and private companies.</td>
</tr>
<tr>
<td><strong>Settings in which AHPs work</strong></td>
<td>The largest proportion of patients are seen by AHPs in hospital settings. Patients were also seen in patients’ own homes, care homes, hospices, GP surgeries or as part of a private practice.</td>
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<tr>
<td><strong>Payment of services provided by AHPs</strong></td>
<td>The majority of services provided were reported as funded by the NHS with a smaller proportion by others, in particular local authorities commissioning services provided by occupational therapists.</td>
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<tr>
<td><strong>Average time AHPs spend with patients</strong></td>
<td>The average time spent by AHPs with a patient with cancer each time they were seen was between 35 and 46 minutes.</td>
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<td><strong>Most common cancer types seen by AHPs</strong></td>
<td>Across the four AHPs a range of tumour types were reported as being seen including brain and central nervous system, breast, colorectal, lung, head and neck and upper gastrointestinal cancer.</td>
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<tr>
<td>Theme</td>
<td>Headline findings</td>
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<tr>
<td>Stages that AHPs see people living with cancer</td>
<td>The majority of the professions (dietitians, physiotherapists and speech and language therapists) saw their patients as they were undergoing treatment. Speech and language therapists reported the largest percentage of patients seen once initial treatment is complete (patient is living with long terms effects of cancer treatment). Occupational therapists reported that the majority of their patients seen had advanced cancer and/or were at end of life with less than a year to live.</td>
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<td>Patients seen by AHPs with metastatic disease</td>
<td>Occupational therapists reported seeing the most patients with metastatic disease. 76% of occupational therapists reported that over half of the cancer patients seen have metastatic disease. The corresponding figures for the other AHP professions are: physiotherapists 63%, dietitians 31% and speech and language therapists 7%.</td>
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<tr>
<td>Problems which AHPs often/always address with patients</td>
<td>AHPs support people living with cancer with a wide range of concerns and symptoms as a result of cancer and treatments received.</td>
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<tr>
<td>Capacity in the AHP workforce</td>
<td>Between 63% and 75% of respondents felt more AHPs were needed to support people living with cancer with between 14% and 22% reporting they felt there were the right number of AHPs.</td>
</tr>
<tr>
<td>Learning and development</td>
<td>Between 75% and 91% of respondents who had a sizeable cancer workload had had formal training in cancer in the past 5 years. This included study days, modules and short courses.</td>
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<td></td>
<td>1229 respondents out of the total 1774 respondents did not report a sizeable cancer workload. Out of those without a sizeable cancer workload only 28% of dietitians, 31% of occupational therapists, 34% of physiotherapist and 37% of speech and language therapists reported having formal training in cancer in the past 5 years.</td>
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Response rates

There were a total of 1774 responses to the online survey from across the four allied health professions.

The responses by profession were:
- Dietitians – 646
- Occupational therapists – 480
- Physiotherapists – 401
- Speech and language therapists – 247

Due to the small number of allied health support workers who responded to the survey their results are not incorporated into this report.

Health and Care Professions Council (HCPC) total registrants for each profession as at April 2018 is provided in Figure 2.

Figure 2 — UK wide HCPC\textsuperscript{25} registrants by profession as at 5th April 2018
Characteristics of the survey respondents

Demographics

Age
The average age of survey respondents was low to mid-forties for each of the professions.

The average age of respondents for each of the professions is shown in Figure 3.

The AHP workforce respondents are slightly younger than the clinical nurse specialist (CNS) workforce. Only 4% of CNSs were under 30 years old compared to AHP respondents where 18% dietitians, 10% occupational therapists, 16% physiotherapists and 14% of speech and language therapists were under 30 years old. The age profile of respondents is broadly in line with the age profile of registrants for each profession with the Health and Care professions Council.

Figure 3 — Average age of respondents by profession
Length of time AHPs have been working
AHPs were asked how long they had been working as registered practitioners. The majority of respondents reported working for 10 years or more (Figure 4).

Only around one in 10 respondents reported that they were looking to retire in the next 5 years (Figure 5).

Figure 4 — Percentage of AHPs who have been working 10 years or more

Figure 5 — Percentage of AHPs looking to retire in the next 5 years
Role details

Country where respondents undertake the majority of their work
Respondents were asked in which UK country they undertake most of their work. Figure 6 provides the breakdown by country and profession.

The largest proportion of respondents undertake their work in England. The least responses were from AHPs working in Northern Ireland which correlates with the number of registrants for each profession in each country (Appendix C) and is perhaps representative of the staffing and size of the different countries, survey reach and the lower number of each profession in these countries.
The number of different roles held by AHPs

Respondents were asked how many jobs they undertook across a week.

The majority of AHPs (85–91% respondents) had just one role with only a few having additional roles which could include freelance and private practice work and/or specific sessions in other clinical settings.

The respondents were asked to answer the survey questions based on their dominant role i.e. the one they spend the majority of their time undertaking. The report findings reflect this.

Working hours

Respondents were asked how many hours they worked in each of the jobs they do. They were also asked about how many hours they worked over their contracted hours. Between 7% and 13% of respondents reported working 20% more than their contracted hours. This is set out by profession in Figure 7.

Figure 7 — Percentage of AHPs who reported working more than 20% of their contracted hours
AHP roles with Macmillan in the job title
Respondents were asked whether they had Macmillan in their job titles. The percentages are shown in Figure 8 by profession. At least one in 10 of the overall respondents had Macmillan in their job title.

This seems quite high based on the number of total responses to the survey. It may have been that those self-selecting to complete the survey were encouraged/motivated to do so due to the Macmillan branding.

Figure 8 — Percentage of each allied health profession with Macmillan in their job title
How AHPs support people living with cancer

Percentage of overall time spent with people living with cancer

Respondents were asked how much time they spend supporting people living with cancer. Figure 9 illustrates the percentage of AHPs who spend over 20% and over 50% of their time supporting people living with cancer. More than a fifth of the total respondents spent over half their time with people living with cancer.

Dietitians who responded reported spending the largest proportion of their time supporting people living with cancer with almost half of the respondents spending 20% or more of their time with people living with cancer. Physiotherapists who responded reported spending the least amount of their time supporting people living with cancer (Figure 9).

Figure 9 — Percentage of AHPs who spend over 20% and over 50% of their time supporting people with cancer
# Average number of cancer patients seen per week

For the questions specifically on cancer we only asked those respondents who had a sizeable cancer workload. This was defined by Macmillan as seeing 9 or more cancer patients on average per week for dietitians, physiotherapists and speech & language therapists. For occupational therapists who reported seeing less patients overall, a sizeable cancer workload was defined as seeing 4 or more people living with cancer on average per week.

Figure 10 shows the average numbers of people living with cancer seen by each profession as part of their overall patient caseload. It also shows the percentage of total respondents by profession who have a sizeable cancer workload based on the above definition.

<table>
<thead>
<tr>
<th>Profession</th>
<th>Average number of cancer patients seen each week on average</th>
<th>Percentage with sizeable cancer workloads of more than 9 cancer patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietitian</td>
<td>10</td>
<td>37%</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>4</td>
<td>29%</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>7</td>
<td>25%</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>8</td>
<td>28%</td>
</tr>
</tbody>
</table>

Figure 10 — The average number of people living with cancer seen each week by profession
Employing organisations, pay grades and settings where AHPs see people living with cancer

Organisations where AHPs are employed

Respondents were asked who their employer was (Figure 11).

The majority of AHPs reported being employed by NHS provider organisations. 4% of dietitians, 5% of speech and language therapists, 13% of physiotherapists and 21% of occupational therapists reported working for other employers including local authorities, hospices, voluntary sector, charity, University, GP practices and private companies.

Figure 11 — Employers of AHPs

Dietitian

Occupational Therapist

Physiotherapist

Speech and Language Therapist
Agenda for Change pay band or equivalent
Overall Band 6 and Band 7 were the most reported grades of the survey respondents. Band 8 was least reported except for speech and language therapists where 18% respondents were Band 8a and 6% were Band 8b (Figure 12).

Figure 12 — Agenda for Change pay band of the respondents
Settings in which patients are seen by AHPs

Respondents were asked in which settings they see patients in their role (Figure 13). It should be noted that respondents reported seeing patients in multiple locations hence the percentages in Figure 13 do not add up to 100%. A large proportion are seen in hospital settings whether as an inpatient on a ward, in an outpatient clinic or in a day unit. Patients were reported as being seen in a range of community settings including the patient’s own home, care home, hospice and GP surgeries however these percentages overall were far lower than those in the hospital setting. This may reflect the current models of service delivery, where staff are currently based and how services provided by AHPs are commissioned.

<table>
<thead>
<tr>
<th></th>
<th>Dietitian</th>
<th>Occupational Therapist</th>
<th>Physiotherapist</th>
<th>Speech and Language Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital – Total</td>
<td>77%</td>
<td>50%</td>
<td>67%</td>
<td>80%</td>
</tr>
<tr>
<td>Hospital – inpatient</td>
<td>63%</td>
<td>43%</td>
<td>36%</td>
<td>71%</td>
</tr>
<tr>
<td>Hospital – outpatients</td>
<td>61%</td>
<td>14%</td>
<td>47%</td>
<td>58%</td>
</tr>
<tr>
<td>Hospital – Day Care/Day Unit</td>
<td>26%</td>
<td>7%</td>
<td>7%</td>
<td>19%</td>
</tr>
<tr>
<td>Patient’s home</td>
<td>33%</td>
<td>57%</td>
<td>27%</td>
<td>52%</td>
</tr>
<tr>
<td>Care home/nursing home</td>
<td>26%</td>
<td>20%</td>
<td>15%</td>
<td>46%</td>
</tr>
<tr>
<td>Community based clinic or service</td>
<td>28%</td>
<td>26%</td>
<td>21%</td>
<td>26%</td>
</tr>
<tr>
<td>Hospice</td>
<td>10%</td>
<td>12%</td>
<td>10%</td>
<td>26%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
<td>6%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>GP surgery</td>
<td>12%</td>
<td>2%</td>
<td>4%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Figure 13 — Settings in which patients are seen by AHPs
Payment of services provided by AHPs

Respondents were asked how their services were funded.

The majority were funded by the NHS. Local authority commissioned services were most commonly reported for services provided by occupational therapists (Figure 14). It should be noted that some services provided by AHPs will be commissioned by more than one organisation and respondents may have reflected this in their responses.

The ‘other’ category includes Non-NHS services commissioned by the NHS (for example an independent provider treating NHS patients), voluntary sector and patients paying directly for services through health insurance.

Figure 14 — Payments of services provided by AHPs
Findings from respondents who reported a sizeable cancer workload

All findings reported in this section of the report are based on the smaller base size (545).

Average time spent with each patient with cancer
Respondents were asked about the average time they spent with each person they saw with cancer. This ranged from 35 minutes to 46 minutes per consultation (Figure 15).

This is expected based on AHPs assessing, treating, educating and goal planning when they see patients within each face to face contact. These times spent are similar to those for non-cancer patients seen by AHPs.26

Figure 15 — Average time spent with each patient with cancer by profession
Description of the patient caseload for each profession
Respondents were asked to match descriptions of their patient caseload to those set out in the survey (Figure 16) which were:

- ‘I support patients who need a therapist, sometimes they have a history of cancer.’
- ‘The health concerns I focus on mean I get a high number of cancer patients’
- ‘My practice is focussed on cancer patients.’

Between 7% and 25% of respondents reported supporting patients who need a therapist, where patients sometimes have a cancer (Figure 16).

Between 6% and 28% of respondents reported that the health concerns they focus on mean they get a high number of cancer patients.

87% of speech and language therapists reported that their practice was focused on cancer patients interpreted as these respondents having cancer focussed roles. The percentages for occupational therapists

Figure 16 — Description of patient case loads
and physiotherapists were still high at 46% and 59% respectively. This may suggest that respondents were seeing patients more as part of a general clinical caseload.

**Most common cancer types seen by each AHP**

Respondents were asked to identify the most common cancer types they see in their role (Figure 17).

Physiotherapists reported seeing on average seven different types of cancer with lung cancer being the highest reported followed by breast, colorectal and brain and central nervous system (CNS) cancer.

Speech and language therapists see predominantly those with head and neck cancer.

Dietitians on average saw those with four different tumour types regularly including upper gastrointestinal, head and neck, colorectal and lung cancer.

Occupational therapists reported seeing those with lung cancer as the highest percentage followed by breast, brain and CNS and colorectal cancer.

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Physiotherapist</th>
<th>Speech and Language Therapist</th>
<th>Dietitian</th>
<th>Occupational Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
<td>88%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head and Neck</td>
<td>84%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain/central nervous system</td>
<td>77%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>76%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colorectal</td>
<td>70%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper gastrointestinal</td>
<td>69%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>56%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Figure 17 — Most common cancer types seen by each allied health profession**
The stages that AHPs see people living with cancer across the pathway
Respondents were asked to identify the proportion of the cancer patients they see who were at the following stages: diagnosis, undergoing treatment, patients living with the long term effects of cancer treatment, advanced/progressive diseases and end of life care.

For the majority of the professions (dietitians, physiotherapists and speech and language therapists) most of their patients are undergoing treatment. This may also be linked to the settings in which AHPs see patients as described in ‘Settings in which patients are seen by AHPs’ i.e. as cancer treatment is predominantly in a hospital setting. Speech and language therapists reported the largest percentage of patients seen once treatment is complete and patient is living with long term effects of cancer treatment. Occupational therapists reported that most of their patients seen were at end of life with less than a year to live.

Between 3% and 14% of AHP respondents’ current cancer workload are those patients that have been diagnosed with cancer but not yet started treatment. There are many opportunities for AHPs to be more engaged and support patients at this time to improve outcomes during and after treatment as highlighted in the recent Macmillan prehabilitation evidence and insight report. Faithful et al. outlined the necessary shift to proactive cancer care, supported self-management and collaborative management if patients’ long-term consequences of cancer and its treatment are to be addressed. Robb made the case for cancer care, especially the after-care post-acute treatment, to a culture that recognises cancer as a chronic illness with self-management and lifestyle advice.

The recently refreshed cancer rehabilitation pathways describe the contribution and importance of the interventions that AHPs can provide from diagnosis through to end of life care.

Interventions provided by AHPs can have a substantial impact across the whole patient journey from diagnosis, through active treatment, living with and beyond cancer, through to palliative and end of life care.

Figures 18–21 illustrate the percentage of patients’ stages that the different AHPs reported seeing patients.
Time of need that Dietitians see people living with cancer

Base size 239

12%  
(Incidence among cancer population* 13%)  
Patient diagnosed with cancer but not yet started treatment.

47%  
Patient currently undergoing cancer treatment.

12%  
(Incidence among cancer population* 11%)  
Treatment complete and patient is living with long term effects of cancer treatment.

12%  
Patient is currently living with advanced/progressive cancer.

9%  
(Incidence among cancer population* 20%)  
Patient is at end of life because of their cancer and has less than a year to live.

*The calculation excludes people who have had cancer but now have no symptoms as they are unlikely to need AHP intervention.

Only AHPs with a significant cancer workload were asked.

Figure 18 — Stages when dietitians see people living with cancer
Time of need that Occupational Therapists see people living with cancer

3% (Incidence among cancer population* 13%)
Patient diagnosed with cancer but not yet started treatment.

16%
Patient currently undergoing cancer treatment.

8% (Incidence among cancer population* 11%)
Treatment complete and patient is living with long term effects of cancer treatment.

24%
Patient is currently living with advanced/progressive cancer.

42% (Incidence among cancer population* 20%)
Patient is at end of life because of their cancer and has less than a year to live.

*The calculation excludes people who have had cancer but now have no symptoms as they are unlikely to need AHP intervention.

Only AHPs with a significant cancer workload were asked.

Figure 19 — Stages when occupational therapists see people living with cancer
Time of need that Physiotherapists see people living with cancer

Patient diagnosed with cancer but not yet started treatment. 5%
(Incidence among cancer population* 13%)

Patient currently undergoing cancer treatment. 29%

Treatment complete and patient is living with long term effects of cancer treatment. 11%
(Incidence among cancer population* 11%)

Patient is currently living with advanced/progressive cancer. 20%

Patient is at end of life because of their cancer and has less than a year to live. 27%
(Incidence among cancer population* 20%)

*The calculation excludes people who have had cancer but now have no symptoms as they are unlikely to need AHP intervention.

Only AHPs with a significant cancer workload were asked.

Figure 20 — Stages when physiotherapists see people living with cancer
Time of need that Speech and Language Therapists see people living with cancer

Base size 69

14% (Incidence among cancer population* 13%)
Patient diagnosed with cancer but not yet started treatment.

33%
Patient currently undergoing cancer treatment.

30% (Incidence among cancer population* 11%)
Treatment complete and patient is living with long term effects of cancer treatment.

9%
Patient is currently living with advanced/progressive cancer.

6% (Incidence among cancer population* 20%)
Patient is at end of life because of their cancer and has less than a year to live.

*The calculation excludes people who have had cancer but now have no symptoms as they are unlikely to need AHP intervention.

Only AHPs with a significant cancer workload were asked.

Figure 21 — Stages when speech and language therapists see people living with cancer
Case studies to illustrate how AHPs support patients at different times of need.
Macmillan has a growing body of evidence from work already underway which helps to illustrate the contribution of AHPs at different times of need. Four case studies are provided below.

An example of AHPs involved in prehabilitation

**The Aintree Prehabilitation Service, Aintree University Hospital NHS Trust, Liverpool**

The Aintree prehabilitation service pilot was set up in August 2017 following a grant from Macmillan comprising a physiotherapist, dietitian and therapy assistant. This service offers pre-operative physiotherapy and dietetic input to all patients undergoing major surgery for colorectal and hepatobiliary cancer at University Hospital Aintree. The input includes personalised physical activity and nutritional plans and exercises classes.

Patients are also followed up post operatively to ensure return to normal physical and nutritional state, referral into appropriate community services are also made at this point.

**Impact and outcomes**
Over a 12 month period 231 patients were seen by the prehabilitation service with 88 complete data sets. Measures from initial prehabilitation contacts to 6 weeks post op have shown –

- An average of 82 metres increase in walking distance
- 6% increase in handgrip strength
- 78% of patients increased or maintained physical activity levels
- 73% of patients maintained or lost less than 5% body mass
- Decreased nutritional risk status overall
- Data suggestive of decreased length of stay

Patient focus groups and feedback forms have been extremely positive with comments such as: ‘This was the best part of my journey at Aintree’

Feedback has also demonstrated that through attending the prehab service that patients felt significantly more prepared for their surgery and that both them and their family are more likely to make long term healthy lifestyle changes.
Macmillan Next Steps Cancer Rehabilitation, Gloucestershire

Macmillan Next Steps Cancer Rehabilitation (MNSCR) is an innovative service that provides wrap around care for those diagnosed with breast, prostate, colorectal and haematological cancers in Gloucestershire.

MNSCR was developed upon compelling evidence\(^3\) that rehabilitation, underpinned by ‘person-centred care’, achieves reduction in demand for health services and adds value and equity to the healthcare system.

The team is made up of specialist cancer AHPs (dietitian, physiotherapist, occupational therapist), healthy lifestyle specialists and volunteers who aim to facilitate self-management, empowering people, through 1:1 and group support to take up healthy lifestyles and improve their quality of life and experience of life after cancer. The team provide expert advice and treatments to prevent and manage, where possible, both the short and long term side effects of treatments. They collaborate with the hospital trust, GP practices, community partners and the volunteer sector.

Alongside clinical care, the team offer educational sessions and events for other health care professionals to enable further sharing of knowledge and skills.

The team strive to provide holistic, individualised personalised care at the right time and in the right place close to home.

The team have captured both surveys and patient stories throughout the project and collected clinical outcome measures including: fatigue, cardiovascular fitness, strength, waist circumference, weight and grip strength. They have also explored dietary habits, experience and overall quality of life through an adapted Friends and Family questionnaire. These have all been both before and after the various interventions. Patient Activation Levels were also captured to explore the ability to self-manage.

Impact and outcomes

Provisional data demonstrates positive feedback in respect of experience and quality of life and improvements in the majority of clinical outcomes including the patient activation level.
During treatment and beyond

Macmillan neuro-oncology rehabilitation service, Barts Health NHS Trust, London

Across Barts Health NHS Trust there are a number of neuro-oncology patients with acute medical and rehabilitation needs being admitted into acute cancer beds, with restricted access to intensive rehabilitation. The therapy provision at St Bartholomew’s Hospital (SBH) is insufficient to meet the needs of these complex patients, resulting in many patients blocking acute beds whilst awaiting inpatient neuro-rehabilitation, impacting on hospital length of stay, care costs and negatively influencing patient experience. Anecdotally, these concerns were not isolated to SBH and are seen nationwide.

The need for a specialist neuro-oncology rehabilitation service within SBH was identified, and funding was secured from Macmillan Cancer Support to recruit a highly specialist physiotherapist, occupational therapist, and a therapy assistant to deliver specialist intensive rehabilitation over a 2-year period, addressing the issues outlined above. The neuro-oncology rehabilitation service was developed and embedded within SBH and the Oncology Therapy team, aiming to:

- Improve functional outcomes and quality of life for patients
- Improve patient experience in the acute setting
- Improve patient flow across Bart’s Health (BH) through reducing length of stay in the acute setting
- Reduce community care costs in the medium to long term
- Improve links with specialist rehab centres and community rehab teams, and to enhance the pathway from acute services to further rehab
- Enhance education and support for patients, their families, and the wider MDT involved in their care
- Contribute to neuro-oncology therapy recommendations and guidelines

Impact and outcomes

Over the initial 6 months the service has shown benefits in the following areas:

- Improvements in functional outcomes
- Reduction in patients’ neurological impairments
- Reduction in Hospital length of stay
- Quality of life and satisfaction has improved for all patients
- Reduced care needs and associated costs in the community
North Manchester Macmillan Palliative Care Support Service (NMMPCSS): a redesigned community, integrated model of care, Manchester

The NMMPCSS, is a multidisciplinary service that integrates Macmillan AHPs and Clinical Nurse Specialist interventions in the community; for complex cancer and palliative care patients. The Macmillan Cancer Improvement Partnership (MCIP) initially funded a project to expand the current service provision to enable better access to holistic care. The service includes a palliative care consultant, clinical nurse specialist, occupational therapist, physiotherapist, dietitian and speech and language therapist. In addition, there is an assistant practitioner, volunteer coordinator, complimentary therapist and lymphoedema specialist.

The service functions as ‘a hub’ working closely with district nurses and wider multidisciplinary team (MDT) including the Crisis Team and Home Intravenous Therapy Team. The operating hours are 8am to 8pm, 7 days a week; during these hours there is a dedicated triage clinician who can be responsive to the needs of the patients in a timely manner. Daily MDT meetings are held led by the triage clinician to discuss updates of the current caseload and discuss new referrals. This regular and consistent communication method enables early identification of symptoms that may require treatment or rehabilitation. This has increased the care and support for patients and carers, relieving pressure, and optimising patient’s physical and psychological functioning.

Impact and outcomes
Ongoing quantitative and qualitative evaluation of the project by the clinical commissioning group has evidenced improvement on all national palliative care data sets, including meeting patient’s preferred place of care and death; leading to significant cost savings. Patients and families accessing the service reported a high level of satisfaction and valued the range and variety of support provided; which was perceived as being ‘joined-up’. This was reflected in the Care Quality Commission report which identified the significant service improvement and awarded an Outstanding for Compassionate Care, in March 2016.
Percentage of patients seen by AHPs with metastatic disease

Respondents were asked to estimate the percentage of cancer patients seen as part of their role that currently have metastatic disease. Occupational therapists reported seeing the most with 76% reporting that over half of their patients have metastatic disease. The corresponding figure for the other AHP professions are physiotherapists 63%, dietitians 31% and speech and language therapists 7% (Figure 22).

Problems which AHPs often/always address for people living with cancer

Respondents were asked to identify how often they provide care to address concerns that people living with cancer commonly exhibit (Figure 23).

The findings demonstrate that overall AHPs support people living with cancer with a wide range of concerns and symptoms as a result of cancer and treatments received.

Dietitians particularly reported regularly addressing concerns related to anorexia/cachexia, nutritional status, dietary advice, fatigue and energy management and dysphagia.

Occupational therapists and physiotherapists reported regularly addressing concerns particularly fatigue and energy management, loss of mobility and function, breathlessness, pain and concerns related to exercise and wellbeing.

Speech and language therapists reported regularly addressing primarily dysphagia and communication difficulties, support with altered body image and pain.

Macmillan Cancer Support have separately conducted an analysis of need for people living with cancer. The analysis looked at where people living with cancer had unmet need and
where they wanted more support. Key areas which met both criteria were fatigue, pain and support with everyday activities.

As is shown from the findings above, AHPs reported supporting patients with a wide range of symptoms including these unmet needs identified in particular fatigue and energy management, pain, concerns related to exercise and physical wellbeing, dysphagia, communication difficulties, breathlessness, nutrition, continence and to an extent lymphoedema.

AHPs deliver specialist interventions that complement the skills of other multidisciplinary team members. Different patients will have different rehabilitation needs, depending on the type, location and stage of their cancer. These findings concur with the evidence based symptom pathways which demonstrate AHPs have the skills, knowledge and expertise to support patients with different symptoms.33,34

<table>
<thead>
<tr>
<th></th>
<th>Dietitian</th>
<th>Occupational Therapist</th>
<th>Physiotherapist</th>
<th>Speech and Language Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue and energy management</td>
<td>64%</td>
<td>96%</td>
<td>91%</td>
<td>45%</td>
</tr>
<tr>
<td>Pain</td>
<td>44%</td>
<td>83%</td>
<td>78%</td>
<td>52%</td>
</tr>
<tr>
<td>Concerns related to exercise and physical wellbeing</td>
<td>39%</td>
<td>76%</td>
<td>96%</td>
<td>35%</td>
</tr>
<tr>
<td>Concerns related to mobility and loss of function</td>
<td>0%</td>
<td>99%</td>
<td>97%</td>
<td>0%</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>76%</td>
<td>0%</td>
<td>0%</td>
<td>97%</td>
</tr>
<tr>
<td>Communication difficulties/disorders</td>
<td>35%</td>
<td>21%</td>
<td>16%</td>
<td>96%</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>0%</td>
<td>88%</td>
<td>76%</td>
<td>0%</td>
</tr>
<tr>
<td>Altered body image</td>
<td>35%</td>
<td>33%</td>
<td>30%</td>
<td>64%</td>
</tr>
<tr>
<td>Concerns related to nutritional status/dietary advice/malnourishment</td>
<td>98%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Anorexia/cachexia</td>
<td>92%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Concerns related to continence in people living with cancer</td>
<td>0%</td>
<td>53%</td>
<td>23%</td>
<td>0%</td>
</tr>
<tr>
<td>Lymphoedema for people living with cancer</td>
<td>0%</td>
<td>23%</td>
<td>31%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Figure 23 — Problems that AHPs identified that they often/always address for people living with cancer
Types of interventions provided to those with a cancer diagnosis
Respondents were asked about interventions they regularly provide to people living with cancer (Figure 24).

This illustrates that AHPs are engaged in a wide range of interventions to provide holistic evidenced based care based on patient need which aligns to current evidence.35,36,37 Responses were similar across the four professions and demonstrate the breadth of interventions and the associated knowledge, skills and expertise required to support people living with cancer.

AHPs are trained to undertake holistic care and as such reported their substantial involvement in supporting the families and carers of patients.

Figure 24 also demonstrates that AHPs regularly provide a range of specialist interventions to support people living with cancer including for those with advanced diseases, complex palliative care and end of life issues, those having a variety of cancer treatments, providing emotional, financial and support for a patient’s practical needs as well as support for functional and cognitive impairment.

AHPs are skilled in working across teams and different organisations and agencies and as such have a substantial role in signposting and referring to other healthcare professionals.
### Figure 24 — Interventions regularly and personally provided to people with a cancer diagnosis

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Dietitian</th>
<th>Occupational Therapist</th>
<th>Physiotherapist</th>
<th>Speech and Language Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making referrals to other healthcare professionals</td>
<td>80%</td>
<td>93%</td>
<td>95%</td>
<td>95%</td>
</tr>
<tr>
<td>Supporting those with commonly presenting side effects and rehabilitation needs</td>
<td>81%</td>
<td>85%</td>
<td>93%</td>
<td>97%</td>
</tr>
<tr>
<td>Advising on self-management</td>
<td>74%</td>
<td>86%</td>
<td>97%</td>
<td>91%</td>
</tr>
<tr>
<td>Delivering interventions that require knowledge and experience of the effects of cancer treatment</td>
<td>83%</td>
<td>78%</td>
<td>85%</td>
<td>92%</td>
</tr>
<tr>
<td>Supporting families of carers of your patients</td>
<td>75%</td>
<td>90%</td>
<td>73%</td>
<td>92%</td>
</tr>
<tr>
<td>Signposting patients to other healthcare providers, sectors or settings without a referral</td>
<td>67%</td>
<td>78%</td>
<td>77%</td>
<td>80%</td>
</tr>
<tr>
<td>Delivering treatment plans</td>
<td>67%</td>
<td>69%</td>
<td>85%</td>
<td>79%</td>
</tr>
<tr>
<td>Delivering specialist interventions for patients with advanced diseases, complex palliative and end of life care issues</td>
<td>64%</td>
<td>82%</td>
<td>77%</td>
<td>77%</td>
</tr>
<tr>
<td>Delivering specialist interventions for patients having radical surgery or combinations of treatments</td>
<td>71%</td>
<td>34%</td>
<td>50%</td>
<td>94%</td>
</tr>
<tr>
<td>Delivering interventions for emotional, financial or practical needs to support patients with activities of daily living</td>
<td>31%</td>
<td>87%</td>
<td>69%</td>
<td>42%</td>
</tr>
<tr>
<td>Delivering specialist interventions to patients with severe functional and cognitive impairment</td>
<td>20%</td>
<td>74%</td>
<td>67%</td>
<td>42%</td>
</tr>
</tbody>
</table>
AHPs undertaking holistic needs assessments
Respondents were asked if they carried out structured holistic needs assessments (HNA) for people living with cancer. Between 22% and 51% reported they did undertake an HNA (Figure 25). However, it should be noted that at the very least all AHPs will undertake an assessment in advance of interventions and treatment being delivered.

Figure 25 — Percentage of AHPs who reported undertaking structured HNA on people living with cancer
Capacity in the AHP workforce
Respondents were asked whether they felt there were sufficient AHPs to support people living with cancer where they worked. Between 63% and 74% felt more were needed with 14%–17% responding that there were the right number of staff (Figure 26).

Figure 26 — Do you think there are sufficient AHPs to support people living with cancer?
Learning and development

Percentage of respondents who have had additional learning and development (formal training) to support people living with cancer

All respondents were asked whether they had had additional learning and development, such as study days, modules and short courses, in cancer in the last 5 years to support people living with cancer.

Out of those who spent 20% of their time with people living with cancer the majority have received cancer specific training in the past 5 years. This varied by AHP profession with 83/84% for both physiotherapists and speech and language therapists. However, close to a third of dietitians and occupational therapists had not received training in cancer in the past 5 years. (Figure 27).

This may reflect the different ways in which AHPs develop and update their knowledge and skills relating to their current scope of practice. Cancer specific training may have occurred prior to the past 5 years however this question was not specifically asked.

Out of those who spent 50% of their time with people living with cancer the majority (80%–93%) had received cancer specific training in the last 5 years.

1,229 respondents out of the total 1,774 respondents did not report a sizeable cancer workload. Out of those without a sizeable cancer workload only 28% of dietitians, 31% of occupational therapists, 34% of physiotherapist and 37% of speech and language therapists reported having formal training in cancer in the past 5 years. It may be that although this group do not report a sizeable cancer caseload they may see people living with cancer at certain times in their roles. It is therefore important that AHPs have some level of awareness of how to support people living with cancer through learning and development opportunities.

The Macmillan AHP competence framework is also designed to inform and guide AHPs in the skills and knowledge required to support people living with cancer.

In addition, as part of the workforce engagement and learning and development programme within Macmillan Cancer Support, we will be developing a framework that describes the type and level of competency required to support people with common unmet needs like fatigue, emotional support and finance. This will be a practical guide for developing the cancer workforce, building on previous work in skill mix. It will be different from existing competency frameworks, as it will be multi professional, cover competencies from volunteers to consultant level and be aimed at improving experience of care for people living with cancer.
Figure 27 — Percentage of respondents who have had learning and development (formal training) in cancer in the last 5 years including AHPs who spend > 20% and > 50% with people living with cancer.
Conclusions and recommendations

This survey helps raise awareness of the contribution AHPs do make and the potential contributions they could play in cancer care, how important their roles are and where and how they intervene with patients in the pathway.

AHPs are key members of the multidisciplinary cancer team, and support many of the strategic aims to transform cancer care and to improve quality of life.

AHPs are key to supporting people living with cancer across different tumour types to improve their independence and quality of life by addressing unmet needs such as; fatigue and energy management, pain, everyday life activities, mobility, nutrition, communication and swallowing difficulties.

Much of the work undertaken by AHPs with people living with cancer is reported as during treatment and beyond and palliative and end of life care. There is an important case for AHPs to support patients from diagnosis in a timely and proactive manner as part of prehabilitation to optimise people living with cancer for treatment and beyond. This has been proven to have substantial benefits in reducing complications, minimising consequences of treatment and increasing quality of life.

AHPs are engaged in a number of interventions when supporting people with a cancer diagnosis including:

- Signposting and making referrals to other healthcare professionals. This is crucial in supporting and guiding people living with cancer to be able to access the most appropriate support and expertise to meet their needs at different times and help navigate people through their journey.
- Supporting people with commonly presenting side effects and rehabilitation needs
- Delivering treatment plans
- Supporting families and carers
- Delivering specialist interventions for patients with advanced diseases, complex palliative and end of life care
- Advising on self-management
- Deliver interventions to support emotional, practical and financial needs and those with functional and cognitive impairment.

This survey helps raise awareness of the contribution AHPs do make and the potential contributions they could play in cancer care, how important their roles are and where and how they intervene with patients in the pathway.
Recommendations

The recommendations from this work are set out below which should be considered as part of the future planning of services for people living with cancer.

1. AHPs should be integral to the development and transformation of services for people living with cancer.

   The findings from the survey read alongside the cancer rehabilitation pathways provide important information to aide decision making when transforming cancer services. AHPs are involved in a wide range of interventions to support people living with cancer. These should be considered when transforming cancer care to ensure AHP input is included at all stages of the development, design and delivery of services.

2. Early intervention has been shown to have a significant impact on people living with cancer to help achieve the best outcome for patients including improving quality of life, proactive management of symptoms and the consequences of treatment. AHPs have a substantial role in early intervention and should be encouraged to lead service transformation in cancer care to support early intervention with people living with cancer in advance of treatment whether surgery and/or chemotherapy and/or radiotherapy.

3. AHPs can provide a wide range of interventions identified as part of Holistic Needs Assessment which can have positive outcomes for patients. AHPs should be included as key members of the cancer multidisciplinary teams, they have a key role in managing complex needs and form a vital part of a skill mix approach to workforce planning.

4. Macmillan has identified AHPs as a prioritised group with which to engage as part of its workforce engagement model. AHPs should continue to have access to formal training to support their professional development in order to provide high quality care for people living with cancer which can be informed by the Macmillan AHP competence framework.
Appendix A

1. Which option best reflects your current working status?

2. (a). What is your current profession?
   (b). What type of professional(s) do you currently support?

3. How many hours do you typically spend in a week directly supporting adult patients through person to person activity for example clinic time, inpatients or telephone consultations? If you work only with children then put 0.

4. Which of these accredited qualifications do you hold (please also include those not related to your role)? Tick all that apply.

5. How long have you been working as a registered Allied Health Support worker?

6. Do you plan to retire from clinical practice in the next 5 years?

7. (a). In the last two weeks, how many different jobs as a [JOB ROLE INSERTED] have you held?
   (b). Please list the name of the jobs in order starting with the role you spend the largest proportion of your time doing. We will then ask you about more detail about the different jobs you hold. We will be asking for additional detail for a maximum of 4 jobs. If you hold the same job title across all your roles then put in brackets the different location where you carry out these roles.
   (c). For your role/each of your roles please select the clinical speciality within which you are working. If you work in multiple areas please tick all the options which apply.

8. For your role/each of your roles which country do you carry out the majority of your work? Select one answer per role.

9. For each of your roles in which postcode do you provide most of your care? (if it’s variable then please give a postcode in the centre of your patch). Please supply a full postcode.

10. Does this/these role(s) have ‘Macmillan’ in the job title? Please select one answer per role.

11. In your role/roles which category below does your employer fit?

12. Where do you deliver care while working in your role/roles?

13. In each of your role(s) who pays for the services you provide?

14. Which Agenda for Change pay band are you on for each of your role(s)?

15. In each of your role(s) what sort of contract do you have?

16. Thinking about each of your role(s) individually, excluding paid or unpaid overtime, how many hours per week are you contracted to work?

17. Thinking about each role individually, including your contracted hours and paid and unpaid overtime, how many hours per week do you actually work?

18. For each of your role(s), out of your total hours, please estimate the percentage of your time you spend supporting cancer patients?
19. Thinking about each role individually, how many patients do you typically see in a week? Please include patients with any health condition and both new and follow up patients.

20. Thinking about each of your role(s) individually, how many cancer patients on average do you see in a week? Please include both new and follow up patients.

21. For each role that you see over 9 (DIETITIAN/ PHYSIOTHERAPIST/ SPEECH & LANGUAGE) 4 (FOR OCCUPATIONAL THERAPIST) cancer patients per week. What percentage of these cancer patients are first-time patient (i.e. you are seeing them for the first time)?

22. For each of the different role(s) that you see cancer patients. Please estimate the average length of your appointments with a cancer patient?

23. For each of the role(s) you see cancer patients which description below best matches your patient case load?

24. For each of your role(s) please select the cancer types you regularly see?

25. In each of your role(s) thinking about a typical week, please estimate the proportion of your cancer patients, who are currently at each of the following stages.

26. For each of your role(s) please estimate the percentage of cancer patients seen as part of this role that currently have metastatic disease? 27. For any of your role(s) do you carry out any structured holistic needs assessments? (Including Macmillan HNAs and others).

27. For any of your role(s) do you carry out any structured holistic needs assessments? (Including Macmillan HNAs and others).

28. In each of your role(s) how often do you provide care to address each of the following concerns to people with a cancer diagnosis?

29. As part of each of your role(s) which of the following do you regularly and personally provide people with a cancer diagnosis?

30. (a). As part of any of your roles, do you delegate clinical tasks to? Please exclude referrals or signposting to other specialities.

(b). As part of any of your roles, do you delegate administrative tasks to? Please exclude referrals or signposting to other specialities.

31. Have you had any additional learning and development (formal training) to enhance the support you give to people with cancer in the last 5 years?

32. Please describe further in the box below the additional learning and development (formal training) you have to enhance the support you give to people with cancer.

33. In the main setting in which you work, do you think there are there sufficient Allied Health Support workers to meet the needs of people living with cancer?

34. In what year were you born?

35. With what gender do you identify?

36. Please select your nationality.
## Appendix B

<table>
<thead>
<tr>
<th>AHP Profession</th>
<th>Total number of AHPs who are registered with the Health and Care Professions Council</th>
<th>Total number of practicing AHPs who are members of their respective professional bodies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietitian</td>
<td>9,585</td>
<td>7,550</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>38,183</td>
<td>27,371</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>55,132</td>
<td>46,703</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>15,932</td>
<td>13,414</td>
</tr>
<tr>
<td>Support worker</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

<p>|                | 116,824                                                                          | 95,038                                                                             |</p>
<table>
<thead>
<tr>
<th>Sampling Method</th>
<th>Survey Sample Achieved</th>
<th>Response Rate based on professional body membership numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Members were contacted directly by the research supplier with an individualised link to the survey. Responses to the survey were monitored and reminders were sent to those who had not yet responded.</td>
<td>646</td>
<td>9%</td>
</tr>
<tr>
<td>Members were contacted directly by their professional body with an individualised link to the survey. This was supplemented by the use of social media (via newsletters, Twitter &amp; Facebook) to promote the survey.</td>
<td>480</td>
<td>2%</td>
</tr>
<tr>
<td>The professional body placed a link to the survey on their website. This was supplemented by the use of social media (via newsletters) to promote the survey.</td>
<td>401</td>
<td>1%</td>
</tr>
<tr>
<td>Members were contacted directly by their professional body with an individualised link to the survey. This was supplemented by the use of social media (via newsletters, Twitter &amp; Facebook) to promote the survey.</td>
<td>247</td>
<td>2%</td>
</tr>
<tr>
<td>Members from each professional body were contacted via the relevant method described above. Some support workers are members of the different professional bodies so this group would be under represented within our final sample.</td>
<td>53</td>
<td>n/a</td>
</tr>
</tbody>
</table>

2,009
### Appendix C

<table>
<thead>
<tr>
<th>Country</th>
<th>Dietitian</th>
<th>Occupational Therapist</th>
<th>Physiotherapist</th>
<th>Speech and Language Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>6,848 (77%)</td>
<td>30,171 (82%)</td>
<td>43,273 (84%)</td>
<td>12,771 (83%)</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>403 (5%)</td>
<td>1,437 (4%)</td>
<td>1,900 (4%)</td>
<td>718 (5%)</td>
</tr>
<tr>
<td>Scotland</td>
<td>1,066 (12%)</td>
<td>3,490 (9%)</td>
<td>4,383 (9%)</td>
<td>1,287 (8%)</td>
</tr>
<tr>
<td>Wales</td>
<td>428 (5%)</td>
<td>1,703 (4%)</td>
<td>1,885 (4%)</td>
<td>571 (4%)</td>
</tr>
<tr>
<td>UK total</td>
<td>8,745</td>
<td>36,801</td>
<td>6,848</td>
<td>6,848</td>
</tr>
</tbody>
</table>

Total Health Care Professions Council registrants by country as at 2nd January 2018
Acknowledgements

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References


3. The survey included four allied health professions: dietitians, occupational therapists, physiotherapists and speech and language therapists.


5. This was defined as 9 or more cancer patients seen per week for dietitians, physiotherapists and speech & language therapists. For occupational therapists who see less patients overall a significant cancer workload was seeing 4 or more cancer patients.


8. This was defined as 9 or more cancer patients seen per week for dietitians, physiotherapists and speech & language therapists. For occupational therapists who see less patients overall a significant cancer workload was seeing 4 or more cancer patients.


11. The survey included four Allied Health professions: dietitians, occupational therapists, physiotherapists and speech and language therapists.

12. The Society and College of Radiographers undertakes an annual census of both diagnostic and therapeutic radiographers across the UK.


This was defined as 9 or more cancer patients seen per week for dietitians, physiotherapists and speech & language therapists. For occupational therapists who see less patients overall a significant cancer workload was seeing 4 or more cancer patients.

http://www.hcpc-uk.org/aboutregistration/professions/index.asp?id=13#profDetails


NHS Provider Trust refers to those in England and Northern Ireland. NHS Health Board refers to the NHS structure in Scotland and Wales

http://www.alliedhealthsolutions.co.uk/PDFs/ProjectOutputsAndPublications/AHPsTheWorkforceAndTheServicesTheyProvideGuide.pdf


To the nearest 10%


https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297633

Health and Care Professions Council. Standards of proficiency for each profession http://www.hpc-uk.org/aboutregistration/standards/standardsofproficiency/


Being told ‘you have cancer’ can affect so much more than your health – it can also affect your family, your job, even your ability to pay the bills. But you’re still you. We get that. And, after over 100 years of helping people through cancer, we get what’s most important: that you’re treated as a person, not just a patient.

It’s why we’ll take the time to understand you and all that matters to you, so we can provide the support you need to take care of your health, protect your personal relationships and deal with money and work worries.

We’re here to help you find your best way through from the moment of diagnosis, so you’re able to live life as fully as you can.

For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk