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CANCER SUPPORT**

# **OLDER PEOPLE LIVING WITH CANCER**

**Exploring the attitudes  
and behaviours of older  
people living with cancer**

Research conducted by Ipsos MORI  
on behalf of Macmillan Cancer Support



**Ipsos MORI**

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# Foreword

In recent years there have been welcome developments in the evidence base on outcomes for older people affected by cancer in the UK. This includes how they vary compared with younger age groups, as well as to those of older people in other countries. It is clear that poor outcomes in older people are a major explanation for the survival gap with other countries and that the disparity in outcomes extends beyond survival to encompass quality of life and patient experience<sup>1</sup>.

We also know more about variations in access to different forms of cancer services, including those relating to referral and diagnosis, treatment and support. In addition, work has been undertaken to explore both clinical attitudes towards treatment in older people<sup>2</sup> and the interventions that can make a difference to older people<sup>3</sup>.

However, little is known about the attitudes of older people themselves towards cancer, including their knowledge, beliefs and behaviours, and how these might impact upon outcomes. This is why Macmillan Cancer Support sought to undertake the research contained in this report. The research, conducted by Ipsos MORI, is the first of its kind to look at older people's attitudes towards cancer and its treatment, and also identifies new factors which could help explain some of the reasons behind the poorer survival rates amongst older people.

Some of the findings challenge ideas around older people's attitudes towards cancer, such as the assumption that older people might be more likely to turn down cancer treatment than younger people – this should raise serious concerns for the NHS about the provision of care and treatment for older people living with cancer.

Too often the healthcare system makes snap judgements on an older person on the basis of their age, as opposed to what matters most to them. This research shows that there are a range of factors and values that determine how older people seek and access support, as well the importance they may place on active treatment.

But these values and attitudes do not translate into older people getting access to treatment. This research helps us, for example, make the case for putting aside the belief that older people were turning down treatment because of issues such as inability to cope with side effects of treatment.

We can now start to move forward on building an in-depth, accurate understanding of why older people might not get treatment, while also supporting older people to address some of their own perceptions about cancer, such as acknowledging that the risk of cancer increases with age.

At its heart, this research shows the importance older people place on getting treatment. If other evidence shows us this doesn't seem to translate into older people actually getting access to treatment, then we all have a duty to find out why this is happening, and remedy it.

**Jagtar Dhandra, Head of Inclusion,  
Macmillan Cancer Support**

1, National Cancer Intelligence Network (2014) Older people and cancer.

2, Department of Health (2012) The impact of patient age on clinical decision-making in oncology.

3, Department of Health, Age UK & Macmillan Cancer Support (2012) Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project.

**1**

# **Summary of findings**

# 1 Summary of findings

## 1.1 Overview

Between January and June 2015, Ipsos MORI Social Research Institute carried out a study on behalf of Macmillan Cancer Support to better understand how patient attitudes influence the outcomes of older people living with cancer. This research examines the patient attitudes and behaviours that can impact on cancer treatment and patient experience, which in turn, may affect clinical and non-clinical outcomes. Attitudes and behaviours are believed to have a significant impact on some of the key determinants of cancer outcomes, including stage of diagnosis, decisions about treatment and support during recovery.

It is important to note that – by necessity – this research has primarily involved people affected by cancer who are in relatively good health and therefore may have a more positive experience of treatment and care. Efforts have been made to engage with older retired people but, again, people have to be well enough to participate so the views of older retired people with multiple co-morbidities may be understated.

This study identifies a range of attitudes and perceptions which will shape the way that older people access cancer services, influencing when and how they seek help, as well as the outcomes they experience. These findings will be of interest to all those with a stake in improving outcomes for older people, including, policymakers, commissioners and providers of health services, health professionals and charities.

It is important to recognise that older people do not respond to cancer in a homogenous way however. Previous research has recognised a 'dichotomy or continuum of empowerment'<sup>4</sup> in

relation to the way that older people react to a cancer, as to many other things in life.

## 1.2 Emerging themes

A number of key themes emerge from the research, including:

- There are differences in the views of older people with cancer and those who have not been diagnosed with cancer, with those with direct experience of the condition having more positive perceptions about it.
- Some of the preconceptions that people may hold about older people's attitudes have been challenged, for example, older people are no more likely to choose not to have treatment than younger people, and no more likely to be concerned about the consequences of having treatment.
- A series of misconceptions about the risk of cancer and eligibility for screening may impact upon early diagnosis efforts and should be addressed.
- Older people are more likely than younger people to place trust in their health professionals but at the same time believe that discrimination against older people does exist (albeit not necessarily in their personal experience).
- Nonetheless, older people say they are willing to seek help, but are not necessarily aware of the services that exist to support them.
- Independence matters to older people.

## 1.3 Attitudes to health and cancer

There appears to have been a shift in attitudes towards cancer.

<sup>4</sup>, 'Experiencing cancer in old age: a qualitative systematic review', Hughes et al., Qualitative Health Research 2009, 19:1139 <http://eprints.whiterose.ac.uk/83251/3/Hughes%5B1%5D.pdf>

Only a small minority of those aged 55 or over living with (3%) and without (8%) cancer agree with the statement that cancer is a 'death sentence'. This compares with a study of the general public, patients and carers, which found much larger numbers of people (42%) who thought so as recently as 2012<sup>5</sup>.

A small majority (51%) of those people interviewed also believe that their life experience better equips them to cope with cancer, while responses to other attitudinal questions also suggest greater resilience. The qualitative research revealed that as people get older, raising a family and work become less central to people's lives, and so they perceive themselves as having less to worry about than younger people.

People living with cancer aged 55 or over expressed similar opinions to those who have never had cancer when describing their health as excellent or very good (38% vs 34% respectively), to say that they look forward to each day (78% vs 74%) and that they enjoy doing what they used to (76% vs 75%).

More generally, older people tend to have a more positive outlook on life, with 79% of the post-retirement age group stating that they look forward to each day, compared with 74% of those in the working age group. While this is not a huge divergence, it is significant.

Satisfaction with health increases with age amongst those living with cancer (33% of those aged 75 or over report excellent or very good health, compared with 25% of the working age cohort). This may reflect the fact that older people in general tend to report higher levels of satisfaction<sup>6</sup>, possibly linked to the common belief that disease and disability are inevitable as people age (43% agree with this

statement compared with 29% who disagree).

A majority of those living with cancer aged 75 or over (56%) feel that they've achieved as much in life as they wanted to (compared with 23% of those of working age).

## 1.4 Attitudes towards risk of cancer and diagnosis

The overwhelming majorities of all age groups over 55 both living with (90%) and living without (84%) cancer do not think that cancer is an age-related disease. This is despite a wealth of evidence that shows older people are at greatest risk<sup>7</sup>. Instead, the qualitative research suggests that people perceive diagnoses of cancer as random, unexpected events that can affect anyone.

The fact that older people do not realise that their age is a significant risk factor for cancer may have implications for efforts to encourage earlier diagnosis of cancer; if people do not believe they are at greater risk, this may impact upon their help seeking behaviour<sup>8</sup>. This is particularly significant given the impact that late diagnosis has on cancer survival. It is particularly relevant for older people as treatments for more advanced cancer are often associated with more invasive or toxic treatment.

Qualitative interviews show there is also confusion around the role of screening for cancer in older people. There was confusion about the age ranges for screening and the options that exist for people who are above the screening age range to 'opt in' to screening. Responses suggest that there may also be confusion amongst some healthcare professionals. For example, a 75 year

5, [http://pacenetwork.co.uk/pace\\_index](http://pacenetwork.co.uk/pace_index)

6, Ipsos MORI Generations – <https://www.ipsos-mori.com/Assets/Docs/Publications/sri-understanding-society-generations-october-2013.pdf>

7, Page 2, 'The Rich Picture on older people with cancer', Macmillan Cancer Support

8, Help seeking for cancer 'alarm' symptoms: a qualitative interview study of primary care patients in the UK Katrina L Whitaker, Una Macleod, Kelly Winstanley, Suzanne E Scott, Jane Wardle [Feb 2015]



old male in Scotland reported that, 'I was told it [bowel cancer screening] wasn't open to people over 75' and a 69 year old woman in England said, 'I was not given the choice. I was told I could not have screening anymore'.

## 1.5 Attitudes towards treatment

Evidence shows that older people are less likely to receive active anti-cancer treatment, be it surgery, radiotherapy or chemotherapy<sup>9</sup>. Very few people in this study reported that they declined treatment (2%) or even opted out of some treatment (14%), and this does not increase with age. However people of working age did report receiving more lines of treatment than people above the retirement age. This supports the notion that younger people may receive more intensive treatment than older people, but also suggests that patient preference is not a major factor in determining treatment rates.

All age groups over 55 appear to have significant concerns about the consequences of cancer treatment. However, perceptions about the impact of treatment appear to be more negative amongst those older people who have not had cancer than amongst those who have actually received cancer treatment, with 46% of those with cancer agreeing with the statement that the side effects of treatment may be worse than the cancer itself, compared with 53% in the non-cancer group. Furthermore, attitudes towards treatment do not become more negative as age increases.

The research revealed some negative attitudes from older people without cancer specifically towards treatment.

For these people, these attitudes may impact upon help seeking behaviours, with a fear of cancer treatment resulting in a reluctance to seek help for symptoms. These negative perceptions may be based on the experience of others, who may have been treated a long time ago and therefore may not accurately reflect the realities of modern treatment.

Personal and direct experience of treatment appears to help to dispel fears and misunderstandings around 'side effects'. This suggests that providers of cancer services may wish to consider how they could tailor information on treatments to educate about potential side effects but also reassure patients about the management of potential consequences. Given the impact that personal experience appears to have, there may be a particular role for peer-to-peer support in this respect.

Information on the many varied consequences – physical, social and emotional – was identified as an area for improvement, with a number of participants in the depth interviews stating that they would have liked more information and regretted not asking more questions of health professionals. This supports the findings of the National Cancer Patient Experience Survey, which shows that older people are less likely to report being given information on the side effects of treatment<sup>10</sup>.

The consequences of treatment go beyond short-term side effects. Older people are particularly concerned about maintaining independence and the longer-term consequences of cancer treatment that can impact upon this<sup>11</sup>. Attitudes towards independence are explored in more detail below.

9, National Cancer Intelligence Network (2014) Older people and cancer

10, National Cancer Patient Experience Survey (CPES) – those aged 66-75 are more likely than their younger counterparts to feel their views were taken into account when clinicians were deciding treatment options (73% 66-75s vs 67% 16-25s), yet they are least well informed about side effects (51% of those aged 76+ report being told about side effects that could affect them in the future, compared with 65% of 16-25s)

11, [http://www.macmillan.org.uk/Documents/AboutUs/Health\\_professionals/OlderPeoplesProject/CancerServicesComingofAge.pdf](http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/OlderPeoplesProject/CancerServicesComingofAge.pdf)

## 1.6 Attitudes towards healthcare professionals

Contrary to received wisdom, people of working age who are living with cancer are actually more likely than older people to avoid going to the doctor because they are worried about wasting their time. For working age people, 3 in 10 (29%) agree that there have been times during their cancer journey they have not gone to see healthcare staff because they didn't want to waste time, compared with just one in six (16%) of those over the age of 65. Evidence from the National Cancer Patient Experience Survey<sup>12</sup> suggests that older people are more likely to have confidence and trust in health professionals than younger patients. This is supported by this study; 71% of people living with cancer in the older retired age group stated that healthcare professionals know what's best for them when it comes to their care, compared with only 58% of those in the working age group.

This trust appears to manifest itself in older people adopting a more passive role in decisions about their treatment. This is supported by previous Ipsos MORI research, which has shown that older people are less likely than younger people to say that they would search for information about possible treatments if they were diagnosed with cancer<sup>13</sup>.

The majority of those living with cancer agree that they feel involved in decisions about their care (84%).

## 1.7 Attitudes towards health services

There is a perception that older people may be treated differently by the health system due to their age, with a majority of those aged 55 or over in

both groups surveyed stating there is at least some prejudice against older people with cancer in the UK (62% of those living with cancer; 58% of those without cancer). However, in terms of personal experience, a relatively small proportion feel that they have experienced this directly, with only one in nine (11%) agreeing that sometimes healthcare staff made decisions about their cancer care based on their age and not how fit they were.

Older age groups have a more positive initial view of their care and treatment, although evidence from the National Cancer Patient Experience Survey shows that a more detailed exploration of their experience often reveals significant issues, for example, in relation to information and communication, coordination of care and access to specialist support<sup>14</sup>.

## 1.8 Attitudes towards independence

As noted earlier, older people feel that they are better able to cope with cancer than younger people. Two thirds (67%) of the older retired group living with cancer agree that the life experience of older people allows them to cope better than younger people. Perhaps unsurprisingly this figure is markedly higher than for those people in the working age group, where the figure agreeing with the statement falls to 38%.

Statements about the ability to 'cope' with cancer may be driven by the desire to maintain independence, which is particularly apparent in older people. Although maintaining health is listed as the most important priority for most people living with cancer, this changes for the older retired group, who state that continued independence (44%) is just as important as maintaining health (43%).

12, <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

13, A 2006 survey showed that people aged 65 or over (41%) are less likely than the population more generally (68%) to say that they would search for information on the internet or the library about possible treatments, if they can cancer. <https://www.ipsos-mori.com/Assets/Docs/Archive/Polls/cancerbackup-report.pdf>

14, <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

Our research shows that older people are less likely to worry about requesting help and support. This is despite recent research from Macmillan Cancer Support which shows that they are less likely to receive support<sup>15</sup>.

Indeed one third of respondents to this study report a perception that older people receive less support than younger people. This suggests that appropriate support is often not available for older people living with cancer. Our interviews also suggest that older people may not be aware of the support that is available to them.

## 1.9 Attitudes towards friends and family

Contrary to received wisdom, older people are more likely to be comfortable seeking help than younger people. Half (53%) of people living with cancer in the post-retirement age group state that they sometimes do not ask for help because they do not want to be a burden to other people, which is somewhat lower than for those of working age (63%).

## 1.10 Next steps from the research

The findings from this research will be relevant to efforts to improve outcomes at every part of the cancer pathway, including:

- Early diagnosis, including raising awareness of how the risk of cancer increases with age and how older people can access screening services.
- Treatment, challenging some of the preconceptions that people may hold about older people's attitudes towards cancer and its treatment.

- Assessment, ensuring that older people with cancer receive a comprehensive assessment of their overall physical and mental wellbeing so that treatment decisions are not made based on age alone.

- Treatment, including reassuring people about the realities of modern cancer treatment, whilst educating them about its consequences and tailoring treatment approaches to reflect what matters most to older people, including maintaining independence.

- Delivering information and support older people to be active participants in their care.

- Support, designing services which better meet the needs of older people and ensuring that they are better signposted to this support.

Experience, acting on intelligence from the National Cancer Patient Experience Survey to ensure that gaps in services for older people are addressed.

The National Cancer Director has indicated that improving services for older people affected by cancer is a personal priority and, as part of this, Macmillan Cancer Support is working in close partnership with him and a multidisciplinary group of clinical experts and patients to initiate research and design interventions to better support older people. The findings from this study will be used to support this process.

<sup>15</sup> Macmillan Cancer Support (2014) *The Rich Picture: Older People With Cancer*.

## Acknowledgments

We wish to thank all of those who participated in the research and shared their experiences with us. We also wish to thank Age UK (Age UK Northumberland and Age UK Leicester), the Older Peoples Advocacy Alliance (OPAAL), Professor M Gosney and all those involved in the development and design for their help in shaping this study.

# 2

## **Background and methodology**

## 2 Background and methodology

**Ipsos MORI was commissioned by Macmillan Cancer Support to carry out a research study to understand how the attitudes of older people may influence cancer outcomes.**

'Living with cancer' was defined as anyone who has received a diagnosis of cancer at any stage of their lives (a definition consistently used by Macmillan). The research focused upon anyone over the age of 55, although there was a particular interest in the oldest age groups given poorer survival rates for those aged over 75. Consequently, three specific age groups are described:

- working age (55-64)
- post-retirement age (65-74)
- older retired (75 and over).

This research examines how the attitudes of older people to cancer may impact upon the outcomes they experience or the way in which they access and experience treatment and care.

It is hoped that the findings of this research will help inform efforts to tailor services for older people affected by cancer so that they better meet their needs, as well as improving the support available to professionals who treat and care for older people with cancer, with a view to improving outcomes.

The study includes a comparison group of people aged 55 and over who have not been diagnosed with cancer (the 'non-cancer sample'). The purpose of the comparison group is to examine whether a cancer diagnosis may lead to a change in attitudes.

The figure below shows an outline of the study design and we go on to briefly describe each phase.

### Methodology



Scoping review of existing literature



A survey of 1,004 people (aged 55+) living with cancer



A survey of 500 people (aged 55+) without cancer



26 qualitative depth interviews with people living with cancer



Two groups of 10 participants with older people who have never had cancer

**The scoping stage of the study ensured the right questions were being asked in the survey and interviews.**

**The primary research consisted of two surveys, in depth interviews with 26 older people living with cancer and two focus groups.**

## 2.1 Scoping phase

Prior to conducting the primary research itself, Ipsos MORI conducted a scoping phase to review existing evidence on older people and cancer.

Following this rapid review, a scoping report was produced, summarising the findings and outlining the proposed areas of focus for this research project, to build on the existing body of evidence. In addition, this scoping report identified pre-existing questions that could be used to ensure rigor in the questionnaire design and allow for benchmarking during the analysis stage.

Macmillan hosted an immersion day to discuss the findings. This was divided into two sections – a session with experts contributing to the development of policy relating to cancer or older people and a session with ‘experts by experience’ (older people living with cancer). The morning session was attended by representatives from Macmillan, Ipsos MORI and Age UK, while the afternoon session was attended by a range of experts by experience, as well as representatives from Macmillan and Ipsos MORI.

Ipsos MORI continued to work with the experts by experience during the research design phase, to ensure that the questionnaire made sense, was sensitively worded, and covered salient and relevant issues to be explored during the research.

## 2.2 Surveys

The primary research tool was an online survey of 1,004 people aged 55 and over living with cancer in Great Britain. A survey was also conducted among a similarly aged non-cancer sample of 500 people, also living in

Great Britain. Fieldwork took place between 6 and 13 May 2015.

Interviews were carried out using Ipsos MORI’s Online Access Panel, which includes 361,000 online panellists aged 16 and over in Great Britain. This panel was used as it provides a fast and a cost-effective way of screening a large number of people to find those eligible for the survey.

Although online research has limitations in engaging with older people where internet usage is lower, it was considered to be the most cost-effective way of rapidly undertaking large scale research.

Corrective weights have been applied to bring the sample in line with the population of older people living with cancer. Nonetheless, it is important to be mindful that the number of very old (aged 85+), and those without access to the internet, is low. We sought to account for these groups during the qualitative depth interviews. The data for each survey were weighted as follows:

- The data for people living with cancer were weighted by gender, age group (55-64, 65-69, 70+) and nation using 2013 cancer prevalence estimates based on data collected from cancer registries in England, Northern Ireland, Scotland and Wales in 2010<sup>16</sup>.
- The data for the non-cancer population were also weighted by gender, age group (55-64, 65-69, 70+) and nation. These weights were calculated by using 2011 census data and the 2013 cancer prevalence estimates to calculate a profile of the population of people who had never been diagnosed with cancer in Great Britain.

<sup>16</sup>, Segmenting the cancer population, Macmillan Cancer Support and National Cancer Information Network

### 2.2.1 Questionnaire design

Ipsos MORI worked with experts by experience and Macmillan to design the questionnaire. The questionnaire, a copy of which is included in Appendix G, includes some questions about attitudes towards ageing and cancer, diagnosis, treatment and support taken from well-established surveys such as the English Longitudinal Survey of Ageing<sup>17</sup> and Cancer Patient Experience Survey<sup>18</sup>: These were used so that validated questions were used over untried questions, and comparative data could be used to add context, where appropriate.

### 2.2.2 Interpretation of quantitative data

All comparisons made between sub-groups in this report are statistically significant, unless stated otherwise. A guide to statistical reliability is provided in Appendix D.

Where percentages do not sum up to 100, this may be due to rounding, the exclusion of 'don't know' or 'prefer not to say' answers, or because respondents could give multiple answers. Throughout the report, an asterisk (\*) denotes any value of less than half of one percent but greater than zero.

## 2.3 Qualitative stage

Ipsos MORI conducted qualitative research with both older people who had experienced cancer at some point in their lives and those who were as yet cancer free.

### 2.3.1 Depth interviews

Trained Ipsos MORI researchers carried out 26 depth interviews with a range of older people living with cancer across the UK. Although participants had a range of different cancer experiences, the vast majority of those we spoke

with were either in remission, or described their cancer as being 'stable'. (See appendix A for a full breakdown of participants).

Half the participants were recruited via the online survey. The remainder were recruited primarily through fully accredited Ipsos MORI in-house recruiters. Additionally, we sought to recruit interviewees by approaching a range of relevant community organisations and national charities.

Eleven interviews were conducted face-to-face in participants' homes, while 15 were conducted by telephone between 11 April and 5 June 2015.

Participants were led through an informal, semi-structured discussion (see appendix E for the discussion guide) lasting up to two hours, covering their experience and attitudes towards life, cancer diagnosis and treatment, and healthcare generally. The interview drew on their personal experiences of cancer, and also their attitudes more generally.

All interviews were recorded, and as a thank you for their time, participants received a thank you gift of £40.

In addition to the usual training researchers at Ipsos MORI receive to conduct qualitative research such as this, the team underwent a 'Communicating with people affected by cancer' training session delivered by Macmillan to ensure that the particular needs and circumstances of older people living with cancer were taken into consideration during the interviews and the design of the research tools.

### 2.3.2 Focus groups

Two focus groups were conducted with people aged 55+ who had not been diagnosed with cancer – one

17, ELSA collates longitudinal data from a range of disciplines, looking at health, economic position and quality of life as people age. It uses a sample representative of the English population aged 50 and older. It is conducted by the Institute of Fiscal Studies, University College London, NatCen and The University of Manchester. The study started in 2002. Further details can be found on the ELSA website: <http://www.elsa-project.ac.uk/>.

18, CPES is a postal survey conducted regularly that provides the NHS and other stakeholders with insight into the experience of cancer patients treated in NHS hospitals, in order to identify improvements in services that can be made, both locally and nationally. Macmillan has been a key partner in developing and using the survey to improve services. The national survey was carried out in 2010, 2011/12, 2013, 2014. The survey results can be found here: <http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>.

19, CPES is a postal survey conducted regularly that provides the NHS and other stakeholders with insight into the experience of cancer patients treated in NHS hospitals, in order to identify improvements in services that can be made, both locally and nationally. Macmillan has been a key partner in developing and using the survey to improve services. The national survey was carried out in 2010, 2011/12, 2013, 2014. The survey results can be found here: <http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>.



in Northumberland and another in Leicester. Each group contained around 10 participants.

The groups were recruited with the help of local Age UK centres, and all participants were involved with those centres (for example, exercise classes and lunch clubs, or volunteer workers or in governance roles).

The participants were guided through an informal, semi-structured discussion (see appendix F for discussion guide) in order to explore their attitudes towards life, cancer diagnosis and treatment, and healthcare generally.

All interviews were recorded, and participants also received a thank you gift of £20.

## 2.4 Acknowledgements

Ipsos MORI would like to thank all of those who participated in the research and shared their experiences with us. We would also like to thank the Older People's Advocacy Alliance, Professor Margot Gosney, Geriatric Consultant and Age UK and their colleagues at Age UK Northumberland and Age UK Leicester for their help with this study.

**3**

# **Attitudes towards health and cancer**

## 3 Attitudes towards health and cancer

**This section looks at attitudes towards age and disease, disability and cancer and health among older people living with cancer, as well as how their attitudes compared to those who have never had cancer, and how they varied by a range of different sub-groups.**

### Summary

Generally, the respondents to the survey of people living with cancer aged 55 or over are just as likely to be positive about their health, age and life as those people interviewed who have never had cancer. In fact, older retired tend to be more likely than working age people to report this – suggesting that they may be better able to cope when dealing with cancer and that in some circumstances, surviving cancer can encourage optimism among older people.

However, both the quantitative and qualitative strands serve to remind us that there is by no means a universal response to cancer. Some people report long-lasting fear and uncertainty as a result of having cancer and any interventions designed for older people living with cancer need to reflect this variety of perspectives.

The way that people think about their age and cancer can have wide-ranging implications for how they approach diagnosis, treatment

and care. The in-depth interviews suggest that if older people feel that they've had a 'good innings', they may be less inclined to 'fight' cancer. Conversely, a majority of people aged 55 or over feel that the life experience of older people equips them better than younger people to cope with cancer and its consequences.

This section also highlights an apparent change in attitudes on cancer. Almost all respondents to both surveys do not think that cancer is a death sentence. This indicates a change from previous surveys, reflecting the improvements in survival for many cancers.

However, another myth perpetuates. A large majority of both those who have and have not had cancer incorrectly think that cancer is not an age-related disease (which may have consequences for recognition of symptoms, participation in screening and early diagnosis among older people).

It has been suggested that one of the reasons that older people with cancer experience poorer outcomes than younger age groups is because they have more negative attitudes towards their own health, disease and cancer<sup>19</sup>.

Consequently, this research looked at the attitudes of people living with cancer regarding health, age, disease and disability and cancer, to see whether there are variations. In this section, we outline some of these variations, which have implications for diagnosis, treatment, care and support for older people living with cancer.

As well as providing insight into the attitudes of older people living with cancer, this section also provides useful context to the later sections looking at diagnosis, screening, treatment, independence, support and care.

### 3.1 Perceptions of health

People living with cancer aged 55 or over tend to perceive that they are in good health. 30% say that their health is excellent or very good, while just 8% describe their health as poor. These figures are only marginally worse than those for the non-cancer population; (35% and 7% respectively)<sup>20</sup>.

Just 25% of the working age cohort report excellent or very good health, compared with 33% of those aged 75 or over. This may indicate that attitudes towards health are relative; that someone who is older may still feel healthy for their age, as a certain level of poor health is to be expected. By contrast, younger people feel that their health is relatively worse, perhaps due to having had cancer at a younger age.

**‘Having gone through what I have I know that I am responsible for my**

**own health. I am responsible for me. That’s what having cancer has taught me.’**

**Man, 65, Northern Ireland**

### 3.2 Perceptions of ageing

The research demonstrates other ways in which older people living with cancer express a positive outlook about their lives. Almost four in five of those aged 55+ say that they look forward to each day, while three in four say that they still enjoy the things that they used to (78% and 75% respectively). This is in line with the findings for the non-cancer sample.

The qualitative research again supports the hypothesis that this is an indication that surviving cancer can actually give people of all ages a more optimistic perspective on life, as indicated by the quote below.

**‘Things have changed for me. I’m more appreciative of stuff since I had the cancer; it makes you realise that you’re not going to live forever.’**

**Woman, 55, Scotland**

Equally, the positive outlook of those who have experienced cancer may be indicative of the fact that effective treatment and care mean that people can live after cancer without a significantly reduced quality of life.

**‘I’ve been left with some problems lifting my arm, but it’s a small price to pay.’**

**Woman, 78, South of England**

However, people living with cancer aged 55 or over are more likely than those who have not been diagnosed with cancer to say that their health stops them from doing things they want to do (41% and 26% respectively). This is not surprising; while treatment and

<sup>19</sup>, “McCaffrey Boyle and Engelking suggest that older people may not seek advice promptly because of their great fear of cancer, and because they may believe that treatment is as bad or worse than the disease and that death is inevitable” Page 613, ‘The needs of older people’, Christopher Bailey, Cancer Nursing: Care in Context 2008, edited by Jessica Corner, 2008 <https://books.google.co.uk/books?id=RI7eS2Z8DHM-C&pg=PA613&lpg=PA613&dq=older+people+attitudes+towards+cancer+fear&source=bl&ots=pl7wPHTiBt&sig=veX-7t8NzRIGQU2-mvV-XINNP-wLo&hl=en&sa=X&ei=W-FqeVZq1Kube7Aakp4XY-BQ&ved=0CEMQ6AEwBA#v=onepage&q&f=false>

<sup>20</sup>, It is worth noting here that research has consistently shown that older people have a positive attitude towards their health. This question is derived from the ELSA, which deliberately uses a more positively balanced scale (including ‘excellent’, ‘very good’, ‘good’ and ‘fair’, versus only one negative term, ‘poor’) to reflect this.

care have improved, cancer still has a serious impact on people's lives. The in-depth interviews indicate that a cancer diagnosis can prove particularly burdensome if it impacts on an individual's ability to work or look after their children. By comparison, some older people felt that their age made receiving a diagnosis of cancer somewhat easier to cope with.

**'If I'd been 53 instead of 73, I know I wouldn't have been able to absorb it all in the manner that I did. I would have been devastated.'**  
**Man, 75, North England**

Two fifths of those aged 55 or over living with cancer say that they have achieved as much in their lives as they wanted to (40%). This rises to 56% among the older retired cohort.

However, there were some indications from the depth interviews older people might be less likely to want to 'fight' cancer beyond a certain age, should they feel contented with their life up to that point.

**'By the time you are 80 you have contributed all you can in life.'**  
**Woman, 83, South England**

This may have consequences for how people approach new diagnoses of cancer. There was a suggestion that, beyond a certain age, if someone feels they have had a 'good innings' they may be less prepared to consider treatment. This is demonstrated in the case study below.

### Case study: Good innings

**Bettina is 93. She was successfully treated for skin cancer three years ago and is now in remission. She is really positive about her experience, including diagnosis, treatment, care and support.**

However, her attitude has changed. She says that, over the last five years she now feels old. She feels that she has had 'a good innings' and this has consequences for how she would feel if she was diagnosed with cancer again and if certain treatments would be required.

**'I don't worry about cancer now because I wouldn't have chemo. My husband had cancer in his 80s and he didn't have chemo. When you hear young women talking about what they've gone through, with chemo and radio... I'd just prefer to take palliative pills, for however long I last.'**



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### 3.3 Perceptions of disease and disability

Two in five people living with cancer aged 55 or over agree that disease and disability are inevitable when people get older (43%), compared with 30% who disagree. This figure does not vary by age group.

**'When you get older you accept that these things are going to happen... nobody's immortal and nobody can live forever.'**

Woman, 81, London

Amongst those living with cancer, those with two or more long-term conditions (45%) are significantly more likely than those without any long-term conditions (36%) to agree with the statement.

At the same time, however, the vast majority of people living with cancer aged 55 or over do not think that cancer is an age-related disease (90%), a view shared by those who have never had cancer (84%) and consistent across all age groups in both samples.

This is contrary to evidence on the relative risk of cancer. For example, 60% of all people alive with cancer are aged 60 or over<sup>21</sup>. While there is a large body of evidence demonstrating that cancer is an age-related disease, this message does not appear to have had much impact with people we surveyed.

**'The older you get, the more likely you are to get everything. It's not just cancer you need to be afraid of.'**

Focus group participant, older people without cancer, Leicester

In fact, being diagnosed with cancer would appear to make people even less likely to think that cancer is age-related. The qualitative research suggests a possible reason for this; participants spoke of cancer as a random or arbitrary disease that could affect anyone, and did not link it to the process of ageing at all.

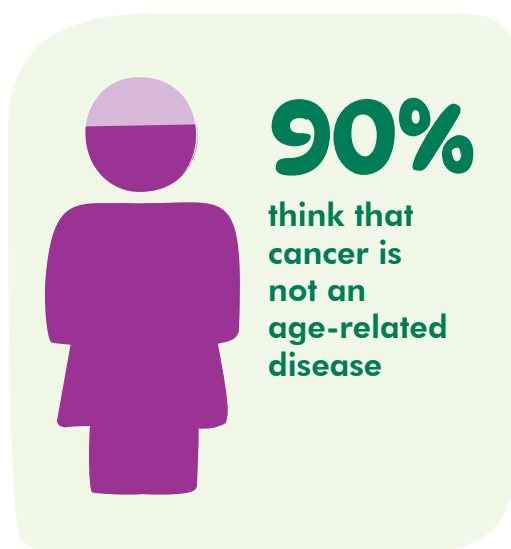
**'It was a shock. You think it won't be me – I'll be one of the lucky ones. It's a bit strange.'**

Woman, 66, South England

Previous research has identified later diagnosis of cancer among older people as a cause of poorer survival outcomes among older people<sup>22</sup>. As suggested above, if older people are unaware that cancer is a disease that is disproportionately likely to affect them, they may attribute symptoms to the process of ageing or other co-morbidities.

### 3.4 Perceptions of cancer as a 'death sentence'

Cancer has often been perceived as a 'death sentence'. However, improvements in long-term survival suggest that this is not the case<sup>23</sup>.



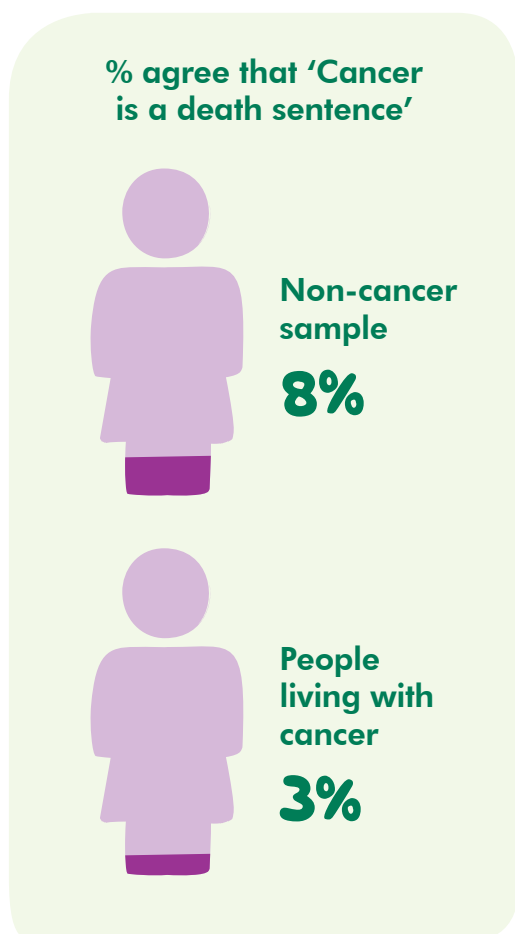
21, Page 2, 'The Rich Picture on older people with cancer', Macmillan Cancer Support.

22, <http://www.cancerresearchuk.org/about-us/cancer-news/press-release/2015-04-02-older-people-at-higher-risk-of-emergency-cancer-diagnosis>.

23, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/survival>

This research would suggest that people have recognised this change. Just 3% of people living with cancer aged 55 or over agree that cancer is a death sentence, compared with 89% who disagree with this statement. The non-cancer sample is almost as vociferous in their view; 8% agree that cancer is a death sentence, compared with 70% who disagree.

The slight variation can perhaps be explained by the fact that those survey respondents living with cancer tended to be in remission or cancer free (65%) or describe their cancer as localised or stable (19%). Just one in six (16%) were still undergoing treatment.



These findings represent a stark shift in public opinion. A 2012 survey of the UK general public, including a small sub-sample of cancer patients and carers, showed that 42% of respondents said that a diagnosis of cancer is a death sentence<sup>24</sup>.

Our qualitative research indicates that people are increasingly aware of improvements in survival rates. However, this does not necessarily explain why there has been such a sudden, recent change in perceptions around this issue<sup>25</sup>.

**'Attitudes towards cancer have changed a lot since I was younger... This is partly driven by the fact that people are much more likely to survive now than in the past. People don't think that cancer is a death sentence like they used to.'**  
 Woman, 56, South England

This is an encouraging finding, particularly given the evidence that the perception of cancer as a 'death sentence' may lead to fatalism, which in turn can impact upon health seeking behaviours or the willingness to consider treatment<sup>26</sup>.

### 3.5 'Generational change'

In both the depth interviews with people living with cancer and the focus groups with people who had never had cancer, participants talked about a 'generational change' regarding cancer; recognising that diagnosis, treatment and support for people living with cancer have improved. This has had consequences for the way that people think about cancer.

24, [http://pacenetwork.co.uk/pace\\_index](http://pacenetwork.co.uk/pace_index)

25, It is important to note that there are differences in methodology, sample and the precise nature of the question, but that is unlikely to account for the full variation.

26, Perceptions of cancer as a death sentence: Prevalence and consequences, Moser et al., Journal of Health Psychology, July 2013 <http://hpq.sagepub.com/content/19/12/1518.abstract>



**'People used to see it as a death sentence. You've got to understand, this is a generational thing as it was not spoken of when they first discovered it. But people know that treatment has improved, that you can recover, and people now talk about it.'**

**Focus group participant, older people without cancer, Northumberland**

While this idea of a generational change was a consistent theme that emerged from the qualitative research, it is not something that was explored in either of the surveys. Consequently, further research might look to explore this in more depth – in particular, to what extent this perceived generational shift does or does not affect behaviours around diagnosis, treatment, self-care, self-management and support seeking.

### 3.6 Coping with cancer

The research suggests that older people living with cancer often feel able to cope with cancer. This is demonstrated by the positive outlook on life that many respondents report. In addition, half of people aged 55 or over who are living with cancer (51%) agree that the life experience of older people allows them to cope better than younger people, compared with just one in seven (14%) who disagree. In fact, those who are aged 75 or over (67%) are almost twice as likely as those in the working age cohort (38%) to think that this is the case.

**'Maybe younger and older people have different outlooks on life and older people are able to cope with it a bit more. They are more mature and may be able to deal with it better. Older generations have had a greater exposure to cancer by seeing more people and members of their family go through it.'**

**Woman, 56, Midlands**

This is explored in more detail in relation to independence and support later on in the report. However, it is worth recognising that, while it is indicative of a positive attitude towards cancer among many people, this is not a homogenous view.

Previous research has recognised a 'dichotomy or continuum of empowerment'<sup>27</sup> regarding the way that older people react to a diagnosis of cancer. While there is the potential for a cancer diagnosis to lead to unexpected self-empowerment, this is not a universal reaction.

**'Cancer is not a death sentence but people fear the suffering and pain. They are afraid of the hurt it causes others. There is more suffering with cancer than other conditions.'**

**Focus group participant, older people without cancer, Leicester**

The in-depth interviews demonstrate that, even following an experience of cancer, there can be impacts for people living with cancer well into their remission. For some older people, the fear of cancer is likely to remain for the rest of their lives and continue to impact on how they live their lives and the decisions that they make.

**'I'm scared of a re-diagnosis. Despite being in pain, I haven't been to see the doctor again. If a mammogram showed that the cancer was back, it would be my own fault. There's always something on the horizon, like a holiday, and I don't want them saying "you need a blood test" and this and that right before a holiday.'**

**Woman, 63, Midlands**

27, 'Experiencing cancer in old age: a qualitative systematic review', Hughes et al., Qualitative Health Research 2009, 19:1139 <http://eprints.whiterose.ac.uk/83251/3/Hughes%5B1%5D.pdf>

4

# Attitudes towards screening, symptoms and diagnosis

## 4 Attitudes towards screening, symptoms and diagnosis

This section looks at attitudes towards symptoms and screening, and explores how these can impact on routes to diagnosis, delayed diagnosis and outcomes.

### 4.1 Routes to diagnosis

#### Summary

Evidence shows that early diagnosis improves survival rates for cancer and that late diagnosis is a cause of poorer outcomes for older people. The research indicates that there is confusion around screening for cancer. Generally, participants had low awareness of guidance of eligibility for different screening programmes and there were indications that health professionals were sometimes unsure about the exact guidance.

While the majority (64%) are diagnosed through a visit to their GP, depth interviews revealed that this non-emergency route to diagnosis may have happened by chance as part of a consultation about something else or may have been delayed because the patient disregarded symptoms when they first appeared.

The research suggest that while people no longer think of cancer as a death sentence, older people still consider it to be a terrible disease and may wish to delay knowing bad news.

As shown earlier, another explanation for delayed diagnosis may be due to a misconception around who cancer most affects; an overwhelming majority of people both living with and without cancer do not think that cancer is an age-related disease.

There are issues with the quality of communication with healthcare professionals regarding provision of details of diagnosis (stage of cancer for example) and getting a second opinion. Those aged 75 or over (39%) are more likely than those of working age (27%) to say that they were not told the stage of their cancer at diagnosis.

Early diagnosis, along with effective treatment, is a critical factor in improving survival<sup>28</sup>. Evidence suggests that older people are more likely than younger people to be diagnosed following an emergency presentation, which is associated with more advanced disease and poorer outcomes.

The first question in this section looks at routes to diagnosis. Among those aged 55 or over living with cancer, two in three (64%) say that their cancer was diagnosed when they went to see their GP because they thought something was wrong, while 17% say that it was via a routine cancer screening and only 6% via an emergency hospital admission. This is somewhat different from large scale analyses of NHS data, where a larger proportion of people were diagnosed following emergency routes<sup>29</sup>. This is probably a result of our sample being necessarily skewed towards people who have experienced a more positive cancer outcome.

## 4.2 Delayed diagnosis

Delays in diagnosis can be caused by delays in patients seeking help for symptoms, clinicians not recognising symptoms as potential cancer or a combination of both. Some participants in our research did identify delays by clinicians as being a factor.

**'I was told several times that my PSA count was rather high. They referred it to my GP and he said "It's a non-specific test anyway, I wouldn't worry about it", and he actually did nothing about it. That was for several years.'**

Man, 79, South England

However, the study highlights some patient attitudes that may have a potential impact on early diagnosis:

1. Cancer is not perceived to be an age-related disease by many people
2. Some people harbour a fear of diagnosis, and so despite noticing symptoms, they may avoid visiting the GP at an early stage.

### 4.2.1 Cancer not perceived as an age-related disease

As discussed in section three, many people are unaware that cancer is a disease that disproportionately affects older people and this is likely to be an important factor in understanding when older people are likely to seek advice from healthcare professionals.

**'I thought it [skin cancer] was a surface flaw. Until the specialist said it had to be cut out, I didn't take it seriously.'**

Man, 81, Dorset

### 4.2.2 Fear of diagnosis

The hypothesis that fear of cancer might delay diagnosis was presented to participants at the qualitative stage using a vignette (see appendices for the full text). Although a couple of participants felt this accurately reflected their own experience, generally others rejected this idea and said that they would always want to be informed of their health status. However, this may be due to poor recall of initial fears, given that participants tended to be in remission at the stage of interview.

**'Fear sometimes makes us avoid things. That might be an issue for some. They don't want to face up to the reality.'**

Woman, 83, Oxford

28, <http://www.cancerresearchuk.org/about-cancer/cancer-symptoms/why-is-early-diagnosis-important>

29, <http://www.cruk.cam.ac.uk/news/latest-news/older-people-higher-risk-emergency-cancer-diagnosis>

**'I would always want to know if there's something wrong with me.'**

Woman, 55, Scotland

**'I'm the opposite to Charlie (the vignette) – I would always want to know if there's something wrong with me.'**

Woman, 55, Scotland

There was a very different reaction among those who had not had cancer. Although some participants said that they would go straight to the doctor to check out potential cancer symptoms, others said they would keep quiet, think about it and/or hope that the symptoms would just go away. Despite acknowledging recent advancements in cancer treatment<sup>30</sup>, they were still concerned about what would happen to them, and their loved ones, if they were diagnosed with cancer. It should be noted that this was a view put forward by just a few participants across two focus groups, nonetheless, it may have implications for late diagnosis, if it is a view that is more widely held.

**'People don't want to mention cancer until they definitely know what is happening. They don't want to worry everyone. Older people are less open about cancer than younger people, but younger people are less expected to get it, and maybe that's why they talk about it more.'**

Focus group participant, older people without cancer, Northumberland

There was also some evidence about fatalism, with a few participants doubtful that a diagnosis could lead to effective treatment.

**'Due to my current medical conditions, it is extremely doubtful (at my age) that the NHS would opt to do anything about whatever they would find.'**

Woman, 61, West Midlands

It is worth emphasising that each of these quotes represents anecdotal evidence, which is not necessarily representative. Because these issues were not covered by the surveys, it is important not to extrapolate these findings to the whole population.

Macmillan may want to explore attitudes towards diagnosis quantitatively in future research projects, to test these hypotheses further.

### 4.3 Attitudes towards screening

Unsurprisingly given the age ranges associated with cancer screening programmes, people aged 60-69 are significantly more likely than younger or older counterparts to say that they were diagnosed as a result of cancer screening (23%, 16% and 13% agree respectively).

However, there appears to be some confusion about the eligibility of older people for screening. The NHS Bowel Cancer Screening Programme offers screening every two years to men and women aged 60-69. Beyond this cut-off point, people must make a request to continue regular screening, or 'opt-in'. Similar programmes are in place for other types of cancer, although eligible age ranges vary between schemes.

30, Cancer Research UK, Cancer survival for common cancers. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/survival/common-cancers-compared#heading-Three>

Of those aged 70 or over who say that they have participated in the named screening programmes, 21% say that they no longer opt-in. This rises to 26% when those who say that they are still eligible for screening are excluded. A caveat here is that there appears to be a degree of confusion about screening cut-off points.

When survey respondents were asked why they no longer opted-in, the responses suggest some uncertainty about eligibility.

**'I was not given the choice. I was told I could not have screening anymore.'**

Woman, 64, North West England

Other survey respondents reported an apparent confusion on the behalf of healthcare professionals.

**'I was told it [bowel cancer screening] wasn't open to people over 75.'**

Man, 80, Scotland

The older people who have not had cancer echoed this confusion. In the Northumberland focus group, participants were not aware that there were cut-off points for screening and could not understand why people beyond a certain age might not be screened, particularly if cancer is an age-related disease.

Members of the other focus group in Leicester shared this uncertainty, confusing the age at which routine screening stops with an actual block on screening. There was opposition to this (incorrect) opinion.

**'For our age, cancer screening is not possible. It's a shame it gets stopped. I feel there is prejudice in the NHS, that once you've reached 70, that's it.'**

Focus group participant, older people without cancer, Leicester

Respondents to the survey also suggested that more could be done to make screening attractive to older people.

**'Lack of dignity, appropriate privacy, sensitivity of staff, lack of clinics aimed specifically at more mature people.'**

Woman, 65, Unknown location

Given that the incidence of cancer rises sharply with age and that the median age of diagnosis is over 70<sup>31</sup>, each of these barriers represents a clear challenge and suggests that more should be done to encourage people to opt-in to screening programmes as they get older.

#### 4.4 Communicating with clinicians at the diagnosis stage

Two fifths (39%) of people living with cancer in the older retired age cohort say that they were not told what stage of disease they had when they were first diagnosed. By contrast, this is just one in four among people of working age (27%). This could mean that health professionals do not explain things as well to older people as they do with younger patients or that older people find it harder to understand the information that is being explained to them.

**'I was told that bowel cancer screening wasn't open to people over 75.'**

Man, 80, Scotland

**39%**  
of people living with cancer aged 75 or over say that they were not told what stage of disease they had when they were first diagnosed

31, Page 3, Evidence Summary: Patient Information for the NHS Bowel Cancer Screening Programme, Paul Hewitson et al, Cancer Research UK Primary Care Education Research Group BCPS Publication Number 4, November 2008 <http://www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp04.pdf>

When participants described their individual diagnoses, these reflected a range of experiences and preferences. On the one hand, it was suggested that a forthright, frank attitude from health professionals can be helpful. As we report in section three, many older people believe they are able to cope with cancer and what comes with it.

**'The consultant did not sugar coat it, he said "you have cancer but it won't kill you". I was shocked at the openness of his attitude but it was direct and reassuring.'**

**Man, 65, Northern Ireland**

However, others were less positive about the process of diagnosis. The suggestion was that necessary steps were not taken to explain what the diagnosis would involve.

**'I think the biopsy is one of the most barbaric and demeaning things they can do to a man. In the 21st Century, if they can't think of a better way to test for prostate cancer then that is disgraceful. I wasn't expecting that, I thought they were going to do something with my blood.'**

**Man, 69, Midlands**

In this instance, the participant felt that his poor care could be at least partly attributed the failure of staff to communicate effectively with older people. He felt that the nurses in particular talked down to him, 'as if because you are older, you are getting towards dementia'.

## 4.5 Challenging decisions

Existing research suggests that throughout the patient journey, older people living with cancer are less likely than younger people to challenge clinicians on decisions made about their care<sup>32</sup>. This tendency reflects high levels of trust placed in clinicians, particularly among older age groups; 71% of the older retired cohort living with cancer agree that healthcare staff know what's best for them, when it comes to decisions about cancer care, compared with 58% of those of working age.

Although further research would be required to confirm a causal link, it is possible that this trusting nature could result in poorer clinical outcomes, if patients take diagnoses or non-diagnosis and decisions about treatment at face value, and do not think to seek a second opinion.

32, Mulley, A., Trimble, C. & Elwyn, G. (2012) Patient's Preferences Matter: Stop the silent misdiagnosis, The King's Fund & The Dartmouth Centre for Health Care Delivery Science. [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/patients-preferences-matter-may-2012.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/patients-preferences-matter-may-2012.pdf)

**5**

# **Attitudes towards treatment**



## 5 Attitudes towards treatment

**One hypothesis for poorer clinical outcomes for older people with cancer is that they are less likely to receive appropriate treatments than younger people<sup>33</sup>. This section explores a number of possible reasons for this, as well as implications for patient involvement.**

### Summary

One suspected reason for poorer clinical outcomes for older people with cancer is that they are more likely than younger people to reject appropriate treatments and care – possibly due to fear of side effects, fear of not being able to cope and other attitudes this research has sought to explore.

The findings challenge the notion that older people are more likely to actively choose not to have treatments. Across all age groups, few people opt-out of treatment all together. However, the survey does show that the working age cohort is the most likely to report having received a range of treatments. Potential reasons for this identified in the depth interviews include: not being explained the options at the treatment stage, a tendency for older people to be more trusting of clinicians and a reluctance to challenge decisions or ask questions.

While it is difficult to disentangle these factors, it does suggest that some older patients are being denied treatment which they might have been offered if they were younger.

While around half of both survey samples agree the ‘side effects’ of treatment are often worse than the disease, this sentiment is stronger among those without cancer, as well as in people still undergoing treatment. Having come through treatment appears to have a tempering effect on this fear of potential side effects.

The in-depth interviews revealed differences in attitudes to physical and social consequences of treatment. Those beyond retirement age felt it would be worse for younger people who they thought might have more at stake. They tended to take physical impacts in their stride, yet had concerns about impacts on their independence, which they kept to themselves.

33, Reducing cancer equality: evidence, progress and making it happen, 2010, National Cancer Equality Initiative [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_114354.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114354.pdf)

### 5.1 Impact of treatment

There is evidence which suggests that people sometimes perceive the consequences of cancer treatment, both clinical and non-clinical, to be worse than the disease itself<sup>34</sup>. This is supported by the survey data, with around half of both samples, of all ages, largely agreeing with the statement ‘the side effects of cancer treatment are often worse than the disease’.

More of the non-cancer sample than the sample of people living with cancer agree (53% vs 46%) with the statement. This suggests that personal and direct experience of treatments helps to dispel fears and misunderstandings around consequences. Stage of cancer at diagnosis does not appear to impact attitude, as people diagnosed with more advanced cancer share the same views as those diagnosed with cancer before it has spread.

In conducting the qualitative interviews, we found that people who had been through cancer treatment reported mixed experiences. There were suggestions that sometimes the consequences of certain treatments (particularly chemotherapy) can be exaggerated, with the reality not always as bad as feared.

**‘Chemotherapy wasn’t that bad for me. People think it’s the worst treatment you can have but it really wasn’t.’**

Woman, 61, London

**‘Yes, you do get side effects, but they’re no way near as bad as they (the media) make out.’**

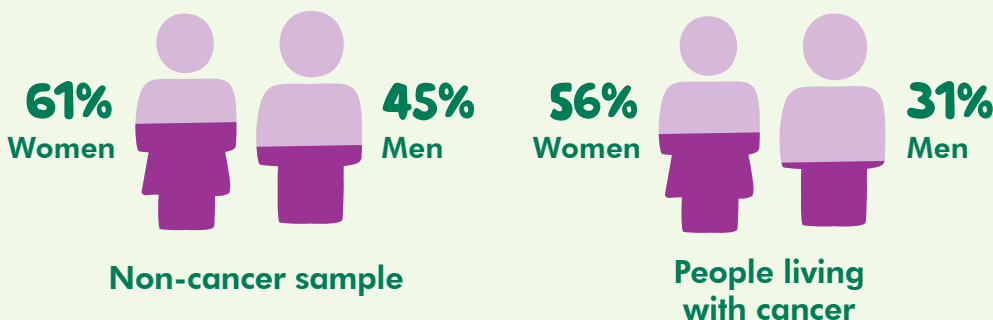
Man, 75, North of England

This suggests that improving patient understanding of the potential consequences might improve take-up of certain treatments.

Women are more likely than men to agree that the side effects of treatment are often worse than the disease. Among those without cancer, 61% of women and 45% of men agree, compared with 56% of women and 35% of men living with cancer. There was no conclusive explanation for this finding, however we can speculate that it may be due to specific concerns related to the consequences of breast cancer treatment (52% of women surveyed had been diagnosed with breast cancer).

**53%**  
of people who have never had cancer aged 55 or over agree that ‘the side effects of cancer treatment are often worse than the disease’.

#### % agree that ‘the side effects of cancer treatment are often worse than the disease’



34, Page 613, ‘The needs of older people’, Christopher Bailey, Cancer Nursing: Care in Context 2008, edited by Jessica Corner, 2008 <https://books.google.co.uk/books?id=R17eS2Z8DHM-C&pg=PA613&lpg=PA613&dq=older+people+attitudes+towards+cancer+fear&source=bl&ots=pl7wPHTiB&sig=veX-7f8NzRIGQU2-mvV-XlNN-PwLo&hl=en&sa=X&ei=W-FqeVZq1Kube7Aakp4XY-BQ&ved=0CEMQ6AEwBA#v=onepage&q&f=false>

**'If you have to have chemotherapy and it will save your life – it's a necessary evil.'**

Older person without cancer, Northumberland

Among those living with cancer, increasing age means that people are less likely to agree that the side effects of treatment are worse than the disease; 57% of working age people compared with 42% of the older retired agree that this is the case. By comparison, there is no age trend among the non-cancer population.

There were some indications from the depth interviews that those of retirement age and above felt better equipped to deal with cancer and had relatively less to worry about in terms of consequences of treatment (eg family to look after, jobs to hold down, mortgages to pay) and they were generally more stoic about such worries (something which is explored in more detail in section 7).

**'You see the way that chemotherapy affects these young women and you think: that's awful for them.'**

Woman, 93, London

An alternative view was that, while physical impacts of treatment can be difficult, they are ultimately worth it.

**'I've been left with some problems lifting my arm, but it's a small price to pay.'**

Woman, 78, Brighton

The qualitative research found that others in the post-retirement age group were concerned about potential physical impacts of treatment and how they could have negative consequences for their quality of life, particularly in regards to their independence – something which the research shows is relatively less important to the working age group. Participants said that treatment can be traumatic, leaving patients with consequences they did not anticipate and interfering with daily activities.

**'If the treatment is going to make your quality of life so bad that it's not worth living, then don't have the treatment.'**

Man, 69, Nottingham

Not all people felt that they received the necessary information to make an informed decision about treatment, particularly in relation to side effects.

**'I didn't know when I had chemo that mouth ulcers would be a side effect.'**

Woman, 83, Oxford

### Case study: I think I was over treated

**Morag is 64 and has been undergoing treatment for the last five years.**

She is now in remission, but has been through a long treatment regime that consisted of a mastectomy and reconstruction, removal of the infected breast implant, chemotherapy, radiotherapy, a second reconstruction, removal of the implant due to a second infection and hormone treatment. The treatments had a range of side effects including prolonged tiredness, depression, sickness and carpal tunnel syndrome which required corrective surgery.

Morag is not sure why she had both chemotherapy and radiotherapy and therefore believes she may have been 'over-treated.' The explanation given to her by oncologists is that 'it is better to be safe rather than sorry'.

She felt she was not given much choice in her treatment – on asking about a procedure she had

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read about online, she was told it was not possible to arrange. In retrospect, she wishes she had insisted on it.

**'I was tired and didn't want confrontation.'**

Despite this she agrees she was made aware of the many side effects of the chemotherapy and the two operations; however she was not prepared for how radiotherapy would make her feel nor did she feel that she had been properly pre-warned about the effects of Tamoxifen and Zoladex. She considered that the chemotherapy was not as bad as the radiotherapy.

Evidence from the focus groups provides further support to the survey findings, demonstrating that people aged 55 or over who have not had cancer can have a more negative attitude towards treatment than those who have had cancer. It was reported by those without a prior diagnosis of cancer that if diagnosed with cancer, there might be caution about committing to treatment options, as they had heard from friends and family that consequences can adversely affect quality of life, and that treatment is not always successful in tackling the disease. The quotes below highlight this.

**'Some of my friends have had treatment which has put them through a lot and ruined their quality of life, and ultimately they died.'**

**Focus group participant, older people without cancer, Northumberland**

**'Treatment in the NHS can be bad. For example, they are afraid to medicate and relieve pain. You want to be treated with dignity.'**

**Focus group participant, older people without cancer, Leicester**

It is therefore possible that some older people are basing decisions on reported experiences of treatment that may be outdated. However, it is worth reiterating that attitudes towards treatment do not become more negative as age increases.

## 5.2 Choice in treatment

Previous research has indicated that older people are less likely to receive active anti-cancer treatments, with suggestions that this may be because older people are more likely to opt out of receiving certain treatments<sup>35</sup>.

This research demonstrates that – when offered treatment – people will usually opt to receive it (only 2% have opted out of any treatment although 14% have opted not to have certain treatments at some stage)<sup>36</sup>. There is no significant difference by age group or stage of cancer at diagnosis on the likelihood of people to opt out of a certain treatment – 15% of people diagnosed with stage 1 or 2 cancer have opted out, vs 12% of stage 3 and 4, for example.

However, there does appear to be some link with treatment type. 1 in 10 (9%) of those aged 55 or over who say they have had chemotherapy report having opted out of another treatment, and this rises to 24% of those who say that they have had 'other' treatments.

35, December 2014, CRUK and NCIN released a report showing that older people were less likely to get surgery (<http://www.cancerresearchuk.org/about-us/cancer-news/press-release/2014-12-05-older-cancer-patients-missing-out-on-surgery>) CRUK's head of statistics said: "We need to understand what is driving this difference... A patient may decide they don't want to undergo surgery... We clearly need more research to better understand the reasons why some older people may be missing out."

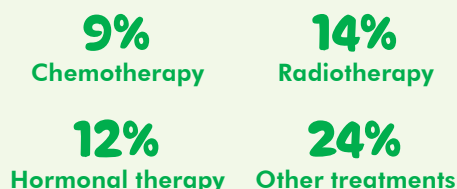
NHS England 2013 published a report showing that older people were less likely to receive chemotherapy, the report (<http://www.england.nhs.uk/wp-content/uploads/2013/12/old-people-rec-cancer-drugs.pdf>) said: "...there may well be good reasons for some decline in chemotherapy rates with age, including co-morbidity and frailty, patient preference and, in some cases, alternative forms of treatment."

36, It should be noted that 65% of those who took part in the survey are currently in remission, which may in part explain this finding, given that those who refuse treatment are likely to have poorer survival rates

**'I felt they were deciding at times if my age hindered how I would cope with the treatment.'**

Man, 62, Shropshire

**'I opted not to have certain types of treatment', by treatment type received**



Given that we do not know which specific treatment they have opted out of, we cannot fully explain this finding without further research.

People in the working age cohort are significantly more likely than those aged 75 or over to have experienced multiple treatments. They are significantly more likely to say that they've had surgery (80% vs. 67%), radiotherapy (41% vs. 33%), chemotherapy (36% vs. 16%) and hormonal therapy (22% vs. 18%).

This supports evidence that the intensity of treatment offered to people reduces with age. There will often be good clinical reasons for this, but participants in our research reported that they did not feel involved in these decisions.

**'I didn't feel like I was involved in the decisions'**

Woman, 78, Brighton

### **Case study: Opting not to have chemotherapy**

Graham is 69 and lives alone in Nottingham. When he was diagnosed with prostate cancer seven years ago, he was unhappy with how he was treated by staff, as he felt they treated him 'like a number to be processed'.

He was told he had only two years to live, and that there was little that could be done, with the exception of chemotherapy.

Graham opted not to have chemotherapy as he felt the side effects would be too severe. He contacted Macmillan, who directed him to a website where he could search for a new consultant. He did some research and settled on a new one several hours from his home. Despite the travel, Graham is pleased as he now feels included in decisions about his treatment, and is satisfied with his current course of hormones and steroids, which allow him to do the things he enjoys in life without being invasive.

Graham would advise others in his position to 'learn all you can about your cancer, then you are in a much better position to know if you are being fobbed off'.

The qualitative research suggests that older people are also more likely to accept information provided without questioning.

**'My son always goes to look things up and find out more; I would never think to do that if a doctor told me something.'**

**Man, 75, Northern Ireland**

This is supported by previous Ipsos MORI research which has shown that older people are less likely than younger people to say that they would search for information about possible treatments if they were diagnosed with cancer<sup>37</sup>.

Linked to this, there is also clear evidence from the Cancer Patient Experience Survey that older people do not receive the same opportunities to take part in clinical research trials, which may provide alternative options for patients<sup>38</sup>.

37, Cancer – A Public Priority? Attitudes towards cancer treatment in Britain (August 2006). <https://www.ipsos-mori.com/Assets/Docs/Archive/Polls/cancerbackup-report.pdf>

38, 2014 National Cancer Patient Experience Survey <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-national-reports>

6

# Attitudes towards care

## 6 Attitudes towards care

This section looks at the attitudes of people living with and without cancer about cancer care, as well as the perceptions of people living with cancer towards the care they received during their cancer journey.

### Summary

There is a perception that older people may be treated differently by the health system due to their age, with a majority of those aged 55 or over in both groups surveyed stating there is at least some prejudice against older people with cancer in the UK (62% of those living with cancer; 58% of those without cancer).

However, in terms of personal experience, a relatively small proportion feel that they have experienced this directly, with only one in nine (11%) agreeing that sometimes healthcare staff made decisions about their cancer care based on their age and not how fit they were. This echoes a 'perception gap' observed by existing research in the general population. It appears that older age groups

have a more positive outlook on their care and treatment. The qualitative research indicates that this may be because older people may sometimes be trying to see the best in their care and treatment, rather than confronting the worst. If older people are receiving poorer care, and this goes unreported, this may have some consequences for patient outcomes.

The contradiction is also an important consideration when studying the attitudes of older people in relation to their cancer and the care they receive; positive responses are not necessarily indicative of appropriate treatment and care. It is an important challenge when designing services and support for older people.

We found that among those aged 55 or over, one in nine (11%) people agree that sometimes they felt that healthcare staff made decisions about their cancer care based on their age and not how fit they were.

When asked explicitly, majorities of both survey samples perceive there is prejudice against older people in the UK health system (84% of people living with cancer aged 55 or over and 82% of those without cancer). This is largely consistent across Great Britain; although that sentiment is particularly strong in England (21% strongly agree in England vs 3% in Wales and 15% in Scotland).

When it comes to prejudice specifically against older people with cancer, the proportion agreeing drops to 62%. The depth interviews indicate that it is hard for people to definitively say whether they were treated differently because of their age, but they suspect an element of this. This might help to explain why only a quarter (26%) of those asked say there is no prejudice at all.

**'I wouldn't have thought you were treated differently. Maybe if I were in my 80s I don't know if they'd do it differently.'**

**Woman, 63, Midlands**



## 6.1 General attitudes versus personal experience

Previous research by Ipsos MORI has documented a ‘perception gap’ between the public’s perceptions of the NHS in general and their own personal experience<sup>39</sup>. This perception gap is echoed in the current study; there is a disparity between the perception that older people living with cancer experience prejudice – (62% say there is prejudice in the NHS towards older cancer patients) – and personal experience of being judged on their age rather than general fitness (11% agree this has happened). This varies little between age groups, however does rise to 20% for those diagnosed with stage 3 or 4 cancer.

**‘On one occasion I was told “after all you are a good age”. That was three years ago when I was 75!’**  
Man, 78, Scotland

This gap may be explained by a coping mechanism described in some of the qualitative interviews. Interviewees felt that participants were sometimes trying to see the best in their treatment, rather than confronting poorer aspects of their care. Additionally, it may in part be indicative of the methodology; we largely spoke to people in remission who might be grateful to have survived cancer, regardless of difficulties they might have had during their clinical journey.

While participants typically summed up their overall experience of staff as positive, there was evidence of elements of care which could have been improved. While expressing satisfaction with care, participants spoke of occasions where they had felt discriminated against, such as

having to wait for younger people to be seen before them in hospital, or not getting the full attention of healthcare professionals.

**‘I thought I was treated very well at the time, but with hindsight looking back, I can only say that the treatment that we’ve had since coming here is far, far better than what we were receiving before.’**  
Man, 79, South England

Furthermore, as demonstrated by Ruari’s experience in the case study ‘Doctor knows best’, some people wish to devolve responsibility in decision-making to professionals and doing so can involve overlooking examples of care that could be improved.

## 6.2 Age related trends in attitudes

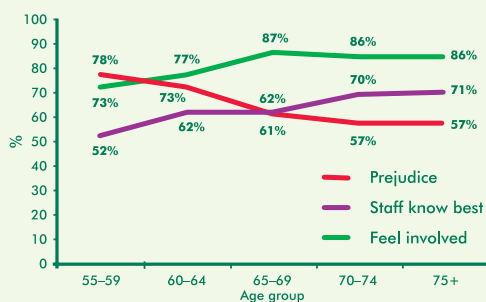
There is evidence that, the more patients are actually involved in decisions about their care, the more likely they are to receive positive outcomes<sup>40</sup>. Not only are the oldest age groups less likely to perceive prejudice (57% of those aged 75 or over vs. 75% of those in the working age group perceive prejudice in the UK against older cancer patients), but they also tend to feel more positively about their level of involvement in their care and treatment (86% aged 75 or over agree they felt as involved as they wanted to be in decisions about their care and treatment compared with 75% of the working age group).

39, Ipsos MORI, Public Perceptions of the NHS and Social Care (2012) conducted on behalf of the Department of Health. More than three quarters of people agree that my local NHS is providing me with a good service (77%). However, two in three agree that the NHS is providing a good service nationally (66%), and only just over a quarter agree that the government has the right policies for the NHS (27%).

40, Empowering patients to make more informed decisions by measuring their needs and satisfaction [http://www.academia.edu/341166/Empowering\\_Cancer\\_Patients\\_to\\_make\\_Informed\\_Decisions](http://www.academia.edu/341166/Empowering_Cancer_Patients_to_make_Informed_Decisions)



**% agreement that 'there is prejudice against older people who have cancer, staff know best, feel involved in decisions'**



However, evidence from the Cancer Patient Experience Survey demonstrates that, while older people tend to report a more positive overall experience, there are elements of care where their experience is significantly less positive<sup>41</sup>.

This may be linked to their higher rates of trust in healthcare professionals. Again, this chimes with findings from the Cancer Patient Experience Survey (89% of those aged 76 or over say they have confidence and trust in doctors treating them, decreasing steadily to 79% of 36-50 year olds)<sup>42</sup>.

**'I thought that he was the doctor and he did this all day every day so he would know what the best route for me was. I trusted him because he was in a position of authority.'**  
Woman, 63, Midlands

## Case study: Doctor knows best

Ruiari is a 66 year old divorcee living alone in Belfast. He was first diagnosed with throat cancer in 2010 when his GP was suspicious about a lump in his neck. He had two surgeries and a course of radiotherapy and has been in remission for three years.

Ruiari had no complaints about the care he received throughout his cancer journey and had nothing but praise for the NHS staff involved (nurses and doctors alike) and the support he got elsewhere. Ruiari claimed he was fully informed about his treatments and care, and felt as involved in decision making as he wanted to be. He did not get a second opinion when diagnosed and agreed to have surgery quickly after his biopsy.

**'I decided to put my life in the hands of consultants. I handed it all over to the doctors and had no difficulty with that. I adopted an optimistic outlook and trusted them.'**

However, when Ruiari went to hospital to prepare for his first surgery, he was not told that the doctors would not be removing the cancerous lump. When he woke up from the operation, he was surprised to find that only his tonsils had been removed and that the cancerous lump would be taken out during a second operation in six weeks' time.

**'I did think, why did they do that? But they explained it well afterwards and I could see why they did it. I did not feel it was necessary to argue.'**

41, Cancer Patient Experience Survey (CPES) – those aged 66-75 are more likely than their younger counterparts to feel their views were taken into account when clinicians were deciding treatment options (73% 66-75s vs 67% 16-25s), yet they are least well informed about side effects (51% of those aged 76+ report being told about side effects that could affect them in the future, compared to 65% of 16-25s).

42, 2014 National Cancer Patient Experience Survey <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-national-reports>

7

# Attitudes towards independence and support

## 7 Attitudes towards independence and support

**44%** of people aged 75+ living with cancer say that being independent for as long as possible is most important to them.

This section looks at support needs and support seeking behaviours of older people living with cancer, and how these vary by a range of different sub-groups. For important context, it starts with a discussion of the importance of independent living among older people, irrespective of whether they have experienced cancer or not.

### Summary

Counter to received wisdom, people in the pre-retirement age cohort are most likely to say they have avoided asking family and friends for help due to feeling like a burden. This challenges the view of older people being disproportionately worried about such things.

The picture around support is naturally more complicated than this. There are indications from the research that even though older age groups are less likely to say they avoid visits to the doctor, they can be more reserved in their interactions with healthcare professionals than their responses to attitudinal questions may suggest. Additionally, the qualitative research suggests they may limit discussions to medical matters and not explore concerns around their social and emotional needs.

Differing expectations of support is a factor that needs further examination. While there appears to be little difference by age in support received overall, the working age cohort are more likely to feel that they are not receiving enough support. The qualitative research indicates that older people living with cancer can be more reserved about asking for support, with low expectations of what is available, and concerns about how it might compromise their independence. Indeed, independence becomes increasingly important for people living with cancer as they get older. The qualitative research suggests that to some, receiving support might signify a loss of independence and this may have consequences for recovery and self-management.

### 7.1 The importance of independence

It has been suggested that one of the reasons that older people experience poorer outcomes than younger age groups is because they are less likely to seek out support which may be seen to compromise their independence<sup>43</sup>.

This research demonstrates that independence is seen as a major priority by older people, alongside staying healthy. When asked to choose what is most important to them as they get

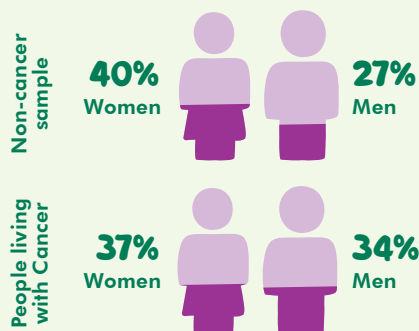
older, a third of both people with cancer (35%) and the non-cancer sample (34%) say being independent for as long as possible. Independence is particularly important for the older retired cohort. For people living with cancer in this age group, being independent becomes as equally important as staying healthy.

Being independent is also particularly important for people who live on their own, with almost half (47% of all people with cancer aged 55 and over and 46% of those without cancer) saying this, and appears to be more important for women living with cancer than men.

43, I'm Still Me: [http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/im\\_still\\_me.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/im_still_me.pdf)

The report *The outcomes and experiences of older women with breast cancer: driving progress in the new NHS*<sup>44</sup> describes how it is important to understand and address the wider needs of older women if their clinical outcomes are to improve, as well as making a real difference to individuals' lives.

### % who say that being independent for as long as possible is most important to them as they get older



In addition, co-morbidities and poor health appear to be a factor in prioritising independence. Almost half (45%) of those aged 55 and over and living with cancer with three or more long-term health conditions prioritise

independence, compared to a third (34%) of those without long-term conditions. Likewise, 49% of those who experience difficulties with three or more everyday tasks say that remaining independent is the most important for them, compared to 30% of those who do not experience any difficulties. Additionally, half (51%) of those who rate their health as 'Poor' also say this compared to 33% of those who rate their health as 'Excellent/very good'.

The research demonstrates that for many of those most in need of support, independence can be as much of a priority as prolonged health. Despite this, the Joseph Rowntree Foundation's report, *A Better Life: Valuing Our Later Years*<sup>45</sup>, suggests that older people are often treated as dependents, lacking the rights of younger people. This, coupled with evidence from later in this report which demonstrates that older people are less likely than younger people to receive (and demand) support, suggests that the health and care system needs to better enable older people to strike a balance between independence and support, which may improve self-management and well-being.

## Case study: Fiercely independent at 85

**Joyce is an 85 year old woman living alone in Manchester. She has had cancer twice; cervical and breast cancer. Despite being in her mid-80's Joyce is very independent. She does not have any close family, is not married and does not have children. Up until the age of 83 she used to drive to Spain and Portugal every year, but gave that up when she started having mobility problems.**

Despite having to give up her annual drive to the Continent, Joyce still feels young and drives around locally.

**'I don't think of myself as old. Even though I am!'**

At 83, Joyce used to drive herself to the hospital for radiotherapy treatment. She is very pleased with the treatment she has received.

**'After a while I didn't think it was necessary for someone to come with me to my appointments.'**

44, The outcomes and experiences of older women with breast cancer: <https://www.breastcancercare.org.uk/sites/default/files/files/outcomes-experience-older-women.pdf>

45, Joseph Rowntree Foundation: *A Better Life: Valuing Our Later Years* (2013) <http://www.jrf.org.uk/sites/files/jrf/older-people-support-full.pdf>





## 7.2 Not wanting to be a burden on friends and family

This research indicates that some people living with cancer aged 55 or over may not seek support because they do not want to feel like a burden on others, in particular their friends and family. This is evidenced in both the quantitative research and also in the qualitative interviews, where participants would often be reluctant to seek both formal support and support from their loved ones.

**'My friend who's the same age as me, she never thinks of asking anybody for any help either.'**

Woman, 81, London

People who have cancer are far more likely than not (55% compared to 24%) to say that they sometimes will not ask for help because they do not want to be a burden on other people.

**'I didn't go out of my way to look for any support...If anything, I kept it from friends and family.'**

Man, 81, South of England

Younger respondents are significantly more likely than older respondents to not ask for help because they do not want to be a burden. Two-thirds (66%) of those of working age agreed with this statement compared to half (49%) of people aged 75 and over.

It could be that the working age group may feel they could potentially be more of a burden because they may be letting down employers, people who rely on them for care, their children and so on. The quantitative research indicates that this age group would find financial support and support from an employer useful significantly more than older groups (see section 7.6).

Two thirds (67%) of those with three or more long-term conditions, and 65% of those who experience difficulties with three or more tasks agree that sometimes they do not ask for help because they do not want to feel like a burden on others, suggesting that those more in need of help can be less likely to request it. The relationship between support needs and reluctance to seek support is something that could be explored in greater depth in future research.

Reluctance to ask for help decreases when respondents are asked about getting help from health and care staff, specifically. While the majority of people aged 55 or over living with cancer (64%) disagree that 'there have been times during my cancer journey I have not gone to see healthcare staff because I didn't want to waste their time', one in five people (19%) agree with this statement. People aged 55-64 are more likely to agree than those aged 65 or over. Evidence from the qualitative research illustrates the minority opinion; a repeating theme was the view that health and care professionals were busy and did not have a lot of time; in some cases this put participants off from going to see them.

The bubble diagram below is an example of what an older person in Northumberland characterises an imagined interaction with a doctor about a cancer diagnosis.



**'You know people have commitments, so you don't want to burden them...'**

Woman, 83, South of England

**67%** of people living with cancer that have three or more long-term health conditions sometimes do not ask for help because they do not want to feel like a burden on others.



**'I was told I had six months – two years to live, and that was it. I had no one to talk to about it. A couple of friends, but you can't get too heavy.'**

Man, 69, Midlands

People with cancer are more willing to seek support from health and care professionals than from family and friends. The qualitative research supports this contention, although more research into these differences in attitudes could be beneficial. Participants did not want to worry loved ones, sometimes taking this to extremes by not informing them of the

cancer at all. They described how they played down their cancer as a means of protecting other people's feelings.

**'I had an ex-wife living in England and my son and daughter...at the time I didn't want them to know... not to worry them.'**

Man, 65, Belfast

### Case study: Stoicism and outside support

**Alex is a 79 year old man living with his wife in Southern England.**

He was diagnosed with prostate cancer, and treated with radiotherapy. He was very private about his health and found support in his religion. He chose not to tell his close family about his cancer as he did not want to worry them.

**'We didn't tell the family at all. But we did mention it to our minister at the church. We didn't tell my younger son...we still haven't told him, in fact.'**

Alex says that he would have liked someone to talk to from Macmillan Cancer Support, but he did not feel as though his disease was serious enough to deserve support.

**'I'd have liked to have popped into Macmillan's and talked to someone...but it was an embarrassment – am I serious enough to be in here?'**

## 7.3 Moral support and encouragement

Previous research by Macmillan suggests that a significant number of people living with cancer do not feel they have any moral support from their friends or family<sup>46</sup>. While the current research shows most people living with cancer aged 55+ say that they had someone to speak to for moral support and encouragement (82%), there is still 1 in 11 people (9%) who say they do not have someone to turn to.

People who are pre-retirement age are much less likely to say that they have someone they can turn to. A fifth (20%) of those aged 55–59 and 12% of those aged 60–64 disagree with this. This links to the findings which suggest that retirement can have positive impacts for people, as they have more time to themselves to cope with cancer and are less likely to be distracted or worried about work responsibilities or childcare for example.

As demonstrated earlier, people with higher health needs might not have as much support as they should have. A higher proportion of people with lower self-rated health say that they do not have someone to turn to; 21% of people who rated their health as 'poor' disagree with this compared to 8% who said that their health was 'excellent' or 'very good'. Additionally, one in eight (13%) people with three or more

46, Macmillan Cancer Support 2013: Facing the Fight Alone: Isolation Among Cancer Patients [http://www.macmillan.org.uk/Documents/AboutUs/MAC13970\\_Isolated\\_cancer\\_patients\\_media\\_reportFINAL.pdf](http://www.macmillan.org.uk/Documents/AboutUs/MAC13970_Isolated_cancer_patients_media_reportFINAL.pdf)

long-term health conditions disagree that they have someone to turn to for moral support, compared with 1 in 20 (5%) who do not have any long-term conditions.

Among depth interview participants with at least one person to turn to for moral support and encouragement, there was still evidence of reticence about receiving such support. Moral support did not always come from those closest to the person living with cancer and included the church and other religious groups and other support groups as described below.

**'I found a lady through the AA who had cancer 18 months before I got it and I asked her about how she dealt with it emotionally. That was useful.'**

Man, 65, Belfast

## 7.4 Age and support

Opinion is divided on whether 'sometimes older people get less support than younger people'. Around the same proportions agree (32%) and disagree (30%) with this statement, with a further 38% saying that they neither agree nor disagree or that they don't know.

Younger people living with cancer tend to agree more with this statement, with 8% of those who are working age strongly agreeing that older people sometimes get less support, compared to only 3% of the older retired cohort. This ties in with a recent research project conducted by Macmillan (2015)<sup>47</sup>, examining the use of Electronic Holistic Needs Assessment tools. It demonstrated that, in the sample group surveyed, older people (aged 65–74) were less likely to receive various forms of support than younger people (aged 0–64). While the methodologies and

samples are very different, a consistent theme appears to emerge.

A consistent theme in the qualitative research was the sometimes reserved and stoic nature of older people, coupled with a greater trust in healthcare professionals. The 'stiff upper lip' attitude of some older people may prevent them from being identified as needing support or stop them from seeking out support. It was purported that younger people may be better at getting support because they are better at sharing their worries and concerns and at attracting the attention of health and care professionals.

**'Younger ones on chemo get very emotional and maybe get more attention than older people who rein it in a bit more. I think younger people are given more staff time... But we are all scared of cancer underneath it all.'**

Woman, 64, London

Belief that younger people can get more support than older people may also tie into ideas of prejudice against older people in health and social care services. There was a perception from the qualitative research that sometimes older people are seen as less of a priority than younger ones.

**'I hate to say this, but it's almost like they are culling the older people. The best treatment will go to the younger ones who have potentially a longer lifespan left.'**

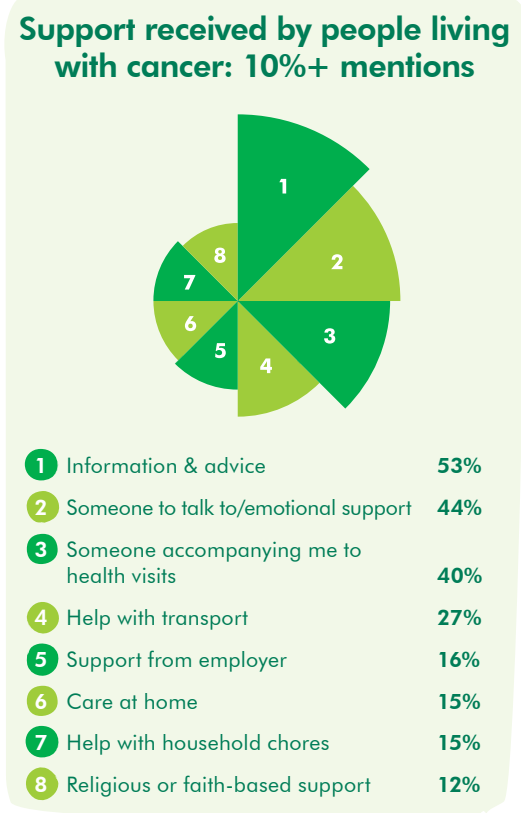
Man, 69, Midlands

## 7.5 Types of support received

The most common form of support that people aged 55 and over living with cancer received during their diagnosis,

47, Macmillan Cancer Support (2015): Electronic Holistic Needs Assessment (eHNA) – analysis of data on older PLWC

treatment or aftercare is information and advice on things such as cancer, treatment and support (53%), followed by having someone to talk to/emotional support (44%). The qualitative interviews support this – participants regularly spoke about having someone who has provided them with useful emotional support.



There were not significant differences by age group in the likelihood to say they receive support overall, which differs from findings from Macmillan’s previous research<sup>48</sup>, which suggested that older people (aged 65–74) were less likely to receive various forms of support than younger people (aged 0–64). However, there are clear methodological differences between the current research and Macmillan’s research into the Electronic Holistic Needs Assessment; the current research exclusively examines those aged 55+ living with cancer, whereas Macmillan’s research also included younger age groups.

There are variations found within the quantitative research regarding the types of support that different age groups receive. Older groups are significantly more likely to say that they had religious or faith based support. 2 in 10 (19%) of those aged 75 and over say this compared to only 1 in 10 (10%) people who are of working age. This finding is supported by the qualitative research, where some older participants noted the support that their religion had given to them.

**‘I’ve been brought up as a Christian and my faith has meant a great deal to me all along...a great help and support to me.’**  
 Woman, 83, South of England

Those who live with a spouse or partner are significantly more likely than people living on their own or with other people (typically children) to have received certain kinds of support. More commonly they have received the following types of support: information and advice on cancer, treatment and support; (57% said this compared to 45% living alone); someone to talk to/emotional support (48% said this compared to 39% living alone); and someone accompanying them to health visits (45% said this compared to 31% living alone). This would suggest that people who might have greater support needs are not necessarily having them met. These findings support Macmillan’s research into the isolation of people living with cancer, which highlighted a significant proportion of people who do not have support from family or friends<sup>49</sup>.

The survey results indicate that one in five people with cancer aged 55 and over (20%) have not received any support at all. Men are more likely to say that they have not had support than women (24% of men compared

48, Macmillan Cancer Support (2015): Electronic Holistic Needs Assessment (eHNA) – analysis of data on older PLWC.

49, Macmillan Cancer Support 2013: Facing the Fight Alone: Isolation Among Cancer Patients [http://www.macmillan.org.uk/Documents/AboutUs/MAC13970\\_Isolated\\_cancer\\_patients\\_media\\_reportFINAL.pdf](http://www.macmillan.org.uk/Documents/AboutUs/MAC13970_Isolated_cancer_patients_media_reportFINAL.pdf)

to 14% of women). One in five (19%) feel that more support should be available to them, although 44% feel as though they have sufficient support.

Again, younger groups are more likely to feel that they are not receiving enough support, with 3 in 10 (29%) of working age people agreeing that more support should be available to them. This is more than double the proportion (14%) of people living with cancer aged 75 and over who think this. This may suggest that either younger people need more support than older people, or that older people's awareness of and expectations of support are lower.

Indeed, the qualitative element of this research suggests that older people living with cancer do have lower expectations of what support they can expect; older participants were largely grateful with the medical or clinical care they had received and were reticent about wanting more or other forms of assistance.

**'I don't think I'd get any help from them [Macmillan nurses]... I managed as it was, on my own.'**  
Woman, 81, London

This reinforces the notion that older groups can be reserved about getting their needs addressed, as the following verbatim comment demonstrates very clearly.

**'I don't think I need any support particularly...I'm on my own a lot, I could do with a bit more company, but I'm alright really.'**  
Woman, 81, London

## 7.6 Types of support older people living with cancer would find useful

Consistent with earlier findings, younger people living with cancer are significantly more likely than their older peers to say that different forms of support would be useful. For example, almost half (46%) of working age people said that they found/would have found someone to talk to/emotional support as useful during their cancer journey. This is significantly higher than for those in the older retired cohort (35%). This supports the notion suggested in the qualitative research that older people can be stoic and reserved, especially about receiving emotional or social support. It also supports the notion from the quantitative research that suggests that older people feel better able to cope with cancer than younger people. Higher proportions of working age people (30%) also say that help with transport would be useful to them than proportions of those aged 75 and over (21%).

There are differences by gender in the types of support that people living with cancer would find useful, most significantly regarding emotional support. Half (48%) of women say that someone to talk to/emotional support would be useful for them, compared with a third (36%) of men. This finding supports previous research into gender differences in people living with cancer seeking support<sup>50</sup>; men generally seek less support for health problems than women.

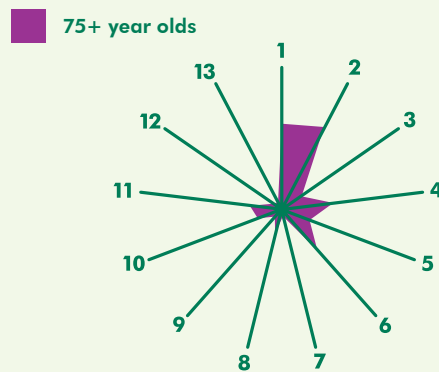
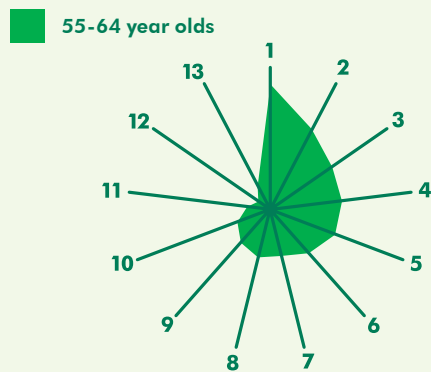
The types of support that people would find useful are shown below by the youngest and oldest age groups in the survey.

50. Identifying vulnerabilities in men with cancer: social support and mental health problems: <http://calls.ac.uk/wp-content/uploads/1786-Men-cancer-DCP-poster-Final-PDF.pdf>

### Types of support that people living with cancer would find useful, by age

- 1 Someone to talk to/emotional support
- 2 Information & advice
- 3 Financial help
- 4 Help with transport
- 5 Help with household chores
- 6 Someone accompanying me to health visits
- 7 Support from employer
- 8 Someone to help me deal with professionals & organisations
- 9 Financial advice & information
- 10 Care at home
- 11 Religious or faith-based support
- 12 Aids and adaptations to the home
- 13 Respite care or short breaks

	55-64 year olds	75+ year olds
1	46%	35%
2	37%	38%
3	30%	10%
4	30%	21%
5	29%	13%
6	25%	21%
7	19%	3%
8	20%	9%
9	19%	5%
10	16%	11%
11	9%	13%
12	7%	4%
13	11%	3%



This research suggests that older people who have been treated with chemotherapy would find different forms of support useful than those who have undergone other treatments. For example, those who have undergone chemotherapy treatment are more likely to state that financial support (28% vs 16% overall) and help with household chores (28% vs 18% overall) would be useful.

Furthermore, people living with cancer who have difficulty with certain tasks

(such as dressing, walking across a room, or preparing a hot meal) are more likely than those who do not have difficulties to receive support. However, they are considerably more likely to need support and it seems many go without. One in six (15%) people aged 55 and over living with cancer who have at least three difficulties in performing everyday tasks claim to have not had any support. Likewise, one in five (19%) of those with three or more long-term health conditions report having not received any support.

This research indicates differences in support needs of the heterogeneous group often referred to in the literature as older people living with cancer. Tailoring support to meet the needs of individuals might help to improve outcomes for people aged 55+ and above living with cancer.

Younger people living with cancer are also more likely to say that many other forms of support would be useful than older people living with cancer, including help with household chores, financial help, and having someone to help them deal with professionals and organisations. In contrast, a third (32%) of people aged 75 and over say 'none of these' when asked what forms of support would be useful. Less than one in ten (9%) of the youngest people with cancer surveyed (those aged 55–59) answer the same way. Again, this may relate to perceptions of independence described earlier in this section. This may well prove to be a barrier to seeking appropriate help during cancer treatment or longer-term recovery. There may also be differences in expectation about the types of support that it is reasonable to expect, with people of working age having higher expectations.

**'I'm just grateful with what I've got... Probably as I've got older, I've sort of got more content.'**

**Woman, 81, South of England**

## 7.7 Ageing and the ability to cope with cancer

Older people feel that they are better able to cope with cancer than younger people. Two thirds of the older retired living with cancer (67%) agree that the life experience of older people allows them to cope better with cancer than younger people, compared with two in

five (38%) of those of working age and 51% overall.

Evidence from the qualitative interviews supports the notion that older people feel they can cope better emotionally with cancer than younger people, and this was generally linked with acceptance that with age comes disease and disability. A prevalent theme in the interviews was the belief that it was far worse for younger people to be diagnosed with cancer than older people.

**'If I'd been 53 instead of 73, I know I wouldn't have been able to absorb it all in the manner that I did. I would have been devastated.'**

**Man, 75, North of England**

It was suggested that younger people might have more to deal with in life regarding jobs, and caring for children, or perhaps elderly parents which adds further pressure and more to cope with.

**'I think for women with younger children it would be a terrifying thing to be going through with those things to look after. How would you find the strength to cope with it?'**

**Woman, 57, Scotland**

However, this research indicates a need for support that is often not met, perhaps because of a lack of awareness of the forms of support that are available or because of a reticence to ask for help.

## 7.8 Next steps from the research

The findings from this research will be relevant to efforts to improve outcomes at every part of the cancer pathway, including:

**51%**  
**of people aged 55 and over living with cancer agree that older people's life experience helps them to cope better with cancer.**

- Early diagnosis, including raising awareness of how the risk of cancer increases with age and how older people can access screening services.
- Treatment, challenging some of the preconceptions that people may hold about older people's attitudes towards cancer and its treatment.
- Assessment, ensuring that older people with cancer receive a comprehensive assessment of their overall physical and mental wellbeing so that treatment decisions are not made based on age alone.
- Treatment, including reassuring people about the realities of modern cancer treatment, whilst educating them about its consequences and tailoring treatment approaches to reflect what matters most to older people, including maintaining independence.
- Delivering information and support older people to be active participants in their care.
- Support, designing services which better meet the needs of older people and ensuring that they are better signposted to this support.
- Experience, acting on intelligence from the National Cancer Patient Experience Survey to ensure that gaps in services for older people are addressed.

The National Cancer Director has indicated that improving services for older people affected by cancer is a personal priority and, as part of this, Macmillan Cancer Support is working in close partnership with him and a

multidisciplinary group of clinical experts and patients to initiate research and design interventions to better support older people. The findings from this study will be used to support this process.

## Acknowledgments

We wish to thank all of those who participated in the research and shared their experiences with us. We also wish to thank Age UK (Age UK Northumberland and Age UK Leicester), the Older Peoples Advocacy Alliance (OPAAL), Professor M Gosney and all those involved in the development and design for their help in shaping this study.

# Appendices



## Appendix A Profile of depth interviews

		<b>Number of interviews</b>
<b>Gender</b>	Male	10
	Woman	16
<b>Sexuality</b>	Heterosexual	20
	LGBT	6
<b>Region</b>	Midlands	3
	South England incl. London	11
	North of England	4
	Scotland	4
	Northern Ireland	4
<b>Cancer type</b>	Hodgkin's Lymphoma	1
	Bowel/Anal	4
	Breast	8
	Lymph nodes	1
	Prostate	7
	Non-Hodgkin's lymphoma	1
	Skin	3
	Throat	1
<b>Ethnicity</b>	White British	21
	BME	5
<b>Internet access</b>	With access to internet	18
	Without access to internet	8

## Appendix B Older people living with cancer survey sample profile

The following table contains details of the demographic profile of the sample of older people living with cancer.

Sample profile	Weighted %	Unweighted %
<b>Gender</b> (1,004 valid responses)		
Male	46	48
Female	54	52
<b>Age</b> (1,004 valid responses)		
55-59	23	38
60-69	17	32
70+	60	30
<b>Cancer status</b> (1,004 valid responses)		
Localised/stable	19	20
Remission	65	65
Other	15	14
Prefer not to say	1	1
<b>Stage of cancer</b> (1,004 valid responses)		
Stage 1 or 2	30	31
Stage 3 or 4	11	14
Not known/wasn't told	55	51
<b>Long-term illness</b> (1,004 valid responses)		
Yes	80	79
No	20	21
<b>Difficulties with daily tasks</b> (1,004 valid responses)		
Yes	52	52
No	48	47

<b>Sample profile</b>	<b>Weighted %</b>	<b>Unweighted %</b>
<b>Time since treatment</b> (1,004 valid responses)		
Within last year	<b>10</b>	<b>11</b>
1-2 years ago	<b>13</b>	<b>13</b>
3-5 years ago	<b>19</b>	<b>19</b>
6 or more years ago	<b>40</b>	<b>38</b>
Still undergoing treatment	<b>16</b>	<b>17</b>
<b>Household type</b> (1,004 valid responses)		
Married/living together	<b>65</b>	<b>67</b>
Other arrangement	<b>35</b>	<b>33</b>
<b>Ethnicity</b> (1,004 valid responses)		
White	<b>98</b>	<b>98</b>
BME	<b>1</b>	<b>1</b>
<b>Carer for others</b> (1,004 valid responses)		
Yes	<b>25</b>	<b>26</b>
No	<b>74</b>	<b>73</b>
<b>Sexuality</b> (1,004 valid responses)		
Heterosexual/Straight	<b>96</b>	<b>96</b>
Gay man	<b>2</b>	<b>2</b>
Gay woman/lesbian	<b>*</b>	<b>*</b>
Bisexual	<b>*</b>	<b>*</b>
Other	<b>1</b>	<b>*</b>
Prefer not to say	<b>1</b>	<b>1</b>

## Appendix C Non cancer survey sample profile

The following table contains details of the demographic profile of the sample of non-cancer sample.

Sample profile	Weighted %	Unweighted %
<b>Gender</b> (500 valid responses)		
Male	47	47
Female	53	53
<b>Age</b> (500 valid responses)		
55-64	42	58
65-69	16	32
70+	42	10
<b>Long-term illness</b> (500 valid responses)		
Yes	77	74
No	22	25
<b>Difficulties with daily tasks</b> (500 valid responses)		
Yes	38	38
No	62	62
<b>Ethnicity</b> (500 valid responses)		
White	99	98
BME	1	1
<b>Sexuality</b> (500 valid responses)		
Heterosexual/Straight	95	95
Gay man	1	2
Gay woman/lesbian	*	*
Bisexual	2	1
Other	*	*
Prefer not to say	2	2

## Appendix D Statistical reliability

The respondents to the survey are only samples of the total 'population', so we cannot be certain that the figures obtained are exactly those we would have if everybody had been interviewed (the 'true' values).

We can, however, predict the variation between the sample results and the 'true' values from knowledge of the size of the samples on which the results are based and the number of times that a particular answer is given. The confidence with which we can make this prediction is usually chosen to be 95% – that is, the chances are 95 in 100 that the 'true' value will fall within a specified range. The table below illustrates the predicted ranges for different sample sizes and percentage results at the 95% confidence level.

Size of sample on which survey results are based	Approximate sampling tolerances applicable to percentages at or near these levels <sup>51</sup>		
	10% or 90%	30% or 70%	50%
	±	±	±
100 interviews	7	11	12
500 interviews	3	5	5
1,000 interviews	2	3	4

Source: Ipsos MORI

For example, with a sample of 1,000 where 50% give a particular answer, the chances are 95 in 100 that the "true" value (which would have been obtained if the whole population had been interviewed) will fall within the range of plus or minus 4 percentage points from the sample result (ie between 46% and 54%).

When results are compared between separate groups within a sample, different results may be obtained. The difference may be 'real', or it may occur by chance (because not everyone in the population has been interviewed). To test if the difference is a real one – ie if it is statistically significant, we again have to know the size of the samples, the percentage giving a certain answer and the degree of confidence chosen. If we assume a 95% confidence level, the differences between the two sample results must be greater than the values given in the table overleaf:

Size of sample compared	Differences required for significance at or near these percentage levels		
	10% or 90%	30% or 70%	50%
100 and 100	10	15	17
250 and 100	8	13	14
500 and 500	4	7	7
1,000 and 500	4	6	6

Source: Ipsos MORI

<sup>51</sup>, Note that the figures presented here take full account of the impact of weighting on the sampling tolerances of the survey.

# Appendix E Depth interview discussion guide

**Throughout discussion, bear in mind co-morbidities, frailty, BME inequalities, LGBT inequalities, issues for people without internet, difference between younger and older age brackets.**

Length of interview – 90 minutes

Section	Notes	Timing
<b>Introduction</b>	<p><b>Introduce self and Ipsos MORI</b> Ipsos MORI is a research agency that works for government, charities and private sector clients. Clients ask us to investigate things for them as we are independent. This means you can be open and honest in what you tell us.</p> <p><b>Briefly explain Macmillan and why they want to do this work</b> Macmillan Cancer Support is one of the best known charities in the UK. The charity provides practical, medical and financial support for people affected by cancer and pushes for better cancer care. They have commissioned this research as they want to find out what life is like for older people living with cancer, in order to better understand how life can be improved for them. By older people living with cancer, we mean anyone aged 55+ who has had cancer at any point in their lives, even if they are now in remission.</p> <p>We are doing around 25 interviews with older people living with cancer, but also are running an online questionnaire of people with and without cancer.</p> <p><b>MRS and anonymity</b> Ipsos MORI is a member of the Market Research Society, and abides by its code of conduct. This means everything you tell us will be anonymous – although we may use quotes, no information will be identifiable with any individual. We will use the information they provide alongside that provided by others to write a report for Macmillan, but personal detail will be removed to ensure individuals can't be identified from the findings.</p>	<b>5 mins</b>

**OK to pause/rearrange**

The interview will last around 90 minutes. Some things we talk about might be a little sensitive, but that's OK, please just take your time – I'm not in a rush. You don't have to answer anything you don't feel comfortable doing so. Please feel free to move on if you do not want to answer a question for any reason. We can take a break at any point, and you can also stop the interview and continue at another time, or decide not to continue at all.

**Incentive**

As a thank you for your time and contribution, Ipsos MORI will give you an incentive of £40 in cash/by cheque.

**Ask if they have any questions, and then seek consent for taking part****Ask for permission to record****Attitudes to life****To start with, would you mind telling me a little about yourself?**

## PROBES:

- Who do you live with?
- Do you/did you work?  
PROBE ON ANY LONG TERM UNEMPLOYMENT

**Could you talk me through what a typical day is like for you?**

## PROBES:

- What is your routine?
- Do you get out and about?
- How do you get about?  
(public transport/drive/lifts/dial-a-ride)

**I'd now like to talk a bit about how you feel about life in general.**

- **What things in life make you feel most happy, relaxed and secure?** How have your thoughts on this changed since you were younger?
- Why has this changed?

This section establishes some context in which to frame their attitudes. Gets at their independence, functioning, support and frailty. **10 mins**

## Attitudes to cancer

**I'd now like to spend a little bit of time talking about how cancer has affected your life. As I mentioned before, if you'd like to pause or move on at any point, just say.**

**Could you tell me a bit about the time when you first thought you might have cancer?**

- How did you go about getting a diagnosis?
- Did you seek a second opinion?
- How did you feel before and after you got your diagnosis?
- Did you have any support, formal or informal, at this stage? IF MULTIPLE, PROBE ON CARE-COORDINATION.
- How did you feel about how healthcare professionals acted towards you? How did this match up to your expectations?
- To what extent did you feel involved in decisions made about at the diagnosis stage?
- Did you expect to be involved in the decision making?

**What treatment, if any, were you offered?**

**ALLOW THEM TO ELABORATE ON TREATMENT IF THEY FEEL COMFORTABLE**

- How did you feel about the treatment options offered to you?
- How did you feel about how healthcare professionals acted towards you at this stage?
- To what extent did you feel involved in decisions made about your treatment and care?
- To what extent do you feel you had choice in terms of your treatment?
- What were your expectations of how you would be treated/treatment options/choice? Did you have a named individual contact during treatment?
- How did the treatment (inc. side effects) match up with your expectations?
- To what extent did you understand what the impact of the treatment would be?
- Did you have any support, formal or informal, at this stage? IF MULTIPLE, PROBE ON CARE-COORDINATION.

If these issues have not already been covered, the vignettes help to address sensitive topics in a way that can help make the participant feel more comfortable.

**30 mins**



**Could you tell me a bit about how day-to-day life has changed for you since you received your diagnosis (and treatment)?**

- Do you require any practical support?
- Where do you get this support from?
- Is there any support you don't have which you would like?

**And how has your outlook on life changed since your diagnosis?**

- Do you require any emotional support?
- Where do you get this support from?
- Is there any support you don't have which you would like?

**I'm going to present you with examples of people's attitudes towards cancer and I'd like to know what you think about each one. To what extent do you agree or disagree with their point of view?**

VIGNETTES –

- Charlie – Fear of diagnosis
- Adele – Good innings
- Maggie – Cancer as a death sentence
- Ken – Positive

**Which one of these most closely matches how you feel about cancer?**

- Why did you pick that one?

**This project is interested specifically in how cancer affects older people. How do you think older people might view cancer differently to younger people?**

PROBES:

- More or less scared?
  - Better or less able to deal with it?
  - What difference do you think having other health issues might have on your attitude towards having cancer?
  - How differently does the older generation feel, if at all, about speaking about cancer than younger generations?
-

---

## Attitudes to healthcare and healthcare professionals

**I'd now like to discuss your thoughts about healthcare, and healthcare professionals.**

**How do you feel about the way in which healthcare professionals act towards older people with cancer in the UK?**

STICK PERSON TASK. IF PARTICIPANTS FEEL HEALTH PROFESSIONALS DISCRIMINATE OR IS UNSURE AND CAN'T ARTICULATE THEN PRESENT DIAGRAM.

**I'd like you to imagine you are the patient in this picture, and you're at an appointment with a healthcare professional who you have met several times.**

CHECK WHO THAT HEALTH PROFESSIONAL IS AND MAKE A NOTE FOR MARKING ON THE BACK OF THE DIAGRAM LATER.

**What sort of conversation characterises the kind of relationship you have with that health professional?**

**Could you describe to me what you and the healthcare professional typically say to each other and what you are thinking?**

IF APPROPRIATE ASK: **Please tell me more about why they are thinking differently from what they are saying?**

**Are there any specific issues you think older people with cancer face specifically which medical professionals should be more aware of?**

PROBES:

- Caring responsibilities
- Issues at home
- Transport needs
- Privacy and dignity on wards
- Flexible appointments

How could healthcare services be set up differently to address these issues?

---

Although we are asking in general terms, we will allow participants to draw on personal anecdotes if they wish to do so.

Do not probe on discrimination, but be mindful of where this is relevant

**15 mins**

---

### Summarising the issues

**I'd like to ask, if you had your time again, what would you do differently with regards to...**

- Getting a diagnosis?
- Treatment?
- Interacting with health professionals?
- Seeking advice, support and help?

**And what would you like other people to have done differently with regards to...**

- Getting a diagnosis?
- Treatment?
- Interacting with health professionals?
- Seeking advice, support and help?

**I'd now like you to imagine you have been appointed as a mentor to an older person who thinks they might have cancer.**

**What advice would you give them about what to expect?**

**What would you warn them to watch out for in terms of living with cancer?**

This may come up naturally earlier in the discussion, but ask overtly if not

**15 mins**

---

### Conclusion

**5 mins**

**We're coming towards the end of our chat now, so is there anything we haven't discussed which you would like to add?**

#### Re-contact question

**Ipsos MORI and Macmillan may wish to re-contact you within the next 12 months as a follow-up part to this project. Would you be happy to be contacted again with regards to...**

- taking part in any follow up research?
- taking part in any media activities (e.g. quotes for press releases, photos, or short videos)?

IF FACE TO FACE, HAND OVER INCENTIVE AND SAFEGUARDING LEAFLET

**We would like to leave you with some contact details in case anything we've discussed today leaves you feeling that you would like to talk to someone about support available to you.**

READ OUT THE NUMBERS FOR THE TELEPHONE INTERVIEWS, THEY WILL ALSO BE INCLUDED ON THE THANK YOU LETTER WE WILL SEND OUT WITH THE CHEQUE. FOR FACE-TO-FACE INTERVIEWS HAND OUT THE THANK YOU LETTER WITH THE NUMBERS BELOW.

**Macmillan Cancer Support**

Support Line **0808 808 0000**

<http://www.macmillan.org.uk/HowWeCanHelp/HowWeCanHelp.aspx>

**Age UK**

Advice line **0800 169 6565**

<http://www.ageuk.org.uk/about-us/what-we-do/>

## Appendix E Non-cancer focus group discussion guide

Throughout discussion, bear in mind co-morbidities, frailty, BME inequalities, LGBT inequalities, issues for people without internet, difference between younger and older age brackets.

Section	Notes	Timing
<b>Introduction</b>		<b>5 mins</b>
<p><b>Introduce self and Ipsos MORI</b></p> <p>Ipsos MORI is a research agency that works for government, charities and private sector clients. Clients ask us to investigate things for them as we are independent. This means you can be open and honest in what you tell us.</p>		
<p><b>Briefly explain Macmillan and why they want to do this work</b></p> <p>Macmillan Cancer Support is one of the best known charities in the UK. The charity provides practical, medical and financial support for people affected by cancer and pushes for better cancer care. They have commissioned this research as they want to find out what life is like for older people living with cancer, in order to better understand how outcomes for people can be improved. As part of the project we are doing around 25 interviews with older people living with cancer, but also are running an online survey of people with and without cancer.</p> <p>The reason we are here to speak to you today is because we are interested to hear how people who do not have cancer think about cancer, and how you think you would feel if you did find yourself with a cancer diagnosis.</p> <p>We are also doing a similar group in another part of the country.</p>		
<p><b>MRS and anonymity</b></p> <p>Ipsos MORI is a member of the Market Research Association, and abides by its code of conduct. This means everything you tell us will be anonymous – although we may use quotes, no information will be identifiable to any individual. We will use the information you provide alongside that provided by others to write a report for Macmillan, but personal details will be removed to ensure individuals can't be identified from the findings.</p>		

**Ground rules**

Some things we talk about might be a little sensitive, so you don't have to answer any questions if you don't feel comfortable doing so. I'd like everyone to have a chance to speak, so please don't speak over each other.

**Incentive**

As a thank you for your time and contribution, Ipsos MORI will give you an incentive of £20

**Ask if they have any questions, and then seek consent for taking part****Ask for permission to record**

---

**Attitudes to life****15 mins**

**To start with let's go round and introduce ourselves. Please just tell me your name, and any hobbies you have.**

**To start off our discussion, I'd like us to talk a bit about how you feel about life in general.**

**I'd like to ask you all, what do you feel is the most important thing in life as you get older?**

**PROBES:**

- Health
- Friends and family
- Independence
- Financial stability

**How content do you feel with life at the moment?**

- Would you like anything to be different?
  - Are you more or less content than when you were younger?
  - Why has this changed?
-

---

**Attitudes to cancer****30 mins**

**We're now going to move on to talk a bit about cancer. It's a sensitive topic, so remember you don't have to answer any questions if you don't feel comfortable doing so.**

**What initially springs to mind when you think about cancer? What words or images?**

**To what extent is cancer something people of your age feel comfortable talking about?**

- Why's that?
- Do you think older people view cancer differently to younger people?

**Do you think cancer is more common in older or younger people?**

- Why do you say that?
- What age do you think people typically get cancer?
- What is the likelihood of someone getting cancer in their lifetime, do you know?

**If someone is diagnosed with cancer, how do you think it would affect their outlook on life?**

- What would they want to get from life?
- How would the reaction differ depending on how old that person is?
- What have other people you know said about how living with cancer affects their attitude to life?

LOOK OUT FOR MENTION OF CANCER BEING SEEN AS A DEATH SENTENCE OR SIMILAR SENTIMENT. FOLLOW UP ON THIS. IF NOT MENTIONED ASK:

**To what extent do you think having cancer is a death sentence?**

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**BREAK IF NECESSARY****5 mins**

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**Diagnosis, treatment and support****20 mins****How much do you think about the possibility of getting cancer?**

- Is it something that worries you?
- Why does it worry you?

As you may or may not know, there are a series of free screening programmes available in the UK for breast, cervical and bowel cancer. These are offered to people up to the age of 74 for bowel cancer, 64 for breast cancer and 70 for cervical cancer. Further screening is available to people above these ages, but only if they request it.

**Did you know this information before or is it new to you today?****What are your thoughts on cancer screening? Is it something you have taken part in/would take part in?****Has anyone here requested cancer screening, even if you are above the age limit for routine screening?**

- What made you decide to request screening?
- To those who have not requested screening, why not?

**What have you read or seen about the symptoms of cancer?**

- Where do you get your information from?

HAND OUT VIGNETTE STIMULUS: CHARLIE (FEAR OF DIAGNOSIS/ NOT WANTING TO WASTE TIME)

**To what extent do you agree or disagree with Charlie's attitude?****Why do you think Charlie is worried about what the doctor would say?****If you recognised a symptom of cancer, what action would you take?**

PROBE ON HESITATION TO SEE DOCTOR

- How would expect your doctor to act?
- What would you expect your doctor to do?



**If you found yourself with cancer, how would you react?**

- What would your immediate worries be?

## PROBES:

- survivorship/life expectancy
- health outcomes
- being independent
- having control
- seeing grandchildren
- paying bills
- Stress on family and friends
- Being a burden
- Having/not having someone to talk to
- What support would you need, and where would you get it from?
- How would you feel about having treatment?

LOOK OUT FOR MENTION OF TREATMENT BEING TOO AGGRESSIVE OR BEING TOO OLD FOR IT, OR SIDE AFFECTS. FOLLOW UP ON THIS.

**Attitudes to healthcare and healthcare professionals**

**I'd now like to put cancer to one side, and discuss your thoughts about healthcare, and healthcare professionals.**

**What specific issues, if any, do you think older people face which medical professionals should be more aware of?**

## PROBES:

- Caring responsibilities
- Language/manners
- Issues at home
- Transport needs
- Privacy and dignity on wards
- Flexible appointments
- Compassionate and kind communication
- Information is tailored
- I am meaningfully involved in decisions – I am the expert on me

**How could healthcare services be set up differently to address these issues?**

**Thinking about any times you've had contact with the NHS or private healthcare, how do you feel about the way in which healthcare professionals act towards older patients in the UK?**

Although we are asking in general terms, we will allow participants to draw on personal anecdotes if they wish to do so.

**15 mins**

STICK PERSON TASK. IF PARTICIPANTS FEEL HEALTH PROFESSIONALS DISCRIMINATE OR IS UNSURE AND CAN'T ARTICULATE THEN PRESENT DIAGRAM.

**I'd like you to imagine you are the patient in this picture. You are meeting with a consultant at the hospital about an ongoing condition. You have met with them several times before.**

- **Please fill in the speech bubbles to reflect the sort of conversation that characterises the kind of relationship you have with that health professional?**
- **Then please fill in the think bubbles to reflect on what they might be thinking about each other or the situation.**
- **Please write who that health professional is above their head.**
- **I'm going to collect all of these drawings from you in a moment but wonder if someone would like to explain their drawing in more detail?**

IF TIME, CHOOSE TWO OR THREE PEOPLE AND ASK:

- **Could you describe to me what you and the healthcare professional typically say to each other and what you are thinking?**

IF APPROPRIATE ASK:

- **Please tell me more about why they are thinking differently from what they are saying?**

---

## Conclusion

5 mins

FLIPCHART ONTO A PRETEND INFO LEAFLET

**This discussion may have raised a few questions for you about cancer, screening, diagnosis and treatment, or support. I thought it would be nice to finish off by Asking you, what one thing could Macmillan do to help inform older people about cancer?**

**We're coming towards the end of our chat now, so is there anything we haven't discussed which you would like to add?**

HAND OVER INCENTIVE AND SAFEGUARDING LEAFLET

**We would like to leave you with some contact details in case anything we've discussed today leaves you feeling that you would like some sort of emotional or practical support.**

**Macmillan Cancer Support**

Support Line **(0808 808 0000)**

<http://www.macmillan.org.uk/HowWeCanHelp/HowWeCanHelp.aspx>

**Age UK**

Advice line **0800 169 6565**

<http://www.ageuk.org.uk/about-us/what-we-do/>

THANK AND CLOSE

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# Appendix G Survey questionnaire

## Macmillan Cancer: Patient Factors research Questionnaire FINAL v7 05/05/2015

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### Module 1: Screening questions

ASK ALL

- 1. Are you... (from panel) SC**
1. Male
  2. Female

ASK ALL

- 2. Can you please enter your date of birth? (from panel)**
1. \_\_\_\_\_
  2. Prefer not to say (SCREEN OUT)

SCREEN OUT IF AGED LESS THAN 55

- 3. Have you ever been diagnosed with cancer? SC**
1. Yes
  2. No (INTO NON-CANCER SURVEY)
  3. Prefer not to say (SCREEN OUT)
- 

### Module 2: Attitudes towards ageing

ALL WHO ANSWER CODE 1 AT Q3

**This survey is being conducted on behalf of Macmillan Cancer Support, and is targeted at people who are currently living with cancer, or have been affected by cancer at some point in their lives**

ALL WHO ANSWER CODE 2 AT Q3

**This is a survey being conducted on behalf of Macmillan Cancer Support and is targeted at people aged 55 years or over.**

ASK ALL

- 4. Would you say your health is...?<sup>52</sup> SC**
1. Excellent
  2. Very good
  3. Good
  4. Fair
  5. Poor
  6. Don't know

ASK ALL

**5. I would now like you to think about what is most important to you as you get older. Which, if any, of the following would be the most important for you?<sup>53</sup> SINGLE CODE ONLY. ROTATE CODES 1-5.**

1. Being healthy for as long as possible
2. Having a good standard of living
3. Having control over major life decisions
4. Being independent for as long as possible
5. Being able to leave an inheritance for your family/friends
6. None of the above
7. Don't know

ASK ALL

**6. The next questions are about your attitudes towards life and towards ageing. To what extent do you agree or disagree with each of the following statements? ROTATE STATEMENTS SC FOR EACH**

1. Disease and disability are inevitable when people get older
2. I look forward to each day<sup>54</sup>
3. I have achieved as much in my life as I wanted to
4. I still enjoy the things I used to enjoy<sup>55</sup>
5. My health stops me from doing things I want to do<sup>56</sup>

1. Strongly agree
2. Tend to agree
3. Neither agree nor disagree
4. Tend to disagree
5. Strongly disagree
6. Don't know

ASK ALL

**7. How much, if any, prejudice do you think there is in the way that health and social care services in the United Kingdom deal with older people?<sup>57</sup> By older we mean people aged 65 years and over. SC**

1. Yes, a lot
2. Yes, a little
3. Yes, hardly any
4. No, none at all
5. Don't know

ASK ALL

**8. And how much, if any, prejudice do you think there is in the way that health and social care services in the United Kingdom deal with older people who have cancer? SC**

1. Yes, a lot
2. Yes, a little
3. Yes, hardly any
4. No, none at all
5. Don't know

53, PHE Care and Support Tracker (although that data is confidential, but have received permission to use question)

54, ELSA

55, Brightlight

56, ELSA

57, Based on British Social Attitudes question Q. "Do you think there is a lot of prejudice in Britain against disabled people in general, a little, hardly any, or none?"

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## Module 3: Attitudes towards cancer

ASK ALL

**9. The next question is about your general attitudes towards cancer. To what extent do you agree or disagree with each of the following statements?** ROTATE STATEMENTS SC FOR EACH

1. The life experience of older people allows them to cope better with cancer than younger people
2. Cancer is not an age related disease
3. A diagnosis of cancer is a death sentence<sup>58</sup>
4. The side effects of cancer treatment are often worse than the disease

1. Strongly agree
2. Tend to agree
3. Neither agree nor disagree
4. Tend to disagree
5. Strongly disagree
6. Don't know

ALL WHO ANSWER CODE 1 AT Q3

**10. Thinking about the care that you have received during your cancer journey, to what extent do you agree or disagree with each of the following statements?** ROTATE STATEMENTS 1-4 SC FOR EACH

1. Healthcare staff know what's best for me, when it comes to decisions about cancer care
2. The possible side effects of treatment(s) were explained to me in a way that I could understand<sup>59</sup>
3. I felt as involved as I wanted to be in decisions about my care and treatment<sup>60</sup>
4. There have been times during my cancer journey I have not gone to see healthcare staff because I didn't want to waste their time
5. Sometimes I felt that healthcare staff made decisions about my cancer care based on my age and not on how fit I am

1. Strongly agree
2. Tend to agree
3. Neither agree nor disagree
4. Tend to disagree
5. Strongly disagree
6. Don't know

ALL WHO ANSWER CODE 1 OR 2 AT 10.5

**11. At the last question, you agreed that sometimes you felt that healthcare staff made decisions about your cancer care based on your age and not how fit you are. Can you please give us any examples of times when this happened?** OPEN QUESTION

1. \_\_\_\_\_
2. Prefer not to say

<sup>58</sup>, Cancer Research International survey

<sup>59</sup>, Taken from CPES

<sup>60</sup>, Taken from CPES

ALL WHO ANSWER CODE 1 AT Q3

**12. Which, if any, of the following have happened during your cancer journey?** *Please tick all that apply.*<sup>61</sup> MULTICODE OK EXCEPT NONE OF THESE AND DON'T KNOW

1. I opted/chose not to have any treatment
2. I opted not to have certain types of treatment
3. I missed treatment appointments
4. I missed follow-up appointments
5. I was unable to pick up prescriptions
6. I did not take my medication as indicated
7. None of these SC
8. Don't know SC

---

## Module 4: Attitudes towards support

ALL WHO ANSWER CODE 1 AT Q3

**13. The next set of questions focuses on some of the other types of support available to people during their cancer journey. To what extent do you agree or disagree with each of the following statements?**

ROTATE STATEMENTS SC FOR EACH

1. I sometimes don't ask for help because I don't want to be a burden to other people
2. There should be more support available to me than there is at the moment
3. Sometimes older people get less support than younger people
4. I am too busy caring for others to look after my own needs
5. There are people that I can turn to for encouragement and moral support when I need some

1. Strongly agree
2. Tend to agree
3. Neither agree nor disagree
4. Tend to disagree
5. Strongly disagree
6. Don't know

ALL WHO ANSWER CODE 1 AT Q3

**14. Which of the following forms of support, if any, did you receive during your cancer diagnosis or treatment or after care? Please include all forms of support you may have received, regardless of who provided it and whether you had to pay for it or not.** *Please tick all that apply.*

MULTICODE 1-15. ROTATE A-C, ROTATE 1-4, 5-9, 10-12, 13-14.

### A. Emotional support

1. Someone to talk to / emotional support
2. Religious or faith based support
3. A self-help and support group or forum
4. Respite care or short breaks



**B. Practical support**

5. Help with household chores
6. Help with transport e.g. lift in car or help on public transport
7. Someone accompanying me to health visits
8. Care at home e.g. personal care, healthcare
9. Aids and adaptations to the home

**C. Financial support**

10. Financial advice and information
11. Financial help e.g. benefits, tax credits and grants
12. Support from employer e.g. paid sick leave

**D. Other**

13. Someone to help me deal with professionals and organisations
14. Information and advice e.g. on cancer, treatments, support
15. Other (please specify)
16. None of these SC
17. Don't know SC

ALL WHO ANSWER CODE 1 AT Q3

**15. And which of the following forms of support, if any, were/ would be/ would have been most useful to you during your cancer diagnosis or treatment or after care?** *Please tick all that apply.*

MULTICODE 1-15. ROTATE A-C, ROTATE 1-4, 5-9, 10-12, 13-14.

**A. Emotional support**

1. Someone to talk to / emotional support
2. Religious or faith based support
3. A self-help and support group or forum
4. Respite care or short breaks

**B. Practical support**

5. Help with household chores
6. Help with transport e.g. lift in car or help on public transport
7. Someone accompanying me to health visits
8. Care at home e.g. personal care, healthcare
9. Aids and adaptations to the home

**C. Financial support**

10. Financial advice and information
11. Financial help e.g. benefits, tax credits and grants
12. Support from employer e.g. paid sick leave

**D. Other**

13. Someone to help me deal with professionals and organisations
14. Information and advice e.g. on cancer, treatments, support
15. Other (please specify)
16. None of these SC
17. Don't know SC

ASK ALL WHERE RESP\_GENDER=1 "MALES"

**16a. Have you participated in the national screening programme for bowel cancer?** SC

1. Yes
2. No
3. Don't know

ASK ALL WHERE RESP\_GENDER=2 "FEMALES"

**16b. Which, if any, of these national screening programmes have you participated in?** SC. ROTATE 1-3.

1. Bowel
2. Cervical
3. Breast
4. None of these SC
5. Don't know SC

ASK ALL CODE 1 AT Q16A OR 1-3 AT Q16B

**17. Did you continue to opt-in to the screening programme/s after you reached the upper age limit?** SC

1. Yes – I continued to opt in
2. No – I did not opt in
3. Not relevant – I am still eligible to take part in the screening programme

ASK ALL CODE 2 AT Q17

**18. You said that you have participated in national cancer screening but did not continue with this after you reached the upper age limit. What are the reasons for this?** (OPEN)

1. \_\_\_\_\_
2. Prefer not to say

---

## Module 5: Demographics

ALL WHO ANSWER CODE 1 AT Q3

**19. Which type(s) of cancer did/do you have?**<sup>62</sup> Please tick all that apply. MC 1-10.

1. Breast
2. Prostate
3. Lung
4. Bowel/colorectal
5. Bladder
6. Stomach
7. Pancreatic
8. Ovarian
9. Unknown
10. Other (open)
11. Don't know SC
12. Prefer not to say SC

ALL WHO ANSWER CODE 1 AT Q3

**20. Which of the following best describes the current status of this cancer? (IF MC AT Q19 ALSO ADD) If you've had more than one type of cancer, please answer regarding the most recent type of cancer.<sup>63</sup> Please select one only.** SINGLE CODE

1. Localised or stable
2. Advanced/secondary/metastatic
3. Recurrence/relapse
4. Remission or cancer-free (cured)
5. Not known/undergoing diagnosis
6. Other (open)
7. Prefer not to say

ALL WHO ANSWER CODE 1 AT Q3

**21. And how long is it since you completed your treatment?<sup>64</sup>**

Please select one only. SINGLE CODE

1. Within the last year
2. 1-2 years ago
3. 3-5 years ago
4. 6-10 years ago
5. More than 10 years ago
6. I am still undergoing treatment
7. Prefer not to say

ALL WHO ANSWER CODE 1 AT Q3

**22. When you were first diagnosed, what stage of disease were you told you had? Please select one only SC<sup>65</sup>**

1. Stage 1
2. Stage 2
3. Stage 3
4. Stage 4
5. Other
6. I wasn't told
7. Prefer not to say
8. Don't know

ALL WHO ANSWER CODE 1 AT Q3

**23. Which, if any, of the following treatments have you had? MC 1-9<sup>66</sup>**

1. Surgery
2. Chemotherapy
3. Radiotherapy
4. Immunotherapy
5. Biological or targeted therapy (e.g. Avastin, Herceptin)
6. Hormonal therapy (e.g. Tamoxifen, Zoladex)
7. Stem cell/ Bone marrow transplants
8. Palliative care
9. Other treatments (please specify)
10. None of these SC
11. Prefer not say SC
12. Don't know SC

<sup>63</sup>, Isolation study

<sup>64</sup>, Isolation study

<sup>65</sup>, From Macmillan

<sup>66</sup>, From Macmillan

ALL WHO ANSWER CODE 1 AT Q3

**24. Which of the following best describes how your cancer was diagnosed?**

SC. ROTATE 1-3.

1. I went to see my GP when I thought something was wrong
2. I attended a routine cancer screening
3. I was admitted to hospital/ went to A&E and then found out I had cancer
4. Other (please specify)
5. Prefer not to say

FOR ALL

**25. Which, if any, of the following long term health conditions do you have?**

**Please tick all that apply, but do not include cancer<sup>67</sup>.** MC 1-18

1. Alzheimer's disease or dementia
2. Angina or long-term heart problem
3. Arthritis or long-term joint problem
4. Asthma, COPD or long-term chest problem
5. Blindness or severe visual impairment
6. Deafness or severe hearing impairment
7. Diabetes
8. Epilepsy
9. Osteoporosis
10. High blood pressure
11. Kidney or liver disease
12. Incontinence
13. Long-term back problem
14. Long-term mental health problem
15. Long-term pain
16. Long-term neurological problem
17. Sleeping disorder
18. Other (please specify)
19. I would prefer not to say SC
20. None of these SC

ASK ALL

**26. Which, if any, of the following activities do you experience some difficulty doing, because of a physical, mental, emotional or memory problem? Please exclude any difficulties you expect to last less than three months.** MC 1-16. ROTATE 1-1668.

1. Dressing, including putting on shoes and socks
2. Walking across a room
3. Bathing or showering
4. Eating, such as cutting up food
5. Difficulty swallowing food
6. Getting in or out of bed
7. Walking 100 yards
8. Using the toilet, including getting up or down
9. Preparing a hot meal
10. Shopping for groceries
11. Climbing one flight of stairs without resting
12. Stooping, kneeling, or crouching
13. Taking medications

67, General Practice Patient Survey (GPPS)

68, ELSA wave 3

14. Lifting or carrying weights over 10 pounds, like a heavy bag of groceries
15. Doing work around the house or garden
16. Managing money, such as paying bills and keeping track of expenses
17. None of these SC

ALL WHO ANSWER CODE 1 AT Q3

**27. Do you have use of a car or van when you need one (either as a passenger or driver)?<sup>69</sup> SC**

1. Yes
2. No

FOR ALL

**28. To which of these ethnic groups do you belong?<sup>70</sup> SINGLE CODE**

1. White – British
2. White – Irish
3. Any other white background
4. Mixed – White and Black Caribbean
5. Mixed – White and Black African
6. Mixed – White and Asian
7. Any other mixed background
8. Asian or Asian British – Indian
9. Asian or Asian British – Pakistani
10. Asian or Asian British – Bangladeshi
11. Any other Asian/Asian British background
12. Black or Black British – Caribbean
13. Black or Black British – African
14. Any other Black British background
15. Chinese
16. Any other
17. Prefer not to say
18. Don't know

ALL WHO ANSWER CODE 1 AT Q3

**29. Which of the following best applies to you?<sup>71</sup> SINGLE CODE**

1. Married/Civil Partnership
2. Living together
3. Single
4. Widowed
5. Divorced
6. Separated
7. Don't know
8. Prefer not to say

ALL CODE 4 AT Q29

**30. You said at the last question that you have been widowed. How long have you been a widowed for? SC**

1. Less than one year
2. 1-2 years
3. 3-5 years
4. 6-10 years
5. More than 10 years
6. Prefer not to say

69, ELSA

70, Standard Ipsos MORI Q

71, Standard Ipsos MORI Q

ASK ALL

**31. Who, if anyone, lives with you in your household?** MC 2-6

1. Nobody, I live on my own
2. A spouse or partner
3. My son(s), daughter(s) or step child(ren)
4. Parent(s)
5. Sibling(s)
6. Other people, related or not related to me
7. Prefer not to say SC

ALL WHO ANSWER CODE 1 AT Q3

**32. Do you look after, or give any help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health / disability or problems related to old age?**<sup>72</sup> SC

1. Yes
2. No
3. Prefer not to say

ALL CODE 1 AT Q32

**33. What relation is this person or people to you?** MC

1. Spouse or partner
2. Child
3. Grandchild
4. Parent/ Parent in Law
5. Other relative
6. Friend or neighbour
7. Other
8. Prefer not to say SC

ASK ALL

**34. This list shows various possible sources of income. Which kinds of income do you (and spouse/partner) receive?**<sup>73</sup> MC 1-14

1. Earnings from employment or self-employment
2. Pension from a former employer
3. State Pension
4. Child Benefit
5. Disability allowance
6. Social care personal budget
7. Continuing Healthcare budgets
8. Income Support
9. Other State Benefits
10. Tax Credits
11. Employment Support Allowance (ESA)
12. Interest from savings etc.
13. Other kinds of regular allowance from outside the household
14. Other sources e.g. rent
15. No source of income SC
16. Prefer not to say SC

72, Based on census

73, Taken from ONS  
Harmonised income questions

FOR ALL

**35. Which of the following options best describes how you think of yourself?**<sup>74</sup> SINGLE CODE

1. Heterosexual/straight
2. Gay man
3. Gay woman/ lesbian
4. Bisexual
5. Other
6. Prefer not to say

ASK ALL

**36. Can you please enter your postcode? Please note that this will only be used for analysis purposes and not to identify who you are**

1. \_\_\_\_\_
2. Prefer not to say

ALL WHO ANSWER CODE 1 AT Q3

**37. Finally, we may want to conduct some further research over the next 12 months with people who have taken part in this survey. Would you be happy to be contacted again as part of this follow up research?**<sup>75</sup> SC

1. Yes
2. No

ALL CODE 1 AT Q36

**38. IF YES – contact details to be recorded:**

1. title (one box)
2. first name\* (1 box)
3. surname\* (1 box)
4. address (4 boxes)
5. postcode\* (maximum 8 digits, minimum 4 digits)
6. landline or mobile number\* (11 digits)
7. email address (to validate)
8. how do you prefer to be contacted

\*Mandatory fields

74, Isolation study

75, EHRC recommended question (doesn't use 'identify')







## For more information

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### **About Ipsos MORI's Social Research Institute**

The Social Research Institute works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. This, combined with our methodological and communications expertise, helps ensure that our research makes a difference for decision makers and communities.