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ADVANCING CARE, ADVANCING YEARS: IMPROVING CANCER TREATMENT AND CARE FOR AN AGEING POPULATION

JUNE 2018

Research commissioned by Cancer Research UK and conducted by the University of Birmingham's Health Services Management Centre and ICF International



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ABOUT CANCER RESEARCH UK

Cancer Research UK is the world's largest independent cancer charity dedicated to saving lives through research. It supports research into all aspects of cancer and this is achieved through the work of over 4,000 scientists, doctors and nurses. In 2016/17, we spent £432 million on research institutes, hospitals and universities across the UK. We receive no funding from the Government for our research and are dependent on fundraising with the public. Cancer Research UK wants to accelerate progress so that three in four people survive their cancer for 10 years or more by 2034.

Cancer Research UK is a registered charity in England and Wales (1089464), Scotland (SC041666) and the Isle of Man (1103)

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LIST OF ACRONYMS

ADL	Activities of Daily Living
CanCORS	Cancer Care Outcomes and Research Surveillance Consortium
CRUK	Cancer Research UK
CPET/CPEX	Cardiopulmonary Exercise Testing
COPD	Chronic Obstructive Pulmonary Disease
CNS	Clinical Nurse Specialist
CGA	Comprehensive Geriatric Assessment
ECG	Electrocardiogram
eFI	Electronic frailty index
EORTC	The European Organisation for Research and Treatment of Cancer
EUSOMA	The European Society of Breast Cancer Specialists
GP	General Practitioner
HDU	High Dependency Unit
HNA	Holistic Needs Assessment
ITU	Intensive Treatment Unit
SIOG	International Society of Geriatric Oncology
MDT	Multidisciplinary team
NCIN	National Cancer Information Network
NCCN	The US National Comprehensive Cancer Network
NICE	National Institute for Health and Care Excellence
RWE	Real-world evidence
SMC	Scottish Medicine Consortium
SDM	Shared decision-making
SCOPES	Systematic Care for Older People in Elective Surgery

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EXECUTIVE SUMMARY

Around 360,000 people in the UK were diagnosed with cancer in 2015. 36% of these people were 75 and over. By 2035, this proportion will rise to almost half (46%)¹, because of the UK's ageing population.

As the patient population changes, services must adapt to make sure they are meeting every person's needs and that no group is left behind. Now and in the future, it is crucial that older people with cancer are given the support they need to access the most appropriate treatment for them, and to have the best possible experience of care.

In this instance, age is a proxy measure for complexity: increasing age is correlated with having multiple health conditions, cognitive issues or complex social care needs – all of which can require cancer treatment and care plans to be modified. However, it is important to note that this is not true for every person over 75 and there are many people under 75 who also have complex needs.

However, it is also highly likely that this group of patients with more complex needs – and therefore many patients over 75 – are the ones who will be most affected by wider pressures facing the NHS. These pressures include severe shortages in key professional groups, as well as a lack of time for long consultations in the clinic and for cancer multidisciplinary teams (MDTs) to discuss patients' cases. So although the recommendations in this briefing are targeted towards ensuring cancer services meet the needs of older people with cancer, if implemented many of them would benefit all patients in the NHS – of all ages.

However, evidence shows that right now there are age-related inequalities in cancer outcomes. Cancer survival is generally lower for older patients and the discrepancy between the UK's performance and the best-performing countries is worse for older patients than it is for younger patients^{2,3,4}. Although overall cancer survival has doubled in the last 40 years, the discrepancy between cancer-specific survival for older and younger patients has persisted. If we are to achieve our ambitions of achieving world-class outcomes for everyone affected by cancer, it is vital that we improve the treatment and care of older patients.

Older patients are also less likely to receive many different types of treatment⁵. Some of the variation in access to treatment can be accounted for by patients choosing not to pursue active treatment. This could be because they are simply too unwell or because, for example, they are prioritising maintaining a good quality of life and spending time with family over lengthening their life. However, there may also be some who are simply not being offered curative treatment that could benefit them, because assumptions have been made about their fitness based on their age. In contrast, we also heard anecdotally that some feel pressured by their clinicians to undergo intensive curative treatment.

We must get this balance right. Treatment decisions should consistently be shaped around each person's individual situation. Achieving this is, of course, important for every person diagnosed with cancer. However, it is most difficult to achieve this for those who have more complex medical or social needs, or who need more time and support to come to a decision about their treatment plan. This is the current challenge.

One reason for this –as highlighted by the 2015 Cancer Strategy for England⁶ – is that methods of assessing older patients are not fit for purpose, resulting in older people’s needs not being identified or sufficiently well-understood⁷. There are also issues with the knowledge and awareness of the cancer workforce about the specific challenges of treating older patients, and there is a lack of evidence to support new cancer treatments in older populations⁸.

This report presents research commissioned by Cancer Research UK (CRUK) and conducted by the University of Birmingham’s Health Services Management Centre and ICF International, which sought to understand the specific needs of older patients, and to explore the process of clinical decision-making for older people with cancer across the UK.

This research involved a literature review, clinical observations at eight case study sites, interviews with 15 national decision-makers and 80 health professionals, and three UK-wide surveys (of primary care professionals, secondary care professionals and older people affected by cancer). The direction of the research was also informed by engagement with a group of older people affected by cancer, and by extensive engagement and interviews with national policymakers. Full methodology is available in Appendix 1.

OLDER PEOPLE AND CANCER

In 2035, it is projected that around 234,000 cases of all cancers combined¹ will be diagnosed in people aged 75 and over in the UK. People aged 75 and over are projected to account for 46% of all cancer diagnoses and 62% of all cancer deaths⁹.

Net survival is generally lower for patients over 75, with survival generally decreasing with increasing age – even after adjusting for mortality from causes other than cancer. Despite overall survival doubling over the past 40 years, the discrepancy between survival for older and younger patients has not improved¹⁰.

There is also evidence that the gap between the UK’s cancer survival and that of the best-performing countries is worse for older patients. For example, most of the survival difference for breast cancer between the UK and Ireland and the European average can be accounted for by the low survival of women age 75 and over¹¹. In colorectal (bowel) cancer, five-year survival was 15% lower in UK patients aged 75 and older than the equivalent patients in Canada diagnosed between 2005-2007, while it was 9.5% lower for patients aged 15-44¹².

There are several reasons why this is the case. For example, older people are more likely to have poorer overall health, and are more likely to be diagnosed in an emergency, which is associated with being diagnosed at a later stage, and with poorer survival¹³. Between 2006 and 2015, 41% of all cancers in those aged 80-84 were diagnosed in an emergency in England, compared with 14% of cancers in those aged 50-59. Although there is a clear need to improve early diagnosis of cancer in older patients, that is outside of the scope of this briefing.

However, there are also discrepancies in access to treatment for older people with cancer. A report by the National Cancer Information Network (NCIN) and CRUK found that across 20

¹ Around 130,000 in males and around 104,000 in females

cancer sites, older patients were less likely to have major surgical resections¹⁴. It has also been reported that the use of chemotherapy declines with age, in several types of cancer¹⁵. Other studies have found similar; for example, older women with breast cancer are less likely to undergo surgery¹⁶; the use of radiotherapy also gradually decreases with age¹⁷. Older people with lung cancer have also been shown to be far less likely to undergo surgery¹⁸.

In some cases, there are legitimate reasons for these lower treatment rates. For example, older patients are more likely to have other health conditions, which could mean they are unable to tolerate either the treatment itself, or the side-effects of the treatment^{19,20,21}. Some studies have adjusted for comorbidities and have still found variation in access^{22,23} – suggesting there could be some inappropriate decision-making based on chronological age.

However, some patients may also choose not to pursue curative treatments, for various reasons. Recent research has found that when considering chemotherapy, over half of older patients surveyed prioritised outcomes other than survival, for example maintaining their quality of life, independence or cognitive abilities²⁴.

FINDINGS AND RECOMMENDATIONS

OLDER PATIENTS OFTEN HAVE MORE COMPLEX CARE NEEDS – AND THE SYSTEM IS NOT SET UP TO DEAL WITH THEM

Older people with cancer are more likely to have complex medical and social needs, which can mean they require additional support to access treatment.

For example, older patients are more likely to have other age-related illnesses, but also more likely to require social care support. Furthermore, up to 40% of older patients present with cognitive issues that can impair their capacity to make complex decisions about treatment, adhere to treatment plans and recognise symptoms of toxicity that might require medical attention²⁵.

Through our engagement with health professionals as part of our research, we identified four main clinical factors which tend to impact the treatment options for older patients:

1. The patient's fitness to withstand the rigours of treatment
2. The likelihood that the patient will die from a cause other than their cancer
3. Whether the patient has comorbidities
4. If there is clinical evidence to support a particular course of treatment in an older patient

Many older people with cancer also have additional social support needs. For example, they might care for a loved one or themselves require carer support. This can also impact treatment choices. The older people affected by cancer involved in our research told us that uncertainty about how they would access non-medical support can be a major barrier to accessing treatment. Similarly, 46% of cancer multidisciplinary team (MDT) members surveyed for this research identified a lack of social or practical support as a barrier to older people accessing the most effective treatment for their cancer.

Unfortunately, the support patients need is often not available. Although our interviewees valued community-based support such as oncology nurses or convalescence homes, availability of this support is variable. Although patients can sometimes arrange their own alternative care, cost can often be a major barrier.

This speaks to a much broader issue with social care, which is crucially important but outside the scope of this research. However, there are defined actions that could help make sure all the support needs of people with cancer are met throughout treatment and recovery. For example, an earlier assessment of a person's support needs would help ensure there is enough time to plan support required for the weeks following a major operation.

Cancer services could also do more to embed consideration of the specific needs of older people with cancer in how services are planned and delivered. Where there are service reconfigurations, there must be a recognition that older patients are more likely to require additional support to travel to treatment. For example, our interviewees based at sites where patients are more likely to have to travel for treatment – such as tertiary centres serving a mostly rural area – expressed concerns that older patients could be excluded from treatment, or from taking part in clinical trials.

So yes, it is more difficult for older people to get transport and it's possible that a lot of them don't want to be a bother to their families ...getting on buses, trains, whatever, is not ideal and the kind of ambulance, minibus service trails them round the country so they don't like that ... it's another burden that they have. (Medical oncologist)

In England, where radiotherapy services are soon to be re-organised into new Radiotherapy Networks, there is a timely opportunity to embed the needs of older people with cancer in this process, through meaningful patient involvement as services are planned.

1. Cancer service managers should ensure that patients' support needs are assessed at an early stage in the pathway, so that they are able to access the support they need during and after completing treatment. Health service regulators should consider ways to ensure that this is done effectively and consistently across the UK.

2. UK health services should ensure that the specific needs of older patients are considered in all new service plans and workforce plans. For example, emerging Radiotherapy Networks in England should consider the impact of changing travel requirements on older patients and should work with charities and providers to ensure all patients are given the support they need to receive treatment.

TREATMENT DECISION-MAKING DOES NOT ALWAYS TAKE ALL RELEVANT FACTORS INTO ACCOUNT

We can only be sure that treatment decisions are right for patients if we are confident that the decisions take into account all relevant information about that person. This is true for every patient, but is particularly important for patients with additional medical and social

needs – which will include many older people.

Unfortunately, these complex needs are often not routinely considered as part of the treatment decision-making process in cancer. This is partly because services lack the right tools to assess frailty in the cancer setting, and Comprehensive Geriatric Assessments are still rarely used in oncology. This is important: it is widely recognised that chronological age alone is not a strong indicator of how well a person will tolerate cancer treatment²⁶.

Frailty assessments can be used to predict how well a patient will be able to tolerate treatment, or to help assess what additional support could help them. In the absence of a robust method, assessment of a patient's fitness for treatment can instead be assumed based on their age, or simply a subjective assessment of how they seem during a consultation.

Our research also found that Comprehensive Geriatric Assessments – or CGAs – are rarely used in oncology. A CGA supports clinicians by providing an evidence-based assessment of frailty, reducing the subjectivity of the assessment, and helps make sure care is centred around the patient and their individual needs.

While 70% of primary care staff surveyed told us that their assessment of a patient's frailty impacts their decision-making, we found very limited evidence of CGA usage and low awareness of the tools available. Similarly, although the most significant factor in clinical decision-making identified by multidisciplinary team (MDT) meeting members was frailty, CGAs were used in few of the sites we observed as case studies. We also heard that many clinicians were unconvinced of the value these tools would add, or thought they would not be worth the extra resources required to implement. Clinicians often tended to favour more informal, intuitive assessment rather than a robust and formal tool.

I mean certainly the data would suggest it (primary care frailty assessment) may be part of the problem. If you look at the sort of the cancer outcomes and sort of stages at presentation, clearly there is a bias and we are serving our elderly patients less well than we are their younger compatriots.

(National interviewee)

These findings are disappointing, however unsurprising: although there is widespread consensus about the value of CGAs in general, and evidence of their beneficial impact in oncology, there is no clear evidence regarding the best tool to use²⁷ and they have not been fully integrated into oncology practice²⁸. Although there are several pieces of guidance about conducting CGAs in cancer, their use is still highly variable – often because of a lack of staff, as well as other institutional and/or funding constraints²⁹.

However, there is clear value in their use: case study sites that had embedded geriatrician-led multidisciplinary CGA clinics into the decision-making process did report better improved adherence to chemotherapy and increased rates of surgery³⁰.

3. UK health services should pilot the routine usage of geriatric assessments for older people with cancer and should seek to gather further evidence of the relative benefits of different tools.

THE RIGHT INFORMATION DOES NOT ALWAYS GET TO THE RIGHT PEOPLE TO SUPPORT CLINICAL DECISION-MAKING

There are also systemic issues in cancer services that limit the amount of information that is available to support clinical decision-making. Again, these issues apply to all patients – but are felt more acutely in more complex cases, and therefore often in older patients. For example, patient data is often not shared between the full range of health professionals caring for a patient, or even with the patient themselves.

INFORMATION DOES NOT FLOW FROM PRIMARY CARE TO SECONDARY CARE

37% of patients diagnosed in England in 2015 were diagnosed through an urgent GP referral, known as the “two-week wait”³¹, a route attached with targets in England and Wales requiring patients to be seen within two weeks of GP referral. These referrals are processed using forms, which are specific to each suspected type of cancer and differ between trusts and regions. These forms are brief and thus there is no space for primary care staff to communicate people’s personal circumstances, comorbidities, their frailty or other medical history. This means that the clinicians making decisions about patients’ treatment often do not have advanced access to information that could later prove critical – and so the person’s age is more likely to be used as a surrogate measure for their overall health.

It doesn’t say what medication they’re on, what are their comorbidities, what are the real issues, what are the social factors, doesn’t tell anything about the person, it just tells you potentially what could be related to the disease. (National Interviewee)

A relatively simple change to these forms could result in a significant improvement in the amount of information available to inform treatment decisions – for all patients. As forms differ from region to region there are some notable examples of good practice, where those making referrals have space for additional information – but this has not been done consistently. For example, a pilot in Leeds developed a digital solution that automatically populates the form with all required information³². There may also be cases where a referring GP has included information in a letter, but this has been lost in the system.

4. Cancer Alliances and devolved cancer networks should explore digital solutions for ensuring that suspected cancer GP referrals can consistently incorporate additional information that could prove relevant to a future cancer treatment plan.

THE RIGHT INFORMATION IS OFTEN NOT INCLUDED IN MDT DECISION-MAKING

Every patient diagnosed with cancer in the UK has their case discussed at a MDT meeting. An MDT is made up of a variety of health professionals involved in treating and caring for patients. The MDT meets, most often weekly, to discuss individual patients’ cases and make treatment recommendations.

If MDTs are to make a treatment recommendation that is truly appropriate for the patient, they must include all relevant information. But recent research by CRUK found that only 14% of MDT discussions included information that did not specifically relate to the patient's tumour³³.

While many MDT members see this as a responsibility of Clinical Nurse Specialists (CNS), nurses did not contribute information in over 75% of the meetings observed in our research. This reflects the lack of time available for full discussion of complex patients in MDT meetings, rather than a lack of willingness to contribute: the average discussion observed in our past research lasted just 3.2 minutes, in meetings lasting up to five hours, and each discussion included an average of just three people – although an average of 14 people were in attendance.

This pressure has major implications for the quality of treatment decision-making. Not including important information about a patient – such as their preference, their psychosocial situation or their comorbidities – is poor for patients and also poor for MDT efficiency: past research has found that between 10 and 15% of recommendations made by an MDT were not implemented because they were later found to be inappropriate for the patient^{34,35}. It is likely that this is a direct consequence of the MDT not taking all relevant information about the patient into account. When that additional information becomes apparent, patients are either discussed again by the MDT – adding a delay to their treatment – or a decision is made solely by their individual clinician, who might lack the expertise to know how to incorporate this information into the treatment plan.

There is a clear need to reform and streamline MDTs, so that more time is available to discuss the most complex patients in enough depth – and therefore, many older patients. It is also important that MDTs consistently have access to all relevant information about the patients they discuss, so that they can make treatment recommendations that are tailored to the patient's individual circumstances.

While 54% of MDT members already use a type of proforma to feed information into the MDT, this does not happen consistently and there is no national guidance on their content. 81% of MDT members surveyed in our past research² felt that using a proforma would have a beneficial impact on meeting efficiency, by minimising the chance of the patient returning to the MDT for re-discussion after the first recommendation was rejected.

5. UK health services should lead the development of national proforma templates, to be refined by MDTs. MDTs should require incoming cases and referrals to have a completed proforma with all information ready before discussion at a meeting.

COMMUNICATION FROM SECONDARY CARE TO PRIMARY CARE SHOULD BE IMPROVED

From our surveys of clinicians, we also identified an issue with the flow of information from secondary care back to primary care. This is important: although cancer care is managed primarily by cancer clinicians, patients' other health conditions might still be managed in

² 1,258 respondents. Full results available at cruk.org/mdts-research

primary care. Patients may also seek advice from primary care about their treatment options or any side-effects they are experiencing.

Although clinicians should inform GPs of a cancer diagnosis within 48 hours, this does not happen uniformly. Primary care staff also told us they would value additional information about a patient's prognosis, their treatment options and their wider care plan.

... it is not uncommon for somebody to be in floods of tears in the car on the way home from the hospital, phoning the GP, asking for an urgent appointment to talk things through but the GP didn't even know they had a cancer diagnosis and wouldn't have been told for days, sometimes weeks. (National interviewee and General Practitioner)

6. Healthcare providers must ensure that primary care staff are updated on the outcome of patient discussions in a timely manner. This should include widespread use of digital solutions.

PRESSURES ON ONCOLOGY SERVICES LIMIT THE QUALITY OF DECISION-MAKING AND COMMUNICATION BETWEEN OLDER PEOPLE WITH CANCER AND THEIR CLINICIANS

The concept of shared decision-making (SDM) originated in the disability rights movement and is now ingrained into the ethos of health services, through the concept of 'no decision about me without me'. The Health Foundation and NICE define SDM as '*a process in which clinicians and patients work together to select tests, treatments, management, or support packages, based on clinical evidence and patients' informed preferences*'³⁶.

There is strong evidence that shared decision-making is beneficial for people with cancer³⁷, for example because it can improve people's experience of care³⁸. However, achieving SDM can be more difficult in patients with multiple health conditions^{39, 40,41}, cognitive impairment, social support needs and caring responsibilities⁴². This is therefore more likely to be the case for older people with cancer.

The older people with cancer who responded to our survey often reported negative experiences with decision-making and some also reported feeling like their questions were not welcomed. We also heard that conversations focused too much on benefits of treatment, glossing over potential side-effects or long-term consequences.

Mostly, it was assumed that I would do whatever they suggested - whilst I was not unhappy with what was being offered, as I knew that there were not a lot of options, I do not feel in hindsight that I was given much choice or indeed support in making such a choice. (A patient)

These difficulties are exacerbated by time pressure in a treatment consultation – and this was reflected in our engagement with both older patients and clinicians. While a lack of time affects all patients, there is a greater impact on patients with complex needs, comorbidities or cognitive issues – and therefore, again, many older people with cancer.

Today I had a patient who has cancer but has other comorbidities ... so I had to discuss

that ... and make it clear to them that these are the risk factors, these are the things that go wrong ... that 20/30 minutes ... just gets dragged on to 45 minutes. We can't just stop the consultation because it's been running out of time. (Anaesthetist)

7. Cancer MDT leads and service managers should consider reviewing the length of consultation slots, factoring in additional time for more complex patients, and providing additional support before, during and after consultations for those who are living with frailty or have multiple comorbidities.

Cancer treatment decision-making in the UK is also strongly impacted by national treatment targets. Several members of cancer MDTs interviewed for this study raised the issue of national treatment targets creating unhelpful pressure, for two reasons: firstly, through putting patients under pressure to make a quick decision, but secondly by limiting opportunities for testing patients' likelihood to be able to tolerate treatment, and then to tailor their plan accordingly.

They're guidelines not tramlines and I think people get so caught up in that, that you forget the patient may not want to work in the timescale that the guidelines say. (National interviewee)

This has been echoed in research, which has found that service targets that focus resource solely on cancer can disadvantage patients with complex wider needs, as individual clinicians may struggle to deliver effective treatment plans without breaching targets⁴³.

8. In ongoing reviews of cancer waiting times targets, UK health services should consider ways to ensure optimal treatment access, a positive experience and better outcomes for older people with cancer.

THE CANCER WORKFORCE COULD BETTER SUPPORT THE NEEDS OF OLDER PATIENTS

Cancer services in the UK are experiencing severe workforce gaps across many key professions, which is having a real impact on the ability to diagnose and treat cancer quickly, as well as to give patients the best possible experience of care⁴⁴.

There are also broader issues relating to the preparedness of the workforce to treat the growing number of older patients, including deficits in education, knowledge and attitudes and in the development of specific roles and services that meet older people's needs⁴⁵. For example, a 2013 survey of UK medical oncology trainees found that only 27.1% were confident in assessing risk to make treatment recommendations for older patients, compared to 81.4% being confident about treating younger patients⁴⁶.

For people with complex needs, it is critical that health professionals with specialist expertise are available to support them throughout treatment decision-making and treatment itself. There is also some evidence of benefit in providing additional specialist support, targeted to groups of older people with complex needs, who are at risk of undertreatment⁴⁷.

Specialist cancer nurses are a particularly critical workforce group for all patients, acting as a 'key worker' throughout diagnosis, treatment delivery and palliative care. Patients and health professionals praised the value of nurses consistently throughout this research.

When I was first diagnosed 7 years ago there was no CNS in haematology at our local hospital and until I was referred elsewhere, I didn't realise these amazing nurses existed. Fortunately, we have a wonderful CNS now who is available by phone or e-mail whenever needed. (Cancer patient, patient survey)

The 2015 Cancer Strategy for England recommended that all patients are given a named Clinical Nurse Specialist (CNS) or key worker to contact. Scotland have also made a strategy commitment to put the necessary levels of training in place to ensure that by 2021, people with cancer who need it have access to a specialist nurse during and after their treatment and care. However, there are significant shortages in the CNS workforce across the UK. Whilst the proportion of patients in England having access to a CNS has risen from 84% in 2010 to 90% in 2016⁴⁸, there is still variation across geographies and across different cancer sites. 84% of patients in Scotland reported access to a CNS in 2015/16⁴⁹; in Wales in 2016, 81% reported access and in Northern Ireland in 2015, this figure was just 72%.

Staffing issues were also recognised by national interviewees for this project, particularly for rarer cancers. This was echoed by a recent census by Macmillan Cancer Support, which found that up to 15% of cancer nursing roles in England are unfilled, and that there is wide geographic variation⁵⁰. While supporting older patients is the responsibility of all staff – across primary, secondary and tertiary care – the nursing workforce is especially crucial for those in hospital care, and so this must be addressed as a matter of urgency.

Frequently there's just one of these nurses in a team and therefore once they're on holiday or they're sick there's no back up, there's nothing else, there's nobody else who can step in. (National Interviewee)

Furthermore, the role of a CNS is highly variable; their job titles and expectations are often inconsistent. Because of wider pressures, CNSs frequently fill service gaps in their local centres, rather than doing the work that best fits their expertise and training. A survey conducted as part of CRUK's 2017 research into the non-surgical oncology treatments workforce found that 50% of CNSs did not feel they had enough patient-facing time and were consistently working an average of 5 additional hours each week – on average, 15% of their working hours⁵¹.

Geriatricians are also important for the medical and social care of older patients, however are not always involved in cancer-specific care. Interviewees in both primary and secondary care noted the value of requesting geriatric consultant reviews – although few MDT members had done this in practice. The role of geriatricians in cancer care should be a key consideration throughout all cancer workforce planning, and especially in Health Education England's phase II cancer workforce plan.

9. Health Education England, and its equivalents in the devolved nations, should use the Cancer Research UK 'best practice treatment model' to project required workforce numbers based on patient demand, not on affordability⁵². Organisations should also include consideration of the specific needs of older people with cancer in all future workforce plans.

WE NEED TO IMPROVE HOW INNOVATION REACHES OLDER PEOPLE

GETTING THE RIGHT EVIDENCE

Research is the key to improving outcomes for all people affected by cancer. However, older patients are typically under-represented in clinical trials⁵³, which can have strict inclusion criteria based on chronological age, comorbidities or cognitive ability. These factors combined mean that there is often relatively limited evidence on the specific effects of treatment on these patients.

This means that decisions about treatment for patients with comorbidities – and therefore often older patients – cannot always be based on strong evidence. At least, not in comparison to decisions for their younger or otherwise fit counterparts.

The most important thing is we don't have any evidence for such patients... the number of patients who are [in] clinical trials above 75 years of age is far and few between and no meaningful conclusions can be made on that. (Medical oncologist)

More could still be done to gather evidence, including boosting numbers of older patients in trials – but also doing research that enables patients with comorbidities or frailty to receive optimal treatment, through understanding the interactions at play.

There is appetite for change: 70% of European health professionals responding to the PREDICT study in 2014 did not believe the present arrangements for clinical trials relating to older people to be satisfactory, and 60% believed that either European or national regulation of clinical trials should be amended to ensure greater representation of older or less fit patients⁵⁴.

Most clinical trials funded by Cancer Research UK do not have an upper age limit, when age limits are applied, researchers are asked to justify the boundary selected. Exclusion criteria relating to comorbidities or patient fitness are used in some trials where they risk confounding results or adding a safety risk, however, and comorbidities do increase with age. CRUK also fund some trials that ask specific questions about treatment for older patients, or patients who are less fit.

The question remains about how best to ensure that there is sufficient evidence of a treatment's efficacy in patients who are frail, have comorbidities or are elderly. One answer is for researchers to identify the priority questions for each cancer type, and to investigate these in clinical trials.

APPROVING NEW TREATMENTS

35% of respondents to our survey of MDT members felt that a lack of clinical evidence about the efficacy of treatment in an older population was a barrier to treatment. This is particularly problematic in cancers where there is a poorer understanding of the disease and its progression. This can make it difficult for clinicians to assess the risks of treatment and to weigh that up against the potential benefit to the patient. However, this is likely part of a broader issue about evidence in comorbid populations, rather than being related solely to chronological age.

There is also scope for making changes to the process of approving new treatments so that it

better supports older people with cancer, who may value outcomes other than just improving survival – such as maintaining a good quality of life, their independence and cognition⁵⁵. For example, national drug approvals should consider incorporating a broader range of evidence, including impact on quality of life – which was recommended in the Life Sciences Industrial Strategy⁵⁶, although the recommendations were not specifically targeted towards older patients.

There is also broader scope for incorporating real-world evidence (RWE) of a drug's effectiveness in all patients. Under the current system, national approval bodies (such as NICE in England or the Scottish Medicine Consortium) must make their decision at a single point in time – often based on a relatively narrow scope of evidence. The price of the drug is then fixed, irrespective of how effective it proves to be in routine use. We would like to see broader use of managed access schemes like England's Cancer Drugs Fund, which allow earlier access to a new drug while further evidence of its effectiveness on all patients is gathered in the NHS. This RWE is then combined with clinical trials data and incorporated into a final decision about approval and pricing.

In the longer term, we encourage UK health services to explore the use of flexible pricing mechanisms such as outcomes-based pricing, in which the price of a drug can be reviewed at agreed stages and aligned directly to patient benefit, being increased or decreased based on emerging new data. This would ensure pricing and access decisions are grounded in the real experiences of patients. To take this forward, Cancer Research UK are exploring the feasibility of outcomes-based pricing through a commissioned research project, in partnership with the Greater Manchester Health and Social Care Partnership.

HIGH-QUALITY DATA

A key enabler to this is robust, routinely collected data about cancer treatment and outcomes. This is not an age-specific issue as it would significantly improve our ability to understand the effects of treatment on all patients. All UK organisations responsible for collecting health data should ensure significant resource is provided for improving the quality and completeness of treatments datasets. Having robust data about treatments and outcomes would enable more in-depth analyses of the extent of variation in access to treatment and outcomes for older patients, which could supplement clinical trial data and support efforts to benchmark services.

10. Research funders should explore how to ensure more proportionate recruitment of older people with cancer into clinical trials, and how to ensure that research addresses any evidence gaps in the effectiveness of treatment in older patients, or those with comorbidities more broadly.

11. National drug appraisal bodies should explore what alternative metrics could be considered during appraisals that would be more relevant to all patients, including older patients – such as quality of life and activities of daily living.

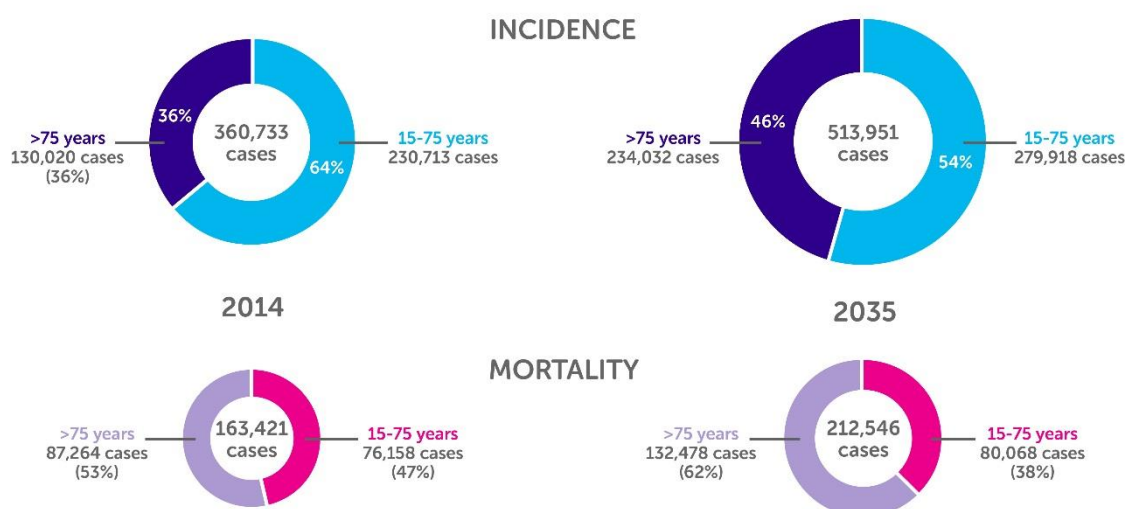
1. BACKGROUND

1.1 OLDER PEOPLE WITH CANCER IN THE UK

Around 360,000 people in the UK were diagnosed with cancer in 2015. By 2035 this number could reach 500,000 – mostly because of the ageing population, but also partly due to lifestyle changes.

In 2015, around 36% of people diagnosed with cancer were over 75. In 2035, it is projected that around 46% of cases of cancer will be diagnosed in people aged 75 and over in the UK. People aged 75 and over are projected to account for 46% of all cancer diagnoses and 62% of all cancer deaths⁵⁷.

FIGURE 1: PROJECTED DEMOGRAPHICS FOR CANCER INCIDENCE AND MORTALITY IN 2035

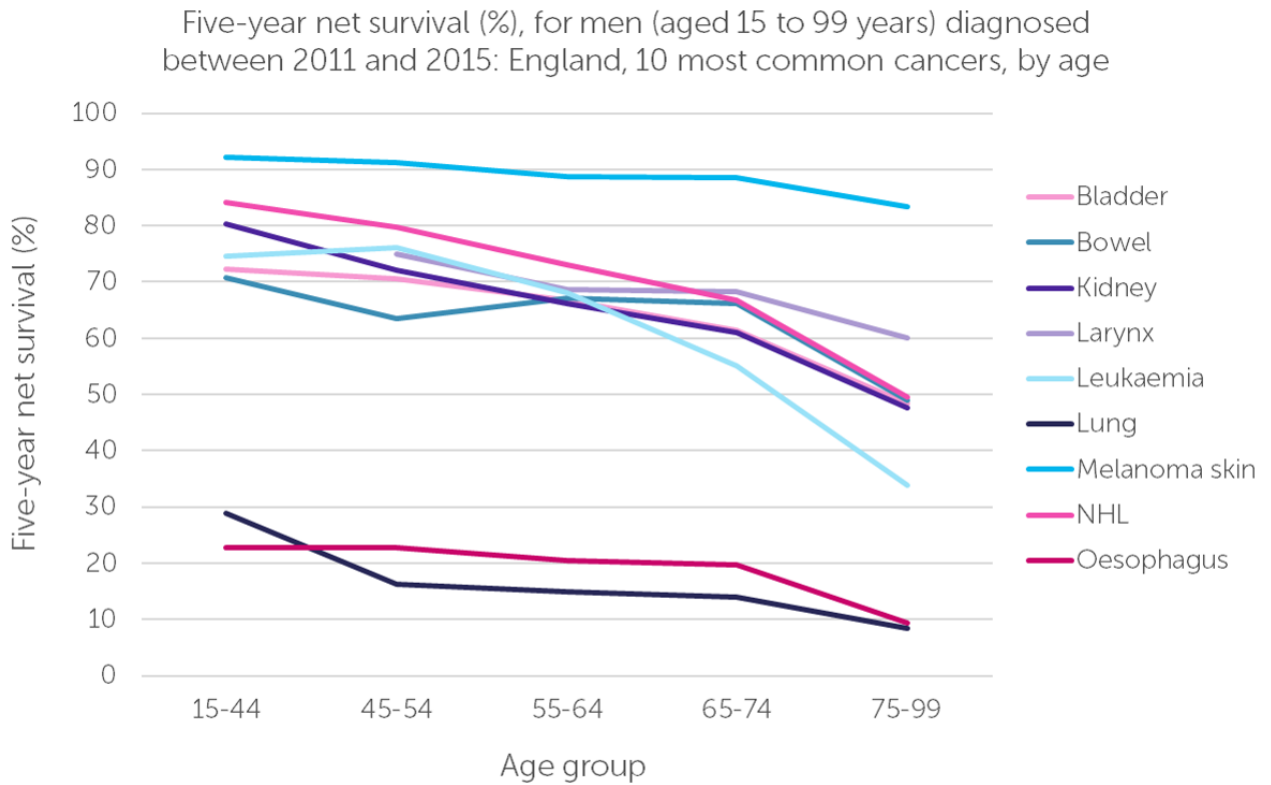


Net survival is generally lower for patients over 75, with survival generally decreasing with increasing age – even after adjusting for mortality from causes other than cancer. Despite overall survival doubling over the past 40 years, the discrepancy between survival for older and younger patients has not improved⁵⁸.

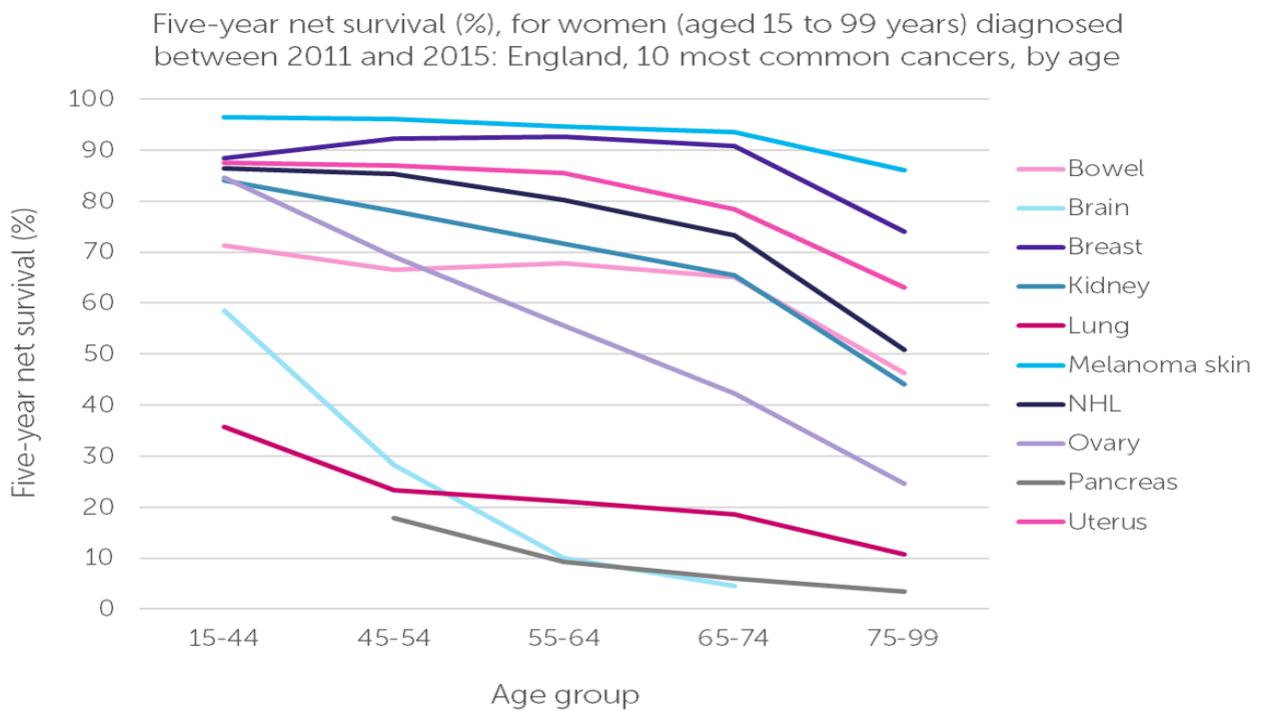
There is also evidence that the gap between the UK's cancer survival and that of the best-performing countries is worse for older patients. For example, most of the survival difference for breast cancer between the UK and Ireland and the European average can be accounted for by the low survival of women age 75 and over⁵⁹. In colorectal (bowel) cancer, five-year survival was 15% lower in UK patients aged 75 and older than the equivalent patients in Canada diagnosed between 2005-2007, while it was 9.5% lower for patients aged 15-44⁶⁰.

There are several reasons why this is the case. For example, older people are more likely to have poorer overall health, and are more likely to be diagnosed in an emergency, which is associated with being diagnosed at a later stage, and with poorer survival⁶¹. Between 2006 and 2015, 41% of all cancers in those aged 80-84 were diagnosed in an emergency, compared with 14% of cancers in those aged 50-59⁶².

FIGURES 2 AND 3: FIVE-YEAR SURVIVAL FOR MEN AND WOMEN DIAGNOSED BETWEEN 2011 AND 2015



Bowel includes anus, NHL excludes 'other specified types of T/NK-cell lymphoma'.
 Larynx included as a proxy for head and neck.
 Prostate shown separately because of different age groups in the data.
 Source: Office for National Statistics and Public Health England.



Brain is only malignant neoplasm of brain, bowel includes anus, NHL excludes 'other specified types of T/NK-cell lymphoma', ovary includes 'other specified female genital organs'.
 Source: Office for National Statistics and Public Health England.

However, there are also discrepancies in access to treatment for older people with cancer⁶³. For example, a recent report by the National Cancer Information Network (NCIN) and Cancer Research UK (CRUK) found that across 20 cancer sites, older patients were less likely to have major surgical resections⁶⁴. Other studies have found similar; for example, older women with breast cancer⁶⁵ are less likely to undergo surgery; the use of radiotherapy also gradually decreases with age⁶⁶. Older people with lung cancer have also been shown to be far less likely to undergo surgery⁶⁷. There is also evidence that usage of chemotherapy with curative intent for lung^{68,69,70}, breast and colorectal cancer⁷¹, and as adjuvant therapy for breast cancer^{72,73}, declines with age.

However, we must bear in mind that in some cases there are legitimate reasons for lower treatment rates in older populations. Older patients are more likely to have multiple health conditions, for example, which may impact treatment tolerance and therefore the treatment options themselves^{74,75,76}.

Some patients may also choose not to pursue curative treatments, for various reasons. Recent research has also found that when considering chemotherapy, over half of older patients surveyed prioritised outcomes other than survival, for example maintaining their quality of life, independence or cognition⁷⁷.

While this can explain some findings, some studies have adjusted for these factors and have still found variation. For example, one study examining breast cancer surgery found that ‘inappropriate undertreatment’ was occurring for women over 85⁷⁸, after adjusting for health measures and patient preferences in treatment decisions. Similarly, a small study looking at the use of chemotherapy and biological treatment in early-stage breast cancer found that age was a major factor in clinical judgement, irrespective of other factors such as age or tumour size⁷⁹.

Given these disparities in access, this study sought to identify the barriers that older patients face in accessing treatment, to examine clinical decision-making and recommend solutions that would ensure older people with cancer can access the right treatments for them.

1.1 THIS RESEARCH

Cancer Research UK commissioned an independent research team from the University of Birmingham’s Health Service Management Centre and ICF International for this research.

The aim of the project was to understand clinical decision-making for older people with cancer across the UK and to identify barriers to optimal decision-making.

This report presents evidence from the following:

- A review of the literature relevant to clinical decision-making for older people with cancer
- Qualitative interviews with representatives of Royal Colleges and professional organisations, researchers and policymakers (n=15)
- Qualitative interviews with cancer multidisciplinary team members, primary care staff and other health professionals involved in clinical decision-making across eight UK sites (n=80)
- A survey of cancer multidisciplinary team members (n=57)
- A survey of primary care health professionals (n=98)
- A survey of older people affected by cancer (n=50)
- Observations of three multidisciplinary team meetings and three multidisciplinary

clinics

The report presents these findings alongside additional Cancer Research UK policy research into improving the effectiveness of cancer multidisciplinary teams (MDTs) (“Meeting Patients’ Needs) and the non-surgical oncology workforce (“Full Team Ahead”).

Further detail on the methodology is available in Appendix 1.

1.2 TREATMENT DECISION-MAKING FOR OLDER PEOPLE WITH CANCER

This research focused on understanding the process of making an initial treatment plan for older people with cancer. In most cases, an initial treatment recommendation is made by a cancer multidisciplinary team (MDT), before a final decision on is made by the treating clinician, in partnership with the patient and their loved ones.

1.3 THE ROLE OF THE MULTIDISCIPLINARY TEAM

Before beginning treatment, the vast majority of patients are discussed at a multidisciplinary team (MDT) meeting. In this meeting, a wide range of health professionals meet to make recommendations regarding patients’ treatment and care. MDT working is a central tenet of cancer services and the 2015 Cancer Strategy for England described MDTs as the ‘gold standard’ for cancer patient management. However, recognising the significant challenges faced by MDTs today, the strategy also made several recommendations for change. The most recent Welsh cancer strategy stated that MDTs remain the cornerstone of patient management in secondary care, and set out the intention to enhance their role as vehicles for governance and improvement⁸⁰. A recent Cancer Research UK report recommended new ways of working for multidisciplinary team meetings, to allow more time for discussion of the most complex patients – including older patients⁸¹.

Understanding how the different professional groups perceive MDT working and its impact on decision-making is an area acknowledged as being ‘under researched’^{82,83}. However, evidence suggests there are benefits of involving geriatricians in MDT meetings, to support discussions of how treatments might interact with comorbidities and subsequent support needs⁸⁴.

1.4 GERIATRIC ASSESSMENTS

Comprehensive Geriatric Assessments (CGAs) exist to support clinicians in making evidence-based treatment decisions for older people, by providing a systematic framework that removes some of the subjectivity involved in assessing an older patient. Although these assessments vary, they most often involve assessing functional status and cognition⁸⁵. They also often include fatigue, comorbidity, cognition, mental health status, social support, nutrition and geriatric syndromes⁸⁶.

Such tools are also an important way of ensuring care is centred around the patient and their individual needs. Patient-centred care is a central pillar of the NHS Constitution, in the form of the principle “no decision about me without me”.

The International Society of Geriatric Oncology (SIOG), the European Society of Breast Cancer Specialists (EUSOMA), the European Organisation for Research and Treatment of Cancer (EORTC) and the US National Comprehensive Cancer Network (NCCN) now recommend the use of some form of geriatric assessment to help determine the best cancer treatments for

older patients, particularly for whom chemotherapy is considered. A CGA is now the most commonly cited and validated example of a geriatric assessment.

The British Geriatrics Society have issued a good practice definition for CGAs:

Comprehensive geriatric assessment (CGA) is a multidimensional and usually interdisciplinary diagnostic process designed to determine a frail older person's medical conditions, mental health, functional capacity and social circumstances. The purpose is to plan and carry out a holistic plan for treatment, rehabilitation, support and long term follow up. CGA is part of an integrated approach to assessment based on the following principles:

- The older person is central to the process.
- Their capacity to participate voluntarily must be assessed, and if lacking, then there needs to be a system to address their needs in an ethical fashion.
- Links between social and health care should be good enough for older people who need comprehensive assessment to receive it in a timely and efficient manner, and proportionate to their degree of need.
- Assessments should be standardised and carried out to a reliable standard.
- Circumstances which warrant a comprehensive assessment include, among others:
 - Acute illness associated with significant change in functional ability
 - Transfers of care for rehabilitation/re-enablement or continuing care
 - A frail patient prior to surgery or experiencing two or more "geriatric syndromes" of falls, delirium, incontinence or immobility.

Despite their wider endorsement, CGAs are still not routinely used in oncology and there is no standardised method for conducting CGAs⁸⁷. Although there is general consensus about which domains should be assessed⁸⁸, there is little consensus on what constitutes a 'comprehensive' assessment or the most effective measurement tools.

1.4.1 COMPREHENSIVE GERIATRIC ASSESSMENTS IN ONCOLOGY

At present there is no clear evidence regarding the best tool to use for CGAs in oncology, or how oncology outcomes are improved through using CGAs⁸⁹.

Overall, there is relatively little strong evidence about the impact of CGAs on cancer treatment decisions. For example, three systematic reviews looking at the usage of CGAs in oncology have concluded that the quality of studies on impact are generally poor to moderate⁹⁰ and there has not been any randomised control trial examining the effectiveness of CGAs in changing treatment plans, or improving overall outcomes for older people with cancer. However, there are some promising findings about the impact of CGAs:

- Several studies have found that CGAs often influence treatment decisions, however the proportion of decisions impacted is disputed⁹¹. One study conducted in 2013 found that CGAs identified previously unknown issues in 51% of the study population, which resulted in changes to treatment decisions for 25% of patients and determined intervention plans for 26% of patients⁹². However, no follow up was done to understand the extent to which these decisions impacted eventual outcomes.
- There is evidence to suggest that CGAs – and specific aspects of CGAs, such as frailty or performance status – have predictive value for chemotherapy toxicity⁹³.

- Kalsi et al concluded that older patients undergoing a CGA were more likely to complete chemotherapy, and fewer had changes made to their treatment plans, as interventions could be made that addressed a patient's wider needs, for example managing existing conditions or providing additional medical or social support⁴⁶. The authors recommended that 'standard oncology care should shift towards modifying coexisting conditions to optimise chemotherapy outcomes for older people'.
- Hamaker et al's systematic review in 2012 found a link between CGA results and the likelihood of perioperative complications⁸⁵.

The Macmillan SCOPES project (Systematic Care for Older People in Elective Surgery) is a particularly interesting case study⁹⁴.

Systematic Care for Older People in Elective Surgery (SCOPES)

This project was developed at Nottingham University Hospitals NHS Trust in 2010 for lower limb joint replacement surgery, but was later extended to upper gastrointestinal cancer surgery.

An outpatient clinic is held once a week, involving a range of health professionals – including geriatricians, specialist nurses, dieticians and social workers. A CGA is undertaken in one visit, with the results fed back to the upper GI cancer MDT.

Patients can then receive additional support or clinical interventions to optimise their fitness before surgery. The SCOPES team can also help coordinate social care, either for the patient themselves or a loved one who is usually cared for by the patient. This approach has resulted in a number of positive results including reducing length of stay.

... at the moment we're looking at a reduction of approximately 28 days down to 16 [in house calculations] now a lot of that will be ITU [Intensive Treatment Unit] care because the purpose of what we do is to optimise patients to get through whatever they're having so if we've optimised them it means less time in terms of care or HDU [High Dependency Unit] which means less time in hospital because of building up their fitness we can get them home because we've got their packages organised for them they don't have to wait on a ward blocking a bed. (SCOPES Project Manager)

Recent evaluation – a prospective cohort study – aimed to examine the effect of the CGA on cancer MDT decision-making and clinical outcomes. This found that significantly more patients in the CGA group (33%) received potentially curative surgery than in the control group (18.2%). Six-month mortality was significantly lower in the control group (30.9% vs 48.5%). Other outcomes were more consistent between CGA and control groups, for example palliative treatment decisions, post-operative length of stay and total use of acute care. This highlights how dietary, occupational therapy and physiotherapy reviews can directly contribute to treatment optimisation.

Although several organisations have produced guidelines on conducting CGAs in cancer³, the use of these is highly variable across countries and centres. This is often because of a lack of staff, as well as other institutional and/or funding constraints⁹⁵.

Furthermore, often the tools that are familiar to geriatricians are not used by oncologists, are not fit for the specific assessment of older people with cancer or are too long and

³ NCCN, SIOG, EUSOMA and EORTC

cumbersome to be used in everyday clinical practice⁹⁶. Because of this lack of standardisation, O'Donovan et al. argue that '...geriatric assessment has yet to be optimally integrated into the field of oncology in most countries'⁹⁷.

This report will discuss the usage of CGAs in the assessment of older people with cancer across the UK, gathering views on their utility from health professionals.

1.4.2 ASSESSING FRAILITY

The British Geriatrics Society defines frailty as a long-term condition; a clinical state of vulnerability caused by decline of psychological and physical reserves⁹⁸.

Recognising and assessing frailty is an essential component of effective care for older people. Recent years have seen an increase in initiatives that aim to improve the quality of care by addressing the specific needs of people with frailty. For example, the British Geriatric society have worked with Age UK, the Royal College of General Practitioners and NHS England to provide best practice guidelines to manage frailty in the community (Fit for Frailty) and specialised quality checklists for people with frailty in acute settings (Frailsafe).

Martin Vernon, National Director for Older People and Integrated Care at NHS England, has argued that frailty should be treated as any other long-term health condition⁹⁹. This is in light of the increasing numbers of people with frailty and the systemic costs of ignoring the impact of this on hospital and community-based care. Vernon sees better identification, targeted assessment and individual care plans as the first steps towards averting a frailty crisis in health and social care. Frailty demands a whole system approach, with Vernon's recommendation focusing on use of the electronic frailty index as standard for routine data in general practice.

The Independent Cancer Taskforce also highlighted interactions between frailty and cancer, as well as the important role of frailty assessments and CGAs in informing treatment recommendations and identifying additional support needs.

1.5 SHARED DECISION-MAKING

The concept of shared decision-making (SDM) originated in the disability rights movement, expressed through the phrase 'nothing about me, without me'. It has since played an increasing role in shaping health and care policy, both in the UK and internationally, with 'person-centred care' more recently at the forefront of NHS England's Five Year Forward View. The National Institute for Health and Care Excellence (NICE) have convened a Shared Decision-Making Collaborative, have published an action plan¹⁰⁰ and have updated their processes for developing guidance so that shared decision-making is a key consideration.

Despite this widespread support for the principle of shared decision-making, there is no universally agreed definition. For the purposes of this report we will use the definition adopted by the Health Foundation and NICE:

*'a process in which clinicians and patients work together to select tests, treatments, management, or support packages, based on clinical evidence and patients' informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and systems for recording and implementing patients' treatment preferences.'*¹⁰¹

People who participate in decisions about their care are more likely to be satisfied with their care¹⁰². There is also strong evidence that SDM can improve patients' self-efficacy, which can in turn have a significant impact on behaviours¹⁰³. There is limited evidence that these improvements in self-efficacy can, in turn, impact quality of life and clinical outcomes. This is because individuals have care which fits better with their lifestyles¹⁰⁴; more involvement in decision-making may also increase the chance that individuals adhere to their medication¹⁰⁵.

However, individual characteristics will affect how willing or able that person is to engage in SDM. For example, their attitudes, opinions and life experience, self-efficacy, activation and health literacy, socioeconomic and demographic status are all relevant factors. When people have low health literacy, self-efficacy or activation, they may lack the confidence, understanding or recognition to take an active role in decisions about their care¹⁰⁶.

Some older patients may face a particular set of challenges in engaging with SDM: they may be more likely to defer to authority, for example, to believe that clinicians should not be questioned, or think they lack the status to decide for themselves¹⁰⁷.

1.5.1 SHARED DECISION-MAKING IN CANCER

SDM, particularly the use of decision aids, has been relatively prominent in cancer care compared to other conditions. This is partly because of the sheer number of decisions cancer patients are faced with throughout their diagnosis and treatment, from participating in screening through to treatment options.

There is strong evidence that shared decision-making is beneficial to cancer patients. For example, the 2015 CanCORS study found that when patients report engaging in shared decisions they more often reported excellent quality care and good communication from their physicians. Importantly, this association held regardless of whether the individual stated an initial preference to make shared decisions¹⁰⁸.

There may also be variation by cancer site; for example there is evidence that patients with prostate and breast cancer are most likely to want to be involved in decisions compared to those with colorectal, gynaecological or lung cancers. However, the evidence on this is limited and cross-cut by other variables that might affect engagement – such as gender, age and disease severity¹⁰⁹.

1.5.2 SHARED DECISION-MAKING FOR OLDER PATIENTS

Older people with cancer face a particular set of challenges which may make SDM more difficult. At the same time, these challenges make the principle of SDM ever more important.

When cancer forms just one aspect of an older person's multiple conditions, decisions become more complex and are not just based on clinical evidence^{110, 111,112}. For older people who are experiencing cognitive impairment, the different options can be challenging to understand and navigate.

In the time-limited context of treatment decision-making, health professionals can perceive this struggle to engage in a conversation as a lack of competence^{113,114,115}. The social and practical context of many older people's lives can also add complexity to treatment decisions. In particular, isolation or caring commitments to others may limit older people's engagement in their own treatment or present practical challenges¹¹⁶.

Treatment decisions are also more likely to be more complex for older patients. Older people,

more so than younger people, may need to not only consider the potential benefits of a treatment option, but also consider their own life expectancy, and the effect of any of their other conditions. They must balance decisions about the quality of life they want to lead, against the length of time they want to live for. This is not only a highly complex medical problem, with an almost impossible to predict 'right' answer, but a challenging emotional decision¹¹⁷.

This complexity is compounded by the fact that the evidence available to both health professions and patients on the potential impact and side effects of any treatment is significantly less than for younger people, partly a result of there being fewer older people, and people with comorbidities, in clinical trials^{118,119}.

1.5.3 THE ROLE OF FAMILY MEMBERS IN SHARED DECISION-MAKING

Family members and carers often play a key role in providing care for people with cancer, particularly for older patients. When it works well, there is some evidence that sharing decisions leads to greater patient satisfaction, better treatment adherence, and allows family members to act as patient advocates, demanding the best care for their family member^{120,121}.

However, issues can arise where there are discordant views. This can be common, particularly when patients are older, caregivers are less educated and the patient-caregiver relationship is parent-child rather than spouse-patient¹²². Qualitative research suggests that this can be particularly difficult when decisions must be made about switching from curative to palliative treatment: family members can be less willing to stop active treatment, even when it causes severe side-effects. Patients themselves are often readier to accept and recognise that they are seriously ill than family members are¹²³.

1.5.4 THE ROLE OF HEALTH PROFESSIONALS IN SHARED DECISION-MAKING

The behaviours and attitudes of health professionals have a significant impact on patients' ability to engage in SDM. As such, health professional training is the key to implementing SDM: it can overcome barriers to engaging with health professionals, for example any falsely held beliefs that they already work in a person-centred way or beliefs on the value and 'cost' of ensuring SDM.

Health professionals often underestimate how much patients want to be involved in decisions about their care and make assumptions about their skills or ability to do so. For example, one study found that health professionals thought patients were far more likely to not take part in bowel cancer screening than they actually were¹²⁴.

Similarly, health professionals may assume that certain groups of older patients are less able to engage in decisions¹²⁵. This is problematic, as there is often significant variation *within* groups¹²⁶. Secondly, as previously noted, individuals may appear unwilling to engage in SDM but this may be because they can't, rather than they won't¹²⁷ – and therefore health professionals should try and support patients to participate in SDM, where possible.

1.5.5 THE ROLE OF THE HEALTH SERVICE IN SHARED DECISION-MAKING

A range of organisational and systemic factors affect the availability and impact of SDM. These include senior support and commitment, alignment with wider agendas, IT systems and

support capacity, and supportive commissioning and payment systems. If these factors are in place, the system has minimal barriers to SDM and includes incentives that encourage patients and clinicians to take part.

Underlying this, there must be sufficient time and integration to allow meaningful SDM. A lack of integration between health services can be a further barrier to SDM, and particularly in cancer where individuals are increasingly living long-term, with and beyond cancer. For these people, care shifts between primary, secondary, community and social care – and information all too often does not flow between those services. If there are breaks in care, patients can feel ignored, demeaned and insulted¹²⁸.

A lack of time is also a common barrier to ensuring SDM; clinicians often perceive SDM as more time-consuming than ‘usual’ care, and there is some evidence that this is true. This makes health professionals less willing to use SDM, particularly when the time available for consultations is short. Patients also report that short consultation times limit their ability to be informed, to reflect on the information received and to ask questions. This is felt particularly acutely in the context of current pressures on cancer services: patients are sensitive to clinicians’ high workloads and are conscious not to ‘take up their time’¹²⁹. These pressures particularly affect older patients, who are more likely to require more time to process information and think through options.

1.6 THE POLICY LANDSCAPE

All UK nations recognise that cancer is predominantly a disease of older age and that the ageing population presents future challenges to the health service. However, given that health is a devolved issue, each nation takes a different approach to tackling the specific challenges of older people with cancer.

1.6.1 ENGLAND

The 2015 Cancer Strategy for England, ‘Achieving World-Class Cancer Outcomes: a strategy for cancer’, gives the most explicit attention to older people with cancer¹³⁰. The strategy highlights that current assessment methods are not fit for purpose, which can result in older people’s needs not being identified or sufficiently well-understood. It also highlights the role of specialist geriatricians in orthopaedics as a positive example, transforming the approach to hip fractures, and identifies that there may be similar opportunities in cancer. The strategy makes two recommendations targeted towards older people with cancer:

Recommendation 41: NHS England, the Trust Development Authority and Monitor should pilot a comprehensive care pathway for older patients (aged 75 and over in the first instance). This pathway should incorporate an initial electronic health needs assessment, followed by a frailty assessment, and then a more comprehensive geriatric needs assessment if appropriate. The pilot should evaluate a model in which the outputs of these assessments are considered by the MDT in the presence of a geriatrician, who would advise on AHP needs, co-morbidities etc., and their implications for treatment and emotional and physical support.

Recommendation 42: NHS England should ask NIHR and research charities to develop research protocols which enable a better understanding of how outcomes for older people could be improved.

The National Cancer Information Network (NCIN) has also investigated the specific characteristics of older people with cancer; the key messages from their 2015 report have underpinned this report¹³¹. The report surmises that assessments are the key to ensuring that older people are offered the best treatment and that they are not excluded on the basis of age alone. The importance of evidence-based, systematic mechanisms of formulating treatment recommendations is central when acting to avoid treatment decisions being made solely on age, with implicit assumptions of frailty. Effective prevention, earlier diagnosis, enhanced support (especially in the community) and increased involvement in research are seen as other major priorities for improving older people's outcomes.

More broadly, NHS England's Five Year Forward View, published in 2014, also focuses on older people¹³². This has translated into setting a research priority for understanding outcomes for older people with cancer, and piloting a comprehensive care pathway for older patients.

1.6.2 SCOTLAND

The most recent cancer strategy in Scotland is 'Beating cancer: ambition and action', published in 2016¹³³. The strategy highlights the increasing number of older people and the (related) growth in long-term conditions, drawing attention to necessary improvements in prevention and diagnosis to mitigate increased demands on services. Engagement with people of all ages is described as key to spreading awareness of cancer symptoms and ultimately improving detection of cancer in the older population¹³⁴, however there is no specific section on the treatment and care of older patients.

1.6.2 WALES

The Cancer Delivery Plan for Wales, published in 2016, focuses on inequalities within the older population¹³⁵. Tackling health inequalities are seen as a priority for Welsh health policy, strategy and governance. Solutions focus on the importance of localised approaches and involvement of partners in public health and the third sector, however there is no specific focus on older people with cancer.

1.6.2 NORTHERN IRELAND

Northern Ireland does not currently have a cancer strategy and so it is difficult to ascertain the extent to which there is a strategic focus on the needs of older people with cancer. However, we do know that there is a particular interest in rural isolation and the related transport issues. The Northern Ireland Assembly cancer services research and information briefings directly challenge the consequences of service centralisation on these grounds¹³⁶.

2 OLDER PATIENTS HAVE MORE COMPLEX CARE NEEDS – AND THE SYSTEM IS NOT SET UP TO DEAL WITH THEM

Older people with cancer are more likely to have complex medical and social needs, and therefore may require additional support to access treatment. For example, older patients are more likely to have other age-related illnesses, but also more likely to require social care support. These factors make it ever more important to ensure that decision-making is shaped around each individual patient’s circumstances – and more could be done to ensure that this is always the case.

2.1 CLINICAL FACTORS

Older people have an increased prevalence of age-related comorbidities such as diabetes, hypotension, atherosclerotic disease, chronic respiratory disease, arthritis and cognitive issues¹³⁷. Cognitive issues can pose a particular challenge; up to 40% of older patients present with cognitive issues that impair their capacity to make complex decisions about treatment, adhere to treatment plans and recognise symptoms of toxicity that might require medical attention¹³⁸.

These factors combined lead to difficult decisions for clinicians forming treatment plans for older patients. As well as treatment efficacy, clinicians must also consider the impact of a treatment regime on the patient’s quality of life and their likelihood to adhere to a treatment regimen, interactions with multiple comorbidities and the likelihood of the patient’s condition deteriorating during treatment because of a pre-existing condition.

Our thematic analysis of all survey and case study material, aside from responses from primary care, has identified four main clinical factors which would determine what treatment an older patient may receive:

1. The patient’s fitness to withstand the rigours of treatment;
2. The likelihood that the patient will die from a cause other than their cancer;
3. Whether the patient has co-morbidities;
4. If there is clinical evidence to support a particular course of treatment in an older patient

2.1.1 PATIENT FITNESS

Where clinicians are concerned about a person’s fitness to withstand treatment, they will often work with the patient to optimise their treatment options – often referred to as “pre-habilitation”. For example, they might focus on improving the person’s fitness before surgery, or they could start with a lower dose of chemotherapy to check how the person responds to toxicity. However, interviewees recognised that this could require older patients to undergo

more investigations to check their fitness. This can be challenging to do while still meeting national targets, as these interventions take more time. This has been echoed in research, which has found that service targets that focus resource solely on cancer can disadvantage patients with complex wider needs, as individual clinicians may struggle to deliver effective treatment plans without breaching targets¹³⁹.

This is particularly relevant for older people with lung cancer, who often have particularly complex needs: many are elderly and can have related comorbidities such as cardiovascular disease, vascular disease, Chronic Obstructive Pulmonary Disease (COPD) and lung disease (from smoking). In this case, even if the individual has a curable cancer, their treatment options can be limited since the patient is simply too unwell to cope with extensive diagnostic tests and treatment.

We have a lot of patients that can't get through tests, because you know they've had bleeding issues from their cancer or they've got poor lung function test [results], they can't do a needle biopsy. Or they bled at bronchoscopy ... Or they have a stair test and they only manage two flights. ... Or they've got lung fibrosis so I can't give them radiation of a curative type. (Clinical oncologist)

The physical mobility of a patient can also limit options, including in terms of diagnostic tests.

So if a patient is unable to elevate their arm that means they wouldn't be able to have radiotherapy ... if I can't elevate their arm the chances are I won't formally assess the axilla [armpit]. (Radiologist)

However, clinicians also reported working around these limitations to provide the best possible care in the circumstances.

...we can't work them up as well as we would somebody younger because they're not physically fit enough to have mammograms say, but I will often and my colleagues will often do a biopsy with them say sitting in their wheelchair so that we can get the hormone receptive status and treatment with chemotherapeutic agents such as Tamoxifen, without the need for more invasive tests. (Radiologist)

A number of interviewees from case study sites with a particularly elderly demographic mentioned their experiences of having 'pushed the boundaries' of what might be considered 'usual practice' when it comes to older patients, with the driver for this being the need to maintain comparable treatment figures to other areas.

And we have had some situations, elderly patients, where they're not fit enough for a general [anaesthetic]. We wouldn't do an auxiliary clearance for example under a local, but we have done mastectomies and wide local excisions under local anaesthetic. (Cancer Nurse Specialist)

Anaesthetists can make a significant contribution towards optimising a patient's options for treatment and those interviewed for the study reported drawing on a range of resources and expertise to facilitate this. This might involve a referral back to the patient's GP to optimise someone's inhaler use, or the administration of iron pre-operatively, or asking cardiologists to adjust someone's medication to improve cardiac output.

2.1.2 COMORBIDITIES AND POLYPHARMACY

Older people with cancer are more likely to have other pre-existing health conditions. As well as implicating a potential treatment plan, this also means that they are more likely to die from something other than their cancer compared to younger patients¹⁴⁰. This can complicate treatment decision-making, since side-effects of cancer treatment could have a significant negative effect– as highlighted by an interviewee for this research.

In elderly patients with small renal masses we are ... more likely to adopt a conservative approach where we will monitor the growth of that tumour before making a decision to treat, because if it turns out to be essentially sessile tumour mass that is not growing, then that patient is probably never going to run into bother with that tumour for the remainder of their natural life expectancy. (Medical oncologist)

It can also be difficult to control for possible interactions between multiple medications, which is known as polypharmacy. Patients and clinicians can be faced with a trade-off between maintaining a drug regime that controls their other conditions and possibly disrupting that to receive cancer treatments. This can be the case for both mental health conditions and physical health conditions.

2.1.3 CLINICAL EVIDENCE

As will be discussed further in section 6, there is often relatively limited evidence to support the use of new treatments in an older population, since older patients are under-represented in clinical trials.

This is an important issue: as well as being more likely to have comorbidities and to be on other medication, older patients can also have biological differences that can impact treatment efficacy. A person's chronological age can have a significant effect on their response to medication. For example, age-related changes in liver, kidney and gut function significantly impact how drugs are absorbed, distributed around the body, metabolised and excreted¹⁴¹.

2.2 SOCIAL FACTORS

Social factors can have a significant effect on how people view their own health and treatment options, particularly if patients must travel a significant distance to receive their treatment.

This research has highlighted a range of potential barriers to older people accessing treatment or to making a decision that is right for them. Some barriers relate to practical issues, whereas others concern attitudes or beliefs. It was also noted that the extent to which these barriers could be removed varies significantly.

2.2.1 COGNITIVE IMPAIRMENT

Healthcare professionals find that treatment discussions are particularly challenging when patients have cognitive impairments. Clinicians are often reliant on the patient's own assessment of their abilities, which may be inaccurate. Patients may also overestimate their activity levels, perhaps from a sense of denial of physical decline, or from a desire to convince

the clinician that they are fit for surgery. In these instances, the involvement of family members or carers is often critical.

Dementia affects 810,000 adults over 65 in the UK and just 40,000 people under the age of 65¹⁴². Dementia has a huge impact on decision-making in general, but particularly on securing patient consent for treatment, since memory problems can impact a patient's ability to retain information and make an informed decision. If an individual has significant mental impairments and is unable to understand the options outlined to them, pursuing active or 'conventional' treatment options can be difficult. This is partly because patients may be unable to recognise negative side-effects or complications of treatment.

However, through our interviews we heard some doubt about how it can be difficult to identify patients with dementia if they do not yet have a formal diagnosis and the progression of their disease is mild. Furthermore, it is unclear how patients with more severe dementia are identified and flagged to the MDT managing their care – as will be discussed later in this report.

Other cognitive issues can also have an impact on treatments. For example, older patients who have suffered a stroke or other brain injury may have difficulty retaining information and making complex decisions. This gives further weight to the case for more widely used robust tools that can factor these issues into decision-making in a consistent way.

2.2.2 SOCIAL SUPPORT NEEDS

For many older people with cancer, their wider social situation has a significant impact on treatment decisions. For example, patients may have caring responsibilities or may themselves need additional social support. A lack of family or carer support can be a concern for clinicians making recommendations, since it can increase the patient's risk of post-treatment complications and make it harder to pursue active, ongoing treatment. This is particularly the case for chemotherapy.

I use chemotherapy to treat cancers and one of the important criteria is to the ability to be supported and the ability to seek help if there is any adverse events or toxicities... the patient needs to be... clued in to seek help and... we know people cope well if they are supported from the family and given the density of some of the chemotherapy, I do take a very cautious view if the patient does not have any adequate social family support. (Medical oncologist)

46% of MDT members surveyed for this research identified the lack of social or practical support as a barrier to older people accessing the most effective treatment for their cancer. This was echoed by patients involved in the study, who felt strongly that a lack of certainty about how they will access non-medical support was a significant barrier to accessing treatment. This fear was often heightened by public reports of financial pressures on the wider health and care system.

It's one thing to choose to decline treatment, because the effort of chemotherapy and how ill it's going to make you feel isn't worth (it)... It's very different to making a decision based on 'I can't get the care for my husband or I can't get the care for my wife or I don't have transport to get to the chemotherapy ... Or I'll feel too rubbish afterwards and there's nobody around to do my cooking and cleaning'.... (National

interviewee)

Reassurance of domiciliary care, adaptations and devices, self-care advice (physiotherapy and diet), carer benefits and respite were described as factors that might have an impact in treatment decision-making, where these needs are identified and addressed early on.

The reality of older patients turning down treatment because it would mean they were unable to fulfil their caring responsibilities was a recurring theme from health professionals and patients involved in this study.

Many older people care for someone who is dependent on them and such responsibilities are more likely to cause difficulties for older patients than younger ones. These issues are particularly prevalent amongst patients whose treatment is long-term and debilitating. This can have a significant effect on how people view their own health and treatment options.

...his wife has severe dementia, he was her main carer, ... And I said to him 'you know we can do this surgery, we can cut the tumour out, but I don't think you'll get out of hospital for three to six months, you need to be aware of that', and he said 'well I can't do that, because I need to care for my wife, and she's deteriorating.' (Anaesthetist)

.... And that's quite a common barrier to treatment actually, because the patient will say, you know, I don't want to compromise my own health because if my own health is compromised, I may not be able to continue looking after my spouse. (Medical oncologist)

Though it is possible for alternative care to be arranged so that people can receive treatment and recover, for many people this will be a logistical and emotional struggle at a time when they are likely to be feeling unwell and vulnerable. These concerns and fears can be exacerbated if the person being cared for has dementia or other cognitive decline, as this can often increase anxieties about how they will cope with a change in circumstances.

Furthermore, there can often be a significant cost associated with arranging alternative care, as well as logistical difficulties¹⁴³. Although some may be eligible for financial assistance, many are not. These considerations might mean that patients delay or discount treatment altogether but it might also lead to unrealistic expectations of how people might cope with recovery and caring for a dependent spouse or partner.

I think sometimes people don't know how big the operation is ... and I don't always think they're fully aware of what the implications may be ... they might think if I'm out of hospital after a week I'm going back to looking after my wife (Anaesthetist)

In these cases, the role of community-based oncology nurses is vital, as are flexible models of delivering treatment such as community- or home-based chemotherapy. However, the range of services available ranges considerably across the country.

...in some parts ... we've got very good support by community oncology nurses so they see patients who are having chemotherapy and can give some chemotherapy at home as well and monitor their side effects but in some other areas ... that service isn't available ...the palliative care services are available across [the region] but again the palliative care occupational therapy services in some areas aren't available for some patients. (Cancer Nurse Specialist)

For surgery, the support available to a recovering patient is important, however did not seem

to limit whether a patient was offered a particular course of treatment.

I don't know if I'd ever deny anybody an operation if they haven't got family support if everything else was kind of in the balance... I think it's a good thing if they've got it but I don't think I'd hold it against them or weigh it against them if they haven't ...
(Anaesthetist)

In some cases, hospital-based care can be extended to ensure that the patient is recovered to a point that they will be able to cope at home. In other cases, patients can be referred to rehabilitation or convalescence homes. Unfortunately, there are significant bed shortages at these facilities and so this is often not an option.

Wider issues with the social care system also have a significant knock-on effect on cancer care. National interviewees and two social workers linked to oncology teams highlighted that the social care assessment process is limited by it being too reactive, meaning patients must wait until after treatment for an assessment to be made.

We can fully anticipate that after major surgery or a period of chemotherapy someone is going to be in a state to need the care. So why can we not plan to put it in and cancel it when we no longer need it? And I think I know what the answer to that is and that's about the fact that we don't have enough resources to cope with what we've already got.
(National interviewee)

2.2.3 TRAVEL REQUIREMENTS

Some patients will be required to travel some distance to access treatment that is more specialised. For example, interviewees at a Northern Irish site spoke of their patients being sent to Leeds for stereotactic radiotherapy until a local service was established. But even for more routine treatment, frequency and inconvenience of travel can be a barrier to access.

...depending what treatment they have that can be quite an intense scanning regime certain types of treatment in the first year requires for you to have four MRI scans which are not the most pleasant things in the world so there can be a lot of travel involved.
(Urologist)

This is a particular issue for radiotherapy, which requires regular attendance, often over several weeks. Though this impacts patients of all ages, older and more socially disadvantaged people are more likely to be reliant on public transport or lifts from friends and family when they access public services¹⁴⁴.

These issues have clear implications for treatment options. For example, clinicians and patients with breast cancer may opt for a mastectomy where there is concern about the ability to manage the daily travel requirements for radiotherapy following local excision surgery.

All our patients who have wide local surgery are offered radiotherapy and if they're really too ill to come up and down to the hospital, ...patients who really can't cope with radiotherapy after breast cancer surgery, we fully recommend the mastectomy, because then there is no risk to the rest of the breast. (Radiologist)

Transport issues are most problematic for tertiary centres which serve a mainly rural area. These issues are then compounded when treatment (and monitoring) requires frequent hospital visits, with minimal scope for remote or community-based support.

Obviously we work with local hospitals and community care to manage toxicities and complications of the disease and the like, but we have no alternative but to see them here. (Medical oncologist)

Interviewees based at sites where patients are more likely to travel expressed concerns that this could exclude frailer or older individuals from treatment. This was also raised as a key barrier to taking part in clinical trials.

So yes, it is more difficult for older people to get transport and it's possible that a lot of them don't want to be a bother to their families ...getting on buses, trains, whatever, is not ideal and the kind of ambulance, minibus service trails them round the country so they don't like that ... it's another burden that they have. (Medical oncologist)

In England, where radiotherapy services are soon to be re-organised into new Radiotherapy Networks, there is a timely opportunity to embed the needs of older people with cancer in this process, through meaningful patient involvement as services are planned.

Recommendation: UK health services should ensure that the specific needs of older patients are considered in all new service plans and workforce plans. For example, emerging Radiotherapy Networks in England should consider the impact of changing travel requirements on older patients and should work with charities and providers to ensure all patients are given the support they need to receive treatment.

2.2.4 FINANCIAL ISSUES

The cost of being ill can be significant. For older people, this cost often relates to the need to fund care for dependents while the caregiver is receiving treatment, as discussed above. Beyond this, there can also be a financial cost of paying for support for the patient themselves, including home care, residential nursing care or more general social care support. Interviewees highlighted that this is often poorly understood by patients and their families.

What I find very strange ...is when people come into hospital and we discharge them with a care package they do not know how much it's going to cost. ...I've never understood why nobody ever challenges that ... nobody asks how much it's going to be and there's no way of us being able to tell them either... (Oncological social worker)

Recommendation: Cancer service managers should ensure that patients' support needs are assessed at an early stage in the pathway, so that they are able to access the support they need during and after completing treatment. Health service regulators should consider ways to ensure that this is done effectively and consistently across the UK.

3 TREATMENT DECISION-MAKING DOES NOT ALWAYS TAKE ALL RELEVANT FACTORS INTO ACCOUNT

We can only be sure that treatment decisions are right for patients if we are confident that decisions have been made with consideration of all relevant information about that patient. This is true for every patient, but is most important for patients with additional medical and social needs – and so often very important for older patients.

Unfortunately, these complex needs are often not routinely considered as part of the treatment decision-making process in cancer. This is partly because services lack the right tools to assess frailty in the cancer setting, and Comprehensive Geriatric Assessments are still rarely used in oncology. This is important: it is widely recognised that chronological age alone is not a strong indicator of how well a person will tolerate cancer treatment¹⁴⁵.

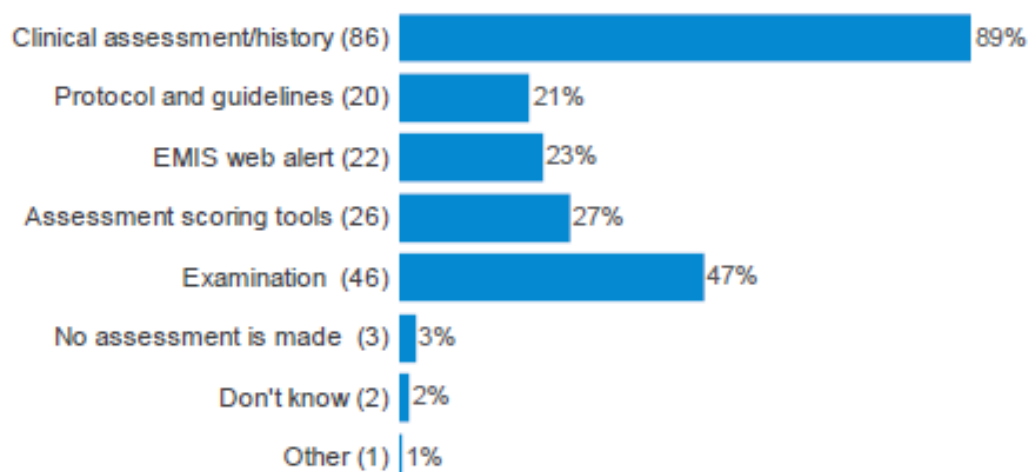
Unfortunately, these complex needs are often not routinely considered as part of the treatment decision-making process in cancer. This is particularly true for frailty assessments – which can have a significant impact on how likely a person is to tolerate treatment. In the absence of a robust method, assessment of a patient’s fitness for treatment can be assumed based on their chronological age, or how they seem during a consultation. One reason for this, as outlined in the most recent Cancer Strategy for England, is that standardised assessment tools – such as a CGA – are rarely used.

A CGA supports clinicians making difficult treatment decisions for older people, by reducing the subjectivity of the decision-making process. More specifically, a CGA can support a clinician to understand a patient’s likely tolerance of treatment and the impact of comorbidities on their outcomes, allowing them to alter treatment and care plans accordingly – and in a systematic, evidence-based way.

3.1 THE USE OF COMPREHENSIVE GERIATRIC ASSESSMENTS IN PRIMARY CARE

In our survey of primary care staff, 70% of respondents told us that their assessment of an older person’s frailty influenced their decisions to refer patients for diagnostic tests or treatment. However, the use of standardised, evidence-based assessment tools to measure frailty objectively was limited. Instead, GPs and other primary care staff tended to rely on clinical assessments, patient history and physical examinations to assess frailty (Figure 4).

FIGURE 4: PRIMARY CARE STAFF'S METHODOLOGY FOR ASSESSING FRAILITY



When exploring this further in national interviews and local interviews with GPs and GP cancer leads, interviewees indicated that GPs might not be very aware of standardised tools and guidelines around assessing frailty, or the evidence supporting their use.

I think very few (in primary care) are using sort of formal frailty indexes or quality of life indexes or even functional assessments. (National interviewee)

I have to admit I do know the seven-point score that's come in quite recently but I've never used any specific scale to assess anyone's frailty. I don't know what the evidence is behind that frailty score, so I guess that's important. (General Practitioner)

However, there are some local tools which are being used, for example the validated electronic frailty index (eFI) developed by academics from the Yorkshire and Humber Collaboration for Leadership in Applied Health Research and Care (CLAHRC). This index uses existing electronic health record data to identify and grade frailty, then identifies the top 2% most vulnerable patients for targeted care planning¹⁴⁶.

The eFI is now available to GPs in electronic health record systems that cover 90% of the UK population and has been included in NICE multimorbidity guidance¹⁴⁷. The developers have recognised that its use in primary care could result in improvements in secondary care and specialist services, including cancer¹⁴⁸. However, we also know that communicating such information to secondary care can be challenging.

3.2 THE USE OF COMPREHENSIVE GERIATRIC ASSESSMENTS IN SECONDARY CARE

Interviews conducted for this study revealed that, while there are some champions, the perception of many acute clinicians is that few appropriate tools currently exist and where they do, the value they might add to the decision-making process still needs to be proven. This finding aligns with the literature: there is currently no standardised method for conducting comprehensive geriatric assessments, and there is no agreement on the most effective measurement tools or the impact the use of certain tools might have on both treatment decisions and treatment outcomes.

It was also suggested by one or two acute clinicians interviewed for this research that more formal assessment tools should not get in the way of the more informal assessments such as ‘just seeing how a patient walks into the consultation’.

While CGA, frailty assessment etc. might sound more technological, I think in reality they would add extra workload and would not improve on the end of bed assessment that someone is fit for intensive treatment or better on less intensive treatment. (Surgeon)

Using a general notion of frailty to assess fitness for treatment was common practice in secondary care, however participants found the objective measurement of this concept challenging – preferring a more intuitive approach.

Some secondary care interviewees mentioned the use of a handgrip test to determine strength and the sitting and standing test but appeared in practice to accept a far more intuitive sense of underlying status among older patients, while recognising there are limitations with this approach. However, there are some tools being used.

3.3 WHAT ASSESSMENT TOOLS ARE BEING USED?

3.3.1 CARDIAC AND RESPIRATORY FUNCTION TESTS

Acute secondary care team members suggested that cardiac and respiratory function tests were the most significant indications of fitness for surgery. ECGs are often used to assess cardiac function, to identify irregularities such as atrial fibrillation – which would be a red flag indicating that the patient would be unable to tolerate a general anaesthetic.

CPET or CPEX¹⁴⁹ testing is considered the gold standard for testing cardiorespiratory function, however it requires specialist equipment, facilities and staff resource – which may not always be available. This testing also requires cycling activity, which many patients may be unable to complete. Instead, study participants spoke of a more informal assessment, in which they ascertain patients’ ability to undertake various activities of daily living (ADL).

So I ask about their activities of daily living what they can do for themselves and then in terms of exercise my first question is if they can climb two flights of stairs we kind of get a rough guide of metabolic equivalents ...so if they can climb two flights of stairs that means they can usually raise it four fold which in the literature is considered adequate for major surgery when they have abdominal surgery. (Anaesthetist)

3.3.2 PERFORMANCE STATUS

Performance status is a World Health Organisation definition describing how mobile a person is, from a scale of 0 to 5 – with 0 being someone who is fully active and able to carry on all pre-disease performance without restriction. However, some clinician interviewees recognised that this is not often detailed enough to inform treatment decisions since it does not take important biological factors into account.

...the age of the patient is an important factor... I’ve treated elderly people with systemic treatment and they are performance status one, but these people have older kidneys, old livers and the drugs that they’re getting are processed and metabolised often through one or either both of those organs. And you’re getting people with older body organs and you’re giving them toxic drugs which already have a risk of death. (Clinical oncologist)

Decisions can be particularly difficult when individuals are functionally fit and perceive themselves to be very fit, but have other health conditions that would jeopardise the success and safety of systemic treatment. One particularly striking example was given of a patient who was physically very fit and active but had stage three kidney disease and a weak heart from a previous heart attack.

For me, that was a very difficult conversation to have because he looked so well and he looked fit ...but I've seen what one cycle of chemotherapy can do with someone whose kidney function is already extremely borderline, I've seen it put people into complete renal failure. I've seen it trigger another heart attack ... (Cancer Nurse Specialist)

This quote demonstrates the value of a more complete frailty assessment that includes medical history as well as functional testing – and that this is particularly pertinent for decisions about chemotherapy.

3.3.3 RISK SCORE ASSESSMENT

Clinician interviewees saw information on risk scores as helpful, particularly in terms of providing information to patients so that they can be involved in decision-making. Risk scores provide an average score for a person of a specific age, without comorbidities or underlying conditions, which can be compared against a risk score for the same patient with specific comorbidities or underlying conditions. These are widely used, for example POSSUM (Physiological and Operative Severity Score for the enUmeration of Mortality and Morbidity¹⁵⁰).

However, these tools also have limitations. One interviewee noted that these risk scores are based on measuring the average performance of US centres undertaking these procedures but may not have the same applicability in a UK context.

...again (it's) done in big numbers but it's still done in America there's a lot of variation from centre to centre. As a big centre we are probably better than some of the American centres ... you expect that it will average out but if you are one of the well performing Trusts your numbers could be better than that, or if you're not so well performing your numbers could be worse than that ... (Anaesthetist)

3.3.4 HOLISTIC NEEDS ASSESSMENT

A Holistic Needs Assessment (HNA) is a wide-ranging assessment that considers physical and practical concerns, as well as the patient's emotional and information needs. This is often linked to the development of a care plan that takes these factors into account.

At one site involved in this research, patients with breast cancer have an hour-long 1:1 pre-operative discussion with a breast care nurse that includes an HNA.

We find out about them, when they worked, what their life was when they were in employment, what life experiences they've had. Whether they've had any experience of cancer, what their family situation, what their home situation is. Finances as well...and we also do our hospital anxiety and depression score as well. (Cancer Nurse Specialist)

While HNAs have significant merit, they are relatively resource-intensive and interviewees reported that a lack of time and capacity limits their use.

3.3.5 SUMMARY

Only one case study site systematically used any form of CGA and in general we found very low usage of validated assessment tools. This is particularly concerning when considering that ‘frailty’ was highlighted as the most influential factors in clinical decision-making in the survey of MDT members (at 79%). Many clinicians interviewed perceived there to be very few appropriate tools and were unconvinced of the value such tools would add to the decision-making process.

Overall, despite several concerns raised as to the variability in how clinicians in acute settings might assess a person’s frailty, we found that validated tools were not widely used in assessing older patients and there was no evidence of the systematic use of any form of comprehensive geriatric assessment in the acute sector – as is echoed in academic literature and in 2012 research by Macmillan Cancer Support¹⁵¹.

We heard concerns amongst some national interviewees that the use of subjective assessments of frailty could result in inequalities in access to treatment for older people with cancer.

I mean certainly the data would suggest it (primary care frailty assessment) may be part of the problem. If you look at the sort of the cancer outcomes and sort of stages at presentation, clearly there is a bias and we are serving our elderly patients less well than we are their younger compatriots. There will be both patient factors and professional factors. And it’s almost what I would call a medical societal issue and it’s sort of along the lines if we want to address it we will have to address both sides of that equation. (National interviewee)

Our interviews also highlighted that people living in care homes could be particularly at risk of being overlooked for potential treatment. In this instance it is possible that, in the absence of any systematic method of assessment, frailty is simply assumed and overestimated, leading to a lack of referral.

I wonder whether they (primary care) investigate patients in nursing homes as much as they would if they weren’t in a nursing home – there may be a degree assumption going on ‘I don’t think Mrs Bloggs is well enough’ and I wonder whether there is a better way of working with GPs to assess performance status. (Medical oncologist)

It is clear from this research that the clinical community has concerns about some older people not being assessed objectively. However, there is also a relative lack of evidence about the most appropriate formal tools and protocols. Several attempts have been made to recommend best tools, however no standardised method has been agreed.

The UK Macmillan Cancer Support and Department of Health Older Persons Pilot demonstrated that geriatrician liaison was the most effective way of delivering CGA. However, Kalsi et al have suggested that CGAs could be undertaken by nurses or other clinicians, if facilitated remotely by a geriatrician. This is likely to be more manageable for the health service at present, given the current workforce shortages.

Recommendation: NHS England and devolved health services should undertake further research to understand the most appropriate form of CGA for older people with cancer and should pilot their wider usage.

4 THE RIGHT INFORMATION DOES NOT ALWAYS GET TO THE RIGHT PEOPLE TO SUPPORT CLINICAL DECISION-MAKING

The information about a patient that is available to the clinician involved in making treatment decisions is highly variable. It depends on the referral route, the pathway the patient is following and the stage of the pathway they are currently at. So, for example, the information available for decisions to be made will be quite different if a patient is seen as: an emergency in A&E; as a result of a two-week urgent referral from their GP; following referral from a local hospital to a tertiary centre; or if they are on a follow-up pathway, having previously received treatment.

There are several key points of focus where the transfer of information is particularly important: between primary and secondary care, and to and from the multidisciplinary team (MDT).

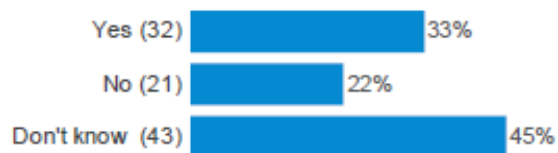
4.1 INCLUDING THE RIGHT INFORMATION FROM PRIMARY CARE

Primary care clinicians often have the most detailed history of a patient, including their level of frailty and any comorbidities. However, this information can only be factored into cancer treatment decision-making if it has been passed from primary care to secondary care. Unfortunately, we heard from both primary and secondary care interviewees that they often find it difficult to get in touch with each other directly.

We tested the idea of increasing the involvement of primary care in pre-treatment optimisation. While primary care respondents to our survey wanted to support older people with cancer, and saw value in using GPs' knowledge, there was widespread concern over their capacity to do this. 45% of respondents said that they did not know if they would like to see a greater role for primary care in pre-treatment optimisation, which is likely due to the tension between what is desirable and what is realistic in the current resource context.

The challenge at this moment in time is that general practice is seeing its worst recruitment crisis that most GPs can remember and there is simply not the resource available to take on more work. There is not the capacity and locally, I see practices close. It's not a lack of willingness, it's just not being able to and I think with regards to improving services, it would need to be done in such a way that it is so time light, it just needs to be done in such a clever, easy, encouraging way, rather than just simply burdening GPs with more work. (General Practitioner)

FIGURE 5 (PRIMARY CARE SURVEY) WOULD YOU LIKE TO SEE A GREATER ROLE FOR PRIMARY CARE IN PRE-TREATMENT OPTIMISATION?



4.1.1 THE TWO-WEEK WAIT REFERRAL FORM

A major issue raised through the primary care survey, national and local interviews was the nature of the two-week wait referral form, which is used when patients are given an urgent referral for suspected cancer. 37% of patients in 2015 were diagnosed through this route in England¹⁵². These forms are brief and thus there is no space for primary care staff to communicate people’s personal circumstances, comorbidities, their frailty or other medical history. This means that the clinicians making decisions about patients’ treatment often do not have advanced access to information that could later prove critical – and so the person’s age is more likely to be used as a surrogate measure for their overall health.

One of the biggest problems we have is that when we refer somebody from general practice with a suspected cancer diagnosis, we use this two-week referral pathway which involves a very basic one page form which essentially says “What’s the thing you’re referring them for and why?” Nothing else. It doesn’t say what medication they’re on, what are their co-morbidities, what are the real issues, what are the social factors, doesn’t tell anything about the person, it just tells you potentially what could be related to the disease. (National Interviewee)

It is understandable that this form is brief: it is by nature urgent, and the vast majority of patients given an urgent referral do not go on to receive a cancer diagnosis. But for those who are then diagnosed with cancer, the clinician responsible for their future treatment has very limited information about their patient to factor into their decision-making. This was described as a waste of a ‘phenomenal resource’ by one national interviewee who is a GP.

In the absence of a comprehensive overhaul of information systems to facilitate data-sharing between primary and secondary care, relatively simple changes to referral forms could result in a significant improvement in the amount of information available to inform treatment decisions. As forms differ from region to region there are some notable examples of good practice, where those making referrals have space for additional information.

The GP below describes how important factors for treatment decisions can be overlooked, such as dementia. These types of situations can lead to reversed treatment decisions – which introduce avoidable delays that can be distressing to patients and caregivers, and ultimately lead to wasted time and resource.

What might be really important is working out how to work efficiently, thinking about information flows. So if there would be, for example, on the two week wait referral form, those five areas of cognition... it would just be a simple tick box exercise to identify areas that the oncologist would need to take into account, because sometimes if a patient has been muddled a bit but nobody has taken the initiative to investigate, this patient could have undiagnosed dementia and [is] being referred by the two-week wait. (General Practitioner)

4.2 THE ROLE OF THE MDT

Every patient diagnosed with cancer in the UK has their case discussed at a MDT meeting. An MDT is made up of a variety of health professionals involved in treating and caring for patients. The MDT meets, most often weekly, to discuss individual patients' cases and make treatment recommendations.

This meeting will often occur before the patient has met a secondary care clinician, meaning any information of frailty must be generated by the primary care team referring the patient. However, we know that means to transfer this information are limited. MDT members responding to our survey also expressed that they would like more information from primary care; specifically, other medications and comorbidities.

Again, knowledge of frailty assessments within MDT members seemed largely weak.

Because there isn't always a sole diagnostic test that you can say this person is frail - it's often a constellation of things and you know we're very good at picking up peoples' comorbidities but how do you define someone as definitely frail I don't think that's taught particularly well in my opinion. (Anaesthetist)

The purpose of the MDT discussion is to make a treatment recommendation; the final decision must then be made by the clinician and the patient. The MDT is an opportunity for a variety of health professionals to come together and share their expertise, to formulate the most appropriate recommendation for their patients.

If MDTs are to make a treatment recommendation that is truly appropriate for the patient, they must include all relevant information. But recent research by CRUK found that only 14% of MDT discussions included information that did not specifically relate to the patient's tumour¹⁵³. Whilst this is concerning for all patients, this is likely to disproportionately affect older patients as they are more likely to be comorbid and to have complex social needs that will impact treatment decisions.

Furthermore, past research has found that between 10 and 15% of treatment recommendations were not implemented because they were too extreme for the patient¹⁵⁴. It is likely that this is because the MDT did not take all relevant factors into account – for example comorbidities, frailty or the patient's preferences.

Whilst Clinical Nurse Specialists are considered to be most qualified to provide such information, nurses did not contribute information in over 75% of meetings observed during that research – perhaps as a result of a shortage of CNSs, as well as the marginalisation of nurses and other allied health professionals¹⁵⁵. This reflects the lack of time available for full discussion of complex patients in MDT meetings: the average discussion observed in our past research lasted just 3.2 minutes, in meetings lasting up to five hours, and included an average of just three people – although an average of 14 people were in attendance.

This pressure has major implications for the quality of treatment decision-making. Not including important information about a patient – such as their preference, their psychosocial situation or their comorbidities – is poor for patients and also poor for MDT efficiency.

There is a clear need to reform and streamline MDTs, so that more time is available to discuss the most complex patients in enough depth – and therefore, many older patients. It is also important that MDTs consistently have access to all relevant information about the patients they discuss, so that they can make treatment recommendations that are tailored to the

patient's individual circumstances.

This report also recommended the use of a proforma to ensure that all relevant information is included in the MDT's discussion. This would be completed by the referring clinician and would include all relevant diagnostic information, as well as information on patient preferences and demographics – including frailty. 54% of MDT members already use some form of proforma, but this is inconsistent and there is no national guidance on their content. 81% of MDT members felt that using a proforma would have a beneficial impact on meeting efficiency, since the patient would not need to be discussed a second time. We see this as having a particularly strong impact on older patients and therefore:

Recommendation: UK health services should lead the development of national proforma templates, to be refined by MDTs. MDTs should require incoming cases and referrals to have a completed proforma with all information ready before discussion at a meeting.

4.3 THE FLOW OF INFORMATION FROM SECONDARY TO PRIMARY CARE

Our surveys and interviews of primary care staff highlighted a parallel frustration, in the gaps in the information flows from secondary care back to primary care. Staff were particularly interested in knowing a patient's diagnosis, treatment recommendations (and rationale), prognosis, further assessment and the information given to the patient. Respondents to our surveys of health professionals also highlighted the role of primary care in supporting patients to manage their comorbidities and thus enabling them to be fit enough to access a greater range of treatment options.

I see my role as a GP is having honest conversations with patients to help them unpick this stuff. Now a lot of cancer care teams are very good at providing people with information and generally what happens is people will have a huge amount of information, feel unable to make a decision and go away then come to their GP with questions to talk them through. (National Interviewee)

Staff also reported that patients would often attend a GP appointment to discuss their diagnosis, treatment and its impact on their lives. This often happens soon after patients have attended a hospital appointment, meaning that this information is needed very quickly after the event.

I don't have the information that's been given to the patient, all I've got is the patient's recollection or print-out, I don't have what the doctor in the hospital was actually thinking, because it takes so long for communications to get through. So greater use of electronic communication whereby... what's said to the patient can be said to the GP almost simultaneously, because it is not uncommon for somebody to be in floods of tears in the car on the way home from the hospital, phoning the GP, asking for an urgent appointment to talk things through but the GP didn't even know they had a cancer diagnosis and wouldn't have been told for days, sometimes weeks. (National Interviewee and General Practitioner)

This is a recognised issue and the standard operating procedure for informing a GP of their patient's diagnosis is often either the same day or within 48 hours of a diagnosis, however the extent to which this actually happens is variable.

We also heard from primary care staff that the diagnosis alone was of fairly limited use. In

addition, they would value information about the prognosis, treatment options and wider plan in order to support them in their care of the patient.

Although staff valued forms and electronic systems, the optimal mechanism would be having a single person who took the lead on coordinating a patient's care plan and communicating their case back to the GP. For this reason, CNSs were highly valued for their contribution; this is especially true for more complex patients, as older people with cancer often are. CNSs relay information between primary and secondary care, ultimately helping appropriate decisions be made. However, primary care staff also flagged that there is significant local variation around CNS availability – and so there is a need for a systematic solution.

Recommendation: Healthcare providers must ensure that primary care staff are updated on the outcome of patient discussions in a timely manner. This should include widespread use of digital solutions.

4.4 PRESSURES ON ONCOLOGY SERVICES LIMIT THE QUALITY OF DECISION-MAKING AND COMMUNICATION BETWEEN OLDER PEOPLE WITH CANCER AND THEIR CLINICIANS

Patients, families and carers can also help provide clinicians with information that can be hugely helpful in formulating treatment decisions, and often provide a useful reality check. However, clinicians are often reliant on a patient's assessment of their own abilities – which can be inaccurate.

This inaccuracy can have a variety of causes. For example, patients may overestimate their activity levels from a sense of denial of physical decline, or from a desire to convince the clinician that they are fit for surgery. Family members and friends often provide a useful reality check in this regard, according to interviewees. Patients can also forget, or not know, most of their medical history.

Patients forget that the fact they had significant disease twenty years ago may be relevant. And of course for a cancer diagnosis, having had a different cancer twenty years ago really could matter ... The fact that they take all manner of things that they don't think are important and don't see as medication. They may be getting B12 injections are a classic one – people don't think of that as medication... They forget to tell hospital those sorts of things.
(National interviewee)

These findings give positive messages about the involvement of family and carers in the decision-making process and highlight the advantages of clear patient information (e.g. medication, medical history) being passed on to clinicians.

Improving communication between older patients and clinicians

There is strong evidence that shared decision-making (SDM) is beneficial to people with cancer⁴. However, achieving meaningful shared decision-making can be more difficult for

⁴ CanCORS study, 2015

older patients, who are more likely to have multiple conditions and who may be balancing decisions about treatment with many other factors. The quality of communication to patients was the strongest theme identified by the patients involved in this research as part of informed decision-making; this theme was also used as the basis for the patient survey.

The older people with cancer and caregivers involved in the design and delivery of this study saw a continuum of decision-making. At one end was 'decision-making as consent', where health professionals merely gain consent from patients for the treatment they prefer. At the most positive end of the spectrum was 'decision-making as reaching consensus', which was a lengthier process with more scope for patients to learn about and discuss the different treatments options, before making an informed choice.

In our survey of older people affected by cancer, the most common style of decision-making reported (by 40% of respondents) was "the doctor or other health professional led (the doctor or other health professionals made all the decisions but took my views into account)". This was frequently reported as a negative experience.

The current context of time-stretched cancer services are further compromising the ability to facilitate true shared decision-making, as evidenced by respondents to our patient survey.

The risks were given very briefly and I was handed this in written form on the consent form. The side effects of radiotherapy were not explained fully and I found out more information for myself and then asked questions. (a patient)

Mostly, it was assumed that I would do whatever they suggested - whilst I was not unhappy with what was being offered, as I knew that there were not a lot of options, I do not feel in hindsight that I was given much choice or indeed support in making such a choice. (a patient)

Another respondent reported feeling that questions were 'tolerated rather than encouraged'. In other cases, patients were expected to make a decision, but did not feel they had the necessary knowledge to do so.

Support was there in the form of 'hand-holding' while it was up to me to make the decision. Statistics showed roughly the same outcome for surgery or radiotherapy. It would have been just as supportive to give me a coin to toss when what I really needed was some indication as to which would be better for my particular circumstances. Perhaps I was looking for guidance that simply isn't there. (a patient)

Some clinicians involved in the research also reported patients not wanting to make the decision themselves.

And so the conversation goes something like this you know; 'now you want treatment, I have a choice of treatments, would you like me to tell you about both of them and you make your decision or would you like me to make a recommendation?' And ninety-eight percent of patients say 'you make the recommendation'. (Medical Oncologist)

These quotes highlight the importance of giving patients all relevant information needed to make a decision, but also of flexing the approach according to the patient's wishes.

4.5 COMMUNICATION CHALLENGES

4.5.1 CONFLICTING INFORMATION

Many negative responses about communication received through our patient survey focused on not being able to understand information, and being given conflicting messages. This reinforces the importance of coordinating care across the multidisciplinary team and presenting a unified message to the patient.

I was concerned that the surgeon and the oncologist did not seem to have quite the same agendas - whilst they superficially work as a team, for example the oncologist was very dismissive of the surgical option, which I found confusing. (a patient)

However, anaesthetists interviewed for this study also acknowledged that on occasion, there may well be differences in opinion between the clinicians involved as to the balance of risks.

So it pays you to know exactly what patients know when they arrive, what they've been told and where they're up to... there's a kind of a golden rule that if you're going to quote figures you must write them down. So if a surgical colleague has quoted figures they should be in his clinic letter, which I will always have read ...so I might say 'well, actually I'm going to adjust Mr X's figures because I don't think I feel quite as optimistic as he does'. So that's how I'd handle that. (Anaesthetist)

4.5.2 BENEFIT VERSUS RISK

As previously discussed, older patients are likely to have to consider a greater number of factors in treatment decision-making. Part of this involves balancing the benefit of treatment with the risk of a lower quality of life, stemming from long-lasting side-effects of treatment. To make these decisions, they must be given the full spectrum of information – but we heard from patients involved in the research that this was sometimes not the case, with emphasis disproportionately placed on benefits.

Benefits [of surgery; removal of the tumour] were clear. However, an ileostomy was involved and little was said about this leaving me unprepared for the result. (a patient)

But [I] would have liked more information on the effects of chemo on your brain as I was definitely affected by the treatment. And although my mental acuity has improved it is not the same as it was. (a patient)

This picture was not reflected by the clinicians interviewed as part of the research, who reported that presenting information on the benefits and risks of different treatment options is an important element of ensuring patients have realistic expectations and can make appropriate decisions. The success of doing this is likely to vary considerably between clinicians.

4.6 HAVING SUFFICIENT TIME TO MAKE DECISIONS

Another common theme from this research was the need to have sufficient time to make an informed decision. Again, this is felt across cancer services but may disproportionately impact older patients because of the complex nature of decision-making. As well as impacting the process decision-making, this is likely to affect patients' broader experience of care.

Again, I was not able to take everything in at the time and it took quite a while to then

calmly go through the carrier bag of leaflets I was handed on the day. (a patient)

This perspective was reflected by national level, primary and acute care interviewees, who all highlighted the importance of giving patients time to think through the implications of treatment and the extent of support they are likely to have available.

This is felt particularly acutely during a consultation, when patients can be sensitive to clinicians' high workloads and are conscious not to 'take up their time'⁵. Again, this often impacts older people more than younger people, as they may require more time to consider options.

Today I had a patient who has cancer but has other comorbidities ... so I had to discuss that ... and make it clear to them that these are the risk factors, these are the things that go wrong ... that 20/30 minutes ... just gets dragged on to 45 minutes. We can't just stop the consultation because it's been running out of time. (Anaesthetist)

At one site observed in this research, a more flexible breast clinic system has been implemented. This provides more realistic clinic slots, redressing the widespread trend for clinics which always run over time – leading to poor experiences for health professionals and patients.

...sometimes we were here till eight o'clock at night ... And it was unfair on the patients. It was draining on the staff ... and by the time you're getting to the end of the clinic, you know, your energy levels are really sort of hitting low and you sort of have to question what have I got to continue to offer this evening... But it's completely different now. So the slots are well spread out, clinics are running to time, patients aren't kept waiting and we're finishing at a reasonable time as well. (Cancer Nurse Specialist)

Recommendation: Cancer MDT leads and service managers should consider reviewing the length of consultation slots, factoring in additional time for more complex patients, and providing additional support before, during and after consultations for those who are living with frailty or have multiple comorbidities.

4.7 NATIONAL PRESSURES ON DECISION-MAKING TIMELINES

Cancer treatment decision-making in the UK is also shaped by national treatment targets. Several members of cancer MDTs interviewed for this study raised the issue of national treatment targets creating unhelpful pressure, for two reasons: firstly, through putting patients under pressure to make a quick decision, but secondly by limiting opportunities for testing patients' likelihood to be able to tolerate treatment, and then for tailoring their plan accordingly.

The other issue is that with the government targets for making a decision, often people are having to make a decision quite quickly and I think you know sometimes we just need to give people more time to help support them make the right decision for them. (Cancer Nurse Specialist)

They're guidelines not tramlines and I think people get so caught up in that, that you

⁵ Joseph-Williams et al, 2014

*forget the patient may not want to work in the timescale that the guidelines say.
(National interviewee)*

And some people need to see family; they need to get daughters and family over from Australia or America. They want to see them before they go through an operation that they may not survive. ..So I think the push to deliver an 18 week pathway sometimes detracts from what that patient's needs are. (Anaesthetist)

Furthermore, national targets can also mean that there are limited opportunities to spend time testing and retesting people for how likely they are to tolerate treatment, and optimising them if necessary. This has been echoed in research, which has found that service targets that focus resource solely on cancer can disadvantage patients with complex wider needs, as individual clinicians may struggle to deliver effective treatment plans without breaching targets¹⁵⁶.

... there's good evidence to show that if you try and optimise people...you can improve their CPEX testing. So we haven't got time to do that for cancer surgery because obviously they're within a window that we have to see them. (Anaesthetist)

Recommendation: in ongoing reviews of cancer waiting times targets, NHS England and devolved health services should consider ways to ensure optimal treatment access, a positive experience and better outcomes for older people with cancer.

4.7.1 IMPROVING THE PROCESS OF DECISION-MAKING

Older people involved in this study identified several means of improving the process of treatment decision-making, such as charity-run cancer support services and peer advocacy.

I was utterly confused [after diagnosis] and couldn't understand why the world was still turning really. It was a break through meeting my advocates. I have been an advocate myself for the last two years. The advocates offer a caring approach and they have been there themselves, we are all on the same level. My third advocate was a great match for me personality wise. They went with me to hospital appointments and provided transport and help me to face the reality.' (Older person with cancer and co-researcher)

Some people also spoke about the value of improving communication through a summary card, held by each patient. This was included as a recommendation of the Oxfordshire 'Cancer, Older People Peer Advocates patient experience Group' report to Healthwatch⁶. The card would include a summary of diagnosis, treatment recommendations, current medications and the details of the professional team assigned to the older patient, as well as how to contact them.

⁶ Young/COPA Peer Advocates Patient Experience Group, 2016

5. THE CANCER WORKFORCE COULD BETTER SUPPORT THE NEEDS OF OLDER PATIENTS

Cancer services in the UK are experiencing severe workforce gaps across many key professions, which is having a real impact on the ability to diagnose and treat cancer quickly, as well as to give patients the best possible experience of care¹⁵⁷.

There are also broader issues relating to the preparedness of the workforce to treat the growing number of older patients, including deficits in education, knowledge and attitudes and in the development of specific roles and services that meet older people's needs¹⁵⁸. For example, a 2013 survey of UK medical oncology trainees found that only 27.1% were confident in assessing risk to make treatment recommendations for older patients, compared to 81.4% being confident about treating younger patients¹⁵⁹.

For people with complex needs, it is critical that health professionals with specialist expertise are available to support them throughout treatment decision-making and treatment itself. There is also some evidence of benefit in providing additional specialist support, targeted to groups of older people with complex needs, who are at risk of undertreatment¹⁶⁰.

5.1 EXPERTISE IN THE MDT

As previously discussed, just 14% of MDT discussions observed during past CRUK research included information that did not directly relate to the patient's tumour¹⁶¹, for example comorbidities, social needs or treatment preferences. This is a direct result of the growing mismatch between an MDT's capacity and the demand they face, which leads to severe time pressure on their discussions. This is likely to have a particularly significant impact on older patients, who are most likely to have complex social and medical needs.

One of the issues for all MDTs is managing to comprehensively get through the cases in a meaningful way in which we [healthcare professionals] make the right selection of treatment strategies when you've maybe got... forty patients plus at an MDT. (Clinical oncologist)

As well as a proforma, ensuring an MDT discussion is centred around the needs of an older patient could be ensured by including relevant specialists in the meeting. However, MDT members responding to our survey expressed concern that their MDT did not routinely include specialists who could add value to a discussion about an older patient, such as social workers, occupational therapists, physiotherapists, dieticians, and pharmacists.

In one MDT meeting observed for this research (SCOPES), one member of staff – a lead nurse – attended the meeting, representing a smaller multidisciplinary team of allied health professionals who had completed a comprehensive geriatric assessment. They could then feed the results of the assessment back to the MDT and suggest the implications for treatment, and likewise could feed the MDT's recommendation back to their team of allied health professionals.

In another site, a joint surgical-oncology clinic had been established so that patients could see both the surgeon and an oncologist for a fully comprehensive discussion to compare surgical options with radiotherapy and chemotherapy. This was introduced to prevent patients being recommended for surgery, found to be unfit and then having to wait again to start radiotherapy. In this case, the clinicians found it valuable to bounce ideas off each other when finalising their plans.

... we always take another opinion ... we don't hesitate to ring or even because we have two of us doing the clinic always pop in next door and say this is what I think and with this information I am giving do you think it is that or do you think differently? (Anaesthetist)

5.2 SPECIALIST CANCER NURSES

Clinical Nurse Specialists (CNS) play an important role in cancer care, supporting good patient experience¹⁶² and acting as a 'key worker' throughout diagnosis, treatment delivery and palliative care¹⁶³. As such, appreciation of CNSs was raised consistently throughout this research.

The older people with cancer surveyed generally reported that they had been well supported by health professionals, with specialist nurses particularly appreciated. Nurses were also recognised for their role in providing practical advice about managing their treatment.

The consultant made clear notes that I could take away. The specialist nurses followed up with clear and necessary advice. (a patient)

However, this was not uniform – reflecting the significant challenges faced with CNS staffing. This is a concern – the 2015 Cancer Strategy for England recommended that all people with cancer should be given a named CNS or key worker contact¹⁶⁴; this is also included in NICE guidelines.

When I was first diagnosed 7 years ago there was no CNS in haematology at our local hospital and until I was referred elsewhere, I didn't realise these amazing nurses existed. Fortunately, we have a wonderful CNS now who is available by phone or e-mail whenever needed. (a patient)

Whilst the proportion of patients in England having access to a CNS has risen from 84% in 2010 to 90% in 2016¹⁶⁵, there is still room for improvement and still variation across geographies and across different cancer sites. 84% of patients in Scotland reported access to a CNS in 2015/16¹⁶⁶; in Wales in 2016, 81% reported access and in Northern Ireland in 2015, this figure was just 72%. Staffing issues were also recognised by national interviewees, with this seen as a particular challenge for rarer cancers.

I mean the cancer nurses are fantastic where they exist and patients are directed to them, that's great. The problem is that they tend to be there for the bigger, more common cancers, so the colorectal teams are often fantastic, the breast cancer teams are fantastic. But where it's more unusual cancers or where the cancer seems to be more of a superficial thing, I mean I come across this less for skin cancer things or less for some of the other gynaecological cancers. Frequently there's just one of these nurses in a team and therefore once they're on holiday or they're sick there's no back up, there's nothing else, there's nobody else who can step in. (National Interviewee)

This has an impact on the ability of a CNS to support patients adequately. For example, past

research has shown that over half of prostate CNSs felt they didn't have the time to attend to the holistic needs and psychosocial assessment requirements of their roles¹⁶⁷.

Furthermore, the role of a CNS is highly variable and the job title and expectations can be inconsistent¹⁶⁸. CNSs often fill service gaps in their local centres, rather than doing the work that best fits their expertise. A survey from CRUK research into the non-surgical oncology workforce found that 50% of CNSs did not feel they had enough patient-facing time and were consistently working an average of 5 additional hours each week – on average, 15% of their working hours.

Recommendation: Health Education England, and its equivalents in the devolved nations, should use the Cancer Research UK 'best practice treatment model' to project required workforce numbers based on patient demand, not on affordability. Organisations should also consider the specific needs of older people with cancer in all workforce plans.

Recommendation: Government should provide investment to support Health Education England's phase 2 cancer workforce plan, which will say how many staff will need to be trained and employed to deliver effective cancer care beyond 2021.

5.3 GERIATRICIANS

Interviewees across primary and secondary care also raised the potential benefit of involving elderly care specialists. GPs commented that if there were concerns around frailty and an older person's capacity to withstand investigative tests, they would seek further advice from local elderly care specialists or geriatric consultants. These measures to avoid simple 'non-referral' may be important steps in the pathway to improve access to treatment for older people.

If they are very frail I would ask for a [geriatric] consultant review rather than send for invasive diagnostic tests (General Practitioner)

Whilst MDT members reported that it was not the norm for geriatricians to attend MDT meetings, some interviewees noted that they were able to refer patients to a geriatrician. However, few had done this in practice and the value of this was contested.

...wouldn't actually think [a] Care of the Elderly physician would know very much about lung health or how that feeds into our ability to give radical treatments... I could see the value of they knew the patient and they had some thoughts about their wishes or their home circumstances or things that you could do to improve the performance status. (Clinical oncologist)

However, others saw increasing value in involving geriatricians in treatment decision-making; in a similar way to how palliative care has been recognised and expanded over recent years.

Many years ago there was a little bit of palliative medicine and a few palliative care physicians and no palliative care nurses – where is there a hospital now without one, or two, or three or four? It's all grown up and my feeling would be that in time we'll see a similar thing for older people – there'll be leaders for that in each department.'
(National Interviewee)

Current evidence suggests that CGAs should be led by elderly care specialists, as part of a multidisciplinary team. For example, the Macmillan/Department of Health Older Persons Pilot

demonstrated that geriatrician liaison was the most effective way of delivering CGA¹⁶⁹. Other research has also highlighted the value of including elderly care specialists in cancer decision-making, although it does not happen routinely.

Elderly care specialists are experienced in co-managing multiple health conditions and polypharmacy, as well as engaging and mobilizing a range of community-based health and social services to provide practical support, but they are rarely involved in decision-making related to cancer treatment. (Maher 2016¹⁷⁰)

There are a number of initiatives which seek to embed input from elderly care specialists into cancer treatment decision-making. For example, Nottingham University Hospital have a geriatrician-led CGA process that feeds directly into MDT meetings (see SCOPES example in section XX).

6 WE NEED TO IMPROVE HOW INNOVATION IN TREATMENT AND CARE REACHES OLDER PEOPLE WITH CANCER

Research is the key to improving outcomes for all people affected by cancer. However, older patients are typically under-represented in clinical trials¹⁷¹, which can have strict inclusion criteria based on chronological age, comorbidities or cognitive ability. These factors combined mean that there is often relatively limited evidence on the specific effects of treatment on older patients.

This means that decisions about treatment for patients with comorbidities – and therefore often older patients – cannot always be based on strong evidence. At least, not in comparison to decisions for their younger or otherwise fitter counterparts.

6.1 OLDER PATIENTS ARE UNDER-REPRESENTED IN CLINICAL TRIALS

Older people are in general under-represented in clinical trials¹⁷², including in cancer¹⁷³. This is particularly acutely felt for “older old patients”, who are typically the most frail and comorbid. This was also recognised by our clinician interviewees:

The most important thing is we don't have any evidence for such patients... the number of patients who are [in] clinical trials above 75 years of age is far and few between and no meaningful conclusions can be made on that. (Medical oncologist)

The discrepancy between a trial population and a “real” clinical population has major implications for how applicable evidence from clinical trials is in the clinic. Older patients can respond very differently to treatment, due to a range of factors¹⁷⁴. For example, age-related physiological changes can impact how a drug works in the body. Older patients may also experience different or worse side-effects, which may not have been predicted from the younger trial population. The effect of this was summarised by an expert committee of the European Medicines Agency: “the drugs we are using in older people have not been properly evaluated”¹⁷⁵.

More could still be done to gather evidence, including boosting numbers of older patients in trials – but also doing research that enables patients with comorbidities or frailty to receive optimal treatment, that accounts for the impact of comorbidities and frailty.

There are several reasons for this under-representation; these are mostly a combination of stringent eligibility criteria and concerns from clinicians about subjecting older – or frailer – patients to rigorous treatment. There are also other complicating factors, for example

challenges in gaining informed consent from patients with cognitive issues, or difficulty assessing outcomes in patients who already have several comorbidities¹⁷⁶. Further practical factors also exist, for example the inaccessibility of trial consent forms¹⁷⁷.

There is appetite for change: 70% of European health professionals responding to the PREDICT study in 2014 did not believe the present arrangements for clinical trials relating to older people to be satisfactory, and 60% believed that either European or national regulation of clinical trials should be amended to ensure greater representation of older or less fit patients¹⁷⁸. There have also been efforts to address this, for example the EMA's 2011 Geriatric Medicines Strategy¹⁷⁹ or the EU-funded PREDICT initiative (Increasing the Participation of the Elderly in Clinical Trials), which proposes ways of boosting recruitment of older patients to clinical trials.

Inclusion of a geriatric patient group may also add to the variability of any endpoint, potentially resulting in decreased effects if the study is not adequately powered. This may result in a need for larger studies of increased complexity and likely longer drug development timelines, unless alternative approaches are also considered (including post-authorisation data collection, as discussed in the next section).

Most clinical trials funded by Cancer Research UK do not have an upper age limit, when age limits are applied, researchers are asked to justify the boundary selected. Exclusion criteria relating to comorbidities or patient fitness are used in some trials where they risk confounding results or adding a safety risk, however, and comorbidities do increase with age. CRUK also fund some trials that ask specific questions about treatment for older patients, or patients who are less fit.

Recommendation: Research funders should explore how to ensure more proportionate recruitment of older people with cancer into clinical trials, and how to ensure that research addresses any evidence gaps in the effectiveness of treatment in older patients, or those with comorbidities more broadly.

6.2 APPROVING NEW TREATMENTS

As well as reviewing clinical trials, there is scope for making changes to the process of approving new treatments so that it better supports older people with cancer by gathering more evidence that applies to those patients. This should include embedding the patient perspective in approvals, but also consideration of how the process could incorporate evidence of a treatment's effectiveness in a more varied patient population – or at least including more flexible criteria in drug assessments.

35% of respondents to our survey of MDT members felt that a lack of clinical evidence about the efficacy of treatment in an older population was a barrier to treatment. This is particularly problematic in cancers where there is a poorer understanding of the disease and its progression, and this can make it difficult for clinicians to assess the risks of treatment and to weigh that up against the potential benefit to the patient. However, this is likely part of a broader issue about evidence in comorbid populations, rather than being related solely to chronological age.

There is also scope for making changes to the process of approving new treatments so that it better supports older people with cancer, who may value outcomes other than just improving

survival – such as maintaining a good quality of life, their independence and cognition¹⁸⁰. For example, national drug approvals should consider incorporating a broader range of evidence, including impact on quality of life – which was recommended in the Life Sciences Industrial Strategy¹⁸¹, although the recommendations were not specifically targeted towards older patients.

In the longer term, we encourage UK health services to explore the use of flexible pricing mechanisms such as outcomes-based pricing, in which the price of a drug can be reviewed at agreed stages and aligned directly to patient benefit, being increased or decreased based on emerging new data. This would ensure pricing and access decisions are grounded in the real experiences of patients. To take this forward, Cancer Research UK are exploring the feasibility of outcomes-based pricing through a commissioned research project, in partnership with the Greater Manchester Health and Social Care Partnership.

6.2.1 HIGH-QUALITY DATA

A key enabler to this is robust, routinely collected data about cancer treatment and outcomes. This is not an age-specific issue as it would significantly improve our ability to understand the effects of treatment on all patients. All UK organisations responsible for collecting health data should ensure significant resource is provided for improving the quality and completeness of treatments datasets. Having robust data about treatments and outcomes would enable more in-depth analyses of the extent of variation in access to treatment and outcomes for older patients, which could supplement clinical trial data and support efforts to benchmark services.

Recommendation: National drug appraisal bodies should explore what alternative metrics could be considered during appraisals that would be more relevant to all patients, including older patients – such as quality of life and activities of daily living.

APPENDIX 1: METHODOLOGY

RAPID EVIDENCE ASSESSMENT

The research began with a rapid evidence assessment (REA), focussed on the identification of evidence to direct and refine the research design. Initial searches were undertaken by HSMC's specialist library and documents were identified via the following databases: Social Science Citation Index; Ageinfo; ASSIA; HMIC; Medline; Embase; Cinahl; Social Care Online. Where particularly relevant literature was identified in this review, additional searches were conducted of the reference lists of those documents.

SURVEYS

Three surveys were carried out, gaining a total of 197 responses. Each survey gathered quantitative evidence using fixed response questions but also contained a number of open ended questions for free text responses. Quotations from these free text survey responses have been used throughout the report. To achieve a wide reach for both of these surveys, a 'snowballing' approach was also employed, with recipients encouraged to share the survey link with their colleagues and contacts.

Full text of surveys is available on request. The surveys were as follows:

Primary care survey: this focused on how primary care responds to older people with suspected cancer, particularly what information is passed on for consideration at the point of referral and how the role of primary care in cancer care may develop in future. We received 98 responses to the survey. The survey was designed with input from Macmillan Cancer Support and piloted with 12 Macmillan GPs who shared feedback on both the design and content of the survey. The survey was distributed through Macmillan GPs, Doctors.net, Cancer Research UK primary care facilitators and engagement team and the Royal college of GPs.

MDT survey: this focused on what information and assessments are being used to make treatment recommendations, and what subsequent decision-making support is offered to older people. The survey was distributed through networks of various Royal Colleges. We received 57 responses to the survey.

Patient survey: a patient survey was designed to understand the experiences and perspectives of older people who have been treated for cancer and how they contribute to their treatment decisions. The survey design was led by our co-researchers. Distribution was through Cancer Research UK's patient involvement newsletter and webpages, Cancer Chat and Macmillan involvement network.

INTERVIEWS AND OBSERVATIONS

The experiences and views of national level interviewees were captured in interviews, with representation across all UK countries. Seven local case studies explored the views of health professionals involved in the treatment decision making process. At a local level, interviews were carried out with MDT members, staff who were involved in assessing and supporting but not involved in MTDs (AHPs and anaesthetists) and primary care staff. Two devolved

nations will be represented in this sample.

It should be noted that this study sampled case study sites to capture practice representative of cancer services for all older people, rather than to identify best practice. As such, including innovation was just one aspect of site selection, alongside: distinctive older population demographics; BME populations; rural poverty; a range of cancer types; primary, secondary and tertiary services; and inclusion of different staff groups (radiologists, anaesthetists etc.).

Semi-structured interviews were undertaken at case study sites with 40 health professionals. Separate topic guides were designed for staff primary care and acute settings. Topic guides were informed by the evidence review findings and aimed to pick up on the survey themes and explore them in greater depth. All interviews were carried out either face-to-face or by telephone, after gaining participants' consent.

Three observations were undertaken; two MDT meetings and a half day multidisciplinary clinic. Non-participative observation can be a valuable unobtrusive method of data collection and can help to provide context and a richer understanding of interaction and the nature of services. The research team designed a set of observational cues that addressed their research questions and topic directly.

All interviews were recorded and transcribed to allow for thematic coding and analysis. Observational notes were incorporated into the analysis. This involves the initial identification of analytical themes derived from the research questions and the literature, to which additional themes are added as new insights emerge from the data. The value of this approach is that it is particularly well suited to the problem-oriented nature of applied and policy relevant research, whilst also allowing for an analytical process which remains grounded in and driven by participants' accounts.

PATIENT INVOLVEMENT

Recognising the significance of patients and carers in the decision-making process, we also recruited a group of seven older people affected by cancer as co-researchers. Across three half-day workshops, this group designed a patient survey and provided guidance on the interpretation of findings, adding an essential perspective to our overall analysis.

APPENDIX 2: PATIENT MESSAGES TO THE NHS

The following messages were contributed by the older people consulted for this research.

‘What do you want to say to the NHS about involving older people in treatment decisions about cancer?’

A lot of older people don't understand the treatments so explaining them all helps. And giving options and some pamphlets about types of treatment can make them feel better.

Age is just a number! What should happen for every patient with cancer is a full explanation of the diagnosis and the treatment options, including no treatment if that is appropriate, and help in making that decision.

Be clear about the after-effects and what support could be available if living on own. Offer information that helps cope with the trauma of being told and how to manage post-op.

Be thoughtful, patient and kind.

Clear explanations of risks/ side effects and benefits of the particular treatment. Possible options of other treatments. Patient and family to feel supported during and importantly after decision making.

Clear supportive communication.

Don't patronise and don't make assumptions!

Employ enough staff to make consultations less hurried. It would be helpful to see the same doctor each time, though I know this is next to impossible. At least it helps if they have actually read your notes before you get in there.

Encourage them to bring someone along to appointments and treatment. Ask for their opinions, listen to them, respond to their questions. Don't be paternalistic. Make sure they have all the help they need at home and help with transport to hospital. Introduce them to local support groups.

Give access to as much information as possible about effects

Give them a clear choice i.e. We can do A for you, or B for you, or C, for you. Or a combination of them. Sadly at the moment the consultant TELLS the patient what is going to happen, offering the patient no choice.

Give them enough information in terms ordinary non-medical people can understand. I had things given to me in Laymen's terms, but I do know of some people where the medical jargon was used and understandably they got very confused.

I am 68 and I could not have wanted a better Dr everything was explained so I understood

I feel all adults should be involved in treatment decision whatever age a patient is

I find this question rather offensive, as well as grammatically flawed. The question seems to confuse and conflate being aged over 55 with having mental capacity issues. "Older people", like any other age group, require accurate, unbiased, objective information - including

potential side effects and average survival times with and without each treatment - in order to make informed decisions about their treatment. People with mental capacity issues, regardless of their age, may need such information to be presented in a more easily understood format - in line with the requirements of the Mental Capacity Act 2005.

I have been treated with respect during my treatment, but after care support could be improved.

I have nothing but praise for the NHS and the way our hospital involves older patients in their treatment.

I really think it's important to stress the side effects of surgery, radiotherapy and chemo. Unfortunately people watch the TV where the side effects are brushed under the table. The only issue seems to be losing your hair! For e.g. the ability of a 40 year old to recover from a mastectomy is going to be better than an 85 year old. Also things like neuropathy are not covered at all. 12 years since my first tranche of chemo and I still have quite painful neuropathy in my fingers. My sister finished chemo and radiotherapy in February and has lost all feeling in her foot and is effectively very disabled now. She has been told her foot may never recover. No one told her this. Also, there are NO rehabilitation services, no Macmillan in many parts of the country. So a fit very elderly person will recover from surgery, but if you've spent the last 30 years sitting in a chair and watching telly then you won't recover at all.

Involve them all along the way.

It is crucial to do so. It may be the first time the person has not been in control and a degree of patient influence is essential.

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