



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

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**CANCER
RESEARCH
UK**

POLICY BRIEFING

The number of people over 75 diagnosed with cancer is set to rise by 80% within the next 20 years.

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 briefing 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.

In this briefing, the research is presented alongside relevant findings from other recent CRUK research and our own statistical analysis. The full report of the study is available cruk.org/treatment-ageing-population

RECOMMENDATIONS

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

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.

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.

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.

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.

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 affordability⁹. Organisations should also include consideration of the specific needs of older people with cancer in all workforce plans.

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.

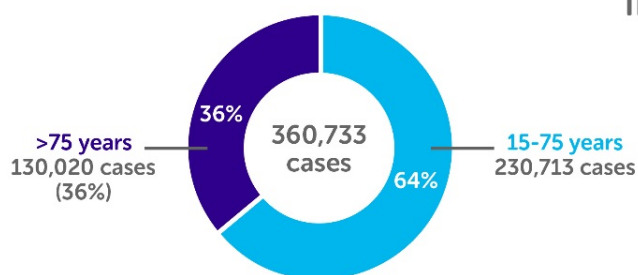
OLDER PEOPLE AND CANCER TREATMENT

In 2035, it is projected that around 234,000 cases of all cancers combinedⁱ 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 deaths¹⁰.

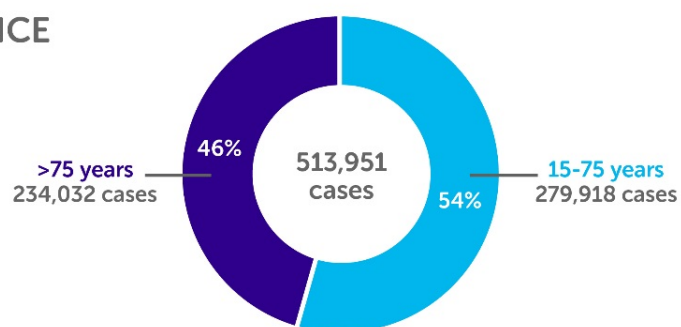
Net survival is generally lower for patients over 75, with survival generally decreasing with increasing age – even after adjusting for mortality from causes other than cancer. Despite overall survival doubling over the past 40 years, the discrepancy between survival for older and younger patients has not improved¹¹.

ⁱ Around 130,000 in males and around 104,000 in females.

INCIDENCE

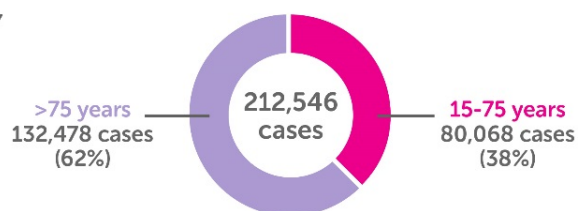


2014



2035

MORTALITY

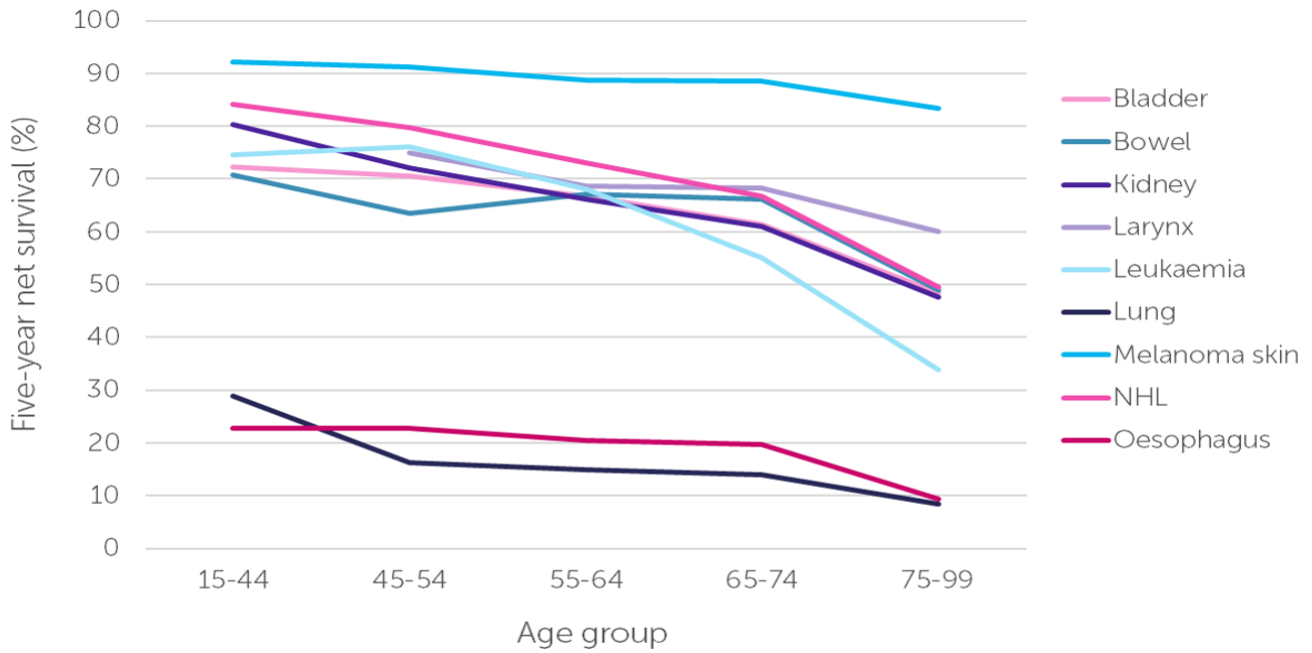


There is also evidence that the gap between the UK's cancer survival and that of the best-performing countries is worse for older patients. For example, most of the survival difference for breast cancer between the UK and Ireland and the European average can be accounted for by the low survival of women age 75 and over¹². 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 15-44¹³.

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 survival¹⁴. 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

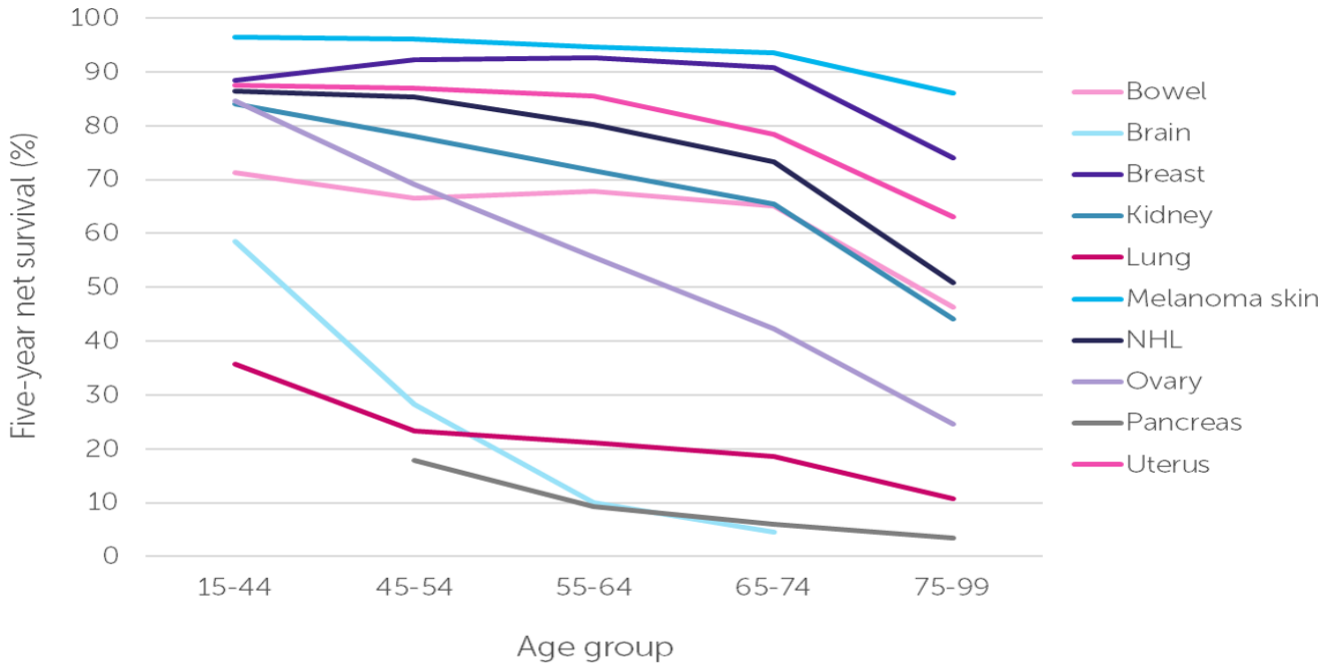
aged 50-59. Although there is a clear need to improve early diagnosis of cancer in older patients, that is outside of the scope of this briefing.

Five-year net survival (%), for men (aged 15 to 99 years) diagnosed between 2011 and 2015: England, 10 most common cancers, by age



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.

Five-year net survival (%), for women (aged 15 to 99 years) diagnosed between 2011 and 2015: England, 10 most common cancers, by age



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 cancer. A report by the National Cancer Information Network (NCIN) and CRUK found that across 20 cancer sites, older patients were less likely to have major surgical resections¹⁵. It has also been reported that the use of chemotherapy declines with age, in several types of cancer¹⁶.

Other studies have found similar; for example, older women with breast cancer are less likely to undergo surgery¹⁷; the use of radiotherapy also gradually decreases with age¹⁸. Older people with lung cancer have also been shown to be far less likely to undergo surgery¹⁹.

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^{20,21,22}. Some studies have adjusted for comorbidities and have still found variation in access^{23,24} – 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 abilities²⁵.

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 attention²⁶.

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 treatment²⁷.

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 use²⁸ and they have not been fully integrated into oncology practice²⁹. 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 constraints³⁰.

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 surgery³¹.

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”³², 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 information³³. 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 have 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 tumour³⁴.

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^{35,36}. 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 researchⁱⁱ 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

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

cancer care is managed primarily by cancer clinicians, patients' other health conditions might still be managed in 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'³⁷.

There is strong evidence that shared decision-making is beneficial for people with cancer³⁸, for example because it can improve people's experience of care³⁹. However, achieving SDM can be more difficult in patients with multiple health conditions^{40, 41,42}, cognitive impairment, social support needs and caring responsibilities⁴³. 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 targets⁴⁴.

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 care⁴⁵.

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 needs⁴⁶. 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 patients⁴⁷.

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 undertreatment⁴⁸.

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 2016⁴⁹, there is still variation across geographies and across different cancer sites. 84% of patients in Scotland reported access to a CNS in 2015/16⁵⁰; 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 variation⁵¹. 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 hours⁵².

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 affordability⁵³. 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 trials⁵⁴, 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 patients⁵⁵.

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 cognition⁵⁶. 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 Strategy⁵⁷, 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.

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