

## **Cancer Services Coming of Age:** Learning from the Improving Cancer Treatment Assessment and Support for Older People Project December 2012



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# Foreword

The Government has set out ambitious plans to improve cancer survival rates in England, and it has recognised that it will not deliver on those plans unless it tackles inequalities in terms of access to and outcomes from treatment.

This is very important in relation to older people, given that cancer is primarily a disease of this age group. The Government has also made commitments to improve the wellbeing of patients living with long term conditions, including cancer, and to improve their experience of care – so it is essential that services provided meet the needs of older people.

We know that older people often present with cancers at a later stage and are more likely to have their cancers diagnosed through emergency routes – factors that have an impact on their survival rates. We also know that cancer treatment rates are lower in older people, which again, of course, has an impact on survival rates. What we do not know, however, is the extent to which treatment rates are lower due to patient choice and clinical factors, such as comorbidities.

We set up this project to test the hypothesis that improved assessment methods of older cancer patients would result in improved access to appropriate cancer treatment. We also aimed to test whether action being taken to address the needs identified during the assessment improved the scope for older people to benefit from treatment. In January 2011, five pilot sites were set up in England to test different approaches to delivering this.

While the nature of such a project is that you cannot get hard numbers about how many additional lives you could save or the extent to which you could improve patient wellbeing and experience, we have learned a lot about the value of a proper assessment of older cancer patients' needs, the importance of giving older patients the right support packages, and the challenges associated with delivering appropriate assessment and practical support.

This report provides further information about the importance of fully assessing older people's needs, about how the projects ran, and what they found. Taking the learning, it then provides clear recommendations for commissioners and providers about what they could do to improve assessment and care of older people with a diagnosis of cancer.



**Sir Mike Richards**, National Clinical Director  
Cancer and End of Life Care



**Ciarán Devane**, CEO  
Macmillan Cancer Support



**Michelle Mitchell**, Charity Director General  
Age UK

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- The project Expert Advisory Group
- The project Steering Group
- All patients, staff and volunteers involved in the project





**“This report provides further information about the importance of fully assessing older people’s needs, about how the projects ran, and what they found. Taking the learning, it then provides clear recommendations for commissioners and providers about what they could do to improve assessment and care of older people with a diagnosis of cancer.”**

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# The Case for Change





**1.1** This chapter sets out the drivers for improving the quality of cancer care provided to older people. In the context of our older population, cancer services face three key challenges over the coming years:

- to improve cancer outcomes in the over 75 population
- to deliver high quality services to an increasing number of older cancer patients, in an environment where resources are becoming increasingly scarce
- to meet the age equality duties of the Equality Act (2010), which were extended to public services in October 2012

## 1.2 Improving Outcomes

**1.21** Cancer mortality rates for older people in the UK are improving at a much slower rate than in the younger population. From 1995-97 to 2003-05, cancer mortality rates fell by 16-17% for those under 75, but increased by 2% in those aged over 85 <sup>1</sup>. To tackle poor cancer mortality, steps must be taken to reduce the number of new cases of cancer and to improve cancer survival rates.

**1.22** In 2011 *Improving Outcomes: A Strategy for Cancer* set out an ambitious plan for the NHS to save 5,000 lives a year by 2014/15 <sup>2</sup>. We will not achieve this if we do not improve cancer survival rates in our older population. It is estimated that if UK cancer outcomes matched the highest performers in Western Europe for 75-84 year olds and outcomes in the USA for those aged 85 and over, then there would be 15,000 fewer cancer deaths every year <sup>3</sup>.

**1.23** Older people also face cancer inequalities in terms of their experience of care. The Cancer Patient Experience Survey 2011/2012 <sup>5</sup> reported that older people are less likely than younger people to be:

- given the name of a clinical nurse specialist
- provided with understandable and written information about possible side effects of treatment
- directed to sources of financial help and benefits
- directed to sources of support and self help groups

**1.24** There is a growing body of evidence to suggest older patients are less likely to receive the most clinically effective treatment for their cancer. Chapter Six of this report summarises some of this evidence, and discusses the possible reasons behind it. Suboptimal treatment can lead to less favourable cancer outcomes, and therefore, may impact negatively on cancer survival rates.

**1.25** Clinicians have raised concerns that current methods of assessing older patients often do not provide sufficient information to make an appropriate cancer treatment recommendation. Furthermore, issues such as a lack of practical and social support, and poorly managed comorbidities, can also present a barrier to patients receiving the most clinically effective treatment for their cancer.

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**“Improvements in mortality have been slower in older people than in younger people. Older people with cancer receive less intensive treatment than younger people. In many cases this may be clinically appropriate. However, there is increasing evidence that under-treatment of older people may occur.”**

<sup>4</sup> *Reducing cancer inequality: evidence, progress and making it happen*, National Cancer Equality Initiative (2010)

**1.26** Taking these concerns into consideration, the Improving Cancer Treatment, Assessment and Support for Older People Project was set up in partnership with Macmillan Cancer Support, the Department of Health and Age UK in 2010. This project aimed to increase access to appropriate cancer treatment for older people, by testing new methods of clinical assessment, and delivering tailored packages of practical support. The detailed rationale for the project, and a description of its methods, are outlined in Chapter Three.

### 1.3 Increasing Productivity and Saving Money

**1.31** Our population is ageing, and as such, the number of older people with a diagnosis of cancer is set to increase. It is estimated that the number of people aged over 65 living with a diagnosis of cancer will treble by 2040 to 4.1 million <sup>6</sup>. Any shortcomings identified within cancer services in relation to treating our older population must be addressed now if services are to be sustainable.

**1.32** The NHS in England is facing the financial challenge of delivering four percent efficiency savings per year by 2015, equating to a total of £15 – 20 billion <sup>7</sup>. As one of the largest components of NHS spending, cancer services must deliver more for less by improving productivity and reducing costs. Not only does effective assessment of patients lead to improved clinical management, it often leads to interventions which are widely accepted to be cost saving (e.g. falls prevention, management of polypharmacy, early identification and management of comorbidities). Proactive assessment and management of patients has also been shown to significantly reduce hospital discharge delay.

**1.33** There is a wealth of evidence to highlight the improved outcomes and cost savings associated with Comprehensive Geriatric Assessment in particular. This evidence is summarised in a recent systematic review undertaken by the Cochrane Collaboration <sup>8</sup>.

### 1.4 Complying with Legislation

**1.41** There is now a legal requirement to ensure cancer services are designed to meet the needs of older people. The Equality Act 2010 <sup>9</sup> requires all public services to eliminate unequal treatment on the grounds of age (**refer to box A**).

**1.42** To minimise the risk of age discriminatory practice, an objective assessment of an individual's circumstances and condition should be undertaken, so that treatment recommendations are not made on age based assumptions. Chronological age and performance status alone are poor predictors of cancer treatment tolerance and life expectancy <sup>10</sup>. Furthermore, assessment may identify additional support needs that must be addressed in order to access cancer treatment.

#### Box A: The Equality Act 2010

**Age discrimination in cancer care is now against the law. In October 2012 the provisions within the Equality Act (2010) which prohibit age discrimination were extended to the field of goods and services. This means that public sector organisations, including cancer services, are required to eliminate unequal treatment on the grounds of age.**

The act applies to “direct” or “indirect” discrimination against a person because of age. Ageism occurs when an assumption is made about an individual based on age. Direct age discrimination is the action that is taken as a result of that assumption. Making an assumption that someone will not tolerate a treatment on the basis of age alone, and subsequently not offering that treatment, is an act of direct age discrimination. Service provision that disadvantages those with needs commonly associated with ageing may constitute indirect age discrimination.

This legislation does not prevent age being taken into account in decision making, where it can objectively be justified. Healthcare providers need to ensure their design and delivery of services can be objectively justified to the satisfaction of a court if challenged.





**“Leaders of health and social care organisations, including the boards of those organisations and Elected Members, will want to set out a clear commitment to their staff and the wider public to meeting the requirements of the age discrimination ban and the public sector equality duty and demonstrate how the health and social care sector can show leadership in tackling ageism in society.”**

<sup>11</sup> *The achieving age equality in health and social care report for the Secretary of State, Sir Ian Carruthers & Jan Ormondroyd (2010)*

# Age Friendly Cancer Services

**2.1** This chapter sets out key principles for good practice, which have been identified as a result of the project findings. Further detail to support these recommendations can be found in Chapters Three and Four.



## 2.2 Age friendly cancer services will:

- Engage elderly care specialists as an active part of the cancer care team and adopt a multidisciplinary approach to the assessment and management of all patients.
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- Ensure an early and appropriate assessment of an older person is undertaken. The assessment should not only inform a dialogue about cancer treatment, but should identify and address unmet physical, psychological and social support needs. Follow up assessments should be undertaken at defined points throughout the treatment journey, to identify and address changes in need.
- 
- Ensure everyone gets the maximum benefit from cancer treatment and associated supporting therapies by effectively managing other health conditions and incorporating reasonable adjustments into care planning to address additional needs.
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- Establish services and clear referral pathways for both outpatients and inpatients to address needs identified by assessment. This includes establishing clear links with voluntary sector agencies, social services, and specialist teams such as falls prevention teams, continence specialists and dementia specialists.
- 
- Ensure effective communication systems are in place to facilitate coordinated care and informed decision making.
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- Ensure all clinical and non-clinical staff are supported with the training and access to resources required to conduct appropriate assessment and follow up care of all patients. In order to do this, it is vital that systems allow sufficient clinic time to undertake this work in day-to-day practice.
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# The Pilot Sites

**3.1** This chapter outlines the importance of assessment and support for older patients, and also gives a high level description of the interventions undertaken by the pilot sites.





**3.2** This project aimed to improve cancer outcomes by increasing access to appropriate cancer treatment for people aged 70 and over. The main interventions included:

- testing new methods of clinical assessment of older cancer patients
- coordinating and delivering packages of practical support for patients throughout treatment
- identifying and addressing staff training needs in order to promote age equality

### 3.3 The Participating Sites

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**3.31** In January 2011, five cancer networks throughout England were selected to participate in the pilot:

- Merseyside and Cheshire Cancer Network (MCCN)
- Thames Valley Cancer Network (TVCN)
- North East London Cancer Network (NELCN)
- South East London Cancer Network (SELCN)
- Sussex Cancer Network (SCN)

### 3.4 Assessment

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**3.41** Pilot sites used a Comprehensive Geriatric Assessment (CGA) approach to assess patients (**refer to Box B**). Although this assessment is new to cancer care, it is common practice in elderly care medicine.

- One cancer network (SELCN) used a self completed screening assessment to identify patients who required full CGA. The other four networks undertook the full CGA approach in all older patients assessed.
- Two cancer networks (NELCN and MCCN) deployed cancer clinical nurse specialists to undertake the assessment. Two cancer networks (TVCN and SELCN) adopted geriatric oncology liaison models, where elderly care specialists led on the assessment of older cancer patients. The SELCN site also tested the feasibility of assessment being undertaken in primary care.
- One cancer network (SCN) undertook two research studies as part of the pilot. As such, research nurses undertook CGA in patients who were recruited to these studies.
- Various aspects of assessment were undertaken across a variety of settings: home, outpatient clinics, inpatient wards, via telephone and in general practice.

## Box B: The importance of assessment in older people with cancer

**Older people are more likely to have comorbidities and geriatric syndromes such as incontinence, falls, functional decline, polypharmacy and delirium. These factors may affect treatment tolerance and, as a result, which cancer treatment and supportive therapies it is most appropriate to offer.**

Due to individual genetic and environmental factors we all experience ageing differently – as such the older population is a heterogeneous one. Chronological age alone is a poor predictor of treatment tolerance.

The International Society of Geriatric Oncology (SIOG) recommends the use of Comprehensive Geriatric Assessment (CGA) prior to medical or surgical intervention for older cancer patients<sup>12</sup>. Not only does this support informed, shared treatment decision making, but also the early identification and treatment of problems such as malnutrition may lead to better tolerance of treatment and improved outcomes. In some countries, such as France and the USA, this assessment is becoming a routine part of cancer care for older people.

CGA is routinely used in geriatric medicine. The British Geriatric Society recognises this assessment as a multidimensional interdisciplinary diagnostic process focused on determining an older person's medical, psychological and functional capability in order to develop a coordinated and integrated plan for treatment and long term follow up.

### Traditional CGA comprises the following elements:

<b>Medical assessment</b>	<ul style="list-style-type: none"> <li>Problem list</li> <li>Comorbid conditions and disease severity</li> <li>Medication review</li> <li>Nutritional status</li> </ul>
<b>Assessment of functioning</b>	<ul style="list-style-type: none"> <li>Basic activities of daily living</li> <li>Instrumental activities of daily living</li> <li>Activity/exercise status</li> <li>Gait and balance</li> </ul>
<b>Psychological assessment</b>	<ul style="list-style-type: none"> <li>Mental status (cognitive) testing</li> <li>Mood/depression testing</li> </ul>
<b>Social assessment</b>	<ul style="list-style-type: none"> <li>Informal support needs and assets</li> <li>Care resource eligibility/financial assessment</li> </ul>
<b>Environmental assessment</b>	<ul style="list-style-type: none"> <li>Home safety</li> <li>Transportation and tele-health</li> </ul>



**“At any age, cancer can have a substantial effect on a person’s independence and it is likely they will experience increased needs due to cancer and its treatment. The side effects of treatment can prevent people from maintaining their normal daily activities, and, therefore, a decision to undergo treatment can have a huge impact on a person’s daily life.”**

### 3.5 Practical Support

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**3.51** Four of the five participating cancer networks established service level agreements with local voluntary sector organisations. Patients could choose to be referred to these organisations for practical support (**refer to box C**). The fifth pilot site (SELCN), created a directory of organisations that could provide practical support. This directory was given to all patients. In this site, a dedicated clinical nurse specialist coordinated support for patients who were unable to make their own arrangements.

### 3.6 Training Needs

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**3.61** All participating cancer networks undertook a baseline staff survey to identify training needs in relation to providing care for older people with cancer. A variety of approaches were taken to training – with some sites choosing to deliver formal training sessions, and others utilising more informal peer education.

### 3.7 Findings

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**3.71** In total, 13 Acute NHS Trusts and one Primary Care Trust introduced new methods of assessing patients prior to, and during, cancer treatment. Throughout the project, over 700 patients were assessed in this way, and over 300 patients were referred to the voluntary sector for practical support.

**3.72** All pilot sites reported their initial findings in September 2012. An extensive independent evaluation has been undertaken. Further follow up of outcomes will be conducted over the coming years. Many of the pilot sites intend to publish more detailed findings in academic journals. More information about the pilots can be accessed at [www.macmillan.org.uk/geriatriconcology](http://www.macmillan.org.uk/geriatriconcology). A more in depth description of the project findings is included in Chapter Four of this report.



### Box C: The importance of practical support during cancer treatment

**At any age, cancer can have a substantial effect on a person's independence and it is likely they will experience increased needs due to cancer and its treatment. The side effects of treatment can prevent people from maintaining their normal daily activities, and, therefore, a decision to undergo treatment can have a huge impact on a person's daily life.**

Poor practical and social support can negatively impact on cancer outcomes. Older patients who live alone are less likely to accept treatment<sup>13</sup>, and those whose social support network does not comfortably meet their needs are less likely to make favorable treatment decisions<sup>14</sup>. Social factors such as access to transportation and available networks for home care influence which treatment is seen as appropriate<sup>15</sup>. Treatments such as radiotherapy can require daily visits to the hospital, which not only places the burden of arranging daily transportation on the individual with cancer, but is also time-consuming and can make carrying out normal daily tasks more difficult.

Older people are more likely to live alone and less likely to receive practical support<sup>16</sup>. Many have existing support needs at diagnosis, which if not addressed, may present a barrier to cancer treatment. In the UK:

- Half of all people aged 75 and over live alone, and one in 10 people have less than monthly contact with friends, family and neighbours<sup>17</sup>.
- One in five people aged 75 and over state they find it very difficult to get to their local hospital<sup>18</sup>.
- 16% of pensioners live below the poverty line<sup>19</sup>.
- 22% of people aged over 60 report they skip meals to cut back on food costs<sup>20</sup>.
- One third of families where the mother is in work rely on grandparents for informal child care<sup>21</sup>.
- Over half a million people aged 65 and over have caring responsibilities that take up at least 20 hours per week<sup>22</sup>.

Pilot sites formed strong relationships with voluntary sector agencies such as Age UK and the British Red Cross. These agencies were able to assess individual's practical support needs, and provide essential services. Services provided included; financial advice, befriending, assistance with transport, assistance with household tasks, and support with correspondence and form filling.

# Putting Learning into Practice

**4.1** This chapter builds on the principles set out in Chapter Two by setting them in the context of learning from the pilot sites. This includes, where appropriate, cross-referencing pilot site findings to published research. A case study has been included for each of the five pilot sites.



## 4.2 Geriatric Oncology Liaison

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**4.21** The benefits of geriatric liaison services are widely accepted in orthopaedic surgery, stroke services and general surgery. This project demonstrated that geriatric liaison is also feasible in an oncology setting. Although longer term follow up is required to quantify the impact of this intervention on cancer outcomes, early project findings suggest that the clinical benefits of geriatric oncology liaison are similar to those observed in other geriatric liaison models.

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**“Engage elderly care specialists as an active part of the cancer care team and adopt a multidisciplinary approach to the assessment and management of all patients.”**

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**4.22** The majority of the patients involved in the pilot had health problems other than cancer. Elderly care specialists are experienced at managing multiple health conditions and any resultant polypharmacy. Two of the five cancer networks involved in the project directly employed elderly care specialists to work alongside cancer services. Pilot sites that did not have the input of an elderly care specialist were less effective in assessing and managing the complex needs of many older cancer patients. Assessments in these sites did not influence cancer treatment recommendations, and often the findings of the assessment were not acted upon.

**4.23** Given the broad range of issues assessed by CGA, a multidisciplinary approach to assessment and management of patients proved to be most effective, with different aspects of assessment and follow up often being undertaken by different professionals. Cancer services staff involved in the project have given overwhelmingly positive feedback about the input of elderly care specialists, reporting specifically advantages in;

- clinical decision making (especially in the case of frailer patients)
- optimising comorbidities prior to and during treatment
- tackling discharge delay
- supporting the management of patients who have additional needs such as dementia
- improving communication between multiple stakeholders
- enhancing skills of the cancer workforce in relation to caring for older people.

**4.24** Some Trusts involved in the pilot did not have access to an elderly care specialist, whereas others reported difficulties engaging elderly care specialists due to existing clinical commitments making it difficult for them to find capacity to support cancer services. This proved challenging – consensus amongst key stakeholders across all pilot sites was that clinical input from elderly care specialists is pivotal in the improvement of care for many older people with cancer.

**4.25** Two geriatric oncology services have been sustained beyond the life of the project (**refer to boxes D and E**). Discussions have commenced in other sites in regards to engaging elderly care specialists in the care of older people with cancer.

### Box D: Geriatric Oncology Liaison Development

**GOLD (Geriatric Oncology Liaison Development) was piloted in SELCN by Guys and St Thomas' NHS Foundation Trust and Bexley Care Trust. The project involved 177 patients aged over 70 undergoing cancer treatment for urological, haematological, breast or colorectal cancers.**

Patients were asked to complete a screening questionnaire assessment prior to a telephone consultation with either a geriatrician or an elderly care specialist nurse. Nearly half of patients screened were invited to an outpatient clinic for a CGA. A small proportion of patients who resided in Bexley were assessed using CGA by their general practice.

Seventy percent of patients screened had three or more co-morbidities. All patients who underwent a full CGA required at least one CGA related intervention. Just under 40% of patients required changes to the management of at least one of their other health conditions. For example, cardiac function was optimised in 54 patients, anaemia in 19 patients, respiratory problems in 17 patients, and nutritional interventions were undertaken in 27 patients.

Feedback from oncologists about the service was positive. On a number of occasions geriatrician involvement directly influenced the cancer treatment and management of patients. Throughout the duration of the project there were a number of patient case studies where clinicians reported that patients tolerated treatment better as a result of input from the GOLD team.

The GOLD team also worked with inpatients. It was observed this intervention significantly reduced length of stay.

To read the SELCN pilot report visit:  
[www.macmillan.org.uk/geriatriconcology/SELCN](http://www.macmillan.org.uk/geriatriconcology/SELCN)

## 4.3 Assessment and Care Planning

**4.31** The importance of assessment and care planning in the care of all cancer patients is widely accepted. Not only does assessment provide useful information to support informed treatment decision making, it may also identify unmet physical, psychological and social support needs that can be addressed to ensure patients are in the best possible condition to benefit from cancer treatment.

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**“Ensure an early and appropriate assessment of an older person is undertaken. The assessment should not only inform a dialogue about cancer treatment, but should identify and address unmet physical, psychological and social support needs. Follow up assessments should be undertaken at defined points throughout the treatment journey, to identify and address changes in need.”**

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**4.32** Assessments undertaken during the project illustrated the heterogeneity of the older population. Encouragingly, many older patients were relatively fit, with good support networks. Other patients had complex needs, which if not addressed, could present a barrier to effective cancer treatment. Pilot site leads agreed that approaches such as Comprehensive Geriatric Assessment (CGA) are useful in older cancer patients. However, they stress this approach may also be beneficial in younger people with complex needs and long term conditions.

**4.33** Clinicians may choose to undertake a full CGA in all older patients, or may take a screening approach to prioritise the patients who are most in need of more in depth assessment. During the project there was much debate amongst lead clinicians as to the strengths and limitations of each approach.



**4.34** A full assessment should look at cognition, nutritional status, functional status, mental health and wellbeing, comorbidities, medication usage, social and financial circumstances (refer to Box E). The European Organisation for Research and Treatment of Cancer (EORTC) has established an active Elderly Task Force (ETF) that recommends a *minimum* data set<sup>23</sup> comprising the G8 questionnaire, the Instrumental Activities of Daily Living (IADL) questionnaire, information about social situation and the Charlson Comorbidity Index (CCI).

**4.35** All pilot sites reported they found it challenging to undertake this assessment prior to the first multidisciplinary meeting. This was mainly due to the lack of additional clinic time to undertake the assessment at this stage of the pathway, and the short window of opportunity to identify patients who required CGA. It is vital that steps are taken to ensure pathways allow for an early and appropriate assessment. The first assessment should ideally be undertaken prior to the treatment decision being made. It is also important that assessment is a dynamic process repeated along the care pathway. Pilot sites observed changes in patient needs during and after cancer treatment.

**4.36** This project demonstrated that approaches such as CGA are feasible within a cancer services setting. The most common challenges reported were lack of time, clinic space and training to undertake assessment. Pilot sites learned the importance of ensuring that those who undertake the assessment have the relevant training, knowledge and skills to not only undertake the assessment, but also to interpret the assessment and act on its findings. The assessment had limited impact when this was not the case.

**4.37** The benefits of CGA are clearly recorded in academic literature. Irrespective of an older person's cancer diagnosis, there is clear evidence to show that this approach is beneficial to older patients. Reductions in early re hospitalisation of older patients and improved mortality rates have been demonstrated following CGA assessment<sup>24</sup>. In 2011 a Cochrane Collaboration review<sup>8</sup> concluded that patients who received CGA on admission to hospital were more likely to be alive and living at home, one year post admission. This can largely be attributed to the early identification and management of problems. Many of the studies included in the review concluded that CGA in a general acute setting was both clinically and cost effective.

**4.38** Once CGA has been undertaken, it is important that a care plan is put in place to address the issues that have been identified. It is also important to clearly document the assessment findings and resultant care plan, and share this documentation with key stakeholders involved in the care of the individual in question. Many pilot site staff felt strongly that failure to do this resulted in the assessment becoming nothing more than a "paper exercise".

**4.39** Some of the patients involved in the project were in relatively good health reporting no other significant health issues, or medication usage. Most patients however had other health issues, which needed to be addressed. Research suggests older cancer patients have an average of three other health conditions<sup>25</sup>. The high prevalence of coexisting health conditions reiterates the importance of ensuring cancer rehabilitation starts at the point of cancer diagnosis<sup>26</sup>.

## Box E: Comprehensive Geriatric Assessment in Practice

In TVCN the Royal Berkshire Hospital NHS Foundation Trust established the Comprehensive Care for Older people with Cancer (COCOC) project to improve care for people aged over 70 with a diagnosis of breast, lung, colorectal or upper gastrointestinal cancer. The “COCOC team” comprised a nurse with significant community nursing experience, and a senior Specialist Registrar geriatrician. The team offered a liaison service to surgery, medicine and oncology.

All 149 patients involved in the pilot underwent Comprehensive Geriatric Assessment at diagnosis, throughout and after treatment. Patients were offered a referral to a buddy scheme that was set up in partnership with the British Red Cross. Just over half of patients were assessed in their own homes.

The Comprehensive Geriatric Assessment used by the COCOC team was composed of the following elements:

- The Hospital Anxiety and Depression (HAD) Score
- The Falls Risk Assessment (FRAT) tool
- Body Mass Index, arm muscle circumference and Malnutrition Universal Screening Tool (MUST) score
- The timed up and go test
- Hand grip strength testing
- Peak flow testing
- The Charlson comorbidity score
- EORTC QLQ C-30 questionnaire

- Barthel’s index
- Performance status
- Lawton-Brody Instrumental Activities of Daily Living
- The Waterlow pressure ulcer risk assessment
- The Abbreviated Mental Score Test (AMT)
- The Mini Mental State Examination (MMSE)

The following issues were identified in the first 70 patients seen by the COCOC team:

- 45% had a history of hypertension
- 43% reported a history of falls
- 41% were taking four or more medications
- 40% lived alone
- 40% had impaired ability to plan and prepare meals
- 38% had three or more comorbidities
- 23% were completely unable to shop
- 19% had a body mass index of less than 20
- 16% showed signs of cognitive impairment on assessment
- 10% required assistance to eat or drink
- 10% had difficulty using the telephone

To read the TVCN pilot site report visit:  
[www.macmillan.org.uk/geriatriconcology/TVCN](http://www.macmillan.org.uk/geriatriconcology/TVCN)

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**“Ensure everyone gets the maximum benefit from cancer treatment and associated supporting therapies by effectively managing other health conditions and incorporating reasonable adjustments into care planning to address additional needs.”**

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**4.310** Polypharmacy was a common issue amongst patients participating in the project. Project findings reflected those of international published studies, where approximately one in three older people have existing problems with their medication regimens prior to the introduction of cancer therapies <sup>27</sup>.

Elderly care specialists involved in the pilot routinely made changes to the medication regimens of their patients. Anti-hypertensive drugs were noted to frequently cause problems such as dizziness and falls, or decreased renal function in older patients.

**4.311** The older population has an increased prevalence of disability, sensory impairment, dementia, and mental health problems. For instance, 71% of people aged over 70 have some form of hearing impairment <sup>28</sup>. One pilot took a particular interest in making reasonable adjustments to care for patients who had these needs (**Refer to Box F**). Clinicians from this site reported improved tolerance of treatment and patient experience.

### **Box F: Assessment and practical support in Merseyside and Cheshire**

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**Three NHS Trusts in MCCN introduced enhanced assessment methods for older patients. Cancer clinical nurse specialists at Southport and Ormskirk Hospital NHS Trust and St Helens & Knowsley Teaching Hospitals NHS Trust undertook CGA of 41 patients aged over 70 who were awaiting breast or colorectal surgery. At Clatterbridge Centre for Oncology 70 patients received Reasonable Adjustment RA assessments which were led by a senior radiographer. Routine medication reviews by a senior oncology pharmacist were also introduced at this Trust.**

Although the CGA did lead to some patients being referred to specialties such as elderly care and dietetics, the results did not influence cancer treatment recommendations. Clinicians decided to discontinue the assessment until they could establish systems that enabled them to use the findings of the assessment to maximum effect (e.g. by engaging the support of elderly care specialists).

All patients who received a Reasonable Adjustment assessment were given tailored care plans as a result of the assessment. Clinicians reported that older patients with sensory impairment, dementia, mental health problems and learning disabilities significantly benefitted from enhanced assessment and care planning.

All patients aged over 70 were offered a referral to Age UK. Patients could also self refer. One local Age UK branch, Age UK Knowsley & West Mersey, acted as a single point of referral and coordinated services across six local voluntary sector organisations.

During the project 130 patients were referred to Age UK from across the Cancer Network. Housework, transport and emotional support were the most commonly reported needs.

To read the MCCN pilot site report visit: [www.macmillan.org.uk/geriaticoncology/MCCN](http://www.macmillan.org.uk/geriaticoncology/MCCN)

## Box G: The Chemotherapy Enhanced Support Programme

**Fatigue is the most common side effect of chemotherapy, and is known to interfere with patients' activities of daily living. Evidence suggests this has the most debilitating effect on older people, who are likely to already have experienced some physical limitations due to the ageing process<sup>29</sup>.**

The Chemotherapy Enhanced Support Programme, based in SCN, aimed to assess whether older patients undergoing chemotherapy are willing to accept a programme of increased practical support whilst they are receiving chemotherapy. The programme also aimed to establish what practical support is needed.

Patients aged over 70 with a diagnosis of colorectal, urological, breast or lung cancer were offered a referral to Age UK prior to commencing chemotherapy. Just over 60% of patients accepted a referral. Of the 62 patients referred:

- 75% were given advice and information
- 61% received confidence building support
- 53% required sign posting/direct referrals to other services
- 41% had regular phone contact
- 15% received a direct referral to the oncology team
- 7% required light housekeeping
- 5% required assistance with shopping
- 5% required escorting on outings or to appointments
- 3% required help with form filling and managing correspondence
- 2% required assistance preparing light snacks

The delivery of this service involved 256 home visits by Age UK staff and volunteers, taking up 352 hours of time. An additional 44 hours were spent on making 234 phone calls. It is important to note that this group of patients may be fitter than the general older population, as they had been pre-selected for chemotherapy. Frailer patients may have greater support needs.

To read more about the SCN pilot visit: [www.macmillan.org.uk/geriatriconcology/SCN](http://www.macmillan.org.uk/geriatriconcology/SCN)





**“This pilot stresses the need for a multidisciplinary approach to assessment and care planning, where Clinical Nurse Specialists play a vital, but not solitary role.”**

## 4.4 Commissioning services

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**4.41** As expected, pilot sites found effective assessment often identified unmet physical, psychological and social support needs. It is widely accepted that these issues can have a detrimental impact on cancer treatment tolerance and outcomes.

**4.42** On some occasions it proved challenging to address these needs in a timely manner due to lack of clear referral processes, unclear referral criteria and limited capacity within services. The findings of this project reiterate the importance of taking an integrated approach to the delivery of health and social care.

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**“Establish services and clear referral pathways for both outpatients and inpatients to address needs identified by assessment. This includes establishing clear links with voluntary sector agencies, social services, and specialist teams such as falls prevention teams, continence specialists and dementia specialists.”**

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**4.43** Pilot site staff reported high levels of variation in service provision between hospital trusts and local authorities. Staff also highlighted an inequity between services available to inpatients and outpatients. Furthermore, even when services were available they often did not have sufficient capacity to respond within a timescale that was compatible with the cancer pathway. A service mapping exercise, undertaken at an early stage in the project, highlighted that some local authorities involved in the pilot had average waiting times for services such as respite care and community occupational therapy services that were in excess of 100 days<sup>30</sup>. It is essential these services have the capacity to respond in a timely manner.

**4.44** A survey of pilot site clinical staff showed that many were unsure how to refer to services, such as psychiatry, falls prevention, and services that could assist with activities, such as pet care, gardening and household tasks. Furthermore, staff encountered patients from a number of local authorities, and often found it difficult to keep their knowledge up to date as to what services were available in each area.

**4.45** Many patients were unaware of the support services that were available to them. There was considerable variation in the uptake of practical support observed between pilot sites. The timing of offering additional support to patients was crucial – many patients at diagnosis could not anticipate what their support needs would be during treatment. It was vital that regular communication was held with patients regarding their support needs. Simple interventions, such as producing an information resource on local support services, received positive feedback from patients.

**4.46** Most pilot sites adopted a model where they could refer patients to a voluntary sector agency, such as Age UK. One cancer network had a single point of referral for all patients, and this proved advantageous as the referring clinician did not need to know which specific organisations operated in each local authority (**refer to Box F**). The voluntary sector agencies that participated in the project had good knowledge of local services and often made referrals to falls prevention services, social services and other local charities.

**4.47** Many voluntary sector providers were able to give information and advice such as financial advice, and had befriending, housekeeping and gardening services. The reported needs of older patients varied significantly by pilot site. Emotional support, and assistance with housework and transportation were the most commonly reported needs.

**4.48** Commonly cited reasons for not accepting a referral for support were the perception that someone else would benefit more from the services (and hence accepting the referral would take resource from someone more needy), and that patients felt adequately supported by friends and family. The latter point stresses the importance of carers also being offered support. Carer support was frequently provided by the voluntary sector organisations that participated in this project.

**4.49** Not only were unmet needs identified at diagnosis, and changing needs observed during treatment – many patients had ongoing needs after treatment. Pilot sites had to develop management plans for patients following treatment in order to seamlessly hand over responsibility for care to appropriate providers. In some local authorities this posed a challenge due to the limited availability of services.

## 4.5 Communication and Documentation

**4.51** Significant communication issues were highlighted which presented a barrier to effective multidisciplinary working. Delays in receipt of information, and lack of information often resulted in duplication of assessment. Key areas to improve were identified as:

- information provided on referral from primary care
- comprehensiveness of information recorded in the patient notes
- feedback of assessment findings to multidisciplinary meetings and cancer clinicians
- communication between clinicians and patients
- ongoing communications between cancer services, elderly care services, primary care, social care and voluntary sector services throughout care and at end of life

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**“Ensure effective communication systems are in place to facilitate coordinated care and informed decision making.”**

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**4.52** During the initial assessment, clinicians reported they often had to contact primary care for more information about their patients. Pilot site staff stated they would find it useful if information about comorbidities, medications and additional needs such as disability, dementia or hearing impairment was provided at the time of referral.

**4.53** A lack of information in the patient notes resulted in duplication of assessment and, as such, impacted on staff time. In some instances clinicians could not determine from patient notes why a particular cancer treatment had been given, as the information that was used to inform the treatment decision was not easily accessible. This also presented a challenge when evaluating the project.

**4.54** On the occasions where patients did not receive standard treatment for their cancer, it was often difficult to ascertain from the medical notes if this was due to patient choice, or clinicians concerns over the safety of giving a particular treatment. Pilot sites reported that they would find it helpful if the most clinically effective treatment was stated for each patient, as well as the treatment that was given, and that the factors that informed that choice are clearly documented (i.e. safety, clinical effectiveness, patient choice, evidence of support offered and steps that had been taken to manage co-existing health problems).

**4.55** The pilots faced challenges in communicating the findings of the assessment at the initial multidisciplinary team meeting. The biggest challenge was the time available per patient in this meeting and this often being insufficient to discuss the highly complex needs of some patients. Further work must be done to determine the most effective way to present assessment findings to multidisciplinary meeting.

**4.56** Communication issues between patient and clinician frequently arose due to sensory impairment, and cognitive impairment. On occasion challenges presented when patients had not been informed of their cancer diagnosis prior to their assessment, leading to some patients being informed of the diagnosis by a non cancer specialist.

**4.57** Communication challenges between various providers of care were experienced by all pilot sites. There is some evidence to suggest that this communication was strengthened with the involvement of elderly care specialists.

**4.58** In the sites where patients were referred to the voluntary sector, elements of assessment which had been undertaken by clinical staff had to be duplicated by voluntary sector staff. Ideally, information sharing agreements should be set up so that useful information can be shared between the clinical care team and the voluntary sector, with the patients consent. Furthermore, systems need to be established to ensure care providers are informed in a timely manner when a patient is admitted to hospital, or when they have died.



## 4.6 Empowering Staff and Patients

**4.61** Most people with a diagnosis of cancer are older people. As such, it is important that all those involved in cancer care are equipped with the skills to meet the specific needs of this age group, and have the time and resources to do this in day to day practice. Many cancer services staff involved in the pilot reported that they felt the time pressures they faced in clinic made it difficult for them to fully assess and manage older patients effectively.

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**“Ensure all clinical and non-clinical staff are supported with the training and access to resources required to conduct appropriate assessment and follow up care of all patients. In order to do this, it is vital that systems allow sufficient clinic time to undertake this work in day-to-day practice.”**

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**4.62** In a survey of cancer services staff involved in the project, although clinicians were generally aware that most of their patients were older people, more than half reported they had never received any training on the specific medical needs of older people. Many of those who had received this training had done so as undergraduates. Nearly half of staff reported they had never received training on the Mental Capacity Act. Although this survey focused on clinicians, pilot site staff stressed the importance of ensuring training and support is also made available to non clinical staff.

**4.63** During the course of the project, pilot sites undertook a number of activities to educate members of the multidisciplinary team on their respective contributions to the cancer care of older patients. Furthermore, significant training needs were identified amongst all stakeholders. Areas of learning and development focused on:

- general elderly care skills for cancer specialists (so basic issues associated with ageing can be assessed and managed within cancer services)
- the role of non cancer specialities and services (so cancer clinicians know when and who to refer to when they cannot manage a particular issue within their own professional capacity)
- cancer specific skills for non cancer specialists

**4.64** The pilot sites undertook a number of learning and development activities including: informal group and one to one sessions, personal study and access to formal training courses. Furthermore, sites observed development of knowledge and skills amongst staff as a direct result of their participation in the pilot and working in partnership with other specialists. There is some evidence to show that these activities resulted in changes in practice.

**4.65** The engagement of staff with various training opportunities was variable for a number of reasons, and reflected the overall engagement of staff with the project. Many staff reported that they did not need training. Others did not recognise the need to improve services for older people. Project leads reported that clinical audit was a useful tool to encourage reflective practice and support people to identify their own learning and development needs.

**4.66** Elderly care specialists invested study time in learning about various cancers and their therapies by both studying formal texts and working closely with their cancer specialist peers. In particular, this helped to tailor assessment and management to take into account the side effects of specific cancer treatments.

**4.67** Some voluntary sector staff received “cancer awareness training” from cancer clinicians. Those who didn’t receive this stated that they would have found it beneficial. All voluntary sector staff had regular support meetings and debriefs. Counselling and training was provided to help voluntary sector staff cope with the emotionally demanding aspects of their role, such as bereavement.

**4.68** In addition to educating staff, pilot site stakeholders highlighted the need to raise awareness amongst patients about the potential benefits of cancer treatment. Staff reported that many older people underestimated their own life expectancy and often overestimated the side effects of treatment. Furthermore, many patients were not aware of many of the support services that were available to them. Pilot sites staff raised concerns that some older people were declining treatment without being given the relevant information to make an informed choice.



## Box H: The role of the clinical nurse specialist in assessment of older cancer patients

Five NHS Trusts across North East London sought to examine the role and impact of the cancer clinical nurse specialist (CNS) in assessment of older people with cancer. Over the course of thirteen months, 90 patients aged over 70, with either a diagnosis of breast or colorectal cancer, were included in the project.

There was significant variation in the number of assessments between Trusts. Fifty of the 90 assessments were undertaken by Barking, Havering and Redbridge University Hospitals NHS Trust. A small number of CNSs were heavily involved in the project. However, others did not assess any of their patients at all, despite repeated attempts to engage them in the project. Very different attitudes between clinical nurse specialists were observed, as to the value completing the assessment brought to their patients.

Nurses who completed the assessment felt they had the necessary skills to undertake the assessment. On the other hand, there were indications that they may have benefitted from further educational input over time. For instance, some nurses found aspects of the assessment awkward to conduct, and this included questions that evaluated cognition or mood. Some parts of the assessment were repeatedly recorded incorrectly and the characteristics of the patient group suggest more referrals to care of the elderly and practical support services were merited. With the exception of taxi services, referrals were much lower than expected:

- Only 7% of patients were referred to care of the elderly physicians
- Only 14% patients were referred to Age UK for practical support
- 29% of patients were referred to taxi services

Staff felt assessment, arranging referrals and overseeing referrals placed additional strain on already high CNS workloads. The assessment results were not used to evaluate patient fitness for cancer treatment. The assessment was largely seen as a paper exercise with results not shared with others.

This pilot stresses the need for a multidisciplinary approach to assessment and care planning, where CNSs play a vital, but not solitary role. In general, the assessment was seen to be the work of the nurses with surgeons, oncologists and elderly care physicians playing a peripheral role.

In addition to increasing the input of other specialities, this pilot shows the importance of ensuring staffing levels of clinical nurse specialists is sufficient to allow time to undertake appropriate assessment and arrange support.

To read more about the NELCN pilot visit: [www.macmillan.org.uk/geriatriconcology/NELCN](http://www.macmillan.org.uk/geriatriconcology/NELCN)

# Measuring Progress



**5.1** The needs identified during assessment should be recorded in a way that high-level data can be generated to inform service delivery. The data provided by the pilots gives some indication of need. However, due to demographic variation between area and treatment group, each older population may have its own specific requirements.

**5.2** In addition to specific patient needs, services should also record what proportion of issues were managed in a timely manner. For example, if 20% of older patients required a referral to dietetics or elderly care, it is useful to know what proportion of those patients were seen within a time frame that was compatible with cancer treatment waiting times.

**5.3** Wherever possible, data relating to the cancer should be published in a way that enables analysis by age. This includes data on interventions such as surgery, radiotherapy and chemotherapy, incidence, survival and mortality, hospital length of stay and admissions.

**5.4** The equity audit for multidisciplinary teams (MDTs) was first announced in *Improving Outcomes: a Strategy for Cancer*. The audit will enable multidisciplinary teams or Network Site Specific Groups to consider demographic characteristics of their patients and reflect on their care and treatment. MDTs who record consistent variables, for example performance status, stage at presentation and comorbidities, will be able to reflect on treatment recommendations for particular groups of patients, for example, older people. This mirrors good practice outlined in the *Achieving Age Equality for the NHS Practice Guide*, which recommends that local variations in access to cancer treatment by age should be regularly monitored and reported.

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**“In future, MDT Health Equity Audits will form part of the National Cancer Peer Review Programme.”**

<sup>2</sup>*Improving Outcomes: a Strategy for Cancer*



# Linking to Research, Policy and Good Practice





**6.1** This chapter sets the Improving Cancer Treatment Assessment and Support for Older People Project in context of wider research evidence, related policy and good practice. It summarises some of the evidence around the clinical management of older people with cancer, and makes reference to relevant policy and good practice guidelines.

## 6.2 Research and Evidence

**6.2.1** A number of factors are thought to contribute to the relatively high cancer mortality observed in the UK older population. Higher incidence of cancer may largely account for this – per head of population there are more cases of cancer diagnosed in the UK older population each year than in comparable nations<sup>31</sup>. Late presentation and diagnosis of cancer in this age group are also thought to play a significant role for some cancer types. There is, however, a growing body of evidence to suggest under-treatment of older people is also a contributing factor.

**6.2.2** Evidence suggests older people are less likely to receive standard cancer treatments such as surgery, radiotherapy and chemotherapy than their younger counterparts. The reasons for the observed discrepancy in intervention rates between age groups are complex. It is important to note that much of the data on cancer treatment intervention rates reports the number of patients who received a particular treatment, and does not take into account factors like patient choice e.g. if treatment was offered and subsequently declined.

**6.2.3** It is important to recognise that, on some occasions, these interventions may not have been given for good reason. To offer aggressive treatment is not always clinically appropriate. The biology of cancer in older people is sometimes different to that of cancer in younger people, and as such may require different management. Older patients may present with more advanced disease where radical therapies are deemed ineffective. For example women aged 75-79 are 46% more likely to be diagnosed with stage III or IV breast cancer than those aged 65-69, who are just 10 years younger<sup>32</sup>. There are significant risks associated with certain treatments in frail older patients, or those with complex comorbidities. It is important to recognise that overtreatment is just as undesirable as undertreatment.

**6.2.4** Some research suggests patient choice and the presence of comorbidities do not fully account for the difference observed in intervention rates between age groups. This implies a proportion of older patients may not be receiving cancer treatment that they could benefit from. A number of studies, detailed in this chapter, have investigated the possible reasons for this.

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**“There is now evidence that older people are not always receiving the same standard of treatment as younger patients. Sometimes healthcare professionals make assumptions about an older person’s preferences about treatment and a decision that an older person will not be able to cope with treatment is often made without fully assessing their overall physical health.”**

<sup>2</sup> *Improving Outcomes, A Strategy for Cancer* (Department of Health, 2011)

## 6.25 Surgery

**6.251** Surgery is widely accepted to be the most clinically effective treatment for most solid cancer tumours. Data published by the National Cancer Intelligence Network (NCIN) shows disparity in surgical intervention rates between different age groups<sup>33</sup>. This data shows clearly that older patients are less likely to receive surgery than their younger counterparts.

**6.252** In 2011, NCIN published a report that showed major resection rates by age and cancer site for patients diagnosed between 2004 and 2006<sup>33</sup>. The report highlighted a notable decrease in the percentage of patients undergoing major resection with increasing age. For example, only 39% of women aged over 80 in the UK receive surgery for breast cancer compared with 90% of women aged under 50\*.

**6.253** Detailed studies relating to breast cancer treatment have shown chronological age as a major factor determining treatment, even when tumour characteristics and comorbidities are accounted for<sup>34</sup>.

**6.254** In 2012, Access all ages<sup>35</sup> looked at the impact of age on access to a number of surgical procedures. The report also explored some of the possible reasons for the observed decrease in surgical intervention rates seen in older patients. The report classifies these reasons into three broad categories:

- clinical factors, such as comorbidities and frailty
- clinical approaches – individual clinicians approach the treatment of older people based on their own experience, attitudes and evidence
- patient awareness and preference – patients may lack the information and support they need to make an informed decision about whether surgery is right for them or not

## 6.26 Chemotherapy and Radiotherapy

**6.261** The physiological consequences of ageing can have major implications when prescribing treatments such as radiotherapy and chemotherapy. There is a need for more clinical trial data on the effectiveness and safety of these therapies in older cancer patients. This lack of evidence presents a further challenge to oncologists. In general, older people are less likely to receive chemotherapy and radiotherapy than their younger counterparts. However, much work remains to be done to determine the extent to which this observed decrease in therapy is clinically appropriate.

**6.262** NCIN has established a Radiotherapy Dataset. Since April 2009, all centres providing radiotherapy are now required to send data to the NCIN analysis team. In 2012, NCIN also introduced a National Chemotherapy Dataset. These datasets will allow for much more detailed analysis of chemotherapy and radiotherapy intervention rates by age, in much the same way as has been done for surgery. These analyses will then form a basis for more in depth analysis to explore the reasons for any observed variation in intervention rates.

**6.263** A 2010 NCIN data briefing, *Breast Cancer in the Elderly*, reports a decrease in the use of radiotherapy with increasing age at diagnosis for women who have invasive breast cancer. The 2010 report showed that in 2006, 74% of patients aged 70 and over with conservatively treated invasive breast cancer had radiotherapy treatment recorded compared with 84% of those aged under 70<sup>36</sup>.





**“Surgery can significantly improve health outcomes both in terms of survival and quality of life. However, across a range of key procedures, surgery rates decline with age, despite the fact that the conditions being treated are more common among older people. In some instances observed emergency rates increase with age while elective rates are shown to fall, which might indicate a lack of early, preventative care for older patients.”**

<sup>35</sup> *Access all ages: assessing the impact of age on access to surgical treatment (Royal College of Surgeons, Age UK 2012)*

**6.264** In 2009 the NHS Breast Screening Programme published the *All Breast Cancer Report*<sup>37</sup>. The report presented an analysis of adjuvant chemotherapy and radiotherapy treatments in different age groups. Older patients were less likely to have radiotherapy recorded as an adjuvant treatment than women in younger age groups. Just over half (53%) of patients aged over 70 with surgically treated breast cancer had radiotherapy recorded, in comparison to 69% of patients aged between 50 and 70, and 70% of patients aged under 50. The report also showed a decrease in adjuvant chemotherapy with increasing age: 16% of patients over 70 years with surgically treated breast cancer had chemotherapy recorded, compared to 38% of patients aged 50-70 and 72% of patients under 50. The authors of the report note that the age related differences in chemotherapy usage may partially be explained by difference in the biology of cancer.

**6.265** A recent international study explored the extent to which chronological age influences clinical decisions in cancer treatment<sup>38</sup>. The study, which included oncologists from England, Canada, Spain, Germany, Denmark and Sweden, used patient scenarios across a number of cancer types to examine the way in which clinical attitudes translate into clinical decision-making. The results showed chronological age played a significant role in decision making, and this was consistent across all participating nations.

**6.266** The Adjuvant Chemotherapy in Older Women with breast cancer (AChEW) study looked into treatment decision making regarding women aged over 70 with early stage breast cancer<sup>39</sup>. The study, undertaken between April 2010 and December 2011 in 24 cancer centres and cancer units in England, recorded only 14% of eligible women were offered adjuvant chemotherapy, and that these recommendations were often made in the absence of information regarding performance status and HER2 status\*. The dominant reason cited by clinicians for not offering chemotherapy was a perception that the benefits of chemotherapy were limited. Patients reported they preferred to be actively involved in decision making and recommendations by physicians played a significant role in accepting or declining treatment.

### 6.3 Policy and Good Practice

**6.31** The learning and evidence from this project may support the delivery of the current policy agenda facing health and social care. Furthermore, there is a wealth of established good practice that may support commissioners and providers to deliver the recommendations set out in this report.

**6.32** The *National Dementia Strategy*<sup>40</sup> has set a clear direction for the development of health and social care services to support people with dementia and their carers. The strategy

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**“The study (referenced) set out to investigate the extent to which age is a factor in treatment decisions. The results suggest that clinicians may over rely on chronological age as a proxy for other factors, which are often but not necessarily associated with age, such as comorbidities or frailty. This finding is in contrast to the perceptions of clinicians, which is that factors such as comorbidity or frailty are more important than age itself.”**

<sup>38</sup> *The impact of patient age on clinical decision-making in oncology, National Cancer Equality Initiative (2012)*

\* footnote: in the context of breast cancer treatment HER2 status informs the extent to which the cancer may respond to monoclonal antibody therapies, such as Trastuzumab.



includes a focus on early diagnosis, learning and development for professionals and providing quality care. A National Dementia Commissioning for Quality and Innovation (CQUIN) payment has been introduced to incentivise the screening, diagnosis and effective management of patients with dementia. Dementia affects one in six people over 80, and one in three people aged over 90 .

**6.33** *Achieving age equality in health and social care: NHS practice guide* <sup>41</sup> was produced by NHS Southwest to help the NHS deliver the recommendations made in the report *Achieving age equality in health and social care* <sup>10</sup>. The guide highlights the importance of delivering personalised care for individual patients and their carers, in order to end age discrimination. It aims to help healthcare providers appropriately take account of age in designing and delivering services. It demonstrates that both the 'one size fits all ages' approach and the use of age as a way to limit access to services without any evidence is not acceptable.

**6.34** In 2011 the National Cancer Action Team published guidance for healthcare professionals undertaking holistic needs assessment. *Holistic Needs Assessment for people with cancer: A practical guide for health professionals* <sup>42</sup> stresses the importance of assessment as part of every cancer patient's care. It highlights the impact assessment can have on patient experience and patient outcomes.

**6.35** *Reducing Inequalities in Commissioning Cancer Services: Principles and Practical Guidance in Good Equality Working* <sup>44</sup> was published by the National Cancer Equality Initiative in 2010. The guide outlines good practice for organisations and individuals who commission services that aim to reduce cancer inequalities. It includes key principles that can be used as a helpful checklist alongside other relevant policy initiatives.

**6.36** The statement "No decision about me, without me" was one of the hallmarks of the 2010 white paper *Equity & Excellence: Liberating the NHS* <sup>45</sup>. Shared Decision Making <sup>46</sup> is a process in which patients can review the treatment options available to them, with current clinical information relevant to their condition, and make a decision in partnership with their clinician, as opposed to a clinician making a decision on their behalf. As such, it is vital that relevant information is obtained from assessment in order to inform a dialogue about cancer treatment options, and ensure patients have the necessary information to make an informed choice.

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**“Hospitals and care homes need to assess older people when they are admitted, so a coordinated care plan can be developed. They need to be reassessed periodically throughout their stay, and before they are discharged, and action should be taken as a result. When undertaking assessments, staff must take time to understand and record the needs and preferences of older people, including cultural and spiritual needs, and their relationships with family, friends, carers and advocates, in addition to recording physical and mental health.”**

<sup>43</sup> *Delivering Dignity, NHS Confederation (2012)*

# Summary and Next Steps



**7.1** There is a compelling argument to improve cancer care for older people. Cancer is predominantly a disease of older age. Not only do the recent changes to the Equality Act place a legal duty on cancer services to ensure this age group are not unduly discriminated against, significant steps must be undertaken to improve cancer outcomes, and improve the efficiency of services.

**7.2** This project illustrates some of the challenges cancer services face when providing care for our older population. Many older people are relatively fit, with minimal support needs. Others have complex requirements, which if not addressed may present a barrier to cancer treatment. Services face the challenge of striking a balance between undertreating and overtreating patients, in addition to ensuring the patients own goals and preferences are taken into account. Effective assessment and care planning play a pivotal role in achieving this balance.

**7.3** The UK has made a great deal of progress in recent years to build our understanding of how we can better care for older people with a diagnosis of cancer. This project has contributed to this learning. However, it has also identified significant areas for further research and policy development.

**7.4** Project findings demonstrate the benefits of engaging elderly care specialists in cancer care, and that approaches such as Comprehensive Geriatric Assessment CGA are feasible within a cancer services setting. Furthermore this assessment can impact positively on treatment decision making and general quality of care. However, debate continues as to the pros and cons of using a screening assessment to identify older cancer patients who would benefit most from CGA. Robust evidence suggests CGA is highly beneficial in the older population at large. However, further research is required to quantify the impact these interventions have on cancer outcomes.

Based on the learning from the project:

- Cancer services providers and commissioners should engage elderly care specialists in both the planning and delivery of cancer services for older patients.
- Cancer services providers and commissioners should ensure that clinical pathways allow for all patients to receive an appropriate assessment prior to a treatment decision being made.
- Primary care should consider providing information relevant to the assessment at the time of referral. For example, details of comorbidities and medications.
- Cancer services providers and commissioners should consider integrating aspects of CGA with Holistic Needs Assessment
- Cancer services providers should ensure those who undertake the assessment have the training, knowledge and skills to also interpret and act on the findings of the assessment.
- Cancer services staff should ensure that the findings of the assessment are clearly documented, and communicated to all relevant stakeholders, including the multidisciplinary team.
- Researchers should continue to validate more streamlined assessment methods to ensure these approaches are sensitive enough to ensure that needs are identified and managed, and older people with less obvious needs are not disadvantaged.
- Researchers, service providers and commissioners should continue to gather evidence in relation to the impact that appropriate assessment and care planning has on cancer outcomes. Further health economic evaluation should also be undertaken.



**7.5** For assessment to have a positive impact on patient care, it is essential that the findings are acted upon. In some of the pilot sites this was not the case. A number of steps should be taken to enable this to happen:

- Service providers should ensure cancer services staff have the skills to manage issues commonly associated with ageing and that they know where to refer patients when these issues cannot be managed within their own professional capacity.
- Commissioners should ensure local services have the capacity to meet the needs of cancer patients in a time frame that is compatible with the cancer waiting times.
- Cancer services should consider setting up direct referral pathways to voluntary sector organisations, so that patients can be referred for practical support.
- Cancer services should provide information to patients about organisations, both local and national, that can provide support during cancer treatment and thereafter.
- Service providers and clinicians should consider undertaking audit and reflective practice exercises to evaluate the extent to which patient needs are being met.

**7.6** Furthermore, there is significant scope to explore the role of GPs in cancer care of all patients, in particular the potential of using the GP Cancer Care Review to support this. The pilot had already highlighted the potential for more detailed information to be provided on referral. The potential for addressing issues, such as medication problems, at the time of referral could also be explored. Some work, such as the Cancer Treatment Record Summary, has been undertaken to improve communication between cancer services and primary care. Learning from this project suggests that this improvement in communication may be of particular benefit to older patients.

**7.7** This project targeted the general older population of cancer patients. The profile of patients included in the pilot suggests that older people from certain equality groups may be under-represented. Further targeted service development is required to reduce further inequalities within the older population. This work should focus on the specific needs of patients with rarer cancers; dementia; mental health problems; and disabilities and patients from Black and Minority Ethnic (BME) and Lesbian, Gay, Bisexual and Transgender (LGBT) communities.

**7.8** Although this report highlights good practice that can be implemented at service level to improve cancer care for older people, it also recognises there are wider issues that must be addressed at a national level to support frontline service improvement. The key issues are:

- There are national shortages within the elderly care workforce that may present a barrier to some cancer services providing the highest quality care to their older patients.
- There is a need for more clinical trial evidence and clinical guidelines to support the treatment of older cancer patients.
- Skills relevant to the specific needs of older people with cancer are not routinely embedded in training provided to the cancer workforce, and there is a shortage of accredited geriatric oncology training courses in the UK.



**7.9** The key messages from this report are relevant to anyone who has an interest in improving cancer care for older people, including; providers of cancer services, clinicians, patients, voluntary sector providers, community and social services. The key messages are:

- **Act now.** Our population is ageing and as cancer is predominantly a disease of older age, so the number of older people with a diagnosis of cancer is set to increase. Challenges cancer services currently face when treating our older population must be addressed now if services are to be sustainable in the future and able to meet our aspiration of saving 5000 lives a year by 2014/2015.
- **We can't afford not to.** The time invested in undertaking appropriate assessment and follow up is time well spent. Not only does assessment inform the clinical management of patients, it often leads to interventions that are widely accepted to be cost saving (e.g. falls prevention, management of polypharmacy, early identification and management of comorbidities).
- **No assessment. No decision.** A truly informed treatment decision should be based on an objective assessment. Treatment recommendations should never be made on age based assumptions – this may result in age discriminatory practice.
- **Effective multidisciplinary and multiagency working is essential.** Many older people have additional needs, which must be managed with their cancer. Services should maximise opportunities for multidisciplinary working in order to provide high quality comprehensive care. This includes forming strong links with the voluntary sector, who are well placed to deliver support services in the community.
- **Design services with older people in mind.** It is vital that cancer services are designed to meet the needs of those who use them. The majority of people who use cancer services are older people. Service provision that disadvantages those with needs commonly associated with ageing may be an act of indirect age discrimination. Services designed for those with the most complex needs potentially benefit everyone.

**7.10** The pilots demonstrate there are a number of achievable evidence based steps that can be taken, which have a tangible impact on the quality of cancer care. Ensuring we get the basics of care right creates a platform to enable older people to access the best possible cancer treatment. Due to the importance of multiple agency working, commissioners are ideally placed to support the development of services that enable front line staff to deliver the highest standards of cancer care to all patients, irrespective of age.

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