# Report

**Title:**

# Older People's Pilots
## North East London Cancer Network

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**Date:** 12th December 2012

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# Executive summary

From 2011-12, nursing and medical staff from across the North East London Cancer Network piloted a new way of working with older cancer patients.  Specially trained clinical nurse specialists conducted a frailty assessment on people aged 70+ years with a new diagnosis of breast or colorectal cancer recruited to the project (n=90).  This included gathering information on living situation, including caring responsibilities, and screening for problems related to comorbidities, activity levels, independence in daily living, cognition, nutrition and mood. The aim of the assessment was to inform treatment decision-making, referrals to local specialists e.g. care of the elderly, to other services and the provision of practical support.  Patients assessed as needing help with practical support during their treatment journey were offered taxi services to attend their hospital appointments and/or a referral to Age UK for services to promote their independence at home during treatment.

Analysis of patient information, interviews with staff and observations of multidisciplinary meetings were used to analyse the extent to which original project objectives were achieved.  The analysis showed that some clinical nurse specialists successfully integrated frailty assessments into their role with older patients, but assessment time was lengthy for complex patients and this had an impact on nursing workload, as did making and overseeing referrals.  Staff reported that patients that have been referred for Age UK and taxi services to hospital appointments have benefitted significantly from the services provided. Almost one third of patients made use of taxi services to get to hospital appointments. The social circumstances and indications of frailty in the patient sample suggest a relatively high level of need for additional referrals and support, but referrals to care of the elderly and for Age UK services were low. The results of the frailty assessment were not used to inform treatment decision-making. Medical and nursing staff identified a need for ongoing professional development on treating and caring for older patients with cancer, and said that the project had drawn useful attention to this client group. Project recommendations centre on continuing practical support services to older cancer patients, and improving integrated working between cancer services and care of the elderly.

# 1. Introduction

In 2011 the Department of Health and Macmillan Cancer Support, in partnership with Age UK, funded five NHS pilot sites in England to undertake service improvement projects focused on better assessment, practical support and treatment decision-making for older people with cancer.  This document reports on the pilot that took place across the North East London Cancer Network (NELCN) between August 2011 and September 2012.  It provides information requested by Macmillan Cancer Support from each of the pilot sites.

## National background

Cancer is largely a disease of older people.  One in eight people in the UK aged 65 years or over are living with cancer and this age group accounts for 63% of cancers diagnosed in the UK (Cancer Research UK, 2012, Maddams et al., 2009).  However UK survival rates for older people with cancer are among the worst in Europe and are actually decreasing for people aged 85+years (Moller et al., 2011).  While greater frailty, more comorbidities and later presentation may account for some of the poorer outcomes for older people, there is strong evidence that older patients may be offered less intensive treatment for cancer (All Party Parliamentary Group on Cancer (APPGC), 2009). In spite of clinician's perceptions to the contrary, chronological age can also be a key influence on cancer treatment decisions (Bailey et al., 2003, National Cancer Equality Initiative/Pharmaceutical Oncology Initiative, 2012, Ring, 2010).  In the absence of substantial research data on effective treatments for older people, clinician anxieties about treatment toxicity, side-effects and burden are probably an important constraining influence on the intensity of cancer treatment offered to older people (National Cancer Equality Initiative/Pharmaceutical Oncology Initiative, 2012).  More research on effective cancer treatments for older patients is needed.

However, there are a number of other factors that are also relevant to older people's outcomes from cancer treatment.  The assessment of older cancer patients has been criticised for being too narrow in focus, in spite of a recognition that for older people in particular, an assessment across wider domains may yield information that is highly relevant to decisions about the best treatment, about the best way to deliver that treatment, about improving patient fitness prior to treatment commencing and about how best to support the patient and their family through the treatment journey (All Party Parliamentary Group on Cancer (APPGC), 2009, Macmillan Cancer Support, 2012).  Older people and their families are also more likely to need social and practical support during and perhaps beyond the cancer treatment journey (Bailey et al., 2003, Bailey et al., 2004, Kennedy et al., 2011).  The Macmillan Older People's Pilots were funded in order to test new methods of assessment for older people with cancer and better ways to coordinate and deliver practical support during treatment.

## Local background

The five sites involved in the North East London Cancer Network project were:

> Barking, Havering and Redbridge University Hospitals NHS Trust (BHRT)
> Homerton University Hospital Foundation NHS Trust
> Newham University Hospital (Barts Health NHS Trust)
> Royal London Hospital/St Bartholomew's Hospital (Barts Health NHS Trust)
> Whipps Cross Hospital (Barts Health NHS Trust)

These five sites represented five individual NHS Trusts at the outset of the project, but three of the trusts merged in April 2012 to form Barts Health NHS Trust.

The local objectives for the service improvement were:

- to identify and test "easy to use" assessment tools which can be used by clinicians to assess an older person's fitness to undergo treatment.
- to assess the impact of facilitating practical support older people may need to enable them to access treatment.
- to identify and address the training needs of all professionals working with older people in order to promote age equality.

Patient recruitment took place between August 2011 and September 2012.  Delays in local R&D approval being granted meant that individual sites joining the project was staged. BHRT began recruiting patients in August 2011, Homerton in November 2011, Newham in January 2012, Whipps Cross in March 2012, and Barts and The London in April 2012.

Ethical approval was granted for the project from NRES Committee London – City Road and Hampstead, REC reference 11/HO721/10.

# 2. Methods

Ninety male or female patients aged 70 years and over at the participating NHS trusts with a new diagnosis of breast or colorectal cancer agreed to take part in the project. For each patient who agreed to take part, the medical and physical examinations had been carried out as usual by the breast or colorectal specialist attending to the patient throughout the diagnostic process. Once the diagnosis had been made, each patient's clinical nurse specialist (CNS)(from the cancer team) conducted an interview-based frailty assessment.  This included gathering information on their living situation including their caring responsibilities and administering the following assessment tools:

> Mini mental status exam (MMSE)(cognitive status)
> Barthel Index (independent function in daily living activities)
> Selected SAOP 2 questions (independent function in daily living activities)
> Mini nutritional assessment (nutrition)
> Geriatric depression score (GDS) (mood)
> ECOG Performance Status (activity levels)
> Charlson Comorbidity Index (comorbidities)

The assessment usually took place in an outpatient setting, although a small number of assessments were carried out in the patient's home (n=3) or by telephone.  Some assessments were conducted pre-operatively at an early stage in the treatment journey, while others were conducted post-operatively and in advance of or during a course of adjuvant treatment.   The aim of the assessments was to inform treatment decision-making, referrals to local specialists such as care of the elderly, to other services e.g. social services and the provision of practical support.  In June 2012 in response to CNS feedback the assessment was shortened through the removal of some demographic questions and the GDS.

Two types of practical support were available to patients.  The first was the provision of taxi services to attend hospital appointments. The second was services provided through their local Age UK service.  Once a referral for Age UK support had been made by the CNS, Age UK conducted their own assessment of the patient and then provided services to meet the needs identified.  Available Age UK services were targeted at providing appropriate support to encourage and promote the client's independence at home during treatment.  They were tailored to the individual and included escorting to appointments, shopping, gardening and befriending.

## Staff training

Project training focused on developing clinical nurse specialists (CNS) in their role in the project. Three 3 hour group training sessions were held between April and September 2011, and attended by a total of 18 nurse specialists.  These sessions focused on:

- Recruiting patients, data collection and research ethics

- The role of the CNS in the project

- Using the frailty assessment, interpreting the results and acting on them

- Making referrals for practical support

They included input from Jackie Bridges (chief investigator), Jennifer Layburn (NELCN Director), Mike Gill (care of the elderly consultant, medical director at Newham and Clinical Champion for the project), and Michelle Parker (Nurse Consultant for Older People at Newham).  Catherine Barton-Sweeney, the NHS Project Manager for the pilot, also developed written guidelines for the clinical nurse specialists as a supplement to the training sessions.

Initiating the projects at the individual sites also gave the opportunity for training the CNSs and other staff associated with the project in their respective roles.  These project initiation events were held at the individual trust sites between July 2011 and March 2013.

Project initiation included the following training:

- The protocol

- Recruiting patients

- The role of the CNS in the project

- Using the frailty assessment, interpreting the results and acting on them

- Making referrals for practical support

- Recording recruitment activity (consent date, decline date and reason)

# Monitoring progress and outcomes

The remainder of this document reports an analysis of patient data gathered through the project and an analysis of the extent to which the original project objectives were achieved. Patient data were gathered to describe the patient population recruited to the project, to assess the level of need for and use of specialist referrals and practical support, and to describe patient outcomes. Data gathered included patient demographic characteristics and social situation, details of diagnosis and treatment and outcomes (mortality, length of stay for surgery, readmissions following surgery). These data, including findings from the frailty assessment, were collected from patient records, multidisciplinary team records and clinician report. Patients were also invited to complete two quality of life questionnaires at the time of initial assessment, and at four and eight months following this: the EORTC QLQ-C30 and ELD-15. A descriptive analysis of clinical, demographic, social, frailty, and quality of life information has informed this report. Patient outcomes are due for follow-up by May 2013 and are not reported here. Taxi service use and Age UK referral information was provided by the service providers – data on taxi usage in outer London is missing for August and September 2012 so taxi service usage is potentially higher than the figures shown later. As part of the Southampton University evaluation that focused on identifying and explaining the extent to which the planned service improvement was implemented into practice , qualitative interviews and focus groups were also held with nursing and medical staff (n=26) involved in providing cancer treatment and support to this group of patients. Observations of some multidisciplinary meetings (n=5) also took place. A thematic analysis of these qualitative data has been used to inform the analysis presented here.

A separate audit of the characteristics and treatment information for all older patients in North East London with breast or colorectal cancer is being conducted and this will enable an assessment of the extent to which patients recruited to the project are representative of the older population in North East London with breast or colorectal cancer.

Details of planned further patient follow-up are provided later in the report on page 22.

# 3. Results

This section reports on the characteristics of patients involved in the project, on the specialist referrals made for further assessment and intervention and on the practical support services used.  It also reports on the use of the frailty assessment tool and staff training needs.

## Patient characteristics

Ninety patients were enrolled in the project, 61 (68% of 90) with breast cancer and 29 (32%) with colorectal cancer. The majority of patients were recruited at BHRT (n=50, 56% of 90), with other sites recruiting between 8 and 12 patients each.  Seventy-three patients were female (81% of 90) and 17 (19%) were male.  Age at diagnosis ranged from 69-99 years, with an average age of 78 years.

*Diagnosis*

Tables 1 and 2 illustrate the UICC staging of patients' cancers[1].

**Table 1: UICC staging and age for breast patients**

| Age | UICC stage | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | I | IIA | IIB | IIIA | IIIB | IV | missing | Total |
| 65-69 | 0 (0%) | 1 (6%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (2%) |
| 70-74 | 5 (42%) | 3 (19%) | 5 (50%) | 1 (50%) | 0 (0%) | 1 (33%) | 4 (25%) | 19 (31%) |
| 75-79 | 3 (25%) | 4 (25%) | 4 (40%) | 1 (50%) | 0 (0%) | 2 (67%) | 6 (38%) | 20 (33%) |
| 80-84 | 1 (8%) | 6 (38%) | 0 (0%) | 0 (0%) | 2 (100%) | 0 (0%) | 4 (25%) | 13 (21%) |
| 85-89 | 2 (17%) | 1 (6%) | 1 (10%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (6%) | 5 (8%) |
| 90-94 | 1 (8%) | 1 (6%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 2 (3%) |
| 95-99 | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (6%) | 1 (2%) |
| Total | 12 (100%) | 16 (100%) | 10 (100%) | 2 (100%) | 2 (100%) | 3 (100%) | 16 (100%) | 61 (100%) |

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[1] TNM staging available for each patient in September 2012 converted to UICC summary staging using UICC methodology (6th edition)SOBIN, L. & WITTEKIND, C. 2002. UICC (2002) TNM classification of malignant tumors. *New York: Wiley&Sons*.

**Table 2: UICC staging and age for colorectal patients**

| | UICC stage | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Age** | I | IIA | IIB | IIIA | IIIB | IIIC | IV | missing | Total |
| 70-74 | 0 (0%) | 3 (30%) | 1 (50%) | 0 (0%) | 1 (17%) | 1 (25%) | 1 (100%) | 1 (33%) | 8 (28%) |
| 75-79 | 0 (0%) | 3 (30%) | 1 (50%) | 1 (100%) | 2 (33%) | 0 (0%) | 0 (0%) | 2 (67%) | 9 (31%) |
| 80-84 | 1 (50%) | 2 (20%) | 0 (0%) | 0 (0%) | 1 (17%) | 1 (25%) | 0 (0%) | 0 (0%) | 5 (17%) |
| 85-89 | 0 (0%) | 2 (20%) | 0 (0%) | 0 (0%) | 1 (17%) | 2 (50%) | 0 (0%) | 0 (0%) | 5 (17%) |
| 90-94 | 1 (50%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (17%) | 0 (0%) | 0 (0%) | 0 (0%) | 2 (7%) |
| Total | 2 (100%) | 10 (100%) | 2 (100%) | 1 (100%) | 6 (100%) | 4 (100%) | 1 (100%) | 3 (100%) | 29 (100%) |

*Treatment given*

Eighty-six percent of patients (69 out of 80) were given treatment with a curative intent, while the remaining patients were classified as palliative.

Patients with breast cancer: 49 had surgery (out of 57 for whom treatment information was available); 1 had neoadjuvant chemotherapy and radiotherapy; 3 had chemotherapy and radiotherapy after surgery; 5 had chemotherapy after surgery and no radiotherapy (1 of these received hormone treatment as well); 6 had radiotherapy as the sole treatment after surgery; 17 had radiotherapy and hormone therapy in addition to surgery; 10 had hormone therapy in addition to surgery. Two breast cancer patients had radiotherapy and hormone therapy but no surgery, and four had hormone therapy as the sole treatment.

Patients with colorectal cancer: 23 had surgery (out of 28 for whom treatment information was available); 5 had neoadjuvant chemotherapy and radiotherapy; 4 had chemotherapy following surgery. In addition, two colorectal patients had palliative chemotherapy. No other colorectal patients had radiotherapy.

Three colorectal and two breast patients did not take up the treatment recommended by the multidisciplinary team. Reasons for this are displayed in table 35 (Appendix 1).

*Demographic information*

Eighty-nine percent (79 out of 89 patients for whom these data were available) of patients classified their ethnicity as "White", 6% (5 out of 89) as "Asian/Asian British", 4% (4 out of 89) as "Black/African/Caribbean" and 1% (1 out of 89) as "Other". Early in the project, nurses reported difficulties recruiting people from ethnic groups other than white British. In spite of the availability of advocates to help with translation to aid recruitment, language was cited as a barrier. Other barriers cited included a desire for privacy and the existence of support through the extended family network.

Index of Multiple Deprivation scores were calculated from patient postcodes and are shown in Table 3, with IMD1 indicating most deprived and IMD5 indicating least deprived.

**Table 3: Index of Multiple Deprivation Scores**

| | IMD1 | IMD2 | IMD3 | IMD4 | IMD5 |
|---|---|---|---|---|---|
| Number | 24 | 18 | 13 | 19 | 10 |
| Proportion | 29% | 21% | 15% | 23% | 12% |

*Social circumstances*

Patients' social circumstances varied, although none were resident in care homes. Forty-eight percent (42 out of 88) lived alone, suggesting a higher need for external support, while the remainder of patients lived with a partner, spouse, family or friend. Most patients (84%, n=76 out of 90) did not report any caring responsibilities at home. Eleven percent (10 out of 90) reported caring responsibilities of 50 or more hours per week, 1% (n=1) had 20-49 hours of caring responsibilities per week and 3% (n=3) had between 1-19 hours per week.

*Frailty information*

The administration of the frailty assessment showed that 57% (46 out of 81) scored 100 on the Barthel Index, suggesting that they were fully independent in activities of daily living relating to personal care such as mobility, dressing, grooming, and continence. Twenty percent had mobility problems (n=17 out of 86), 20% needed help with climbing stairs or could not manage stairs (n=17 out of 87), 16% needed help with transfers (n=14 out of 89), 14% with dressing (n=13 out of 89) and 10% with bathing (n=9 out of 89). Eight percent of patients reported continence problems with their bowels (7 out of 89) and 7% with their bladder (6 out of 88).

In a separate assessment (SAOP), 40% (34 out of 84) reported that they had tripped or fallen in the last year, 32% (27 out of 85) needed help with shopping or could not go shopping, and 55% (56 out of 86) were not able to drive or had never driven.

Fifty-two percent (22 out of 42) patients were identified as being malnourished or at risk of malnutrition. Twenty five percent (5 out of 20) of colorectal patients were identified as being malnourished, and 40% (8 out of 20) as at risk of malnutrition.

Fifteen percent (10 out of 66) of patients scored under 25 on the MMSE, indicating that referral for further assessment was merited. Prevalence was particularly high in the group of colorectal patients (27%, 7 out of 26).

Twenty percent (10 out of 49) scored sufficiently highly on the Geriatric Depression Score to merit referral for further assessment. Prevalence was particularly high in breast patients (29%, 7 out of 24).

Fifty percent (45 out of 90) of patients had no comorbidities reported, although the Charlson Index used does not comprehensively list all diagnoses. Colorectal patients (66%, 19 out of 29) appeared more likely than breast patients (43%, 26 out of 61) to have one or more comorbidities. Comorbidities identified included diabetes (n=18), secondary malignancy (n=12), COPD (n=10), peripheral vascular disease (n=7) and liver disease (n=7). Four patients had hemiplegia and two patients were identified as having an existing diagnosis of dementia.

*Quality of Life*

Twenty patients with breast cancer and 20 with colorectal cancer completed baseline QLQ-C30 questionnaires. These reflected that global health status quality of life (GHSQOL) was much lower in patients with breast cancer (mean 41.25 (out of 100), SD 29.18) than with colorectal cancer (mean 67.08, SD 23.18). Reported GHSQOL did not decrease with increased age, appeared to increase if patients were widowed or lived alone, and decreased for people living in the most deprived areas. Reported symptoms included fatigue (22.5% of patients scoring overall on relevant items equivalent to "quite a bit" and "very much"), pain(15%) and nausea/vomiting (7.5%). Other reported symptoms included dyspnoea (28% of patients reporting "quite a bit" or "very much"), appetite loss (28%), insomnia (18%), pain (17.5%), constipation (15%), and diarrhoea (15%). There was no difference between cancer types in prevalence of diarrhoea or constipation. Fifteen percent of patients reported financial difficulties ("quite a bit" or "very much") associated with their physical condition or medical treatment.

Supplementary data on patient characteristics can be found in Appendix 1.

# Referrals to care of the elderly

In spite of assessment findings (see patient characteristics) that merited referral to care of the elderly services for more comprehensive assessment and potential intervention, referral rates were low (8%, 7 out of 88). One nurse specialist routinely referred her project patients to care of the elderly (n=4) and nurses at another trust reported that relationships with care of the elderly were excellent, although they did not refer any of their project patients. Patients from two trusts (BHR and Homerton) were referred to care of the elderly, with no care of the elderly referrals reported from the other three trusts. Relationships between cancer services and care of the elderly were reported to be variable in some trusts – at an early focus group, some nurse specialists reported that they did not know who their local care of the elderly physicians were. When asked about their role with older cancer patients generally (rather than with project patients) care of the elderly physicians reflected that their surgical and oncology colleagues did not always understand what the

specialty had to offer. They reported typically being involved when patients developed problems such as post-operative delirium in spite of strong evidence (and emerging models of care in other trusts) that earlier involvement (i.e. pre-operatively) could optimise patient fitness and aid with developing an individualised pathway.

Project patients referred included the three patients with the highest Charlson comorbidity score (11, 14 and 16) and four patients with low MMSE scores (see Table 4).

**Table 4: Assessment findings for patients referred to care of the elderly**

|  | Tumour type | Lives with others | Barthel Index score[2] | Charlson score[3] | MMSE score[4] | Nutrition score[5] | GDS[6] |
|---|---|---|---|---|---|---|---|
| 1 | Breast | Yes | 100 | 1 | Missing | 13 | 0 |
| 2 | Breast | No | 95 | 2 | 17 | 12 | 4 |
| 3 | Breast | No | 100 | 2 | Missing | 14 | 2 |
| 4 | Colorectal | Yes | 90 | 11 | 22 | 9 | 4 |
| 5 | Colorectal | Yes | 100 | 16 | 23 | 5 | 0 |
| 6 | Colorectal | Yes | 90 | 6 | 22 | 14 | 1 |
| 7 | Colorectal | Yes | 65 | 14 | Missing | 8 | Missing |

# Practical support

*Age UK*

Sixteen percent of patients (14 out of 90) were referred to Age UK. Seven patients were referred to Age UK Redbridge, five to Age UK East London and two to Age UK Waltham Forest. Neither MMSE score or whether or not an individual lived alone appears related to whether or not an Age UK referral was made.

Of the patients referred, three refused Age UK's offer of services, one patient had not yet begun services at the time of data collection and Age UK was unable to provide the services needed to one of the clients referred. Services were therefore provided to 10% of project patients. On referral, Age UK staff conducted their own assessment of patient need to determine what services were required. Services provided included shopping, housework, bathing help, accompaniment with hospital visits, liaison services to sort out, for example, washing machine being plumbed in and befriending (daily phone calls providing an opportunity for a chat, but also for early intervention in the event of problems and liaison with health/social care professionals if needed).

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[2] Barthel scores 0-100 with 100 reflecting full independence in activities of daily living

[3] Charlson comorbidity index scores 0-37 with 0 reflecting that patient has none of the comorbidities listed. It is a weighted score (with some conditions scoring more than one) so scores above 1 do not necessarily reflect the actual number of comorbidities.

[4] Mini mental status exam (MMSE) score below 25 merits referral for further assessment

[5] Mini nutritional assessment score 0-7 indicates patient is malnourished, 8-11 indicates risk of malnutrition, 12-14 indicates normal nutritional status

[6] Geriatric depression score (GDS) score of 5 or more merits referral for further assessment

Age UK Redbridge reported that project patients liked to know the service is there, even if they only used it for a short time.  Age UK Redbridge reported that patients liked the quality of the service, thought that staff were well trained, liked that they had the same person every week, were treated with respect and knew that their choices took priority.  Nurses interviewed supported this positive evaluation, stating that Age UK provided important support to patients referred and that Age UK's tailored approach was well received by patients.  A number of nurse specialists have gone on to refer other clients to Age UK and say that the project has raised their awareness of the services that Age UK provides.

In spite of a generally positive evaluation by staff for Age UK services, not all Age UK agencies offered the same services.  One client (mentioned above) was referred to Age UK for support with gardening and window cleaning but was told that these services were not provided - even though neighbouring Age UKs provide them. It transpired that it was not possible to provide the service through a neighbouring Age UK without the agreement of the CEOs of both Age UK agencies involved.  Subsequently the client went on to pay for her own services and these costs were later reimbursed directly from the project budget.

*Taxi services*

Thirty-one percent (28 out of 90 patients) used the taxi services to attend hospital appointments.  In total, 264 taxi journeys were made.  This is an average of 9 journeys per patient who used the taxi services, but the frequency of taxi use between individual patients varied widely, between 2 journeys for several patients and 63 journeys for one patient (mode=2, median=3.5).  In the early weeks of the project, the taxi services were reported to be problematic (sometimes turning up late or not at all).  Arranging and overseeing referrals placed additional strain on already high CNS workloads.  Early problems with the taxi services created high anxiety for patients and the supervising nurses, and an absence of trust-based clerical support to the project meant inadequate back-up if things went wrong.   These problems were later resolved by centralising taxi bookings at the cancer network office.  There were reports from staff of a high quality service from some taxi drivers, for example, coming up to the ward to pick up a patient on discharge, carrying their bag for them, and carrying their bag into the house on arrival home.  Overall, in spite of the early difficulties, taxi services were seen by nurses and doctors interviewed as very beneficial in light of other less appropriate transport options for this patient group.  A number of staff interviewees commented on the poor quality of transport options for cancer patients living in outer London who were required to travel to central London for treatment.

# Use of frailty assessment tool

The assessments were viewed by some nurses and their medical colleagues as taking up a great deal of nurses' time on top of already heavy workloads.  Generally nurses who had carried out a number of assessments found that they became quicker at doing them, and nurses who tried the more concise assessment form introduced in June 2012 reported that it took less time.  Nurses reported that the length of time the assessment took was dependent on patient characteristics.  Only 31 of the 90 assessments completed included a record of the time taken to complete them.  Of the 13 "old" assessments reported, the average assessment time was 39 minutes, the shortest time was 20 minutes and the longest was 75 minutes.  Of the 18 "new" assessments reported, the average assessment time was also 39 minutes, the shortest time was 15 minutes and the longest assessment time was 75 minutes.  Concerns about long assessment times were reported to delay the participation of some nurses in the project and one nurse commented that the length of the assessment had been over-emphasised during the training.

Finding the right time in the patient's diagnosis and treatment journey to do the assessments was also seen as problematic, especially when patients had to make an extra visit to the hospital in order to have the assessment.

Some nurses also found some aspects of the assessment awkward to conduct, and this included questions that evaluated cognition or mood, or asked about sexuality.  Generally, nurses reported that over time they developed strategies to introduce these aspects of the assessment in a comfortable way.

Staff reported that the results from the frailty assessment were not used to evaluate patients' fitness for cancer treatment.  When questioned about it, staff reported that the assessment results were not available in time for the team discussion in which the initial treatment plan was formulated.  Existing national cancer targets created a time pressure which meant that initial treatment decisions were made before patients had been more holistically assessed.  Staff also reported that factors considered relevant to treatment decisions, such as presence of comorbidities, were part of existing medical assessments and so did not need to be repeated in the nurse-led assessment.  Most of the nurses interviewed reported that the frailty assessment was a structured version of what they already assessed, or duplicated existing assessments, but a small number of people saw it as providing a more in-depth assessment than was routine.  In general, staff reflected that the frailty assessment findings were not shared with colleagues in the multidisciplinary team.

Consideration of wider factors such as social situation, cognitive or nutritional status was not always seen by staff interviewed as relevant to multidisciplinary team discussions about what treatment to recommend to a patient and this focus on clinical factors was confirmed during observations of multidisciplinary meetings. In meetings observed (described as typical by staff) clinical information was reviewed and treatment plans were formulated for between 9 and 49 patients per meeting (average of 30 patients per meeting). For each patient case, there was systematic use of radiological, histopathological and other information directly related to making the cancer diagnosis. Comorbidities were also considered in making the treatment plan for some patients. Patient fitness for treatment was discussed if the information was known. However, in the meetings observed, the introduction and use of other patient information was limited. Staff interviewed observed that existing multidisciplinary meetings lacked the capacity to extend the scope of discussions to using a wider range of information to inform the treatment plan.

Some medical staff reflected a view that social factors were very much in the domain of nursing and clearly had high levels of trust that they would be involved if the nurse judged this to be important. Other doctors reflected a more proactive role in seeking out the information either directly from patients or inviting it at multidisciplinary team meetings. This perception of the role of the nurse and the lead role that nurses took in implementing the intervention meant that other team members had very little involvement in delivering the intervention, in spite of high support for the project from senior clinicians across the network.

## Staff training needs

The difference in recruitment rates between individual nurse specialists reflected a range of influencing factors, but one of these was a difference in perceptions as to the value of the project for older patients. Some nurse specialists did not recruit any patients to the project in spite of repeated efforts to engage the nurses and address the concerns they raised. A small number of clinical nurse specialists were heavily involved in the project and recruited high numbers of patients, while others were keen to participate but had a range of difficulties in recruiting the target number of patients. Some nurses commented that needing to recruit patients and getting them to sign consent forms was hard work and took up valuable time. The nurses who became involved generally saw the half day training on delivering the intervention as sufficient, reflected that the project drew on skills they largely already held but also found that experience helped them to develop skills in the areas that they were originally less familiar with, for instance, cognitive assessment. Some individuals then trained their nurse specialist colleagues themselves and this also worked well in helping people feel they were adequately skilled to make the assessment and act on the results. However, less is known about the group of nurses who did not engage in the project and if their lesser enthusiasm about the project reflected a need for more intensive training.

While nurses who participated felt adequately skilled in carrying out the assessment and acting on the results, there was some indication that they would have benefitted from educational input over time. For instance, some assessment tools were consistently not filled out correctly, and the characteristics of the patient group suggest that more referrals to care of the elderly and practical support services were merited (although some nurses reported that patients did not want to be referred for practical support). Nurses were offered regular action learning sets at the outset of the project but they did not think it would be feasible to attend them, especially if they were held off-site.

Other staff groups did not receive any training during the project, although some medical staff identified in the early interviews that they would appreciate learning more about how to improve their treatment of older cancer patients. All of the care of the elderly physicians interviewed expressed a willingness to help with staff education, and a desire to keep abreast of new developments in cancer treatment and care.

Interviewees reported that project had drawn useful attention to and promoted proactive discussions about the needs of this client group. For instance, one clinical nurse commented "I think the whole thing has highlighted the issue, and makes us think more carefully about how we treat people who are over 70 and whether we do treat them any differently".

## 4. Summary of key findings to date

Some clinical nurse specialists have successfully integrated frailty assessments into their role with older patients, but assessment time can be lengthy for complex patients and this had an impact on nursing workload, as did making and overseeing referrals.

Staff report that patients that have been referred for Age UK and taxi services to hospital appointments have benefitted significantly from the services provided. Almost one third of patients made use of taxi services to get to hospital appointments.

The social circumstances and indications of frailty in the patient sample suggest a relatively high level of need for additional referrals and support, but referrals to care of the elderly and for Age UK services have been low.

The results of the frailty assessment have not been used to inform treatment decision-making.

Medical and nursing staff identified a need for ongoing professional development on treating and caring for older patients with cancer.

# 5. Discussion

This pilot has illustrated that, given the right support, it is feasible for cancer clinical nurse specialists to take on a role in screening older patients for practical support needs and identifying patient issues that require specialist evaluation. Taking on this role is dependent on adequate staffing levels, training and ongoing mentoring, and help with practicalities such as scheduling assessment appointments, and clerical support to make and oversee practical support referrals.

The high uptake of taxi services and the reported benefits to patients of Age UK services suggest that older patients can benefit from the provision of these services in terms of better patient experiences but also, in some cases, being able to take up the recommended cancer treatment (see Appendix 2). More robust evidence is needed to precisely establish the impact and to identify which older patients gain the greatest benefit. Early teething problems, with taxi services in particular, have highlighted the importance of assuring service quality and consistency at the outset.

However, the pilot has also illustrated that the use of assessment findings to prompt improvements in patient fitness and inform treatment decision-making is dependent on a number of factors outside of the clinical nurse specialist role. Firstly, the frailty assessment was conducted too late to inform initial treatment recommendations and multidisciplinary meetings in their current format do not have the capacity to use the resulting information. Secondly, care of the elderly specialists were not routinely involved in assessing frail older patients and optimising their fitness for cancer treatment, in spite of frailty assessment findings that appeared to merit this.

The findings from this analysis are limited by patient recruitment being lower than expected, by the extent of missing patient data in some domains and by the lack of information at the time of writing on how representative this patient cohort is of the wider older patient population with breast or colorectal cancer in North East London. However the project has clearly had value in drawing attention to the needs of older patients with cancer in North East London, and in highlighting some of the issues that need tackling to make sustainable improvements.

# 6. Conclusions and recommendations

Project findings suggest a value for some older cancer patients in providing them with practical support during their cancer treatment journey, but more evidence is needed to precisely establish the impact and to identify which older patients gain the greatest benefit. Recommendations based on project findings are:

- Review the quality of transport for older cancer patients and its relationship to how local cancer services are provided, especially to patients in outer London who need access to oncology services in central London.
- Continue to provide Age UK services and taxi services to older patients during their cancer treatment, and provide clerical support to enable this to happen.
- Ensure quality and consistency of practical support services offered, regardless of locality, either through contracting process with individual agencies, or the appointment of a lead agency to coordinate referrals across the patch.

Other ideas raised by staff about practical and social support are:

- Review and improve the involvement of hospital-based and community social services in optimising practical support to older cancer patients.
- Compile and distribute a directory of local practical support services for use by practitioners, patients and their families.

The low referral rate to care of the elderly meant that it was not possible to evaluate the impact of this specialist evaluation and intervention. However the strong evidence base for comprehensive geriatric assessment and the views of staff interviewed have led to the following recommendations regarding care of the elderly input:

- Review and improve where needed the input of care of the elderly specialists into cancer services, including into multidisciplinary team meetings, and into staff training in cancer services. Negotiating associate status for care of the elderly specialists in the cancer multidisciplinary team (MDT) could be a good start here.
- Consider the introduction of comprehensive geriatric assessment (CGA), led by care of the elderly specialists, for all older cancer patients early enough in the treatment pathway to optimise fitness for treatment and to influence the cancer treatment and support plan.
- Review the role of surgeons and oncologists in improving the potential of early geriatric assessment and intervention to influence treatment decision-making and improve patient outcomes.

The nature of integrating care of the elderly input into decisions about cancer treatment and support, in addition to resourcing implications, will dictate the role that the cancer nurse specialist takes in relation to frailty screening. If CGA for all older cancer patients is not achievable because of, for instance a shortage of care of the elderly physicians in the short to medium term, then project findings suggest that nurse specialists, with adequate training, support and capacity in terms of adequate staffing levels, could play a useful part in administering a concise screening tool to determine the need for CGA by a care of the elderly specialist.

- Align the nurse specialist's role and function in screening and assessment with the role of care of the elderly specialists, and with existing assessments e.g. holistic needs assessment, single assessment process.
- Ensure that clinical nurse specialist staffing levels are sufficient to continue with screening role, to make and oversee referrals to practical support services and to provide adequate keyworker support to all older patients with cancer.
- Ensure adequate clerical support to clinical nurse specialists to enable them to properly arrange and oversee practical support.

Project findings have highlighted the educational needs of clinical nurse specialists but also suggest that there is scope to improve all staff knowledge about the contribution that care of the elderly and practical support services can make to improving outcomes for older cancer patients:

- Provide clinical nurse specialists with ongoing education and supervision from care of the elderly specialists to support their role with older patients.
- Ensure all members of the cancer multidisciplinary team are aware of the role and contribution of care of the elderly specialists.

- Ensure that all staff who can make referrals are aware of what practical support services are available and how to make a referral.

A number of other ideas emerged from staff involved in the project based on their experiences during the project or their views about how to improve older people's outcomes in other ways. These include:

- Appoint medical and nursing project champions from cancer and care of the elderly to lead the implementation of project recommendations.

- Consider the value of improved assessment, care of the elderly input and better practical support to other patient groups – to older patients with other cancers, to older patients with cancer admitted to hospital with another disease, to younger patients with cancer who have complex needs.

- Establish integrated clinics that include input from care of the elderly, social services, dietician, physiotherapy and occupational therapy.

- Provide more cancer treatment in people's local hospitals and/or people's own homes.

- Enable hospital-based prescribers to prescribe nutritional supplements, continence products and similar to avoid patients having to visit their GP for these prescriptions.

- Improve GP involvement in devising treatment and care plans for individual patients.

- Patient education campaign and/or buddying system with older cancer survivors to encourage earlier presentation, and provide reassurance to patients with a new cancer diagnosis about what cancer treatment involves and its likely impact.

Finally, while it is not known the extent to which project patients are representative of the wider older patient population in North East London (at the time of writing), the prevalence of some problems among project patients (e.g. malnutrition, cognitive impairment, low mood, history of falls) merits a closer look at these issues and the extent to which local services other than care of the elderly (e.g. dietetics, memory clinics, clinical psychology, falls clinics) are available to and used by older cancer patients.

# Limitations and challenges

A number of challenges limited the impact of the project.  The process of gaining NRES committee approval was very lengthy followed by delays in securing local R&D approval at individual trusts.  The initial NRES application was submitted in January 2011.  Delays in approving amendments requested plus a need to change project sponsor (because of the chief investigator's job move) meant that NRES approval was not granted until June 2011.  BHRT local R&D approval was obtained in July 2011 and data collection began there that month.  In contrast, Barts and The London approval was not granted until the end of January 2012, in spite of repeated interventions by the chief investigator and Cancer Network staff.  These delays were compounded by changes of personnel involved in providing approvals, changes in approval structures and having to provide the same information at multiple points in the system.

The project took place during a period of unprecedented intense structural reorganisation, including the merger of three project sites (hospitals) into one NHS Trust, the development of a provider network (London Cancer) and the transition of cancer networks into commissioning vehicles and strategic clinical networks.   These activities impacted negatively on the project and on the personnel involved in delivering the project.

Short staffing (of nurse specialists) delayed the start of the project for some groups (e.g. Newham breast, Whipps Cross colorectal) and halted the project for others (Newham colorectal).  Some nurses became so busy with the project that patients who had consented to take part in the project did not get a timely assessment because the nurse did not have time to do it.  The use of research nurses at a later stage of the project to help recruit and consent patients helped free up staff time, and in retrospect these posts should have been used earlier in the project.

There were some early problems with delivery of practical support services.  At BHRT, the project started before the nurse specialists were confident that local practical support services were in place. Taxi services to BHRT patients were not always on time, and this led to high anxiety for patients who sometimes missed their hospital appointment as a result.  These problems also highlighted a lack of clerical support to the nurse specialists who were unable to deal with problems of this kind as they arose if, for instance, they were in clinic at the time.  There were also early misunderstandings about what services Age UK should and should not be providing.

In spite of active efforts to involve a wide range of stakeholders in the project, not everyone who should have known about the project at a local trust level was included in communications about it. Many nurses interviewed complained that doctors not nurses had been consulted about the project even though it had the biggest implications for nurses. One nurse specialist complained that no one had told her local radiotherapy or chemotherapy department staff about the project.  In one of the trusts, a team of colorectal clinical nurse specialists were "discovered" some months into the project even though they could have been involved from the start.  Local care of the elderly teams expressed varying levels of commitment to the project, some very enthusiastic and others unsure as to the value of the intervention and/or concerned about the workload implications.  Some doctors interviewed said that the intervention lacked clarity and this meant that they were unsure of their role in the study, or felt this limited its value.  Earlier involvement and leadership at a local level may have addressed some of these issues.

Delays to starting the project meant that patient recruitment was low for the early months of the project but low rates of recruitment continued beyond the time all the sites were theoretically ready and able to engage with the project. Reasons for low recruitment included patients not wanting to take part (anecdotal evidence suggests that many did not think that they would need the extra help on offer), high nursing workload, lack of engagement by medical staff in helping to recruit patients, some nurses not wishing to bother patients about taking part in the project, and some nurses not feeling motivated to help with the project  - either because they felt they had not been involved in setting the project up or because of other concerns as to the value of the project.  Recruitment was improved by working with the principal investigators at each site, reducing the size of the assessment, using research nurses to help with recruiting and consenting patients, and reviewing site visits and project management support to the CNSs.

A reduction in the project manager's working hours affected aspects of the programme's development, for example, service improvement. The project manager left in September 2012 and this meant that data collection and entry were co-ordinated through other members of the team.

Issues of data completeness also featured in the project, with the assessment booklet often being used to gather data on the assessment and then not returned to for recording what services had been arranged or referrals made in addition to updating clinical information.  Systems should have been put in place to monitor and more proactively address gaps in the data throughout the project.

# Plans for further follow up and evaluation

The use of practical support services by project patients will continue to be monitored for as long as these services are provided. At four and eight months following diagnosis, patients are invited to repeat the two quality of life questionnaires: the EORTC QLQ-C30 and ELD-15. Twenty-eight day readmissions following surgery, and mortality at six months are also being monitored.

Two peer review publications based on the qualitative data are planned. These are likely to focus on the role of the clinical nurse specialist in cancer care for older people, and the work of multidisciplinary meetings in making treatment decisions about older people with cancer.

# Appendix 1: Tables

## Sample characteristics

**Table 5: Breakdown by hospital site and tumour**

| | | Hospital site | | | | | |
|---|---|---|---|---|---|---|---|
| | | BHRT | Homerton | Barts/Royal London | Newham | Whipps Cross | Total |
| Tumour site | Colorectal | 14 | 4 | 2 | 6 | 3 | 29 |
| | Breast | 36 | 5 | 10 | 5 | 5 | 61 |
| Total | | 50 | 9 | 12 | 11 | 8 | 90 |

**Table 6: Age at diagnosis**

| Age (years) | Number | Percentage |
|---|---|---|
| 65-69 | 1* | 1.1 |
| 70-74 | 27 | 30.0 |
| 75-79 | 29 | 32.2 |
| 80-84 | 18 | 20.0 |
| 85-89 | 10 | 11.1 |
| 90-94 | 4 | 4.4 |
| 95-99 | 1 | 1.1 |
| **Total** | **90** | **100** |

*Aged 70 at assessment

# Demographic characteristics

**Table 7: Ethnicity**

|  | Frequency | Percentage |
|---|---|---|
| White | 79 | 88.8 |
| Asian/Asian British | 5 | 5.6 |
| Black/African/Carribean | 4 | 4.5 |
| Other | 1 | 1.1 |
| Total | 89 | 100.0 |

1 missing

**Table 8: Religion**

|  | Frequency | Percentage |
|---|---|---|
| Christian | 35 | 87.5 |
| Buddhist | 1 | 2.5 |
| Jewish | 2 | 5.0 |
| No religion | 2 | 5.0 |
| Total | 40 | 100.0 |

50 missing

**Table 9: Sexual orientation**

|  | Frequency | Percentage |
|---|---|---|
| Heterosexual | 59 | 98.3 |
| Prefers not to say | 1 | 1.7 |
| Total | 60 | 100.0 |

30 missing

**Table 10: Employment status**

|  | Frequency | Percentage |
|---|---|---|
| Working | 2 | 2.9 |
| Unemployed | 2 | 2.9 |
| Retired | 63 | 92.6 |
| Homemaker | 1 | 1.5 |
| Total | 68 | 100.0 |

22 missing

**Table 11: Educational achievement**

|  | Frequency | Percentage |
|---|---|---|
| School only | 54 | 83.1 |
| College / university | 9 | 13.8 |
| Postgraduate studies | 2 | 3.1 |
| Total | 65 | 100.0 |

25 missing


**Table 12: Living arrangements**

|  | Frequency | Percentage |
|---|---|---|
| Lives with partner/spouse/family/friend | 46 | 52.2 |
| Living alone | 42 | 47.7 |
| Total | 88 | 100.0 |

2 missing


**Table 13: Marital status**

|  | Frequency | Percentage |
|---|---|---|
| Married | 25 | 39.7 |
| Divorced | 4 | 6.3 |
| Widowed | 30 | 47.6 |
| Single | 4 | 6.3 |
| Total | 63 | 100.0 |

27 missing

# Frailty characteristics

**Table 14: Independence in daily living (Barthel Index)**

| | Independence in Daily living TOTAL | | | | | | | | | | Total |
| | 50 | 60 | 65 | 70 | 75 | 80 | 85 | 90 | 95 | 100 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Colorectal Count | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 4 | 4 | 19 | 29 |
| % | 3.4% | .0% | 3.4% | .0% | .0% | .0% | .0% | 13.8% | 13.8% | 65.5% | 100.0% |
| Breast Count | 1 | 1 | 1 | 1 | 1 | 2 | 2 | 8 | 8 | 27 | 52 |
| % | 1.9% | 1.9% | 1.9% | 1.9% | 1.9% | 3.8% | 3.8% | 15.4% | 15.4% | 51.9% | 100.0% |
| Total | 2 | 1 | 2 | 1 | 1 | 2 | 2 | 12 | 12 | 46 | 81 |
| % | 2.5% | 1.2% | 2.5% | 1.2% | 1.2% | 2.5% | 2.5% | 14.8% | 14.8% | 56.8% | 100.0% |

9 missing

Score of 100=fully independent

**Table 15: Responses to Barthel Index**

| Domain | Response | Count of patients |
|---|---|---|
| FEEDING | Independent | 86 |
| | Need help | 2 |
| | Unable | 1 |
| BATHING | Independent | 80 |
| | Dependent | 9 |
| GROOMING | Independent | 84 |
| | Dependent | 4 |
| DRESSING | Independent | 76 |
| | Need help | 13 |
| | Unable | 0 |
| TOILET USE | Independent | 82 |
| | Need help | 5 |
| | Unable | 0 |
| TRANSFERS | Independent | 75 |
| | Minor help | 13 |
| | Major help | 1 |
| MOBILITY | Independent | 69 |
| | Walks with help | 13 |
| | Wheelchair | 2 |
| | Immobile | 2 |
| STAIRS | Independent | 70 |
| | Need help | 10 |
| | Unable | 7 |

**Table 16: Barthel Index responses about continence**

|  | Continent (count) | Occasional accidents (count) | Incontinent (count) |
|---|---|---|---|
| Bowels | 82 | 6 | 1 |
| Bladder | 82 | 5 | 1 |

**Table 17: Charlson comorbidity index score**

|  |  | Charlson comorbidity index score | | | | | | | | | | | | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 9 | 11 | 14 | 16 | Total |
| Colorectal Count | | 10 | 5 | 4 | 3 | 1 | 0 | 2 | 1 | 0 | 1 | 1 | 1 | 29 |
| % | | 34.5% | 17.2% | 13.8% | 10.3% | 3.4% | .0% | 6.9% | 3.4% | .0% | 3.4% | 3.4% | 3.4% | 100.0% |
| Breast Count | | 35 | 8 | 7 | 4 | 2 | 1 | 2 | 1 | 1 | 0 | 0 | 0 | 61 |
| % | | 57.4% | 13.1% | 11.5% | 6.6% | 3.3% | 1.6% | 3.3% | 1.6% | 1.6% | .0% | .0% | .0% | 100.0% |
| Total Count | | 45 | 13 | 11 | 7 | 3 | 1 | 4 | 2 | 1 | 1 | 1 | 1 | 90 |
| % | | 50% | 14.4% | 12.2% | 7.8% | 3.3% | 1.1% | 4.4% | 2.2% | 1.1% | 1.1% | 1.1% | 1.1% | 100.0% |

NB Score shown is a weighted score not a count of comorbidities. 0=no comorbidities

**Table 18: Activity levels**

|  |  | Activity levels TOTAL: | | | | | Total |
|---|---|---|---|---|---|---|---|
|  |  | 1 | 2 | 3 | 4 | 5 | Total |
| Colorectal | Count | 12 | 11 | 1 | 2 | 0 | 26 |
|  | % within Tumour site | 46.2% | 42.3% | 3.8% | 7.7% | .0% | 100.0% |
| Breast | Count | 17 | 10 | 4 | 3 | 1 | 35 |
|  | % within Tumour site | 48.6% | 28.6% | 11.4% | 8.6% | 2.9% | 100.0% |
| Total | Count | 29 | 21 | 5 | 5 | 1 | 61 |
|  | % within Tumour site | 47.5% | 34.4% | 8.2% | 8.2% | 1.6% | 100.0% |

29 missing
1= I am fully active and more or less as I was before my illness; 5= I am in bed or in a chair all the time and need a lot of looking after

**Table 19: Grouped MMSE (cognition) scores**

| | | MMSE score | | |
| --- | --- | --- | --- | --- |
| | | <25 | 25-30 | Total |
| Colorectal | Count | 7 | 19 | 26 |
| | % within Tumour site | 26.9% | 73.1% | 100.0% |
| Breast | Count | 3 | 37 | 40 |
| | % within Tumour site | 7.5% | 92.5% | 100.0% |
| Total | Count | 10 | 56 | 66 |
| | % within Tumour site | 15.2% | 84.8% | 100.0% |

24 missing
A score of <25 indicates further patient assessment is needed, as cognitive impairment may be present

**Table 20: Answer to "Have you tripped or fallen in the last year?"**

| | | Have you tripped/fallen in the past year? | | |
| --- | --- | --- | --- | --- |
| | | Yes | No | Total |
| Colorectal | Count | 10 | 18 | 28 |
| | % within Tumour site | 35.7% | 64.3% | 100.0% |
| Breast | Count | 24 | 32 | 56 |
| | % within Tumour site | 42.9% | 57.1% | 100.0% |
| Total | Count | 34 | 50 | 84 |
| | % within Tumour site | 40.5% | 59.5% | 100.0% |

6 missing

**Table 21: Answer to "Are you able to drive?"**

| | | Are you able to drive? | | | |
| --- | --- | --- | --- | --- | --- |
| | | Yes | Have never driven | No | Total |
| Colorectal | Count | 13 | 5 | 11 | 29 |
| | % within Tumour site | 44.8% | 17.2% | 37.9% | 100.0% |
| Breast | Count | 17 | 14 | 26 | 57 |
| | % within Tumour site | 29.8% | 24.6% | 45.6% | 100.0% |
| Total | Count | 30 | 19 | 37 | 86 |
| | % within Tumour site | 34.9% | 22.1% | 43.0% | 100.0% |

4 missing

**Table 22: Answer to "Are you able to prepare your own meals?"**

| | | Are you able to prepare own meals? | | | |
| | | Yes | Yes with help | No | Total |
|---|---|---|---|---|---|
| Colorectal | Count | 24 | 1 | 4 | 29 |
| | % within Tumour site | 82.8% | 3.4% | 13.8% | 100.0% |
| Breast | Count | 48 | 5 | 3 | 56 |
| | % within Tumour site | 85.7% | 8.9% | 5.4% | 100.0% |
| Total | Count | 72 | 6 | 7 | 85 |
| | % within Tumour site | 84.7% | 7.1% | 8.2% | 100.0% |

5 missing

**Table 23: Answer to "Are you able to go shopping?"**

| | | Are you able to go shopping? | | | |
| | | Yes | Yes with help | No | Total |
|---|---|---|---|---|---|
| Colorectal | Count | 24 | 3 | 2 | 29 |
| | % within Tumour site | 82.8% | 10.3% | 6.9% | 100.0% |
| Breast | Count | 34 | 15 | 7 | 56 |
| | % within Tumour site | 60.7% | 26.8% | 12.5% | 100.0% |
| Total | Count | 58 | 18 | 9 | 85 |
| | % within Tumour site | 68.2% | 21.2% | 10.6% | 100.0% |

5 missing

**Table 24: Answer to "Can you take care of your finances?"**

| | | Can you take care of your finances? | | | |
| | | Yes | Yes with help | No | Total |
|---|---|---|---|---|---|
| Colorectal | Count | 23 | 3 | 3 | 29 |
| | % within Tumour site | 79.3% | 10.3% | 10.3% | 100.0% |
| Breast | Count | 47 | 9 | 1 | 57 |
| | % within Tumour site | 82.5% | 15.8% | 1.8% | 100.0% |
| Total | Count | 70 | 12 | 4 | 86 |
| | % within Tumour site | 81.4% | 14.0% | 4.7% | 100.0% |

4 missing

**Table 25: Answer to "Can you use the telephone?"**

| | | Can you use the telephone? | | |
|---|---|---|---|---|
| | | Yes | No | Total |
| Colorectal | Count | 27 | 1 | 28 |
| | % within Tumour site | 96.4% | 3.6% | 100.0% |
| Breast | Count | 56 | 1 | 57 |
| | % within Tumour site | 98.2% | 1.8% | 100.0% |
| Total | Count | 83 | 2 | 85 |
| | % within Tumour site | 97.6% | 2.4% | 100.0% |

5 missing

**Table 26: Answer to "Do you remember to take your medications?"**

| | | Do you remember to take your medications? | | |
|---|---|---|---|---|
| | | Yes | No | Total |
| Colorectal | Count | 27 | 1 | 28 |
| | % within Tumour site | 96.4% | 3.6% | 100.0% |
| Breast | Count | 55 | 2 | 57 |
| | % within Tumour site | 96.5% | 3.5% | 100.0% |
| Total | Count | 82 | 3 | 85 |
| | % within Tumour site | 96.5% | 3.5% | 100.0% |

5 missing

**Table 27: Body mass index**

| | | BMI | | | | |
|---|---|---|---|---|---|---|
| | | <18.5 Underweight | 18.5-24.5 Healthy weight | 25-29.5 Overweight | 30+ Obese | Total |
| Colorectal | Count | 1 | 11 | 7 | 3 | 22 |
| | % within Tumour site | 4.5% | 50.0% | 31.8% | 13.6% | 100.0% |
| Breast | Count | 0 | 7 | 10 | 10 | 27 |
| | % within Tumour site | .0% | 25.9% | 37.0% | 37.0% | 100.0% |
| Total | Count | 1 | 18 | 17 | 13 | 49 |
| | % within Tumour site | 2.0% | 36.7% | 34.7% | 26.5% | 100.0% |

41 missing

**Table 28: Mini Nutritional Status score**

| | | Mini Nutritional Assessment banding | | | |
|---|---|---|---|---|---|
| | | Malnourished (<8) | At risk of malnutrition (8-11) | Normal nutritional status (12-14) | Total |
| Colorectal | Count | 5 | 8 | 7 | 20 |
| | % within Tumour site | 25.0% | 40.0% | 35.0% | 100.0% |
| Breast | Count | 2 | 8 | 12 | 22 |
| | % within Tumour site | 9.1% | 36.4% | 54.5% | 100.0% |
| Total | Count | 7 | 16 | 19 | 42 |
| | % within Tumour site | 16.7% | 38.1% | 45.2% | 100.0% |

48 missing

**Table 29: Geriatric Depression Score**

| | | Geriatric Depression Score Bands | | | |
|---|---|---|---|---|---|
| | | No indication of depression (0-5) | Suggestive of depression (6-10) | Strong indication of depression (10+) | Total |
| Colorectal | Count | 22 | 2 | 1 | 25 |
| | % within Tumour site | 88.0% | 8.0% | 4.0% | 100.0% |
| Breast | Count | 17 | 7 | 0 | 24 |
| | % within Tumour site | 70.8% | 29.2% | .0% | 100.0% |
| Total | Count | 39 | 9 | 1 | 49 |
| | % within Tumour site | 79.6% | 18.4% | 2.0% | 100.0% |

41 missing

# Assessment and treatment

**Table 30: Date of diagnosis**

| Month | Breast | Colorectal |
|---|---|---|
| June 2011 | 1 | 0 |
| July 2011 | 1 | 1 |
| August 2011 | 2 | 1 |
| Sept 2011 | 1 | 1 |
| Oct 2011 | 6 | 2 |
| Nov 2011 | 4 | 3 |
| Dec 2011 | 5 | 1 |
| Jan 2012 | 3 | 3 |
| Feb 2012 | 2 | 4 |
| Mar 2012 | 2 | 6 |
| April 2012 | 4 | 4 |
| May 2012 | 4 | 0 |
| June 2012 | 6 | 0 |
| July 2012 | 4 | 2 |
| August  2012 | 7 | 1 |
| September 2012 | 2 | 0 |
| Missing | 7 | 0 |
| Total | 61 | 29 |

**Table 31: Date of frailty assessment**

| Month | Breast | Colorectal |
|---|---:|---:|
| August  2011 | 2 | 1 |
| October  2011 | 3 | 1 |
| November  2011 | 4 | 3 |
| December 2011 | 1 | 0 |
| January 2012 | 8 | 0 |
| Feb 2012 | 1 | 2 |
| Mar 2012 | 2 | 6 |
| April 2012 | 3 | 3 |
| May 2012 | 2 | 1 |
| June 2012 | 1 | 1 |
| July 2012 | 7 | 1 |
| August 2012 | 11 | 3 |
| September 2012 | 13 | 0 |
| Missing | 3 | 7 |
| **Total** | **61** | **29** |

**Table 32: Treatment intent**

| | | Treatment offered (intent) | | |
|---|---|---:|---:|---:|
| | | Curative | Palliative | Total |
| Colorectal | Count | 23 | 6 | 29 |
| | % within Tumour site | 79.3% | 20.7% | 100.0% |
| Breast | Count | 46 | 5 | 51 |
| | % within Tumour site | 90.2% | 9.8% | 100.0% |
| Total | Count | 69 | 11 | 80 |
| | % within Tumour site | 86.3% | 13.8% | 100.0% |

**Table 33: Consent to treatment**

|  |  | Did the patient consent to treatment? | | Total |
|  |  | Yes | No |  |
|---|---|---|---|---|
| Colorectal | Count | 25 | 3 | 28 |
|  | % within Tumour site | 89.3% | 10.7% | 100.0% |
| Breast | Count | 57 | 1 | 58 |
|  | % within Tumour site | 98.3% | 1.7% | 100.0% |
| Total | Count | 82 | 4 | 86 |
|  | % within Tumour sites | 95.3% | 4.7% | 100.0% |

4 missing

**Table 34: MDT recommended treatment given**

|  |  | Was MDT recommended treatment given? | | Total |
|  |  | Yes | No |  |
|---|---|---|---|---|
| Colorectal | Count | 24 | 3 | 27 |
|  | % within Tumour site | 88.9% | 11.1% | 100.0% |
| Breast | Count | 55 | 2 | 57 |
|  | % within Tumour site | 96.5% | 3.5% | 100.0% |
| Total | Count | 79 | 5 | 84 |
|  | % within both Tumour sites | 94.0% | 6.0% | 100.0% |

6 missing

**Table 35: Reasons given for not giving MDT recommended treatment**

| |
|---|
| Initially, at MDT a decision to offer chemotherapy was made. However, the patient spoke with the oncologist and decided not to accept this but did agree to surgery (breast) |
| Patient declined chemotherapy although fit (breast) |
| Patient was too worried about surgery at his age (colorectal) |
| Does not want chemotherapy (colorectal) |
| Palliative chemotherapy offered - team concerned about co-morbidities and patient concerned about quality of life. Patient declined but may re-consider (colorectal) |

**Table 36: Patient age a decision in MDT treatment decision**

|  |  | Was patient age a decision in MDT treatment decision? | | Total |
|  |  | Yes | No |  |
|---|---|---|---|---|
| Colorectal | Count | 1 | 26 | 27 |
|  | % within Tumour site | 3.7% | 96.3% | 100.0% |
| Breast | Count | 0 | 54 | 54 |
|  | % within Tumour site | .0% | 100.0% | 100.0% |
| Total | Count | 1 | 80 | 81 |
|  | % within both Tumour sites | 1.2% | 98.8% | 100.0% |

9 missing

**Table 37: Assessment completion time (original and revised versions)**

Mode = 45

| | | | Statistic | Std. Error |
|---|---|---|---|---|
| Completion Time (minutes) | Mean | | 38.87 | 2.800 |
| | 95% Confidence Interval for Mean | Lower Bound | 33.15 | |
| | | Upper Bound | 44.59 | |
| | 5% Trimmed Mean | | 38.13 | |
| | Median | | 40.00 | |
| | Variance | | 243.116 | |
| | Std. Deviation | | 15.592 | |
| | Minimum | | 15 | |
| | Maximum | | 75 | |
| | Range | | 60 | |
| | Interquartile Range | | 25 | |
| | Skewness | | .462 | .421 |
| | Kurtosis | | .072 | .821 |

# Appendix 2: Illustrative case histories

Mrs. A was over 70 years old, and was diagnosed with breast cancer in March 2012.  She has arthritis and lives with her husband, who is becoming increasingly forgetful.  Following her diagnosis Mrs A had two surgical procedures to treat her cancer and unfortunately had some complications with her surgical wound . These complications meant additional trips to and from the hospital for appointments with the specialists.  Initially Mrs. A's daughter-in-law had taken time off of work to support her but was concerned about the amount of time she was spending away from work.  In addition Mrs A was worried about leaving her husband alone at home. Simply providing a taxi service meant that not only was Mrs A able to attend all her appointments but her husband was also able to accompany her in the taxis and her daughter-in-law did not have to take any time off work. Mrs A was "overwhelmed with the help she had received".  Her clinical nurse specialist said "it made such a difference to her for her husband to be able to accompany her." The taxi drivers were really helpful, making an effort to physically collect them from the clinic rather than insisting the patient finds them parked outside, and seeing them safely to their front doors.

Mrs. B is a 90 year old lady who lives on her own.  She had surgery for breast cancer in April 2012. This was followed by a course of radiotherapy.  She developed wound problems post-operatively which required frequent return visits to the hospital. Although her son lives nearby, he has a full-time job, so was struggling to get Mrs. B to hospital for her clinic appointments. He had to negotiate going into work late so that he could get her to hospital before he began work. The clinic staff then felt pressured to prioritise Mrs B on her arrival in spite of other patients' needs.  Mrs B felt she was a burden to her son.  Being part of the project, the clinical nurse specialist was able to organise taxi rides to hospital appointments for wound checks.  This meant that her son was able to go to work as usual and not have to worry about his mother.  Mrs B also had daily phone calls from Age UK to see how she was doing and she found this a great support. She also had assistance from Age UK with six baths/showers.  She was offered more bathing help but occasionally she didn't feel up to it and once or twice coped unassisted.   She was so grateful for the support that she has received through the project that she made a generous donation to Macmillan Cancer Support on her 90th birthday.

Mrs C needed to come into hospital for a course of intravenous chemotherapy following surgery for colorectal cancer. She was concerned about her husband who had just been told that he could no longer drive due to a degenerative eye disorder. The Clinical Nurse Specialist explained the project to the patient and arranged for a taxi to and from the hospital during the chemotherapy course and for additional follow-up appointments. This meant that her husband did not have to drive her to the hospital for her appointments and he could accompany her which is not permitted under hospital transport rules. The patient is recovering well and the clinical nurse specialist reports that both the patient and her husband are very grateful for the taxi service.

# Appendix 3: Financial summary of project spend

**<u>Clinical Nurse Specialist time</u>**
Estimated 3 hours assessment/referral per patient x 90 patients = 270 hours= 36 days at top point of Band 7 £40,157

**<u>Service Support</u>**

**Taxi**
£3,374.63

**Practical Support (AGE UK)**
£1,675.68

**<u>Management Support</u>**

**Meetings**
£109.10

**Project Manager (8A)**
£44,609

**<u>Admin support</u>**

£27,625 (top point - band 5) (figure based on 3.5 hours a week / 182 hours a year)

 **<u>TOTAL  £117,550</u>**

Reflects actual expenditure (plus estimated expenditure on CNS time) from September 2011 to September 2012 (one calendar year).  Does not reflect service cost of care of the elderly physician input.

# Appendix 4: Dissemination plan

Nursing Times webchat "Making time to assess older cancer patients"
http://www.nursingtimes.net/opinion/webchats/webchat-archive/

Nursing Standard article on the role of nursing and comprehensive assessment in improving cancer care for older people
http://nursingolderpeople.rcnpublishing.co.uk/news-and-opinion/opinion/help-combat-ageism

Presentation at Macmillan Learn and Share day, October 2012

International Society of Geriatric Oncology conference, October 2012

Circulation of written preliminary report to individual stakeholders at each hospital site: nurse specialists in cancer care, consultant surgeons, consultant oncologists, hospital directors and managers.  Also local Age UK.


Planned dissemination

Circulation of final written report to individual stakeholders at each hospital site: nurse specialists in cancer care, consultant surgeons, consultant oncologists, hospital directors and managers.  Also local Age UK, London Cancer, National Clinical Director for Older People, Nursing Task Force for International Society of Geriatric Oncology – wider circulation list to be decided with help of Cancer Network staff and Hazel Brodie at Macmillan Cancer Support

Written project summary to patients involved and staff interviewed

2-3 papers reporting findings in international peer review and professional publications

Conference presentations including:

International Society of Geriatric Oncology conference, October 2013

Organisational Behaviour in Health Care conference, April 2014

# References

ALL PARTY PARLIAMENTARY GROUP ON CANCER (APPGC). 2009. *Report of the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer* [Online]. http://www.macmillan.org.uk/GetInvolved/APPG/ReportsAndEvents/InquiryIntoInequalityReport2009.aspx. [Accessed 20.11.2012].

BAILEY, C., CORNER, J., ADDINGTON-HALL, J., KUMAR, D. & HAVILAND, J. 2004. Older patients' experiences of treatment for colorectal cancer: an analysis of functional status and service use. *European Journal of Cancer Care,* 13**,** 483-493.

BAILEY, C., CORNER, J., ADDINGTON-HALL, J., KUMAR, D., NELSON, M. & HAVILAND, J. 2003. Treatment decisions in older patients with colorectal cancer: the role of age and multidimensional function. *European Journal of Cancer Care,* 12**,** 257-262.

CANCER RESEARCH UK. 2012. *Cancer incidence by age - UK statistics* [Online]. http://info.cancerresearchuk.org/cancerstats/incidence/age/ [Accessed 24.02.2012].

KENNEDY, S., BIRD, L., CLARKE, A., COX, K. & SEYMOUR, J. 2011. Improving support for older people looking after someone with advanced cancer. Nottingham: University of Nottingham.

MACMILLAN CANCER SUPPORT. 2012. *The Age Old Excuse: the under treatment of older cancer patients* [Online]. http://www.macmillan.org.uk/Aboutus/Healthprofessionals/Improvingservicesforolderpeople/ProjectImprovingcancertreatment,assessmentandsupportforolderpeople.aspx. [Accessed 20.11.2012].

MADDAMS, J., BREWSTER, D., GAVIN, A., STEWARD, J., ELLIOTT, J., UTLEY, M. & MØLLER, H. 2009. Cancer prevalence in the United Kingdom: estimates for 2008. *British journal of cancer,* 101**,** 541-547.

MOLLER, H., FLATT, G. & MORAN, A. 2011. High cancer mortality rates in the elderly in the UK. *Cancer Epidemiology,* 35**,** 407-412.

NATIONAL CANCER EQUALITY INITIATIVE/PHARMACEUTICAL ONCOLOGY INITIATIVE 2012. The impact of patient age on clinical decision-making in oncology. London: Department of Health.

RING, A. 2010. The influences of age and co-morbidities on treatment decisions for patients with HER2-positive early breast cancer. *Critical Reviews in Oncology/Hematology,* 76**,** 127-132.

SOBIN, L. & WITTEKIND, C. 2002. UICC (2002) TNM classification of malignant tumors. *New York: Wiley&Sons*.

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