

**Evaluating the development of a pathway for patients presenting with metastatic cancer of unidentified primary origin**

**End of study report for Macmillan Cancer Support**

**Philippa Hughes1, Peter Bath2, Clare Farrington1, David Brooks3 & Bill Noble1**

**1Academic Unit of Supportive Care, School of Medicine and Biomedical Sciences, University of Sheffield**

**2Information School, University of Sheffield**

**3Chesterfield Royal Hospital NHS Foundation Trust, Chesterfield**

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**University of Sheffield**

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|  |  |  |
| --- | --- | --- |
| Philippa Hughes & Bill Noble |  | Peter Bath |
| AUSC, University of Sheffield  Trent Palliative Care Centre  Little Common Lane  Sheffield S11 9NE |  | Information School  University of Sheffield  Regent Court  211 Portobello Street  Sheffield S1 4DP |
| Telephone: 0114 262 0174 |  |  |
| Email: [p.m.hughes@sheffield.ac.uk](mailto:p.m.hughes@sheffield.ac.uk) and [bill.noble@sheffield.ac.uk](mailto:bill.noble@sheffield.ac.uk) |  | Email: [p.a.bath@sheffield.ac.uk](mailto:p.a.bath@sheffield.ac.uk) |

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**Executive summary**

**Introduction**

* A new pathway was successfully established for the management of care of patients presenting with metastatic cancer of unknown primary (CUP) origin.
* Developing the pathway involved assessment of the different ways in which these patients presented; establishment of new routes of referral and transfer; new ways of working with MDTs and the establishment of a new out-patient clinic at Chesterfield Royal Hospital.
* Knowledge and information derived from this process has been fed into the process of establishing new guidance from NICE in this area.

An evaluation study was set up with the following aims and objectives:

**Aim**:

To assess the clinical outcomes, service quality outcomes, patient experiences and economic outcomes following the implementation of a pathway for the management of patients with cancer of unknown primary origin

**Objectives**:

1. To compare the times between referral and the instigation of definitive treatment before and after the initiation of a new pathway
2. To compare the times between referral and the instigation of specialist palliative care before and after the initiation of a new pathway
3. To compare oncology referral, and oncology treatments offered, accepted, and completed.
4. To document patient and carer experiences of receiving care, including symptoms, quality of life and comments on care and treatment received, before the initiation of a new pathway and those occurring after the start of the new pathway.
5. To compare number and length of hospital admissions, numbers of investigations, and costs before the new pathway to those occurring after the start of the new pathway.

**Process**

* **Setting up the new pathway for patients presenting with malignancy of undefined primary origin**

This involved highlighting the clinical need to the hospital management team; developing the pathway, and involvement in the development of NICE guidelines for patients with cancer of unknown primary. Colleagues at the hospital supported the process.

* **Initiation of the pathway**

With agreement to start the MDT the service was launched initially for inpatients and MDT discussion of patients reviewed in others outpatients. The service was advertised through cascade, word of mouth and through education meetings. Availability of a room for clinical out-patient consultation was only possible at a point where phase 2 data collection was well under way.

* **Implementing the new pathway for patients presenting with malignancy of undefined primary origin.**

It was underestimated how long it would take to fully establish the pathway and therefore more of the six month post pathway research period occurred during the transition phase of establishing the pathway than was anticipated. We would hope to go on to do a future project evaluating the effect of a fully implemented pathway.

* **Identifying the patients appropriate for the CUP pathway**

Three main patterns of presentation were identified: primary care referral to primary investigation out-patient clinic; initial referral to CUP team for discussion at CUP MDT or patient review; and inpatient review on ward by CUP team

The cohort in the post CUP pathway group who had no input from the CUP team were identified afterwards for completeness through the same process as we used to identify the pre CUP pathway group.

* **Challenges with the accuracy of data and wider implications**

**Coding:** Through the implementation and evaluation of this pathway for patients with metastatic disease of unidentified primary it has further highlighted the current difficulties in even identifying and coding these patients.

**National Databases:** National databases of patients with cancer are now kept so that systems can be audited and progress monitored. Open Exeter is a national database which is used in Chesterfield Royal Hospital (CRH). Through developing and evaluating this pathway it was highlighted that these databases are incomplete.

* **Estimating the financial cost of the investigatory period for patients presenting with metastatic cancer of unidentified origin**

The process of costing an investigatory period was more complex and protracted than initially envisaged. The financial implications of a new process can be priced with regard to the cost to the hospital itself or the primary health care trust (PCT). Within this report we have used the former based on estimated costs supplied by the finance department at CRH. We are awaiting a more in depth pricing which will be based on what the PCT was charged for each patient during their investigatory period.

**Findings**

1. **Dataset**

Data was collected on two cohorts of patients. The first related to the pre-pathway phase, and numbered 50. The second was from the pathway implementation phase, and numbered 38. Data is presented from the whole group of 88 first, followed by that from the two groups separately.

1.1 This group is a relatively elderly group, fairly evenly divided as to gender. A minority had a performance status at a level where treatment would be considered, with a majority being moderately or highly disabled.

1.2.1 Sixty-three patients (71.6%) had one CRH admission, 11 patients (12.5%) had two CRH admissions and one patient each had three and four CRH admissions. Twelve patients had no CRH admissions (13.6%). The total number of nights spent in hospital varied from 0 (n=12) to 45 nights (mean = 14.13 nights; median = 13 nights). The total cost of nights spent in hospital varied from £0 to £7830 (mean = £2457; median = £2262).

1.3.1 Forty patients (45.5%) had onward referral for tumour-directed treatment. For forty patients (45.5%) onward referral was not considered suitable, and eight patients (9%) died before a decision on onward referral could be made.

1.3.2 Twenty-three patients had tumour-directed treatment as planned or with modifications (26.1%), seven patients (8.0%) had tumour-directed treatment planned but the patient was too ill for it to begin and six patients (6.8%) commenced tumour-directed treatment but this was stopped because the patient was too ill.

1.4.1 Forty-three patients (48.9%) had a final diagnosis of cancer of unknown primary, and 45 patients (51.1%) did not have a final diagnosis of cancer of unknown primary.

1.5.1 43.2% of patients died in the Chesterfield Royal Hospital (n=38), 19.3% died at the Ashgate Hospice (n=17) and 21.6% died at home (n=19). Of the remainder, 7.9% (n=7) were still living at the time of review, three died in Whitworth Hospital, and one died in each of The Royal Hallamshire Hospital, Weston Park Hospital and the Northern General Hospital.

1.6.1 There was no statistically significant difference in the mean rank of the ages of the pre-pathway patients compare with the post-pathway patients. There was no statistically significant association between gender whether the patient was pre-pathway or post-pathway There was no significant difference between the pre-pathway patients and the post-pathway patients in terms of the performance status.

1.7.1 Thirty-three of the pre-pathway patients had one CRH admission (66.0%) and 30 of the post-pathway patients had one CRH admission (78.9%). Seven of the pre-pathway patients had two CRH admissions (14.0%) and four of the post-pathway patients had two admissions. Nine pre-pathway patients had no admissions (18.0%) and three post-pathway patients had no admissions (7.9%).

1.7.2 For the pre-pathway group, the total number of nights spent in hospital varied from 0 (n=9) to 40 nights (mean = 14.04 nights; median = 13.5 nights). For the post-pathway group, the total number of nights spent in hospital varied from 0 (n=3) to 45 nights (mean = 14.24 nights; median = 13.00 nights). There was no significant difference between the pre-pathway patients and the post-pathway patients in the mean total number of nights spent in hospital (t=-0.088; df=86; *p*=0.930).

1.7.3 The total estimated cost of nights spent in hospital varied within the pre-pathway patient group from £0 to £6960 (mean = £2442.96; median = £2349) and in the post-pathway group from £0 to £7830 (mean = £2477.21; median = £2262).

1.8.1 Twenty two of the pre-pathway patients (44%) received onward referral for tumour-directed treatment compared with 18 of the post-pathway patients (47.4%). For 23 (46%) patients in the pre-pathway group onward referral was not considered suitable; and for 17 (44.8%) patients in the post-pathway group onward referral was not considered suitable. Five patients in the pre-pathway group (10%) , and 3 (7.9%) in the post-pathway group died before a decision on onward referral could be made.

1.8.2 Fourteen of the pre-pathway patients (28.0%) had tumour-directed treatment as planned or with modifications and nine of the post-pathway patients (23.7%) had tumour-directed treatment as planned or with modifications. One of the pre-pathway patients (2.0%) had tumour-directed treatment planned but it was not begun because they were too ill, and six of the post-pathway patients (15.8%) had tumour-directed treatment planned but it was not begun because they were too ill. Four of the pre-pathway patients (8.0%) commenced tumour-directed treatment but it was stopped because they were too ill, and two of the post-pathway patients (5.3%) commenced tumour-directed treatment but it was stopped because they were too ill.

1.9.1 There was no significant difference between the pre-pathway patients and the post-pathway patients in whether they did or did not have a final diagnosis of cancer of unknown primary

1.10.1 We speculated that a death in Chesterfield Royal Hospital, as opposed to a death elsewhere, might be a proxy for an incomplete resolution to the investigatory period. The grounds for this are that in those cases where care reached a point of resolution, patients would ideally be discharged home, or referred to tertiary care. There was a difference between patients who died in the pre-pathway group and the post-pathway group in whether they died in the Chesterfield Royal Hospital or elsewhere, although this did not reach statistical significance (χ2=3.255; df=1; *p*=0.071). Of the 48 pre-pathway patients who had died, 27 died in Chesterfield Royal Hospital (56.3%), whereas only 11 of the 33 post-pathway patients who had died (33.3%) died in Chesterfield Royal Hospital.

# 1.10.2 More people died at home in the post-pathway group: 7 people in the pre-pathway group and 12 people in the post-pathway group. Numbers are small however, and could have arisen due to chance. Of the pre-pathway group, 30 died in hospital (60%), and of the 38 post-pathway group, 14 died in hospital (37%). Of the 50 pre-pathway patients, 10 died in a hospice (20%), and of the 38 post-pathway patients, a similar proportion, 7 (18.4%), died in a hospice.

1.11.1 There was no difference between the pre-pathway patients and the post-pathway patients in the mean rank of the time from CUP referral to instigation of definitive treatment (Z=-1.2348; p=0.217), although the small sample size may have resulted in the significance not being detected (Type 1 error) and it is difficult to draw meaningful conclusions from this. The mean rank for the 44 pre-pathway patients was 40.05 and the mean rank for the 32 post-pathway patients was 33.77.

1.12.1 There was no difference between the pre-pathway patients and the post-pathway patients in the mean rank of the time from referral for specialist palliative care (Z=-0.716; p=0.474) although the small sample size may have resulted in the significance not being detected (Type 1 error) and again it is difficult to draw meaningful conclusions from this. The mean rank for the 41 pre-pathway patients was 36.96 and the mean rank for the 29 post-pathway patients was 33.43.

1. **Data from patient participants**

2.1.1 The data from the questionnaires indicates a considerable symptom burden for some patients, particularly weakness/tiredness, and pain. Nevertheless, all patients reported life to be worthwhile all or some of the time, and eight of the ten reported quality of life scores of 4 or above. Most reported receiving as much information as they wanted; practical problems being or having been addressed and no wasted time on appointments. More respondents reported an increased enablement after consultation or care across the range of questions, than reported it to be the same or less.

2.2.1 Pre-pathway, the three patients interviewed were dealing with powerful emotional issues, such as receiving information with devastating implications or accepting loss of ability. They gave credit for good care in hospital, but drew attention to delays and deficiencies, which they attributed to pressure of work. Diagnosis was important: delays, uncertainties and change of personnel all caused difficulties. Patients wanted communication from professionals to be clear, but did not want it to be done in a harsh way. The single interview post-pathway indicated similar important emotional issue, with additional support offered in this instance. Poor care witnessed on the ward had caused distress, although personally care in hospital had not been an issue. Communication, clear and complete, from clinicians, was valued, as was being treated as a person of value.

1. **Data from bereaved carers**

3.1.1 These two samples both represent only a minority (around a third in each case), of the total numbers who were sent the VOICES questionnaire. Caution should be exercised in interpreting the findings, as the responders may not be representative of the groups as a whole. Additionally, some differences can be seen between the respondents in the two groups. Firstly, the pathway implementation group report much greater satisfaction with the help and support received for providing personal care in the home setting. Secondly, more of the patients in the implementation group died at home or in a relative’s home, as opposed to in hospital or a hospice. These factors are likely to be related to other reported elements, such as the provision of enough care in the last three days of life, and feeling that the place where heir relative had died was the right place for them.

3.2.1 Experiences of help and support at home are reported to be satisfactory by nearly all who received them in the pathway implementation group, in contrast to the pre-pathway group, where significant failings were reported by some. GP care as reported in both groups appears variable, with reports of both good and poor care.

3.3.1 There are various reports of the quality of hospital care from both groups, with both high praise and reported very bad, neglectful care. One instance where a respondent describes poor care on one ward and good care on another supports the view that some wards deliver good care and some do not. The reports of poor care are such as to cause serious concern in some cases.

3.4.1 In contrast, the small numbers in either group reporting on hospice care record it as generally excellent.

3.5.1 Better experiences of care in the last three days of life are reported by the pathway implementation group, compared to the pre-pathway group. Greater satisfaction with the help and support from health and social services is also reported by the pathway implementation group. Both these findings may reflect the larger number in this group cared for at home and dying at home, and the reported better personal care services provided.

**Conclusion**

A fuller account of costs will be provided at a later date.

The study confirmed the importance to patients of reducing delays, uncertainties and lack of continuity. This study appears to indicate that instituting a CUP pathway in a district general hospital has the potential to contain the length of time taken for investigation and increase the proportion of patients with CUP who are discharged or transferred before death.

Within the project, implementing and establishing the pathway was delayed by the complexity of the task. The second phase of the evaluation took place at a time when the pathway infrastructure and uptake was still incomplete. A third phase of the evaluation would be necessary to detect the whole effect of this intervention.

**Evaluating the development of a pathway for patients presenting with metastatic cancer of unidentified primary origin**

# Background & rationale for the study

#### Cancer of unknown primary

Cancer of unknown primary (CUP) accounts for a significant proportion of cancer diagnoses, reported as between 2% and 6% (Pavlidis et al. 2003, Shaw et al.; James; Pentheroudakis et al.; ESMO; all 2007). It is defined as a histologically confirmed metastatic carcinoma in the absence of a detectable primary cancer despite investigation (Shaw et al 2007).

In the majority of cases (over 80%) investigations fail to identify the primary, and almost 70% of primaries remain unidentified at post-mortem (Pavlidis et al. 2003). Strategies focused on identification of the primary tumour may expose patients to time-consuming investigations, and stays in hospital without necessarily improving care given or quality of life (Pavlidis et al. 2003, Shaw et al. 2007, James 2007).Median survival time has been variously reported as 4 months (Shaw et al. 2007); 6-9 months (Pavlidis et al. 2003); 3-6 months sub-groups known to be unfavourable and 10-16 months in favourable sub-groups (Penteradoukis et al. 2007). Favourable prognostic factors are reported to include female gender, good performance status and absent liver metastases (Shaw et al. 2007).

Some work discusses the possibility of a “primary metastatic disease” (Pentheroudakis et al. 2007), while other work has focussed on identification of strategies to establish groupings based on likely primary diagnosis to optimise treatment (Varadhachary et al. 2004, Pavlidis et al. 2007).

Published studies and guidelines offer a framework for identifying the most appropriate strategies for treating individual patients (Pavlidis et al., 2003; ESMO, 2007). Authors have for some time proposed limited diagnostic procedures aimed at gaining information of value while minimising the burden for patients (Abbruzzese, 1995; Briasoulis and Pavlidis 1997; Shaw et al. 2007).Studies recognise the burden of investigations for patients, with Shaw et al. (2007) reporting 19 investigations for patients with liver or multiple metastases, and James (2007) reporting tests commonly repeated. Economic costs are also important (Shaw et al. 2007).

Notwithstanding the above, audits in the UK have shown that there is great variation in the approach to management of patients with cancer of unknown primary (Shaw et al., 2007; James, 2007). It is suggested that earlier referral to oncology and supportive care would improve things for patients by facilitating better symptom management.

**Cancer of Unknown Primary at Chesterfield Royal Hospital**

The small local audit conducted at Chesterfield Royal Hospital (James 2007), highlighted the same issues of concern as revealed in the wider literature. In this group of 14 patients, average age was 76, and average length of hospital stay was 3 weeks. Referral to specialist palliative care appeared to have a beneficial effect on length of stay, in reducing unnecessary tests and medication, and addressing of spiritual and psychological issues. However, referral was often very late. In addition, continuity of care was compromised by multiple referrals between teams.

## Development of Pathway

Despite positive results of the Cancer Plan, compared to patients with a site specific diagnosis, patients with an unknown primary may not access equitable and appropriate management. In the Trent area unknown primary accounts for 5.8% of all cancer diagnoses. Patients presenting with unknown primary may be very ill (possibly suffering general malaise, pain, fatigue), and with a likely survival of only a few months. First consideration should be given to relief of symptoms rather than a potentially futile search for the underlying condition, which will remain unknown even at post-mortem for most patients. Until the publication of the NICE guideline on metastatic disease of unknown primary origin (July 2010), there was no National Guidance on management of such patients.

In Chesterfield, there was no mechanism that routinely identified patients with cancer of unknown primary origin as a distinct group. Patients were treated under a range of specialities, with no single co-ordinating agency.

The Pathway Project aimed to achieve a number of things: identification of the population of patients who present with primary cancer of unknown origin referred to Chesterfield Royal Hospital, development of a pathway of care; development of a multi-disciplinary approach to the management of these patients; development of a formal, NICE approved Improving Outcomes Guidance (IOG) for unknown primary; and the setting up of a research project examining clinical, quality of services, patient experiences and economic outcomes of implementation of the pathway

**Identifying patients with cancer of unknown primary**

There are approximately a thousand cancer deaths in North Derbyshire each year. The North Trent cancer registry indicates that 5% to 7% of all cancer diagnoses are cancers of unknown primary origin. Other data suggests that 10% of all cancers seen at Chesterfield Royal Hospital are cancers with unknown primary. Identifying this group of patients was a key element to be addressed. Patients present with either metastases, or with malignant effusions, and may be under the care of a number of different teams.

Routes for identifying patients included radiology (via the Chesterfield Hospital *Unexpected Findings Alert* System); pathology (requests for cytological examination of pleural or ascitic fluid); multi-disciplinary team meeting meetings (unknown primary and metastatic presentation); the database of Clinical Radiology Information System requests; and the Target Breach database.

Developing the pathway of care involved a number of stages: developing a clinical review pro-forma; developing a investigative algorithm strategy for presenting metastatic site; identification of which parts of current pathways worked well and less well; agreement of a new pathway/service, and a costed business plan. At each stage there was collaboration with the views of lead clinicians, oncologists, radiologists and pathologists, alongside NICE, ESMO, NCCN and current local guidelines,

**Research study**

**Aim**

This study had the following aim:

To assess the clinical outcomes, service quality outcomes, patient experiences and economic outcomes following the implementation of a pathway for the management of patients with cancer of unknown primary origin

**Objectives**

The study had the following objectives:

1. To compare the times between referral and the instigation of definitive treatment before and after the initiation of a new pathway
2. To compare the times between referral and the instigation of specialist palliative care before and after the initiation of a new pathway
3. To compare oncology referral, and oncology treatments offered, accepted, and completed.
4. To document patient and carer experiences of receiving care, including symptoms, quality of life and comments on care and treatment received, before the initiation of a new pathway and those occurring after the start of the new pathway.

1. To compare number and length of hospital admissions, numbers of investigations, and costs before the new pathway to those occurring after the start of the new pathway.

##### Methodology

##### Design

There were three elements to the multi method research study:

1. A retrospective comparative cross-sectional study of all patient clinical record data before and after the intervention focussing on service and financial indications
2. A qualitative analysis of the experience of patients and bereaved carers, comparing two cohorts, before and after the intervention.
3. A longitudinal cohort study of the quality of life, palliative care outcomes and experiences of patients in a new care pathway for cancer of unknown primary

##### Retrospective comparative cross-sectional study of all patient clinical record data

##### As part of the clinical development, a review of notes took place, conducted by the clinical team to identify the population presenting with this diagnosis, and to establish their progress through care and treatment, and to document outcomes. Information gathered from case notes was to be transferred to a research database in anonymised form and the data made available to the evaluation team. The data will include no patient identifying features, and will include all who can be identified as presenting with a cancer of unknown primary.

The date of referral was to be counted as the point where a secondary care physician is first alerted to the presumed or probable presence of metastatic disease that requires investigation.

##### Following the establishment of a new pathway, the evaluation study used non patient-identifiable data taken from a repeat review of patient notes undertaken by the clinical team.

###### Patient experiences of treatment and care- pre-intervention

The recent audit of patients at Chesterfield Royal Hospital indicated that the survival time for patients identified was limited and that 11 of 14 patients died in hospital without being discharged home (James 2007). This presented a considerable challenge for exploring patient perspectives since identification of patients was likely to be limited, have occurred late in their care, or be only possible in retrospect.

However, information from patients is important in the development of the proposed pathway of care, so efforts were made to include patients in this part of the study. In cases where patients were considered well enough by health care professionals, they were invited to participate in a short semi-structured interview, and to complete questionnaires on health, quality of life, and care received. Individual clinical records were reviewed.

###### The following instruments were used to measure quality of life, symptom burden, and other concerns:

* Palliative care Outcomes Scale (POS)
* European Organisation for Research on Treatment of Cancer Quality of Life Questionnaire 15 item version for palliative care (EORTC QLQ-C15-PAL)
* The Patient Enablement Instrument (PEI)

After the establishment of the pathway, it was hoped that earlier and more systematic identification of patients would be possible. Initial questionnaires for participating patients were to beusedas closeas practicable to the referral date. Repeated measures would be made 1 month after referral, at 3, 5 and 8 months after referral where patients survive, with a brief semi-structured interview at the 3 month follow up.

**Bereaved carer survey**

In view of the difficulty of identifying patients prospectively within this limited time-frame at the start of the study, the evaluation team proposed to gather relatives’ family perspectives on care received, using a retrospective questionnaire, VOICES (Views ofInformal Carers- Evaluation of Services). Once an appropriate period of time had passed, a relative or carer could be invited to participate by completing a postal questionnaire.

##### Methods

**Summary of the methods**

**Before development of new pathway**

**Retrospective data analysis, including:**

* time from referral to definitive treatment
* time from referral to palliative care
* time from referral to death;
* place of death
* number of investigations,
* chemotherapy treatment;
* hospital appointments;
* hospital stays (and length);
* Performance status at oncology review

**Bereaved Carer reports of patient experiences**

Evaluated using retrospective VOICES questionnaires to bereaved carers

* Where patients have died, bereaved carers would be contacted **after 3 months**, with the option of completing a VOICES questionnaire
* VOICES includes several sections:
  + Support with care at home
  + GP care in the home setting
  + Care in hospital
  + Care in nursing or residential home
  + Care in hospice
  + Care in the last three days of life
  + Care at the time of death, and in bereavement

**Patient Experiences**

* 3 months after referral
* Where appropriate, patients will be invited to complete three brief research questionnaires (EORTC QLQ-C15- PAL, POS, PEI) and to participate in a semi-structured interview

**After development and implementation of the new pathway:**

**After development of new pathway**

**Retrospective data analysis, including:**

* time from referral to definitive treatment
* time from referral to palliative care
* time from referral to death;
* place of death
* number of investigations,
* chemotherapy treatment;
* hospital appointments;
* hospital stays (and length);
* Performance status at oncology review

**Bereaved Carer reports of patient experiences**

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  + Care in nursing or residential home
  + Care in hospice
  + Care in the last three days of life
  + Care at the time of death, and in bereavement

**Patient Experiences**

* Within two weeks of referral
* Where appropriate, patients were invited to complete three brief research questionnaires (EORTC QLQ-C15- PAL, POS, PEI). These measures were to be repeated at one, three, five and eight months after referral, if appropriate.
* At the three month point patients were to be invited to participate in a semi-structured interview

## Primary outcome measure

* Time from referral to instigation of definitive treatment

**Secondary outcome measures**

**Service and financial indications**

* Time from referral to instigation of specialist palliative care
* The number and length of hospital admissions
* The number of hospital appointments
* The number of investigations carried out
* The number of multi-disciplinary team discussions
* The costs associated with the above
* Oncology treatments offered
* Oncology referral
* Acceptance of oncology treatment
* Completion of oncology treatment

***Patient survival and care***

* Prognostic factors
* Survival time
* Place of death

In addition, from the sub-groups of patients and bereaved carers participating in the study, the following outcomes will be examined:

Patient experiences

* Patient symptom burden
* Patient quality of life
* Patient experiences of service response
* Patient enablement

Carer experiences

* Comments on quality of service received
* Comments on explanations of care and treatment
* Comments on end of life care

**Contribution to the development of a new pathway**

Information gained from the above will contribute, alongside the views and experiences of clinicians and service users, to the development of a new pathway of care for patients with cancer of unknown primary origin. This will be led by the new Unknown Primary co-ordinator.

**Measurement tools**

The **Palliative Outcome Scale (POS)** was developed by a team from King’s College, London (Hearn and Higginson, 1999). It is a 12-item self-complete questionnaire, with parallel versions for patients and staff. Most questions use a Likert scoring (0-4). Use can be made of scores for individual questions, as well as summary scores. It has been used in clinical, audit and research situations, and is acceptable to patients (Corner et al., 2003; Stevens et al., 2005)

The **European Orgainsation for Research on Treatment of Cancer Quality of Life Questionnaire 15 Item version for Palliative Care (EORTC QLQ-C15-PAL)** was developed as a shorter version of the EORTC QLQ-C30, specifically for use in palliative care settings. It includes questions on individual symptoms as well as a global quality of life measure (Groenvold et al., 2006).

The **Patient Enablement Instrument (PEI)**

This scale is a brief questionnaire, intended to assess the extent to which patients feel empowered by their most recent contact with a health care professional. It has been used in cancer care and other contexts. (Howie at el., 1997; Howie at el., 1999). We will use it in its original form, but add an additional section to assess patients’ sense of empowerment relative to the whole period of their care under the hospital for cancer of unknown primary, as well as their most recent consultation.

The **Views of Informal Carers- Evaluation of Services (VOICES)**

This is a self-complete postal questionnaire gathering the views of informal carers on care and treatment received by the patient, either by tick-box responses, or by free-text comments. It can include sections on a range of settings: hospital, hospice, community and nursing home. It has been widely used in cancer and other illnesses, and has been found acceptable to respondents (Addington-Hall et al., 1998, Ingleton et al., 2004).

**Eastern Cooperative Oncology Group (ECOG) Performance status**

This is a well-established scale to assess patients’ health status.

|  |  |
| --- | --- |
| **Eastern Cooperative Oncology Group (ECOG) Performance status** | |
| **Grade** |  |
| 0 | Fully active, able to carry on all pre-disease performance without restriction |
| 1 | Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work |
| 2 | Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours |
| 3 | Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours |
| 4 | Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair |
| 5 | Dead |

(Oken et al. 1982)

**Recruitment & Sample size**

It can be seen from the outline of the development project that identification of patients with cancer of unknown primary was itself a difficulty to be addressed by the development of the new project. This was likely to have implications for the recruitment of patients into the evaluation study, who would be much less easily identified under existing arrangements. Estimates from the North Trent Cancer Registry data, and from other sources indicates that there may be 50 people per year seen at Chesterfield Royal Hospital with a diagnosis of cancer with unknown primary.

For patient experiences: we aimed to invite participation from all patients considered well enough to be approached. These were expected to be far fewer in the early part of the study. Attrition will also be significant in the patient groups. Initial approach and arrangements for consent and baseline measures will be carried out by the clinical team, with follow up and interviewing carried out by the research team. This plan was to avoid complex arrangements for patients, while still allowing appropriate time for them to consider whether they wish to participate.

For carer experiences: this part of the study was conducted retrospectively, with bereaved carers of those who have died approached by post, after a suitable interval had elapsed. Recruitment from both before and after the new pathway will present fewer problems than the recruitment of patients. Appropriate carer or nearest relatives were identified by the clinical team, and a letter of invitation sent by post along with an information sheet and the questionnaire. Those willing to respond replied directly to the research team.

## Analysis

The first part of the analyses followed an analysis/review of case notes from these patients. Because this is a population-based study statistical testing was not appropriate. However, descriptive analyses permits comparison of the mean time between referral and the institution of definitive treatment or supportive/palliative care for the two groups of patients, pre and post intervention. Comparison was also planned of the mean number and length of hospital stay, the number of investigations, the service outcomes as described above, along with costs incurred, in the two groups of patients.

The second part of the study is population-based in that all patients with a diagnosis of cancer with unknown primary at Chesterfield Royal Hospital were considered for inclusion in the study. We expected that a small number of patients and carer groups would be likely to be recruited, and not representative of the population. As statistical testing assumes that the sample is representative of the wider population, it was not be appropriate to undertake statistical tests. Descriptive statistics will be prepared on patient and carer reports on symptoms, quality of life, care received, and other factors. Summary measures for the individual instruments used will be calculated according to the recommendations of those who have developed them.

Interviews were analysed qualitatively using a framework approach to identify themes. Free-text comments from the carer and patient questionnaires were subject to a content analysis, with longer text comments examined for themes, in a process paralleling that of the interviews.

**Project Management**

The unknown primary co-ordinator managed the new clinical development, with a designated project team.

For the evaluation study, the study team included Bill Noble (Macmillan Senior Lecturer), Philippa Hughes (Research Associate), consumer representatives, (via local panel), and Pauline Hutchinson (secretary). Jill Bartrop, Alison Gethin and Deirdre Revill (North Trent Cancer Network Consumer Research Panel ) provided user perspectives for the study at all stages . In addition, we reported at regular intervals to the meetings of the Consumer Research Panel.

Data from the clinical service was provided by Dr David Brooks. The Specialist Registrars Dr Lingesan Gokulkrishnan and Dr Clare Farrington also worked on data extraction, and in identifying research participants.

**Process**

**Setting up the new pathway for patients presenting with malignancy of undefined primary origin**

* **Highlighting the clinical need for the pathway to the hospital clinical management team**

The first part of getting the organisation signed up to a new pathway for patients presenting with malignancy of undefined primary origin was achieved during the process of obtaining sign up to the research. The research presupposed that after the initial data collection period on current state that changes would be made to improve this. The key decision makers who needed to be influenced were the cancer executive which consisted of the Cancer Manager, Lead Clinician, Lead Nurse, Lead Oncologist, GP Cancer Lead and Commissioning lead. Also Dr Brooks, Palliative Medicine Consultant, who was driving the project, was a member of the Cancer executive which facilitated access.

Illustrating the need by describing cases of poor management by non-cancer clinicians or where patients had been bounced between site specific MDTs was reinforced by experiences of clinicians in the group and in fact the case was so clear that the commissioner was keen for us to start a service before the first data collection period. However as finances were tight she was not offering any funding as these were not “new activity” but service redesign within current activity. The cancer executive took the case to the Hospital’s Clinical Management Team who were supportive of the research but not wanting pump priming money from Macmillan for starting a service but wanting to review with the results of the first data.

* **Development of the pathway and NICE guidelines for patients with cancer of unknown primary**

The first major decision was which patients would we call “Unknown Primary” and suitable for such a service and thus appropriate for the research. We clearly did not want to interrupt referral pathways that worked well such as neck lump diagnostic clinics or put an unnecessary step in the way of patients who could properly be directed to the appropriate service with a simple test (e.g. males with bone metastases who needed only a PSA to direct them. A proposed definition of patients appropriate for an unknown primary service was developed that was then put out to consultation to relevant clinicians to revise and agree.

*‘For patients who have presumed/probable metastatic disease that requires investigation with no known (or highly suspected) primary disease. Or those patients in which the suspected primary disease has been excluded and that site-specific pathway/MDT is no longer appropriate.’*

Shortly after the agreement to participate in the research the opportunity to be a member of the NICE Guidance Development Committee on diagnosis and management of metastatic malignant disease of unknown primary origin was advertised and both Dr Brooks and Nicky James (the Cancer Lead Nurse) applied and were accepted. This provided a forum where both the learning from our early research development could be fed into the guidance development process and the evidence from the developing guidance could be used to influence our own pathway development. The description of the characteristics of patients appropriate for the service that was developed for the study forms part of the published NICE guidance.

* **Formulating a Business Case for new pathway**

Data collection from the first part of the study was more complex than originally envisaged as described elsewhere so clear data to use for a business case were not available at the time when the case needed to be made for the commencement of the service. Also increasing austerity measures were being applied throughout the Hospital such that new resources were almost impossible to achieve. Therefore it became evident that we would have to “pilot” the service based on largely goodwill.

What the original data collection had showed was that this was not going to be large numbers of patients - usually one or two a week. Many of the patients were going through the Upper GI MDT anyway with liver metastases or abdominal masses so Dr Brooks approached the lead clinician to propose that an addendum of Unknown Primary patients be added to the Upper GI MDT. He became an enthusiastic supporter and through individual discussion other members of the Upper GI MDT were persuaded to support the case. The Upper GI Oncologist took on the oncology management of the unknown primaries. Dr Brooks agreed to be the first port of call for patient review and investigation with triage to the oncologist for those suitable for treatment.

The difficulty was persuading the administrative staff as they were, as part of the austerity measures being forced through a “workforce review” in which posts were being downgraded, staff reallocated against their will and numbers reduced. The staff were demoralised, demotivated and had had all the goodwill sucked out of them. Asking staff to take on any extra duties in these circumstances was clearly not going to be met with enthusiasm.

This problem was taken to the Cancer Manager who, persuaded by the need to progress with the research he had signed up to and the impending publication of NICE guidance which would direct this development, found some funding from the research budget for data collection to increase a staff member’s hours. This final obstacle overcome we were able to move forward.

Although both the Specialist Palliative Care (SPC) Nurses and Upper GI nurse specialist agreed to support the work, due to maternity leave and the fact that the Palliative Care Consultant was doing most of the clinical work the burden of Specialist Nurse input, and support, up to now has fallen mostly on the SPC Nurses.

* **Initiation of the pathway**

With agreement to start the MDT the service was launched initially for inpatients and MDT discussion of patients reviewed in others outpatients. Guidance was developed and taken through the appropriate channels and posted on the intranet (Appx). The service was advertised through cascade, word of mouth and through education meetings. However as with many services it was a slow and gradual start with many referrals coming late in the diagnostic process. Encouraging clinicians to refer early is demanding an on-going process of education.

One of the aims of the service was to reduce inpatient stays for patients simply waiting for investigations that could be done as outpatients however this was inhibited by the lack of an outpatient clinic. Also the commissioner and lead GP were keen for a referral service to be made available to GPs but again without any extra funding as this was not new but redirected activity.

After discussion with the Upper GI oncologist there was agreement between clinicians that Dr Brooks could use a room in her clinic to see patients. Again negotiation with the Directorate management team only achieved agreement on the basis that this was a pilot within research time with no extra funding and using the existing clinic staff. And this was started as the second data collection period ended.

Initial problems in setting up this clinic included the fact that there was no two week wait unknown primary clinic type on the choose and book service and so Dr Brooks had to write to the national Choose and Book lead to get this set up.

**Implementing the new pathway for patients presenting with malignancy of undefined primary origin.**

The aim of this project was to evaluate the development of a pathway for patients presenting with metastatic cancer of unidentified primary origin. Therefore the evaluation process began as soon as patients started being referred to the service. This point signified the start of the six month period, and the identification of patients known henceforth as the post-cancer of unknown primary (CUP) pathway group.

As illustrated above the setting up and initiation of the pathway was more staggered than anticipated, with hospital procedures and systems leading to delays in establishing a primary investigation out-patient clinic for example.

The new pathway was advertised, as described earlier, in a number of ways to try and raise clinicians’ awareness regarding it. Despite these efforts it takes time for a new service to be embedded within a hospital and for referral pathways to be established. This is one of the disadvantages of evaluating the pathway during the developmental stage because it will have incomplete penetration and therefore the potential effect of the pathway may be blunted. It was underestimated how long it would take to fully establish the pathway and therefore more of the six month post pathway research period occurred during the transition phase of establishing the pathway than was anticipated. We would hope to go on to do a future project evaluating the effect of a fully implemented pathway.

* **Identifying the patients appropriate for the CUP pathway**

Within the research protocol it was highlighted that identifying the CUP population was a key element to be addressed. It is well recognised in the literature that this is a difficult group to characterise. This population is incredibly diverse in health status and mode of presentation. However, through the development and evaluation of this pathway for patients who present with metastatic disease of unidentified primary origin three distinct groups have emerged. Below we have given clinical examples to illustrate this and highlighted potentially the means by which they are integrated into the pathway.

For example some patients present with non-specific symptoms to their GP and are found to have abnormal liver function tests and subsequently on ultrasound liver metastases. If they have no clinical symptoms that suggest a primary tumour site then this patient is recognisable as a patient with malignancy of unknown origin and referral, should occur, to the primary investigation out-patient clinic which is part of the CUP pathway. As mentioned above it took time to establish this clinic and then for referral pathways from primary care to be established.

* **Primary care referral to Primary Investigation Out-patient Clinic**

Others initially present with metastatic disease but do have a symptom which suggests a primary site. This cohort need to be appropriately investigated by that site specific MDT , and if this site is excluded as the origin of the metastatic disease it is then appropriate to identify these patients as presenting now with CUP.

* **Initial Referral to CUP team for discussion at CUP MDT or patient review**

Another cohort of patients are those who are unwell and admitted to hospital. Metastatic disease may be listed amongst other disease processes as possible differential diagnoses. During the course of preliminary investigations it may become clear that the patient has metastatic cancer of unidentified primary origin.

* **Inpatient review on ward by CUP team**

These three scenarios illustrate the challenge in identifying patients who present with metastatic cancer of unidentified primary origin because they present to both primary and secondary care, and it is the absence of a diagnosis rather than specific presenting clinical symptoms or signs that links them. However as the NICE guidelines emphasise it is important to have a clinical team who are focused on having a consistent, cohesive approach dedicated to this challenging diverse population with the aim of minimising the symptom burden and only investigating further if it is going to change treatment.

This research was designed to evaluate the development of the pathway for those patients presenting with CUP. The challenges of developing this pathway has meant that the establishment of it and the embedding of the process took longer than was what anticipated therefore the experiences of patients pre and post pathway are not as distinct as we would have hoped.

Of the 38 patients in post pathway group:

8 (21%) were initiated on the pathway early in the diagnostic process

8 (21%) were referred for discussion at CUP MDT

5 (13%) were referred to the CUP team late in the diagnostic process

5 (13%) were picked up due to specialist palliative care referral

12 (32%) had no input from the CUP team

The cohort in the post CUP pathway group who had no input from the CUP team were identified afterwards for completeness through the same process as we used to identify the pre CUP pathway group.

A number of processes were used to try and ensure completeness and comparability of the group’s pre and post CUP pathway. Both groups include all of those patients who presented with metastatic disease of unidentified origin over a six month period. To identify the pre CUP pathway population we reviewed all the site specific MDT lists for this period, in addition to screening the serious/unexpected radiological findings and all patient admissions which had been coded C77-C80. This process was repeated after the completion of the post CUP pathway study period which enables some assessment to be made regarding the penetration of the pathway and the groups to be as comparable as possible in a population based research study.

* **Challenges with the accuracy of data and wider implications**
* **Coding**

Through the implementation and evaluation of this pathway for patients with metastatic disease of unidentified primary it has further highlighted the current difficulties in even identifying and coding these patients.

The WHO ICD (World Health Organisation International Classification of Disease) codes are used in the UK for capturing information regarding trends in diseases. CUP however does not have a specific code but is usually coded C77-C80. The definitions are listed below:

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **C77** |  | | **Secondary and unspecified malignant neoplasm of lymph nodes** | | | |
| **C78** |  | | **Secondary malignant neoplasm of respiratory and digestive organs** | | | |
| **C79** |  | | **Secondary malignant neoplasm of other sites** | | | |
| **C80** |  | | **Malignant neoplasm without specification of site** | | | |
|  | |  | | Cancer  Carcinoma  Carcinomatosis  Generalized:  · cancer  · malignancy  Malignancy  Multiple cancer | }  }  }  }  }  }  }  } | unspecified site (primary)(secondary) | |
|  | |  | | Malignant cachexia  Primary site unknown | | | |

|  |  |  |  |
| --- | --- | --- | --- |
|  | | | |
|  |  |  |  |  |
|  |  |  | | |

During this process we liaised with the CRH coding department, who explained the code C80 for example would be applied to anyone who has cancer in a secondary site which is unspecified, rather than exclusively to cases in which primary site of malignancy is unknown e.g. patients with CUP. In addition staff in the coding department are not medically trained and are dependent on the medical notes. Coding also applies to the final diagnosis pertaining to a specific inpatient admissions rather than the diagnostic journey which a patient has been on. Therefore some patients will initially have a provisional diagnosis of cancer of unknown primary, as per the NICE definition, then as a result of seeing a specialist and being integrated onto the CUP pathway then a primary site may be potentially identified. Therefore this patient would be coded using the primary site. Hence the complexity of these patients is inadequately described and yet these tools are used to define in part these populations.

* **National Databases**

National databases of patients with cancer are now kept so that systems can be audited and progress monitored. Open Exeter is a national database which is used in Chesterfield Royal Hospital (CRH). Information from Open Exeter helps, for example, audit waiting times and other targets. Through developing and evaluating this pathway it was highlighted that these databases are incomplete. For example if a decision is made on the ward not to investigate a patient with metastatic disease of unidentified origin further, then frequently their data would not be captured on the national database. The explanation is that database entries are made by the MDT co-ordinators and therefore is dependent on a patient being discussed, prior to the establishment of the CUP MDT, at a site specific MDT.

Different clinicians and site-specific MDT’s have different thresholds for diagnosing metastatic disease with a probable/possible site of primary tumour site rather than CUP. These practices impact on the collection of data on CUP for national statistics, and the development and usage of pathways such as this one.

**Estimating the financial cost of the investigatory period for patients presenting with metastatic cancer of unidentified origin.**

Analysing the financial implication of the pathway on the cost of the investigatory period in patients who present with metastatic cancer of unidentified origin was one of the aims of the research. It was of interest whether the pathway would have financial implications through patients having potentially fewer and more targeted investigations. Also the potential impact if the investigatory period for some patients took place as an outpatient, rather than an inpatient, with the introduction of the pathway.

The process of costing an investigatory period was more complex and protracted than initially envisaged. The financial implications of a new process can be priced with regard to the cost to the hospital itself or the primary health care trust (PCT). Within this report we have used the former based on estimated costs supplied by the finance department at CRH. We are awaiting a more in depth pricing which will be based on what the PCT was charged for each patient during their investigatory period.

**Flow Diagram of Process**

**Identification of Clinical Need**

-evidence of poor management of patients with CUP within the hospital.

**Liaison with Cancer Executive & Hospital Clinical Management Team**

-Recognised need for pathway

-No new funding available as deemed service redesign, rather than new clinical activity

**Development of NICE guidelines**

-involvement of lead clinician on committee NICE Guidance Development Committee on Diagnosis and management of metastatic malignant disease of unknown primary origin

**Development of Pathway within the Hospital**

-Agreed definition of appropriate patients

-Designed Service: CUP MDT, inpatient and outpatient referral and service

Data collection of Pre-Pathway Patients

Early NOV 2008-End APRIL 2009

Identified through

-Site-specific MDT’s

-Unexpected/serious radiological findings

-Coding of inpatient admissions

Data Collection of Post-pathway Patients

Mid APRIL 2010-Mid OCT 2010

Identified through

-Referral to pathway as inpatient, for discussion at MDT or as outpatient

-Referred to Palliative Care team and then identified by team as appropriate for pathway

-same means as Pre-pathway patients

**Initial Implementation of Pathway**

-Inpatient review and referral for discussion at MDT

**Subsequent Full Implementation of Pathway**

-Addition of Outpatient Clinic

-Delays due hospital systems and financial constraints, and unknown primary clinic not being recognised as a service on the choose and book system

**Planned development of pathway to improve participation**

-third phase of evaluation to detect whole effect of intervention

**Findings**

Evaluating the development of a pathway for patients presenting with metastatic cancer of unidentified primary origin occurred, as described above, over two six-month periods: pre-CUP pathway early Nov 2008-end April 2009 and during implementation of CUP pathway Mid-April 2010-Mid Oct 2010.

The findings of the research are presented below in two formats. The first is with these two cohorts grouped together so general characteristics of patients who present with metastatic disease of unidentified primary origin can be described. Then the two groups are compared. It should be highlighted that the post-pathway group was collected during the period of development and implementation of the pathway, with some of the services within the pathway, such as outpatient clinic, not being established until well into this period.

1. **Sample characteristics** 
   1. **Age-gender (whole group)**

The age range of participants was from 44-98 years old (mean = 72.51; SD = 11.21; median = 75). Forty-eight patients were female (54.5%) and 40 were male (45.5%).

* 1. **Performance status (whole group)**

The ECOG (Eastern Cooperative Oncology Group)performance status scale was used in assessing this area (Oken et al., 1982). In this scale, the higher the number, the greater the impact of disease or disability on normal activities. 0 represents full activity, while 4 indicates complete disability. In cancer care, oncological treatment would be thought appropriate for those whose performance status was 0 or 1, with consideration of the appropriateness of treatment for those with a performance status of 2.

Table 1 shows the performance status of patients in the sample.

**Table 1: Frequency of Performance status**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | | Frequency | Percent | Valid Percent | Cumulative Percent |
| Valid | 0-1 | 20 | 22.7 | 23.0 | 23.0 |
| 2 | 15 | 17.0 | 17.2 | 40.2 |
| 3-4 | 52 | 59.1 | 59.8 | 100.0 |
| Total | 87 | 98.9 | 100.0 |  |
| Missing | System | 1 | 1.1 |  |  |
| Total | | 88 | 100.0 |  |  |

Twenty patients (22.7%) had a performance status of 0-1, 15 patients (17.0%) had a performance status of 2 and 52 patients (59.1%) had a performance status of 3-4.

This group is a relatively elderly group, fairly evenly divided as to gender. A minority had a performance status at a level where treatment would be considered, with a majority being moderately or highly disabled.

1. **Presentation of metastatic disease**

**Imaging modality (whole group)**

For all patients in the group, with one exception, the presence of metastatic disease was discovered from imaging: x-ray, ultrasound scan, CT (computerised tomography) scan, MRI (magnetic resonance imaging) scan, or bone scan (using isotopes).

Table 3 shows the distribution of the imaging modalities for the patients in the sample.

**Table 3: Imaging modality**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | | Frequency | Percent | Valid Percent | Cumulative Percent |
| Valid | X-ray | 13 | 14.8 | 14.8 | 14.8 |
| CT scan | 39 | 44.3 | 44.3 | 59.1 |
| Ultrasound scan | 28 | 31.8 | 31.8 | 90.9 |
| MRI scan | 5 | 5.7 | 5.7 | 96.6 |
| Bone scan | 2 | 2.3 | 2.3 | 98.9 |
| No imaging - found during surgery | 1 | 1.1 | 1.1 | 100.0 |
| Total | 88 | 100.0 | 100.0 |  |

The most commonly occurring imaging modality was CT scan , which occurred in 39 of the patients (44.3%). The data illustrate the value of CT scan and ultrasound scanning, alongside plain x-ray investigation, in identifying metastases. A wide range of presentations of metastases was found: these data are summarised below.

From the 13 x-rays, six instances of pleural effusion (with or without masses) were identified; six instances of lung or pleural metastases, and one instance of bone metastases.

From the 39 CT scans, 13 instances of liver metastases were identified, including 7 with additional metastases at other sites; 7 instances of ascites/abdominal or pelvic mass; 9 instances of brain metastases; 4 instances of lung metastases (with or without other metastases); 4 instances of enlarged lymph nodes (with or without other metastases); one instance of hydronephrosis, and one instance of skull lesions.

From the 28 ultrasound scans, 23 instances of liver metastases were identified; three instances of ascites (with or without masses); one enlarged lymph node and one pleural effusion.

From the 5 MRI scans, 3 instances of brain, spinal cord, or extradural masses were identified; one instance of bone metastases associated with malignant spinal cord compression, and one instance of liver metastases.

From the 2 bone scans, two instances of bone metastases were identified.

1. **Investigations and care at Chesterfield Royal Hospital**
   1. 'Number of CRH admissions'

Sixty-three patients (71.6%) had one CRH admission, 11 patients (12.5%) had two CRH admissions and one patient each had three and four CRH admissions. Twelve patients had no CRH admissions (13.6%). The total number of nights spent in hospital varied from 0 (n=12) to 45 nights (mean = 14.13 nights; median = 13 nights).

* 1. 'Number of day case attendances and in-patient stays '

Eighty-two of the patients (93.2%) had no day case attendances and three patients had one day case attendance and three had two day case attendances. One patient (1.1%) had one in patient day stay, the remainder had none (n=87).

* 1. 'No of clinic appts'

Over half of the patients had no clinic appointments (52.3%; n=46), 10.2% had one (n=9), 17.0% had two clinical appointments (n=15) and 12.5% had three (n=11). Seven people had four or more clinic appointments.

Over half of the patients had their investigatory period as in-patients. For most, this meant a single admission to hospital. A minority had no hospital admissions, and were able to have their investigations as out-patients. Where patients had out-patient appointments, multiple appointments were more common than a single appointment.

* 1. Costs associated with hospital admissions

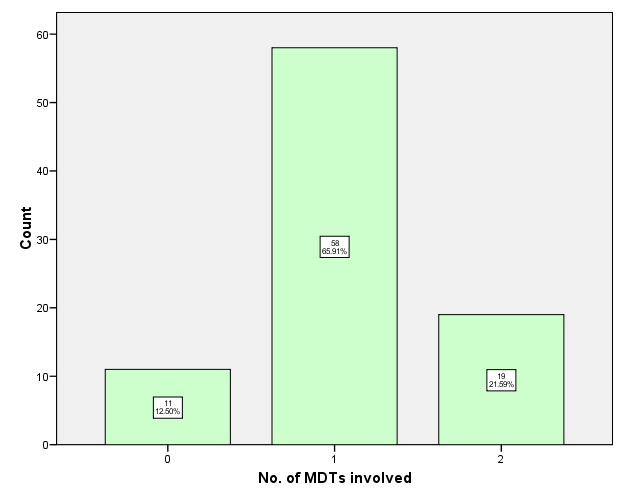
The total estimated cost of nights spent in hospital varied from £0 to £7830 (mean = £2457; median = £2262).

For the three patients who had a single day case attendance, the total cost = £135 per patient, and for the three who had two day case attendances the total cost = £270 per patient. Cost data was not available for the in-patient day stay.

1. **No. of site-specific MDTs involved, including Cancer of Unknown Primary MDT (whole group)**

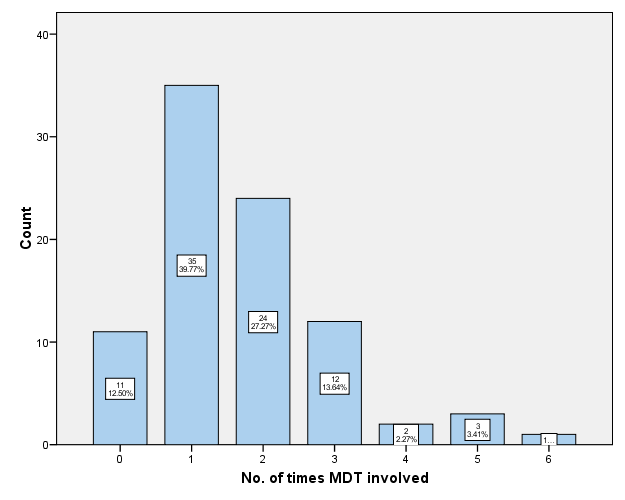
Figure 1 shows a bar chart to show the frequency of patients with different numbers of multi-disciplinary teams (MDT) involved.

**Figure 1: Frequency of patients with different numbers of multi-disciplinary teams involved**



Fifty-eight patients (65.9%) had one site-specific MDT involved and 19 patients had two site-specific MDTs involved (21.6%). Eleven patients (12.5%) had no site-specific MDT involved. Involvement of one site-specific MDT was the commonest situation. For the patients with no site-specific MDT recorded, discussion happened at ward level rather than at a formal meeting.

**Figure 2: Distribution of the number of times an MDT was involved.**



The total number of times that the MDT was involved varied from 0 to 6 (mean = 1.68; median = 1.00).

1. **Referral for oncology care or other tumour-directed treatment**

Forty patients (45.5%) had onward referral for tumour-directed treatment. For forty patients (45.5%) onward referral was not considered suitable, and eight patients (9%) died before a decision on onward referral could be made.

Table 4 shows details of the oncological or other tumour –directed treatment.

**Table 4: Tumour Directed Treatment (TDT) -Referral decision and outcome of plan**

|  |  |  |
| --- | --- | --- |
| **Referral decision and outcome of plan** | **Number** | **%** |
| TDT not given - decision not to refer | 40 | 45.5 |
| TDT not given - did not reach decision point | 8 | 9.1 |
| Tumour Directed Treatment given as planned/or with modifications | 23 | 26.1 |
| TDT planned, but not begun, as too ill | 7 | 8.0 |
| TDT offered but declined | 1 | 1.1 |
| TDT begun, but stopped, as too ill | 6 | 6.8 |
| TDT held in readiness | 1 | 1.1 |
| TDT not given - decision not to attempt treatment | 1 | 1.1 |
| TDT not given -patient declined further investigations/treatment | 1 | 1.1 |
| **Total** | **88** | **100.0** |

Twenty-three patients had tumour-directed treatment as planned or with modifications (26.1%), seven patients (8.0%) had tumour-directed treatment planned but the patient was too ill for it to begin and six patients (6.8%) commenced tumour-directed treatment but this was stopped because the patient was too ill.

Of the 23 patients who had treatment as planned or with modifications; 8 had radiotherapy; 7 chemotherapy; 3 a combination of radiotherapy and chemotherapy; 2 had surgery; 1 endocrinal treatment; one a combination of surgery and radiotherapy; and one a combination of surgery and chemotherapy. Of the six who began treatment, but had to stop because they were too ill, 5 had chemotherapy and 1 radiotherapy.

1. **Final diagnosis**

Forty-three patients (48.9%) had a final diagnosis of cancer of unknown primary, and 45 patients (51.1%) did not have a final diagnosis of cancer of unknown primary.

**Site or sites of final diagnosis**

Table 2 shows the distribution of final diagnoses of the patients in the sample.

**Table 2: Final diagnoses grouped**

|  |  |  |  |
| --- | --- | --- | --- |
| Final Diagnosis | Total  Frequency | Total % | Cumulative % |
| CUP | 43 | 48.9 | 48.9 |
| Lung | 14 | 15.9 | 64.8 |
| Colorectal | 9 | 10.2 | 75.0 |
| Upper GI | 4 | 4.5 | 79.5 |
| Pancreatic | 2 | 2.3 | 81.8 |
| Hepatobiliary | 1 | 1.1 | 83.0 |
| Lymphoma | 2 | 2.3 | 85.2 |
| Brain | 2 | 2.3 | 87.5 |
| Breast | 1 | 1.1 | 88.6 |
| Gynae/Ovarian/Peritoneal | 4 | 4.5 | 93.2 |
| Prostate | 1 | 1.1 | 94.3 |
| Urological (excluding prostate) | 2 | 2.3 | 96.6 |
| Neuro-endocrine/carcinoid | 2 | 2.3 | 98.9 |
| Mesothelioma | 1 | 1.1 | 100.0 |
| **Total** | **88** | **100.0** |  |

**Place of death**

43.2% of patients died in the Chesterfield Royal Hospital (n=38), 19.3% died at the Ashgate Hospice (n=17) and 21.6% died at home (n=19). Of the remainder, 7.9% (n=7) were still living at the time of review, three died in Whitworth Hospital, and one died in each of The Royal Hallamshire Hospital, Weston Park Hospital and the Northern General Hospital.

1. **Differences between Pre-pathway and Post-pathway groups**
2. **Age-gender**

There was no statistically significant difference in the mean rank of the ages of the pre-pathway patients compare with the post-pathway patients (W=928; Z = 0.853; *p*=0.853). The mean rank for the 50 pre-pathway patients was 44.94 and for the post-pathway patients it was 43.92. There was no statistically significant association between gender whether the patient was pre-pathway or post-pathway (χ2=0.00; df=1; *p*=1) Of the 38 post-pathway patients, 21 (55.3%) were female compared with 27 of the pre-pathway patients (54.0%).

1. **Performance status**

There was no significant difference between the pre-pathway patients and the post-pathway patients in terms of the performance status (χ2trend =0.261; df=1; *p*=0.610). Of the 49 pre-pathway patients, nine (18.4%) had a performance status of 0-1, 11 patients (22.4%) had a performance status of 2 and 29 patients (59.2%) had a performance status of 3-4. Of the 38 pre-pathway patients, 11 (28.9%) had a performance status of 0-1, four patients (10.5%) had a performance status of 2 and 23 patients (60.5%) had a performance status of 3-4

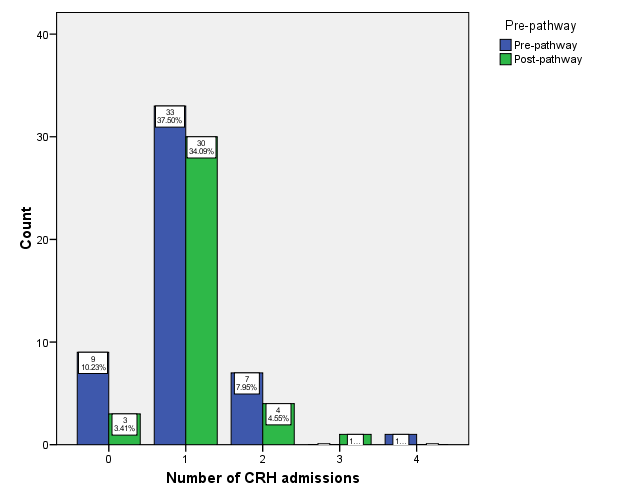
1. **Investigations and care at Chesterfield Royal Hospital**
2. 'Number and cost of CRH admissions'

Table 7 and Figure 4 show the number of admissions according to pathway.

**Table 7: Cross-tabulation of number of CRH admissions according to pathway**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | |  | Pre-pathway | | Total |
| Pre-pathway | Post-pathway |
| Number of CRH admissions | 0 | Count | 9 | 3 | 12 |
| % within Pre-pathway | 18.0% | 7.9% | 13.6% |
| 1 | Count | 33 | 30 | 63 |
| % within Pre-pathway | 66.0% | 78.9% | 71.6% |
| 2 | Count | 7 | 4 | 11 |
| % within Pre-pathway | 14.0% | 10.5% | 12.5% |
| 3 | Count | 0 | 1 | 1 |
| % within Pre-pathway | .0% | 2.6% | 1.1% |
| 4 | Count | 1 | 0 | 1 |
| % within Pre-pathway | 2.0% | .0% | 1.1% |
| Total | | Count | 50 | 38 | 88 |
| % within Pre-pathway | 100.0% | 100.0% | 100.0% |

**Figure 4: number of admissions to Chesterfield Royal Hospital according to pathway**



Thirty-three of the pre-pathway patients had one CRH admission (66.0%) and 30 of the post-pathway patients had one CRH admission (78.9%). Seven of the pre-pathway patients had two CRH admissions (14.0%) and four of the post-pathway patients had two admissions. Nine pre-pathway patients had no admissions (18.0%) and three post-pathway patients had no admissions (7.9%).

For the pre-pathway group, the total number of nights spent in hospital varied from 0 (n=9) to 40 nights (mean = 14.04 nights; median = 13.5 nights). For the post-pathway group, the total number of nights spent in hospital varied from 0 (n=3) to 45 nights (mean = 14.24 nights; median = 13.00 nights). There was no significant difference between the pre-pathway patients and the post-pathway patients in the mean total number of nights spent in hospital (t=-0.088; df=86; *p*=0.930).

1. 'No of clinic appts'

Six of the pre-pathway patients had one clinic appointment (12.0%) and three of the post-pathway patients (7.9%) had one clinical appointment. Twenty-six of the pre-pathway patients (52.0%) had no clinic appointments and 20 post-pathway patients had no clinic appointments. (52.6%).

1. 'Number of day case attendances and in-patient stays'

Three of the pre-pathway patients (6.0%) had one day case attendance and three had two day case appointments (6.0%). None of the post-pathway patients had any day case attendance. One of the pre-pathway patients had one inpatient day stay, but none of the post-pathway patients had an inpatient day stay.

1. Costs associated with hospital admissions

The total estimated cost of nights spent in hospital varied within the pre-pathway patient group from £0 to £6960 (mean = £2442.96; median = £2349) and in the post-pathway group from £0 to £7830 (mean = £2477.21; median = £2262).

1. **No. of site-specific MDTs involved, including Cancer of Unknown Primary MDT**

Among the pre-pathway patients, the total number of times that the MDT was involved varied from 0 to 5 (mean = 1.72; median = 1.00) and among the post-pathway patients, the total number of times that the MDT was involved varied from 0 to 6 (mean = 1.63; median = 1.00).

1. **Referral for oncology care or other tumour-directed treatment**

Twenty two of the pre-pathway patients (44%) received onward referral for tumour-directed treatment compared with 18 of the post-pathway patients (47.4%). For 23 (46%) patients in the pre-pathway group onward referral was not considered suitable; and for 17 (44.8%) patients in the post-pathway group onward referral was not considered suitable. Five patients in the pre-pathway group (10%) , and 3 (7.9%) in the post-pathway group died before a decision on onward referral could be made.

Fourteen of the pre-pathway patients (28.0%) had tumour-directed treatment as planned or with modifications and nine of the post-pathway patients (23.7%) had tumour-directed treatment as planned or with modifications. One of the pre-pathway patients (2.0%) had tumour-directed treatment planned but it was not begun because they were too ill, and six of the post-pathway patients (15.8%) had tumour-directed treatment planned but it was not begun because they were too ill. Four of the pre-pathway patients (8.0%) commenced tumour-directed treatment but it was stopped because they were too ill, and two of the post-pathway patients (5.3%) commenced tumour-directed treatment but it was stopped because they were too ill.

Of the 14 patients pre-pathway who had treatment as planned or with modifications; 4 had radiotherapy; 3 chemotherapy; 3 a combination of radiotherapy and chemotherapy; 2 had surgery; one a combination of surgery and radiotherapy; and one a combination of surgery and chemotherapy. Of the four who began treatment, but had to stop because they were too ill, 3had chemotherapy and 1 radiotherapy.

Of the 9 patients pre-pathway who had treatment as planned or with modifications; 4 had radiotherapy; 4 chemotherapy; and 1 had surgery. Of the two who began treatment, but had to stop because they were too ill, both had chemotherapy.

1. **Final diagnosis**

There was no significant difference between the pre-pathway patients and the post-pathwapatients in terms of the final diagnosis (χ2 =0.00; df = 1; *p*=1.00). Of the 50 pre-pathway patients, 24 patients (48.0%) had a final diagnosis of cancer of unknown primary, and 26 patients (52.0%) did not have a final diagnosis of cancer of unknown primary. Of the 38 pre-pathway patients, 20 patients (52.6%) had a final diagnosis of cancer of unknown primary, and 18 patients (47.4%) did not have a final diagnosis of cancer of unknown primary.

**Table 5: Cross-tabulation - Final diagnoses grouped according to pathway**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Pre-pathway**  **Frequency** | ***Pre-pathway %*** | **Post-pathway**  **Frequency** | ***Post-pathway %*** | **Total**  **Frequency** | ***Total %*** |
| CUP | 24 | *48.0* | 19 | *50.0* | 43 | *48.9* |
| Lung | 8 | *16.0* | 6 | *15.8* | 14 | *15.9* |
| Colorectal | 7 | *14.0* | 2 | *5.3* | 9 | *10.2* |
| Upper GI | 3 | *6.0* | 1 | *2.6* | 4 | *4.5* |
| Pancreatic | 1 | *2.0* | 1 | *2.6* | 2 | *2.3* |
| Hepatobiliary | 1 | *2.0* | 0 | *0.0* | 1 | *1.1* |
| Lymphoma | 0 | *0.0* | 2 | *5.3* | 2 | *2.3* |
| Brain | 0 | *0.0* | 2 | *5.3* | 2 | *2.3* |
| Breast | 0 | *0.0* | 1 | *2.6* | 1 | *1.1* |
| Gynae/Ovarian/Peritoneal | 3 | *6.0* | 1 | *2.6* | 4 | *4.5* |
| Prostate | 0 | *0.0* | 1 | *2.6* | 1 | *1.1* |
| Urological (excluding prostate) | 1 | *2.0* | 1 | *2.6* | 2 | *2.3* |
| Neuro-endocrine/carcinoid | 2 | *4.0* | 0 | *0.0* | 2 | *2.3* |
| Mesothelioma | 0 | *0.0* | 1 | *2.6* | 1 | *1.1* |
| **Total** | **50** | ***100.0*** | **38** | ***100.0*** | **88** | ***100.0*** |

**Time from instigation of definitive treatment to death, and time from CUP referral to death**

There was no difference between the pre-pathway patients and the post-pathway patients in the mean rank of the time from instigation of definitive treatment to death (Z=-0.607; p=0.544). The mean rank for the 42 pre-pathway patients was 34.58 and the mean rank for the 32 post-pathway patients was 31.60.

There was no difference between the pre-pathway patients and the post-pathway patients in the mean rank of the time from CUP referral to death (Z=-1.488; p=0.137). The mean rank for the 48 pre-pathway patients was 43.66 and the mean rank for the 32 post-pathway patients was 35.77. The median time from CUP referral to death for the pre-pathway patients was 43.50 days (n=46; 2 missing) and the median time from CUP referral to death for the post-pathway patients was 35.00 days.

There does not appear to be any impact on survival following the introduction of the new pathway. If there is any change in survival associated with the pathway, it can only be confined to longterm survivors for whom we have insufficient data to detect an effect.

**Place of death**

We speculated that a death in Chesterfield Royal Hospital, as opposed to a death elsewhere, might be a proxy for an incomplete resolution to the investigatory period. The grounds for this are that in those cases where care reached a point of resolution, patients would ideally be discharged home, or referred to tertiary care.

There was a difference between patients who died in the pre-pathway group and the post-pathway group in whether they died in the Chesterfield Royal Hospital or elsewhere, although this did not reach statistical significance (χ2=3.255; df=1; *p*=0.071). Of the 48 pre-pathway patients who had died, 27 died in Chesterfield Royal Hospital (56.3%), whereas only 11 of the 33 post-pathway patients who had died (33.3%) died in Chesterfield Royal Hospital.

The table shows the full details of place of death in the two groups.

|  |  |  |
| --- | --- | --- |
| **Place of death** | **Pre-pathway** | **Post-pathway** |
| Chesterfield Royal Hospital | 27 (54%) | 11 (28.9%) |
| Whitworth Hospital | 2 (4%) | 1 (2.6%) |
| Weston Park Hospital | 0 | 1 (2.6%) |
| Northern General Hospital | 0 | 1 (2.6%) |
| Royal Hallamshire Hospital | 1 (2%) | 0 |
| Ashgate Hospice | 10 (20%) | 7 (18.4%) |
| Home (or relative's home) | 7(14%) | 12 (31.6%) |
| Place of death unknown | 1 (2%) | 0 |
| Living at time of review | 2 (4%) | 5 (13.2%) |
| **Total** | **50 (100%)** | **38 (100%)** |

# There are some points to note about place of death in the two groups. More people died at home in the post-pathway group: 7 people in the pre-pathway group and 12 people in the post-pathway group. Numbers are small however, and could have arisen due to chance. Of the pre-pathway group , 30 died in hospital (60%), and of the 38 post-pathway group , 14 died in hospital (37%). Of the 50 pre-pathway patients, 10 died in a hospice (20%), and of the 38 post-pathway patients, a similar proportion, 7 (18,4%), died in a hospice.

**Outcomes**

**Main outcome** There was no difference between the pre-pathway patients and the post-pathway patients in the mean rank of the time from CUP referral to instigation of definitive treatment (Z=-1.2348; p=0.217), although the small sample size may have resulted in the significance not being detected (Type 1 error) and it is difficult to draw meaningful conclusions from this. The mean rank for the 44 pre-pathway patients was 40.05 and the mean rank for the 32 post-pathway patients was 33.77.

The range in the pre-pathway group was from 0 to 115 days, and the range in the post-pathway group was from 0 to 74 days. This indicates that it is possible that the intervention shortens the pathway of those who wait the longest for definitive treatment.

There was no difference between the pre-pathway patients and the post-pathway patients in the mean rank of the time from referral for specialist palliative care (Z=-0.716; p=0.474) although the small sample size may have resulted in the significance not being detected (Type 1 error) and again it is difficult to draw meaningful conclusions from this. The mean rank for the 41 pre-pathway patients was 36.96 and the mean rank for the 29 post-pathway patients was 33.43.

This might suggest that existing routes of referral to palliative care have been functioning satisfactorily. It is possible that referral to palliative care had already triggered some targeted investigations into cancer of unknown primary.

**Report of patient experiences**

The study design included questionnaires and interviews with patients from both the pre-pathway and post pathway part of the study. As noted in the methodology section, part of the project itself concerned issues of identifying patients for the study. Additionally, some patients would be too unwell, or too near the end of life for participation in a study. Consequently, we were expecting only a limited number of patients to be able to participate in this part of the study. The institution of the intervention meant that different routes of recruitment were used in the two parts of the study, and different time points. This, alongside the small numbers involved, meant that formal comparisons between the pre and post pathway patients would not be appropriate.

The data provide important qualitative information about the experiences of patients: of their illness, time in hospital, care as outpatients, and their thoughts and feelings about the process.

**Recruitment of patients**

For the questionnaire section, five patients were recruited in the pre-pathway part of the study, and five in the post pathway part. The different schedule for post-pathway patients was designed to recruit them at an earlier stage, and follow them up during their subsequent care. In fact, as described in an earlier section; identification of patients continued to be an issue, since procedures for the new pathway had not had long enough to be completely embedded into care at the hospital.

**Questionnaires for patients**

There were three elements to the patient questionnaires: the Palliative Outcome Scale (POS); dealing with symptom burden and psychosocial issues; the Organisation for Research on Treatment of Cancer Quality of Life Questionnaire 15-item version for Palliative Care (EORTC QLQ-C15-PAL) dealing with activities of daily living as well as symptoms, and including a global quality of life measure; and the Patient Enablement Instrument (PEI). The PEI measure the extent to which consultations have enabled understanding and coping with illness and with life.

Review and clarification of the of the study sample time in the post-pathway group meant that the care for one individual who had completed questionnaires was found to fall slightly outside the study period. This data has been retained in the report.

Overall the numbers across the two groups are too small for meaningful comparison. They do provide, however, important qualitative data from a group of people presenting with with cancer of unknown primary who were receiving care.

**Symptoms: physical and psychological**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **(POS) Over the last three days, have you been affected by pain/other symptoms?** | | | | | |
| **Symptom** | **Not at all** | **Slightly** | **Moderately** | **Severely** | **Overwhelmingly** |
| Pain | 3 | 2 | 3 | 2 | 0 |
| Other symptoms | 4 | 2 | 3 | 1 | 0 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **(POS) Anxiety and worry over the last three days** | | | | | |
| **Symptom** | **Not at all** | **Occasionally** | **Sometimes** | **Most of the time** | **Always preoccupied** |
| Have you felt anxious/worried about your illness/treatment? | 3 | 1 | 4 | 2 | 0 |
| Have your family/friends been anxious/worried about you? | 0 | 2 | 3 | 3 | 2 |

Family members/friends were reportedly more anxious than patients themselves.

|  |  |
| --- | --- |
| **(POS) Over the last three days, have you been able to share how you are feeling with friends and family?** | |
| Yes, as much as I wanted to | 6 |
| Most of the time | 3 |
| Sometimes | 0 |
| Occasionally | 0 |
| No, not at all | 1 |
| **Total** | **10** |

With one exception, this picture is a positive one.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **(POS) Over the last three days, have you felt that life was worthwhile/Have you felt good about yourself as a person?** | | | | | |
|  | **Yes, all of the time** | **Most of the time** | **Sometimes** | **Occasionally** | **No, not at all** |
| Have you feel that life was worthwhile? | 7 | 3 | 0 | 0 | 0 |
| Have you felt good about yourself as a person? | 3 | 4 | 3 | 0 | 0 |

Participants reported feeling life to be worthwhile all or most of the time, with seven of the ten feeling good about themselves as a person all or most of the time.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **(Q-PAL) Over the last week, have you had pain/other symptoms?** | | | | |
| **Symptom** | **Not at all** | **A little** | **Quite a bit** | **Very much** |
| Pain | 2 | 3 | 4 | 1 |
| Shortness of breath | 3 | 3 | 3 | 1 |
| Trouble sleeping | 2 | 3 | 3 | 1 |
| Feeling weak | 1 | 3 | 4 | 2 |
| Lacking appetite | 4 | 2 | 1 | 3 |
| Feeling nauseated | 4 | 3 | 1 | 2 |
| Feeling constipated | 4 | 2 | 2 | 2 |
| Feeling tired | 2 | 2 | 3 | 3 |
| Did pain interfere with your daily activities? | 4 | 2 | 3 | 1 |
| Did you feel tense? | 3 | 2 | 5 | 0 |
| Did you feel depressed? | 4 | 4 | 1 | 1 |

**Activities of daily living**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **(Q-PAL) Rating activites of daily living** | | | | |
|  | **Not at all** | **A little** | **Quite a bit** | **Very much** |
| Do you have any troule taking a short walk outside of the house? | 3 | 1 | 2 | 4 |
| Do you need to stay in bed or in a chair during the day? | 3 | 3 | 2 | 2 |
| Do you need help with eating, dressing, washing yourself, or using the toilet? | 6 | 1 | 2 | 1 |

Reported symptom burden can be seen to have been considerable in this patient group, with weakness and tiredness the symptoms experienced the most, followed by pain and feeling tense. Nevertheless, eight of the ten participants rated their quality of life at 4 or above, on a 7-point scale: where 1=very poor and 7=excellent.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **(Q-PAL) Global Quality of Life Score (1-7 scale: where 1=very poor and 7=excellent** | | | | | | | |
| **Score** | **1** | **2** | **3** | **4** | **5** | **6** | **7** |
| **No of patients** | 0 | 1 | 1 | 2 | 4 | 2 | 0 |

In the two follow up questionnaires, one respondent reported increased symptoms, and one symptoms at about the same level. Both reported further restrictions on their activities of daily living. Global quality of life decreased one point for point respondents over time.

**Information giving, time wasted on appointments, and addressing practical matters**

|  |  |
| --- | --- |
| **(POS) Over the last three days, how much information have you and your family been given?** | |
| Full/as much as we wanted | 8 |
| Information given but hard to understand | 0 |
| Information given on request but we would have liked more | 1 |
| Very little given and some questions were avoided | 1 |
| None at all: when we wanted information | 0 |
| **Total** | **10** |

|  |  |
| --- | --- |
| **(POS) Over the last three days, how much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport, or repeating tests?** | |
| None at all | 8 |
| Up to half a day wasted | 1 |
| More than half a day wasted | 1 |
| **Total** | **10** |

|  |  |
| --- | --- |
| **(POS) Over the last three days, have practical matters resulting from your illness, either financial or personal been addressed?** | |
| Practical problems have been addressed and my affairs are as up to date as I would wish | 3 |
| Practical problems are in the process of being addressed | 5 |
| Practical problems exist which were not addressed | 0 |
| I have no practical problems | 2 |
| **Total** | **10** |

Respondents were invited to state what their main problems, if any, had been in the last three days. Four gave two problems, and one gave one.

The problems stated were:

*“Lack of appetite”* and *“mobility”*

*“Breathlessness, bedsores”* and *“constipation and mobility”*

*“get up in the night to go to the toilet”*

*“the frustress of not really knowing what going off”* and *“sure a lot more could have been done while I've kept waiting”*

These comments generally reflect the answers reported in other parts of the questionnaires.

**Patient Enablement Instrument**

Participants were asked to rate their responses in two way: firstly, in reference to their most recent consultation with a doctor at the hospital, and secondly, in reference to all the care they had received at Chesterfield Royal Hospital.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **As a result of your most recent consultation with the doctor at Chesterfield Royal Hospital, do you feel you are....** | | | | |
|  | **much better** | **better** | **same or less** | **not applicable** |
| **...able to cope with life?** | 3 | 3 | 3 | 1 |
| **...able to understand your illness?** | 4 | 2 | 4 | 0 |
| **...able to cope with your illness?** | 4 | 2 | 4 | 0 |
| **...able to keep yourself healthy?** | 2 | 3 | 3 | 2 |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **As a result of your most recent consultation with the doctor at Chesterfield Royal Hospital, do you feel you are....** | | | | |
|  | **much more** | **more** | **same or less** | **not applicable** |
| **...confident about your health?** | 3 | 1 | 5 | 1 |
| **...able to help yourself?** | 1 | 4 | 3 | 2 |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **As a result of the overall care you have received at Chesterfield Royal Hospital,**  **do you feel you are....** | | | | |
|  | **much better** | **better** | **same or less** | **not applicable** |
| **...able to cope with life?** | 4 | 3 | 2 | 1 |
| **...able to understand your illness?** | 3 | 5 | 1 | 1 |
| **...able to cope with your illness?** | 4 | 2 | 3 | 1 |
| **...able to keep yourself healthy?** | 2 | 3 | 3 | 2 |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **As a result of the overall care you have received at Chesterfield Royal Hospital,**  **do you feel you are....** | | | | |
|  | **much more** | **more** | **same or less** | **not applicable** |
| **...confident about your health?** | 1 | 5 | 3 | 1 |
| **...able to help yourself?** | 1 | 6 | 2 | 1 |

More respondents reported an increased enablement across the range of questions than reported it to be the same or less.

**Summary**

The data from the questionnaires indicates a considerable symptom burden for some patients, particularly weakness/tiredness, and pain. Nevertheless, all patients reported life to be worthwhile all or some of the time, and eight of the ten reported quality of life scores of 4 or above. Most reported receiving as much information as they wanted; practical problems being or having been addressed and no wasted time on appointments. More respondents reported an increased enablement after consultation or care across the range of questions, than reported it to be the same or less.

**Interviews with patients**

Interview data came from four patients altogether, three in the pre-pathway phase, and one following implementation of the pathway. Of the initial in the pre-pathway stage, one had died shortly after returning the initial questionnaires, and one, although willing to be interviewed, had become too ill for this to be carried out. In the period following implementation of the pathway, where the design of the study required recruitment at an earlier stage, 4 of the 5 participants became too ill, or had died, before the time point designated for interviews.

Semi-structured interviews were carried out, using an aide-memoir. The following areas were used as starting points for conversation, with the interviewer following the lead of the patient:

* *How did you come to be receiving care?*
* *Can you tell me something about the care you have received at Chesterfield Royal Hospital?*
* *Do you have any suggestions for how the care at CRH might work in the future?*
* *Do you have any other comments you would like to make?*

In the report below, major points from each of the interviews are summarised. There is then an overview of the interviews.

**Points from the interview with Patient A: pre-pathway**

* Good care with advance thinking by the orthopaedic surgeon
* Good pain control, *trauma manager* in charge of care for the first 48 hours
* Supposed to be MDTs, but not actually happening- found out later that surgeon not included in the MDT
* Initially several oncologists, then one central one – this was better
* Travel to Weston Park is difficult, would be better at CRH, but parking at CRH is as bad as parking at WPH
* Electronic transfer of scans etc very variable – could take up to two weeks
* Breaking of initial news- done by someone junior:“*I suppose they have to learn how to do it*- *I don’ t think it’s relevant to comment [....]can you break this news any other way? Maybe not...”*
* Further comment on emotionally destructive “*doom and gloom”* from the oncology registrars *: “destroyed me emotionally twice”*
* Good care from Macmillan nurses, especially at WPH . Focus around pain control, but “*I was driving this”*
* Excellent care at Chesterfield Royal
* More forthcomingness needed at Weston Park – had to insist on review of how the tumour was doing
* *“Don’t want this* [the report] *just to gather dust in a drawer”*

**Points from the interview with Patient B: pre-pathway**

* Began with saying there were no gripes with the care received at Chesterfield Royal Hospital.
* Illness began with pain in shoulder, then investigation, then bowel primary suggested. No primary found
* Moved from *‘this might /might not be cancer’,* to this definitely was cancer. *“Not ever discussed how this took place..”*
* Would have liked more credence given to his own observations on his condition
* Communication not always clear: holding back, going round the houses, sense of being kept in the dark
* Waiting time: for investigations, hinted also for other things.
* Emphasised NHS can’t help having waiting times etc: all under pressure
* Spell in the hospice to control pain, as facilities not available in hospital to do this
* Better for the chemotherapy
* Uncertainty remains around the diagnosis of cancer

**Points from the interview with Patient C: pre-pathway**

* Sense of loss after her stroke- all the things you can’t do any more
* Care in CRH was excellent – nothing to say about it
* Stroke in April, on three different wards: 3 weeks, 12 days, one other stay
* Not sure if there were three different consultants
* Doctors came on the round – not sure what they said
* Physio in hospital
* ‘*You don’t know how many tumours you’ve got*’
* Said it was unlikely to be from the hysterectomy four years ago, although this was cancerous
* Taking steroids – *“they make you eat and put on weight”*
* *“Luckily I have my son and he is my carer...”*
* Help at home from carers, with bathing and dressing
* Adaptations at home: bath with descending seat
* Some things were upsetting for her and we stopped a number of times, but she wanted to continue with the interview

The differences and similarities between these accounts are summarised below:

***How they came to be receiving treatment***

For one person (C) the route to admission was as an emergency, following a stroke, having previously been well. For another (A), an initial injury to his knee was followed by GP consultation, physiotherapy, then a GP emergency callout for suspected DVT, with emergency admission to A&E by ambulance. A pathological fracture to his femur occurred in the ambulance. For the third person (B), pain below the shoulder prompted consultation with the GP, medication, then referral for chest x-ray, which produced a phone call and urgent appointment with a lung surgeon.

*Well I had a stroke. I got out of bed one night and couldn’t get back in. I kind of just collapsed in the bathroom.* [Patient C]

*“In September 2008 I knelt down to repair a radiator in the lounge, and suffered great discomfort and pain in my knee. Ten days later I went to my local GP [..who..] referred me to the local physiotherapist [..who..] prescribed a series of exercises.... two weeks later, I was so uncomfortable [....]I rang the out of hours GP [...]he thought I had got a deep vein thrombosis [...] and arranged for me to be admitted [...]my left femur fractured in the ambulance....”* [Patient A]

*“Twelve months ago I started with a problem, with a pain just below my shoulder blade, and after trying to take normal household remedies to try and cure the problem, which wasn’t working. I decided I would go and see the GP [...] who decided to prescribe a type of pain killer, and also, it was a tablet that would reduce inflammation, to try and get rid of the problem. The course of the treatment was three weeks [..... ] I decided to go back to the GP [...who....] decided to refer me to the Royal Hospital [...]I did receive a phone call within forty eight hours [....]advising to go and see a lung surgeon.....”* [Patient B]

***Arriving at the diagnosis***

For patient A this happened quickly, with initial treatment for the fracture carried out, diagnosis of it as a pathological fracture, and scans identifying the primary. For patient B the process was more complex and longer, with a lump identified, but biopsies producing uncertainty as to whether this was malignant, and a search for a bowel primary proving negative. Chemotherapy was started, although the diagnosis still appeared uncertain, until at some point professionals started to talk about cancer rather than uncertainty. Patient C talked initially of a stroke, then later referred to tumours, and that where they had come from was unknown, as it was felt unlikely that the origin was a uterine malignancy treated some years ago.

***Ongoing treatment***

Patient A had the presenting fracture treated at CRH, followed by referral to an oncologist from WPH, and radiotherapy to the femur. There was then review by the orthopaedic surgeon at Chesterfield. Then chemotherapy as an outpatient at WPH, with scans after the 4th of 6 treatments. The main issue for patient A was pain, and this was well dealt with: initially in A&E, where a ‘trauma manager’ was allocated to ensure this and other trauma aspects were under control. Macmillan nurses were involved at WPH and CRH, with the WPH Macmillan nurse giving excellent support, particularly around pain management. He felt this process was driven by him (which he concluded was alright). Pain was well-enough controlled.

*“..the pain levels have been erm quite low. It might be worth mentioning something about pain management here, because from the beginning I was allocated a Macmillan nurse at Weston Park, also in Chesterfield. So I have two sources of Macmillan support, the main support seems to be, at this moment in time, at this stage in the process, pain control and pain management. And it has, it's been good, although I seem to drive it, and presumably that’s okay, because I judge my own pain levels. And they go along with that. So the pain management has been dealt with quite effectively. Its never a 100%. You are never totally pain free, but you get your pain levels down to a point where [?] you can live, and exist and you know talk to people...”* [Patient A]

Patient B’s experience seemed to centre on the uncertainty of whether this was or wasn’t cancer, and on the length of time waiting, although he also said that they had been quick to act. One investigation (colonoscopy) was not arranged quickly, leaving him waiting until Christmas Eve. The length of the process of diagnosis (October to Feb) seems to have made him comment on uncertainty and unclear information rather than delay. He was treated with several cycles of chemotherapy. He commented extensively on the problems of insufficient resources in the NHS (a political issue), while saying that staff are doing the best with what they have. He feels the reason he was admitted to Ashgate Hospice for pain control in the earlier part of the year rather than to Chesterfield was because of insufficient staff there to deal with monitoring that.

*“...The consultant, lung consultant did say that we wasn’t, they wasn’t sure whether or not it was cancerous or not. Erm, it was too close to call, but he did say your lungs are okay, but they thought that the cancer was coming from the bowels, which may or may not be, at this moment in time I am not sure..”.*

*“...However, whether or not it’s the, it’s a growth in the bowels I don’t know. Because this it has been identified as you very well know yourself on the letter that I received with the questionnaire before I filled it in, secondary cancer in the lung identified by an unknown source...”*

*“...I was an NHS patient, you expect delays. You expect problems...”* [Patient B]

Patient C’s comments on care were to do with adapting to a situation where she was disabled and unable to be independent, as she had been before. She had been prescribed steroids. She referred to hospital care rather generally, in the context of helping her until she was well enough to be at home, with adaptations and assistance.

“*I’m so very, you know feels as though you have had such a lot taken away from you. [...]When you used to be able to go out. As you wished, go in the garden as our wished. Do your own housework as you wished. Well you can put all that down”.*

*“And then I came home. And they had reduced the steroids, and then I fell again. So I went back into hospital again for another twelve days approximately. And then they reduced them again...”*

*“Very nice staff. I did try to be, look after myself you know shower. No I don’t know what else to say. Very nice food.” [Patient C]*

***Communication***

Patient A valued the care and communication about treatment on admission, and also the open communication from the orthopaedic consultant. He felt the information about the cancer could have been given more sensitively, and said this had been done by a junior doctor (also recognising that doctors may be learning this aspect). Other comments also illustrated the greater skill of the oncology consultant above that of the registrars. He felt that information on the progress of the illness/treatment had been hard to obtain. The registrars emphasised the gloomy aspects of the situation, whereas the consultant was compassionate and sympathetic. Patient A felt that some information had been harshly put, and had been emotionally difficult for him. He recognised that the disease could be controlled not cured, but wanted to take up other options such as trials, and felt that the oncology consultant was accommodating his wishes here.

*“Erm I was told initially by the house doctor, if that’s if that’s the expression, one of the junior doctors on the ward who had only just started. But I guess he’s got to start somewhere he’s got to learn. So I didn’t mind that at all. You know probably the first time he’s had to break such news to somebody like a patient”.*

*“But I think they could have been a little bit more forthcoming with some information, the registrars that I dealt were always doom and gloom erm, in fact they virtually destroyed me emotionally twice, when I went in and said, well we have found this problem with your kidneys; and I am thinking, oh dear, to put it bluntly. Erm and we have discovered this on erm, your right femur, but nothing very positive you know. Which is not what I want to hear, you can put it in a different way.”* [Patient A]

Patient B had his initial care at CRH, then investigation at the NGH, then care from a consultant at Weston Park (possibly at CRH – not clear from the interview). An episode of acute pain was treated at Ashgate Hospice. Regarding the hospital care, he felt that communication could have been much clearer and precise, that he would have preferred more direct communication without going round the houses. The uncertainty in arriving at a diagnosis made things difficult, and he said a number of times that he supposed he must have cancer, as he had been told so, but that he was not convinced. He was still waiting for a definite result. He would have liked his own feelings and observations on his illness to have been taken into account here, which they were not.

*“...I am the sort of person if I have got a problem I prefer to know about it. And I am sure there are thousands more like meself if they have got a problem, if you are going into hospital with something similar to what I have got you know darn well what, you have got an idea of what the problem is. Don’t go round the houses. Get to the point and get on with the job...”*

*“....everybody is saying to me that I have got cancer, but nobody is being precise about it [...]. I suppose I must have cancer,* *they are telling me I have got cancer, you put your life in their hands. And you take on board and you believe what they are telling you.*  *But I am not convinced that I have got cancer. I just am not convinced...”*

*“..some sort of feedback on what your feelings are and what you believe might be happening would be advantageous. But it was ignored...” [Patient B]*

Patient C said she could not remember very well, but spoke of different wards and perhaps different doctors. She felt perhaps she didn’t know what to say, and that the doctors didn’t have the patience for listening.

*“Well no you don’t know what to talk about I didn’t, I don’t think they have got patience to listen to you.” [smiles]*  [Patient C]

***Liaison between individuals/hospitals***

Patient A commented on a difference in approach between the orthopaedic surgeon and the oncologist, with the former wanting to identify and pre-emptively pin other compromised areas, and the latter wanting to wait and see. Patient A knew there was a multi disciplinary team, and said he was surprised that the orthopaedic surgeon was not part of this. Patient A noted that electronic images could take up to two weeks to travel from Chesterfield to Sheffield, although sometimes this process took only 24 hours. Patient A had seen more than one oncologist initially, which was confusing: the situation improved when it was made clear who would be managing this care. Travelling to CRH would be preferable to travelling to WPH- this had been very hard in the winter weather.

*“Or MDT’s, now obviously an essential part of that team, had it been operating when I was in, was the orthopaedic surgeon. And it has, it it's emerged through subsequent conversations with her, that at no stage has she been involved with further consultations with the oncologists as to er, treatment with an orthopaedic bias for me..”.*

*“On the oncologist front erm, I saw one or two oncologists initially, and was quite confused as to who I had to refer to in the early days of treatment. Before it was made clear that Dr [Name] was the consultant involved. And once I had left hospital all subsequent consultations have been through Dr [Name] and Weston Park”* [Patient A]

Patient B did not comment on liaison. He had had care at DRH, the Northern General Ashgate Hospice and WPH. Comments were focused on the strain on NHS staff, facilities under-resourced (an issue unresolved for political reasons), and on the uncertainty of the diagnosis.

*“...And find out what problems there are in hospitals, how stretched the doctors and nurses are to breaking point...”*

*“...instead of admitting me into the Royal Hospital they admitted me into Ashgate Hospice where I could be monitored twenty four hours a day, and the pain control could be sorted out, where they could try various drugs, various strengths of the drugs and see what was happening from a day to day basis. Which unfortunately could not be done at the Royal Hospital because they have not got the man power to be able to do that...” [Patient B]*

Patient C spoke more vaguely about this area: she referred to being on three different ward. Many people came round and she said it was difficult to know who was in charge. She said the stroke and the steroid treatment made it hard for her to remember names.

“*...They kind of all came round and er, and you didn’t know who was in charge that was the trouble.”*

***Quality of Care received***

Patient A felt the care at Chesterfield Royal was excellent and that people were on the ball. Patient B felt the care was pretty good. Patient C said the care was excellent.

*“In terms that the care that I have received from the moment I was sent into Chesterfield Royal Hospital as an emergency admission, the care on, on entering into the hospital was excellent. They were very much on the ball.”* [Patient A]

*“I found the care pretty good. I found it pretty good [.....] I find that the treatment I have received from them has been very ,very good. Erm they have been quick to act, they have been very courteous.”*  [Patient B]

*“Oh no it was excellent actually, and all the gadgets I have got at home are wonderful.”*

*“.....everything is excellent actually. I couldn’t decry them in anything.”* [Patient C]

**Post pathway interviews**

There was a single interview, and points from this interview are summarised below, followed by a section relating this to the earlier interviews from the pre-pathway stage.

**Points from the post pathway interview**

* Long delay in referral to hospital, following their consultation with the GP with urological symptoms.
* Previous traumatic episode with complications from treatment of breast lump
* Traumatic family history of cancers
* Very shocked at the poor care she saw on the ward she was admitted to, not so much for herself, but for the elderly patients whose care she described as neglectful
* Distress at being led to believe initially that the tumour was operable
* Reported excellent care from the oncologist and from the palliative care physician
* Praised the full communication from the consultants,
* Pleased to be valued by them and by new GPs: “they make you feel like you are worth something..”
* Offered additional psychological support, in view of the history, but does not feel this is necessary

***How they came to be receiving treatment Post-pathway***

This person consulted their GP with tongue numbness, and was admitted to hospital with a suspected stroke.

*“....me tongue went a bit numb, and er I want to me local GP, and he thought I had had a stroke. So he sent me into hospital.”*

***Arriving at the diagnosis -Post-pathway***

The CT scan showed a lesion in the head, thought to be a secondary tumour. Further CT and MRI scans showed a kidney tumour and lung nodules.

*“And they gave me a CT scan and they found a lesion in me head.[....] Then er, one of the doctors came to see me, it was cancer, and she said it had actually come from somewhere else. But there was a primary tumour. And I had er, what’s it an MRI and CAT scan and it showed up that I had a very large tumour on me kidney and some small ones nodules in me lungs.”*

***Ongoing treatment -Post-pathway***

This patient reported being led to believe originally that the cancer was operable, at least one of the tumours. It seemed that at oncology review this turned out not be the case, to her great distress. Radiotherapy followed, and then follow up care was from the palliative care physician.

*“...that’s another thing and all with doctor at er Chesterfield Royal she led me to believe that that was operable and this was operable. And all they would take it out [....] So that gave me a bit of hope and then I just broke down in his office when I saw him. You know told me he wasn’t going to touch them. It was the first time I saw him out patients at Royal. Then I went for radiotherapy, up at Weston Park. Yes he were brilliant. Really good. Then I saw [Palliative Care Consultant] after that and he’s wonderful, he explains everything to you keeps nothing from you.”*

***Communication Post Pathway***

There was praise for the communication by oncology and palliative care from this person: in particular, explaining everything, concealing nothing, and treating them as a person of value. Further psychological support had been suggested, in view of the history, but this was not wanted. The consultants’ care was described as very good.

“*Several times yes. Really nice. And you get everything explained to you,you know..”*

*“The one thing that does bug me, is that even with [oncologist] and [palliative care consultant], Macmillan nurses and me doctor all think I should see a psychiatrist because not crying and moaning and you know”.*

*(Interviewer: “And what do you think?”)*

*“Well it's happened what am I going to do? There is nothing. No amount of getting depressed and everything is going to make it any better is it? So just get on with life don’t you? That’s it.”*

*“Mmh I can’t fault treatment I have had off [oncologist] and [palliative care consultant]really, really good”.*

***Liaison between individuals/hospitals Post Pathway***

This patient did not raise liaison issues, but gave praise to the oncology and palliative care doctors. She did have criticisms of a delay of some years on the part of the GP in referring her on, following her initial reporting of symptoms.

*“Say the only thing I’m angry about is what’s ... going on with me GP over last four year. Cos I do believe if they had investigated those blood tests they could have caught that in time. And it won’t have spread. You know. It is annoying especially as there is a lot of cancer in our family”.*

***Quality of Care received Post-pathway***

This patient reported extremely poor care on the ward she was in. Her concerns were not for her own care, but for that given to others, particularly a number of elderly patients.

*“There were things that went on that ward when I was in there you wouldn’t – just would not believe it. There was a little old lady in bed next to me she was laughing and joking with me. And er, you know that camera down your throat and they ripped her gullet. And they just after about two or three days they just took all her tubes out and left her to die. You know - so other woman across from me. I don’t know what they are the ones that wear the yellow uniforms. I know they are not nurses but she was feeding this old lady that had had a stroke. And obviously her mobile went off in her top pocket and she just walked away and left her. This poor woman was shouting I’m a still hungry and just walked away and left her. Another one she was screaming and shouting, said she wanted to move her bowels and they just left her and she did it in bed, and they just put it in the bin on the ward and left it and it just stunk all night long. Then there was another woman ....side of me they forgot to give her, her medication and she’s standing over me poking me, are you trying to frighten an old lady and all this lot. It was just horrendous.”*

*(Interviewer: “ And what about the care you got in hospital?”)*

*“Fine. [...]It was for me, yes.”*

**Comments on the interviews**

As previously stated, this qualitative data does not allow formal comparisons. However, it indicates issues of importance to those interviewed, and sheds light on the clinical care given.

Pre-pathway, the three patients interviewed were dealing with powerful emotional issues, such as receiving information with devastating implications or accepting loss of ability. They gave credit for good care in hospital, but drew attention to delays and deficiencies, which they attributed to pressure of work. Diagnosis was important: delays, uncertainties and change of personnel all caused difficulties. Patients wanted communication from professionals to be clear, but did not want it to be done in a harsh way. The single interview post-pathway indicated similar important emotional issue, with additional support offered in this instance. Poor care witnessed on the ward had caused distress, although personally care in hospital had not been an issue. Communication, clear and complete, from clinicians, was valued, as was being treated as a person of value.

**Case studies**

We present here four case studies to further illustrate the varied ways in which patients’ illnesses presented; what the outcome was for care and treatment, and what were the experiences during this process. These were chosen as a small purposive sample: two case studies in the pre-pathway stage, and two following the implementation of the new approach. An example is given in each group where a patient went on to receive oncology treatment, and an example where they did not. We made use of data from patients themselves, as well as that recorded in the patients’ notes. It should be noted that these are not necessarily representative, but designed to illustrate the material presented elsewhere in this report.

**Patient 1: pre-pathway phase**

**Presentation of the initial illness, and care during the period of investigation**

This person’s illness began with chest problems: a pleural effusion and consolidation in the lungs. Examination of the drained pleural fluid showed malignancy. There were two appointments in outpatients, then admission and a stay of ten days in hospital. During this time they had colonoscopy and biopsies (indicated by the nature of the cells in the pleural fluid analysis), and other investigations. After this they were discharged and seen in outpatients a further four times over a period of about five weeks. They then saw the oncology consultant, and began chemotherapy treatment. The time from initial indication of malignancy to start of definitive treatment was 59 days. Referral to palliative carewas two weeks after the initial indication that this was a malignancy.

**Ongoing treatment and outcome**

This patient had palliative chemotherapy treatment, which was halted after two months, as the disease was progressing, and their condition deteriorating. During this period they had also had palliative radiotherapy to their spine. Their final place of care was Ashgate Hospice, and they died ten days after the cessation of the chemotherapy. The time from starting the treatment to the time they died was 71 days.

**Patient A – estimate of some care costs**

This includes investigations, in-patient stays, and clinic costs during the period between presenting with metastatic cancer of unidentified primary origin, and the instigation of definitive treatment. It does not include estimated costs of oncology treatment or care once the definitive treatment had commenced.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Patient 1 –estimates of investigation costs** | | | | | |
| FBC | 6 | £ 21.00 | CRP | 1 | £ 4.12 |
| U&E | 5 | £ 14.90 | Blood culture | 1 | £ 4.12 |
| LFT | 2 | £ 5.96 | Sputum cult | 1 | £ 9.22 |
| Gluc | 1 | £ 4.12 | CXR | 5 | £ 112.25 |
| Clotting | 3 | £ 34.80 | USS abdo | 1 | £ 41.51 |
| CA199 | 1 | £ 29.77 | Bone scan | 1 | £ 87.70 |
| HCG | 1 | £ 7.29 | Colonoscopy | 1 | £ 409.00 |
| Phosphate | 1 | £ 4.12 | Bowel biopsies | 1 | £ 48.38 |
| **Total £ 838.26** | | | | | |

|  |  |  |
| --- | --- | --- |
| **Patient 1 – estimates of investigation and care costs** | | |
| Total no/cost of investigations | 32 | £ 838.26 |
| Nights in hospital | 10 | £ 1,740.00 |
| Clinic appointments | 6 | £ 842.00 |
| **Total cost of this care** |  | **£ 3,420.26** |

Alongside the financial cost of investigations, there is also the burden to the person concerned. Blood tests (such as Full Blood Count, phosphate, or glucose level are a relatively slight burden, particularly as several tests may be taken on a single occasion. More burdensome are investigations such as chest X-rays, or ultra-sound scan, where a journey to another department may be involved. A more extreme burden is caused by invasive investigations such as colonoscopy with biopsies taken: a longer procedure, in another department, which may be painful and uncomfortable.

**Patient report: patient 1: pre-pathway phase**

This patient completed evaluation questionnaires at the point when the chemotherapy treatment had been halted: around ten days before they died.

**Palliative Outcome Scale (POS)**

They reported pain at a severe level, with other symptoms affecting them moderately. They were sometimes anxious, and their family/friends were worried about them most of the time. They reported that information had been given on request, but they would have liked more. They had been able to share feelings with family and friends as much as they wanted, contined to feel that life was worthwhile all the time, and felt good about themselves most of the time. No time had been wasted in healthcare appointments, and practical problems were being addressed.

**Quality of Life Questionnaire – Palliative Care (EORTC QLQ- C15-PAL)**

They reported not needing help with such activities as eating or dressing, but needed to stay in bed or a chair a little during the day. They reported a little trouble taking a short walk outside of the house. Feeling pain, shortness of breath, trouble sleeping, weakness and lack of appetite were reported ‘quite a bit’, as were constipation, tiredness, tension, and pain interfering with activities. Nausea and depression were rated ‘a little’. Overall quality of life was reported as ‘5’ (on a 7-point scale where 1 represented ‘very poor’ and 7 excellent).

**Patient Enablement Instrument (PEI)**

Following their most recent consultation with a doctor at Chesterfield Royal Hospital (CRH), their ability to cope with life, understand their illness, cope with their illness , and keep themselves healthy, was reported as the ‘same or less’; as was their confidence about their health, and their ability to help themselves. On the care overall from CRH, they reported their ability to cope with life and their confidence about their health as the ‘same or less’; but their ability to understand their illness, cope with their illness and keep themselves healthy was ‘better’. They felt able to help themselves ‘more’.

**Summary: patient 1**

This person’s illness began with chest problems. The period of investigation lasted for 59 days, after which a treatment decision was reached and treatment started. There was a further period of 71 days before they became more ill, and died, in Ashgate Hospice. The final diagnosis was metastatic adenocarcinoma of unknown primary.

**Patient 2: pre-pathway phase**

**Presentation of the initial illness, and care during the period of investigation**

This person was admitted to hospital, initially because it was thought that she had had a stroke. A CT scan of her head showed brain lesions: confirmed as metastatic malignancy by an MRI scan. Her single stay in hospital lasted 23 days. During this time she had a range of investigations. She was reviewed by an oncologist and a decision taken that oncology treatment would not be of benefit. The time from initial indication of malignancy to the decision that definitive treatment was 19 days. Referral to palliative carewas 8 days after the initial indication that this was a malignancy.

**Ongoing care and outcome**

This care did not take place under Chesterfield Royal Hospital, so details are not available. She had care at home from her son, and attended Ashgate Hospice as a day patient. Her final place of care was Ashgate Hospice, where she died later in the year. The time from starting the treatment to the time she died was 166 days.

**Patient 2 – estimate of some care costs**

This includes investigations, in-patient stays, and clinic costs during the period between presenting with metastatic cancer of unidentified primary origin, and the instigation of definitive treatment. It does not include estimated costs of treatment or care once the definitive treatment had commenced.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Patient 2 –estimates of investigation costs** | | | | | |
| FBC | 2 | £ 7.00 | Blood culture | 1 | £ 4.12 |
| U&E | 2 | £ 5.96 | CRP | 1 | £ 4.12 |
| CEA | 1 | £ 29.77 | CT-CAP | 1 | £ 199.78 |
| CA125 | 2 | £ 59.54 | CT-head | 1 | £ 47.16 |
| CA199 | 2 | £ 59.54 | Mammogram | 1 | £ 35.78 |
| CA153 | 1 | £ 29.77 | MRI scan brain | 1 | £ 151.20 |
| HCG | 1 | £ 7.29 |  | | |
| **Total**   **£ 634.03** | | | | | |

|  |  |  |
| --- | --- | --- |
| **Patient 2– estimates of investigation and care costs** | | |
| Total no/cost of investigations | 17 | £ 634.03 |
| Nights in hospital | 23 | £ 4,002.00 |
| Clinic appointments | 0 | £ 0 |
| **Total cost of this care** |  | **£ 4,636.03** |

Alongside the financial cost of investigations, there is also the burden to the person concerned. This patient had a range of blood tests, and also several of the more burdensome investigations such as CT scan and mammogram.

**Patient report: patient 2: pre pathway phase**

This patient completed evaluation questionnaires around three months after their initial referral, which was about three months before their eventual death.

**Palliative Outcome Scale (POS)**

They reported no pain and no other symptoms. They themselves were not feeling anxious, but they reported that their family/friends were worried about them some of the time. They reported that full information/or as much as they wanted had been provided. They had been able to share feelings with family and friends as much as they wanted, continued to feel that life was worthwhile all the time, but felt good about themselves only ‘sometimes’. Up to half a day had been wasted in healthcare appointments, but practical problems had been addressed.

**Quality of Life Questionnaire – Palliative Care (EORTC QLQ- C15-PAL)**

They reported not needing help with such activities as eating or dressing, but needed to stay in bed or a chair ‘a little’ during the day. They reported ‘quite a bit’ of trouble taking a short walk outside of the house. Shortness of breath, trouble sleeping, and weakness were reported as ‘quite a bit’, but pain, loss of appetite or nausea not at all. Tiredness was reported as ‘a little’, tension as ‘quite a bit’ but constipation, pain interfering with activities and depression ‘not at all’. Overall quality of life was reported as ‘4’ (on a 7-point scale where 1 represented ‘very poor’ and 7 excellent).

**Patient Enablement Instrument (PEI)**

Following their most recent consultation with a doctor at Chesterfield Royal Hospital (CRH), their ability to cope with life and understand their illness was reported as the ‘same or less’, as was their confidence about their health. Their ability to cope with their illness, and keep themselves healthy was reported as ‘better’ as was their ability to help themselves. On the care overall from CRH, they reported their ability to cope with their illness and keep themselves healthy was the ‘same or less’; but their ability to understand their illness was ‘better’ and their ability to cope with life was ‘much better’. They felt more confident about themselves and more able to help themselves.

**Interview data**

The interview took place shortly after completion of the questionnaires.

This person’s recollection of events and of those looking after her was now not very clear. She had felt confused by seeing different staff in different settings, and feeling uncertain about who was in charge. She felt perhaps she didn’t know what to say, and that the doctors didn’t have the patience for listening She spoke of her sense of loss of ability to do things, but felt fortunate to have a son who cared for her at home, along with professional carers. Her home had been adapted to enable her to live there. Some things were upsetting for her to recall and we stopped the discussion a number of times, but she wanted to continue with the interview. She described the care in Chesterfield Royal Hospital as excellent.

**Summary: patient 2**

This person’s illness began with a suspected stroke. The period of investigation lasted for 19 days, after which a treatment decision for palliative care only was reached. There was a further period of 166 days during which she was looked after at home, and attended Ashgate as a day-patient, before she became more ill and died, in Ashgate Hospice. The final diagnosis was metastatic carcinoma of unknown primary.

**Patient 3: pathway implementation phase**

**Presentation of the initial illness, and care during the period of investigation**

This person was admitted to hospital with shortness of breath and was found on clinical examination to have a pleural effusion and multiple abdominal masses were palpable. A CT scan confirmed widespread metastatic disease including omental, liver and peritoneal lesions in addition to ascites and a pleural effusion. The patient was referred to the CUP team at the point of diagnosis of metastatic disease of unknown primary origin. She was reviewed as an in-patient by the CUP team within 24hours. The patient expressed the wish not to have any further investigation or invention other than a chest drain which could be both therapeutic and potentially diagnostic. In keeping with the patient’s wishes her definitive treatment was specialist palliative medicine rather than potential further investigation and onward referral for oncological treatment. This was her only admission during the period of investigation, and it was 12 nights in total. The time from initial indication of malignancy to start of definitive treatment, which was specialist palliative care, was 1 day.

**Ongoing treatment and outcome**

This patient had on-going input from the specialist palliative care team. Their final place of care was Ashgate Hospice. The time from starting the treatment, specialist palliative care to the time they died was 156 days.

**Patient 3 – estimate of some care costs**

This includes investigations, in-patient stays, and clinic costs during the period between presenting with metastatic cancer of unidentified primary origin, and the instigation of definitive treatment. It does not include estimated costs once the definitive treatment had commenced, or the investigation that alerted the clinician to the presence of metastatic disease.

|  |  |  |
| --- | --- | --- |
| **Patient 3 –estimates of investigation costs** | | |
| Pleural Fluid Cytology | 1 | £ 52.51 |
| **Total £ 52.21** | | |

|  |  |  |
| --- | --- | --- |
| **Patient 3 – estimates of investigation and care costs** | | |
| Total no/cost of investigations | 1 | £ 52.51 |
| Nights in hospital | 12 | £ 2,088.00 |
| Clinic appointments | 0 | £ 0 |
| **Total cost of this care** |  | **£ 2140.51** |

Alongside the financial cost of investigations, there is also the burden to the person concerned. This patient chose not to have further investigations/interventions aside from a chest drain which was placed mainly for therapeutic relief of her shortness of breath rather than for diagnostic purposes.

**Patient report: Patient 3: pathway implementation phase**

This patient completed evaluation questionnaires a few days after the treatment decision had been made. There was a further follow-up questionnaire, with data from a period 7 or 8 weeks after the first questionnaire.

**Palliative Outcome Scale (POS)**

She reported no pain and no other symptoms. She herself was not feeling anxious, nor were her family/friends were worried about her. She reported that full information/or as much as they wanted had been provided. She had been able to share feelings with family and friends as much as she wanted, continued to feel that life was worthwhile all the time, and felt good about herself all of the time. No time had been wasted in healthcare appointments, and there were no practical problems to be addressed. In the subsequent questionnaire, there was a deterioration in symptoms: slight pain and other symptoms, and occasional anxiety for herself and friends and family. Other aspects remained positive, as before.

**Quality of Life Questionnaire – Palliative Care (EORTC QLQ- C15-PAL)**

She reported not needing help with such activities as eating or dressing, or needing to stay in bed or a chair ‘a little’ during the day, and had no trouble taking a short walk outside of the house. There was ‘a little’ shortness of breath, but no trouble sleeping, no weakness, lack of appetite or nausea, nor any constipation, tiredness, tension, pain interfering with activities, or depression. Overall quality of life was reported as ‘6’ (on a 7-point scale where 1 represented ‘very poor’ and 7 excellent). In the subsequent questionnaire, there was ‘a little’ trouble in taking a short walk, and ‘quite a bit’ of need to stay in a bed or chair during the day. Regarding symptoms, only the lack of tension stayed the same. To the shortness of breath ‘a little’, was added ‘a little’ trouble sleeping, lack of appetite and nausea, constipation, pain interfering with activities, and depression. Weakness and tiredness were rated ‘quite a bit’. Overall quality of life was reported as ‘5’ with a question mark written in the margin.

**Patient Enablement Instrument (PEI)**

Following her most recent consultation with a doctor at Chesterfield Royal Hospital (CRH), she felt her ability to understand her illness and cope with her illness, was ‘much better’, while her ability to cope with life, keep herself healthy was ‘better’. She felt ‘more’ confident about her health, and more able to help herself. On the care overall from CRH, she reported that her ability to cope with life, understand her illness and cope with her illness, was ‘much better’, while her ability to keep herself healthy was ‘better’. She felt ‘more’ confident about her health, and more able to help herself. In the follow-up questionnaire, these had changed: all questions were rated ‘same or less’ following the most recent consultation. Overall, on the care from CRH, she reported her ability to understand her illness, was ‘much better’, while her ability to cope with life, cope with her illness, and keep herself healthy was ‘better’. Confidence about her health, and ability to help herself, was now ‘the same or less’.

**Summary: patient 3**

This person’s illness began with shortness of breath. The period of investigation lasted for only one day. The patient was referred to the CUP team when she was diagnosed with metastatic disease of unknown primary origin, and the decision was taken, in accordance with the patient’s wishes, for no further investigations and that she would receive specialist palliative care only. The patient was discharged home with on-going palliative care input. Her final place of care was Ashgate Hospice where she died 156 days after diagnosis. The final diagnosis was provisional carcinoma of unknown primary due to the limited investigations undertaken in accordance with the patient’s wishes.

**Patient 4: pathway implementation phase**

**Presentation of the initial illness, and care during the period of investigation**

This person was admitted to hospital with weak legs. A CT head showed multiple brain metastases. The patient had two admissions during the period of investigation of metastatic disease of unknown primary origin. He was referred late during his second admission, approximately two weeks after the CT scan showing metastatic disease, to the CUP team and for discussion at the CUP MDT. After review he was able to be discharged from hospital to have subsequent investigations and review as an outpatient. He was seen three times during this period as an outpatient, two of these at CUP clinic over a period of three weeks. Further investigations showed enlarged supraclavicular lymph nodes, which were subsequently biopsied and confirmed as probable lung adenocarcinoma. The time from initial indication of malignancy to start of definitive treatment was 35 days. Referral to the CUP team and palliative carewas two weeks after the initial indication that this was a malignancy. He was reviewed by an oncologist and had palliative radiotherapy.

**On-going treatment and outcome**

This patient had palliative brain radiotherapy treatment. Their final place of care was his home. The time from starting his radiotherapy treatment to the time he died was 95 days.

**Patient 4– estimate of some care costs**

This includes investigations, in-patient stays, and clinic costs during the period between presenting with metastatic cancer of unidentified primary origin, and the instigation of definitive treatment. It does not include estimated costs of oncology treatment or care once the definitive treatment had commenced or the investigations that alerted the clinician to the presence of metastatic disease.

|  |  |  |
| --- | --- | --- |
| **Patient 4 –estimates of investigation costs** | | |
| FBC | 1 | £ 3.50 |
| U&E | 1 | £ 2.98 |
| LFT | 1 | £ 2.98 |
| Amylase | 1 | £ 4.12 |
| CEA | 1 | £ 29.77 |
| PSA | 1 | £ 7.29 |
| HCG | 1 | £ 7.29 |
| MSU | 1 | £ 4.12 |
| Phosphate | 1 | £ 4.12 |
| CXR | 1 | £ 22.45 |
| AXR | 1 | £ 61.21 |
| CT-CAP | 1 | £ 199.78 |
| USS-guided biopsy | 1 | £ 250.00 |
| Lymph node histology | 1 | £ 81.17 |
| **Total** **£ 680.78** | | |

|  |  |  |
| --- | --- | --- |
| **Patient 4 – estimates of investigation and care costs** | | |
| Total no/cost of investigations | 14 | £ 680.78 |
| Nights in hospital | 9 | £ 1,566.00 |
| Clinic appointments | 3 | £ 839.00 |
| **Total cost of this care** |  | **£ 3,085.78** |

Alongside the financial cost of investigations, there is also the burden to the person concerned. Many blood tests (such as Full Blood Count) are a relatively slight burden, particularly as several tests may be taken on a single occasion. In this case there were several of the more burdensome investigations such as x-ray, ultrasound or CT scan, involving a journey to another department. Biopsy taken under ultrasound guidance will have involved a more extreme burden, being an invasive investigation: a longer procedure, in another department, which may be painful and uncomfortable.

**Patient report: patient 4; pathway implementation phase**

This patient completed evaluation questionnaires just before the start date for definitive treatment.

**Palliative Outcome Scale (POS)**

He reported moderate pain limiting some activities, but no other symptoms. He was not himself anxious, but his family/friends were ‘always preoccupied with worry about him’. He reported that full information had been given. He had been able to share feelings with family and friends as much as he wanted, continued to feel that life was worthwhile all the time, and felt good about himself most of the time. No time had been wasted in healthcare appointments, and practical problems were being addressed.

**Quality of Life Questionnaire – Palliative Care (EORTC QLQ- C15-PAL)**

He reported not needing help with such activities as eating or dressing, did not need to stay in bed or a chair during the day, and had no trouble taking a short walk outside of the house. He had pain and weakness ‘a little’ but no shortness of breath, lack of appetite or nausea. He reported no constipation, pain interfering with activities, tension, or depression; but was tired ‘a little’. Overall quality of life was reported as ‘5’ (on a 7-point scale where 1 represented ‘very poor’ and 7 excellent.

**Patient Enablement Instrument (PEI)**

Following their most recent consultation with a doctor at Chesterfield Royal Hospital (CRH), he reported that his ability to cope with life, understand his illness, cope with his illness , and keep himself healthy, was reported as the ‘much better’; as was his confidence about his health, and his ability to help himself. On the care overall from CRH, his ability to cope with life, understand his illness, cope with his illness, and keep himself healthy, was reported as ‘much better’; as was his confidence about his health, and his ability to help himself.

**Summary: patient 4**

This person’s illness began with weak legs. The period of investigation lasted for 35 days and he was referred late in this period to the CUP team, after which a treatment decision was reached and treatment started. There was a further period of 95 days before he became more ill, and died, at home. The final diagnosis was probable lung adenocarcinoma.

**Views of Informal Caregivers – Evaluation of Services (VOICES)**

**Survey of Bereaved Caregivers**

VOICES is a self-complete postal questionnaire, with several sections covering different places of care. It includes questions on: support with care at home; GP care in the home setting; care in hospital; care in nursing or residential home; care in hospice; care in the last three days of life; and care at the time of death, and in bereavement. Views of bereaved caregivers and next of kin are important, particularly in this context; given the difficulty in capturing patient interviews, as seen in the earlier section.

A total of 71 VOICES questionnaires were sent out to the next of kin of those identified to have presented with a cancer of unknown primary who had died. These questionnaires were sent out a minimum of 3 months after the patient’s death: a time period endorsed by the consumer research panel representatives involved with this study. Forty of these were sent out before the new approach was instigated, and thirty one afterwards. Fifteen (37.5% response), were returned from the first cohort, pre instigation of the cancer of unknown primary pathway and eleven (35.5%) from the second cohort, post instigation of the pathway. These response rates are comparable with those in other studies.

**Pre-pathway respondents**

Nine of the pre-pathway respondents were women, and six were men. Eight were the spouse or partner of the person who had died, and seven were the son or daughter. Eight were aged between 60 and 79, and seven between 30 and 59. All were resident locally, with one exception.

**Post-pathway respondents**

Nine of the pre-pathway respondents were women, and two were men. Five were the spouse or partner of the person who had died, four were the son or daughter, and two were related in another way. Six were aged between 60 and 79, and five between 40 and 59. All were resident locally, with one exception.

**Section A: Pre pathway data: Care in the home setting**

# *Home health care, equipment, and feeling confident in providing care: pre-pathway*

Of the fifteen patients pre-pathway whose experience was reported by family members, fourteen had spent time at home in the final three months of life. The majority (11 out of 15) had been ill for a month or more.

Ten had needed **home health-care** (e.g. bathing/dressing,) and three not (one *not applicable* and one missing reply). Five of the ten reported *no problem in getting this help*. Two others reported a *small/big problem* (three missing replies).

There were some comments, such as:

*“Social Services were very responsive. Sometimes difficult to get visits at requested times e.g. wanted 9.00 but may not arrive until 10.30, therefore he had got up which was very tiring and limited what he could then do.”*

[following ‘Not a problem’]

Eleven patients had required **special equipment** (e.g. wheelchair). Nearly always, *getting this was not a problem*, with one report of a *small problem*.

Half of the ten reported that p**ersonal care needs had** *always or usually* **been attended to as well as they should have been.**, and half felt that they had **received as much help and support from health and social services as they** wanted. One reported failure to provide help, and three that more was needed.

Nine respondents **felt** *very confident* or *fairly confident* **in taking care of their relative at home.** Three felt *not confident*. Of these three, all had received support: one as much as they wanted, two not as much as they wanted.

***Help at home from nursing/homecare services: pre-pathway***

Five respondents reported that no help was received, with one *not applicable,* and one missing response. The remaining eight responses are shown in the table below (question A5).

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **A5: In the last three months of his/her life, did he/she receive any help at home from any of the services listed below (District Nurse; Macmillan Nurse; Marie Curie Nurse; any other nurse at home; home care worker; Meals on Wheels** | | | | |
| **District or community**  **Nurse** | **Macmillan Nurse or hospice nurse** | **Home Care worker** | **Other help** | **Description of other help received** |
| yes | yes | yes | no |  |
| yes | yes | yes | no |  |
| yes | yes | yes | no |  |
| yes | yes (by phone) | yes | no |  |
| yes | no | yes | no |  |
| yes | yes | yes | yes | GPs mentioned by name |
| yes | yes | no | yes | I provided all care - District nurse provided incontinence pads etc. |
| yes | yes | no | no |  |
| No-one reported help from aMarie Curie Nurse, any other nurse at home, or Meals on Wheels. | | | | |

Respondents were asked **whether they had found providing care a reward or a burden.** Replies are shown in the table (A10).

|  |  |
| --- | --- |
| **A10: On balance, would you say that you and your family found looking after them rewarding or a burden, or would you say it was equally balanced between the two?** | |
| Rewarding | 7 |
| A burden | 0 |
| Equally balanced | 2 |
| Unsure | 2 |
| Not applicable, they did not need any help | 1 |
| Missing | 2 |
| No care at home | 1 |
| **Total** | **15** |

There were some comments, such as:

*“It was hard but she was my mum I would have done anything for her so helping her when she couldn’t do it for herself was a natural thing for me to do.”*  [ Rewarding]

*“I did what I would expect to do as her husband”.* [Missing]

The **overall comment on the help and support received** was *excellent* from three respondents; *good* from three; *fairly good* from one and *poor* from one, with four saying that no help had been needed, and one missing reply.

***Section A Pre-pathway***

Respondents reported a range of experiences, in which good ones predominate, but where there are also significant failings for some carers, such as problems in getting help with personal care, not enough help or care that was poor overall.

**Section****A: Post pathway: Care in the home setting**

# *Home health care, equipment, and feeling confident in providing care: post-pathway*

All of the patients reported on the post-pathway phase had spent time at home in the final three months of life, and nine been ill for a month or more.

Nine had needed **home health-care**, and seven relatives reported *no problem in getting this help*. The remaining two respondents explained their situations:

*“My grandmother had had home care which she had been having for years and myself had taken care of her. Her cancer was not discovered until 2 weeks before she died. And that 2 weeks she remained in hospital.”*

*“My wife needed assistance which was provided by me. I didn’t think about arranging for any home health care.”*

Six patients had required **special equipment:** none reported any problem in getting this, although one commented on the time taken before it arrived.

Seven reported that p**ersonal care needs had** *always or usually* **been attended to as well as they should have been**, with three needing no help. Eight felt that they had **received as much help and support from health and social services as they** wanted

Ten respondents **felt** *very confident* or *fairly confident* **in taking care of their relative at home** (one indicated no care was needed).

***Help at home from nursing/homecare service: post-pathway***

Three respondents reported that no help was received. The remaining eight responses are shown in the table below (question A5).

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **A5: In the last three months of his/her life, did he/she receive any help at home from any of the services listed below (District Nurse; Macmillan Nurse; Marie Curie Nurse; any other nurse at home; home care worker; Meals on Wheels** | | | | |
| **District or community**  **Nurse** | **Macmillan Nurse or hospice nurse** | **Home Care worker** | **Other help** | **Description of other help received** |
| yes | yes | yes |  |  |
| no | no | yes |  |  |
| yes | yes | yes | yes | Dr [name] & Dr [name] at [name] surgery |
| yes | yes | yes | yes | Occupational therapist /physiotherapist |
| yes | yes | yes | yes | Marie Curie Nurse |
| yes | no | no |  |  |
| yes | no | yes | yes | Help from another nurse at home |
| yes | yes | yes | yes | Ashgate hospice help |
|  |  |  |  |  |

Respondents were asked **whether they had found providing care a reward or a burden.** Replies are shown in the table (A10).

|  |  |
| --- | --- |
| A10: On balance, would you say that you and your family found looking after  him/her rewarding or a burden, or would you say it was equally balanced between the two? | |
|  | number |
| Rewarding | 6 |
| A burden | 0 |
| Equally balanced | 1 |
| Unsure | 1 |
| Not applicable, they did not need any help | 2 |
| Other reply | 1 |
| **Total** | **11** |

There were some comments, such as:

*“ I’m not sure that any of these apply. I just know we wanted him at home so that we could all help to make him as comfortable as possible and give him some tender loving care.”* [Other reply]

The **overall comment on the help and support received** was *excellent* from six respondents; *good* from one; and *fairly good* from one. Three said that no help had been needed.

***Section A: Post-pathway***

All of these respondents reported receiving as much help and support as they needed and seven of eight receiving support found it excellent or good. In comparison with the pre-pathway group, experiences appear to have been better both in terms of the help received and in the level of confidence felt.

**Section B: Pre-pathway data: Care from the General Practitioner**

## *GP communication, visiting, and overall care: pre-pathway*

Half of the fourteen respondents whose relative had spent time at home felt that **the GP had had time to listen and discuss things with them**. Half had had explanations from GPs, with five reporting that **the GP explained things** in a way that was *very easy* or *fairly easy* to understand. Five were able to **discuss worries or fears as much as they wanted**, two *discussed them but not as much as they wanted*. Two said they were *not able to discuss these, although they tried* to, one *had not tried to*, and one reply was missing. Twelve answered no to a question on **whether information had been given in an upsetting way**, with two saying *yes*, and one missing response.

Nine respondents described **the way the GP looked after their relative** as *very understanding*; 2 as *fairly understanding*; and 2 as *not very understanding;* with 2 missing replies. There were several comments, such as:

*“The GP was slow to send Mum for further tests, dismissing her complaining as 'only wind.”* [Not very understanding]

*“They came to see her every day and talked to my mum, not at her like some doctors can. They explained everything and were so easy to talk to; they really helped me and mum.”*  [Very understanding]

Eight respondents said that it had been *very easy*or*fairly easy* **to get the GP to agree to a home visit** and one that it had been *fairly difficult*, with five reporting that *the doctor did not need to visit* and one that *they had not been wanted*. Two respondents reported that there had been occasions when **they wanted to see a GP for something urgent, but someone at the surgery made it difficult**.

Five respondents reported the **overall** **GP care** as being *excellent*, four *good*, two *fair* and one *poor*, with one indicating no GP contact.

## *GP treatment of symptoms: pain and breathlessness: pre-pathway*

Eleven of the fourteen respondents who spent time at home reported that there had been **distressing or bothersome pain**, with all eleven treated for pain. Eight had complete relief some of the time, or partial relief, but the other three had no relief at all.

Seven of the fourteen respondents who had spent time at home reported **distressing or bothersome breathlessness**, with five treated for this. Four had partial relief some of the time, two had no relief at all, and there was one *don’t know* response.

There were further comments, both positive and negative

*“GP and district nurses were very involved. DN called each week and I know he valued that.”*

*“Think towards end of mum's illness, became a burden to GP.”*

***Section B - Pre-pathway***

Care received from GPs was variable, with examples of both good care and poor care in communication, home visiting and control of pain and breathlessness.

**Section B: Post pathway Care from the General Practitioner**

### ***GP communication, visiting, and overall care: post-pathway***

Eight of the respondents felt that **the GP had had time to listen and discuss things with them**, and seven reported that **the GP explained things** in a way that was *very easy* or *fairly easy* to understand (two *not applicable* and two missing replies). Five were able to **discuss worries or fears as much as they wanted**, one *discussed them but not as much as they wanted*. Two had not tried to discuss these, and one reply was missing. Two had no worries or fears to discuss. Nine answered no to a question on **whether information had been given in an upsetting way**, with one saying *yes*, and one saying this was not applicable.

Six respondents described **the way the GP looked after their relative** as *very understanding*; one as *fairly understanding*; and two as *not very understanding*; with one ‘not applicable’ reply. There were comments, such as:

*“He complained about pain in his back GP sent him to pain clinic about a year before he died, and all they said was to lose some weight, he was 19 stone and to take some pain killers, but he was never free of the pain.”*

Eight respondents said that it had been *very easy* or *fairly easy* **to get the GP to agree to a home visit**, one that they *had wanted the GP to visit, but they* *would not*, and one that *the GP did not need to visit*. Two respondents reported that there had been occasions when **they wanted to see a GP for something urgent, but someone at the surgery made it difficult**.

Three respondents reported the **overall** **GP care** as being *excellent*, four *good*, two *fair* and two *poor*. The two *poor* responses were where someone at the surgery had made it difficult for them to see the GP for something urgent.

## GP treatment of symptoms: pain and breathlessness: post-pathway

Nine of the respondents reported that there had been **distressing or bothersome pain**, with seven treated for pain and two not. Four had complete relief all or some of the time, and two partial relief, but the other three had no relief at all.

Six respondents reported **distressing or bothersome breathlessness**, and one had breathlessness that was not distressing or troublesome. Three were treated for breathlessness, and all had complete relief some of the time.

There were further comments, such as:

*“As stated on the previous page, after Mum's fall from bed it was over 24 hours before she was diagnosed with a fractured pelvis. It wasn't until the following day that a morphine pain relief system was set up.”*

***Section B: Post–pathway***

The overall picture for the post-pathway group for GP care appears similar to that for the pre-pathway group. Care received from GPs was variable, with examples of both good care and poor care in communication, home visiting and control of pain and breathlessness.

##### Section C: Pre and post-pathway: Care in a nursing or residential home

No respondents in either the pre-pathway or post-pathway group reported that their relative had been care for in a nursing or residential home in the last three months of their life.

**Section D: Pre-pathway: Care in hospital**

## *Fourteen of the fifteen respondents reported that their relative had spent time in hospital in their last three months of life.*

Eight said that *their relative had died on that admission*, and one said that *they had been transferred to hospice care*. Four felt *they were discharged at the right time*, one that *they were discharged too late*. There was one missing response.

There were six comments, for example:

*“He was diagnosed as terminally ill and requested to come home but nursing staff refused until he had been assessed, requiring him to remain in hospital an extra 24 hours.”* [No, he was discharged too late]

#### Hospital care: communication and explanations: pre-pathway

Half the respondents reported that they were *always* or *usually* **kept informed about their** **relative’s condition**. Three reported this *sometimes,* and three *never* (two missing replies). There was one comment:

*“But only because I asked on every visit”* [Always]

Eight reported that their relative’s **condition, treatment or tests were explained** in a *very easy* or *fairly easy* way. Two reported this was *fairly difficult* or *very difficult.* Two said **doctors or nurses had given any information in an upsetting way** and nine this had not happened, with three who had *not talked to any doctors or nurses* (one missing responses). There were five comments, all negative:

*“Every time I saw mum I asked about her condition but there was always some excuse not to talk to us it was either 'change over' or the Dr has the notes or I'm not her nurse.”*  [I did not talk to any hospital doctors or nurses]

Three respondents were able to **discuss worries or fears** *as much as they wanted, and* six *could* *discuss them, but not as much as they wanted.* Four were *not able to discuss worries* *although they tried to discuss them,* and two replies were missing.

## *Hospital care: staffing, confidence in staff, and personal care: pre-pathway*

Four respondents thought that **there were enough nurses on duty to care** for their relative *always or nearly always*, with five saying that this was true *sometimes.* Four said *there were rarely or never enough nurses,* and two replies were missing.

Six respondents reported **enough help for personal needs such as bathing, dressing, eating and going to the bathroom**. Seven said there was not enough help, and one did not know (one missing response). There were two comments, for example:

*“I tried to go at meal times to get her to eat as the food was left in front of her and she found it hard work to eat it so she would leave it.”* [not enough help]

Five reported **trust and confidence** *in all of the nurses*, eight *in some of them,* and one *not in any of the nurses* (one missing reply). Nine reported that their relative was **treated with respect and dignity by staff** *always* or *most of the time,* four *some of the time*, and one *never* (one missing response).

## *Hospital care: involvement in decisions on care: pre-pathway*

Nine respondents were *very involved* or *fairly involved* with decisions made about their relative’s care. Five were *not involved* (one missing reply). Eight *would have liked to be more involved,* while four were involved *as much as I wanted* (three missing replies). Of the five who had said they were *not involved with decisions*, four *would have liked to be more involved*.There were comments, for example:

*“I felt decisions were made about his treatment in isolation of his terminal condition - the treatment focused on a specific condition when probably 4 or 5 conditions were having an impact.”* [fairly involved- would have liked to be more involved]

Eight thought that **no decision had been made about their relative’s care that their relative would not have wanted**, but four felt that such a decision had been made (two *don’t know*, one missing reply).

There were three comments, for example:

*“She was given an enema for no significant reason and without explanation.”*

## *Hospital treatment of symptoms: pain and breathlessness: pre-pathway*

Twelve of the respondents reported that there had been **pain**, and ten said this had been **distressing or bothersome pain.** Eleven had **treatment** for pain, with one reply of *don’t know.* (One response was missing throughout this section). Six respondents reported complete relief all or some of the time, four partial relief, but two had no relief at all.

Seven reported **breathlessness**: five said this had been **distressing or bothersome breathlessness**, one that it was not distressing or troublesome (one respondent didn’t know). Six were treated for breathlessness, and two had complete relief all or some of the time, and four partial relief.

Four respondents commented further on symptoms, for example:

*“She always felt sickness and was given treatment which helped.”*

## *Overall comments on hospital care: pre-pathway*

Respondents were asked **what they felt about the care received from doctors in hospital**. Five reported it *good*, five *fair*, and three *poor*. One rated two different wards: *poor to adequate* and *great improvement*. One reply was missing. There were six comments, for example:

*“Diagnosis should have been discussed with his family around him.”*  [poor]

Respondents were asked **what they felt about the care received from nurses in hospital**. Two reported it *excellent,* five *good*, three *fair*, and two *poor*. One rated two different wards: *poor to adequate* and *great improvement*. One reply was missing. There were four comments, for example:

*“Some of the nurses were excellent some could do with lessons of how to treat patients with a lot more dignity and respect.”* [fair]

Six respondents wrote general comments, such as:

*“My wife's condition baffled all the doctors from start to finish. After her scan discovered the tumours, the consultant [name] told my wife "We are talking years, not weeks or months." He was wrong to say that. He gave us false optimism. My wife didn’t live 3 weeks after that scan. She had a biopsy on the Friday and was told she would be able to go home for five days until the following Friday when the results would be back. She passed away 48 hours after the biopsy (not as any result or side effects of the biopsy). Not-one seemed to know how ill she was or how rapidly she was deteriorating.”*

*“Re Chesterfield Royal Hospital. All in all they were absolutely brilliant and I cannot thank them enough. The only comment was that she could have done with moving to a hospice or cottage hospital earlier in her hospital stay so she and we could have benefitted from the greater freedom there. When she was bed-ridden totally she was quite happy, as were we, and she was moved to a side ward and we were allowed to stay with here for the final week or so. THANK YOU CRH.”*

**Section D: Pre-pathway**

It seems that for this group of respondents some had received good care in hospital, but very often the care received was not of a good enough standard, or actually poor. One respondent’s rating of two different wards suggests one reason for these differences. Respondents’ comments illustrate the considerable distress caused by poor care and failures in care.

**D: Post-pathway Care in hospital:**

## *Nine of the eleven respondents reported that their relative had spent time in hospital in their last three months of life*

Four said that *their relative had died on that admission*. One felt *they were discharged at the right time*, two felt that *they had been discharged too soon,* and one that *they were discharged too late*. One was *not sure.*

There were comments, for example:

*“Not sure. Had I known how close my husband was to dying I would have asked for him home sooner. As non medical people ourselves we accepted the advice given.”*  [Not sure]

#### *Hospital care: communication and explanations: post-pathway*

Six respondents reported that they were *always* or *usually* **kept informed about their** **relative’s condition**. Two reported this *sometimes.* There was one other reply:

*“When I asked! I did not always feel automatically included as the wife of the patient”*

[Other reply]

Eight reported that their relative’s **condition, treatment or tests were explained** in a *very easy* or *fairly easy* way. One reported this was *fairly difficult.* Five said **doctors or nurses had given any information in an upsetting way** and three that this had not happened, with one who had *not talked to any doctors or nurses*. There were five comments, such as:

*“Information was not given voluntarily. Always had to ask and then replies were rushed. Made to feel a nuisance. Very bad.”* [Yes]

Two of the five comments seemed at variance with the reply that information had been given in an upsetting way, for example:

*“We had to ask to see a doctor when we wanted an update on her condition. The doctor was very kind and diplomatic in the way he told us the bad news. It was the news that she was going to die soon that upset us not the doctor.”* [Yes]

Four respondents were able to **discuss worries or fears** *as much as they wanted, and* five *could* *discuss them, but not as much as they wanted.*

## *Hospital care: staffing, confidence in staff, and personal care: post-pathway*

Three respondents thought that **there were enough nurses on duty to care** for their relative *always or nearly always*, with five saying that this was true *sometimes.* One said they did not know.

Five respondents reported **enough help for personal needs such as bathing, dressing, eating and going to the bathroom**. Three said there was not enough help, and one did not know. One person gave a further comment:

*“No, no, no, no - personal care appalling.”* [No]

Four reported **trust and confidence** *in all of the nurses*, four *in some of them,* and one *not in any of the nurses*. Five reported that their relative was **treated with respect and dignity by staff** *always* or *most of the time,* andfour *some of the time*.

One person gave a further comment:

*“Quality of nurses and levels of care given varied greatly.”*[Sometimes enough nurses]

## Hospital care: involvement in decisions on care: post-pathway

Seven respondents were *very involved* or *fairly involved* with decisions made about their relative’s care. One were *not involved* and there was one other reply:

*“I felt the onus was on me to ask”.*

Fivewere involved *as much as I wanted*, and four *would have liked to be more involved*. Of the four who had said they were *fairly involved with decisions*, two *would have liked to be more involved*.

Eight thought that **no decision had been made about their relative’s care that their relative would not have wanted**, and only one felt that such a decision had been made.

## Hospital treatment of symptoms: pain and breathlessness: post-pathway

Eight of the respondents reported that there had been **pain**, and all said this had been **distressing or bothersome pain.** All had had **treatment** for pain. Five respondents reported complete relief all or some of the time, and two partial relief (one missing reply).

Six reported **breathlessness**: five said this had been **distressing or bothersome breathlessness** and one that it was not distressing or troublesome. Five were treated for breathlessness, and four had complete relief all or some of the time, but one no relief at all.

Two respondents commented further on symptoms, for example:

*“As stated earlier an enlarged abdomen due to ascites and a secondary problem of heart failure and asthma contributed. He had oxygen but the real problem was an inability to sit in the correct position.”*

[Breathlessness treated but not relieved at all]

## Overall comments on hospital care: post-pathway

Respondents were asked **what they felt about the care received from doctors in hospital**. One reported it excellent, four reported it *good*, and three *fair*. One reply was missing.

Respondents were asked **what they felt about the care received from nurses in hospital**. One reported it *excellent,* four *good*, three *fair* and one *poor*. There were four comments, for example:

*“Communication/compassion/consistency. My husband spent five and half weeks in five different wards at Chesterfield Royal Hospital plus one week in Weston Park during the last two months of his life. Consequently he was cared for and treated by numerous different people. Whilst some were excellent, others I felt needed to view my husband as a whole person. It was too often assumed that he was capable of more than he was and at times I could have been shown more sensitivity. I appreciate it was impossible to absorb all information from copious medical notes but I feel no one should have dealt with my husband without bullet point knowledge of his condition. Lack of consistency in dealing with pressure sores meant they grew steadily worse and caused him real distress until he died.”*

[doctors: good- nurses: fair]

*“Inconsistencies in nursing staff some very good, some worse than poor.”*

[doctors: fair- nurses: poor]

Five respondents wrote general comments, such as:

*“I was with my Nan a lot of the time she was in hospital. I had been told she was dying and spent as much time as I could with her. The staff were excellent with her and all of us.”* [doctors: excellent- nurses: excellent]

*“Care is not a word that should be used to describe the treatment given to this elderly patient during his last 3 weeks of life. Medical needs were attended to but neglect experienced in most other areas. He was not washed, shaved: was left in dirty pyjamas and bedsores were left untreated. No help given with drinking/feeding despite becoming too weak to hold a cup. ' I don’t ask for help because they do not come' he said. Where is the respect and compassion? Please let your research make a difference and improved the service given to those too ill, frail or afraid to make a fuss or ask themselves - no one deserves to be left to die in this neglected, undignified way. Families should not have to watch their loved ones suffer and be treated like this and have no voice. Animals are treated better.”*  [doctors: fair- nurses: poor]

***Section D:Post- pathway***

It seems that for this post-pathway group of respondents that although communication, quality of staff and symptom control seemed more often to be good than not, responses and comments from respondents show also some quite shockingly poor care. The comments from relatives give details of the areas of failure, which are in all areas: personal care, communication, addressing complex needs and including relatives in decision and care. With two such small groups of respondents, it is not appropriate to make formal comparisons: what does emerge from the responses is the continuance of both good and bad care within the hospital setting.

**Section E: Pre-pathway: Hospice care**

Three of the fifteen respondents reported that their relative had spent **time in a hospice** in their last three months of life. All three had died in the hospice.

#### *Hospice care: communication and explanations; pre-pathway*

Two respondents reported that they were *always* **kept informed about their** **relative’s condition**, with one reporting this *sometimes.* Asked **whether condition, treatment or tests were explained in an easy or difficult way**, two said *very easy*, and one response was missing*.* Asked if **doctors or nurses had given any information in an upsetting way**, two said *no,* and one reply was missing. There was one comment:

*“A doctor came to talk to us every visit even if we went 3 times a day they found time to see me”* [following a ‘no’ response]

Two of the three respondents were able to **discuss worries or fears** *as much as they wanted* (one missing response)*.*

## *Hospice care: staffing, confidence in staff, and personal care: pre-pathway*

Two respondents thought that **there were enough nurses on duty to care** for their relative *always or nearly always*, with one saying that this was true *sometimes.* All three respondents reported **enough help for personal needs such as bathing, dressing, eating and going to the bathroom**.

All three reported **trust and confidence** *in all of the nurses*, and all reported that their relative was **treated with respect and dignity by staff** *always*.

## Hospice care: involvement in decisions on care: pre-pathway

Two of the three respondents were *very involved* **with decisions made about their relative’s care**, and one was *not involved*.

This respondent *would have liked to be more involved*, and gave a further comment:

*“There was (in my opinion) no proper discussion with me by Doctors about my wife’s condition, or treatment. It was apparent she was being cared for & I shall always be grateful for this -but a sit-down explanation would have been appreciated.”*

[following a ‘would have liked to be more involved’ response]

All three thought that **no decision had been made about their relative’s care that their relative would not have wanted**.

## *Hospice treatment of symptoms: pain and breathlessness: pre-pathway*

All three of the respondents reported that there had been **pain**, and all said this had been **distressing or bothersome pain.** All three had **treatment** for pain, which *relieved it completely all or some of the time.*

One of the respondents reported **breathlessness,** which had been **distressing or bothersome.** This had been treated, and relieved the breathlessness *completely, some of the time.*

One respondent wrote a further comment here:

*“For the pain she had a Driver fitted - which helper her a lot she was more relaxed and at ease”* [following the *completely, some of the time* response on breathlessness]

## *Overall comments on hospice care*

Respondents were asked **what they felt about the care received from doctors at the hospice**. Two reported it *excellent* and one reported it *good*.

One respondent gave a comment:

*“They were everything you could wish for in nursing and doctors they were* *amazing. They cared about Mum as well as me and my family.”* [excellent]

Respondents were asked **what they felt about the care received from nurses in hospital**. All three reported it *excellent.*

Two respondents wrote comments:

*“Ashgate Hospice were fantastic. All the staff were excellent”.*

*“They do an amazing job. I found it strange as first that they were concerned for MY well being. Kept asking how I was and if they could help in any way- I wasn't used to it. When I went to the hospice I felt I was amongst friends.”*

***Section E: Pre-pathway***

These respondents found hospice care to be of a high standard. There were one or two indications of possible improvement, but in a general picture of good care.

**Hospice care –Post-pathway**

Two of the eleven respondents reported that their relative had spent **time in a hospice** in their last three months of life. Both had died in the hospice.

#### *Hospice care: communication and explanations: post-pathway*

Both respondents reported that they were *always* **kept informed about their** **relative’s condition***.* Asked **whether condition, treatment or tests were explained in an easy or difficult way**, both said *very easy.* Asked if **doctors or nurses had given any information in an upsetting way**, both said *no*. Both respondents were able to **discuss worries or fears** *as much as they wanted.*

## *Hospice care: staffing, confidence in staff, and personal care: post-pathway*

Both respondents thought that **there were enough nurses on duty to care** for their relative *always or nearly always.* Both respondents reported **enough help for personal needs such as bathing, dressing, eating and going to the bathroom**.

Both reported **trust and confidence** *in all of the nurses*, and both reported that their relative was **treated with respect and dignity by staff** *always*.

## *Hospice care: involvement in decisions on care: post-pathway*

Both respondents were *very involved* **with decisions made about their relative’s care**, and both were *involved as much as they wanted*.

Both thought that **no decision had been made about their relative’s care that their relative would not have wanted**.

## *Hospice treatment of symptoms: pain and breathlessness: post-pathway*

Both respondents reported that there had been **pain** that had been **distressing or bothersome pain.** Both had **treatment** for pain: one respondent reported that this had relieved the pain *completely, all of the time,* and onethat the pain was relieved *completely, some of the time*.

One of the respondents reported **breathlessness,** which had been **distressing or bothersome.** This had been treated, and relieved the breathlessness *completely, some of the time.*

## *Overall comments on hospice care: post-pathway*

Respondents were asked **what they felt about the care received from doctors at the hospice**. Both reported it *excellent*.

Respondents were asked **what they felt about the care received from nurses in hospital**. Both reported it *excellent.*

***Section E: Post-pathway***

Care at the hospice was reported as being of high standard in all respects by both respondents. The overall picture from the small group of five who commented on hospice care in either the pre or post stage of the study is of excellent care.

**Section F Care during the last three days of life: pre-pathway**

Eight people were cared for all three days in hospital, two at home and three in a hospice. One person was transferred home (from hospital) for their last day, and one person was admitted (from home) to hospital. There was one comment:

*He wanted to come home and we were starting to discuss what that would involve. I didn't really think it was practical and we also requested a hospice bed but none were available in time*.” [‘In a hospital all the time’]

***Final three days of life: help with personal and nursing care: pre-pathway***

Just over half the respondents reported **enough help for personal needs such as bathing, dressing, eating and going to the bathroom**. Three said there was not enough help (four missing responses. More than half respondents reported **enough help with nursing care, such as getting dressings changed and help with medication**. One said there was not enough help, (three others: *don’t know/* *not applicable/missing*.

## *Final three days of life: involvement in decisions on care: pre pathway*

Seven respondents were *very involved* and three *fairly involved* with decisions made about their relative’s care. Four were *not involved* (one missing reply). Sevenwere involved *as much as I wanted*, and six *would have liked to be more involved*.

Eight thought that **no decision had been made about their relative’s care that their relative would not have wanted**, and only one felt that such a decision had been made. Respondents were also asked whether **they did not want any of the** **decisions made about their relative’s care or treatment**. Nine said *no*, and two *yes*, (three *don’t know/missing* replies). There were two comments, for example:

*“She was catheterised which we didn't think was necessary as she had not eaten or drunk for days.”* [Yes]

***Final three days of life: approaching death: pre-pathway***

Respondents were asked if **it seemed likely that their relative would die very soon**. Nine said *yes* and four *no (two* *don’t know/missing* replies). There were three comments, such as:

*“Only comment made to me during this period was 'your wife is very ill!' - this was never elaborated on.”* [No]

Asked about **unconsciousness or drowsiness***,* nine reported their relative *unconscious all of the time,* or *unconscious some of the time*, and four reported them *drowsy some of the time*, or *drowsy all of the time*. (Two said *none of these*.)

## *Final three days of life: treatment of symptoms: pain and breathlessness: pre-pathway*

Eleven of the respondents reported that there had been **pain**, and nine said this had been **distressing or bothersome pain.** Eleven had **treatment** for pain, which *relieved it completely all or some of the time* for five patients. Five had partial relief, but one had no relief at all.

Six of the respondents reported **breathlessness**, and five said this had been **distressing or bothersome.** Four treated, and for two this relieved the breathlessness *completely, all or some of the time.* Two had partial relief (outcome unknown for one).

There were three further general comments, for example:

*“He had a permanent catheter fitted. Unfortunately he caught it in the bath board he was given & pulled it out with subsequent damage and heavy bleeding. It then fell out a couple of times, the last leading to his final admission to hospital. I feel this accident made his last weeks harder – may even have been instrumental in him dying in hospital rather than at home.”*

***Section F: Pre-pathway***

There seems to have been sufficient care for a majority of patients, a goodish level of involvement in care and few unwanted decisions made, but this section indicates a wish for fuller involvement, some failures in communication at the end of life, and some symptoms uncontrolled.

**Care during the last three days of life: post-pathway**

Five people were cared for for all three days at home, five in a hospital, and two in a hospice.

***Final three days of life: help with personal and nursing care: post-pathway***

Ten of the eleven respondents reported **enough help for personal needs such as bathing, dressing, eating and going to the bathroom**. One said there was not enough help. Nine of eleven respondents reported **enough help with nursing care, such as getting dressings changed and help with medication**. One said there was not enough help, (one *not applicable)*.

## *Final three days of life: involvement in decisions on care: post pathway*

Nine respondents were *very involved* with decisions made about their relative’s care: these ninewere involved *as much as I wanted.* One respondent was *fairly involved* and did not know if they would have wanted more involvement. One gave an initial *not applicable* response, and then *would have liked to be more involved*.

Eight thought that **no decision had been made about their relative’s care that their relative would not have wanted**, one felt that such a decision had been made, and one said *don’t know*.

There were two comments, describing opposite experiences:

*“The GP and community nurses were prepared to compromise and took all his views into consideration.”* [no]

*“We were not involved in decision making - decision to withdraw treatment had already been made prior to our being called in for discussion, i.e. we were told what was going to happen and we would be overruled if we objected/refused.”* [yes]

Respondents were also asked whether **they did not want any of the** **decisions made about their relative’s care or treatment**. Ten said *no*, and one *yes*.

***Final three days of life: approaching death: post-pathway***

Respondents were asked if **it seemed likely that their relative would die very soon**. Ten said *yes* and one *no*. Asked about **unconsciousness or drowsiness***,* six reported their relative *unconscious all of the time,* or *unconscious some of the time*, and three reported them *drowsy some of the time*, or *drowsy all of the time*. (Two said *none of these*.)

## *Final three days of life: treatment of symptoms: pain and breathlessness: post-pathway*

Five of the respondents reported that there had been **pain**, and that this had been **distressing or bothersome pain.** Five reported **treatment** for pain, which *relieved it completely all or some of the time* for four patients. But one had no relief at all.

Three of the respondents reported **breathlessness**, and two said this had been **distressing or bothersome** and one did not know.Three were treated, and for one this relieved the breathlessness *completely, all of the time.* One had partial relief, but one no relief at all..

There were three further general comments, for example:

*“He wanted to be aware of his surroundings. He had a morphine syringe driver but no sedation in it at his request.”*

***Section F: Post-pathway***

Nearly all respondents reported enough care for patients at the end of life, a majority were very involved with care and few unwanted decisions were made. Communication was satisfactory for nearly all, and uncontrolled symptoms were fewer.

**Circumstances surrounding the person’s death: pre-pathway**

***Place of death, preparation for death, and personal beliefs: pre-pathway***

Nine of the fifteen patients died in **hospital**, three at **home**, and three in a **hospice**. Eleven of the respondents reported that they were able to be with their relative when they died. There were four comments, about varying experiences, for example:

*“I noticed a change in attitude by nurses at the end. Very sympathetic and very prompt at responding to any requests therefore less stressful for me after having had earlier difficulties.”*

Ten respondents felt that their relative had died **in the right place**, with three saying it was **not the right place** (one *not sure* and one *don’t know)*. Reasons given were: *it was not where they wanted to die*; t*he care they received there was poor;* and *they were too far away from family and friends*.

Eleven had been told their relative was **likely to die shortly**, and four had not. Of the eleven, ten had been **given a chance to talk about this**, and all felt they had been **given enough privacy** for this. No-one reported **being told in an upsetting way.**

Six respondents said that they **knew what to expect** when their relative was dying, and five said *yes, partially* to this question. There were two comments, for example:

*“The nurses were good at knowing how close we were by the way his breathing changed and one came in when we buzzed as his breathing stopped and talked us through the last minutes. She was excellent.”*

Ten respondents felt that their relative’s **personal and religious beliefs were taken into consideration**, and one felt they had not (three saying *don’t know*, and one missing response).

***Help from health and social care services, work and financial issues: pre-pathway***

Asked whether **health and/or social services could have helped to make things easier for their relative**, five said *yes*, six *no,* with two saying *don’t know* and two missing responses. Six respondents gave comments, for example:

*“My mother was a very private person, and the assistance received from social services, although needed by family, did upset Mum. Her dignity was intruded on.”*

Five respondents said they **had had to give up work/make a major change** to care for their relative, with ten saying this was not the case.

One respondent reported that their relative’s illness had meant using **all or most of their savings**, and this respondent reported that **covering the cost of care** had been *very difficult*. Three respondents reported this as *somewhat difficult*, and nine *not difficult at all* (one *don’t know,* one *not applicable)*.

***Care in bereavement: pre-pathway***

Three respondents would have liked **another chance to discuss the death** with those involved with their care, with four *not sure*. Seven said *no* to this question, and one that they *already had done*. Seven had **talked to someone from health, social, or bereavement services** and five reported this as *helpful*, with one *don’t know*, and one *both yes and no*. Of the eight who had not had this, four did not want to (two *don’t know;* two missing responses).

Asked about any other **help or support that health/social services** could have offered in bereavement, there was one mention of bereavement counselling, from the respondent who had talked to a hospital doctor.

***Support from health and social care services, and comments on care: pre-pathway***

Respondents were asked if there were any ways in which health or social services **could have made things easier for the respondents themselves**: five said *yes* and five *no (*three *don’t know;* two missing responses).

Comments on **good and bad aspects of the care** were invited, and there were four comments, for example:

*“I know no one can be exact and that each patient is different but I really struggled to get anyone to talk about how long he had and what the progression of his illness would be. I felt I could have got a better plan in place for getting him out and about before he couldn't do that and then organised a better place for his death.”*

Further comments on **any aspect of the care received** were invited and five respondents made further comments, for example:

*“A 24 hour admission not covered by the structure of this questionnaire (in the medical unit) 6 days before her final admission was an absolute waste of time (with terrific wear on everyone’s nerves) and she should NOT have been discharged so easily!”*

*“My brother and I had very good help from G.P. and social services. as I had one when my husband died last October. Macmillan Nurses and Ashgate Hospice therapists were wonderfully helpful. I am really grateful to them all and really couldn’t have coped without them.”*

***Section G: pre-pathway phase***

For a majority of patients the place where they died was considered the right one, with a majority of relatives able to be present. Most had been told that their relative would die soon, and this had been done in a good way. There were mixed reports about whether services could have helped their relative more, and mixed comments on the availability of bereavement care

**Circumstances surrounding the person’s death: post-pathway**

***Place of death, preparation for death, and personal beliefs: pre-pathway***

Four of the eleven patients died at **home**, and two in the **home of another family member**, three in **hospital**; and two in a **hospice**. Eight of the respondents reported that they were able to be with their relative when they died. There were four comments, about varying experiences, for example:

*“Mum was surrounded by her family when she died and she was never left alone for a second from the time we were told she was going to die though it was about 5 days.”*

Ten respondents felt that their relative had died **in the right place**, with one saying it was **not the right place**. The reasons given was t*he care they received there was poor*.

Nine respondents had been told their relative was **likely to die shortly**, and two had not. Of the nine, eight had been **given a chance to talk about this**, and seven felt they had been **given enough privacy** for this, with one saying this was not the case. (There was one missing response.) One person reported **being told in an upsetting way**. There were two comments, for example:

*When we eventually got to see a doctor for an update on her condition, there were not enough private consultation rooms available. The doctor had to use the nurses’ mess room. Whilst he was telling us the upsetting news that my wife was going to die soon, a nurse burst in to ask for her lunch that was in the fridge in the room! [....] This is the only negative experience I had with the nurses....* [No]

Four respondents said that they **knew what to expect** when their relative was dying, and two said *yes, partially* to this question. Three said *they did not know what to* expect.

Seven respondents felt that their relative’s **personal and religious beliefs were taken into consideration**, and one felt they had not (one *don’t know;* two missing responses). There were three further comments, for example:

*“ No personal or religious beliefs were stated.”* [No]

***Help from health and social care services, work and financial issues: post-pathway***

Asked whether **health and/or social services could have helped to make things easier for their relative**, two said *yes*, six *no,* with one saying *don’t know* and two missing responses. Two respondents gave comments, for example:

*“[Name] was obviously seriously ill from March 1st when he first went to his GP. He saw 7 different doctors in the 2 months before being taken to hospital on 1st May, but was repeatedly told to keep taking the tablets even though his condition was deteriorating. [Name] felt he was not being listened to and was treated like a hypochondriac even though he had rarely visited the surgery before this illness. Apart from an early blood test which proved negative. [Name] was offered no further tests until 4 weeks before he died, by which time he had been taken to hospital.”* [Yes]

Five respondents said they **had had to give up work/make a major change** **to care for their relative**, with five saying this was not the case (one missing response). There were five comments, for example:

“*I had to work half days to share in looking after her.”* [Yes]

One respondent reported that their relative’s illness had meant **using all or most of their savings. Covering the cost of care** was reported as *not* *very difficult* by two respondents, and *not difficult at all* by seven; with one *not applicable* and one missing response.

***Care in bereavement: post-pathway***

Three respondents would have liked **another chance to discuss the death** with those involved with their care, with three *not sure*. Four said *no* to this question (one missing response). Four had **talked to someone from health, social, or bereavement services** (one had this planned), and two reported this as *helpful (*one *don’t know;* one missing response). Of the six who had not had this chance to talk, four did not want to, with two missing responses.

Asked about any other **help or support that health/social services** could have offered in bereavement, one person said *yes* and there was one comment made:

*“Found it very difficult to understand why the young lady who came in on a weekly basis to sit with my husband and who became very good friend and support to me was unable to have anything to do with me after he died. I was devastated at this unfeeling attitude and thought it so wrong.”* [Other reply]

***Support from health and social care services, and comments on care: post-pathway***

Respondents were asked if there were any ways in which health or social services **could have made things easier for the respondents themselves**: three said *yes* and five *no (* one other comment; two missing responses).

Comments on **good and bad aspects of the care** were invited, and there were three comments, for example:

*“Better staffing of hospitals at weekends - having the possibility of having tests (MRIs) done at weekends.”* [Yes]

*“After Mum's fall from bed and subsequent diagnosis of a fractured hip- the Calow hospital social services sprang into action and carers were despatched immediately [...]. The hospice team were also amazing anything we wanted we got i.e. wheelchair commode bed bath lift etc etc.”* [Missing]

Further comments on **any aspect of the care received**, were invited and four respondents made further comments, for example:

*“Not knowing exactly where her cancer originated. I felt that once they knew my wife was not going to survive, no further time was spent dealing with this aspect of the illness. It would be useful (from a preventative point of view) for the rest of the family to know.”*

*“Out patient appointments at Chesterfield Hospital. I did wonder if the liver biopsy and the colonoscopy were necessary - they happened after terminal cancer had been diagnosed. The procedures are not without pain; they raise false hopes or perhaps are not the best use of hospital resources.”*

***Section G: post-pathway phase***

For nearly all the patients the place where they died was considered the right one, with a majority of relatives able to be present. Most had been told that their relative would die soon, and this had been done in a good way. A minority felt that services could have helped their relative more, and a minority would have liked more bereavement care.

**Summary: VOICES survey of bereaved carers**

These two samples both represent only a minority (around a third in each case), of the total numbers who were sent the VOICES questionnaire. Caution should be exercised in interpreting the findings, as the responders may not be representative of the groups as a whole. Additionally, some differences can be seen between the respondents in the two groups. Firstly, the pathway implementation group report much greater satisfaction with the help and support received for providing personal care in the home setting. Secondly, more of the patients in the implementation group died at home or in a relative’s home, as opposed to in hospital or a hospice. These factors are likely to be related to other reported elements, such as the provision of enough care in the last three days of life, and feeling that the place where heir relative had died was the right place for them.

Experiences of help and support at home are reported to be satisfactory by nearly all who received them in the pathway implementation group, in contrast to the pre-pathway group, where significant failings were reported by some. GP care as reported in both groups appears variable, with reports of both good and poor care.

There are various reports of the quality of hospital care from both groups, with both high praise and reported very bad, neglectful care. One instance where a respondent describes poor care on one ward and good care on another supports the view that some wards deliver good care and some do not. The reports of poor care are such as to cause serious concern in some cases.

In contrast, the small numbers in either group reporting on hospice care record it as generally excellent.

Better experiences of care in the last three days of life are reported by the pathway implementation group, compared to the pre-pathway group. Greater satisfaction with the help and support from health and social services is also reported by the pathway implementation group. Both these findings may reflect the larger number in this group cared for at home and dying at home, and the reported better personal care services provided.

**Discussion**

Evaluating the development of a pathway for patients presenting with metastatic cancer of unidentified primary origin was a challenging process. This cohort of patients presents diversely and can be difficult to identify even retrospectively. Identifying the pre-CUP pathway group entailed extensive searches of a number of sources. This was to ensure that we generated as complete a dataset as possible. For example site-specific MDTs may have different thresholds for identifying a patient as having a possible primary site, rather than diagnosing as CUP.

Not all patients are referred for MDT discussion and a decision can be made a ward level regarding further investigations and future treatment. As a result of this, patient data can be lost with regard to national databases as data entry was done by the MDT co-ordinators. All inpatient admissions are coded, on the patients discharge, and this pertains to their diagnosis. Yet currently CUP does not have a specific code and therefore coding data is not as useful as it would be for other conditions in defining the population. This impacts when trying to do research and for service planning for patients.

Clinically some patients are more easily identifiable as presenting with metastatic cancer of unidentified primary origin. For example those who present to primary care with non-specific symptoms, or are found to have abnormal liver function tests and subsequently liver metastases on ultrasound. However with other patients, the diagnosis of CUP emerges once the initial presumed origin of the metastatic disease has been excluded. Another group are those patients who present acutely unwell and metastatic disease may be amongst the differential diagnoses. The CUP pathway was designed to cater for this diverse population, with the CUP team providing inpatient ward reviews, a MDT to which patients could be referred and a outpatient clinic.

The establishment of the whole pathway, particularly the outpatient clinic, took longer than anticipated. Therefore this report is a pre-CUP group and during development and implementation group, rather than a true post-CUP pathway group. For instance the outpatient CUP clinic was not established until well into post intervention period and it was this that was thought would be one of the mechanisms that enabled length of hospital stay to be reduced. The mechanism being that they could then be investigated in a timely fashion as an outpatient rather than wait for investigations as an inpatient. Described in the process section is the reason why the CUP outpatient clinic was delayed and hence patients who presented as an outpatient with having metastatic disease of undefined primary origin could only be referred to the team for discussion at CUP MDT as they had to remain, until the CUP outpatient clinic was established, under another physicians care.

It takes time for referral pathways and processes to be established within primary and secondary care, therefore of the 38 patients identified in the six-month post-CUP pathway period, 26 (68%) did have some input from the CUP team. In addition 12 (32%) patients were identified retrospectively using the same methods as were used to identify the pre-CUP pathway. However, only 8 (21%) patients within the post CUP group were initiated on the pathway early in the diagnostic process. For the pathway to have the desired effect in reducing unnecessary hospital admissions and lengths of stay, in addition the time taken from presentation with metastatic disease to definitive treatment then the proportion of patients who are referred early in the diagnostic process would need to increase. With the CUP pathway now being full implemented, clinicians gaining experience with the referral process and with ongoing education regarding the service it is hope that early referral rates should improve.

There was no difference between the pre-pathway patients and the post pathway patients in the mean rank time from the date they were identified as presenting with metastatic disease of unidentified primary origin to instigation of definitive treatment. However, as described above, with only a small proportion of patients (21%) being referred early in the diagnostic process the result is to be expected.

Despite the limitations of evaluating the outcomes of a new pathway so early on in its development and implementation there are some indications of potentially interesting outcomes and findings. There is some indication from the research that the pathway reduces the length of the investigatory period for those patients who have the longest investigatory periods (pre-CUP pathway range 0-115 days vs. post-CUP pathway 0 to 74 days). However this interpretation needs to have the caveat that this is involving only small numbers in each group.

Another difference between the pre and post pathway groups was the proportion of patients who died at home (14 %pre-CUP pathway vs. 31% post-CUP pathway). The numbers within this study are small (7 patients vs. 12 patients) and therefore statistical analysis is not appropriate. However we have drawn attention to it because it is was supported by the qualitative material within the VOICES questionnaires from bereaved carers and next of kin. Within the VOICES questionnaires, in the pre and post pathway, in most sections what were evident were examples of both good and bad practice and care. The post-pathway group experiences appear to have been better both in terms of help received and in the level of confidence felt.

The evaluation of the pathway was designed to be multi-method and incorporate qualitative data from patients presenting with metastatic cancer of unidentified primary origin so to shed light on the issues of importance to them. This was extremely difficult to collect because the majority of patients at presentation had a poor performance status (59% performance status 3-4) and the window of opportunity was short. The aim had been to be able to collect sequential quantitative and qualitative data from patients on the pathway however the median time from instigation of treatment to death in these patients was just 35 days. The case studies within the report are a means of illustrating some of the different presentations and individual journeys patients within this population can have. Interviews were obtained in 3 cases pre-pathway and one case post pathway, no formal comparison can be done on such small numbers but issues that were highlighted by the patients were delays, uncertainties and change of personnel all cause difficulties. One aim of the pathway is that patients are led through the investigatory period by one team, who are then able to have a consistent approach and with good communication skills handle some of the uncertainty which comes with the provisional diagnosis of metastatic cancer of unidentified origin.

**Conclusion**

A fuller account of costs will be provided at a later date.

The study confirmed the importance to patients of reducing delays, uncertainties and lack of continuity. This study appears to indicate that instituting a CUP pathway in a district general hospital has the potential to contain the length of time taken for investigation and increase the proportion of patients with CUP who are discharged or transferred before death.

Within the project, implementing and establishing the pathway was delayed by the complexity of the task. The second phase of the evaluation took place at a time when the pathway infrastructure and uptake was still incomplete. A third phase of the evaluation would be necessary to detect the whole effect of this intervention.

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| **Protocol Development and peer review. URMS form** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Ethics submission & review** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Recruit patients for pre-intervention phase** |  |  |  |  |  |  |  |  |  |  |  |  |
| **VOICES** |  |  |  |  |  |  |  |  |  |  |  |  |

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|  | **Feb 09** | **Mar 09** | **Apr 09** | **May 09** | **Jun 09** | **Jul 09** | **Aug 09** | **Sep 09** | **Oct 09** | **Nov 09** | **Dec 09** | **Jan 10** |
| **Intervention applied** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Recruit patients for pre-intervention phase** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Recruit patients for post-intervention phase** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Analyse date from pre-phase** |  |  |  |  |  |  |  |  |  |  |  |  |
| **VOICES** |  |  |  |  |  |  |  |  |  |  |  |  |

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|  | **Feb 10** | **Mar 10** | **Apr 10** | **May 10** | **Jun 10** | **Jul 10** | **Aug 10** | **Sep 10** | **Oct 10** | **Nov 10** | **Dec 10** | **Jan 11** |
| **Intervention Applied** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Recruit patients for post-intervention phase** |  |  |  |  |  |  |  |  |  |  |  |  |
| **VOICES** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Analysis** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Reporting** |  |  |  |  |  |  |  |  |  |  |  |  |

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