An investigation about transferring patients in critical care home to die: experiences, attitudes, population characteristics and practice
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Executive Summary

Background

Providing patients at the end of life with choice regarding where they die has become an important goal of health services as research reports that the majority of people, when asked, express a preference to die at home. Currently, however, most people die in hospital.

A proportion of hospital deaths occur in critical care areas where transferring a patient home to die, whilst a potential option, is rarely undertaken. Low transfer rates are likely to be influenced by the severity of the patient’s condition and associated treatment and care which limits the time available to consider and organise transfer. In countries other than the UK transfer home to die is reported in small numbers and linked to cultural norms and expectations related to what end of life care should entail, who should be involved and where death should happen. Relatively little is known about what is needed to facilitate this practice. Furthermore, what the current level of provision in the UK is, and whether this option is one that health care professionals are able and willing to facilitate, is also unclear.

Aims

The study aimed to scope the experience, attitudes, and views of critical care health care professionals regarding the feasibility of transferring critical care patients home to die. The objectives for the study were to:

1. Investigate current experience of, practices related to, and views towards transferring critical care patients home to die

2. Identify factors that enable or challenge service providers to transfer patients in this care setting home to die

3. Scope the size and characteristics of the potential ‘transferring patients home to die’ critical care population

4. Explore factors that might influence the feasibility of transferring critical care patients’ home to die, including resources and infrastructure required

5. Make recommendations on models of care/service specifications in this area.
Methods

The study was carried out in three phases.

Phase I included a review of the literature with findings subsequently being used to explore this topic in six focus groups carried out with: i) health care professionals from critical care, ii) health care professionals from community services, and iii) members of a patient and public forum. Focus groups aimed to gain information about experiences of, and views and attitudes toward, transferring patients home to die from critical care settings.

After completion of the focus groups a web-based survey was developed and an invitation to participate was sent to lead consultants and nurses (756 individuals) working in 409 critical and high care units across the UK. The aim of the survey was to: establish the current level of transfer activity in UK, identify how many critical care staff had direct experience of organising a transfer home from their unit, and what attitudes, views and concerns are related to providing this service. A further aim was to establish what level/type of care/treatment would facilitate or obstruct potential transfer home to die in this population. Participants were asked to rate their top five facilitators and barriers to transfer from a list of 11 options.

Following on from the survey, individual telephone interviews were carried out with 21 doctors and nurses who had been actively involved in transfer/s, or had been involved in discussions about the possibility of transferring a patient home to die. These interviews aimed to identify the practical issues that needed to be considered when providing this type of service, and the factors that they indicated as facilitating or obstructing a transfer.

Phase II involved an audit of medical records of 7,844 patients who were inpatients in 7 critical or high care units at two hospitals in the South of England over a one year period. The audit aimed to identify: the number of patients who died on the units, and of these, how many patients (if certain criteria applied) could potentially have been offered the option of being transferred home to die.

Phase III convened a national Stakeholder Event of 85 representatives from professional organisations, critical and community care health care professionals, patients and relatives. Vignettes were used to stimulate discussion as a further aim of the Stakeholder Event was to identify models of care, potential elements of a service specification and clinical guidance to inform practice in this area. In addition, a nominal group technique aimed to identify and prioritise barriers most likely to influence transferring patients from critical care home to die, as well as prioritise areas within the process that required further development.
Results

Phase 1 Literature Review

The literature review found there are few published studies that report the transfer of patients home to die from critical care units, and those that are available have small sample sizes or articulate case studies that illustrate the influence of cultural factors on the decision making process and service provision. The current literature lacks detail of the procedure involved in transfer, and critique or evaluation of the process.

Phase 1 Focus Groups

Whilst focus group participants held positive views about transfer home to die from critical care, this was an uncommon event and was perceived to be a complex process. Due to the majority of focus group participants having little or no experience of transfer home to die the key issues raised by clinical participants included: the problems associated with identifying suitable patients, lack of knowledge of how to coordinate transfer arrangements to the community, managing unrealistic expectations of families related to how death at home might proceed, and an urgent need for guidance to inform service development. Key drivers associated with implementing transfer included: patient and/or family request, support for the idea from family members (when patient has initiated the request), and access to care in the community.

Phase 1 Web-based Survey

Of the 756 critical care staff invited to participate in the survey 191 (25.3%) participated, with 180 (23.8%) respondents providing sufficient data for analysis. Of these 180, 71 (39.4%) were consultants and 97 (59.9%) were nurses. A minority of respondents 65 (36.1%) had been actively involved in transferring patients home to die and only 28 (15.5%) had had been involved in discussions about this possibility.

The survey indicated that respondents were supportive of the idea of transfer home to die and that in terms of patient characteristics patient stability was a key factor in decision making.

The top three ranked barriers to transfer were: i) lack of access to care in the community, ii) patients’ relatives unlikely to be able to cope with transfer and death at home and iii) lack of guidelines on transfer home to die.

Phase 1 Follow-on Interviews

Those participants who had experience of transfer were positive about the feasibility of offering this service and saw it as an important part of end of life care in appropriate circumstances. Findings indicated that
the request for transfer home usually came from family members and patients. Interview participants indicated access to care in the community and relatives’ ability to cope with care at home were key factors during decision making. Participants indicated the need for a named clinician to lead in liaising with individuals across clinical, organisational and geographical boundaries if transfer was to be successful. Participants also stressed the speed at which services and equipment could be identified, accessed, orchestrated and implemented was a crucial factor in facilitating transfer home to die.

Participants who had carried out transfer reported effective links and working relationships with rapid discharge and/or specialist palliative care teams expedited transfer home as these teams were able to identify and deal with the relevant legal, health and safety and ethical issues arising from a decision to transfer a patient home to die. Aftercare was also identified as important from the interview findings.

**Phase II Audit**

Of the 7844 patients’ notes audited: 422 (5.4%) patients had died. Patients were identified as unlikely to be suitable for transfer if certain pre–determined criteria were identified in their notes and these included: cardiac arrest or sudden death (n = 62 patients, 14.7%); instability as judged against agreed audit criteria (n = 225 patients, 53.3%), and 35 (8.3%) due to other factors (coroner’s cases, complex family dynamics, and high level of nursing care needs). Therefore a total of 322 (76.3%) patients were unlikely to be considered for a possible transfer, leaving 100 (23.7%) patients who, judged against the audit criteria, could have been transferred home to die as they were clinically stable and did not present with specific physiological or care factors. None of the 100 patients identified as potentially suitable through this process were transferred.

**Phase III Stakeholder Event**

When healthcare professionals were asked to prioritise what they saw as the top three barriers to transfer the barriers were similar to those identified during earlier phases of the study and included: access to care in the community; responsibility for care of patient, and expectations of relatives about death at home. In addition, participants were asked to identify the area that needed the most development to enable the practice to be more fully developed. The following three areas were prioritised: 1) increased awareness of community support services (30%), 2) refine transfer process (15%) and 3) look at new activities/pathways (14%).

The event was a success from the researchers’ point of view and served to generate a level of detail about the transfer process that combined
with findings from each phase, informed development of clinical guidance.

*Phase III Guidance*

Findings from the study were used to generate clinical guidance that relates to considerations for the transfer process. Two different formats were developed and presented to experienced clinicians (n=14) for initial testing. The guidance was generally well received by clinicians but clinicians differed in their views on how it might be used. Some suggested a version of guidance for use in discussions with patients and relatives, others as a potential educational tool (developing awareness for this practice on the unit and the processes necessary to underpin the practice). Clinicians saw the benefit of having clear guidance to aid the organisation of transfer home to die. A final version was developed incorporating suggestions provided by the experienced clinicians.

*Conclusions*

To our knowledge this is the first study internationally to conduct an in-depth examination of the concept of transferring patients from critical care home to die, and whilst there have been initiatives to improve end of life care in the critical care environment these have not extended to consideration of preferred place of death.

The study has scoped the size and characteristics of the critical care population with potential to transfer home to die and found that very few patients are offered or request this option. Findings clearly indicate the positive view of health care professionals toward the possibility of transferring patients home to die with physiological stability of the patient, as well as psychological, social, spiritual and contextual factors playing an equal role in the decision making process.

The logistics of transfer to community services is uniformly perceived to be a complex, highly time dependent, process which currently lacks evidence based guidance to enable and direct practice in this area. A lack of guidance and the availability of tools to facilitate the transfer process may be contributing to critical care teams not routinely considering the option of transfer home to die.

*Recommendations for practice*

Findings from the study have generated clinical guidance that relates to considerations for the transfer process. In order to further develop practice in this area we recommend:

- Staff in critical care environments actively consider the practice of transferring patients home to die
• Clinical teams in secondary and primary care use the guidance as a point of reference to develop local policy and procedures to underpin the process

• Critical care units establish which local (both secondary and primary care) resources might be mobilised in the event of a transfer being considered and engage with stakeholders in discussions and clinical policy development. These should address cases where death will be very rapid once the person reaches home but also where a longer dying trajectory is anticipated (or occurs unexpectedly)

• A community of practice be established whereby the experiences and solutions to effecting rapid and effective transfer can be shared between units with the aim of developing practice in this area

Recommendations for further research

The efficacy and usability of the guidance generated in this study needs to be tested in an implementation study carried out in conjunction with critical care units and their linked community care providers.

In addition, work is needed to better understand the experiences and practices of community-based staff in relation to caring for patients who have been transferred home to die from critical care.

Equally, it is essential to understand what happens once transfer has taken place and how events are managed in the home before and after death. This should include examining the process and outcome from the perspective of family members of which little is known.

Finally, implementing any change in healthcare practice is fraught with challenge as barriers to implementation can arise at multiple levels of care delivery: the patient and family level, provider team level, organisational level or policy level. Studies to develop and evaluate tools to help healthcare teams, patients and their families consider how suitable the option of arranging for a person to die home might be in a particular case are necessary.
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Introduction

Increased choice and improved care at the end of life is a key component of health policy (Department of Health (DH)) with the concept of preferred place of care central to this.\textsuperscript{2,3} Research undertaken as part of the End of Life Care Programme\textsuperscript{1} suggests that the majority of people (between 56 and 74%) express a preference to die at home. Despite this figure, 58% of deaths occur in hospital.

A proportion of these deaths will occur in the fast paced, technologically focussed environment of critical care. Some of these deaths will be expected i.e. where a decision has been taken to withdraw life sustaining treatments, but with time between decision and death occurring expected to be very short (hours and at the most a few days). Therefore the question arises as to whether for patients who are not responding to treatment and a decision is in the process of being made to withdraw life sustaining treatment if it is possible for choice of preferred place of death to be honoured.

There is evidence in case reports and opinion pieces\textsuperscript{4,5} of patients being discharged home to die from a critical care environment\textsuperscript{6-13}, which suggests this may be a viable option in terms of choice of location of death for some. The complexity of arranging transfer home to die from critical care has been described. To a great extent this is influenced by the clinical characteristics of patients in critical care; they tend to be clinically very unstable and time between withdrawal of treatment and death is likely to be short. This leaves clinicians and families with very little time to make important decisions and organise a transfer home if this is the desired course of action. Consequently, the prevalence of transferring patients home to die is low, with units seemingly only transferring only a few patients home to die each year, if the practice is well embedded\textsuperscript{14,15}. Moreover, there is evidence of a strong cultural component to the practice with some cultures emphasising the importance of dying at home surrounded by family, which in turn has impacted the provision of this service in different countries. While the complexity of transfer home has been outlined in several case study reports, relatively little is known about this practice.

This report presents findings from a three phase study which aimed to scope the experience, attitudes, population characteristics and views of critical care health care professionals regarding the feasibility of transferring critical care patients home to die, for whom withdrawal or withholding of treatment has been discussed by the clinical team and with the patient (where possible) and relatives.

Aims of the study

This three phase study explored experiences, attitudes, population characteristics and feasibility of transferring critical care patients home to die from the perspective of health professionals.
Study objectives were to:

1. Investigate current experience of, practices related to, and views towards transferring critical care patients home to die

2. Identify factors that enable or challenge service providers to transfer patients in this care setting home to die

3. Scope the size and characteristics of the potential ‘transferring patients home to die’ critical care population

4. Explore factors that might influence the feasibility of transferring critical care patients’ home to die, including resources and infrastructure required

5. Make recommendations on models of care/service specifications in this area.

To achieve these aims a three phase exploratory sequential study was carried out, developing insights from qualitative and quantitative data collection and data analysis. In Phase I current experiences of, practices in, and views towards transferring patients in critical care areas home to die were investigated as well as identifying factors that enable or challenge the ability of service providers to transfer patients home to die. In the first instance a scoping review of the literature was undertaken which in turn informed the content of focus groups which were conducted with health professionals from critical care and the community and patient and relative representatives. Subsequently, a web-based survey was developed to gain insight about views and experiences of critical care staff in the UK. To establish a more in depth picture of these aspects follow-on interviews were conducted with critical care staff who had experience with transfer home to die, or who had had discussions with and about a patient (and/or relatives) who had expressed a wish to go home to die. In Phase II an audit of deceased patients from several critical care units was carried out to establish the size and characteristics of the potential critical care population who might be transferred home to die. Finally, in Phase III the feasibility of transferring people home to die was explored by organising a national Stakeholder Event, bringing together representatives of professional organisations, health professionals from critical and community settings and representatives of patients and relatives. This event enabled the formulation of clinical guidance to inform practice in this area.
Phase I: Scoping review of the literature

Aims

A scoping review of the literature, using the structure proposed by Arksey and O’Malley⁴⁶, was undertaken to inform the development of the focus groups and the national survey, which in turn was aimed at exploring experiences of units and gathering opinion on feasibility of transfer home to die from ITU.

Methods

The scoping review search included Medline, CINAHL, Psychinfo and Embase databases using the following search terms: ‘Critical Care’, ‘Intensive Care’, ‘ITU’ ‘CCU’, ‘Palliative Care’, ‘Terminal Care’, ‘end of life’, ‘Euthanasia (Passive)’, ‘Death’, ‘dying’, ‘Withholding Treatment’, ‘withdraw* treatment’, and ‘Home’ (January 1980–January 2012). The searches yielded 533 results. All abstracts were reviewed by one reviewer to assess whether the study was eligible for inclusion in the review based on the following criteria: 1) publication discusses the transfer of adult patients from critical care home to die 2) publication comments on the ‘importance’ of transferring patients from critical care home to die. Abstracts were excluded if they were in a foreign language, (except for Dutch as author 2 is Dutch speaking), or had a paediatric focus. One hundred and three abstracts were selected for full paper review. Every tenth abstract was assessed by a second reviewer (MC) and no disparity in decision to include or exclude was found. Thirteen publications were included in the review and are detailed in Table 1.

Results

The small amount of literature that is available regarding taking patients home to die from critical care reports the experiences of intensive care units from around the world (Netherlands, Tunisia, New Zealand, UK, Taiwan, Australia, USA) in cases where this option has been offered or actively considered [to varying degrees]. The main findings from the scoping review were: i) prevalence of transferring patients home to die is low, ii) practice often driven by cultural preference, and iii) patient/family choice in informing the decision to transfer home. These findings are discussed in more detail below.
<table>
<thead>
<tr>
<th>Author/paper details</th>
<th>Patient/cohort sample characteristics</th>
<th>Methods and sample</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kallel et al., 2006 A good death: another break in the wall. Tunisia⁶</td>
<td>76 year old man with chronic obstructive pulmonary disease, atrial hypertension and congestive cardiac failure admitted to Emergency room with diffuse cerebral haemorrhage.</td>
<td>Case report of one patient</td>
<td>Patients had expressed a wish to die at home. Family supported this wish. Patient transported home. All mechanical support, support drugs were withdrawn in home situation. Patient died within minutes. ICU team support view that the patient ‘wish’ regarding place of ‘deathbed’ should be facilitated where possible.</td>
</tr>
<tr>
<td>Tellett and Davis, 2009 Fulfilling a patient’s wish to go home from intensive care. UK⁷</td>
<td>58 year old man with Epstein’s anomaly [congenital heart defect]. Long-standing tricuspid regurgitation with right ventricular failure, diabetes, chronic renal and liver failure</td>
<td>Case report of one patient</td>
<td>Patient knows he is dying and wants to go home. Need for discussions with multidisciplinary team. Withdrawal of support drugs and hemofiltration in CICU. Transfer home with CICU nursing staff in attendance. Care provided by community team headed by GP. Patients dies at home three days after discharge from CICU.</td>
</tr>
<tr>
<td>Ryder-Lewis, 2005 Going home from ICU to die: a celebration of life. New Zealand⁸</td>
<td>14 patients [mainly Maori] transferred home over 4 years. No patient characteristics available.</td>
<td>Paper discussing the development of the ‘taking home to die’ service.</td>
<td>Role of philosophy of care underpinning a ‘good’ death Cultural demand for service Need for team discussion and preparation of family and patient [including information about recognising death] regarding what will happen at home. Liaison with, and involvement of, a committed community team who meet ICU team and patient before discharge. Clarification of roles and responsibilities of family and community team when patient transferred. Positive family feedback to date.</td>
</tr>
<tr>
<td>Kompanje, 2009 Should we discharge comatose patients</td>
<td></td>
<td>Editorial commentary on four studies</td>
<td>Differentiates ‘Western’ and ‘Non Western’ views regarding the importance of dying at home [Non-Western limited to USA].</td>
</tr>
<tr>
<td>From intensive care to die in their own bed at home after withdrawal of mechanical ventilation? Netherlands(^4)</td>
<td>Discussing taking patients home to die</td>
<td>Differentiates taking patients who are conscious and have longstanding conditions/cancer home to die, from unconscious, ventilated, ICU patients. Asks the question ‘in whose best interest’ is this done.</td>
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<tr>
<td>Huang et al., 2009 Going home to die from surgical intensive care units. Taiwan(^{14})</td>
<td>Patients within five units: cardiovascular surgery, neurosurgery, trauma, chest surgery and general surgery. Annual discharge to die at home figures decrease from 2003 – 2007 from a high of 44.1% of ICU admissions to 24.1% of admissions.</td>
<td>Retrospective observational comparison of patient demographics comparing those who died at home and those who died in ICU.</td>
<td>Patients who went home to die were older than those who died in ICU. Patients who went home to die received more ‘advanced treatments’ than did those who remained in ICU. Transfer home to die was not a move to a palliative pathway as intensive care continued at home. Going home to die from ICU is reported as ‘a cultural tradition’.</td>
</tr>
<tr>
<td>Boussarsar and Bouchoucha, 2006 Dying at home: cultural and religious preferences. Tunisia(^6)</td>
<td>Critically ill non–cancer patients Muslim. 10 of 102 deaths in 2005</td>
<td>Case report</td>
<td>Family members asked about their preferences for end of life care. If family preference is for death at home, discussion about what will happen takes place and transfer home is arranged. Nurse and medic transfer patient home and withdrawal of all interventions take place. ICU staff remain with patient until death.</td>
</tr>
<tr>
<td>Beuks et al., 2006 A good death The Netherlands(^{10})</td>
<td>1) 56 year old woman with acute heart failure 2) 58 year old woman</td>
<td>Case report</td>
<td>What constitutes a ‘good deathbed’ [sic] is a personal opinion influenced by cultural aspects. Whole team needs to agree prognosis and support patients decision. Patient must make the decision in ‘full understanding’ of the situation. Family involvement in decision making is key as well as their capabilities. Need for ‘good and clear’ communication with the family in</td>
</tr>
<tr>
<td>Authors, Year</td>
<td>Description</td>
<td>Type</td>
<td>Notes</td>
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<tr>
<td>Lusardi et al., 2011</td>
<td>The going home initiative: getting critical care patients home with hospice. USA\textsuperscript{11}</td>
<td>Evidence based practice development report</td>
<td>Need for discussions about leaving the unit and what this entails [where, who, what]. Coordination of services to transfer and care for the patient in the home [ICU staff do not transfer]. Communication with the family post transfer home.</td>
</tr>
<tr>
<td>Clinch and Le, 2011</td>
<td>Withdrawal of mechanical ventilation in the home: a case report and review of the literature. Australia\textsuperscript{12}</td>
<td>Case report/lit review</td>
<td>Patient decision to cease elective ventilation, but to be moved home for palliative care. Family supported this decision. Extensive discussion with family, ICU team, wider hospital executive and community team. Medico legal situation for ICU team withdrawing in the home situation checked. Community palliative care team agreed to transfer home. Respiratory physician, clinical nurse, palliative care physician accompanied patient home. Pre withdrawal analgesia and anxiolytic given, ventilation discontinued. Further analgesia and anxiolytic given and ICU team leave. Patient commenced on ‘infused’ morphine. Patient dies 2.5 hrs. after going home.</td>
</tr>
<tr>
<td>Mann et al., 2004</td>
<td>Caring for patients and families at the end of life: withdrawal of intensive care in the patient’s home. New Zealand\textsuperscript{15}</td>
<td>Retrospective study</td>
<td>All patients were Maori or Polynesian. Sixteen out of 17 patients were ventilated for transfer. Extubation took place at home. Seven of 17 were on inotropic support which was withdrawn at home. Family agreement in place with family being aware that all treatment will be withdrawn in the home situation immediately after return home. ICU accompany staff and stay with patient until death [less than 12 hrs] or hand over to community team [pre-planned]. Good palliative care support in the community.</td>
</tr>
</tbody>
</table>

| Dataset | 7 patients in 2 years (1.5%) from medical–surgical non–cardiac ICU. Restricted to those who are not ventilated. | Case report/lit review | No notes provided. |

| Dataset | 71 year old man with meningoencephalitis and pneumonia leading to hypoxaemic bradycardiac arrest. | Case report/lit review | No notes provided. |

<p>| Dataset | 17 patients transferred over a 6 year period: Diagnosis; Intracranial haemorrhage [n = 3] Community cardiac arrest linked to sepsis [n=5] Cerebral bleeds secondary to hypertension [n=3] Brain death post meningitis [n=1] Bronchiectasis leading to multi organ failure [n=1] Cellulitis leading to multi organ | Retrospective study | No notes provided. |</p>
<table>
<thead>
<tr>
<th>Failure</th>
<th>Respiratory failure</th>
<th>Post-operative complications</th>
<th>Who signs the death certificate arranged prior to transfer.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kumar et al., 2009</td>
<td>71 year old female with end stage congestive heart and renal failure.</td>
<td>Case report</td>
<td>Patient wanted to die at home Patient was not ventilated, but on inotropic support Transfer involved: Discussion with in-house palliative care team Senior management, Coroner and GP. DNR order in place ICU nurse accompanied patient and remained until after the patient died.</td>
</tr>
<tr>
<td>De Vries et al, 2011</td>
<td>64 year old man with different health problems</td>
<td>Case report</td>
<td>Care organised by ITU HCPs The piece of mind of being at home for patient and family is crucial Transport home as a continuation of care from ITU. ITU staff have primary responsibility for patient’s care (even in case of transfer) Importance of family support, collaboration with GP, good support from nurses. A good death is an important part of Intensive care medicine</td>
</tr>
<tr>
<td>Jackson, 2006</td>
<td>15 patients since 1999. 66% were Maori, 20% Pakeha, 7% Samoan, 7% Pacific Island.</td>
<td>Retrospective review (conference abstract)</td>
<td>Role of ICU nurse moves from primary caregiver of life support therapy to supportive coordinator Positive experiences: meeting family’s wishes, meeting cultural needs Negative experiences: concerns around nurse safety, inadequate knowledge and experience, unfamiliarity of providing home care, lack of support after hours, out of date policies. Importance of liaising with primary care teams</td>
</tr>
</tbody>
</table>
Type of publications

Of the thirteen publications, seven were case reports, two correspondence or editorials and a further four were retrospective studies (of which one was a conference abstract) reporting the number of patients transferred home to die over a period of years. The majority of publications are case reports suggesting that the evidence base for this development in clinical practice is currently limited. In addition, there is a lack of detail in the case reports about the process underpinning transfer home to die, which could impede implementation. Most publications emphasised the practical barriers that needed to be overcome before transfer can be achieved.

Culture

One of the key features of the publications was that this intervention was strongly related to the cultural background of the patients involved. The practice was described for patients in the Muslim community8,9, Maori and Pacific Island community15, and Taiwanese community14. The authors of these studies emphasised the cultural importance of dying at home surrounded by family members, which resulted in practice being developed to meet a need.

Patient and family choice and decision-making

The importance of patient of personal opinions of what constitutes a good death10, decision-making and capacity7,10 were highlighted. In addition, strong emphasis was placed on the family involvement in decision-making7,8,11. Moreover the need for preparation and discussion with relatives was highlighted, in order for everyone to understand what is likely to happen in the home after transfer11,17. Finally, communication with the family after the transfer was deemed a crucial element of such a complex process11.

Patient characteristics

The determination of whether intubated patients, or those on inotropic support were able to go home was based on: i) the willingness of the family to accept that such support would be ‘withdrawn’ immediately on arriving home13,15, and ii) the willingness of community based healthcare professionals to accept the responsibility of care provision and certification of death after it occurred5,15,17. Also of importance was the issue of ‘who’ made the request for transfer home, as more often than not the patient would request to go home. Indeed Kompanje (2009) questions transferring an unconscious patient home to die as the patient is unlikely to benefit and it would only be for the relatives.
**Overall findings**

The main considerations reported included: i) resources required by the unit instigating the transfer (available staff, time to organise the transfer, transport being available, distance to home etc.), ii) good community links and level and nature of the support available in the community setting [family commitment, support networks], and iii) involvement of palliative care teams. Entering into the process of managing a transfer home to die from critical care appeared to be highly influenced by practical issues, as indicated above, and by specific patient characteristics.

**Discussion**

The scoping review has shown that there are very few published studies on transferring patients home to die from critical care. Several publications are case studies of patients, which often lack critical details on how this transfer was actually achieved. Larger scale studies on this topic have to date not been published. The review did highlight the importance of cultural preference around transfer, emphasising this practice in order to achieve a good death. In addition, another important aspect is the issue of patient and family choice. Most studies discussed how the process is influenced by practical considerations such as the logistics of transfer, patient characteristics (such as clinical stability and respiratory support) and finally care in the community. Without support from family members and support from staff in the community the transfer process is less likely to succeed. The results from the scoping review were used to develop questions for subsequent focus group discussions with health professionals in critical care and the community, and patient and public representatives. The aspects of the transfer process, identified in the publications, and prioritised for investigation in the subsequent focus groups and survey were: individual and unit wide experiences, barriers to achieving a transfer, and the identification of specific relevant patient characteristics.
Phase I: Focus Groups

Aims
The aims of a series of focus groups were to: to investigate the views and current experiences of health care professionals (HCPs) from critical care and those in the community to transferring patients home to die; to explore current practice where it existed and to identify factors that enable or challenge the ability of service providers to transfer patients in this setting home to die. A further aim was to assess the views of members of a Patient and Public Forum to the potential of this option.

Methods

Recruitment
HCPs from four critical care units in the South of England were approached to take part, specifically Cardiac Intensive Care Unit (ITU), General ITU, Neuro ITU and Oncology ITU. The objective was to include intensive care HCPs with differing backgrounds in terms of unit speciality in order to be representative of the different patient populations to whom transfer home might apply. In addition, the aim was to include both consultant anaesthetist/intensivists and critical care nurses (senior experience nurses, band 6 or higher), thus targeting experienced HCPs, encultured in critical care practice. A further group of HCPs was approached from primary care, through a primary care trust also in the South of England, to explore the views and experiences from the community perspective. Finally, patient representatives were asked to take part in the study by approaching members of a Patient and Public Forum affiliated to a General ITU. This forum consisted of patients, partners of patients and several health professionals (nurses, consultants and physio-therapists). Ethics approval for this part of the study was obtained from the relevant regional Ethics committee (REC reference 11/SC/0031) and R&D approval was obtained from the different NHS Trusts.

Development of focus group guide
The development of the focus group guide was informed by themes distilled from the scoping review of the literature. More specifically the focus was on views, patient characteristics, logistics and barriers/facilitators and HCPs’ views on feasibility of this practice. Initial questions were developed by ASD and TLS and refined through discussion. A vignette was developed of a patient who could potentially be transferred home to die (Text box 1).
Data collection

A health psychologist (ASD), conducted all the focus groups. Focus groups were all organised to coincide with already organised staff meetings or Patient and Public Forum meetings. Participants were sent a participant information sheet before the meeting and all participants signed a written consent form prior to the start of the focus groups (after being given the opportunity to ask questions). For focus groups involving critical care unit HCPs or community HCPs, a vignette was used to stimulate discussion alongside a semi-structured focus group guide (see text box 1). All focus groups were facilitated and moderated by ASD and observed by an experienced researcher with expertise in qualitative research methods.

Text box 1.

Vignette
A 65 year old man is critically ill and is not responding to treatment. Treatment withdrawal is discussed with the family and they would like him to die at home.

Questions
• What are your views about transferring critically ill patients home to die?
• Do you think it is important to transfer critically ill patients home to die?
• When would you transfer a critically ill patient home to die?
• When would you NOT transfer a critically ill patient home to die?
• What is needed to offer to transfer a critically ill patient home to die?
• Do you think it is feasible to transfer a critically ill patient home to die?

For the focus group involving members of the Patient and Public Forum, questions were limited to those in Text box 2.
Text box 2

Questions
- What are your views about transferring critically ill patients home to die?
- Do you think it is important to transfer critically ill patients home to die?
- Do you have any worries or concerns about transferring critically ill patients home to die?
- Which patients would be eligible to be transferred home to die?

Data analysis

All focus group discussions were recorded and transcribed. Transcribed discussions underwent thematic analysis. NVivo software was used to facilitate coding, store and manage data, and generate reports. In the first instance the transcripts were read by ASD. Secondly, transcripts were each reviewed line by line, applying codes for detailed descriptions. A sample of four transcripts was selected and independently analysed by TLS and MC to validate the coding at this stage. Finally the developed codes were grouped into themes and compared. The first iteration of themes was reviewed by the project's steering group in one of its six-monthly meetings. The final framework of themes and subthemes is presented in Figure 1.

Results

Participants

Six focus groups were carried out, four involving senior health care professionals [both nursing and medical] in general intensive care [n=7], cardiac intensive care [n=10], neurological intensive care [n=11], and oncology intensive care units [n=8], one involving health professionals (GPs and community nurses n=6,) working in the community, and one involving members of the Patient and Public Forum (n=7) from an intensive care unit. In total 49 participants contributed to the focus group discussions.

Membership of each focus group is presented in Table 2. The average length of the focus group discussions was 45.00 minutes.

Table 2 Focus group participants

<table>
<thead>
<tr>
<th>Nurse</th>
<th>Critical Care Consultant</th>
<th>GP</th>
<th>Physiotherapist</th>
<th>Lay person</th>
</tr>
</thead>
</table>

| 26 |
Findings

Findings are outlined under five major themes; Experience, Views, Patient characteristics, Barriers/Facilitators and Concerns, as shown in Figure 1.

Figure 1. Outline of themes and subthemes of Focus Group data

Experience

Participants were asked to what extent they had any experience of transfer home to die. The majority had never transferred a patient home to die but there were several who had experience of transfer and could provide more detail on the processes involved. Some participants
had had discussions with and about patients who had expressed a wish to be transferred home to die but for whom this could not be arranged.

Views

Positive and negative views about the general concept of transferring patients home were expressed:

“As a, just the other point, I always actually think the intensive care is a very nice place to die, I’ve never, the care and the cleanliness” (FG04)

“I think what’s one of the messages from this is that there aren’t actually massive clinical objections from our point of view for doing this, our reservations come from what actually happens out there to our patients when we’ve given them back to the community” (FG02)

Patient characteristics

There was much debate about patient characteristics in terms of eligibility for transfer. These focused on the extent of breathing support (e.g. ventilated, tracheostomy) and the extent to which patients were considered to be stable enough for transfer:

“Patients who are requiring a lot of say Inotropes or on like the oscillator or things like that I don’t think they’d even survive the transfer to get them home” (FG03)

In addition, the intensity of nursing care required, need for regular medication and the distance between the hospital and home were also taken into consideration:

“At a practical level some patients may have an awful lot of diarrhoea or something, you’d have to be very careful about taking them home because the level of support to look after that might not be possible” (FG03)

Further description of specific patient characteristics included patients who were unconscious, bariatric, extremely incontinent, or oedematous patients, coroner’s cases, patients who had infections, or patients with difficult family dynamics.

Barriers/facilitators

Participants, regardless of their general views about transferring patients home to die, identified areas which could be labelled as barriers and facilitators of transferring patients. First of all, the community package; participants were unanimous in their emphasis on the importance of having access to community services without which
the transfer would not be possible. This would involve questions around the availability of good palliative care in the community, in terms of who and what was available in the community. In addition, participants expressed a lack of knowledge about how to organise care at home and were unsure about how quickly they would be able to organise this care. Finally, there was concern about being able to get through to the GP and about the care patients receive after the ITU staff left the home.

“Yes it’s that care after they arrive back home I would be most concerned about in particular ensuring they had good palliative once they’re home” (FG02)

A second subtheme was the home environment and information about this. Lack of information or poor access to the home environment could potentially impede a transfer. Thirdly, participants highlighted the need for care after the patient had died, and feedback from relatives to ensure that the experience was a successful one. A fourth barrier was around the logistics and included: organising and overseeing the process of transfer (who needs to do what and with whom), organising transport, equipment (e.g. a bed), medicines (liaising with pharmacy) and backfill of staff on the unit. Another important barrier was time, with issues around enough time to organise the transfer, the uncertainty of the time until death and timing of the transfer, such that transfers are less likely to be realised on a Friday afternoon or a weekend.

“Is there enough time to get him home so that he can die at home depending upon the severity of his critical illness would be my concern” (FG02)

Guidelines and criteria were highlighted as possibly facilitating the organisation of a transfer. This subtheme included expressions of interest in developing criteria for transferring critically ill patients home to die and indications that starting with a selective service, in terms of patient characteristics was preferable. The lack of local and national guidelines on transferring patients from critical care home to die were discussed and considered to be a barrier.

Critical care culture was mentioned as a possible barrier, which referred to the critical care mind-set of focusing on cure, the difficulty of changing from curative to palliative care and the fact that nowadays patients tend to die in hospital. More general cultural aspects were mentioned with regard to specific cultural groups for whom dying at home is paramount and the fact that the younger generation is not used to caring for relatives. Finally, ‘support’ was an important subtheme; support for nurses, potentially working in an unfamiliar environment (the patient’s home), and support for relatives in taking care of the dying patient.
Concerns

A strong theme was ‘concerns’ which differed from barriers and facilitators as these did not stop HCPs from taking action; rather these were aspects that required more attention before transfer could occur. Major concerns were expressed about family members and to what extent they fully understand what caring for a dying patient in the home means and to what extent they were deemed strong enough to take on this task. There was concern that their expectations would be unrealistic, whereas death can be a burdensome and complicated situation in terms of care in the home for relatives.

“It’s also assessing how the family would cope being outside of the hospital environment, because an ITU patient in a home environment is completely different to being in a hospital. How will they cope, how have they been when, how have they been physiologically when he’s been on ITU. Are they just saying oh they want him home to die have they really thought through the process” (FG03)

Concerns were also raised about legal and responsibility issues, when transferring from tertiary care to primary care: safeguarding issues, the need for a DNR order, who would complete a death certificate and who would prescribe and administer any drugs that might be needed. In terms of insurance the question was whether critical care staff are insured when working in the community, in case they travelled with the patient to their home.

Participants expressed concern about the process of decision-making, with health care professionals stating that relatives are often passive which consequently made HCPs worry that relatives would just say yes, or that relatives would feel pressured into saying yes. Possibly offering the service could result in another choice that relatives have to make and could result in feelings of guilt if they declined to have the patient transferred home. Another question raised by the HCPs was ‘who is this for?’ HCPs recognised that the patient belongs to the relatives and that transfer of a patient could equally benefit relatives, as they have to live with the consequences and memories. A further subtheme which was highlighted was around the ethics of transfer home and whether transfer should be pursued if the patient was unconscious (which relates back to the question of who this is for). Finally concerns were raised about the ethics of keeping a patient alive in order to facilitate a transfer home.

“But I almost have a slight ethical issue with it as well of prolonging someone’s life to the point of going home” (FG03)

Finally, alternatives to transferring patients home to die were discussed for example transferring to hospice, or ensuring end of life care was excellent in ICU so that a transfer would not be necessary.
Discussion

Findings from the focus groups indicate that transferring a patient home to die was a relatively rare event for those participants involved. Participants articulated differing views, both positive and negative, about this topic but focussed on the clinical characteristics of patients, logistical arrangements and possible barriers. In terms of clinical characteristics, participants indicated that the patient would need to be stable enough to be transferred. Many logistical arrangements were mentioned, highlighting the complex nature of transferring a patient home to die from critical care. There were numerous perceived barriers and facilitators associated with this process and care in the community dominated. Participants often did not know how to access adequate care in the community, nor did they feel confident that excellent care would be available in the community to assure a ‘good death’. Some concerns were mentioned as well and the most important one was their concern for family members; concern that family members might have unrealistic expectations about dying at home, as well as not be able to cope with their relative dying at home.

Data from the phase 1 focus groups informed the development of the survey tool aimed at scoping the practice and experience of transferring patients home to die across the UK.
Phase I: Web-based survey

Aims

Findings from the scoping review and focus groups were synthesised to inform development of a web-based survey. This survey was designed to explore experiences, practices, and views towards transferring patients in critical care areas home to die from the perspective of lead nurses and medical consultants of critical care units in the UK, and explore the relationship between these and patient, professional and unit level factors that may impact on clinicians’ decision-making in this area.

Methods

Survey development

The survey was developed around 4 domains reflecting earlier findings: experience, views, patient characteristics and barriers/facilitators (see Figure 2). To maximise participation, the number of questions in the questionnaire was restricted. The developed questionnaire was imported into ISurvey software, a package to develop and administer online surveys, developed by the Department of Psychology at the University of Southampton.

All aspects and components of the survey were pilot-tested with 23 doctor and nurse volunteers, from ITU units in the South of England, and seven experienced researchers from the Faculty of Health Sciences at the University of Southampton. This process allowed experts to evaluate whether the survey assessed the most important elements of transferring patients in critical care home to die thus ensuring content validity, while also assessing face validity of the individual items (REC reference 11/SC/0031).
Survey description

Questions in section one collected demographic information (including respondent’s role, speciality of the unit, number of beds in the unit). Section two explored prior experience with transfer home to die or discussions held about possible transfers. Respondents with these experiences were then invited to register their interest in further participation in the study through taking part in a future telephone interview. Section three contained 17 statements on views about transfer home to die. Respondents were asked to indicate to what extent they agreed or disagreed with the statements on a five-point Likert scale (1=strongly disagree to 5=strongly agree). Section four contained a list of patient characteristics and respondents were asked to indicate whether they would consider transferring a patient with these characteristics home to die. Respondents were asked to make a forced choice between ‘yes’ and ‘no’. Section five asked participants to rank barriers and facilitators to transferring patients home to die, from 1 (most important) to 5, from a list of 11 possible barriers. The same procedure was followed for possible facilitators. The final section contained six questions about the individual unit’s end of life policies (questionnaire in Appendix A)
Recruitment

The original plan was to use the UK Intensive Care directory to identify contact details for all critical care units. However, contact with the publishing company revealed that recent editions of the directory were no longer available. Therefore a new list of all critical care units in England, Scotland, Wales and Northern Ireland, including contact details of the lead medical and nursing staff was compiled by the research team.

Using the developed contact list, the web-based questionnaire was sent out (June/July 2012) to all lead consultants and lead nurses of critical care units in the UK (n=409). Two reminders were sent to all participants after ten and twenty days. In total 756 health care professionals received an invitation to participate in the web-based survey.

Data analysis

Frequencies of responses are expressed in raw scores and percentages. The responses to the ‘views’ statements are also presented as means (SDs). Rankings of barriers and facilitators are presented as the raw numbers and percentages of the first choice of response, as well as the summed responses of all respondents to present the three barriers/facilitators most likely to feature in the first three choices. Subgroup analyses were carried out using Predictive Analytics SoftWare (PASW) 19.0 to investigate differences between doctors and nurses, and HCPs with experience of transfer and HCPs without experience of transfer.

Results

Participant characteristics

A total of 191 HCPs completed the questionnaire (or sections of it) and 180 respondents provided sufficient data for analysis (11 HCPs only completed the questions on demographic information and did not complete any questions after this first section). This represents a response rate of 23.8%.

Of those 180 respondents who provided sufficient data for analysis 71 were consultants and 97 nurses. In terms of professional background, information was missing for 4 participants and for 8 participants their professional background was unclear (‘former lead’, ‘research’, ‘clinical governance lead’, ‘acting ward manager’, ‘clinical educator’, ‘trauma rehab lead’, ‘ward manager’ or ‘educator’). In terms of type of unit, 8 participants worked on HDU, 27 on ITU and a further 121 on combined HDU/ITU. Twenty three participants responded ‘other’ to the question of type of unit and provided additional information: ‘mixed ITU/HDU& separate ITU beds’, ‘acute cardiac services’, ‘acute dependency unit’,
Section one: Experience

65 (36%) participants indicated they had experience of transfer home to die in the last three years. Of those with experience 20 (31%) had transferred 1 patient home to die, 15 (23%) had transferred 2 patients, 12 (19%) had transferred 3 patients, 1 (2%) had transferred 4 patients, 1 (2%) transferred 5 patients and a further 6 (9%) had transferred more than 5 patients home to die. Data was missing for 10 participants.

28 (16%) had had discussions about transfer home to die. In terms of the numbers of patients that discussions were held about 6 (21%) respondents had discussions about 1 patient, 14 (50%) about 2 patients, 4 (14%) about 3 patients and one respondent (4%) had had discussions about more than 5 patients. Data was missing for 3 respondents.

In the sample 87 (48%) respondents did not have any experience of transfer home to die, nor had they ever had any discussions about transfer home to die.

Section two: Views

The results from the respondents’ views on transfer home to die, presented as percentages as well as means (on a scale of 1–5, with 5 representing ‘strongly agree’), showed that respondents reported high agreement with positively phrased statements, as well as low agreement with negatively phrased statements about transfer home to die (Table 3). This indicates that on the whole participants had positive views about transfer, which is illustrated by the means of the following statements: ‘transferring critically ill patients home to die is a good idea in principle but difficult to achieve in reality’ (mean = 4.20, SD=0.81); ‘it is satisfying to enable a patient to die at home’
(mean=4.20, SD=0.73) and ‘transferring critically ill patients home to
die is important because patients should be able to die at home if that
is their preferred place of death’ (mean=4.10, SD=0.83). Equally,
participants tended to disagree with statements such as ‘taking critical
care patients home to die is a waste of health care resources’ (mean
1.91, SD=0.88) or ‘critical care staff have more pressing clinical
priorities than organising home transfers for dying patients’
(mean=2.22, SD=0.97).
Table 3. Responses of participants to statements, in raw numbers, percentage and means (SD).

<table>
<thead>
<tr>
<th>Statement</th>
<th>1 Strongly disagree</th>
<th>2 Disagree</th>
<th>3 Neutral</th>
<th>4 agree</th>
<th>5 Strongly agree</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transferring critically ill patients home to die is a good idea in principle but difficult to achieve in reality</td>
<td>0 (0%)</td>
<td>11 (6.5%)</td>
<td>8 (4.7%)</td>
<td>86 (50.9%)</td>
<td>64 (37.9%)</td>
<td>4.20</td>
<td>0.81</td>
</tr>
<tr>
<td>Critical care is a perfectly good place to die</td>
<td>16 (9.4%)</td>
<td>54 (31.8%)</td>
<td>69 (40.6%)</td>
<td>30 (17.6%)</td>
<td>1 (0.6%)</td>
<td>2.68</td>
<td>0.89</td>
</tr>
<tr>
<td>I have limited experience of transferring patients home to die and wouldn’t know where to start</td>
<td>8 (4.7%)</td>
<td>60 (35.5%)</td>
<td>42 (24.9%)</td>
<td>45 (26.6%)</td>
<td>14 (8.3%)</td>
<td>2.98</td>
<td>1.07</td>
</tr>
<tr>
<td>It is better for critically ill patients to die in Critical Care</td>
<td>28 (16.5%)</td>
<td>74 (43.5%)</td>
<td>62 (36.5%)</td>
<td>5 (2.9%)</td>
<td>1 (0.6%)</td>
<td>2.28</td>
<td>0.79</td>
</tr>
<tr>
<td>It would be better to transfer a patient to a hospice than to transfer them home to die</td>
<td>18 (10.5%)</td>
<td>69 (40.4%)</td>
<td>70 (40.9%)</td>
<td>11 (6.4%)</td>
<td>3 (1.8%)</td>
<td>2.49</td>
<td>0.84</td>
</tr>
<tr>
<td>It is satisfying to enable a patient to die at home</td>
<td>0</td>
<td>2 (1.2%)</td>
<td>25 (14.8%)</td>
<td>79 (46.7%)</td>
<td>63 (37.3%)</td>
<td>4.20</td>
<td>0.73</td>
</tr>
<tr>
<td>We would be able to organise the transfer home to enable someone to die at home</td>
<td>5 (2.9%)</td>
<td>23 (13.5%)</td>
<td>40 (23.5%)</td>
<td>83 (48.8%)</td>
<td>19 (11.2%)</td>
<td>3.52</td>
<td>0.96</td>
</tr>
<tr>
<td>It is unethical to prolong a patient’s life so they can be transferred home to die</td>
<td>11 (6.5%)</td>
<td>43 (25.4%)</td>
<td>54 (32.0%)</td>
<td>50 (29.6%)</td>
<td>11 (6.5%)</td>
<td>3.04</td>
<td>1.04</td>
</tr>
<tr>
<td>It would be too distressing for the patient</td>
<td>25</td>
<td>90</td>
<td>45</td>
<td>9 (5.3%)</td>
<td>2 (1.2%)</td>
<td>2.26</td>
<td>0.81</td>
</tr>
<tr>
<td></td>
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<td></td>
</tr>
<tr>
<td>patient and relatives to take them out of the familiar critical care environment</td>
<td>14.6</td>
<td>52.6</td>
<td>26.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients will still receive the best possible care if they are transferred home to die</td>
<td>2 (1.2%)</td>
<td>22 (13.1%)</td>
<td>60 (35.7%)</td>
<td>70 (41.7%)</td>
<td>14 (8.3%)</td>
<td>3.43</td>
<td></td>
</tr>
<tr>
<td>Transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death</td>
<td>2 (1.2%)</td>
<td>5 (3.0%)</td>
<td>23 (13.6%)</td>
<td>83 (49.1%)</td>
<td>56 (33.1%)</td>
<td>4.10</td>
<td></td>
</tr>
<tr>
<td>It is more important to offer good end-of-life care on the unit than to transfer patients home to die</td>
<td>7 (4.1%)</td>
<td>60 (35.5%)</td>
<td>66 (39.1%)</td>
<td>29 (17.2%)</td>
<td>7 (4.1%)</td>
<td>2.82</td>
<td></td>
</tr>
<tr>
<td>Critical care staff have more pressing clinical priorities than organising home transfers for dying patients</td>
<td>33 (19.9%)</td>
<td>88 (53.0%)</td>
<td>25 (15.1%)</td>
<td>15 (9.0%)</td>
<td>5 (3.0%)</td>
<td>2.22</td>
<td></td>
</tr>
<tr>
<td>Transferring critically ill patients home to die is a feasible option in critical care</td>
<td>5 (3.0%)</td>
<td>8 (4.8%)</td>
<td>46 (27.4%)</td>
<td>85 (50.6%)</td>
<td>24 (14.3%)</td>
<td>3.68</td>
<td></td>
</tr>
<tr>
<td>Transferring patients home to die is not worth the risk of dying in the ambulance or having a really bad death at home</td>
<td>21 (12.3%)</td>
<td>83 (48.5%)</td>
<td>45 (26.3%)</td>
<td>18 (10.5%)</td>
<td>4 (2.3%)</td>
<td>2.42</td>
<td></td>
</tr>
<tr>
<td>Dying in critical care is better than home for patients because of the higher nurse patient ratios</td>
<td>27 (15.8%)</td>
<td>90 (52.6%)</td>
<td>41 (24.0%)</td>
<td>10 (5.8%)</td>
<td>3 (1.8%)</td>
<td>2.25</td>
<td></td>
</tr>
<tr>
<td>Taking critical care patients home to die is a waste of health care resources</td>
<td>55 (32.4%)</td>
<td>88 (51.8%)</td>
<td>19 (11.2%)</td>
<td>3 (1.8%)</td>
<td>5 (2.9%)</td>
<td>1.91</td>
<td></td>
</tr>
</tbody>
</table>
Section three: Patient characteristics

Participants were asked to indicate whether they would consider transferring a patient home with a specific characteristic. Table 4 outlines the responses with ‘yes’ or ‘no’ being the only response options. The majority of participants responded ‘yes’ to most characteristics except for patients described as either: unstable (yes=63 (38.2%), no=102 (61.8%), ventilated via an endotracheal tube (yes=52 (31.5%), no=113 (68.5%), or needing cardiovascular support (e.g. inotropes; yes=57 (34.3%), no=109 (65.7%). Participants were divided regarding patients who were ventilated via tracheostomy (yes=96 (57.8%), n=70 (42.2%).

Table 4. Responses to question about patients participants would consider (or not consider) transferring, expressed as raw scores and percentages

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>is unconscious</td>
<td>101 (61.6%)</td>
<td>63 (38.4%)</td>
</tr>
<tr>
<td>is conscious</td>
<td>166 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>is unstable</td>
<td>63 (38.2%)</td>
<td>102 (61.8%)</td>
</tr>
<tr>
<td>is stable</td>
<td>163 (98.8%)</td>
<td>2 (1.2%)</td>
</tr>
<tr>
<td>who is ventilated via an endotracheal tube</td>
<td>52 (31.5%)</td>
<td>113 (68.5%)</td>
</tr>
<tr>
<td>who is ventilated via tracheostomy</td>
<td>96 (57.8%)</td>
<td>70 (42.2%)</td>
</tr>
<tr>
<td>who is receiving non-invasive ventilation</td>
<td>126 (75.4%)</td>
<td>41 (24.6%)</td>
</tr>
<tr>
<td>is self-ventilating breathing oxygen</td>
<td>159 (95.2%)</td>
<td>8 (4.8%)</td>
</tr>
<tr>
<td>who is self-ventilating breathing air</td>
<td>167 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>needs cardiovascular support e.g. inotropes</td>
<td>57 (34.3%)</td>
<td>109 (65.7%)</td>
</tr>
<tr>
<td>has intense nursing needs e.g. frequent turning and washing</td>
<td>128 (77.6%)</td>
<td>37 (22.4%)</td>
</tr>
<tr>
<td>has high level emotional needs</td>
<td>146 (88.0%)</td>
<td>20 (12.0%)</td>
</tr>
<tr>
<td>has relatives with high level emotional needs</td>
<td>131 (78.9%)</td>
<td>35 (21.1%)</td>
</tr>
<tr>
<td>needs regular medication for symptom management (e.g. pain, nausea)</td>
<td>150 (90.4%)</td>
<td>16 (9.6%)</td>
</tr>
<tr>
<td>lives outside local catchment area</td>
<td>135 (81.3%)</td>
<td>31 (18.7%)</td>
</tr>
</tbody>
</table>

Section four: Barriers and facilitators

Participants were asked to rank the top 5 barriers to transfer home to die from a list of predetermined options. The data is presented as the barrier which was most often listed as first choice. In addition, the first 3 choices for all participants were summed to calculate which barriers and facilitators featured most often in participants’ top 3 (Table 5). The majority of respondents (n=56, 34.1%) chose ‘lack of access to care in the community’ as the most important barrier. 24 (14.6%) respondents indicated that ‘patient’s relatives unlikely to be able to cope with
transfer and death at home’ was the most important barrier and a further 22 (13.4%) respondents chose ‘lack of guidelines on transfer home to die’ as their first choice. The accumulated responses over the first 3 choices indicate that ‘lack of access to care in the community was most important, followed by ‘patient’s relatives unlikely to be able to cope with transfer and death at home’ and ‘unclear responsibility for care of patient during and after transfer’.

Table 5. Percentages of respondents who chose a given barrier as their first choice, in their top three and in their top 5.

<table>
<thead>
<tr>
<th></th>
<th>First choice</th>
<th>In top 3</th>
<th>In top 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of access to care in the community</td>
<td>34.1</td>
<td>58.1</td>
<td>70.8</td>
</tr>
<tr>
<td>Lack of backfill of staff in Critical Care</td>
<td>7.3</td>
<td>15.3</td>
<td>25.4</td>
</tr>
<tr>
<td>Lack of contact with patient’s GP</td>
<td>1.2</td>
<td>14.8</td>
<td>35.7</td>
</tr>
<tr>
<td>Lack of guidelines on transferring patients from Critical Care home to die</td>
<td>13.4</td>
<td>29.4</td>
<td>48.4</td>
</tr>
<tr>
<td>Lack of information about home environment to ensure transfer can be achieved</td>
<td>4.3</td>
<td>22.1</td>
<td>48.1</td>
</tr>
<tr>
<td>Lack of time to organise the transfer home</td>
<td>5.5</td>
<td>25.2</td>
<td>42.3</td>
</tr>
<tr>
<td>Legal issues with transfer home are unclear</td>
<td>2.4</td>
<td>11.1</td>
<td>30.7</td>
</tr>
<tr>
<td>Other</td>
<td>1.8</td>
<td>4.9</td>
<td>9.3</td>
</tr>
<tr>
<td>Patient’s relatives unlikely to be able to cope with transfer and death at home</td>
<td>14.6</td>
<td>38.0</td>
<td>53.8</td>
</tr>
<tr>
<td>Unclear responsibility for care of patient during and after transfer</td>
<td>7.9</td>
<td>33.1</td>
<td>55.9</td>
</tr>
<tr>
<td>Unpredictability of time to death</td>
<td>3.7</td>
<td>17.2</td>
<td>29.2</td>
</tr>
<tr>
<td>Unrealistic expectations of relatives about death at home</td>
<td>3.7</td>
<td>30.8</td>
<td>50.4</td>
</tr>
</tbody>
</table>

In addition participants were asked to rank the top 5 facilitators to transfer home to die from a similar list of predetermined options. The results from this ranking follows a similar pattern as for ‘barriers’ in terms of results with the majority of respondents (n=56; 34.4%) choosing ‘access to care in the community’ as the most important facilitator. 26 respondents (16.0%) indicated that ‘established guidelines on transfer home to die was the most important facilitator and a further 19 (11.6%) respondents chose ‘patient’s relatives able to cope with transfer and death at home’ as their first choice. The accumulated responses over the first 3 choices indicate that ‘access to care in the community’ was most important, followed by ‘patient’s
relatives able to cope with transfer and death at home’ and ‘clear responsibility for care of patient during and after transfer’.

Section five: End of life care

Participants were asked to indicate if they used an end of life care pathway in the unit. 126 (80.3%) of respondents who answered this question (n=157) indicated that they used the Liverpool Care pathway and 24 (15.3%) indicated using a different pathway, such as a pathway based on the Liverpool Care Pathway or local guidelines. Seven participants (4.4%) indicated not using any end-of-life care pathway. 104 respondents (65.4% of n=159) indicated that the unit had a team with a focus on improving end-of-life care, whereas 51 (32.1%) did not. Four participants did not know (2.5%). In terms of development of end-of-life care in the unit 71.7% of respondents indicated the unit having developed or reviewed end of life practice guidelines or standards; 31.4% of units had undertaken an end of life audit; 31% had delivered EOL education as part of staff development and 75.5% of units had reviewed documentation as part of end-of-life care. As the majority of respondents work in a unit which either uses an EOL pathway and focuses on improving end of life care it was not possible to carry out meaningful subgroup analyses using these data as groupings.

Subgroup analyses

Subgroup analyses using non-parametric tests (Mann–Whitney U test) were carried out comparing nurses and doctors as well as HCPs with and without experience of transfer, on their views about this topic.

Differences between doctors and nurses were found for several views. For the majority of variables for which a difference was found nurses scored higher than doctors, indicating more positive views: ‘It is satisfying to enable a patient to die at home’ (U=3678, p=0.018), ‘patients will still receive the best possible care if they are transferred home to die’ (U=3573, p=0.035), ‘transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death’ (U=4230.5, p=0.000) and ‘transferring critically ill patients home to die is a feasible option in critical care (U=3942, p=0.001). Furthermore for two views, which were negatively phrased, doctors scored somewhat higher indicating more agreement with the statement; ‘critical care staff have more pressing clinical priorities than organising home transfers for dying patients’ (U=2162, p=0.002) and ‘taking critical care patients home to die is a waste of health care resources’ (U=2307, p=0.002).

Differences between those respondents with experience of transfer and those who did not have experience of transfer were found for the majority of views. The respondents with experience of transfer scored higher (therefore indicating more agreement) with statements about being able to achieve transfer, such as ‘it is satisfying to enable a
patient to die at home’ (U=4523.5, p=0.00), ‘we would be able to organise the transfer home to enable someone to die at home’ (U=4664, p=0.000), ‘patients will still receive the best possible care if they are transferred home to die’ (U=4161.5, p=0.003), ‘transferring critically ill patients home to die is a feasible option in critical care’ (U=4801, p=0.000) as well as emphasising its importance in light of choice, ‘transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death’ (U=3980.5, p=0.028). The respondents without experience of transfer were likely to score higher on views about experience (‘I have limited experience of transferring patients home to die and wouldn’t know where to start’ U=1529, p=0.000), concerns (‘it would be too distressing for the patient and relatives to take them out of the familiar critical care environment ’ U=2695.5, p=0.011), ‘transferring patients home to die is not worth the risk of dying in the ambulance or having a really bad death at home’ U=2159, p=0.000) ITU as a good place to die (‘it is more important to offer good end-of-life care on the unit than to transfer patients home to die’ U=2646.5, p=0.014, ‘dying in critical care is better than home for patients because of the higher nurse patient ratios’ U=2766.5, p=0.022) and finally the view ‘taking critical care patients home to die is a waste of health care resources’ (U=2375, p=0.000).

**Discussion**

In general HCPs held positive views about transfer home, although only around a third of respondents had experience of transfer home. In terms of the characteristics of patients respondents would consider taking home, they were divided about patients who were either unstable, ventilated via an endotracheal tube needing cardiovascular support (e.g. inotropes) or patients who were ventilated via tracheostomy. The most important barrier highlighted by respondents was lack of access to care in the community, followed by concerns about patients’ relatives unlikely to be able to cope with transfer and death at home and lack of guidelines. The accumulated responses revealed one other important barrier; unclear responsibility for care of the patient during and after transfer. The facilitators that participants were asked to identify were similar in nature to barriers highlighted.

The majority of respondents reported using the Liverpool Care Pathway or another similar pathway in their unit. In addition, the process of reviewing and engaging with end-of-life practice in the unit was well established. Therefore any subgroup analyses were not possible using these data. However, subgroup analyses were run looking at differences between nurses and doctors, which showed that nurses tended to score slightly higher when rating the statements of views of transfer home. Differences were also found, in terms of views, between respondents who had experience of transfer home and those who did not. Those
respondents who had experience of transfer scored slightly higher on views about the feasibility and importance of transfer home to die.
Phase I: Follow-on interviews

Aims

Whilst the web-based survey provided representative views, it was not a suitable research method for collecting detailed information on decision-making and practice in specific cases where decisions were made about transferring patients home to die. A series of telephone interview post survey were undertaken to explore these aspects in more depth.

The follow-on interviews were conducted over the telephone with those who had indicated in the web-based survey that they had experience of transfer home (and had indicated willingness to be interviewed), or had had discussions about patients who had expressed a wish to be transferred home.

Methods

Follow-on telephone interviews were conducted with health care professionals who had completed the online survey. Thirty HCPs indicated they would be willing to be interviewed as part of this follow-on study and all were contacted to arrange an interview. Interviews were conducted over the telephone and audio-recorded with the participants’ permission. Two interview schedules were developed from the focus group, literature, survey data and research team discussions; one [Appendix B] for use in interviews where the HCP has been actively involved in the transfer home of a patient, and the second [Appendix C] for use with those HCPs who had been involved in a discussion about transfer that did not result in the patient going home. All interviews were transcribed and underwent thematic analysis (Ethics Committee approval, REC reference 11/SC/0031).

Results

Participants

A total of 23 HCPs were interviewed, however two participants were later found to have worked on a ward, rather than a critical care unit, and therefore 21 interviews were analysed. 15 nurses and 6 consultants participated and table 6 outlines whether they had experience of a transfer or had had discussions about transfer home. Interviews lasted between 10 and 55 minutes, with a mean of 27 minutes.
Table 6  Overview of participants in telephone interviews

<table>
<thead>
<tr>
<th>Profession</th>
<th>Transfer home to die</th>
<th>Discussions about transfer home to die</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Consultant</td>
<td>5</td>
<td>1</td>
</tr>
</tbody>
</table>

The following findings represent an in-depth analysis of participants’ responses to questions about their experience of, or reflection on, the (potential) transfer of a dying patient, from critical care, to a preferred place of death, home. Findings are presented as a three phase linear process (Table 7) so factors impacting each phase can be clearly illustrated; however, the process itself was not linear; it was a dynamic, interactive process of assessment and action requiring intention, leadership and multi-agency working. Findings are supported by exemplar quotes.

Table 7  Phased process of transfer

<table>
<thead>
<tr>
<th>Phase 1 – Working toward a decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment</td>
</tr>
<tr>
<td>Can we do it?</td>
</tr>
<tr>
<td>What do we need to know?</td>
</tr>
<tr>
<td>Action</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Phase 2 – Operationalising transfer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation</td>
</tr>
<tr>
<td>Action</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Phase 3 – Post transfer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Handover</td>
</tr>
<tr>
<td>Feedback</td>
</tr>
</tbody>
</table>
Phase 1: Working toward a decision

Assessment

The process of working toward a decision appeared to commence with the articulation of a number of questions linked to assessment. Initial assessment was triggered by a request to consider home transfer. Requests for transfer most usually came from family members or less usually, the patient themselves. Questions were linked to specific issues or considerations that needed to be assessed in response to this request. Concurrently, a period of action was instigated during which the practicalities and knowledge needed to conduct a transfer was sought. The outcome of questioning and action either promoted or stalled transfer.

Should we do it?

Data from the interviews identified an individual and team level reflection on whether transfer home to die was something that they as professionals ‘should’ consider as part of end of life care. Findings indicate that the majority of staff were positive about the idea of transfer; however, about a third of staff reported concerns that were potential barriers to transfer, including: views that remaining in hospital or transfer to a hospice was a better care option, that a hospice was a better place to go for care reasons than home. However, all units were willing to consider transfer when the issue was raised by family members.

“I mean we wouldn’t recommend it as a first line in kind of choice and I think it’s only if it was brought up by a patient and/or relative in the first instance and pursued then we might consider it.” (Nurse, ID17)

“Everyone was quite willing to consider it...there was nobody who thought it was not do–able or not worth considering” (Nurse, ID05)

Can we do it?

Participants reported a range of concerns related to their (critical care units) ability to facilitate transfer and these included: is the patient suitable for transfer, is there sufficient resource to facilitate transfer, and how would this work with community services.

Consideration of the physical characteristics and needs of the patient at the end of life was a key factor in decision-making regarding potential transfer
“It’s got to be a certain type of patient...it’s got to be the right kind of circumstances...the right patient.” (Nurse, ID01)

Patients identified as not the ‘right sort of patient’ included those patients who: were ventilated, had an ischaemic bowel (with continuous diarrhoea), needed regular surgery, had open wounds, a tracheostomy, experienced uncontrolled pain, were receiving high levels of sedation, were unconscious, or assessed as having inadequate mental capacity.

“I think if somebody was having absolutely continuous diarrhoea that would pretty much be exclusion, I know it sounds like a relatively simple thing but actually I think that is one of our exclusions because just the practicalities for the family of constantly rolling and changing sheets, it’s just not going to happen.” (Consultant, ID12)

These practical and pragmatic reasons appeared to be part of a process of assessing the patients stability and the likelihood of a patient leaving the ICU and arriving home. If the assessment was that the patient was unlikely to get home, or that they would die in the ambulance, then any consideration of transfer would halt.

“I couldn’t safely transfer someone who had quite changing and complicated needs.” (Consultant, ID15)

“The couple of times we’ve discussed it the patients have then gone on to deteriorate before we could even sort of start looking at getting people home. Which probably reflects a fact that by the time we are deciding someone will not survive in intensive care they are also demonstrating quite dramatically that they will not survive intensive care and what we don’t want is to be halfway home and have the patient die in the ambulance with the family following in the car behind or something because that would just be a disaster. So it would be better if they’re here slightly longer and then die with the family.” (Consultant, ID11)

Furthermore, if clinical assessment based on experience and concerns for the family resulted in a view that the patient would not die within a certain time frame after arriving home, this would impact on transfer decision-making.

“...some patients when you’re making the decision to withdraw treatment, for instance you can sort of tell by the amount of support that they are on that they are going to pass away very quickly...in that circumstance it isn’t going to work...it’s only
going to probably be for a couple of hours maybe a couple of days at the very most.” (Nurse, ID01)

“People who are on an end of life care pathway, if they end up on oxygen and ventilation they can linger a long time...in the home circumstance I know what a stressful time it is for the family...looking after someone, you know, even though they’re well supported by the district nurses in keeping them alive...I don’t want to seem to gruesome about all of this but there is a time that is too long to do it...all of that time is precious but the longer it goes on the more uncomfortable everybody gets.” (Consultant, ID15)

Pre-decision assessment regarding feasibility of transfer also included the issue of resources, for example, the impact of staff absence due to their involvement in transfer activities.

“...to have a doctor and a nurse out of the unit for a period of time to get somebody home will make a difference to the staffing on the unit. Now, the nurse that goes home with the patient will be the patient’s nurse. That’ll probably have less of an effect on the general staffing of the unit but if one of the medical staff disappears that’s going to be a quarter of the medical staff at least disappeared. That might be important.” (Consultant, ID11)

Assessment also included how transfer activity would work with community services. Openness and awareness of each other’s activity would appear to support transfer but ICU staff also had clear concerns about the ability of community staff.

“I think most units would be supportive of the idea but it is the logistics of it... you are often dealing in unique circumstances, with a team that you’ve not met before and there needs to be sort of openness on all sides.” (Consultant, ID14)

“The community services don’t have the skills to be able to manage a ventilated patient in their own home. Particularly if it’s for their end of life or it’s a kind of terminal episode.” (Consultant, ID18)

**What do we need to know?**

Prior to making the decision to transfer, participants reported their thoughts about what they may need to know to make a transfer decision. Many had a range of concerns about an incomplete set of appropriate knowledge prior to deciding to transfer. These were described as uncertainties with people and/or future parts of the
transfer process. Whilst not always clear in each individual case, these uncertainties prior to the decision are likely to have complicated the situation prior to the decision to transfer.

Staff was uncertain about different responsibilities of transfer, financial arrangements and what the legal situation was in this type of transfer.

“I don’t know whether we would take responsibility...whether we would take responsibility up to the ambulance transfer and then it’s an ambulance that then takes over...when they’re in the community they are then under the care of the GP I think, I don’t know.” (Nurse, ID01)

“The Trust would have to pay I think...maybe they would pay for the transfer home...and whether the PCT take it on after that I’m not entirely sure.” (Nurse, ID01)

“We do have liability coverage for when we do transfers out of the hospital, which is another issue that needs to be considered. Because normally you are covered for good Samaritan acts if you are providing healthcare outside of your establishment and the transferring patients then you should be covered but this is above and beyond what is normally considered and had anything happened to us during the transfer then I’m not sure on if the liability side of things would have been covered.” (Consultant, ID14)

In relation to the family situation, some staff reported a concern about not knowing enough about the quality of care a patient would receive from relatives at home:

“The family were very supportive but there were concerns from nursing staff that she wouldn’t have access to all the things she would have had in the hospital.” (Consultant, ID14)

Whilst not clear about the outcome of such concerns, a lack of knowledge about internal arrangements and the future home situation for the patient, should transfer occur, was likely to have stalled the situation prior to the decision to transfer.

**Action**

**Discussion with the family about transfer**

Interview findings indicated that an early action point was to assess the family situation. Importantly, staff highlighted situations in which family expectations of transfer differed from health professionals and stressed the importance of exploring this issue prior to the decision to transfer:
“Sometimes families are very keen with the concept ‘Oh yes, we want to take him home. We want to take him home’ and then when we say well we need to sit down and talk about it because you’re not going to have a nurse there all the time. ‘Oh, are we not?’ ‘No, you’re not.’ You know, you’ll have a telephone number you can contact for out-of-hours if you have any concerns. The nurses will come but their actual input is very minimal, to be honest. It’s very much the symptom management, changing the driver...I think the relatives perceive that when their loved ones go home to die that means that what they get here is what they’re going to get there.” (Nurse, ID13)

Whilst there was no clear information about the order of activity by staff in relation to family discussion, it was possible to establish different activities being enacted across the sample. ICU staff sought to establish patient and family intentions for transfer and by doing so facilitated transfer.

“So I started talking to the patient and establishing she wanted to do this and the patient’s husband was very keen as well because obviously they both have to agree.” (Consultant, ID12).

Staff also engaged in discussions with the family about their perceived ability to care for a patient at home. By doing so they established the level of support required and this action facilitated transfer.

“The family didn’t feel they could watch him die without nursing support, they wanted a nurse there twenty four hours a day and that’s fair enough because you know it’s a lot to, they just felt that if they died they wouldn’t know how to handle it and they’d be phoning 999 and didn’t feel that they wanted to be in that position.” (Nurse, ID10)

It was also apparent staff engaged the family about the possibility of patient death during transfer.

“...we also make it very clear to the family and the patient that they might die in the ambulance.” (Consultant, ID12)

**ICU staff knowledge seeking activities**

A large number of professionals focused their comments on two types of knowledge seeking activity conducted prior to making a decision about transfer. Firstly, they sought to expand their knowledge of community services available in their area in order to facilitate transfer, and secondly, they sought to understand more about the physical home environment of the patient/family into which the patient was being transferred.

Most ICU professionals were not familiar with community services available in their local context, and sought support.
“I was trying to find who I needed to speak to...I did find out that we had a community liaison person who worked in the hospital but finding out who that was quite difficult.” (Nurse, ID03)

Most professionals were concerned with the physical patient/family home environment and sought to ‘scope out’ that situation in order to facilitate transfer:

“Basically what we did was actually look at what we had to do to facilitate it so, we talked through what specialist equipment would be needed so things like a bed, you know they hired quite a big bed, there was a discussion around the facilities and obviously because our member of staff you know who was quite senior was able to say, well the house is suitable to do it in a downstairs room, you know there’s toileting facilities downstairs, not that he was at that stage, he was bed, fairly bedbound, so it was you know a location exercise of ‘is it feasible to have a hospital bed and enough room for the Nurses to work around’.” (Nurse, ID08)

Phase 2: Operationalizing transfer

This is phase is characterised by a period of post-decision preparation and then action to achieve transfer. Activity in each of these areas could promote or stall transfer.

Preparation

Identifying a leader

Interview findings indicated that once a decision to transfer has been agreed within the team it then fell to an individual/champion to lead and coordinate the transfer process.

"You need to have somebody who can, you know, be assertive and articulate...and be clear and concise with [the] objectives of why and what we are trying to achieve, how we’re trying to achieve this and then pull everything together. I think having a dedicated person is pivotal to do that, otherwise we wouldn’t have been able to do it smoothly at all. (Nurse, ID09)

Importantly, the majority of professionals reported nurses as the professional group leading the process of transfer. This perception was widely and strongly held by participants, as described by this nurse and consultant:

“We are very much a multi-disciplinary team here but I do find that end of life care is very much a nurse led thing here. My consultants are more than happy to support us and obviously
there would need to be an agreement but I see it as nurses leading it, suggesting it and facilitating it.” (Nurse, ID03)

“I’m looking at it very much from the medical side and we have much less to organise than the nurses do, particularly trying to organise community district nursing to go in and support and palliative care teams and Macmillan nurses and things and drugs in the house and oxygen in the house and everything else that has to go with that, all the equipment that has to be taken sometimes…a lot of that’s actually sorted out by the nurses.” (Consultant, ID04)

**Action**

**Engaging in discussion with hospital colleagues**

Professionals’ discussion about transfer focussed on internal arrangements. Four internally-related arrangements were discussed by professionals and these were contact and communication with the following teams: rapid discharge teams; palliative care teams, ambulance services and finance managers.

“The fast track discharge team…we contacted them and they appeared and have to do a whole lengthy assessment about the patient, the patient’s needs, what level of care they require, what equipment they require and then we have to apply, they have to apply directly to the PCT to have the funding agreed to send this patient home, so we did all of that.” (Nurse, ID16)

“The palliative care team were very supportive…and we facilitated his discharge home” (Nurse, ID17)

“…the ambulance service…that was the least problematic, I think that was the least difficult thing to arrange…it was easy, it was just a case of phoning them and asking for a transfer home of an ITU patient and that happening.” (JR08)

But ICU staff stated the need to be clear with their local ambulance service about the resuscitation issue in order to facilitate this type of transfer:

“We faxed the ambulance service their documentation to say, they’re quite specific for obvious reasons, they have a DNAR in situ so they know what their processes are should anything happen on route.” (Nurse, ID13)

However, some staff reported problems with the ambulance service. This was often a significant barrier to transfer. The concerns were largely characterised by problems with ambulance staff not prioritising this type of transfer:
“We’ve had lots of problems with ambulances, that’s been a real issue because obviously we view it that every single hour we can offer the patient at home is valuable, it’s a significant part of the rest of their life, so it’s a real priority for us and it’s been a real issue that you know sometimes they’ve been told we’re twenty fifth in the queue for an ambulance.” (Consultant, ID12).

Professionals acted to coordinate with their colleagues responsible for financial decisions relating to patient transfer:

"[We] make sure I suppose the fiscal part was aware that [transfer] was something that we’re doing and no qualms about it." (Consultant, ID11)

Other internal factors professionals reported as factors important to arrange were: a bed for the patient at home, patients’ medication, oxygen for ventilated patients, continence supplies.

Difficulties were encountered when seeking an appropriate bed from hospital services to use in the patient/family home. Whilst this not always prevent transfer, it did stall transfer and risk the successful completion due to the patient passing away prior to transfer.

**Engaging in discussion with colleagues in the community**

In addition to a large amount of discussion with internal colleagues, ICU professionals also reported discussion with colleagues external to their unit or hospital environment. Those teams reported as necessary to arrange externally-related activities included community services, namely the patients GP, and other support agencies such as district nurses and palliative care teams such as Macmillan.

“The community services have to be fully involved and also fully signed up to this happening. There’s no point in us taking the patient home, dumping the patient home and running away if there’s no services in place to take over...that’s not fair on the patient or the family. So the GP and other community services have to be in a position where they are willing to accept the patient home and are in a position to provide the appropriate palliative care.” (Consultant, ID11)

Furthermore, professionals’ reported the existence of prepared community services available in area facilitated transfer:

“I think we were also lucky enough that the area where he lived happened to have some specialist nursing...community nursing input for care of the dying...he went home the day after we made all the arrangements. It happened quite smoothly.” (Consultant, ID15)
However, a major barrier to transfer reported by many staff was the availability of community resources to support transfer. This would result in not transferring patients, as exemplified by this nurse:

“...funding was secured by the Primary Care Trust but there were no community services to back it up...they just didn’t have the community nurses to support that patient’s discharge...they couldn’t support it so we didn’t pursue it.” (Nurse, ID09)

“The GP and the community services has to be fully involved and also fully signed up to this happening.” (Consultant, ID11)

“Then we spoke to her GP surgery and her GP was wonderful...so by probably by mid-afternoon we had everything teed up for her to go home.” (Consultant, ID12)

The other widely reported arrangements were contacting and engaging with district nurses and Macmillan nurses for home-based support. Whilst less frequently reported, several other types of arrangements appeared to be important for transfer. These included engaging with: other organisations about transfer; local coroners in case of death during transfer; occupational therapists; community palliative care teams; social workers; agency nurses for home support; and arranging multi-disciplinary meetings.

**Phase 3: Post transfer**

This phase characterises professionals’ discussion about their post-transfer experience.

**Handover**

Several professionals stated a need for a handover to community teams, as described by this consultant:

“Ideally you’d like to be met by the community team for a sort of handover, that would be lovely...there then could be a formal handover in the same way as we’re used to doing handovers in hospitals...that needs to be formalised.” (Consultant, ID14)

“So on the occasions that we’ve done these transfers home we have asked the district nurses to meet our nurse at the home to have a direct handover.” (Nurse, ID13)

Interestingly, one consultant wanted to hand over the patient to another doctor which raises the issue of responsibility and how handover should conducted. Further information on this issue was not available from the interview analysis.
Feedback

Professionals’ described a varied level of feedback post-transfer. In roughly equal measure, professionals received positive feedback from the family or no feedback after the patient had died.

Positive feedback from the process may act as a facilitator for the next transfer:

“We got feedback from the family and I got feedback from the patient before he died, got feedback from the patient in the ambulance. The first thing he said to me in the ambulance was ‘green trees’ because he’d not seen a green tree for probably four or five months...and the family, once he arrived in his house and was settled in his bed his grandchildren came in from school and jumped on the bed and all the family were there. We took a little bit of a back seat and sat in the kitchen...and the family were just incredibly grateful.” (DH18)

Interestingly, some professionals reported they rarely knew what happened after transfer, particularly in the context of a good death. Potentially, the absence of feedback about transfer may consolidate existing negative views or fail to reinforce positive views held. In either case it may act as a barrier to transfer.

“I received no further feedback as to what went on. I assume he died. I often find that when you telephone GP practices you don’t get...it’s quite difficult to get to speak to anybody who knows what went on. But I didn’t get any follow up. I think that would have been nice to have done.” (JR15)

Whilst some professionals made efforts to follow up the aftermath of transfer, this did not appear to be the norm. Most professionals discussing their post-transfer experiences described not making an active effort to follow up the outcome of transfer:

“We don’t do follow ups, we say to all relatives we don’t have a follow up clinic but we always say to patients and relatives from critical care that they can come back and discuss any issues.” (Nurse, ID21)

Discussion

The telephone interviews were conducted to explore factors that influence the feasibility of transferring critical care patients' home to die in more detail. There were several aspects that were highlighted as especially important when operationalizing a transfer home. First of all, timing is crucial. Secondly, knowledge and availability of care in the community was identified as a crucial element in achieving a successful transfer. The resource required to facilitate transfer was acknowledged and therefore it is important that funding is addressed. Another aspect
that was highlighted was the importance of identifying a coordinator in the process of transfer home to die, who can liaise across clinical, organisational and geographical boundaries. However, a strong theme generated from analysis, but not linking to process, was the reported lack of guidance and instructions to support the transfer of patients home to die from critical care. Whilst units had developed individual check lists there was a broad consensus by the vast majority of participants that guidelines and instructions were urgently needed along with community staff training to support the planned activity in the patient’s home.
Phase II: Audit

Aims
A retrospective 12 month audit of patients who died in critical care, or within five days of discharge, was undertaken to determine size and characteristics of the population who may potentially be transferred home to die.

Methods
The objective of the audit was to assess all patients from two hospitals in the South of England, who died between 01.01.2011 and 31.12.2011. The audit was undertaken in the same units as studied in the Focus Groups in Phase 1, which included General ITU, Cardiac ICU, Neuro ITU and Oncology ITU. In addition, patients who had died while admitted to a Medical High Dependency Unit (MHDU) and a Surgical HDU in the same institution were also assessed. Patient characteristics were explored of those who had 1) died on the unit or 2) died within five days of being discharged.

Development of audit proforma
Date from phase 1 of the study gave some insight into the patient characteristics which might be judged to be important when considering transferring patients home to die, e.g. respiratory support, cardiovascular support and gastrointestinal fluid loss, therefore audit criteria and the data extraction proforma was developed based on those. Demographic data was collected e.g. age) for all patients, including date/time of discussion of withdrawal with family, date/time of death, underlying diagnosis and reason for admission to the unit.

Subsequently the first exclusion criterion was applied: patients who had died as a result of a cardiac arrest (see figure 3); due to the sudden and unexpected nature of the death, considering transferring the patient home to die would not have been possible. This group was excluded at this first stage and no further information recorded for these cases. The next crucial criterion was clinical instability (stage 2), defined by the research group as ‘patient observations show significant variability/deterioration or introduction of new therapy as result of patient deterioration’. Defining strict clinical criteria was deemed too complex and therefore an element of clinical judgement, based on the data from the notes, was required by those undertaking the audit. Any instances of uncertainty on the part of the audit nurse were discussed with experienced clinicians, to arrive at a decision as to whether a patient met criteria or not.
Focus group discussions had identified certain clinical characteristics which could potentially complicate or prevent transfer home to die. The first set of criteria focused solely on clinical characteristics: 1) consciousness state (conscious or unconscious), 2) respiratory support and 3) cardiovascular support. Detailed information was collected on these aspects. In the survey these were aspects which could influence the decision-making around transfer but were not necessarily aspects that would always prevent the team from considering this (unlike instability). The second set of criteria, identified mostly from the focus group discussions, were factors that would deter the team from carrying out a transfer even if the patient was deemed stable enough to survive the transfer home: 1) Coroners cases/police involvement, 2) Family with complex issues that might prevent discharge 3) Intense manual handling (e.g. morbid obesity, unstable spine) and 4) High gastrointestinal losses requiring intensive nursing care (e.g. diarrhoea, wound loss, vomiting). Information on these characteristics were collected, but patients with one or more of these characteristics were not a priori excluded. Organising the data collection as a two stage process in this way allowed us to assess the number or patients who were, in principle, stable enough to be considered for the journey home in the ambulance and then within this group the number of patients for whom the transfer may be undesirable or impossible due to other circumstances.

The form was revised after extensive discussions with the audit teams from the two hospitals to ensure usability and feasibility. The audit teams consisted of audit nurses with a background in critical care, with a strong understanding of the clinical characteristics of patients and the complexity of decision-making in critical care. This background enabled them to make judgements about patient stability from information recorded in the notes. In addition, the form and the predetermined criteria were pilot-tested with the notes from 10 patients who died. First the audit team completed the form for these 10 patients, after which they were independently reviewed by an ITU consultant. Specific attention was paid to assessment of ‘stability’ for patients. Stability was the most difficult patient state to assess from written note information. (Proforma in Appendix D)
Figure 3. Overview of stages of exclusion of patients for clinical audit

- **Stage 1**
  - Exclude patients:
  - Cardiac arrest or
  - Sudden death

- **Stage 2**
  - Exclude patients who are ‘unstable’:
  - Patient observations show significant variability/deterioration or introduction of new therapy as result of patient deterioration

- **Stage 3**
  - Exclude patients:
  - 1) Coroners cases/police involvement,
  - 2) Family with complex issues that might prevent discharge
  - 3) Intense manual handling (e.g. morbid obesity, unstable spine)
  - 4) High gastrointestinal losses requiring intensive nursing care (e.g. diarrhoea, wound loss, vomiting

**Data analysis**

Descriptive statistics are presented for all variables. Data on patients are presented for each stage of the assessment; stage 1 – exclusion of patients dying of cardiac arrest or sudden death, stage 2 unstable patients and stage 3 exclusion of patients with physiological or care factors that were deemed unsuitable for transfer home. Subgroup analyses have been carried out to explore to what extent level of care (ITU versus HDU) influences whether patients could potentially be transferred home.

**Results**

In the cohort of patients a total of 7844 patients notes from 7 units were audited: General ITU n=1548, Surgical HDU n=869, Cardiac ICU n=1298, Neuro ICU n= 738, Cardiac HDU n= 1717, Medical HDU
\( n=361 \) and Oncology ITU \( n=1313 \). Of these \( n=422 \) died, while none were transferred home to die.

In stage one 62 of the 422 (14.7\%) patients were excluded, i.e. those who had died of a cardiac arrest or sudden death. In stage two a further 225 patients (53.3\%) were excluded for being deemed too unstable to be transferred. Finally in stage three 35 patients (8.3\% of total) were excluded due to physiological or care factors. Therefore a total of 76.3\% (\( n=322 \)) of patients were excluded from consideration for transfer. In this sample \( n=100 \) (23.7\%) patients were included as patients who could potentially be transferred home as they were clinically stable and did not present with specific physiological or care factors that would prevent them from being transferred based on this information.

**Description of patients stable enough for transfer**

Of the 100 patients identified as eligible for transfer based on the data collected through the audit. 44 patients were women (44\%) and the average age was 70.4 years (\( \text{SD}=13.03, \text{range 23–92 years} \)). The majority of patients were treated in ITU (57\%) rather than HDU (44\%). 53\% of patients were conscious, and a large proportion were either self-ventilating on oxygen mask (34\%), self-ventilating breathing air (13\%) or receiving non-invasive ventilation via a mask (18\%). However 20\% were ventilated via an endotracheal tube. In terms of cardiovascular support 76\% received no inotropes/vasopressors, 8\% single inotrope/vasopressor (excluding renal dopamine), 3\% single dopamine, 1\% single inotrope/vasopressor with renal dopamine and 4\% multiple inotropes/vasopressors (information was missing for 8 cases). 31\% of patients were level 1 in terms of care, 45\% level 2 and 24\% levels 3. The majority of patients had been diagnosed with respiratory (41\%), neurological (19\%) or cardiac disease (19\%). The mean time between discussion about withdrawal of treatment with family and time of death was 36.4 hours.

**Differences between included and excluded patients**

Comparisons were carried out between patients who were included for potential transfer and those who were excluded from potential transfer. No statistically significant difference was found in terms of age (Mann Whitney \( U =17475, p = 0.15 \)) or patient sex (\( \chi^2 = 0.001, p=0.53 \)). Patients who were eligible for transfer (included group) were statistically significantly more likely to be treated in HDU than ITU compared to patients who were excluded (\( \chi^2 = 19.80, p=0.000 \)).

**Discussion**

These data have given an indication of the potential size and profile of patients who might possibly be suitable for transfer home to die from critical care. Based on the exclusion criteria outlined about over 20\% of
patients could potentially be transferred home to die. Patients who were eligible for transfer had relatively low levels of care requirements, in terms of respiratory or ventilator support, and were more likely to be treated in a HDU. However, patient and family wishes were not ascertained, and therefore the number of patients actually requesting this practice is likely to be lower. For those patients who express a wish to be transferred home mechanisms need to be in place to facilitate this practice.
Phase III: Stakeholder event

Aims

The aim of the national stakeholder event was to bring together health care professionals, representatives of professional organisations and service users to discuss transfer home to die from ITU. We sought to include participants from a variety of backgrounds, representing all key stakeholders directly or indirectly involved in such a process. Specifically, the event was aimed at validating the study findings generated from the various elements of data collection and to gain consensus around aspects that should be considered around the process of transfer home. This information was subsequently used to inform the development of clinical guidance.

Methods

Drawing on data collected in the previous phases vignettes of exemplar cases that might conceivably be transferred home to die were developed. The vignettes were used to facilitate debate with the wider healthcare community about the structures and process needed to underpin the transfer of critical care patients home to die. This approach, involving the use of vignettes to explore opinion and views about specific clinical issues, has been successfully used in the past by the research team. The national stakeholder event aimed to host approximately 100 participants from primary and secondary care settings including doctors, nurses, purchasers and commissioners, and support services e.g. ambulance staff, community pharmacists. In addition, representatives of UK Clinical Networks, professional organisations (e.g. Intensive Care Society), charities (e.g. Marie Curie Cancer Care) and patient representatives were invited to attend the event. Finally, participants from the follow-on interviews were also invited to attend.

During the stakeholder event (Programme in Appendix E), findings from the survey and audit were presented and with reference to the vignettes (in Text box 3), the following question was posed: ‘What would need to happen to enable transfer of a critically ill patient home to die?’ A nominal group approach underpinned the stakeholder event proceedings in order to identify and prioritise barriers most likely to influence the feasibility of transferring this population home to die.

Outcomes from the event were used to inform the development of a framework to guide decision-making in this area and underpin the clinical guidance presented in the next chapter.

The stakeholder event brought together stakeholders who might be involved in a transfer home to die from ITU, either directly or indirectly. The aim was to involve stakeholders in a discussion about aspects that need attention when contemplating and organising a transfer in order
for this information to be used to develop guidance. The aim was not to
debate positive and negative views on transfer home to die, as these
were explored in previous phases, specifically during focus groups and
the web–based survey. To this end the stakeholder event was organised
in such a way that attendants were first given an overview of the project
aims and results to date.

Prior to the presentation of results the study topic was placed in the
wider palliative care context through a keynote address by Dr Teresa
Tate, the Medical Director of Marie Curie Cancer Care. In addition,
attendees were also asked to respond to several generic questions, in
order to engage the audience and gather data on their views. The
following questions or statements, which mirrored items from the
online survey, were presented: 1) **Have you transferred a critically ill
patient home to die in the last three years?** (possible answers ‘Yes, I
have’, No I haven’t, but I have had discussions about possible patients’
and ‘I have no experience’), 2) **Transferring critically ill patients home
to die is a good idea in principle**, (possible responses from ‘Strongly
agree’ to ‘Strongly disagree’ on a 5–point scale) 3) **Taking critical care
patients home to die is waste of health care resources** (possible
responses as previous statement) and 4) **Please identify the most
important barrier to transfer home to die** (from 10 predefined option).
Attendants were asked to use an electronic devise (Zappers) to respond
to the questions. The responses were summarised and displayed in the
PowerPoint presentation in real time. Finally, the vignettes were
presented and discussed in small groups. This last part of the
stakeholder event was designed to generate discussion and input from
the stakeholders. The group discussions were led by Professor Ruth
Endacott, Professor of Critical Care Nursing from Plymouth University
and Professor Maureen Coombs. The information gained from these
discussions was subsequently used to inform development of the
clinical guidance.

**Stakeholders**

Relevant stakeholders from across different organisational and
professional groups and acute and community settings who might have
direct or indirect involvement in transferring patients from ITU home to
die were identified and subsequently invited. These included members
of the study steering group, clinical champions (affiliated with the
study), professional organisations (e.g. the Intensive Care Society),
national charities (e.g. Marie Curie Cancer Care), clinical networks,
researchers, medical consultants and nurses who had been interviewed
as part of the study in a previous phase (identified through survey
study), ambulance service, community health professionals and
hospital rapid discharge teams.
Development of vignettes

Vignettes were developed to facilitate debate during the stakeholder event, and formed a discrete activity during the stakeholder event. The vignettes were developed from details described by clinicians during the follow-on interviews. One of the issues that generated debate throughout the study was related to patient clinical characteristics, in particular mechanical ventilation, and whether it is feasible to transfer such a patient home to die. Therefore participants were asked to consider two separate scenarios, one of which described a patient receiving mechanical ventilation. The discussions around the vignettes were facilitated by experienced researchers or clinicians. The facilitators were given instructions on the format and the aim of the discussions.

Text box 3 Vignettes used during Stakeholder event

<table>
<thead>
<tr>
<th>Case A</th>
</tr>
</thead>
<tbody>
<tr>
<td>A gentleman suffering with chronic liver disease in ICU, he’d been intubated and ventilated and he had been weaned off the ventilator, still had a tracheostomy in situ and there was nothing further that they could offer him. He was... being filtered and they talked to him, he was able to participate in conversations and decisions, although he was tracheotomised.... He said that he no longer wanted to be filtered and that he wanted his treatment to be stopped and he wanted to go home...he’s had the tracheostomy for quite a period of time, he requires a very, very minimal amount of suction... he’s able to cough himself and he was almost self-caring with it...[he needed] prescription medications at home...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case B</th>
</tr>
</thead>
<tbody>
<tr>
<td>A gentleman in his 60's was admitted into intensive care with breathing difficulties and subsequently turned out to have motor neurone disease...the plan was to withdraw ventilation at his request as he wished to die at home...because the options were either his ventilation was withdrew on ITU and he died there...or we could pursue the opportunity for him to die at home because he had spent quite a long time in hospital, probably nearly 4 or 5 months...his wish was one to watch a football match but also to be at home with his grandchildren and his dog. [He needed] community support, nurses to manage his infusion, ventilator and his comfort...an occupational therapy home assessment...a hospital bed...and ambulance transfer...</td>
</tr>
</tbody>
</table>
Results

Participants

The stakeholder event was attended by a total of 85 people (not including the research team members). For the afternoon discussion sessions participants were seated at 9 different tables; each table comprised as far as possible representatives from different disciplines and backgrounds to form ‘virtual clinical teams’ to reflect discussions that would occur in clinical practice and to stimulate debate.

Participant questions and response

All stakeholders were asked to answer four questions to explore experience and views of attendees. The first question was related to experience about transfer home. Of the 71 stakeholders who responded to the question 18.3% (n=13) indicated they had experience of transferring a patient home to die from critical care. Almost half of responders (49.3% (n=35) had not transferred a patient home but had had discussion about possible patients and a further 32.4% (n=23) did not have any experience at all. Stakeholders were also asked about their views about transfer home and most (n=36, 52.2%) strongly agreed that it is a good idea in principle and most (n=49, 69.0%) strongly disagreed that it is a waste of health care resources. Stakeholders were also asked to indicate which barrier they considered to be most important and the three options which received most responses were ‘access to care in the community’ (n=22, 31.4%), ‘responsibility for care of patient’ (n=17, 24.3%) and ‘expectations of relatives about death at home’ (n=8, 11.4%).

Discussions

The two vignettes were discussed at each of the 9 tables and delegates were asked to structure their thinking and discussions in a linear fashion, starting with the decision-making process, through to the organisation of transfer, to the actual transfer and finally around the care required after transfer and after death. The main question delegates were asked to answer was ‘What would need to happen to enable transfer of a critically ill patient home to die?’. The main themes highlighted in table 8 are themes which had not emerged in previous phases (either literature review, focus groups, or follow-on interviews) and added in depth information.

Table 8. Outlines of themes highlighted during Stakeholder event, in response to the question ‘What would need to happen to enable transfer of a critically ill patient home to die?’ based around the two vignettes.
<table>
<thead>
<tr>
<th>PHASE OF ACTIVITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to transfer</td>
</tr>
<tr>
<td><strong>Theme: Staff reflection on:</strong></td>
</tr>
<tr>
<td>-Patient/family social background</td>
</tr>
<tr>
<td>-Patient is no longer a critical care patient once decision for no more active treatment made</td>
</tr>
<tr>
<td>-What if patient changes their mind?</td>
</tr>
<tr>
<td>-Agreed inclusion criteria between commissioner, providers, ambulance services, and MDT prior to process</td>
</tr>
<tr>
<td>-Difference between “going home” and “going home to die” by medical/nursing staff</td>
</tr>
<tr>
<td><strong>Theme: Discussion with the family about:</strong></td>
</tr>
<tr>
<td>-Tissue/organ donation</td>
</tr>
<tr>
<td><strong>Theme: Discussion with professionals:</strong></td>
</tr>
<tr>
<td>-Develop communications team of key people (GP, nurses, pharmacy)</td>
</tr>
<tr>
<td>-Consider withdrawal of treatment plan</td>
</tr>
</tbody>
</table>

The findings from the stakeholder event added another layer of detail to the complexity experienced by health professionals (experienced or anticipated) of transfer home. Delegates were also asked to report back to the group about the topic that generated the most discussion and the topic that needed most development and these are presented in Table 9. In addition, participants were asked to prioritise the area that needs the most development to more fully develop transfer home and
prioritised the following three areas: 1) increased awareness of community support services (30%), 2) refine transfer process (15%) and 3) look at new activities/pathways (14%).

Table 9. Discussion topics that generated the most discussion and needed the most development

<table>
<thead>
<tr>
<th>Topic that generated the most discussion</th>
<th>Topic that needs the most development</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>VIGNETTE A</strong></td>
<td></td>
</tr>
<tr>
<td>1 Engaging with the complexity and depth of the task before transfer</td>
<td>The need for a single person to lead on the task and the related paperwork.</td>
</tr>
<tr>
<td>2 Engaging with planning prior to discharge</td>
<td>The need for knowledge of what is out there in relation to community services</td>
</tr>
<tr>
<td>3 (i) Engaging with what the patient wants, (ii) ICU team communication</td>
<td>ICU liaison role needed</td>
</tr>
<tr>
<td>4 (i) Engaging with the capacity of the patient to decide about transfer, (ii) the need for an agreed pathway and combined team approach to determine who does what and when</td>
<td>The need for key stakeholders to agree on a pathway for transfer</td>
</tr>
<tr>
<td>5 Engaging with the complexity of patients’ home environment needs prior to transfer</td>
<td>(i) Knowledge deficits in the community, (ii) the postcode problem of what is available in a particular locality</td>
</tr>
<tr>
<td>6 What about the non-believers in transfer?</td>
<td>What is available to assist in the community? What are the existing links between hospital and community?</td>
</tr>
<tr>
<td>7 Thinking about transferring patients without relatives/any form of support and what exists in community services</td>
<td>The need for more involvement of palliative care teams and rapid discharge teams</td>
</tr>
<tr>
<td>8 (i) Engaging with the care needs of the patient and who provides this at home, (ii) what happens if the patient wants to go home but the family disagree?</td>
<td>(i) The need for more knowledge of available care, and (ii) how to set up a care package for transfer home</td>
</tr>
<tr>
<td></td>
<td>VIGNETTE B</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>9</td>
<td>Is there a home to go? (based on patient characteristics and their home environment characteristics)</td>
</tr>
<tr>
<td>10</td>
<td>The need for a timeline plan to know when to turn the ventilator off</td>
</tr>
<tr>
<td>11</td>
<td>Engaging with legal issues (example given: what happens if a patient’s/relative’s dog goes crazy?)</td>
</tr>
<tr>
<td>12</td>
<td>Engaging with issues about the patient’s state of consciousness</td>
</tr>
<tr>
<td>13</td>
<td>Engaging with patients’ priorities</td>
</tr>
<tr>
<td>14</td>
<td>The “what if’s” (example given: what if the patient/relatives changes their mind?)</td>
</tr>
<tr>
<td>15</td>
<td>(i) Professionals’ concerns that ventilated patients at home is a worrying concept (example give: who will deal with extubation and how will it be dealt with?) (ii) When does the discussion between hospital and community services stop? (iii) How is transition managed?</td>
</tr>
<tr>
<td>16</td>
<td>Engaging with planning prior to transfer through (i) assembling the right people to do it and (ii) establishing the commissioning/funding interface between hospital and community services</td>
</tr>
<tr>
<td>17</td>
<td>(i) Pre-transfer planning/timelines and (ii) consider the skills of people available to support transfer</td>
</tr>
<tr>
<td>18</td>
<td>This table reiterated their issues about patient characteristics and home environment characteristics</td>
</tr>
</tbody>
</table>
Evaluation of event

All delegates were asked to complete a feedback/evaluation form, asking them to rate the different elements of the event as ‘excellent’, ‘good’, ‘fairly good’ ‘poor’ or ‘very poor’. Table 10 shows that the majority of delegates rated the event as excellent or good and only a small minority rated the event as fairly good. In particular the programme and organisation were rated highly.

Table 10. Results from delegate feedback forms

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Good</th>
<th>Fairly good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programme</td>
<td>47</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>Organisation</td>
<td>52</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Venue</td>
<td>38</td>
<td>21</td>
<td>4</td>
</tr>
<tr>
<td>Catering</td>
<td>35</td>
<td>23</td>
<td>5</td>
</tr>
</tbody>
</table>

Discussion

The aim of the stakeholder event was to bring health professionals and representatives from professional organisations together to discuss, in detail, the process of transferring critically ill patients home to die. We succeeded in attracting many clinicians (with some having to join a waiting list to attend), from different backgrounds and engaging them in detailed discussion on this topic. The delegates were able to provide a high level of detail on many of the aspects needed to be considered for this practice. This information was subsequently used to inform the development of clinical guidance. The event was a success from the researchers’ point of view and served to generate a further level of detail about the transfer process and revealed some areas not easily resolved through discussion, such as what happens when patients change their mind. The enthusiastic attendance by a range of different stakeholders demonstrated interest in and commitment to the topic.
Phase III: Guidance

Aims

In developing the guidance the aim was to consolidate all data collected in the previous phases and develop guidance to inform clinical practice. In addition, the aim was to receive feedback from potential users of the guidance and refine the guidance based on this.

Methods

Findings from all previous phases were reviewed to inform the development of guidance for clinicians. In addition, we searched for and looked at guidance on transfer to generate ideas about common formats that appeal to clinicians and infer usability. Content was guided by the key stages to the process identified from the data; i.e transitioning from decision-making to operationalization of a possible transfer, through to actual transfer and post-transfer care. A flow chart was created consisting of all aspects needed to be considered for each stage of the process.

Two different formats were created: 1) a flowchart developed in PowerPoint which represented stages of initial decision-making and action. This version included exit points for patients who identified as unlikely to be suitable based on certain criteria (such as being clinically too unstable for transfer; Appendix F) and 2) a funnel shaped format which represented the sifting of patients’ suitable for transfer as various inclusion and exclusion criteria were considered (Appendix G).

The first draft of these two formats of the guidance was presented to a group of experienced clinicians, the majority of whom had participated in the web-based survey, follow-on interviews and Stakeholder Event. These drafts were also presented to a lay person from the project’s steering group. Most of the clinicians involved in reviewing the guidance had experience of transferring a patient home to die. Telephone conversations were organised in groups (conference calls) or individually, and clinicians were asked to comment on the format, content and usability of the guidance. In addition, they were asked to state whether they thought it would be a helpful tool. Finally, they were asked for input regarding initial testing and dissemination strategies.
Results

Participating clinicians

Initially 20 participants were approached and a total of 14 provided feedback on the two draft formats of guidance. Nine were nurses and five were consultants and all with a critical care background. Feedback was also provided by a lay member of the project’s steering group.

Clinician feedback

General

Two formats of the guidance were presented. Clinicians indicated that the guidelines looked straightforward, easy to assimilate in a busy environment. Some indicated that the guidance might potentially be used to speak to families about the process of transfer home to die even though the tool was not developed for this purpose. In addition, some suggested it could signal intent on the part of the medical team. In a practical sense clinicians considered the possibility of using the checklist to record information to keep in a patient’s notes. Participants commented on the timing of the tool in relation to all the recent work around the Liverpool Care Pathway.

Format

Clinicians presented a mixed picture in terms of their preference for a particular format. Some preferred the inverted triangle (essentially a funnel shape) and others preferred the more traditional flow-chart as it was similar to guideline formatting used in the NHS. Some preferred the more traditional formatting as it provided clear exit points when considering patients for transfer.

Content

Clinicians provided feedback on the content of the guidance, including the following: consider medical certification; equity in relation to exclusion criteria; coroner’s cases should not necessarily be excluded; organisation of care when the patient arrives in the home (organising regular phone calls with the family); update DNAR information – DNACPR instead of DNAR; address continuity of care in terms of responsibility for patient; use examples of patients to humanise process; risk assessment of storing oxygen in home; indemnity issues.

Dissemination

Clinicians offered several suggestions in terms of the testing and dissemination of the guidance. The importance of getting buy in from consultants and patients (for instance Motor Neuron Disease Society) was emphasised. Several professional organisations were mentioned,
such as the nurses’ Critical Care Network, the British Association of Critical Care Nurses, the Association of Anaesthetists, and the Intensive Care Society, which also provided a possible route for scientific publication of findings. The recommendation was also made to ask different Colleges (e.g. Royal College of GPs, Royal College of Nursing) to endorse the guidance. In addition, some participants suggested contacting the Faculty of Intensive Care Medicine for input and comment on the tool.

In terms of testing clinicians suggested trialling the guidelines in several units, and assessing how they fit with local existing paperwork. A suggestion was also made to tap into knowledge from clinicians involved in organ donation, in terms of implementing a service at the end of life.

**Discussion**

The guidance was on the whole well received by clinicians but they differed in their views on how it might be used. Some suggested a version of guidance for use in discussions with patients and relatives, others as a potential educational tool (developing awareness for this practice on the unit and the processes necessary to underpin the practice). Clinicians indicated that any tool would likely to be re-formatted and adjusted according to local preferences once disseminated. On the whole clinicians could see the benefit of having clear guidance to aid operationalisation of a transfer home to die. A final version of the guidance has been developed (Appendix H). The final key features of guidance in terms of content and format should now be subject to testing and revision based on use in practice.
Conclusions and recommendations

To our knowledge this is the first study internationally to conduct an in-depth examination of the concept of transferring patients from critical care home to die as evidence of best practice to date is all but absent. With reference to the UK situation, this study sought to describe who transfer home to die happens to and how it happens in an environment that is usually dedicated to preserving and prolonging life. Whilst there have been initiatives to improve end of life care in the critical care environment [refs], these have not extended to considering preferred place of death. Underpinning our investigation was the notion of choice and attending to individual patient and family wishes. Whilst a patient might be cared for in a critical care environment at the point at which withdrawal of life sustaining treatment begins to be considered, this should not preclude consideration of where a patient might prefer to die.

A major part of the study was focussed on investigating healthcare professionals’ current experience of, practices related to, and views towards transferring critical care patients’ home to die. This largely focussed on staff in critical care. Whilst healthcare professionals had largely very positive views about transfer home to die from critical care it remains an uncommon event. Key issues for clinicians focussed on assessing patient's clinical suitability, addressing the logistics of the transfer arrangements to the community and dealing with unrealistic expectations of families of patient dying at home. Transfer home was uniformly perceived to be a complex, highly time dependent, process. Most staff did not have experience of transfer home to die and readily identified need for guidance to enable and direct practice in this area. Request for transfer home usually came from family members and less frequently from patients. The communication and organisational processes that accompany the possibility of transfer were seen as crucial.

The study also set out to scope the size and characteristics of the critical care population with the potential to transfer home to die. The scoping review revealed very few published accounts describing the practice of transferring patients home to die from a critical care environment. Most of these were case studies, lacked data on procedural details and did not seek to critically examine the practice. In a number of published accounts the influence of cultural factors on the instigation of transfer was evident. In terms of the size of the population this practice might apply to, if solely physiological indicators are taken into account when determining potential suitability, the multi-site audit revealed around 20% of patients might be suitable. But psychological, social, spiritual and contextual factors were recognised to play an equally significant role. Patients on low levels of respiratory and cardiovascular support were judged more
likely to be suitable for transfer. But alongside consideration of physical characteristics, a strong desire to die at home as expressed by the patient and/or family (dependent on the circumstances) was a key influencing factor in raising the possibility of transfer in the first place.

In order to inform future implementation of the practice, the study sought to identify factors that enable or challenge service providers to transfer patients in this care setting, home to die. Characteristics of patients were key to informing decision-making: the concept of patient stability central. Lack of understanding of relevant community services and ready access to care in the community were frequently raised as impediments to transfer from the perspective of critical care staff alongside relatives abilities to cope (or not) with the situation and demands of the experience once home. Support from family members for the concept of transfer home and a positive reception from community staff to the idea were critical to perceptions around achieving a successful transfer.

Through recourse to different types of data collection a number of factors were identified as having an influence on the feasibility of transferring critical care patients home to die, including resources and infrastructure required. Where a named individual took the lead in liaising with different individuals and across clinical, organisational and geographical boundaries, this was recognised as making an important contribution to effective co-ordination. Critical care staff’s understanding of the nature of services and means to mobilise these (often in a space of a few hours) influenced perceptions about feasibility. In units where transfer was not an isolated event it was often the case that effective links and working relationships had been brokered with rapid discharge team and/or specialist palliative care teams who worked with the critical care team to effect transfer to the home environment. They had also sought to actively develop local solutions to what they saw to be relevant legal, health and safety and ethical issues, rather than see these as things that stopped them taking action and initiating transfer. Furthermore, these units reflected on the importance of follow up of the family (especially where the critical care team did not remain in the home until the point of death) and team debriefing (including feedback from community service providers) in order to learn and refine practices and procedures.

Findings from the study have generated clinical guidance that relates to considerations for the transfer process. In order to further develop practice in this area we recommend:

- Staff in critical care environments actively consider the practice of transferring patients home to die
- Clinical teams in secondary and primary care use the guidance as a point of reference to develop local policy and procedures to underpin the process
• Critical care units establish which local (both secondary and primary care) resources might be mobilised in the event of a transfer being considered and engage with stakeholders in discussions and clinical policy development. These should address cases where death will be very rapid once the person reaches home but also where a longer dying trajectory is anticipated (or occurs unexpectedly)

• A community of practice be established whereby the experiences and solutions to effecting rapid and effective transfer can be shared between units with the aim of developing practice in this area

In terms of further research there are a number of avenues that would be fruitful to pursue. A study to further understand the experiences and practices of community-based staff in relation to caring for patients who have been transferred home to die from critical care is warranted. Whilst we sampled from the community in relation to focus groups and the consensus event our primary focus in this study was on critical care professionals. It is clear we need to better understand what happens once the transfer has taken place and how events are managed in the home before and after death. This should include examining the process and outcome from the perspective of family members. We have no knowledge of the experiences of family members and the impact of this practice on bereavement outcomes. Findings could be triangulated with data from the current study to further develop and refine intervention directed at supporting integrated working across care sectors – critical care and community teams.

Implementing any change in healthcare practice is fraught with challenge as barriers to implementation can arise at multiple levels of care delivery: the patient and family level, provider team level, organisational level or policy level. Studies to develop and evaluate tools to help healthcare teams, patients and their families consider how suitable the option of arranging for a person to die home might be in a particular case are necessary. Studies that develop and evaluate integrated pathways of working to support hospital and community teams to manage an effective and safe transfer from this clinical speciality are now required. For example, a study to further refine and introduce the guidance into a number of critical care units in partnership with community care providers and assess the outcome of this and the extent to which implementation is effective would be useful. It would need to be introduced within the context of integrated working between critical care, specialist palliative care, discharge teams and community care providers alongside a shared training programme. This should be underpinned by implementation theory and informed by implementation science to further understand what works where and why across different contexts. From this it would be possible to identify, characterise and develop the nature of further interventional tools that could facilitate practice in this area and support integrated
working. As transfer home to die is a relatively rare event, studies to observe practice (either as currently stands or following introduction of intervention) would be difficult to undertake. Consideration should be given to using simulation methods to model any new intervention and following this test feasibility and effects of tools on staff, patients and families. Simulation could also be employed to study how healthcare teams across the secondary/primary care interface together and respond to being asked to consider orchestrating transfer home of particular groups of patients and compare characteristics and experiences for cases with and without intervention. This would in part enable assessment of the effectiveness of different service models in this context (particularly orchestrating the transfer and subsequent provision of care at home).
References


Dissemination

Conference presentations

*Oral presentations*


Darlington AS, Long–Sutehall T, Richardson A, Coombs M. A qualitative study of health professionals’ views of scope and feasibility of transferring patients from critical care home to die in the UK. Oral presentation. European Association of Palliative Care conference, Prague, Czech Republic, 30 May–1 June 2013.


*Poster presentations*


*Invited presentation*


Published abstracts

Appendix A

Questionnaire

Thank you for taking the time to complete this questionnaire. We are interested in your experience and views in relation to transferring adult critically ill patients home to die.

We are referring to patients who are not responding to treatment for whom treatment withdrawal has been discussed.

Please complete the following questions, which should not take more than 10–15 minutes.

Background information

1) What post do you hold in the critical care unit?

Lead nurse / Matron
Lead consultant / Clinical director
Other.....

☐ Please provide information

2) Type of unit (please tick one box)

ITU
HNU
ITU/HNU combined
Other.....

☐ Please provide information

3) Clinical specialty of the unit (please tick one box)

Burns
Cardiac Surgery
Coronary care / Cardiology
General
Medical
Neuro
Oncology
Renal
Surgical
Other.....

☐ Please provide information

4) How many beds does the unit have?
5) Which Strategic Health Authority (England), Health Board (Scotland, Wales) or Trust (Northern Ireland) is the unit part of?

**England**
- East Midlands
- East of England
- London
- North East
- North West
- South Central
- South East Coast
- South West
- West Midlands
- Yorkshire and The Humber

**Scotland**
- NHS Ayrshire and Arran
- NHS Borders
- NHS Dumfries and Galloway
- NHS Fife
- NHS Forth Valley
- NHA Grampian
- NHS Great Glasgow and Clyde
- NHS Highland
- NHS Lanarkshire
- NHS Lothian
- NHS Orkney
- NHS Shetland
- NHS Tayside
- NHS Western Isles

**Wales**
- Aneurin Bevan Health Board
- Abertawe Bro Morgannwg University Health Board
- Cardiff & Vale University Health Board
- Hywel Dda Health Board
- Cwm Taf Health Board
- Betsi Cadwaladr University Health Board
- Powys Teaching Health Board

**Northern Ireland**
- Belfast Health and Social Care Trust
- Northern Health and Social Care Trust
- South Eastern Health and Social Care Trust
- Southern Health and Social Care Trust
- Western Health and Social Care Trust
Experience of transferring patients home to die

1) Has your unit transferred a critically ill patient home to die in the last 3 years?

Yes  □  (If Yes continue to question A)
No   □  (if No continue to question 2)

IF YES:

A) How many patients has your unit transferred home to die in the last 3 years?  □

B) Would you be willing to participate in a telephone interview about these transfers? This would help us learn more about your experiences in order to inform future practice. We expect the interview to take no more than 30 minutes.

Yes  □  Thank you. Please complete your contact details. Anne-Sophie Darlington, the project researcher, will contact you shortly to discuss the interview with you more fully.
No   □
I am not sure □  Please complete your contact details and Anne-Sophie Darlington, the project researcher, will contact you shortly to discuss the interview with you more fully to help inform your decision.
**IF NO**

1) Has your unit transferred a critically ill patient home to die in the last 3 years?

Yes □ (If Yes continue to question C)

No □ (if No continue with questions on Views)

**IF YES:**

C) For how many patients have you held discussions about transferring home to die over the last 3 years?

D) Would you be willing to participate in a telephone interview about these discussions? This would help us learn more about your experiences in order to inform future practice. We expect the interview to take no more than 30 minutes.

Yes □ Thank you. Please complete your contact details. Anne-Sophie Darlington, the project researcher, will contact you shortly to discuss the interview with you more fully.

No □

I am not sure □ Please complete your contact details and Anne-Sophie Darlington, the project researcher, will contact you shortly to discuss the interview with you more fully to help inform your decision.
Views
In this section we want to find out what **your personal views** are about transferring critically ill patients home to die. There are no right or wrong answers in this section.

Please indicate to what extent you agree or disagree with the following statements:

- Strongly disagree (1) – Disagree (2) – Neutral (3) – Agree (4) – Strongly agree (5)

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<tr>
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<tbody>
<tr>
<td>Transferring critically ill patients home to die is a good idea in principle but difficult to achieve in reality.</td>
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<tr>
<td>Critical care is a perfectly good place to die.</td>
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<tr>
<td>I have limited experience of transferring patients home to die and wouldn’t know where to start</td>
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<tr>
<td>It is better for critically ill patients to die in Critical Care</td>
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<tr>
<td>It would be better to transfer a patient to a hospice than to transfer them home to die.</td>
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<td>It is satisfying to enable a patient to die at home.</td>
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<tr>
<td>We would be able to organise the transfer home to enable someone to die at home</td>
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<tr>
<td>It is unethical to prolong a patient’s life so they can be transferred home to die</td>
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<tr>
<td>It would be too distressing for the patient and relatives to take them out of the familiar critical care environment</td>
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<tr>
<td>Patients will still receive the best possible care if they are transferred home to die</td>
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<tr>
<td>Transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death</td>
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<tr>
<td>It is more important to offer good end-of-life care on the unit than to</td>
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<tr>
<td>transfer patients home to die.</td>
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<td>-----------------------------</td>
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<tr>
<td>Critical care staff have more pressing clinical priorities than organising home transfers for dying patients.</td>
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<tr>
<td>Transferring critically ill patients home to die is a feasible option in critical care</td>
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<tr>
<td>Transferring patients home to die is not worth the risk of dying in the ambulance or having a really bad death at home</td>
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<tr>
<td>Dying in critical care is better than home for patients because of the higher nurse patient ratios.</td>
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<tr>
<td>Taking critical care patients home to die is a waste of health care resources.</td>
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</table>
### Patient characteristics

In this section we want to find out **which patients, if any**, you would consider transferring home to die.

Would you consider transferring a patient home to die who:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>is unconscious</td>
<td></td>
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<tr>
<td>is conscious</td>
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<td></td>
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<tr>
<td>is unstable</td>
<td></td>
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<tr>
<td>is stable</td>
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<tr>
<td>who is ventilated via an endotracheal tube</td>
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<tr>
<td>who is ventilated via tracheostomy</td>
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<td></td>
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<tr>
<td>who is receiving non-invasive ventilation</td>
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<td></td>
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<tr>
<td>is self-ventilating breathing oxygen</td>
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<td></td>
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<tr>
<td>who is self-ventilating breathing air</td>
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<tr>
<td>needs cardiovascular support e.g inotropes</td>
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<tr>
<td>has intense nursing needs e.g frequent turning and washing</td>
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<tr>
<td>has high level emotional needs</td>
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<td></td>
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<tr>
<td>has relatives with high level emotional needs</td>
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<tr>
<td>needs regular medication for symptom management (e.g pain, nausea)</td>
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<tr>
<td>lives outside local catchment area</td>
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</tbody>
</table>
**Barriers**

We are interested in understanding your views on aspects that could act as **barriers or facilitators** to transferring a patient home to die.

Please rank the **five most important** aspects that could act as **barriers** to transferring a patient home to die. Please rank from 1 to 5 with 1 being the most important.

- Lack of access to care in the community
- Lack of contact with patient’s GP
- Unpredictability of time to death
- Lack of information about home environment, to ensure transfer can be achieved
- Lack of backfill of staff in Critical Care
- Lack of time to organise the transfer home
- Patient’s relatives unlikely to be able to cope with transfer and death at home
- Unrealistic expectations of relatives about death at home
- Unclear responsibility for care of patient during and after transfer
- Legal issues with transfer home are unclear
- Lack of guidelines on transferring patients from Critical Care home to die

**Facilitators**

Please rank the **five most important** aspects that could **facilitate** transferring a patient home to die. Please rank from 1 to 5 with 1 being the most important.

- Access to care in the community
- Established contact with patient’s GP
- Predictability of time to death
- Available information about home environment, to ensure transfer can be achieved
- Available backfill of staff in Critical Care
- Time to organise the transfer home
- Patient’s relatives able to cope with transfer and death at home
- Realistic expectations of relatives about death at home
- Clear responsibility for care of patient during and after transfer
- Legal issues with transfer home clearly addressed
- Established guidelines on transferring patients from Critical Care home to die
End-of-life in the unit

1) Does your unit use the following? Please tick one box

- Liverpool Care Pathway
- Another end-of-life pathway? ______please provide information
- No end-of-life pathway

2) Does your unit have a team with a focus on improving care at the end of life?

- Yes
- No
- I don’t know

3) Over the last 2 years has your unit undertaken any of the following?

- Developed/reviewed end of life practice guidelines/standards
- Undertaken end-of-life audit?
- Delivered end-of-life education as part of staff development
- Reviewed documentation as part of end-of-life care

4) How many times is the hospital palliative care team consulted in your unit?

- Weekly
- Monthly
- Every other month
- Rarely
- The hospital does not have a palliative care team

If you would like to make any additional comments about transferring patients home to die please use the box below.
# Appendix B

Interview schedule for telephone interviews with HCPs who had been involved in a transfer home to die

<table>
<thead>
<tr>
<th>Process through time</th>
<th>Topics</th>
<th>Main questions</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dying trajectory and decision making process</td>
<td>Can we start with you giving me an overview of the patient? (keeping one specific patient in mind) Could you talk me through the decision-making process?</td>
<td>Triggers Drivers</td>
<td>Who initiated the request for transfer? How did a transfer come up as something to discuss as a possibility Details about the patient. Who was involved in the discussion about possible transfer; team members, pall care team, patient, relatives, community, GP, ambulance, pharmacist? Was there anyone in the team who took the lead on this? What issues were discussed, e.g. certainty of time to death, distance to travel, community links, availability of specialists etc. Was there support from the family and for the family Did you consider a transfer to hospice rather than home (or any other care environment)?</td>
</tr>
</tbody>
</table>

| Action process Prep work for transfer | Could you tell me about preparing for the transfer? | Barriers/ Facilitators/ Drivers | Tell me about any particular barriers and challenges (and facilitators), e.g. contact(s) in the community? How did you organise transportation? Who led on this? Who else was involved? (e.g. palliative care team, GP?) Were there time pressures? Did you have information about the home environment? |

<p>| Actual | Please tell me | Logistics/ | Which team members |</p>
<table>
<thead>
<tr>
<th>transfer</th>
<th>about the actual transfer</th>
<th>Practicalities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>took the patient home? [what level were they] How many were involved? Did relatives go with them, or follow, or wait at home? Did anyone from the team stay in the home? Who? How long did members of your team stay in the home? And what were they responsible for doing?</td>
</tr>
<tr>
<td>Home-handing over care</td>
<td>If possible can you tell me about care at home</td>
<td>Barriers/ Facilitators</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Was the care handed over to HCPs in the community? Who and how did this occur? Who was responsible for the patient in the home? Was the patient extubated (and so by whom?) Was patient on inotropes and if so what happened to them? Was the patient on medication, how were symptoms managed Intravenous lines, and what happened?</td>
</tr>
<tr>
<td>Death</td>
<td></td>
<td>When did the patient die? (from time they arrived home) Who was with the patient when he/she died?</td>
</tr>
<tr>
<td>Experience</td>
<td>How would you assess the experience of transferring patients home to die? (as HCP, patient, relative, team?)</td>
<td>Was the experience a negative or positive one? Are there things that you would have done differently? Would you do it again? What were the differences/similarities between patients? What would deter you from doing it again? What would encourage you to do it again? Was resource an issue and in what way?</td>
</tr>
<tr>
<td>Other</td>
<td>Drawing on your experience, what would your advice be to other</td>
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</table>

| 91 |
| clinical teams considering a transfer. What would support this in practice? |   |
## Appendix C

<table>
<thead>
<tr>
<th>Topics</th>
<th>Main questions</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opening question</td>
<td>Could you tell me first of all about how many patients you have had a discussion about transferring them home to die.</td>
<td></td>
</tr>
<tr>
<td>Dying trajectory and decision making</td>
<td>Could you start by talking me through the one specific patient about whom or with whom you have had discussions about transferring them home to die.</td>
<td>Triggers Who initiated the discussion? Details about the patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Drivers Who was involved in the discussion about possible transfer; team members, pall care team, patient, relatives, community, GP, ambulance, pharmacist? What aspects were discussed? E.g 1) certainty of time to death?, 2) support from the family and for the family 3) clinical factors? Did you consider a transfer to hospice rather than home?</td>
</tr>
<tr>
<td>Why didn’t transfer happen?</td>
<td>Could you tell me why the patient was not transferred home? What were deciding factors? Can you remember what happened to the patient?</td>
<td>Barriers (which stop transfer from happening) Contact(s) in the community? Transportation? Timing of death important? Lack of time? Home environment? No backfill? Family members unable to cope? Unrealistic expectations of family? Legal issues/responsibility of patients (whose is it?) Resource an issue? No specialist advice available? No drugs/equipment available?</td>
</tr>
<tr>
<td>Experience</td>
<td>What would need to be in place for you to consider transferring a patient home to die? What would deter you from doing it? What would encourage you to do it? Drawing on your experience, what would your advice be to other clinical teams considering a transfer. What would support this in practice?</td>
<td></td>
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<td>------------------------------------------------------------------------------------------------------</td>
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Appendix D

Audit form

Marie Curie Cancer Care study ‘An investigation about transferring patients in critical care home to die: experiences, attitudes, population characteristics and practice’

General information

<table>
<thead>
<tr>
<th>Study ID</th>
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<tbody>
<tr>
<td>Patient DOB</td>
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<tr>
<td>(date)</td>
<td></td>
</tr>
<tr>
<td>Patient sex</td>
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<tr>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>Female</td>
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<td>Area of residence</td>
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<table>
<thead>
<tr>
<th>ITU/HDU</th>
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<tr>
<td>ITU HDU</td>
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<tr>
<td>ITU/HDU Combined</td>
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<table>
<thead>
<tr>
<th>ITU/HDU speciality</th>
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<tbody>
<tr>
<td>General</td>
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<tr>
<td>Neuro</td>
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<td>Oncology</td>
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<td>Other</td>
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<table>
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<th>Level of care*</th>
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<tr>
<td>2</td>
<td></td>
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<tr>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

*Department of Health: Comprehensive Critical Care, 2000

What was the primary cause for admission?

What was the secondary cause?
| for admission? | |
| Other significant condition in past medical history | |
| Date/time of withdrawal discussed with family |   |
| Date/time of death |   |

**STAGE 1: Sudden death**

| Cardiac arrest or sudden death |   |
| Other |   |

**STAGE 2: Stability: in last 24 hours before treatment withdrawal discussed with family**

- **Unstable**: i.e. patient observations show significant variability/deterioration or introduction of new therapy as result of patient deterioration
- **Stable**: i.e. patient observations show no variability/deterioration and no introduction of new therapy as result of patient deterioration
Stage 3: Observations in the last 24 hours before withdrawal discussed with family

<table>
<thead>
<tr>
<th>State</th>
<th>Conscious (alert and orientated; GCS 15 or equivalent)</th>
<th>Unconscious</th>
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**Respiratory support**

<table>
<thead>
<tr>
<th></th>
<th>Self-ventilating breathing air</th>
<th>Self-ventilating on oxygen mask</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Self-ventilating with room air/oxygen with endotracheal tube in situ</td>
<td>Self-ventilated with tracheostomy</td>
</tr>
<tr>
<td></td>
<td>Receiving non-invasive ventilation via mask</td>
<td>Receiving non-invasive ventilation via tracheostomy</td>
</tr>
<tr>
<td></td>
<td>Ventilated via a tracheostomy</td>
<td>Ventilated via an endotracheal tube</td>
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**Cardiovascular support**

<table>
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<tr>
<th></th>
<th>No inotropes/vasopressors</th>
<th>Single inotrope/vasopressor (excluding renal dopamine)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Single dopamine</td>
<td>Single inotrope/vasopressor with renal dopamine</td>
</tr>
<tr>
<td></td>
<td>Multiple inotropes/vasopressors</td>
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</table>


### Care/Environmental factors

<table>
<thead>
<tr>
<th>Coroner cases/police involvement</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Family with complex issues that might prevent discharge</td>
<td></td>
</tr>
<tr>
<td>Intense manual handling (e.g. morbid obesity, unstable spine)</td>
<td></td>
</tr>
<tr>
<td>High gastrointestinal losses requiring intensive nursing care (e.g. diarrhoea, wound loss, vomiting)</td>
<td></td>
</tr>
</tbody>
</table>
# STAKEHOLDER EVENT

An Investigation about Transferring Patients in Critical Care Home to Die

**Tuesday, 30th April 2013**

Hilton Southampton Hotel, Chilworth, Southampton, SO16 3RB

## PROGRAMME

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>0945-1030</td>
<td>Registration and Refreshments</td>
<td>The Boardroom</td>
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<tr>
<td>1030-1040</td>
<td>Welcome and introduction to the day</td>
<td>Library Suite</td>
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<tr>
<td>1040-1050</td>
<td>Opening presentation</td>
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</tr>
<tr>
<td>1050-1100</td>
<td>Study outline</td>
<td></td>
</tr>
<tr>
<td>1100-1120</td>
<td>Views on transferring patients in critical care home to die</td>
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<tr>
<td>1120-1200</td>
<td>Enabling and challenging factors associated with transferring patients in critical care home to die</td>
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<tr>
<td>1200-1245</td>
<td>Lunch</td>
<td>The Pavilion</td>
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<tr>
<td>1245-1300</td>
<td>Introduction to the population: transferring patients in critical care home to die</td>
<td>Library Suite</td>
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<tr>
<td>1300-1420</td>
<td>Round table group work: mapping the transfer process – Case A</td>
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<tr>
<td>1420-1440</td>
<td>Coffee / Tea Break</td>
<td>The Boardroom</td>
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<tr>
<td>1440-1545</td>
<td>Round table group work: mapping the transfer process – Case B</td>
<td>Library Suite</td>
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<tr>
<td>1545-1600</td>
<td>Conclusions from the day and close</td>
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</table>
Appendix F

Guiding principles

- This guideline is a guide for **critical care** professionals
- The guideline has been developed from data collected in a study exploring views, practice and feasibility of transfer home, from the point of view of health professionals

Key considerations
- For Patients who are not responding to treatment and for whom withdrawal or withholding treatment has been discussed.
- **Communication** and coordination are key
- **Timing** is important: transfers just before weekend or during are less likely to succeed
- **Relatives:**
  - Will relatives be able to cope with the patient dying at home?
  - Do relatives really understand what it means to have someone die at home?
- **Organ donors** are unlikely to be able to be transferred home to die.
- **Debriefing and collating** important (local) information after a transfer home to die
## Transfer home to die checklist

<table>
<thead>
<tr>
<th>Arrangements</th>
<th>Yes</th>
<th>No</th>
<th>Not applicable</th>
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<tbody>
<tr>
<td>Access to care in the community (including Macmillan nurses, community nurses)</td>
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<td>☐</td>
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<tr>
<td>Ambulance</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>DNAR</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Assessment of home environment</td>
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<td>☐</td>
<td>☐</td>
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<tr>
<td>Contact GP</td>
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<td>Backfill of staff</td>
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<tr>
<td>Medication</td>
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</tr>
<tr>
<td>Bed</td>
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<tr>
<td>Continence supplies</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Syringe driver</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Oxygen (for ventilated patients)</td>
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<table>
<thead>
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<td>☐</td>
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<tr>
<td>Expected death form</td>
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<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>ITU discharge letter to GP</td>
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<td>☐</td>
<td>☐</td>
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<tr>
<td>Rapid discharge forms</td>
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<td>Risk assessment</td>
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<td>Health and Safety</td>
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<tr>
<td>Insurance</td>
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<table>
<thead>
<tr>
<th>Communication:</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Patient and relatives informed about the risk of dying in the ambulance</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Ask relatives for permission to contact them several hours after arrival at home</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Transfer home to die from critical care

Stage 1:
Patient is clinically stable

Yes: stage 2

No: Transfer unlikely

Stage 2:
Patient has expressed a wish to go home to die

Yes: to stage 3

No: No transfer

Stage 3:
Family have the capacity to cope with patient going home to die

Yes: to stage 4

No: No transfer

Stage 3:
Family are supportive of patient going home to die
There is enough time to organise transfer
There is consensus across clinical teams

Stage 4:
Patient does not present with any of the following characteristics:
- Tissue donor
- Coroners case or have police involvement
- Family with complex issues that might prevent discharge
- Requires intense manual handling (e.g., morbid obesity)
- High gastrointestinal losses requiring intensive nursing care (e.g., profuse diarrhoea, high levels of wound exudate, intractable vomiting)
Appendix G

Transfer home to die from critical care

If the answer to any of these stages is "No" then transfer is unlikely

Stage 1
Patient is medically stable

Stage 2
Patient has expressed a wish to go home to die

Stage 3
Patient is in comfort measures (e.g. sedation, analgesia)

Stage 4
Family are supported by palliative care team

Stage 5
Patient does not present with any of the characteristics listed on the right

Transfer home to die is possible

Pre-transfer arrangements

Arrangements:
- Parent or carer in the community
- Ambulance
- Chain of command
- Assessment of home environment
- Contact plan

Pre-transfer organisation

- Form: DNR
- Document: Death certificate
- Equipment: Oxygen (for ventilated patients)
- Conference supplies
- Springfield

Communication:
- Patient and relative informed about the risk of transfer
- Refer to the home team
- Permission to transfer
- Relative notified
- Relative informed of the process

Pre-transfer contact options:
- Hospital Haematology Team
- Hospital Palliative Care Team
- Community Palliative Care Team
- Occupational Therapy
- Social Work
- Community Nursing

Post-transfer:
- Follow local policy for transfer of critically ill patients

Post-transfer follow-up:
- Communicate with community teams
- GP community nurse
- Debrief for staff
Appendix H

Clinical Guidance for Critical Care Staff on Transferring the Critically Ill Patient Home to Die

The right patient characteristics:
- Patient with mental capacity preserved and able to give informed consent
- Patients clinically stable for transfer
- The right time:
  - Synchronise to arrange transfer
  - Transfer planned during non-working hours
- The right circumstances:
  - Family supportive of the decision to transfer home
  - Patients clinical status supportive of transfer home to die

If transfer not possible then:
- Discuss end of life management plan with family
- Consider best place of care e.g. remain on ICU or alternate care setting

Consider:
- Patient/family issues:
  - Is patient/family realistic about care package at home?
  - Is patient/family aware of risk of dying during transfer?
  - Has healthcare staff been discussed with family/given consent?
- Intensive care issues:
  - Who will take the lead in the transfer arrangements?
  - How will the transfer team be arranged?
- Community issues:
  - What will happen at home?
  - Is care available at home?

Community needs:
- Will GP support transfer to a patient home?
- How will patient be supported by staff at home?
- Will any other support be provided?

Potential contact personnel:
- General Practitioner
- Community nursing services
- Social services
- Oxygen and respiratory support
- Carer support
- Medications and prescriptions

Equipment and supplies:
- Specialist beds and mattresses
- Oxygen and respiratory support
- Carer support
- Medications and prescriptions

Documentation:
- ICU discharge letter
- 24/7 contact number
- Expected death form
- Rapid discharge form

Stage 1: Assessing suitability for transfer home to die

Stage 2: Preparing for transfer

Stage 3: During the transfer

Stage 4: On arrival at home

Stage 5: Follow up after the transfer

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