

Stakeholder's views on the vision for the Academic Palliative Care Unit (APCU): A qualitative case study

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FINAL REPORT

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SECTION 1: BACKGROUND

1.1 Background

The Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUHT) has a comprehensive Academic Palliative and End of Life Care Department incorporating the Academic Hospital Specialist Palliative Care Team (AHSPCT), which includes consultants, doctors in training, clinical nurse specialists, volunteer support service and a complementary therapist. The AHSPCT helps patients with life limiting illnesses to manage their complex symptoms, such as pain, worries and concerns and provides support for their families. The AHSPCT sees a wide variety of patients with complex care needs; offering advice and support to other health care professionals across the hospital, as well as to the patients themselves and their families and friends. The growing need for specialist palliative care (SPC) support within the trust, along with the high number of patients with complex needs has prompted the service to consider how provision and access to SPC services can be improved.

To build upon the SPC provision in Liverpool, a 12-bedded inpatient Academic Palliative Care Unit (APCU) was allocated clinical space by the Trust Executive Team to be refurbished on the Royal Liverpool University Hospital (RLUH) site at the University Trust. The APCU will be the first UK academic unit that will incorporate a specific place of care within the hospital for those patients who have complex SPC needs (i.e. palliative care needs that cannot be met by the staff on other wards) and who require ongoing treatment within the acute hospital setting and was opened in January 2016.

Hospital Palliative Care Teams emerged in the 1970's with the creation of a Terminal Care Support Team at St Thomas' Hospital, London. As palliative care developed as a medical speciality there was a gradual increase in the number of hospitals with a dedicated team. Various models exist with some teams covering the community as well as hospital settings (Robbins 1998). Other models include dedicated palliative care units which have been particularly adopted in the United States, where they are founded on the belief that a speciality-level trained palliative medicine team working in the same location can best meet the needs of palliative care patients (Nathaniel et al 2014). Furthermore, it is argued an on-site unit enables patients to be easily transferred from other wards such as the intensive care unit (Grogan et al 2016). One of the key measure of the success of these units has been the increased symptom control (Eysayem et al 2004), patient satisfaction (Grogan 2004), as well as reported cost savings (Eysayem et al 2004, Nathaniel et al 2014, Smith et al 2003)

Within the United Kingdom, the Northumbria Healthcare NHS Foundation Trust has developed two in patient palliative care units which reported an average length of stay of 13 and 12 days for the two units (situated on two sites) with a death rate of around 50%. The units allow direct patient entry from the community, as well as internal transfers from within the hospital, are reported as having increased the profile of palliative care in the Trust, as well as suggesting it is a cost-effective model (Grogan et al 2016).

Although the model of an in-patient hospital specialist palliative care unit is not new (albeit rare in the UK), what is proposed is an Academic Palliative Care Unit, with a key focus on research and

education. This is a novel approach and draws upon developments in Germany and Australia of which representatives from both countries have been part of the advisory team for the development of the unit.

The Academic Palliative and End of Life Care Department currently sits within the Division of unscheduled care within a defined business unit model. The Academic Department drives the Trust Specialist Academic Palliative Care Service and the Trust End of Life Care (EoLC) Strategy. This encompasses all care given to patients who are approaching the end of their life including care in the last days and hours of life and bereavement support. This enables more patients to live and die in the place of their choice balancing the delivery of clinical best practice with robust measurement and investigation.

The Academic Palliative and End of Life Care Department incorporates:

- The Academic Hospital Specialist Palliative Care Team (AHSPCT) Advisory seven-day service and Out of Hours support
- The Academic Palliative Care Unit (APCU) 12 bedded In-patient unit
- The coordination of the Trust EoLC Strategic Programme including EoLC complaints and a Research and Innovation Reference Group
- The Specialist Palliative Care Bereavement Service
- The Care for the Dying Patient Volunteer Programme
- The Service Innovation and Improvement Division of the MCPCIL
- The Chaplaincy Service
- The Trust EoLC learning and teaching programme and EoLC Network Nurse Programme

The Key Strategic aims of the Department are:

Safe Care – To maintain safety and reduce the risk of harm, as we continue to transform palliative and end of life care delivery; and support the APCU to represent a hub of clinical excellence.

Caring – To deliver compassionate and compelling palliative and end of life care and enhance the patient and care experience, transforming organisational culture, to determine lasting improvements.

Responsive – To work with our patients and staff in designing solutions that truly transform the care we can provide. To reduce length of stay, to enable the patient to be cared for and die in the place of their choice.

Effective – To underpin care delivery with a robust research and development portfolio. All interventions should be based on robust evidence; however, where evidence is lacking or still emerging, the Department can take a lead role in developing reasoned decision making to determine best practice.

As this will be the first academic palliative care unit in the UK, it is important to capture the original vision of the academic unit from the perspective of key stakeholders who have had a direct role in its development and/or delivery. This study will form part of a larger project, centred on the development, evolution, and outcomes of the APCU. This report will only focus on the first phase of the study.

1.2 Research Aim

To explore the views of key stakeholders as to their vision of the APCU (pre-opening)

1.3 Objectives

1. Explore with key stakeholders (staff involved with the development of the APCU, pre-APCU) to capture the overall vision, purpose, and the anticipated benefits and challenges of the APCU.
2. Explore with members of the HSPCT (pre-APCU) to capture the overall vision, purpose, and the anticipated benefits and challenges of the APCU.

SECTION 2: STUDY DESIGN

2.1 Research Ethics and Approvals

All standard processes including recruitment, consent, confidentiality and storage of data were adhered to. The University of Liverpool Research Ethics Committee granted approval for the study to be undertaken (see Appendix A), with R&D approval from the Royal Liverpool and Broadgreen University Hospitals (RLBUHT) NHS Trust. Permission to use direct quotations was obtained and participants were advised that all identifying data would be removed during transcription.

All data storage adhered to EHU Data storage and Management Policy. All data is stored on the Edge Hill University (EHU) server and access limited to the research team. Interview recordings were destroyed at the end of the study; anonymised interview transcripts and electronic data, such as analysed material, will be kept securely for 5 years (as the approval was from the University of Liverpool who have a policy of 5 years) before being disposed of securely.

None of the stored material will contain any personal details that would breach participants' confidentiality or anonymity. Any personal details retained (e.g. on consent forms) will be held securely in accordance with the Data Protection Act (1998) and GCP guidance and separately from any other study materials (such as interview transcripts) in a locked cupboard accessible only by the research team.

2.2 Methodology

The overall study adopted a case study approach. This approach focuses around a clearly defined case or specific event, phenomenon or system, with the case being the APCU. The case study will focus on the development, evolution, and outcomes of the APCU. This method lends itself well to exploring the 'how', 'why' and 'what' questions, feeding into what constitutes an APCU model and what key components need to be in place to facilitate success. It also allowed the use of a variety of methods to investigate the phenomenon and allow future phases of the study to build an overall detailed case study that includes patient and family carer experiences (Stake 1995, Yin 2009). To meet the aim of the study in this phase, a qualitative approach was undertaken drawing upon a naturalistic interpretative design (Ritchie & Lewis 2003). This allowed us to gain an in-depth, rich, understanding of the participants' experiences and perceptions of the APCU (Robbins 1998, Polit & Beck 2009).

2.2.1 Sample and recruitment procedure

A purposive sampling approach was employed (Polit & Beck 2009), with specific inclusion criteria to meet the aims of the study that participants were either employed with the HSPCT or held a role within the Hospital that resulted in involvement with the development of the APCU.

All clinical members of the HSPC team and a list of key stakeholders (developed in consultation with the research team and the Marie Curie Palliative Care Institute directorate team) were identified; key stakeholders included hospital senior managers, specialist Palliative Care Directorate Senior Management Team and Care of the Dying Volunteers. An invitation was sent out to all potential participants by the HSPCT administrator and those who expressed an interest

were sent the project information sheet. For those who agreed, a convenient time was arranged for the focus group (HSPCT) and individual interviews (Key Stakeholders). 15 members of the HSPC team and 10 Stakeholders were invited to participate.

2.2.2 Data Collection

This phase of the study included two elements; firstly, one digitally recorded focus group comprising nine members of the HSPCT, to promote discussion and debate (Goodman & Evans 2010, Polit & Beck 2009). This lasted for approximately one hour and comprised a mixture of health care professional attached to the HSPCT including doctors, nurses and social workers. To ensure clarification of the main points and enhance the trustworthiness of the findings, a summary of the key issues raised in the focus group were identified at the end of the interview, as recommended for the running of focus groups (Goodman & Evans 2010). This allowed additional comments to be made by the respondents and can lead to the formation of tentative themes being developed.

The second element comprised digitally audio recorded semi structured telephone interviews with eight key stakeholders, lasting between 15 and 50 minutes. Telephone interviews were adopted for the study as they are widely used when researching with clinical professionals. All interviews were conducted by one researcher (BJ) who was external to the organisation and data collection took place between August 2015 and January 2016, prior to the APCU opening. Verbal consent was confirmed at the start of the interview.

2.3 Data Analysis

2.3.1 Process

Interviews were transcribed verbatim and a thematic approach adopted incorporating a number of stages to systematically organise, reduce, refine and ultimately analyse the data (Braun & Clarke 2006). During the transcribing stage all data were anonymised and all identifiable characteristics removed to preserve participants' anonymity.

All transcripts were read through in their entirety by three researchers independent to the organisation (BJ, OC, AC). Each transcript was read and re-read until a thorough understanding of the content was achieved and commonalities and differences amongst the accounts were identified as patterns, or themes, within the data (Green & Thorogood 2004). Categorisation of the data followed, whereby these early themes were formed into descriptive codes and the data defined and redefined ensuring all data were represented and subsequently reduced to provide support for the initial conclusions (Miles & Huberman 1994). To increase the rigour of the analytical phase and reduce the likelihood of introducing bias, coding was undertaken independently by the researchers before meeting together to compare and ultimately agree on the final descriptive codes (Saks & Allsop 2007). Consensus was then reached on the final coding frame, which was then applied across all transcripts to support the initial conclusions drawn from the data (Miles & Huberman 1994).

SECTION 3: RESULTS

3.1 Sample identifiers

Participants were assigned an ID code by the research team. Due to the small sample size and potentially identifying features of job roles the participants are only identified as being a member of the focus group or interview participant. Numbers were allocated according to the order in which interviews were conducted or when they first spoke for the focus group data. The quotations presented are best exemplars as illustrations.

3.2 Themes

Several key themes emerged including; the consultation in the establishment of the unit, the value of the unit in ensuring best care for the dying, the impact on potentially reducing hospital in-patient length of stay, the value of a dedicated environment, benefits for the organisation, research opportunities and potential challenges facing the unit and measures of success.

3.3 Establishing the unit

Most of the respondents had some level of involvement with the establishment of the unit. This ranged from attending or delivering briefing sessions, consultation regarding the design and for some of the managers, involvement with the staffing and recruitment. This was illustrated by a respondent who was part of the core development team:

“I think the, from the moment we had the idea, we’ve driven it as a core group within the organisation and within the institute to make this a reality, but we have had extensive discussions with various stakeholders in order to get to this point, so testing out the idea in terms of our community colleagues across the health economy, we’ve done some work with advancing quality, we ran workshops, we’ve spoken to community groups, relative

and carer, bereaved relatives we've shared it right through, just at the ideas stage, through the quality governance framework across the Trust to get some sense of other people's perspectives on this, what challenges they thought that this would bring"(Respondent 7)

A respondent who had been involved since the conception of the idea, referred to how a benchmarking exercise had been undertaken with similar units in Germany and Australia. This in addition provided valuable insights and lessons, facilitating the opportunity for future collaborative working.

3.4 Dedicated unit that will ensure best care

There was a general consensus across all respondents that the overarching focus for the APCU, was to ensure that patients with complex symptoms were to be managed by specialist staff and therefore ensure they receive best care. One respondent further expanded on the care stating:

"I would see it as a place where patients who are approaching the end of their life, whatever stage of that journey they're on up to dying, receive the best care that anybody could deliver based on evidence and research and expertise and skill and knowledge" (FG Respondent 1)

Furthermore, it was reported that currently it was challenging to ensure the provision of best end of life care due to them being located across the hospital and being managed by a variety of clinical teams:

"Providing the best possible care for patients who are at the end of life and meeting the needs of a population who currently aren't getting the best treatment and aren't being managed in the best environment" (Respondent 1)

With a need for input from a specialist team, one respondent went on to say:

“We felt for a long time that, you know, we could improve the quality of the care for those patients if they were in a, you know, central place with input by a specialised team- - I think the patient and the relative will have a better experience because there will be kind of trained staff there whose sole purpose in life is to make sure they’re comfortable and that the quality of care they get is of the very best” (Respondent 4)

This level of complex care, also referred to some patients who were too ill to be transferred to the hospice, one respondent stated:

“I think we have a group of patients that are actually too poorly to move to the hospice but they still need that environment where we can give that complex symptom management or psychological support to the patients and the families” (Respondent 5)

Additional to the physical care that the APCU can provide it was also reported that the unit will be able to provide psychological support as well as support for the family. Currently there are gaps in service provision, which the specialist palliative care team were widely aware of, one of the focus group respondents stated:

*“Psychological support needs, be it specific complex symptoms or family support needs, there's definitely, you know, a gap identified for a long period of time”
(FG Respondent 3)*

3.5 Impacting on shortening length of hospital stay

The provision of the APCU was seen to have the potential impact of reducing inpatient hospital length of stay. The dedicated unit was seen as having the expertise to get the symptoms under control faster, and therefore support a more timely discharge, but at the same time providing a better and specialist quality of care. One respondent commented:

“Patients where their end of life care specialist palliative care needs outweigh anything else, so any other interventions that they’re having in the acute hospital, their end of life care needs are paramount, get a patient to the place of their choice quicker and faster and get on top of their symptoms more quickly” (Respondent 7)

It was also noted that the perception was that care would be better quality, as well as supporting a more timely discharge:

“A better quality of care for patients who are at their end of life in hospital. Also, it would assist patients who wanted to get home, to get home in a much speedier way” (Respondent 3)

“So if they’re on the unit we can make sure they get to where they want to quicker and in a more kind of controlled manner” (Respondent 4)

Another respondent explained that delays were often caused by not having the correct management plan in place:

“Before –[APCU] often that management plan may have to be compromised because of the clinical situation the patient is being cared for--- We can reduce length of stay because we’re doing everything a lot more effectively and a lot more efficiently and

reducing the length of time that patients need to be in hospital to get them to their preferred place of care” (Respondent 5)

One respondent referred to delays in the treatment which the specialist palliative care team had advised for patients:

“Patients are dotted all over the hospital and you don’t really have a lot of control over what happens to them when you’re not with them. So, you might see them once a day, give your suggestions, leave, come back the next day and the suggestions haven’t been taken. So, we felt for a long time that, you know, we could improve the quality of the care for those patients if they were in a, you know, central place with input by a specialised team” (Respondent 4)

Furthermore, the importance of starting the discharge process a lot quicker and to be able to work with the team on the ward, was also noted with one respondent stating:

*“We can start looking at the discharge process a lot quicker and then we can work with the team on the ward to get them where they want to be, rather than delays”
(FG Respondent 7)*

3.6 Dedicated environment

There was an overwhelming consensus as to the value of the dedicated ward and how it had been suitably refurbished. The layout and the design, including a reception area rather than a nurse’s station, were all commented upon. The family and friends room was also noted as being valuable for the family as one respondent stated that this could allow the staff to look after the families:

“We've also got a family and friends room which - we'll hopefully be able to look after those relatives and friends of the patient in APCU” (FG Respondent 4)

The family room was also seen as beneficial for the patients so that they could use the opportunity to have some normality by sharing a meal with their family:

“Having the patient and relatives room where people can sit and have a meal together, where patients and relatives can go and sit and make themselves a drink, I think will, I think it will have a huge benefit for patients and relatives” (Respondent 1)

Additionally, the unit includes a ‘quiet room’ which was seen to be valuable space for staff to talk to families in private:

“--they've taken into consideration the families that they've got somewhere to sit, obviously they've got somewhere to talk to the staff” (Respondent 2)

The dedicated space for a family and friends room and a ‘quiet room”, was also the most widely reported potential challenge that the unit is likely to face. At the time of data collection the plan was for families of patients (who had been referred to the Specialist Palliative Care team) would also be allowed to use these facilities. This was a widely reported concern and although there would be the benefit for these families, it raised the issue as to whether they may wish for their family member to be on the unit as one participant stated:

“Well again, one of the problems with, you know, and I know there has been talk about the family room being open for use by the relatives of patients who are not on the unit,

and I think there is a real danger there that the relatives will come across, they might make themselves a cup of tea, use the shower and think, oh, why isn't my relative being cared for in this environment? And that's going to be quite a difficult challenge, I think. And I think it's going to be a daily challenge. And I think there are a number of reasons why people might not be moved, because they don't have specialist needs, because they need the support of whichever particular ward they are on that particular time. But I think that will be a problem and inevitably word will get out, because people talk and other staff will talk. I'm sure we will have people demanding their relatives be moved" (Respondent 1)

Conversely, one respondent commented how this could be seen as additional support:

"Yes I guess one of the challenges may be that they would like their loved one to be on our unit and not where they are. Although I have to say a lot of people being cared for in the hospital, particularly when people are dying, they are generally being cared for in a side room on a ward and the relatives often know the nurses and doctors on that ward and normally feel well supported there so I think at times it may be a challenge but at other times I think it will just be an additional support to the care we're giving to patients" (Respondent 6)

3.7 Benefits for the organisation

Another key potential benefit of the APCU was for the organisation. As well as the previously mentioned enhanced patient and family care, there is also the anticipated impact on the Trust staff and driving excellent care. This included:

"I think it will have an impact on the wider hospital. Because at the moment, I think, a lot of the teams within the hospital and a lot of the senior clinicians are very supportive of palliative care, but they see it as something fairly distant. So, something that happens

on the other side of the city in a hospice. They probably don't fully understand it. So I think it will have a benefit on a lot more staff, both at training grade and also the more established senior staff. In terms of actually physically getting them into a specialist palliative care unit. Because we will inevitably be asking their advice, we'll be calling on them to see patients on the unit. So I think that will be a real benefit" (Respondent 1)

This was further expanded upon with the potential for rotation of staff to get experience of the ethos, as well as the opportunity for education:

"It is an opportunity I think for us to use the unit for education purposes and to get everybody really to think about what their practice is around palliative care and how that can be strengthened" (Respondent 8)

"I think also we can use APCU to rotate staff from other clinical areas to demonstrate the ethos that we're working to and hopefully then that can be sort of shared back into their clinical area that they've come through" (Respondent 5)

Similarly, it was commented on the ethos of palliative care nursing that would be provided on the APCU, as being an opportunity for the wider hospital to reconnect with patient care. One respondent referred to how this included the basics of care and compassion stating:

"How nurses reconnect with the basics of care and compassion and patient centred care and you know maybe lessons for the rest of the hospital and other staff about you know how we can do that in other busy medical and surgical areas" (Respondent 8)

The value to the overall organisation and enhancement of care was also identified with one respondent looking ahead to the long term benefit of the unit:

“Demonstrate that the good care that we deliver you can deliver on any other ward in the hospital, so as a learning environment as a hub of clinical excellence that’s really alive and that we can move staff through, rotate staff to is really exciting and that’s a key driver for me” (Participant 7)

3.8 Research opportunities

The value of the unit in having the opportunities for undertaking research was reported in particular by participants who held more senior positions. This covered two facets: the opportunity for patients and their families to be part of research studies and the value to organisation including the links of the APCU to the University and resulting grant income.

3.8.1 Value for patients and families

Although patients and families who receiving the support of a palliative care service are deemed to be vulnerable and are often not included in studies, there is a growing awareness that in fact they find it valuable experience. One respondent commented that the APCU would provide the ideal opportunity for them to participate in research to be a valuable experience stating:

“We could hopefully give patients and their families more options to be part of research, and that will be quite heartening to them, I think, because they'd be doing it thinking that what they're doing - it gives people - it helps people - it gives some people a purpose of their disease and their condition at that time” (FG Respondent 2)

3.8.2 Research focus

The opportunity for the APCU to have a clear research focus, was reported by the majority of participants. One respondent noted how a dedicated unit would allow the collaborative partnership with the University to expand and drive the agenda:

“Because we haven’t had a cohort of in-patient beds in the past, where we can really commission and drive the research agenda, the research we’ve done via the university and the Institute has been a little more fragmented so this is a massive opportunity that the university is absolutely supportive of to really engage in some new and innovative research” (Participant 7)

Similarly, the unit being a part of a culture of research will help to drive palliative care research stating:

“--And I suppose that the whole culture of research is far stronger here within the university hospital than perhaps it is out there in the community or hospice setting. So I think that drives research and development but also for service innovation we’ll be at the forefront of what we will be doing in the unit” (Respondent 6)

This dedicated unit also includes the possibility of major trials and pharmacological studies as one respondent noted:

“It allows us access to governance and sponsorship which could then more easily extend to the hospice population. I think it would be, it’ll be a lot easier for us to do pharma (pharmacy) studies. We already have some discussion with pharmaceuticals about undertaking drug studies in the new unit and linked with the new unit” (Respondent 6)

Additionally the opportunity to undertake research around the novel staffing recruitment values based approach and the use of band 4 nurses on the unit were noted. Along with the

unit being seen as a test bed for service innovation and quality, showing the wider potential for the organisation.

3.9 Challenges facing the APCU

Due to the careful planning and a consultation exercise prior to the opening of the unit, the key challenges had been clearly identified. In the main they centred on the admissions criteria for the unit, the need for patient flow to maximise bed occupancy and the focus on getting the patient to their preferred place of care. The need for clear communication to patients and families regarding the focus of the APCU were all noted, as well as policies and procedures being established to address them. As previously reported, the remaining challenge was the access to the family and friends unit by families of patients (referred to the Specialist Palliative Care Team) located on other wards. The other challenge was how other health care professionals would perceive the unit, the fact it has dedicated staffing and had been refurbished when the new hospital was being built, were all referred to. One respondent stated how it was important to share the overarching message of what the unit was aiming to do:

“I think some of the challenges are more around how it will be seen by other health care professionals and ensuring that it is obvious to people that this is something different. That this is not a unit where we carry out advanced handholding. That it is actually trying to drive up the quality of care and this is how we are doing it” (Respondent 1)

3.10 Measures of Success

All participants were asked what they thought an indicator of success of the APCU would be and how could it be measured. This included:

- Adherence to the Trust Key performance Indicators (KPI) and dashboard reported outcomes, quality indicators
- Reduction in inpatient bed occupancy (financial benefit)
- Good bed occupancy and patient flow
- Reduced complaints (around end of life care)
- Enhanced symptom control
- Good patient and carer experience
- Research grants
- Publications
- The overarching success of driving up the overall hospital quality of care and patient and family experience

SECTION 4: DISCUSSION

4.1 The APCU

As the APCU is the first academic palliative care unit in the UK it was important to capture the original vision of the unit. The aim of this study was to explore key stakeholders vision of the APCU pre-opening to investigate their views, perspectives, potential challenges and proposed measures of the success of the APCU. Data were collected from members of the HSPCT, as well as key stakeholders who have had a direct role in its development. There was an overall consensus as to the vision for the APCU from all the respondents and clearly the planning and communication with staff was inclusive and important in identifying potential issues. This is highlighted as a valuable point and it is suggested that the planning team may wish to write a paper on the process to share with other hospitals that may plan to open a unit.

4.2 Overarching vision

The overarching vision of the APCU being a unit that would provide the best care for patients with complex symptoms was reported by all respondents. In particular, clinically based staff commented on how there were patients with complex symptoms who were not getting the best care and more so this was potentially impacting on them having a longer hospital in-patient stay due to delays in treatment. Psychological support and the care of the family were also reported as being something that could be enhanced by having a dedicated unit. This finding is in keeping with the literature on the value of hospital palliative care inpatient units (Robbins 1998).

4.3 Environment

All participants commented on the environment and the way the unit was refurbished, to maximise the space to provide the most comfortable area for patients and also their families. The provision of the family and friends room was seen to be beneficial and would contribute to the overall experience for patients and their families. However, this was also noted as being a potential challenge, with the plan (at the time of data collection), for the family and friends room to be used by families of patients referred to the HSPCT, but located in different wards. Clinical staff, in particular, were concerned that families who saw the APCU facilities, would be wanting their family member to be transferred to into the unit.

4.4 Organisational benefits

The theme of benefits to the organisation was also widely reported with participants feeling that having a hub of excellence would allow for staff to be rotated into the unit, for ongoing education to be provided and to enhance the role and value of the HSPCT. Both clinical staff and managers felt that the unit would help to 'drive up' care of the dying across the whole of the Trust, including one respondent suggesting that it could enable nurses to '*reconnect with the basics of care and compassion*'. The recent paper by Grigan et al (2016) has also suggested that their unit has raised the profile of palliative care in the hospital, although they do not provide evidence of how they can show this.

4.5 Academic unit

When exploring the vision around the 'academic' element to the APCU, there was a consensus of the importance of being able to undertake research in a dedicated unit, including clinical trials, models of staffing and innovation with the resulting contribution to the evidence base for end of life care. Additionally, the opportunity for patients to take part in studies was also reported.

Previously there had been the view that this group should not be involved in research studies due to them being a vulnerable group. However, there is an emerging support for palliative care patients and their families to be included in research studies, with the reported personal value for them (Germain et al 2015, Jack 2016).

4.6 Challenges

Clearly the careful planning of the APCU with an in-depth consultation exercise has helped to identify and address potential challenges. These include clear admissions criteria to ensure patient flow is maximised and ultimately making sure the patient reaches their preferred place of care when possible. The importance of the need to articulate the vision of the unit to the wider hospital and the issue of the family and friends room usage, are the two remaining challenges that were reported.

4.7 Recommendations

From undertaking this preliminary study it is clear that the careful planning appears to have been vital to articulate the vision. Measures of success are also suggested and the proposed list of secondary outcomes stated in the Cochrane systematic review protocol on *'The effectiveness and cost-effectiveness of inpatient specialist palliative care in acute hospitals for adults with advanced illness and their caregivers'* (Daveson et al 2015) are worthy of consideration for adoption. These include: quality of life, satisfaction with care, carer burden, economic costs including length of stay, investigations, medications etc as well as incremental cost effectiveness ratios etc.

4.8 Conclusion

This external review of the vision for the APCU prior to the opening of the unit has met the Research and Development objective in the academic strategy for the development of the APCU and provided a record of the vision and its overarching value for patients, families and the

organisation. The clear planning process has highlighted potential issues and in the main these were addressed pre-opening. Further research is clearly needed to firstly revisit stakeholders (or key people in post if staff have moved on), but also to include patients, families, the unit staff and the wider hospital staff to explore the impact, along with the outcome measures suggested by Daveson et al (2015). Funding applications to support this research is required and sources such as the Health Foundation are suggested.

Dame Cicely Saunders, the pioneer of the hospice movement in the UK, said "*You matter because you are you. And you matter until the end of your life. We will do all we can, not only to help you die peacefully but also to live until you die.*" The modern-day palliative care movement aims to help people realise a good death and is central to the core value of the APCU. This innovative unit, which has the opportunity for education and research, will help to drive forward the evidence base for palliative care and ensure that care provided to patients and their families is at the level of the best.

SECTION 5: LIMITATIONS OF THE STUDY AND RECOMMENDATIONS FOR FURTHER RESEARCH

5.1 Sample

The participants in the study only included clinical staff from the HSPCT and further research including participation from clinical staff from the wider hospital would be valuable. Furthermore, the selection of the stakeholders in a purposive sampling approach may have led to the omission of some of the senior hospital stakeholders. The inclusion of a wider sample is recommended for the further elements of the study along with including patients, family carers' views as well as recording quantitative outcome measures.

5.2 Strengths of the study

Strengths of the study are the inclusion of the Care of the Dying Volunteer as a participant, the data collection and analysis being undertaken by members of the research team who were external to the organisation. Finally, the data were all collected prior to the opening of the APCU which provides a valuable benchmark for the ongoing research.

SECTION 6: REFERENCES

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SECTION 7: APPENDICES

Appendix A : Briefing paper

Project Aim

To build on the specialist palliative care service provision in Liverpool to develop an Academic Palliative Care (APCU) 12 bedded In-patient Unit on the Royal Liverpool Hospital site at the University Trust that will then transition into the new Hospital build.

- To enhance patient and carer experience, patient choice and safety at the end of life and develop a specific appropriate environment for the support of patients and their relatives and carers.
- To reduce the length of stay whenever possible so as to allow return to home or other place of care for the most complex specialist palliative care patients.
- To drive up quality and promote productivity, partnership working and academic development of personnel by providing a hub of best end of life care practice to ensure focused high quality, effective, equitable specialist palliative care services.
- To deliver an enhanced local national and international reputation and profile of the Hospital as part of the leading integrated End of Life Care Programme within the Trust and MCPCIL Research and Development portfolio.

Clinical Rationale: The APCU will:

1. Ensure our patients and their relatives and carers are confident that our organisation can deliver good end of life care as part of the organisations core business within a sustainable health system, delivering a 7 day service in support of the existing 7 day face to face Consultancy Service.
2. Improve equity of access for patients and carers living in Central Liverpool where there is currently a gap in service provision and uptake of existing services.
3. Improve the quality of end of life care for our patients by improved coordination and management of complex patients who need inpatient care at the RLBH for diagnostics or interventions but whose primary need is specialist palliative care when time is crucial. Often multiple team engagement can fragment rather than augment care delivery.
4. Deliver an exceptional patient experience for our patient cohort by providing an environment that is more conducive to the care of patients at the end of life. Directly reducing length of stay, enabling patients to be cared for and die in the place of their choice, which is usually not the acute environment.
5. Ensure the workforce has the knowledge, skills and capability to ensure enhanced communication and shared decision making with our patient cohort. To enable generic clinicians to see and learn how excellent communication enhances patient well-being with supported practical hands on experience.
6. Demonstrate that we have responded and learned from concerns and complaints outlining poor experience and care by committing to best care at the end of life based on identified need and helping to create a positive lasting memory for those relatives and carers who will need to live on after a loved one has died.

7. Achieve national recognition for our research and innovation to drive up the quality of end of life care and clearly demonstrate in practice that we have responded to the national agenda and the recommendations for best care for the dying within the Francis Report and the recent Independent Neuberger Review; and to sustain and develop further the Innovative TRANSFORM Programme – DH Route to Success in Acute Hospitals.
8. Enable us to work with this patient cohort in a much more proactive manner to ensure they can participate in the research agenda. Whilst this will clearly attract research income into the organisation we will more importantly enable patients to participate in a research agenda that may not directly impact on their care but enables them to provide a lasting legacy to others who may benefit from this learning into the future.
9. Determine a focus for clinical excellence that can be emulated across other clinical teams that demonstrates compassion, empathy, kindness and dignity, not just because of what we do, but how that we do it.
10. Drive up quality and promote productivity, partnership working and academic development of personnel by providing a hub of best end of life care practice to ensure focused high quality, effective, equitable specialist palliative care services.
11. Work with other clinical partners across our international community to enhance the learning regarding best care at the end of life, to drive up clinical excellence, shape care delivery and enhance the patient and staff experience into the future.

Appendix B : Ethical Approval letter

(Original email on file)

DATED 24/7/15

Dear Dr Mason and Dr Reid,

I am pleased to inform you that your application for research ethics approval has been approved. Details and conditions of the approval can be found below.

Reference: RETH000872
Review type: Expedited review
Principal: Dr Stephen Mason
Investigator:
Co-Investigator: Dr Victoria Reid
Department: Marie Curie Palliative Care Institute
Title: An exploratory case study towards the development of an Academic Palliative Care Unit
First Reviewer: Dr Maria Flynn
Second Reviewer: Ms Carol Gray
Date of initial review: 14/07/2015
Date of Approval: 24/07/2015

The application was APPROVED subject to the following conditions:

Conditions

All serious adverse events must be reported to the Subcommittee within 24 hours of their occurrence, via the Research Integrity and Governance Officer (ethics@liv.ac.uk)

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Subcommittee should be notified. If it is proposed to make an amendment to the research, you should notify the Subcommittee by following the Notice of Amendment procedure. If the named PI / Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the Research Integrity and Governance Officer at ethics@liverpool.ac.uk in order to notify them of a change in PI / Supervisor.

Appendix C: Project Invitation Participation Invitation Email

An exploratory case study towards the development of an Academic Palliative Care Unit

Dear [recipient name]

My name is Dr Stephen Mason and I am the Chief Investigator for a project being conducted by the Marie Curie Palliative Care Institute Liverpool (MCPCIL). Ahead of the opening of the Academic Palliative Care Unit (APCU) within the Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUHT), this project will explore the overall vision, purpose and anticipated benefits and challenges of the APCU from key stakeholders directly involved in its development and/or delivery.

I am contacting you in your capacity as [job title] within the RLBUHT, to invite you to express an interest in participating in a [one to one interview/focus group discussion], in order to gain your views on the APCU prior to its opening. Please see the attached participant information leaflet for further information regarding this project, and for information on what will happen should you decide to take part. Please take time to read this information sheet, and if you do wish to express an interest to take part please complete the response form attached.

If you wish to discuss this project further, please don't hesitate to contact me using the contact details in the attached information sheet.

Kind regards

Dr Stephen Mason
Research & Development Lead
The Marie Curie Palliative Care Institute Liverpool
Cancer Research Centre
University of Liverpool
200 London Road
Liverpool L3 9TA
+44 (0)151 794 8876
stephen.mason@liverpool.ac.uk

Appendix D: Participant Information Sheet Focus Group

PARTICIPANT INFORMATION SHEET FOR FOCUS GROUP



1 Title of study

An exploratory case study towards the development of an Academic Palliative Care Unit.

2 Version Number and Date

Version 1.6, 17th July 2015

3 Invitation Paragraph

We would like to invite you consider participation in a research study. Before you decide whether to participate, it is important for you to understand why it is being done and what your participation will involve. Please take time to read the following information carefully and feel free to contact Dr Stephen Mason (Principal Investigator – details at the end of this information sheet) if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

4 What is the purpose of the study?

To build on the specialist palliative care (SPC) service provision in Liverpool, a 12-bedded inpatient Academic Palliative Care Unit (APCU) will be built on the Royal Liverpool University Hospital (RLUH) site at the University Trust, which will then transition into the new hospital build. The APCU will enable a suitable place of care for those patients who have complex SPC needs that require ongoing treatment within the acute hospital setting. Although there are existing SPC units within acute hospitals in the UK, this will be the first *academic* palliative care unit. This potentially creates a new and innovative model of care, which could be transferable and which others may wish to replicate. Therefore, it is important to capture the original vision of the academic unit from key stakeholders who have had a direct role in its development and/or delivery. Additionally, it is important to capture these views before the unit has actually opened (pre-APCU).

We are going to conduct a study to explore the overall vision, purpose and anticipated benefits and challenges of the APCU from key stakeholders pre-APCU. This study will form the initial phase of a larger research project that will focus on the development, evolution, and outcome of the APCU.

5 Why have I been chosen to take part?

You have been identified as a member of the HSPCT at the RLUH who will have a significant role in the operation of the APCU.

6 Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do wish to take part you will be given this information sheet to keep and will be asked to sign and date a consent form; a copy of which you will also keep. You will be allowed several days to consider whether you wish to participate. If you give your informed, written consent to take part you will be free to withdraw from the study at any time, without giving a reason. A decision to withdraw at any time or decision not to take part will not affect your involvement in the management of the APCU or any other element of your role within the RLUH.

7 What will happen if I take part?

You will be required to take part in a focus group discussion with other members of the HSPCT, which will be facilitated by one of our experienced researchers. The focus group will take place face to face at a mutually convenient time for all participants. It will be relatively informal discussion, which will focus on views and perceptions of the APCU. The focus group will last around 60 minutes and will be digitally recorded. Only the researchers and the person who transcribes the data will have access to these digital recordings. The recordings will be stored on the University of Liverpool password protected computer server and, once a transcription has been made and the content checked and verified, the digital recordings will be securely deleted. The electronic transcriptions will be stored on the University password protected computer server and kept for a period of 5 years after the end of the research study, when they will be securely deleted. None of the quotations used in any report or subsequent publication will identify you.

8 Expenses and / or payments

There will be no formal reimbursements available in this evaluation study.

9 Are there any risks in taking part?

We do not expect there to be any risks in taking part in this evaluation study. The general subject content is not unduly sensitive as it is focused specifically on perceptions regarding the development of an APCU.

10 Are there any benefits in taking part?

We do not expect there to be any direct benefits to you for taking part in this evaluation study. However, your input will contribute to the overall development of the service and in particular ensure that we:

- Understand the collective staff vision for the development of the APCU.
- Identify the keys components that need be in place to facilitate success.
- Determine what should be asked at subsequent interviews that will evolve from this initial phase of the study.

11 What if I am unhappy of if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting the Principal Investigator, Dr Stephen Mason (0151 794 8876, stephen.mason@liverpool.ac.uk) and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the

Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

12 Will my participation be kept confidential?

Yes. We will follow current ethical and legal practice and all information about you will be handled in confidence. However, we may need to breach confidentiality for any issues that may arise where we have a statutory duty to disclose. For example, if during the course of the focus group issues of malpractice, sub-optimal care or abuse are identified, the researcher will report the incident in line with risk and governance arrangements operating within your organisation.

All collected data will be anonymised and stored on a password-protected computer within the University of Liverpool. Access to the material will be restricted to the interviewer, the person who transcribed the digital recording and the researchers. Whilst the digital recordings will be destroyed once the content has been transcribed and verified, all other data will be kept for 5 years after the end of the study on the University of Liverpool password protected computer server. None of the stored material will contain any details that would breach your confidentiality or anonymity.

13 What will happen to the results of the study?

All of the information that we collect will be brought together and analysed to help us to understand participants' perceptions of the APCU. This study will form the first phase of a larger project centered on the development of an APCU model. It will provide background data as well as providing a future comparative reference point. This study will help provide initial guidance about the key components needed to ensure the model of care was successful and enable further reflection and guidance for the future.

A research report will be produced for the MCPCIL. We also intend to publish the findings in peer-Reviewed journals and make presentations to national and international research conferences in order to make sure that the messages from this study are appropriately disseminated.

14 What will happen if I want to stop taking part?

You are free to withdraw at any time from the study without the need for explanation. Your responses up to the period of withdrawal may be used, if you are happy for this to be done. Otherwise you may request that they are destroyed and no further use will be made of them.

15 Who can I contact if I have further questions?

Please contact the Principal Investigator, Dr Stephen Mason if you have any further questions.

Dr Stephen R Mason
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200 London Road

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stephen.mason@liverpool.ac.uk

Appendix E: Participant Information Sheet Interviews



PARTICIPANT INFORMATION SHEET FOR INTERVIEWS

16 Title of study

An exploratory case study towards the development of an Academic Palliative Care Unit.

17 Version Number and Date

Version 1.7, 17th July 2015

18 Invitation Paragraph

We would like to invite you consider participation in a research study. Before you decide whether to participate, it is important for you to understand why it is being done and what your participation will involve. Please take time to read the following information carefully and feel free to contact Dr Stephen Mason (Principal Investigator – details at the end of this information sheet) if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

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We are going to conduct a study to explore the overall vision, purpose and anticipated benefits and challenges of the APCU from key stakeholders pre-APCU. This study will form the initial phase of a larger research project that will focus on the development, evolution, and outcome of the APCU.

20 Why have I been chosen to take part?

You have been identified as a key stakeholder at the RLUH or the Marie Curie Palliative Care Institute Liverpool (MCPCIL) who has either had a direct involvement in the development of the APCU, or intend to have a significant role in its operation.

21 Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do wish to take part you will be given this information sheet to keep and will be asked to sign and date a consent form; a copy of which you will also keep. You will be allowed several days to consider whether you wish to participate. If you give your informed, written consent to take part you will be free to withdraw from the study at any time, without giving a reason. A decision to withdraw at any time, or decision not to take part will not affect your involvement in the management of the APCU or any other element of your role within the RLUH.

22 What will happen if I take part?

You will be required to take part in an interview facilitated by one of our experienced researchers. The interview will take place over the telephone or face to face at a time that is suitable to you. It will be an informal interview, which will focus on your views and perceptions of the APCU. The interview will last no longer than 60 minutes and will be digitally recorded. Only the researchers and the person who transcribes the data will have access to these digital recordings. The recordings will be stored on the University of Liverpool password protected computer server and, once a transcription has been made and the content checked and verified, the digital recordings will be securely deleted. The electronic transcriptions will be stored on the University password protected computer server and kept for a period of 5 years after the end of the research study, when they will be securely deleted. None of the quotations used in any report or subsequent publication will identify you.

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- Identify the key components that need to be in place to facilitate success.

- Determine what should be asked at subsequent interviews that will evolve from this initial phase of the study.

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All collected data will be anonymised and stored on a password-protected computer within the University of Liverpool. Access to the material will be restricted to the interviewer, the person who transcribed the digital recording and the researchers. Whilst the digital recordings will be destroyed once the content has been transcribed and verified, all other data will be kept for 5 years after the end of the study on the University of Liverpool password protected computer server. None of the stored material will contain any details that would breach your confidentiality or anonymity.

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29 What will happen if I want to stop taking part?

You are free to withdraw at any time from the study without the need for explanation. Your responses up to the period of withdrawal may be used, if you are happy for this to be done. Otherwise you may request that they are destroyed and no further use will be made of them.

30 Who can I contact if I have further questions?

Please contact the Principal Investigator, Dr Stephen Mason if you have any further questions.

Dr Stephen R Mason
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Cancer Research Centre
University of Liverpool
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Liverpool L3 9TA

Appendix F: Interview Guide



An exploratory case study towards the development of an Academic Palliative Care Unit

APPENDIX III: SUGGESTED TOPIC GUIDE FOR SEMI-STRUCTURED INTERVIEWS

The individual interviews will be very informal in nature, and the participant will be encouraged to take control of the discussions to ensure that the findings are participant led. However, the following prompts will be used as and when necessary:

Role of the participant

- *What is your role within this organisation?*

Origin

- *How did the idea for an 'Academic Palliative Care Unit' come about?*
- *At what stage(s) have you been involved?*
- *What were the key drivers to develop an APCU?*

Expectations

- *What will be the purpose of the APCU?*
- *What do you hope it will achieve?*
- *What types of patients do you expect to have on the wards (any criteria)?*
- *What is it that makes it an 'academic' unit rather than just a palliative care one?*
- *What are the anticipated challenges?*

Outcomes

- *What will a successful APCU look like?*
- *How will we know whether the APCU has been successful?*
- *What would help demonstrate this 'success' (data; documentation; other means)?*

Final Comments and Closure

