







## Recruitment in hospice research

that actively recruiting dying people to participate in research that could increase distress is both unethical and philosophically incompatible with the tenets of compassionate care (Payne, et al, 2013; Hanratty et al, 2012), although systematic review evidence suggests that these ethical concerns are often unjustified (Gysels et al, 2013).

Third, hospices may not fit neatly into the established governance procedures for health care research more generally. This is because hospices are often charitable organisations funded outside of the mainstream of health care funding. A lack of clarity over whether hospices are National Health Service (NHS) sites or not often leads to delays and difficulties in obtaining research ethics and governance approvals (Payne et al, 2013) and identifying who is responsible for granting such approvals.

Fourth, recruitment to end-of-life research is very resource intensive. Many hours of staff time can be required to recruit relatively few research participants (Gibbins, Reid et al, 2012; Hanratty et al, 2012) because of the rapidly changing health status of patients. For example, rates of attrition from randomised clinical trials for people with advanced cancer have been noted as ranging from 30- 72% (Campbell and Campbell, 2012). This can be due to failing health or death, and results in the need for larger sample sizes in order to achieve statistical power, increasing the resource requirements.

Fifth, many hospices, certainly in the UK setting in which this research was undertaken, are relatively new to taking part in, or developing ideas for, research. They may not have established governance processes for research or may be newly developing these. Their staff may be 'research naïve', having had little exposure either to the use or the conduct of research. This may hinder the understandings of clinicians, who may then be required to assist with recruitment, and thus reduce their confidence in and willingness to introduce research to their patients. When hospice staff become involved only late in the research design and planning, they may perceive that their patients are merely a recruiting ground for research teams. Therefore there is the potential for very unequal partnerships and miscommunication between hospice staff and the academic research teams who wish to study their patients.

Sixth, recruitment can also be challenging from a staff perspective. Whilst support for the clinical team members involved in palliative and hospice care has previously been identified as an important

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component of staff resilience (Harris, 2013), the emotional strain that can be experienced by staff who are involved directly in the recruitment of, or data collection from, participants in end-of-life research has only been noted recently (Kavanaugh and Campbell, 2014). Such strain can result from repeated exposure to challenging emotional and spiritual experiences through working with people who are quite unwell, many of whom die during the course of a study. These impacts may be felt even by those who do not have direct contact with research participants, such as those dealing with data entry or transcribing audiotaped interviews (Kavanaugh and Campbell, 2014).

Given these practical difficulties, this paper proposes a team approach to hospice research, akin to the notion of the multi-disciplinary team (MDT) approach to clinical care. A multidisciplinary approach involves drawing on multiple disciplines to redefine problems outside of disciplinary boundaries and reach solutions based on a new understanding of complex situations (Plsek and Greenhalgh, 2001). In health care, this is considered important to the development of patient-centred clinical decision making (NHS National Cancer Action Team, 2010). MDT or Multiagency working (as it is sometimes referred to) involves appropriately utilising knowledge, specialised skills and expert practice from multiple disciplines and across service provider boundaries, e.g. health, social care or voluntary and private sector providers. The members of the MDT are usually nursing and social care staff, who collaborate to make recommendations that can redefine, re-structure and reframe health and social care based on an improved collective understanding of complex patient needs (UK NHS England 2015). Multi-disciplinary clinical working is common in the hospice environment and the benefit for patients is that care recommendations from the MDT consider not only the physical, but also the psychosocial issues that contribute to meaningful care in advanced progressive illness (NHS National Cancer Action Team, 2010).

Promoted in the UK by NHS England (2015), the MDT should have three core development elements to work effectively: continuum (which describes the functioning, and progressive changes of the care team); common principles (for the team to adhere to together); and commissioning (of services for the MDT) (UK NHS England, 2015). One of the positive principles is the shared commitment to the objective of delivering person-centred coordinated care. This encourages leadership within a culture of collaboration, working within and across boundaries and along pathways based upon patient need

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(UK NHS England, 2015). Empowering all members of the team at every level is also considered vital.

Thus we propose the notion of a multi-disciplinary research team (MDRT) approach for the complex research area of the hospice environment. A cornerstone for the life of the MDRT is the focus on the development of a shared commitment to the research and to ensure that all voices are heard and valued, and each one contributes to research aims.

This paper applies the concept of a MDRT to a case study of recruitment to a research study within a hospice environment, showing how the MDRT worked at several system levels (Ferlie and Shortell, 2001) to overcome recruitment obstacles relating to political and governance factors, organisational factors and personal factors within and across teams. The paper aims to show how a MDRT approach to recruitment of patients in a research study collecting data from hospice patients, family members and health professionals drew on these ideas to successfully recruit the required number of patients. It explains the case study setting and research, and explores the nature of the MDRT, its ways of working and how it resolved recruitment problems within the study. It is hoped that this detailed reporting of such issues will be helpful to other novice collaborators attempting to conduct research in the hospice setting.

## THE CASE STUDY

**The case study setting.** The case study setting was a community-based voluntary-sector hospice in the United Kingdom. This hospice is part of a broader national organisation that has identified research as one of the components of its strategic plan. In 2010, a new post (for a full time research lead) was established within the hospice to support the development of a research-active culture.

The hospice provides care to people living in the community with advanced progressive illnesses, and their families. Care is provided by a community outreach team visiting people in their own homes, through a day-care centre ('day hospice'), or a 24-bed inpatient care unit (IPU). People remaining at home generally have physical and emotional symptoms that can be managed effectively with the support of a clinical nurse specialist, the general practitioner (GP), a district nurse, a community care assistant and volunteers. Day hospice patients may be receiving active treatment or palliative care at home. Day hospice services include clinical evaluation, treatment or therapies such as blood transfusions or intravenous medications and counseling provided by a member of the inter-professional team. People are admitted to the IPU periodically to receive care during a crisis or an uncontrollable deterioration in their symptoms, and for end-of-life care when death is near. People receiving these forms of care (care at home, day hospice or IPU) are at different points along the trajectory of a life-limiting illness, with multiple physical, cognitive and emotional issues. They also have a range of functional statuses from self-care in all activities of daily living (ADLS) to being confined to bed and needing help with all ADLS. Inevitably, this has an impact on the potential for patients to both provide informed consent to participate in research, and undertake tasks associated with the research. This is underlined by UK statistics that indicate that whilst people receive day hospice support for a mean of six months, and community care for a mean of 90 days, their stay in the inpatient unit averages just over 14 days, with 55% dying during their stay (National Council for Palliative Care [NCPC], 2014).

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To implement the research component of the strategic plan an academically trained non-clinical research lead was hired and had been in place for less than a year at the time that the research began. Key to the award of funding for this research lead was the ability of the hospice to demonstrate fertile early relationships with an interested academic lead within a local university. At this point, staff within the hospice had undertaken some small independent research projects, largely associated with completion of educational qualifications, but no external research teams had recruited from within the hospice. The hospice had not yet undertaken research in full partnership with a research organisation. It is the experience of partnership working within a MDRT, that provides the particular focus for this case study. The university-based research team included a health economist and comprised expert researchers in a variety of academic disciplines (palliative care, nursing, pharmacy, health economics and outcomes research), with varying experience in the conduct of end-of-life research.

### **A description of the research study**

The research study aimed to develop new frameworks for the economic evaluation of end of life care. Funded through the European Research Council, ‘EconEndLife’ comprises a number of separate work streams aimed at achieving different tasks. The work stream that comprised this element of the research focused on assessing the feasibility of completion of a new instrument for measuring the benefits of end of life care for use in economic evaluation, the ICECAP-SCM (ICE-CAP Supportive Care Measure) (Sutton and Coast, 2014). The measure focuses on the individual’s capabilities at the end of life in areas such as choice, love, support and preparation. It is a simple two page measure comprising seven items. Feasibility of completion was assessed for patients receiving care from the hospice and for those who might act as potential proxies (divided into two groups of those close to patients (close persons), and health professionals). Two other measures were assessed alongside: the ICECAP-A, a capability index for use in the entire adult population (Al-Janabi et al, 2013); and the EQ-5D-5L, a health related quality of life instrument for use in developing Quality-Adjusted Life-Years (QALYs) (Euro-QOL, 2014). Feasibility of completion was assessed using a cognitive interview technique known as think-a-loud (Ericsson and Simon 1980; Willis 2005) alongside a semi-structured interview. During the think-aloud part of the interview, participants were asked to verbalise their thoughts whilst completing the written questionnaires; during the semi-structured

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interview they were asked to discuss aspects of their completion of the measure. The aim of the research was to consider feasibility in patients at different stages in the trajectory towards death (Bailey, Kinghorn et al., 2016), and to that end, the initial recruitment plan included seeking participants from both the day hospice setting and the in-patient unit. (The planned sample size was related to achieving not only sufficient numbers for the analysis of the think-a-loud segments (previous think-a-louds with the ICECAP measures have included 20 (Horwood, Sutton and Coast, 2014) and 50 participants (Al-Janabi et al, 2013), but also for achieving data saturation when the semi-structured interviews related to the feasibility of completion are analysed (Walker, 2012). Given the three groups of interest, it was anticipated that interviews of up to 35 patients, 25 close persons and 25 healthcare professionals would be required.

Human Subjects Protections: The study was given favourable ethical approval from North Wales Research Ethics Committee - West (ref: 12/WA/0076).

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### APPLICATION OF THE MDRT APPROACH TO RECRUITMENT

#### **The structure of the multi-disciplinary research team (MDRT)**

The Multi-Disciplinary Research Team (MDRT) for this work stream comprised four elements or sub-teams: the hospice team, the university team, a wider project group and an external advisory group. The core research team comprised the hospice and university sub-teams. The hospice team included the hospice research lead (who facilitated research activities for the organization), the hospice research nurse (who had dedicated funded research time for one day per week during the period of recruitment) and those leading various clinical aspects of care (day hospice, in-patient unit, and community). The hospice nurse interacted with each of these, singularly or in combination. Because of the nature of the research, the university team mainly comprised health services researchers and economists; two had a background in economics and qualitative research, one a background in economics and pharmacy and one a background in nursing and qualitative research. The wider project group met monthly through structured telephone calls; in addition to members of the hospice and university teams, the wider group also included experts in palliative care research, valuation methods and economic evaluation. The external advisory group included all of these and independent experts in economics, statistics, palliative care research and ethics.

#### **The working of the MDRT**

Each member of the MDRT took one of five roles in achieving the overall aims of recruiting to, and conducting the research. There was a single ‘leader’ of the research, the PI from the University team, and a single ‘facilitator’ for the research, the hospice research lead. Other members of the research team took on one of three roles: ‘retriever’ (those whose focus was to collect data); ‘enabler’ (those who enabled access to patients); and ‘supporter’ (those who advised on recruitment and other issues based on their previous experience). Among the enablers, there was a mix of skill and experience in relation to research recruitment, ranging from the key enabler who co-ordinated recruitment, through to those who had a less frequent and direct relationship with the research, but whose willingness to engage when necessary was vital in ensuring recruitment. At the start of the research process the key

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interactions were between the research leader (PI from the University team) and the facilitator (the hospice research lead), with minimal involvement of the supporters. These interactions were critical in setting the tone for the conduct of the research and ensuring key research processes were in place. Subsequently, key interactions were primarily between the retrievers and the enablers, supported by the research leader (PI from the university team), the hospice research lead and supporters, as recruitment procedures moved from the planning stage to the action stage. When the research ran smoothly, interactions were limited to the retrievers and enablers; however, when there was some point of stress that was affecting recruitment, there was greater involvement of all members of the MDRT. The MDRT can thus be seen as being dynamic in nature, with shifting emphases across the life-cycle of the research. A diagrammatic structure for the MDRT is provided in figure 1.

### **A team approach to recruitment**

From the outset, the whole team was involved in recruitment, with extensive discussion between the hospice and university sub-teams about how best to approach patients, their close persons, and health professionals. The researcher team benefitted from working in partnership with clinicians, receiving early feedback on what was feasible and acceptable in practice.

Early drafts of recruitment procedures were circulated and discussed extensively among these two sub-teams and the wider project group. Only then was the final protocol agreed upon and subsequent paperwork for ethics and governance approvals developed and submitted. Advice was also solicited from the external ethics group on the issue of using a proxy to provide consent to participate and complete the forms on behalf of those who were not able to write or had difficulty communicating verbally. This resulted in an amendment to the ethics proposal for the research.

Prior to recruitment the research leader (University PI) and the facilitator (hospice research lead), guided a process to familiarize the hospice's staff and senior management (which supported governance within the hospice) on the underlying rationale for the work, the planned research and the specific recruitment procedures. Meetings were held with the day hospice and inpatient clinical team and the community nurse teams. Each of these meetings aimed to communicate information, and also to increase the interaction between the retrievers and enablers, enhancing trust and rapport. As

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the research progressed, there was increasing focus on empowering enablers by increasing their understanding of, and engagement in, research.

The recruitment procedures developed in collaboration between the hospice and university team members. The first step in recruiting eligible patients demanded communication between the key enabler, the hospice research nurse, and the hospice clinical leads. This was followed by interaction between the potential patient participant and the hospice research nurse. The hospice research nurse discussed the study with the patient, using an information guide, and asked the patient if they were willing to speak to a (university) researcher about taking part in the study. There was then communication between the hospice research nurse and a retriever from the university research team to let the retriever know that the patient was willing to speak with the university researcher. Finally, the potential participant was approached by the university researcher and, if they consented to participate, the interview was conducted. The interview was generally conducted within the hospice setting, and the research nurse and other hospice staff were on hand if the patient became distressed. Participation of close persons and health professionals was dependent on the patient consenting to their participation, so recruitment of these groups occurred only after patient recruitment. The hospice research nurse, in the role as key enabler, worked with senior staff in hospice teams who could identify potential research participants from the inpatient unit or the community.

Given the challenging and emotive subject matter of the research, both the physical and emotional safety of the research team were integral components of the study protocol. We developed a *lone* researcher protocol to ensure the physical safety of a team member who was doing fieldwork outside the hospice or university setting. This meant the researcher leaving details of locations of interviews in a sealed envelope with a named contact who would be contacted immediately on completion of the interview. If the researcher did not communicate with the contact within a defined period of time there were a series of escalating steps defined, culminating with alerting the police if the researcher did not communicate with the contact. Regular de-briefing was done to provide for the emotional well-being of the researchers involved in data collection.



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### *External factors with unexpected impact*

#### ***(i) Hospice relocation***

When recruitment that had initially looked promising dropped off in month four, the reason was clear: movement of the hospice from its initial location to a new one a short distance away. This shift in location resulted in a period of upheaval as staff had additional work associated with such a move and adjustment to the new environment (Perry, Orlando, Coast and Armour, 2013). Although the hospice move was a clear and unavoidable reason for low recruitment, it also effectively masked underlying problems around delays in recruitment, and resulted in a less speedy response than might otherwise have been the case. Ultimately, the hospice move also enhanced the research, providing much better facilities for the conduct of the research, such as the availability of private rooms in which to conduct interviews.

Whilst this specific occurrence is unlikely to affect other research studies, it illustrates the potential impact of unexpected large and external changes in the research environment.

#### ***(ii) Change in research personnel***

The second drop in recruitment was primarily related to a single factor: a change in personnel on the university research team. The departure of the first main researcher at the end of month 10 was followed by a short period with no researcher in post and then a delay as the new researcher had to build relationships with the hospice team and become accustomed to the methods of working within the MDRT. The change in personnel also occurred at the time when there was a shift in the focus of recruitment from the day hospice to the in-patient unit.

#### ***(iii) Overlapping research study***

A less severe impact on recruitment was also experienced when a separate qualitative interview-based research study commenced shortly after this study. Whilst some patients were eligible for both research studies, the hospice research nurse had to ensure that no patient or their family was overwhelmed by approaches for research. On two occasions, eligible potential participants could not be approached due to the conduct of this second study.

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***Difficulty engaging hospice staff in research***

The majority of hospice staff had very limited research experience. At the beginning of the data collection, many were unsure of the purpose of the research and its potential value. It took time for staff to feel comfortable with researchers being present in the clinical setting and to understand how the research process worked. This also affected recruitment as not all staff members prioritised the identification of potential research participants. Staff turnover within some areas of the hospice added to the difficulty of achieving patient engagement. Acceptance of the research was particularly challenging amongst those staff whose focus was caring for inpatients. Inpatients tended to be more unstable and unwell than those elsewhere in the hospice, and staff were more likely to take on the role of ‘gatekeepers’, acting to protect patients from what might be perceived as unnecessary activity.

***Difficulty in gaining physical access to parts of the hospice***

There were clear differences in the researchers’ physical accessibility to certain parts of the hospice. The majority of the hospice was quite accessible with an open floor plan. The hospice had a café, communal seating areas and daily activities that were readily available to all who wanted to participate. The inpatient unit (IPU) was where patients were admitted for intensive supportive care e.g. pain and symptom control, infections or following emergency admissions. Whilst the IPU was in the same hospice building, it was not visible from the main reception area and could only be accessed by authorisation from the hospice staff. The appearance of the IPU was much more clinical, akin to a hospital ward with single bedrooms and designated clinical areas designed to provide quality care for patients (Maben et al, 2015). Given the ‘secure’ appearance of the unit, it was perceived as less

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physically accessible. In addition, staff appeared to be very busy, and patients were located in individual rooms, behind doors that were often closed.

### **Solutions to recruitment challenges**

#### *Greater visibility of the researcher – spending more time in the hospice to become ‘part of the furniture’*

To reduce the time between initial patient contact and recruitment, and to enhance communication between the hospice and university teams, supporters from the external advisory group advised the university researcher to make specific efforts to be more visible within the hospice. The PI and the hospice research lead agreed, and subsequently the university researcher spent entire days based in the hospice, not in an office, but ‘around and about’, so as to become more familiar to patients, families and hospice staff. These days were co-ordinated with the hospice nurse’s ‘research days’ to enable greater co-ordination in recruitment between retriever and enabler.

#### *Increased communication between the hospice nurse and the researcher*

Those on the core research team also generated ideas to reduce delays in recruiting participants, working out an SMS text messaging system between the hospice and university teams. When a potential participant indicated that they were ready to meet with the university researcher, the hospice research nurse texted the researcher to alert her. This text did not contain any patient information but merely an alert to contact the hospice. The researcher then telephoned the hospice research nurse, received the contact information and made contact with the patient within 48 hours.

In the IPU, researchers learnt to be flexible with their time and responsive to the changes the patients were experiencing. Even when people were unwell at the time that the interview had been initially planned, as their condition improved they were often happy to participate later in the day following medication or rest. Again, communication between the researcher, care recipient and clinical staff was vital in ensuring safety, comfort and research integrity.

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### *Ongoing dialogue with potential participants as a means of reducing staff 'gatekeeping'*

One means of reassuring staff about the participation of their patients in the research was to have researcher team members share de-identified comments that previous participants had made about taking part in the research. This was done through informal feedback from the retrievers, key enabler and the facilitator, but the facilitator also used more formal means, such as including comments from participants on posters that were displayed in the hospice. In general, both staff and patients were more keen to be involved in the research once they had been informed about it and understood its purpose and the value it might have.

*If it helps other people, I'm prepared to do it, it's not going to do-do a lot for me I wouldn't think, well you never know but (laughing) if it can do something to help other people  
(Inpatient, pt35)*

Many of those who were initially reluctant about participation agreed to participate once they engaged with the research staff and built a rapport with them, often finding it a positive experience.

*It [taking part] doesn't upset me. Oh, no, no I don't mind who knows... It's a pleasure (Day hospice patient, pt26)*

*I'm only too pleased if one question helps one person, I'll be happy about that (Community patient, pt12)*

*I can tell everybody now, my brothers and everything [about taking part in university research], when they come up, they won't believe me (Community patient, pt21)*

Staff responded well to this positive feedback about the research, which increased their confidence in the research and further assisted in recruitment.

## **Learning from this case study – opportunities for action of the MDRT**

There were some key lessons from the case study that are likely to be helpful in taking forward this notion of the MDRT into other hospice research settings.

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1. Creating an environment where all team members feel empowered to communicate, to identify problems and work towards solutions.
2. Identifying key members of the MDRT early in the research process.
3. Having a clear and constant communication stream between core research team members and regular, structured meetings for the wider MDRT.

## Discussion

This paper has proposed the concept of engaging hospice staff in research through a multidisciplinary research team. Such teams comprise the clinical staff within the hospice alongside the research teams within academic settings. Whilst clinical researchers within hospitals are often familiar with this approach to research, it is much less familiar to nursing staff working in hospice environments. A detailed description of one case study in which the approach was used shows how the initial collaborative approaches were helpful in setting the right tone for the collaboration (particularly given the issues around patient vulnerability, staff concerns about recruitment and lack of research understanding outlined in the introduction), but also how, in any research study, there are unanticipated delays in recruitment. These may arise from the need to build communication, confidence and trust across the different elements of the team, as well as unexpected events in the life of an organization. The positive message is that, with a good initial structure and a willingness amongst all members of the team to learn from those with different expertise, these challenges can be overcome, to enable the conduct of successful research. One of the major recruitment problems experienced in this research related to the need for greater responsiveness in the recruitment of people near the end of life. Other research teams have also noted this need for urgency, with the rapidly deteriorating clinical status of people with end-stage conditions, requiring timely response (Fischer et al, 2012) and another research team noted the value of increasing the hours for which the research team was available (Gibbins, Reid et al, 2012). A system of open discussion and an acceptance that different team members bring different expertise, both clinically and in research terms, can enhance the speed with these changes are made in the research.

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This study has both strengths and limitations. It draws on a clinical concept (MDTs) but applies this to research, developing the concept of a MDRT. This is largely a conceptual notion, arising from the work that was conducted rather than having been generated a priori and then formally tested. It is not clear whether other groups are pursuing similar strategies even if they are not referred to quite in this way.

The paper rests on a single case study; nevertheless, the detailed descriptions and discussion can provide important insights to others embarking on such research about how to structure their collaborations and deal with emerging problems in an ongoing manner. Inevitably, the success of any MDRT will be dependent on both the general principles of the MDRT in relation to collaboration and openness and the specific individual members who comprise that team. It is our view that even with highly performing individuals, the collaboration, willingness to learn and inclusion of team members with differing skills, including clinical and nursing staff, is integral to research success, and that these MDRT principles are what contributes to a high functioning team.

Further research that more explicitly starts with the notion of a MDRT may be helpful in elaborating this concept. Other case studies that draw on teams made up from different academic disciplines and within different hospice settings may also be helpful. It is worth noting the important role of the hospice facilitator (hospice research lead) in drawing together the hospice and academic team members and engaging with governance issues, and it would be helpful to know whether this role is integral to the development of a successful MDRT in the hospice setting.

Hospice research is an expanding area, although still small in absolute terms. The James Lind Alliance (JLA) aims to raise awareness among health research funders about what matters to both patients and clinicians so that clinical research is relevant and beneficial to the end user. The JLA commissioned a scoping study to identify how clinical research organisations currently set research priorities and how patients and the public are involved (Oliver and Gray, 2006; Staley and Hanley, 2008). Across multiple healthcare settings, the study directors of the scoping study discovered several challenges to identifying research priorities, including a lack of agreement about best practice, resistance to developing a research strategy, and difficulties in managing expectations for the speed with which priorities can be addressed. In light of our study experience, their recommendations are





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31Sutton, E, Coast, J (2014) Development of a supportive care measure for economic evaluation of end-of-life care using qualitative methods *Palliat Med* 28(2): 151-157