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Transitions to palliative care for older people within acute hospitals

Chief investigator

Professor Christine Ingleton and
Professor Merryn Gott

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1. Summary

The UK Cancer Tsar has identified that 'a proportion of...dying patients receive very poor care' in hospitals. This is reflected in the fact that half of patient complaints to the NHS relate to the end of life. As 90% of people spend time in hospital in their final year of life and 56% of people die in hospital, this 'proportion' translates into a significant number of patients receiving poor care, most of whom are older.

The study will examine the potential to improve care for older people at the end of life by exploring need for, and provision of, palliative care at two hospitals in England. Using a method developed by one of the study applicants, a census will be carried out of all inpatients present in the hospitals during the two week study period. Medical and nursing staff will be asked to answer questions about each inpatient to help identify whether they have palliative care needs. For patients with palliative care needs, further questions will explore whether the patient's care incorporates a palliative element and whether this information has been transmitted to the patient. We will also explore whether the current hospital admission could have been prevented. Where possible, patients will be asked to complete a short questionnaire about their health to identify palliative care needs from their perspective. Interviews will then be conducted to explore these issues in more detail with patients and their families and professionals involved in planning and delivering services.

The proposal has been refined in the light of comments made by service users/research partners with experience of palliative and end of life care. Four service users will be invited to sit on the project steering group and be involved in all aspects of the study.

2. Aims/Objectives:

A recent World Health Organisation (WHO) report concluded that addressing the 'substandard care' older people receive at the end of life is a key public health concern (WHO, 2004). An area of particular policy priority is palliative care provision in acute NHS hospitals (Richards, 2007: 1), where 'a proportion of...dying patients receive very poor care'. As 90% of people spend time in hospital in their final year of life (Dixon et al, 2004) and

56% of all deaths occur in this setting (Gomes and Higginson, 2008), this 'proportion' translates into a significant number of patients receiving poor care, the vast majority of whom will be older people.

This proposal addresses this identified need to improve palliative care management within acute hospital through a study focusing on 'transitions'. Within this context, a transition is defined as a change in the approach to a patient's care from 'active treatment' (where the focus is on cure or chronic disease management) to 'palliative care' (where the focus is on maximising quality of life). Transitions in care may or may not be associated with a change of care setting. The transition will not be complete or unproblematic in all cases. Indeed, it is recommended that curative and palliative approaches to treatment are adopted concurrently (Ahmedzai and Walsh, 2000), particularly for older people (Jerant et al, 2004: 2) where adopting a transition late in the disease trajectory can lead to 'missed opportunities for palliation'. How this process is managed within acute hospitals, however, remains unknown. The extent to which a transition in care setting to the acute hospital corresponds with a transition in care approach is also unclear, although repeat hospitalisations have been identified as a trigger to moving to a palliative approach in certain conditions (<http://www.goldstandards%20framework.nhs.uk/>). This study will enable these 'unknowns' to be clarified and a model of best practice about managing transitions within this setting to be developed. Adopting a proactive approach to palliative care management through a managed transition in care may result in several tangible benefits for both patients and the wider NHS. These include facilitating patient involvement in advance care planning (where desired) and enabling a proactive care plan to be developed. Current practice in palliative care management in the UK is predicated upon the identification of a time when palliative care should begin (<http://www.goldstandards%20framework.nhs.uk/>). However, the acceptability of a palliative care transition to patients with conditions other than cancer remains unexplored within the context of UK acute hospitals, the setting where most people will die. There is evidence that many more people are dying in acute hospitals than would wish (Higginson, 2004). Not only does this result in people not having the death they would have chosen, but it also incurs significant unnecessary financial cost for the NHS. Health care costs are most significant in the last three years of life (Dixon et al, 2004), with high rates of hospitalisation.

A key aim of this study will be to examine the 'appropriateness' of inpatient admissions amongst people with palliative care needs using the *Appropriateness Evaluation Protocol Criteria*, a validated methodology recommended for use by PCT commissioners as a basis for service planning (DoH, 2006a). As the applicability of this protocol within a palliative care context has not been examined, findings from this study component will be reviewed by the two grant applicants who are Palliative Medicine Consultants. The value of the approach is that it enables the 'inevitability' of an admission to be determined within a particular health locality (for example, an admission may be 'appropriate', but not 'inevitable', i.e. it could have been prevented by additional community services; DoH, 2006a). Local cost data will be obtained and combined with the admissions data to estimate the scale of the economic impact of avoidable inpatient admissions. Information will be collected directly from patients with palliative care needs regarding their preferences for, and experiences of, transitions in place of care, such as admission to acute hospital, as well as their current use of health care resources. This would enable an economic case to be explored for expanding community services to reduce avoidable acute hospital admissions amongst people with palliative care needs which takes into account the views and preferences of older people themselves. The palliative care provision being explored within this study will primarily be 'general' palliative care, defined as 'palliative care provided by the patient and family's usual professional carers as a vital and integral part of their routine clinical care' (NCHPCS, 2001:1). This is because the vast majority of older people will not receive specialist palliative care, particularly if they are dying from conditions other than cancer (NCPC, 2007).

Research aim

To examine how transitions to a palliative care approach are managed and experienced in acute hospitals and to identify best practice from the perspective of older patients and key service providers and commissioners.

Research objectives

- 1) To explore the extent and current management of palliative care need within acute hospitals.
- 2) To identify patient factors predictive of key aspects of palliative care need and, in particular, physical and psychological symptom load.
- 3) To examine the circumstances under which transitions to a palliative care approach occur

within acute hospitals, with a particular focus upon the influence of age and disease type on decision-making.

- 4) To explore how decisions to move to a palliative care approach are made and who is involved in decision-making.
- 5) To examine if and how information about a transition to a palliative care approach is communicated to patients and their families and how they are involved in decision making.
- 6) To explore the perspectives of patients, service providers and commissioners regarding acute hospital admissions and discharges associated with a transition in care.
- 7) To identify those hospital admissions amongst people with palliative care needs that were avoidable but occurred because of a lack of alternative service provision or support in the community.
- 8) To identify patient factors predictive of avoidable hospital admissions
- 9) To quantify the cost of avoidable acute hospital admissions amongst those patients with palliative care needs.

Relevance to SDO call for proposals

This proposed work will address and build on a number of the recommendations arising from the SDO-commissioned scoping exercise which was undertaken to determine priorities for improving generalist end of life care for adults (Higginson et al, 2007). This review found that the majority of studies on generalist care at the end of life were concerned with service delivery organisational issues and health professionals' perspectives. Fewer were concerned with patients' experiences and the majority of studies were located in community settings; few were set in hospital. A central focus of this study will be to identify best practice for older people in managing the transition to palliative care within an acute hospital setting from their perspective. Higginson et al. 2007 advocate mixed method designs for research in palliative care and the use of case studies in this study will facilitate a good understanding of the context in order to see how the findings might apply elsewhere. Resource and health economic evaluation was identified as a cross-cutting theme and 'one that should be an important component of future commissioned research' (Higginson et al. 2007:2). A key aim of this study will be to measure economically the proportion of hospital patients with palliative care needs where the admissions can be termed 'avoidable' and identify where gaps in community services have resulted in acute hospital admissions. This proposal addresses the final question of the SDO research brief (REF: PCC198) theme B,

topic 4. We will examine the transition from "active treatment", aimed at cure or chronic disease management to palliative care in the context of two acute hospitals, the care setting that currently delivers end of life care for the majority of the population.

3. Background:

In the summer of 2008, the new End of Life Care strategy will be unveiled as part of Lord Darzi's review of the health service. It is clear from preliminary reviews at a regional level that identification of this activity within the NHS will require the ability to identify the point at which end of life care becomes appropriate. Policy is changing to allow health professionals to respond to patients needs and preferences in a more timely fashion than is customary at present. Any initiatives in the organization or delivery of clinical care will depend on a transition of care such as that which we intend to study. We have chosen the context of the acute hospital sector, the most common care setting for UK patients at the end of their lives.

Research in the UK has identified that older people are disadvantaged at the end-of-life, particularly if they are dying from chronic conditions other than cancer. However, there are still clear gaps in the evidence base to underpin improvements in service delivery and organisation in this area, despite improved palliative care for older people having been identified as a key challenge for the NHS (DoH, 2001; Philp, 2006). A recent review (Higginson et al, 2007) identifies that little is known about how general palliative care is, or should, be provided in acute hospitals, particularly from the perspective of patients dying from diseases other than cancer (who make up the majority of these patients and who are primarily older people). However, there is evidence that the extent of palliative care need amongst inpatients is high. A census of palliative care need in one acute hospital in Sheffield identified 23% of the 453 inpatients as having palliative care needs (according to a standard definition) by medical and/or nursing staff responsible for their care (Gott et al, 2001). Three quarters of these patients were over 60, with the greatest proportion aged between 81 and 90 years. Only 2% had received specialist palliative care input and any palliative care they were receiving was 'general' palliative care. Current palliative care policy and practice within acute NHS hospitals focuses primarily upon the period immediately prior to death. The Liverpool Care Pathway (LCP), promoted by the End of Life Care Programme for use on all acute hospital wards, is argued to be effective at changing practice (Ellershaw, 2007), but focuses exclusively on the 'last days of life'. However, as discussed in the

Introduction, it is increasingly being argued that attention needs to be paid to palliative care needs earlier in the disease trajectory (Ahmedzai and Walsh, 2000; NICE, 2006). Finally, providing care closer to home and preventing inappropriate hospital admissions is a current NHS priority (DoH, 2006b). This study will explore the extent to which it is in line with the views and preferences of older people with palliative care needs and will explore the economic impact of avoidable hospital admissions within an end of life context.

4. Methods:

a. Design

Plan of investigation

The research aims will be addressed through use of a case study design in two contrasting acute NHS hospitals in England. The case study will comprise the following stages:

- 1) Census of palliative care needs amongst inpatients at the two settings collecting information from patients, medical and nursing professionals working in primary and secondary care.
- 2) Case note review; medical notes of all consenting hospital inpatients will be examined to identify (and collect additional information about) patients with palliative care needs according to standardised criteria.
- 2) Interviews and focus groups with key health and social care professionals and service commissioners/planners.
- 3) Interviews with older people identified in the census as having palliative care needs on two occasions, six months apart; and
- 4) An on-going literature review conducted in conjunction with data collection to ensure the findings are interpreted within the context of best international evidence and policy guidance for palliative care management in acute hospitals.
- 5) Retrospective case note review: twelve months after the census, a retrospective case note review will be undertaken of all inpatients present in the hospital at the time of the census who have died in the 12 months following their hospital admission.

Rationale for study design

Organisational case studies have been found to offer pragmatic solutions to real-problems in palliative and end-of-life research (Payne et al, 2007; Ingleton, 2007). They are an appropriate design for examining processes and outcomes in dynamic healthcare

organisations, where it is important to obtain multiple perspectives, and are suitable for exploring practically and ethically complex situations where flexibility is desirable. Detailed insights from well constructed case studies also have an explanatory potential (Seale, 1999).

Selection of cases

The case studies selected for inclusion in this study are two acute NHS hospitals in England: Sheffield Northern General Hospital and Royal Lancaster Infirmary. These settings have been selected as they serve socio-demographically distinct populations. Royal Lancaster Infirmary serves a predominantly white Caucasian semi-rural / remote rural population. By contrast, Sheffield Northern General hospital services a largely urban, more economically disadvantaged and ethnically diverse area. There are 1,100 in-patient beds at the Northern General Hospital Sheffield and 550 beds at the Royal Lancaster Infirmary.

Methods (including the plan of analysis)

Exploratory focus groups to determine census methodology (n=8)

A review of the literature and discussions with clinical colleagues identified complexity and lack of concurrence regarding 'indicators' that a transition to palliative care has occurred in acute hospital settings. An initial list of indicators was drawn up, including: 1) any evidence of advance care planning (this may include consideration and/or completion of a DNAR form; 2) entry on a GP palliative care register; 3) referral to any palliative care service; 4) decision not to perform investigations or treatments aimed at cure because of QOL issues; 5) prescription of certain key drugs; and 6) decision to withhold or withdraw any treatment on grounds of futility. However, it is apparent that medical and nursing staff working in primary and secondary care are likely to identify additional/alternative indicators. Therefore, 8 preliminary focus groups (4 at each research site) will be held with medical and nursing staff to explore these issues. Half of these focus groups will be held with acute hospital staff and half with community staff. This preliminary research phase will enable an initial exploration of how transitions to palliative care are made and, crucially, what impact this has upon care and treatment. The exact indicators used in the census will be determined by this preliminary work (to be undertaken during the first 6 months of the project).

Census methods

Inpatients aged >18 years on all hospital wards during the two-week census period will be eligible for inclusion in the census. Although the focus of the study is on older adults, patients of all ages will be included to enable an exploration of the effect of age on palliative care need and management (DoH, 2001; Ahmed et al, 2004; Burt and Raine, 2006; Grande, Addington-Hall and Todd, 1998). A list of patients present on the ward will be obtained from the ward manager or designate. A member of medical and nursing staff most involved in day-to-day patient care will then be interviewed for each patient (expected to be the named nurse and the Foundation Training doctor). Previous work suggests an approximate achievable patient sample of 1,200 across both hospitals. Interviews will gather socio-demographic and diagnostic information, identify patient ability to consent to the study, examine self-assessed training needs regarding palliative care management and then explore professional perception of palliative care need according to multiple standardised criteria (Appendix B). The remaining questions will only be asked of patients with identified palliative care needs according to any of the one definitions used (Appendix B). However, during data analysis a more in-depth exploration of palliative care need will be made and decisions made on the ground that a patient did have palliative care needs may be over-ridden. Subsequent questioning will explore perceived appropriateness of the current admission, discharge plans, current approach to care (palliative/active or a mixture of both), whether prognosis and care approach have been discussed with the patient, resuscitation status, any psychological/spiritual assessment of patient and carer needs, and any referral to specialist palliative care. Additional indicators of a palliative care transition as identified during the preliminary focus group work will also be examined. All patients resident in the ward and identified as not having capacity issues by the medical/nursing staff will also be asked to complete the Sheffield Profile for Assessment and Referral to Care (SPARC) (Ahmed et al., 2004), and an 18-item service use questionnaire developed for use with a palliative care population (Gott et al, 2007). They will also be asked to indicate willingness to participate in a future interview. The word 'palliative' will not feature on any patient information (see ethical issues section). In order to include patients with dementia and cognitive impairment in the study, where ward staff identify patients are unable to consent, the patient's relative/friend/carer will be asked to complete the SPARC questionnaire on the patient's behalf. The exact process by which this occurs will be

discussed with an NHS ethics committee to ensure compliance with the MCA.

Brief telephone administered questionnaires will also be conducted with the GPs of patients identified in the survey as having palliative care needs (following approval to contact them from the patient). The view of the GP regarding the goal of treatment for the patient will be explored, as will whether the patient has been registered on a general practice end of life register in line with the Gold Standards Framework. In cases where the GP is unable to participate, for example due to time constraints, a primary care nurse (e.g. practice nurse, district nurse, community matron) will be approached in their place. The Practice Administrator will also be asked to inform the research team when patients participating in the study die (the Research Secretary will contact each Practice 3 months before the end of the study to ensure this information is complete).

Case Note Review

Medical notes will be reviewed for all consenting hospital inpatients during the 2 week census. Notes will be examined for evidence of palliative care need according to the Gold Standards Framework prognostic indicators (GSF, 2005). For those patients with identified palliative care needs, supplementary information will be gathered including number of hospital admissions, evidence of resuscitation status and evidence of an advanced decision to refuse treatment or lasting power of attorney for health and social care (MCA, 2005). Clinical information regarding the current admission will be considered in relation to the 'Appropriateness Evaluation Protocol Criteria' for hospital admission (DoH, 2006a). Final 'appropriateness' and 'inevitability' of the admission will be reviewed by the two grant applicants who are Palliative Medicine Consultants.

Retrospective case note review

Twelve months after the census has been undertaken, researchers will retrospectively identify census patients who have died in the preceding 12 months i.e. patients who died within 12 months of their hospital admission. Lists of inpatients obtained at the time of the census will be matched against hospital death records (from the medical records department) in order to identify those patients who have died. Reason for patient death will be examined in the first instance and patients who died an accidental death (i.e. road traffic accident) will be excluded. For the remaining patients, case notes will be examined and

information recorded concerning various aspects of their care (see retrospective case note proforma v1). Case notes will be obtained from medical records, where notes are kept for up to 4 years after patient discharge. Notes will be examined on hospital premises away from patient areas, by experienced clinical academics.

The census method is adapted from a study developed to survey palliative care needs in an acute hospital in Sheffield (Gott, Ahmedzai and Woods, 2001). In this research, a structured interview was conducted with ward nursing staff for 99% of inpatients (n=449) and medical staff for 81% of inpatients (n=367). In the proposed study, a similar method will be used as it elicited a very high response rate, high quality data, and has been identified as a template for studying palliative care need in acute hospitals (Boyd et al, 2006).

To ensure the census element of the study is effective, experienced health researchers with clinical experience will be required. They will comprise employees at the University of Sheffield with a PhD or equivalent experience in a relevant discipline who will be released from their usual duties for the data collection periods and additional training. Eleven researchers will support the existing project team to conduct the census in Sheffield, and approximately four in Lancaster (as bed numbers are lower). Training will be provided by grant applicants (JS and CI conducted the previous census; MG conducted and managed it), with input from our research partners.

Interviews (n=40) and focus groups (n=6) with key health and social care professionals and service commissioners/planners

Following initial analysis of the census data, individual interviews and focus groups will be conducted within each locality with service commissioners/planners and key health and social care providers involved in the care of older people and people with palliative care needs within the hospital setting and in the community. Current practice in palliative care management for older people within the locality will be explored, with a particular focus upon transitions to palliative care. The results of the census will be fed back to all interviewees as a trigger to applying a SWOT analysis (strengths, weaknesses, opportunities and threats) to develop a model for best practice.

Interviews with older people (n=40)

Approximately 20 patient interviews will be conducted at each research site. Purposive sampling of all patients who return a reply slip indicating willingness to participate in an individual interview will be utilised to ensure a diverse sample in terms of key characteristics (gender, age, diagnosis, family carer status). Interviews will focus on satisfaction with health and social care received and communication with health professionals regarding diagnosis and prognosis. Self-defined need for palliative care will be explored according to key patient centred factors underpinning Steinhauser's [1] multi-dimensional definition of palliative care (symptom management, support of autonomy and function, advance care planning and desired levels of participation in decision-making, patient satisfaction, patient-provider communication, quality of life, patient education and provider continuity).

Preferences for end-of-life care (including place of care) will be initiated where appropriate (Gott et al, 2007) and views of (current and best practice) in transitions to a palliative care approach explored, again if appropriate. Repeat interviews will be conducted at six months to look at changing experiences of, and preferences for, care (identified as a priority by Higginson et al, 2007). Where patients have died during this period, bereaved family carers will be invited to participate in an interview to explore the circumstances of death and their bereavement support needs (Gott et al, 2007).

b. Data analysis

Analysis of the qualitative data will adhere to the principles of grounded theory and follow the National Centre for Social Research 'Framework' approach, involving a structured process of 'sifting, charting and sorting material' according to key issues (Ritchie & Spencer, 1994). Recurring themes and concepts will be identified to make up a thematic framework or index which will then be systematically applied to the transcripts. Analyses will be conducted by the Research Fellow, together with two study applicants (MG and CI) who will work together to ensure data quality (for example, using double-coding and participant validation). Comparison of the findings from each case will then take place, to aid the process of identifying a transferable set of insights from the project. Quantitative data will be coded onto SPSS and analysed on the advice of a medical statistician with expertise in research with older people in a palliative care context (Chris Parker). Key multivariate analyses to be undertaken will include an identification of the main predictors of avoidable hospital admissions amongst patients with palliative care needs (including age, diagnosis, living arrangements etc) and the main predictors of physical and psychological symptom

load as measured by the POS.

Economic analysis

An experienced health economist who worked on the NICE guidelines for Cancer and Palliative Care will support this area of work (Sue Ward). This study will measure the proportion of hospital patients with palliative care needs where the admissions can be termed 'inappropriate' and identify where gaps in community services have resulted in 'inevitable' admissions using the *Appropriateness Evaluation Protocol Criteria* described above (DoH, 2006). The length of the hospital admission amongst patients with palliative care needs will be obtained by returning to the hospital at a later date; the exact mechanism to do this will be negotiated with the individual Trusts. The cost of an average inpatient day for palliative care patients will be obtained from the local institutions and used to estimate the scale of the economic impact of inappropriate inpatient admissions within this patient group. There is an urgent need to develop methodologies for the economic analysis of palliative care use (Higginson et al, 2007). A description of resource use will be built up using data gathered from patients in the Census. For those patients who participate in an individual interview, this will be explored in more detail and reviewed by Sue Ward (Health economist). She will explore the potential to use this information as a basis to economically cost resource use amongst palliative care patients. This exercise will inform the development of a further grant application to explore the economic aspects of resource use in palliative care.

5. Contribution to existing research:

This project will improve insights into the delivery of general palliative care in acute hospitals and will specifically identify suggestions for best practice for older patients in this context. This will comprise guidance on when and where discussions about palliative care should occur, by whom, with what information and how these decisions should be communicated. These elements have the potential to form a care pathway to fit alongside other organisation-wide strategies and practices on palliative care, including end of life care. Adopting a proactive approach to palliative care and facilitating appropriate transitions between active to palliative care is likely to result in several tangible benefits. First, patients and their families will be more engaged in

decisions affecting their healthcare, particularly those that surround withdrawal or withholding of burdensome treatments. This will contribute to the appropriate and effective use of healthcare resources. Second, decisions about place of care may be communicated earlier leading to greater chance of the patient being in a place of their choosing. This is likely to be at home or other community based facility and not within the acute hospital. The study will enable an economic case to be examined for moving a proportion of care for people with palliative care needs

out of the acute hospital and into the community, something which fits with wider NHS policy. Thirdly, communication of these decisions with primary healthcare teams will improve and enable better planning of future care by such teams, particularly at times of crisis when re-admission to hospital might be avoided. Fourthly, complaints brought by patients and families regarding lack of communication on management decisions, exposure to un-necessary treatments, and poor quality of death are likely to be reduced. Tailored reports of recommendations will also be provided to each research site which it is hoped will bring specific benefits to the NHS within these localities.

6. Plan of Investigation:

The project will run from January 2009 - December 2011. Ethical and research governance approval will be secured for the exploratory focus groups prior to the start of the project to save costs to the SDO. See Appendix A for a gantt chart of the study timetable.

7. Service users/public involvement:

At least two service users from each location (Sheffield and Lancaster) will be represented on the study steering group, drawn from the Cancer Experiences Collaborative research partner's forum, a collaborative group of academics, clinicians and service users from five UK Universities with expertise in supportive and palliative care research. A preliminary consultation with the CeCo research partner's group (Appendix C) identified that they did feel this was an important and worthwhile project with key ethical challenges (summarised below). One member of the group (who is in her 80s) has already agreed to sit on the project steering group. Key roles

for these individuals will include helping to train the census researchers, having input into

how patients are approached within the hospital, and designing the interview and focus group schedules. They will also be asked to comment on all study materials, as well as emergent findings. It is hoped they will participate in study dissemination.

On-going training and support will be provided to service user members of the research team. This will include appropriate research training and any other support they identify as appropriate and necessary. A highly experienced educator (Maddie Welton) with a clinical background in specialist palliative care practice and management and experience of working with service users in similar research projects will help facilitate these sessions. She will also provide psychological support to the service users, and any other members of the research team who feel they require it, in line with best practice in palliative and end of life care research. Those who plan, manage and deliver services will be included in the study through targeted interviews and focus groups. In addition, one representative from the Acute Trust and one from the PCT within each locality will be invited to sit on the project steering group.

8. Plans for dissemination of results

There are four main audiences to consider in disseminating the lessons learnt from this project: (1) The local health care trusts that participate in the project and the wider communities of policy makers and practitioners responsible for the governance and planning of local health and social care for those with palliative and end of life care needs, especially among older people. (2) Policy makers and practitioners at national level. (3) Academics. (4) The wider public. We propose to use a range of methods of dissemination to engage with these audiences, drawing on our networks of contacts including the NHS End of Life Care Programme, The Department of Health,

The National Council for Palliative Care, Help the Hospices, Help the Aged and other similar statutory and third sector organisations. Elements in our dissemination strategy will include:

(1) The preparation of a short summary of findings, including key recommendations for policy, practice and research, written in accessible language. (2) The development of a project website which will outline the project's aims and objectives and list details of publications and presentations arising from the research as they become available. (3) Presentations will be made by the applicants at relevant national and international conferences to professional and academic audiences. (4) Dissemination of findings via

publication in relevant professional, clinical and lay journals. (5) Mention of the study in invited seminars and lectures and teaching activities. (6) The preparation of a press release with the help of media experts based at the University of Sheffield. Applicants have considerable experience in managing media dissemination and conducting interviews on radio and television. (7) The publication of a leaflet summarising the main findings to disseminate to the general public.

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