

Study Protocol

Out-of-hours doctors' confidence when dealing with symptom control in palliative care patients

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1.0 Abstract:

Since the introduction of the new out-of-hours (OOH) provisions under the General Practitioner Contract in October 2004, care provision outside normal working hours has changed drastically and only a small percentage of the overall general practitioner workforce still works in this specific setting. The term 'out-of-hours' in the United Kingdom is defined as evenings, weekends from Friday evening to Monday morning, and public holidays. This reflects the working hours of many primary care and palliative care staff, although GP surgeries' opening hours vary within the working hours of 8 am and 6.30 pm.

By interviewing 10 General Practitioners who provide out-of-hours care for the Cardiff area, this project sets out to explore factors influencing their confidence in dealing with symptom control and palliative care provision outside regular working hours.

2.0 Introduction:

The evidence base on the topic of out-of-hours doctors providing care for palliative care patients in the community is scant. This study aims to focus specifically on general practitioners who work in the out-of-hours setting on a regular basis. Since the introduction of the new out-of-hours (OOH) provisions under the General Practitioner Contract in October 2004, this area of care has changed drastically and only a small percentage of the overall general practitioner workforce still works in this specific setting. We explore factors influencing confidence in dealing with symptom control and palliative care provision within this group of doctors.

3.0 Context:

3.1 General context:

It is estimated that patients with cancer spend 90% of their last year of life in their home and at least two-thirds of this falls within out-of-hours-time.^{1 2} The term 'out-of-hours' in the United Kingdom is defined as evenings, weekends from Friday evening to Monday morning, and public holidays. This reflects the working hours of many primary care and palliative care staff, although GP surgeries' opening hours vary within the working hours of 8 am and 6.30 pm.³

Centralised services including NHS Direct in England and Wales and NHS 24 in Scotland have presented a new framework providing 24-hour telephone advice, which acts as a point of access to out-of-hours services. The intention of this service is to offer advice and effective triage, in order to deliver appropriate care quickly and efficiently.⁴ Patients are now unlikely to receive care out-of-hours from their usual practice doctor. There has been a shift from out-of-hours care provided by local general practices and their co-operatives to more distant emergency clinics or telephone advice.⁵

The research question in the title lends itself to a qualitative design. It will hopefully provide valuable answers and insight into the interaction between doctors and palliative care patients out of normal working hours and may help identify perceived positive and negative influences on confidence in this group of doctors.

3.2 Current hot topic: national context

More than half the population want to die at home, but less than a fifth of deaths actually take place in the domiciliary setting.⁶ Lord Darzi, recently appointed Parliamentary Under-Secretary of State at the Department of Health, thinks the National Health Service should respond swiftly to these problems; increasing the options available locally to encourage more flexible opening hours for general practices is one of his priorities. In addition, end-of-life care will be one of the topics to be given detailed consideration by clinicians in working groups across England.⁷

A research summary from the National Institute for Health Research recently produced a report detailing research priorities in this area.⁸ One of the key areas, is defining and evaluating models of out-of-hours provision. The summary stated that research to understand more about factors affecting place of care and death, about the experience of dying, resource, support and care needs within the home, hospital, and care homes were priorities.

The National Health Service aims to empower, enable, train and support general practitioners, district and community nurses, and encourage them to work in conjunction with specialist palliative care services where necessary. Programs underpinning this policy include a £6 million Government investment in education and training for district nurses (DNs) in palliative care (at the time of writing no education and training program exists specifically aimed at out-of-hours doctors). End of Life Care Strategies in England have looked at uptake of three initiatives: the Gold Standards Framework (GSF see also Appendix 1), the Liverpool Care Pathway (England only see Appendix 2), and Preferred Place of Care plans to enhance the choice of dying at home if patients wish.⁹⁻¹⁵

These programs have come into effect during a time of change in the organization and delivery of primary care. The introduction of a new contract for NHS general practitioners (GPs) and the reconfiguration of out-of-hours services have altered the activities of GPs, and may affect their role in the provision of palliative care.^{16 17} It is not yet known how this has affected out-of-hours providers and whether general practitioners working in this setting feel supported and informed on aspects of care such as symptom management.

For GPs working day-time (in-hours), support patterns and their uptake can vary. Some GPs use specialist palliative care services only infrequently, whilst others use them as a resource (the most common model), or work with them as part of an extended team. A final group of GPs look to hand over care or responsibility completely to specialist services.¹⁸ These widely varying approaches have important implications for specialist providers who offer advice and support to primary care within their local area. They also have implications for out-of-hours providers in the primary care setting.

It will be interesting to bear the above in mind when this project starts, as perceived confidence-factors from the point of view of out-of-hours doctors could inform future strategy and needs assessments. Solutions to overcome potential difficulties could form a more detailed research project, for instance, piloting a scheme specifically for out-of-hours doctors and palliative care.

3.3 Local Context- existing services:

In the local context, Cardiff and South Wales' responsibility for health care was transferred in 2004 from GPs to local primary care organisations, providing unscheduled care services. There is an allocated out-of-hours care provider for every local health board. In Cardiff, this is covered by a private company called Serco <http://www.serco.co.uk/markets/health/community/index.asp>. Serco aims to work with the NHS to improve community-based health services. They provide out-of-hours GP services to more than one million people in Cardiff, Oxford and Cornwall handling calls from the public, running clinics and providing home visits to urgent cases.

Their telephone out-of-hours service itself is called "Connect 2 Cardiff" (C2C) which is also known as "Connect to Out of Hours Cardiff". This service is run in conjunction with Cardiff City Council and the Local Health Board.

In Cardiff, from 30 September 2004, the provision of out-of- hours General Practitioner services became the responsibility of Cardiff Local Health Board rather than that of individual GPs. The out-of-hours service operates between 6.30pm and 8.00 am during weekdays, and for the full 24 hour period on Saturday, Sunday and Bank Holidays.¹⁹

If Cardiff residents need immediate medical attention outside of normal surgery hours, and cannot wait until their practice is next open, they call their usual GP number. A recorded message will give them the phone number for the out-of-hours service. A registered nurse will then ring the patient back in respect of the most appropriate course of action. This action can include advice, self-medication or advising patients to see their own GP during normal surgery hours.

If patients need to be seen by a health care professional immediately, they will be advised to attend one of the two new out-of-hours primary care centres - based at Cardiff Royal Infirmary and University Hospital of Wales. The unit at Cardiff Royal Infirmary is the main primary care centre, and has been refurbished to provide a modern healthcare facility. Home visits are arranged if a patient is too unwell to attend one of the out-of-hours centres.

All patients who are asked to attend one of the out-of-hours centres are assessed face-to-face by a nurse on arrival, and referred to an appropriate health professional. Any immediate medication that is needed is dispensed to patients when they are seen.

If a patient contacts NHS Direct initially and requires input from the regional out-of-hours provider, then this is arranged via the local provider.

4.0 Background

4.1 General practice and palliative care provision

A qualitative study published in 2006³ explores the experiences and perceptions of out-of-hours care of patients with advanced cancer, and their informal and professional carers including their own General Practitioners, in Scotland. This study analyses interview data obtained from GP-cooperatives, where data was collected sequentially, between January 2002 and April 2003, before the introduction of NHS 24 in Scotland, and before the current out-of-hours arrangements as specified above.

Professionals expressed concern about delivering good palliative care within the constraints of a generic acute service, including inability to spend much time with this patient group and problems accessing other health and social care services. General Practitioners felt that improved communication between in-hours and the out-of-hours services, particularly provision of up-to-date information from daytime to out-of-hours services, was crucial for improving triage, decision making and continuity of care.

A further study looked at a recently introduced out-of-hours protocol for palliative care to the area of Calderdale and Kirklees, and found that the protocol had made a positive contribution to provision of care in the area.²⁰ In the study, GPs from different practices were asked about their experiences with a protocol for provision of palliative care outside normal hours. The consensus was that a protocol specifying areas such as provision of medication and information handover sheets, faxed from the patients' regular GP, was seen as very useful.

Both the abovementioned studies were conducted prior to the introduction of the new General Medical Services Contract, at a time when nearly all GPs worked in the out-of-hours setting, for example via local cooperatives. Now, comparatively, only a small percentage work outside normal working hours. The new General Medical Services contract has produced a very different, self-select group of doctors who work in this setting because they choose to, and who form a much smaller percentage of the General Practitioner workforce locally than used to be the case.

As a more general group, GPs are keen to learn more about palliative medicine and symptom control however when faced with increased difficulty in accessing information locally, this is associated with reduced confidence in symptom control.⁵

Palliative care patients who receive holistic support (i.e. incorporating different professionals for different approaches and involving family and friends in the process) in the community may be less likely to require admission to hospital, and often futile treatments at the end of their lives.²¹ Good support mechanisms, such as hospital at home services for patients nearing the end of their lives, are associated with improved

home care and reduced need to contact the out-of-hours services.²² Community palliative care is becoming more established with assessment tools such as the Gold Standards Framework²⁰ (Appendix 1). Doctors working in primary care have the potential as well as the ability to provide end of life care.^{23 24} The out-of-hours service should form an important part of this process, as it has to provide more hours of care each week than the in-hours services do.

4.2 What research has already been done on palliative care training for general practitioners and existing knowledge base

It is worth looking at research on palliative care education, knowledge base and accessibility of specialist services for General Practitioners as a group in general, as this could form an important factor influencing their perceived levels of confidence in symptom control. One of the main aims of specialist palliative care is to empower generic healthcare workers to care for dying patients; transfer of best practice from a hospice setting to other care settings, including for non-cancer patients, is a major challenge.²⁵

The UK General Medical Council (GMC) identifies palliative care and care of patients terminally ill, as one of the core content areas for undergraduate medical education.²⁶ Hallenbeck²⁷ argues that adequate training in palliative medicine should be a necessity, not a luxury, especially for generalists who get involved in treating the chronically ill, and that it must go well beyond what is taught in medical school and residency years. Conversely, available evidence suggests that senior physicians tend to overestimate their knowledge and competence on palliative care related matters.²⁸ Skeff in 1992 highlighted the inadequacy of palliative care training for general physicians.²⁹

A study of UK General Practice Registrars revealed they had mixed perceptions about their palliative care education and concluded that future educational packages should ensure that these trainees receive planned systematic training in bereavement care and some practical experience in the use of syringe drivers.³⁰

A survey of 399 Welsh GPs by Barclay et al found small, but significant deficiencies in palliative care training during the GP registrar year. Whereas 30% cited an absence of training in bereavement care, 20% reported no training in controlling non-pain symptoms, and 15% reported a lack of training in communication and pain control.³¹

Charlton et al studied 210 GP registrars in 1999 in the West Midlands, UK, to evaluate their self-perceived skills in palliative care. Perceived skill ratings were seen to increase throughout the GP registrar year in the absence of a specific course, but the anxiety about caring for the dying patient was not observed to decrease.³² This finding confirms Doyle's study 17 years earlier in the United Kingdom that vocational training in general practice has a positive impact on palliative care knowledge and skills.³³

A survey of 79 Exeter and East Devon qualified GPs in the south of England in 1993 revealed over a third had received no education relevant to palliative care in the previous 3 years. An analysis of the perceived difficulties of these GPs found a quarter either "frequently" or "always" had problems controlling

symptoms other than pain.³⁴

This is interesting in the context of some of these trainees likely forming the next generation of out-of-hours doctors, and GP-registrar training schemes generally require their trainees to work 72 hours in the setting during the training year, some of which may cover palliative care patients.

The out-of-hours primary care service covers nights, weekends and bank-holidays and is responsible for providing care for 75% of the hours in the week. Services are used to dealing with acute emergencies and, as such, often struggle to meet the medical, nursing, and social care needs of dying people and their families.²¹ The Gold Standards Framework aims to provide a regular stream of information between daytime primary care and the out of hours service.³⁵ In addition, one study indicates that areas that have GP-facilitators in palliative care appear to improve attitudes towards specialist palliative care services, with results suggesting increased satisfaction with out-of-hours services for patients.^{34 36}

Conversely, a postal survey in London sent out to GP practices found a distinct lack of local service knowledge; 65% of GPs were currently providing palliative care to patients on their practice list; 72% agreed or strongly agreed palliative care was a central part of their role. 27% wanted to hand care over to specialists. Most GPs (66%) disagreed with the statement that “palliative care is mainly district nursing work”. Many were unaware of out of hours district nurse and specialist palliative care services.³⁷ This survey was conducted before the new General Medical Services contract for general practitioners.

An analysis of calls to an out-of-hours palliative care advice line in Liverpool showed that advice requested was largely related to management of pain and the use of opiates, e.g. breakthrough dose of opiates and conversion of drugs to syringe drivers.³⁸

There is therefore, amongst general practitioners a very wide-ranging knowledgebase when it comes to palliative care; some have had training and are more confident, others are not. It would seem reasonable to assume the same for out-of-hours doctors, most of whom are GPs in their own right and often work in-hours as part time or even full GPs. Interviewing this group specifically will provide an evidence-base.

There are some unanswered questions here; for example, why do so many people tend to die in hospital and could the same level of care have been provided at home, with a good out-of-hours support service? Are out-of-hours doctors referring palliative care patients to an inpatient setting due to a lack of training and confidence in areas such as symptom control?

5.0 Aims

- Focus on doctors working in the out-of-hours setting and how confident they feel about symptom control for palliative patients in this setting
- Perceptions on what helps or hinders their confidence in palliative care; symptom management will be explored

- Aim to interview this self-select group of out-of-hours GPs, as ‘out-of-hours specialists’ in their own right

Whereas most studies on the topic focus on surveying general practitioners indiscriminately (at a time when most of them provided out-of-hours provision regularly), this would no longer appear appropriate today, as most GPs no longer work out-of-hours, and only a minority work these shifts on a regular basis. The proposed MSc project will focus on doctors working in the out-of-hours setting and how confident they feel about symptom control for palliative patients in this setting.

In particular, their perceptions on what helps or hinders their confidence in palliative care symptom management will be explored. The aim is to interview this self-select group of out-of-hours GPs, as ‘out-of-hours specialists’ in their own right and to analyse the data accordingly, compared to previous studies that interviewed and looked at GPs as a whole group.

6.0 Methodology

6.1 Initial Reflection and Preparation

In the interest of reflexivity, it is worth my explaining how I will fit into this process and what my background is. I am a Specialist Registrar in Palliative Medicine in my second year and entered the specialty via General Practice training, which I undertook in Gwent, a county in South Wales, UK. As part of this training I fulfilled 72 hours of out-of-hours work in the Gwent area. I therefore bring some experience of the setting and have seen palliative care patients at night and at weekends. This is why I have an interest in this field.

The purpose of this MSc is to find out if out-of-hours doctors perceive themselves as confident in symptom control in palliative care and what factors influence this. To prepare this project I have done some general, wider reading on the topic of qualitative research and have had a discussion with my project tutor. Having been involved in General Practice out-of-hours provisions brings advantages and disadvantages; it will introduce some form of bias and in fact, some of the GPs locally may know me and remember me. It will, however, also give me an insider perspective, which would be difficult to achieve for a researcher who has never worked in General Practice.

To this effect I have looked at interpretative phenomenological analysis (IPA) as a process that specifically looks at individuals experiences of specific events and what meaning and context this has for them. Personal experience is explored in depth via interviews rather than trying to objectify an event or experience. But IPA also puts an emphasis on the researcher and his potential prior experience, not so much as a potential bias but as an aid to interpret and see things from an insider perspective.³⁹

Access both depends on and is made more complicated by the fact that I have my own experiences and conceptions in the field of General Practice, out-of-hours work and also specialist palliative medicine. It will, according to Smith and Osborn,³⁹ create a two stage interpretation process (a double hermeneutic process): the participants are

trying to make sense of their world, whilst I, the researcher am trying to make sense of them trying to make sense of *their world*.

6.2 Study Design:

Semi structured taped interviews with General Practitioners working for the Cardiff out-of-hours service provided by “Connect2Cardiff”.

6.3 Recruitment

- Connect2Cardiff and Cardiff Local Health Board will be approached and asked whether they agree for General Practitioners working for their out-of-hours-service to be interviewed
- General Practitioners will be invited in writing and verbally to participate in the study. To this purpose, they will receive a participant information sheet (**Appendix 3**) and requested to contact the principal investigator (PI) if they wish to take part.

6.4 Inclusion criteria

- General Practitioners who work in the out-of-hours service on a regular basis, ie at least two shifts a month
- General Practitioners should have worked in this setting for at least one year.

6.4 Exclusion criteria

- General Practice Registrars and Specialty Trainees will not be included

6.5 Interview procedure

Potential participants will be given study contact details, so that they can volunteer and/or seek further information. Interested volunteers will receive written (**Appendix 3**) and verbal information about the purpose of the study, methods, handling and outcome of data from the study as well as details regarding storage of information and its disposal. General Practitioners will be asked to give consent in writing (consent form in **Appendix 4**) to participate in the study once they have understood its purpose and methods and agreed to participate.

Taped interviews between the interviewer and participant will take place at a pre-agreed times and locations. Approximately thirty minutes will be allocated for interviews, but they are open-ended. Data on the interviewees work experience, as well as training and current positions will be obtained. During interviews, participants will be asked to reflect on their experiences with palliative care patients in the community and out-of-hours setting and to talk about symptom management in this context. Interview will be lead by the interviewer using several pre-defined sentences which will act as prompts.

7.0 Data analysis

Transcript data will be analysed in light of the research question and will be IPA. The process will be started without a pre-defined hypothesis in mind, as advised by Silverman in his book "Doing Qualitative Research".⁴⁰ Following interviews, tapes will be transcribed by the principal investigator and/or secretarial staff. Each transcript will receive a code number and any identifying key data will be removed to keep participants and their subject matter anonymous. On reading transcripts, concepts and commonalities will be highlighted and categorized. A specific system of coding will be used in order to group answers to prompts during the interviews. The emergent themes and the research question will form the basis of the coding strategy.

8.0 Data storage

Transcribed data will be coded for anonymity. Names and addresses will not appear on transcripts. Transcriptions will be kept on secure, password-protected file on the principal investigators work computer at Velindre Hospital in Cardiff. This computer is located within the principal investigator's own office, which is locked when he is not using it.

Transcribed tapes will be destroyed immediately, and participants will therefore not be given a copy on request. They will be informed about this at the beginning of the study.

Consent forms will be stored in a lockable cupboard in the principal investigators office at Velindre Hospital.

9.0 Ethics

The principal investigator will undertake a Good Clinical Practice course in April 2008 and the study will be conducted in accordance with GCP guidance. The local risk review committee will be consulted. Local research ethics committee approval will be sought.

10.0 Adverse Events

No adverse events are anticipated arising from the proposed study. No therapeutic experimental interventions are taking place and there is no patient involvement.

11.0 Cost and Expenses

The principal investigator will transcribe data himself and will not require secretarial support for this. A tape recorder will be purchased, born out of the principal investigators own expenses. GPs participating in the study will receive a remuneration of £60 each.

12.0 Sponsor

Any projects that require Research & Development (R&D) and Ethics approval will need sponsorship. This usually applies when a project involves NHS staff, patients and/or relatives.

For the purpose of the MSc in Palliative Medicine, Cardiff University's Research and Commercial Division (RACD) has agreed to act as a sponsor for MSc students undertaking a research project as part of their MSc course. (see document "Guidance and Standard Operating Procedure"

http://cue.cf.ac.uk/webapps/portal/frameset.jsp?tab_id= 2_1&url=%2Fwebapps%2Fblackboard%2Fexecute%2Flauncher%3Ftype%3DCourse%26id%3D_80381_1%26url%3D_)

13.0 Timetable of events:

- Sept 2007-Nov 2007: Introductory MSc course and formulate a research question and research interests. Find a research project supervisor.
- Nov 2007-Feb 2008: Formulate a research proposal, including background, local/national context, relevance and aims. Incl. some methodology. Meet with supervisor to discuss this. Keep working on draft. E-mail versions to supervisor regularly for input. Get similar MSc for some guidance (Dr Helen Johnson's project)
- Feb 2008: second residential course (14th and 15th Feb). Get National Research Ethics account (NRES), download relevant qualitative study forms
- March/April 2008 : Write a risk review and submit to risk review people/board
- April 2008: Submit to Ethics. Submit to local NHS Research & Development management section for approval
- April/May 2008: GCP course for new staff
- May 2008-August 2008: Chapter plan
- August 2008-Dec 2008: Very provisional dates for data collection. Try to write up transcripts at the same time
- Dec2008- April 2009: Write-up, i.e. chapter drafts, one by one
- 30th Sept 2009: Deadline for MSc submission

14.0 Appendices

Appendix 1:

Gold Standards Framework and out of hours cover:

It is worth giving special mention to the Gold Standards Framework (GSF) here, as practices that institute it consider informing out-of-hours services of their palliative care patients a priority. GSF is a systematic evidence based approach to optimising the care for patients nearing the end of life in the community.^{13 41}

It was originally developed from within primary care for primary care by Dr Keri Thomas (a GP with a Special Interest in Palliative Care and NHS National Clinical lead for Generalist Palliative Care), supported by a multidisciplinary reference group of specialists and generalists, to improve palliative care provided in the community by the patient's usual health care team.

General Practitioners set up the Gold Standards Framework in their practices for their palliative care patients and follow seven sets of standards when implementing them:

‘communication’, ‘co-ordination’, ‘control of symptoms’, ‘continued learning’, ‘carer support’, ‘care in the dying phase’ and importantly for the context of this MSc ‘continuity including out of hours’. This means that ideally the general practitioner who sees palliative care patients ‘in-hours’, will supply the out-of-hours service with regular updates, for example via weekly faxes, or when there is a change in patients’ health status. Practices are thus encouraged to have a constantly updated register of their palliative care patients and are encouraged to hold regular meetings with specialist community palliative care patients. Areas that have taken up the Gold Standards Framework have had a positive response from general practitioners, although increased work-load was a concern for participating practices and GSF co-ordinators.⁴² Also of special note is the continued learning arm of this framework, which encourages education in palliative care related matters within practices.

Appendix 2:

Liverpool Care Pathway (England only):

The Liverpool Care Pathway for dying patients¹⁵ was developed to transfer the hospice model of care into other care settings including the community. It is not used in Wales, but interviewees who have worked for out of hours services in England may have seen it in use. It consists of a multiprofessional folder/document, providing a framework for the dying phase. Guidance is given on different aspects of care, including anticipatory prescribing of medication, comfort measures, and discontinuation of inappropriate interventions such as blood tests. Furthermore, the document provides guidance on psychological, spiritual and family support. In Wales, many healthcare professionals incl. GPs access advice on medications from the pallcare.info website

Appendix 3:

Participant information sheet

You are invited to take part in a research study. This leaflet explains what the study is about and what it will involve should you volunteer to take part. Please ask or write to the principal investigator if there is anything unclear or you have further questions.

Study Title

Out-of-hours doctors' confidence when dealing with symptom control in palliative care patients

What is the purpose of the study?

There has been a lot of press-coverage on the topic of out-of-hours care over the last years.

However, the evidence base on the topic of out-of-hours doctors providing care for palliative care patients in the community is scant. This study aims to focus specifically on general practitioners who work in the out-of-hours setting on a regular basis. Since the introduction of the new out-of-hours (OOH) provisions under the General Practitioner Contract in October 2004, this area of care has changed drastically and only a small percentage of the overall general practitioner workforce still works in this specific setting. We explore factors influencing confidence in dealing with symptom control and palliative care provision within this group of doctors. By interviewing 10 General Practitioners who provide out-of-hours care for the Cardiff area, this project sets out to explore factors influencing their confidence in dealing with symptom control and palliative care provision outside regular working hours.

The research study will be conducted during 2008 by Dr. Mark Taubert as part of an MSc in Palliative Medicine with Cardiff University. He works as a specialist registrar in palliative medicine at University Hospital of Wales, Heath Park, Cardiff.

Why have I been asked to participate?

You have been asked to take part because you work in the out-of-hours setting and have contact with palliative patients in the community, dealing with symptom control issues in this group of patients, for instance administering pain killers and adjusting the dose of syringe drivers.

Do I have to participate?

Absolutely not, this study relies on voluntary contribution. If you do take part you will be given this information leaflet to keep and will be given a consent form to sign. You will be free to change your mind at any point without giving a reason.

What will happen if I take part?

The research is in the form of an interview with Dr Mark Taubert, which is open-ended, but expected to last for about half an hour. Dr Taubert will arrange a time and location that is convenient to you. The interview will take place at Cardiff Royal Infirmary or at a location convenient to you. You will only be interviewed once.

The interview will be audio-tape-recorded and then transcribed by the researcher. Your name will not appear on the tape-recording or on any of the written transcripts. The transcripts will be used in conjunction with other interview transcripts

to gauge an understanding of out-of-hours GPs' confidence in palliative symptom control. Direct quotes from the interview might be included in the published study but it will not be possible to identify you from this or any other information. After the audio-recordings are transcribed the recordings will be destroyed.

Possible disadvantages and risks of taking part

The interview will take up to an hour or so of your time.

Discussing the topic of palliative medicine and palliative patient and their relatives can sometimes be emotional and upsetting.

Possible benefits of taking part

You will help in giving us more of an understanding of what out-of-hours doctors' needs are in this setting. There appear to have been no studies so far actually directly interviewing out-of-hours doctors and asking them how they feel about care-provision in this area. This study may help develop national policy in this area.

What if something goes wrong?

The interview can be stopped at any point if you wish to stop. If you want to complain, or have any concerns about the interview or interviewer or any aspect of the way you have been approached or treated during the study, the Cardiff University complaint mechanism is available to you.

Confidentiality

Any information collected will be anonymised. All information will be kept strictly confidential. The audio recordings and other information will be locked away and destroyed after interviews have been transcribed. It will not be possible for anyone to identify you from the written research. Cardiff Local Health Board and Serco are aware that this study is taking place and have given their consent.

What will happen to results?

The study will be written up as part of an MSc in Palliative Medicine by Mark Taubert and submitted to Cardiff University in September 2009. Results will be published in one or more learned medical journals and conference abstracts *(see Appendix) to inform a wider group of doctors.

Organisation/ Funding

The research is being organised by Dr Mark Taubert under the supervision of Dr Annmarie Nelson, a lead researcher at the Wales Clinical Trials Unit at University Hospital of Wales. The researcher will not be paid for carrying out the research.

Who has reviewed the study?

The local Cardiff Research Ethics Committee will be reviewing this study.

Contact for further information

If you would like further information or would like to participate in the study please contact:

Dr Mark Taubert
Department of Palliative Medicine
University Hospital of Wales Heath Park
Cardiff CF14 4YS

e-mail: mtaubert@ work: 02920 74 3 77

Thank you for reading this leaflet and considering taking part in this study. If you decide to take part you will keep a copy of this leaflet and a signed consent form for your own records.

Date:..... Version: 1

Appendix 4:

Consent Form:

Doctor identification number for this study: xxxxxxxxxxxxxxxxxxxxxxxx

Title of Project:

Out-of-hours doctors' confidence when dealing with symptom control in palliative care patients.

Name of Researcher: Dr. Mark Taubert

Please initial boxes below

- 1. I herewith confirm that I have read and understood the information sheet dated version for the above study and have had the opportunity to ask questions

- 2. I understand that participation is entirely voluntary and that I can withdraw at any time, without giving a reason and that this will not affect my work with Cardiff out-of-hours service.

- 3. I agree to the research interview being audio-tape-recorded.

- 4. I am willing to participate in a taped interview and understand that the tape will be destroyed after transcription. I am willing for anonymised data to be used for the purposes of publication in a peer reviewed journal or dissemination at a peer reviewed or educational medical meeting

- 5. I agree to take part in the above study

.....
Name of Participant

.....
Signature

.....
Date

.....
Researcher

.....
Signature

.....
Date

1 copy for participant

1 copy for researcher

Appendix 5 (added 2011):

Resulting Publications (i ii iii iv) 43-46

2011:

Taubert, M. 2011. Palliative Care provided by out-of-hours doctors - setting the scene and implementing an education programme. Presented at: BMJ International Forum Quality and Safety in Healthcare, Amsterdam, 05-08 April 2011.

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