**Introducing an electronic Palliative Care Summary (ePCS) in Scotland: patient, carer and professional perspectives**

**Mrs Susan Hall1**

*Project Researcher*

**Dr Peter Murchie1**

*Senior Clinical Lecturer and co-lead Scottish School of Primary Care Cancer Research Programme*

**Dr Christine Campbell2**

*Senior Research Fellow and co-lead Scottish School of Primary Care Cancer Research Programme*

**Prof Scott A Murray2**

*St Columba's Hospice Chair of Primary Palliative Care*

1. Centre for Academic Primary Care, University of Aberdeen, Foresterhill Health Centre, Westburn Road, Aberdeen AB25 2AY

2. Primary Palliative Care Research Group, Centre for Population Health Sciences, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG

**Correspondence to:**

Dr Peter Murchie

Telephone: 01224 437222

Fax: 01224 437285

Email: p.murchie@abdn.ac.uk

**Contributors**

PM, CC, PK and SAM designed the study. SH conducted the interviews. SH, PM, CC and SAM analyzed the data and wrote the manuscript.

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**ABSTRACT**

**Background:** An electronic Palliative Care Summary (ePCS) is currently being implemented throughout Scotland to provide out of hours (OOH) staff with up to date summaries of medical history, patient understanding and wishes, medications, and decisions regarding treatment of patients requiring palliative care: automatic twice daily updates of information from GP records to a central electronic repository are available to OOH services.

**Aims:** To identify key issues related to the introduction of ePCS from primary care and OOH staff, to identify facilitators and barriers to their use, to explore the experiences of patients and carers, and to make recommendations for improvements.

**Methods:** Twenty-two semi-structured interviews were carried out with a purposive sample of health professionals (practice nurses (3 interviews) GPs (12 interviews), a practice manager (1 interview) from practices using different computing software systems; and patients and/or carers (6 interviews for whom an ePCS had been completed. Interviews were digitally recorded, transcribed, and analysed thematically.

**Results:** Patients and carers were reassured that OOH staff were informed about their current circumstances. OOH staff considered the ePCS allowed them to be better informed in decision– making and in carrying out home visits. GPs viewed the introduction of ePCSs to have benefits for in-hours structures of care including advance care planning. No interviewee expressed concern about confidentiality. Barriers raised related to the introduction of new technology including unfamiliarity with the process, limited time and IT skills.

**Conclusions:** The ePCS has clear potential to improve patient care although several implementation issues and technical problems require to be addressed first to enable this. GPs and community nurses should identify more patients with malignant and non-malignant illnesses for completion of the ePCS.

**Keywords**: Palliative care, continuity of care, communication, electronic health record, qualitative research

**How this fits in**

An electronic Palliative Care Summary (ePCS) is being introduced throughout all practices in Scotland

Patients and professionals consider this a very useful initiative to help continuity of care, although the introduction of a new technology is challenging in some practices

Many patients who might benefit from an ePCS are not having it completed, as they are not being identified as “palliative”

All patients with advanced progressive illnesses could be identified, and their treatment plans communicated using the ePCS, modified for particular conditions, as it becomes increasingly available throughout Scotland.

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**Ethical Approval**

The opinion of the Lothian and North of Scotland Research Ethics Committees was sought. Both committees decided that the project was a service evaluation and formal ethical approval was not required. The Universities of Aberdeen and Edinburgh acted as co-sponsors for the study.

**Competing Interest**

All authors declare that they have no conflict of interest to declare.

**INTRODUCTION**

General practitioners (GPs) and community nurses have an important role in the provision of high quality end of life care, and this strategic role is increasingly recognised [1]. Supporting multi-disciplinary primary care teams in delivering such care has been the focus of much recent research, policy initiative, and service innovation [2-3]. In particular, reorganisation of out-of-hours primary care services in the UK over the last decade has raised important issues regarding the delivery of integrated care for those with palliative and end-of-life care needs: we and others have highlighted concerns regarding continuity of care and optimal and timely information transfer to the relevant sectors of the health service, while ensuring patient confidentiality and care based on need, not diagnosis [4-6].

The use of health information technology (IT) in quality improvement initiatives is widespread in the UK National Health Service [7] and internationally [8, 9]. There is a growing body of evidence documenting the positive impact of technologies such as electronic medical records, specialised decision support, and computerised prompts in chronic illness management, despite a number of identified barriers such as costs, concerns regarding privacy and data security, and workload implications [10]. The use of IT in supporting primary care in the provision of palliative and end of life care is more recent, and provides both exciting opportunities and some specific challenges in ensuring high quality end of life care to patients and their families [11].

The Scottish Government’s publication Living and Dying Well: A national action plan for palliative and end of life care in Scotland states that Community Health Partnerships (CHPs) and palliative care networks should encourage GP practices to make full use of the upgraded IT systems available to support patients to die at home should that be appropriate. This should include GPs using upgraded IT system to record patients' palliative care needs, plan review dates and assist multi-disciplinary team meetings, and sharing summary information with Out Of Hours (OOH) services and NHS 24 (equivalent to NHS Direct in England). [11] Electronic Palliative Care Summaries (ePCS) have been developed to utilise the upgraded IT systems to improve on the existing basic Emergency Care Summary (ECS), and it allows electronic rather than fax transmission to NHS24 of details of palliative care patients. The ePCS is an electronic template embedded within existing primary care electronic patient record systems. The ePCS template collects detailed information on a patient’s current diagnosis, their medical history, their current medication, their wishes with respect to the management of their illness and information on their wishes regarding resuscitation. It is designed to be paper-free with patient information being uploaded in the practice by GPs and Nurses onto their practice software system initially. Subsequently, any changes to the information can be made manually, or in the case of medications the update is automatic, and GPs receive on-screen prompts to review the information at regular intervals [12, 13]. The ePCS allows, with patient/carer consent, automatic twice-daily updates of information from computerised GP records to a central store, from where they will be made available to Out of Hours (OOH) services, NHS 24, Acute Receiving Units, Accident and Emergency (A&E) Departments and shortly to the Scottish Ambulance Service [12, 13]. This allows vital, structured information on vulnerable patients to be available both in routine surgery time, and OOH. The aspirations underpinning the ePCS are consistent with the 2010 Healthcare Quality Strategy for Scotland that seeks to support clear collaboration and communication between patients, carers and health professionals, and to promote continuity of care and clinical excellence [14]: similar initiatives for palliative care patients have been introduced in England [15]. The ePCS was piloted in 2009 within the Lothian and Grampian healthboard areas of Scotland. These areas have a combined population of approximately 1.3 million, around 25% of the Scottish population. The ePCS is now being implemented Scotland-wide.

In this paper we present the views and experiences of sixteen primary care and out-of-hour health care professionals, and 6 patients and carers, obtained when the electronic Palliative Care Summary (ePCS) was being used in two early implementer Scottish regions: Grampian and Lothian. These regions are contrasting with Lothian having a mostly urban population as opposed to Grampian which has a mixed urban and rural population. The sample was purposively selected to ensure a spread of gender, age, professional role, urban or rural setting and socioeconomic factors, likely to reflect the people and places in which ePCS implementation is proposed.

**METHODS**

***Setting***

The ePCS was implemted from 2009 in general practices using EMIS, VISION or GPASS in Grampian and Lothian in Scotland. The participants interviewed for this study were recruited from urban and rural practices in these areas.

***Participants***

This was a pragmatic qualitative study conducted with limited resources. We specifically aimed to capture representative views of key stakeholders to inform widescale implementation of ePCS. We did not aim to achieve data saturation and our purposive recruitment methods reflected this. Health professionals (three practice nurses, 12 GPs, one practice managers) were recruited by one of the authors Mrs Susan Hall (SH). SH was provided with a list of practices currently using ePCS. SH used the list to stratify practices by location (rural or urban), list size and number of GPs. Within practices she stratified the GPs according to gender and whether they worked in the out-of-hours service. SH then used this list to purposively recruit 12 GPs reflecting a representative spread of location, list size, gender and out-of-hours experience (table 1). Seven of the GP participants had experience of working both “in-hours” and in the NHS 24 OOH service. In order to capture some data on the perspectives of associate health professionals SH recruited three practice nurses and one practice manager for interview on the recommendation of GP participants. Since recipients were in a palliative care situation recruitment of a small number of recipients (patients and carers) proceeded sensitively and opportunistically. Potential recruits were approached initially by a GP participant to enquire whether they would consent to be interviewed and, if agreeable, identified to SH. SH subsequently contacted them by telephone by SH. Participants recruited by email and interviewed on the telephone recorded verbal consent, participants interviewed face to face signed consent forms.

***Data collection and analysis***

Interviews were semi-structured based on an interview schedule (figure 1-3), and were digitally recorded with consent, were arranged at the convenience of the participants and were conducted either face to face or on the telephone, again at the participants request. The method of interviews is indicated in Table 1. Data saturation was not predetermined but interviews with health professionals and continued until no new themes were emerging. A smaller number of carer and patient interview were conducted and data saturation was not determined in these recipient interviews. This is explained in the results. Interviews were then transcribed verbatim and analysed. Transcripts were read and re-read then coded using QSR NVivo7 to assist with sorting and retrieval of data. [16] A subset of transcripts were coded independently by two reviewers (PM and SH) to ensure inter-rater reliability. The data were then subject to first order analysis at a general descriptive level to explore issues raised through the interview schedules and any other emerging themes [17]. In second order analysis all transcripts and first order data were read by all of the authors. Subsequently the authors held a face to face meeting to interpret the data within the emergent themes. This enabled the different experiences and training of the researchers to inform the analysis.

**RESULTS**

22 semi-structured interviews were conducted with two patients, four carers and 16 health professionals (12 GPs (6 with OOH experience) 3 district nurses and a practice manager. 10 were conducted face to face and 12 by telephone. The characteristics of participants with respect to status (professional or carer), gender, geographical location and involvement in out of hours care are summarised in Table 1. Table 1 also indicates the awareness of ePCS and experience of OOH care amongst recipients. In the health professional group as a whole interviews continued until data-saturation was reached. In conducting interviews with patients and carers it became quickly apparent that they were largely unfamiliar with the technicalities of the ePCS. This is understandable but limited the value of these data for this purpose. Therefore a smaller number of recipient interviews were conducted and the limited data viewed in context with the responses from health professionals.

***Main Issues***

The introduction of ePCS was widely supported as a useful and feasible innovation, with applicability for a wide range of patients. Some general practitioners reported it had been easy to implement:

*“I’m very happy with it, I have lots of positives and I think it’s great for patient care when people use it properly and so far the kind of EMIS way has been very, very easy, very straightforward to use, very easy to do. I’ve nothing but positives for it, it’s a massive step up from what we had before.” HP002*

Sometimes minor implementation difficulties had occurred but these had not changed the generally positive views of the new system:

*“No problem with that. We did have a couple of minor blips to begin with when the prescribing wasn’t right and there was a bit about patients understanding the diagnosis,……but that’s now been sorted so, you know,…… so no I don’t think we had any problem with that” HP010*

*“I think any new form you get to fill in or anything new you get to do on the computer always seems difficult to begin with, you’re like oh now what do I do and where do I click and so it was equivalent to any other change like that. I couldn’t say it was so easy you didn’t have to think about it or it was so difficult I couldn’t find my way round it” HP009*

However, a few respondents identified more marked difficulties with implementation:

*“I think it’s quite hard to add actually. As a beginner that’s what I mean, I think once you’re used to doing it it’s not a big deal but it’s not one of these very intuitive interfaces either I don’t think.” HP011*

Most practices were only completing summaries for their cancer patients. There was a general view that an ePCS could also improve care for those with non-malignant life limiting conditions, but would require amendments to be useful in this context:

*“I think it works very well for cancer patients…., it doesn’t lend itself quite so well to,....there are quite a few things in it that are inappropriate for people that don’t have a cancer diagnosis, so if you’re using it for somebody that’s just got end stage COPD or, you know, end stage dementia 208 a lot of it is irrelevant so I think it would probably be quite good to have, you know, an ePCS developed for non cancer conditions.” HP002*

Patients and carers expressed no worry regarding confidentiality, but a concern was raised by GPs about issues surrounding obtaining informed consent from patients with dementia, especially in care homes. Related to this, there was a widespread misunderstanding of what palliative care entails amongst patients and family members:

*“The other problem there is that a number of them have a degree of dementia so getting consent and whether or not that is really informed consent becomes a problem in which case next of kin are the ones that we’d be discussing with but that depends on their understanding of palliative care. A lot of people don’t understand and they just think if my mum takes unwell you’re not going to do anything for her which isn’t what it is, it depends on what she’s got and what we can or can’t do.” HP14*

Many of the problems with ePCS could be viewed as implementation difficulties which time, familiarity and refinements would address:

*“It’s not come through in a particularly well constructed form, it kind of looks as if it’s been through a mincer a wee bit so it doesn’t come out like the neat summary you see from ePCS that you produce in the practice it tends to be a wee bit garbled once it’s been through NHS24 and ASTRA the out of hours systems. The information is there it just doesn’t look particularly tidy.” HP11*

Another major issue highlighted by GPs in the OOH service was that not enough palliative care patients had an ePCS: because of this the OOH staff did not automatically look for nor access the form, leaving staff without up to date information on the patient they are about to see.

*“Because there’s so few people using it at the moment it falls down at the out of hours service, again just because people don’t know that it exists so people don’t know to look for it and they do actually need a specific prompt to look for it.” HP02*

***Advantages of ePCS***

Health professionals were strongly of the view that ePCS offered benefits to their patients in the out of hours setting

*“It puts across patient wishes to the out of hours department so when we’ve had a discussion about things like resuscitation, where they want to die, what kind of process they want to follow that all gets put in and gets submitted to the out of hours so that saved quite a lot of secondary discussion. There’s a lot of kind of anxiety alleviating so when you actually chat with people about it, relatives especially, to say well this information is all going to the out of hours department they like that I guess because the feedback from before it was in was always that they didn’t like phoning out of hours because they’ve got to trawl over quite a nasty story” HP02*

Furthermore, health professionals perceived an actual improvement in the quality of OOH care due to the ePCS in OOH. This was illustrated by a GP with daytime responsibility for a large nursing home:

*“With the nursing home yes, there are a number of patients where they have taken poorly…and we’ll get the G-MED sheet in the morning it always states they’re on the palliative care register as such and that’s worked, they haven’t had to be shipped into the hospital.I know there have been other patients where that discussion hasn’t been had, they aren’t on the register and they have been taken into hospital, so there have been a number of patients where its worked quite well but there have been others where if it had been in place they wouldn’t necessarily have been transferred” HP14*

Health professionals actually working in OOH were especially appreciative of ePCS. They gained increased professional confidence because they had a clearer picture of the situation in the home before they visited or gave advice:

*“I know myself it’s much easier to deal with a patient that’s got a very up to date electronic palliative record”. HP12*

*“You’re often going to see somebody with advanced disease with a variety of people in the house when you go in to see them and you have to make that fairly, consider judgement often about who’s who and who’s thinking what and what degree of information the carer, carers have or relatives have and what information the relatives have and sometimes that’s not altogether apparent. …Sometimes you used to have to guess how informed people were in terms of the disease and what their feelings about it were, … …but the work of all that has been done and you go in and you know the patient is fully aware, relatives aware of prognosis and outcome, … and you know their wishes, … …it’s very helpful and it saves you putting your foot in it and appearing a total idiot” HP11*

*“To go in blind as is done on various different occasions with no notes on a patient is absolutely crucifying, it’s horrific, you look so stupid”. HP16*

Health professionals attributed some benefits to in hours care from introduction the ePCS. They felt that ePCS improved the routine information available on their palliative patients and also provided an aid that facilitated case meetings within the practice. They also felt that it helped them to anticipate thetype of problems their patients may encounter.

From the perspective of family carers ePCS appeared to provide a source of reassurance:

*“I thought it was a good thing and a sensible precaution. I suppose you could say it made me feel happier. I just thought at the time oh yes what a good thing at least they’ll know what I’m talking about. When we did have to phone, between Christmas and New Year I was very favourably impressed with the whole reaction.” C002*

Another carer said:

*“They were aware of the situation because they can access our records through their computer and they know the score in this house and they come in here full of knowledge, everyone was spot on and they resolved the problem....it was first class........they just went right ahead and did what they had to do. It was all there, the information was there, very comprehensive”. C003*

Data from patient and carer interviews revealed that GPs had informed patients and carers about the working of the ePCS:

*“She’s gone through all their patients who are on long term care and filled in the form. So my husband is a “fast-track patient at the surgery, he’s on the, I don’t know exactly what it’s called, fast track, or alert, or super alert system at the 24 hour service”. C001*

*“but I do know that I have special files on the out of hours register that can be accessed. I’ve to be nursed at home. Yes and also the do not resuscitate stuff is all on the files as well.” P002*

***Challenges concerning the ePCS***

There were some technical software problems identified with ePCS, (which have since been addressed). Nevertheless, one of these issues is worth highlighting since it has considerable implications for the philosophy adopted by health professionals, patients and carers toward end of life care:

*“The second thing is that again it tends to say preferred place of death......as opposed to preferred place of care and we much prefer to use preferred place of care because obviously that’s a question that we can ask relatively early on but it’s much harder to say well where would you like to die” HP012*

There were some more fundamental problems. One issue raised was lack of buy-in by all members of the practice team:

*“No, I think there has been a real issue in terms of bringing it to the collective consciousness of the practice as a useful tool for updating out of hours information. We have in the practice made significant attempts to make people aware of it but I think it’s still very much a kind of out in the left field kind of thing, I don’t think it’s something that people are automatically doing without prompting” HP011.*

Underutilisation, possibly related to lack of widespread buy in was also highlighted. For instance, the majority of GPs were unaware of any access or use by nurses, and in fact only one of the nurses interviewed had used the system herself and was prompted to do so by the interview for this study:

*“So actually I haven’t put anybody new on but I have updated the details of somebody that’s on already and it was OK”. HP03*

As a community nurse she felt that she would now be happy to update and use the summary regularly and, as she saw many of the palliative patients more often than the GPs, she felt that this would be a particularly useful tool. On the other hand, the two other community nurses interviewed had seen the summaries but felt it would be GP would have the key responsibility to maintain and update the summary.

OOH staff identified that some general practices were much better than others in completing an ePCS, and that many GPs rarely completed a form for non-cancer patients. In essence, however, a widespread view amongst respondents was that with continued use and growing familiarity the ePCS would positively reinforce itself.

*“Once you’ve created the thing and I think maybe that’s part of the problem of why people are finding it a little bit hard to buy into it because you kind of do all this work and then it seems like nothing is happening but what you’re actually doing is laying a foundation for hopefully some good pieces of clinical work and care at a later date.” HP05*

**DISCUSSION**

***Summary of main findings***

Patients, their carers, primary care and OOH staff considered that the ePCS was a potentially useful and feasible innovation. It must be acknowledged, however, that a relatively small number of participants were included. Additionally, several caveats were expressed including a number of implementation difficulties and technical problems that require to be addressed, as well as a need to clearly specify which health professional should be responsible for maintaining the summary. Importantly, it was felt that many more (especially non-cancer) patients could potentially benefit, if recognised as being eligible for the ePCS. Some GPs also believed that the experience of completing ePCS has had benefits for in-hours structures of care such as advance care planning, with for example the ePCS being used as the basis for palliative care team meetings.

Where disadvantages existed, many related to those associated with the introduction of a new technology. Such issues include unfamiliarity with the process, limited time and IT skills and reticence from some members of the team to engage, and a concern that time spent on data entering may mean less time for discussion with the patient in already time-constrained consultations.

More specific issues included the difficulty of GPs knowing when it was appropriate to broach and complete the ePCS with patients. Additionally, many GPs had colleagues who had not completed an ePCS for any of their patients, thus potentially disadvantaging these patients in the event of an OOH visit being required. There was little evidence of primary care nursing staff accessing or updating information. OOH staff were highly supportive of electronic summaries as they felt more informed and confident and appeared more professional and in control when entering what may be an already tense situation, although experience was limited.

***Comparison with other literature***

Greenhalgh et al emphasise that the adoption of innovations should be viewed as a complex process, involving the interaction of attributes of the innovation, the system and the adopters. [18] In exploring the key factors influencing the adoption of a computer-based innovation in primary care (albeit one related to lifestyle, not palliative care), Carlfjord and colleagues highlight the importance of the perceived characteristics of the innovation (including the relative advantage over previous practice, and compatibility of the new technology) and staff characteristics (their opinions about the relevance of the issue, and opinions about organisational change) as being critical [19]. Both these elements are equally applicable in this study: introduction of ePCS was widely perceived to be advantageous but concerns about the initial ‘fit’ of the ePCS with existing computer systems was raised, and staff simultaneously prized the opportunity to provide best quality end of life care to patients, i.e. it was compatible with primary care values, while voicing concerns about the potential for additional workload.

It is noteworthy that a number of GPs highlighted that the introduction of ePCS had brought benefit to the ‘in hours’ provision of care as well as to OOH service, and were used in practice team meetings. This is in keeping with recommendations about the use of IT in the management of chronic illness, where the need for appropriate non-IT system of care is paramount, and new technology must fit in and enhance (rather than disrupt) established systems of care [10].

***Strengths and weaknesses***

This small study included a range of health professionals drawn from two contrasting Scottish regions. Lothian has a mostly urban population as opposed to Grampian which has a mixed urban and rural population. The sample included a spread of gender, age, professional role, urban or rural setting and socioeconomic factors, likely to reflect the people and places in which ePCS implementation is proposed. The evaluation was conducted at a difficult time when participants were immersed in the practical issues of introducing ePCS.

This study was based on a qualitative sample, and did not involve the collection of quantitative data from participating practices, or from the Health Boards involved. Therefore, the results reported here need to be understood as an in-depth subjective exploration of a system intervention, and interpreted within the context of data from the wider project evaluation (NHS Scotland). Due to delays in the implementation of this project and significant IT issues (relating to early implementation, now being addressed), some professionals, patients and carers had limited exposure and knowledge of the ePCS system. Consequently, the numbers, particularly of patients and carers, available to us were limited.

As with all studies of this nature there is the risk of selection bias. It could be that only those individuals well-disposed to ePCS agreed to participate. On the other hand participants did express reservations about ePCS suggesting that a range of perspectives were represented. A further potential problem is inherent in the fact that, out of necessity, some interviews were conducted on the telephone, others face-to-face. This introduces the risk that the interviewer is unable to respond to visual cues during telephone interviews perhaps limiting the richness of the data obtained.

In addition, although requested to do so, few GPs volunteered one of their patients, or a carer, for interview, reflecting an unwillingness to involve palliative care patients in research [20]. We have presented very little data indeed from carers and patients and these interviews did not reach data saturation and we would suggest that the reader interpret these data with extreme caution. We do, however, believe that they should be included. Firstly, we feel it is important to report the views of the two individuals willing to participate during the palliative phase of their illness. Second, our recruitment difficulties in this group of patients have been experienced by others. We believe that people with life limiting illness should be given the opportunity to participate in research and wonder whether health professionals are over-sensitive about raising the issue in this group of patients. We include our data to demonstrate that such individuals are willing to participate in this kind of research and can do so in a meaningful way.

***Implications***

Professionals with early experience of the ePCS system welcomed it and believed it to be a significant advance in care for their palliative care patients, despite the initial implementation difficulties, and the challenge to existing IT skills and clinical time in introducing this resource-intense intervention into the primary care setting. Inclusion of ePCS in the Quality & Outcomes Framework may create useful incentive and motivation. It is likely also that some additional training for GPs and nurses will support implementation and consolidate potential care benefits. Further research should also assess the impact of the introduction of ePCS on primary care workload. The current emphasis on nurse-led care in the community perhaps means that greater emphasis should be given to involving community nurses to a greater extent in the implementation and ongoing development of ePCS, especially as many palliative care patients will see a community nurse more frequently than their GP: such initiatives have been successfully utilised by others in a palliative care setting [21].

Continuity of care remains critical to the primary palliative 424 care: although OOH services results in a lack of continuity of personnel, the ePCS appears to contribute to ensuring this core value of primary care is maintained through facilitating continuity of patient information between GP surgeries and OOH services. The introduction of an electronic ePCS means that GPs routinely inform their patients that they are sending this information, with consent, which was not always done before. Thus not only the information was sent, but the patient knew this, and knew that there was continuity of information, if not of personal care.

UK clinical practice, as recommended by the GSF is to initiate a PCS when a patient is placed on the palliative care register. Thus we recommend that GPs are supported to identify and place more patients with advanced progressive illnesses on their palliative care registers, so that they can not only benefit from holistic care, but from having a ePCS completed. Should GPs remain concerned about what they perceive as too early identification of “palliative” patients, consideration could possibly be given to renaming the ePCS to an electronic “supportive care summary” so that professionals might more easily explain to patients that this “should help them get more support, especially OOH”, rather than trying to explain what “palliative” care is.

**Recommendations**

• Patients with advanced cancer, and perhaps other progressive advanced illness, could potentially benefit from having an ePCS completed in the event they need care out-of-hours.

• Inclusion on the practice palliative care register and completion of the ePCS could be carried out at the same point in time for all patients with advanced cancer

• OOH staff should be made routinely and reliably aware of an ePCS where it exists for specific patients, and access these as a matter of course.

• Training in ePCS completion and updating should be available for all GPs and community nurses.

• Community nurses should be included in the implementation and ongoing development of the ePCS initiative

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**REFERENCES**

1. Murray SA, Sheikh A. Palliative Care Beyond Cancer: Care for all at the end of life. BMJ 2008;336 : 958 doi: 10.1136/bmj.39535.491238.94

2. Delivering Better Care at End of Life: the next steps. The King’s Fund 2010. Editors Addicott R, Ashton R.

3. Shaw KL, Clifford C, Thomas K, Meehan H. Improving end-of-life care: A critical review of the Gold Standards Framework in primary care. Palliative Medicine, Vol. 24, No. 3, 317-329 (2010)

4. Worth A, Boyd K, Kendall M, Heaney D, Macleod U, Cormie P, Hockley J, Murray SA. Out-of hours palliative care: a qualitative study of cancer patients, carers and professionals. BJGP 2006;56:6-13.

5. Schweitzer B, Blankenstein AH, Deliens L, van der Horst HE. Out-of-hours palliative care provided by GP co-operatives: availability, content and effect of transferred information. BMC BMC Palliative Care 2009; 8:17.

6. Burt J, Barclay S, Marshall N, Shipman C, Stimson A and Young J. Continuity within primary palliative care: an audit of general practice out of hours co-operatives. Journal of Public Health Medicine 2004; 26(3): 275-276

7. NHS Connecting for Health http://www.connectingforhealth.nhs.uk/ (accessed 15th January 2011)

8. Ortega Egea JM, González MV, Menéndez MR. eHealth usage patterns of European general practitioners: a five-year (2002-2007) comparative study. Int J Med Inform. 2010 Aug;79(8):539-53.Epub 2010 Jun 9.

9 Mars M, Scott RE. Global e-health policy: a work in progress. Health Aff (Millwood). 2010 Feb;29(2):237-43.

10. Dorr D, Bonner LM, Cohen AN, Shoal RS, Perrin R, Chaney E et al. Informatics systems topromote improved care for chronic illness: a literature review. J Am Med Inform Assoc. 2007; 14:492 156-163.

11. Kidd L, Cayless S, Johnston B, Wengstrom Y. Telehealth 494 in palliative care in the UK: a review of the evidence. J Telemed Telecare. 2010;16(7):394-402. Epub 2010 Sep 2. Review.

12. Living and Dying Well: A national action plan for palliative and end of life care in Scotland The Scottish Government, Edinburgh, 2008. http://www.scotland.gov.uk/Publications/2008/10/01091608/0 (accessed 15th January 2011).

13. Scottish Clinical Information in Practice. http://www.scimp.scot.nhs.uk/documents/ePCS\_Overview\_Nov\_09 (accessed September 15 2010).

14. The Healthcare Strategy for Scotland. The Scottish Government: Edinburgh, 2009. http://www.scotland.gov.uk/Publications/2009/10/16100145/0 (accessed 15th January 2011)

15.Royal College of General Practitioners. End of Life strategy document, 2009. London: Royal College of General practitioners, 2009 [http://www.rcgp.org.uk/pdf/CIRC\_RCGP%20End%20of%20Life%20Care%20Strategy%20FINAL%](http://www.rcgp.org.uk/pdf/CIRC_RCGP%20End%20of%20Life%20Care%20Strategy%20FINAL%25) 20Jan09%20(Prof%20Keri%20Thomas).pdf (accessed 15th January 2011)

16. Mason J. Qualitative researching. London, Sage Publications Ltd 2002.

17. Miles and Huberman Qualitative Data Analysis Second Edition Sage London 1994

18. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. Milbank Q. 2004;82(4):581-629. Review.

19. Carlfjord S, Lindberg M, Bendtsen P, Nilsen P, Andersson A. Key factors influencing adoption of an innovation in primary health care: a qualitative study based on implementation theory. BMC Fam Pract. 2010 Aug 23;11:60.

20. Harris F, Kendall M, Bentley A, Macguire R, Worth A, Murray S, Boyd K, Brown D, Kierney N,Sheikh A. Researching experiences of terminal cancer: a systematic review of methodological issues and approaches. European Journal of Cancer Care 2008;17:377-386.

21. Brumley D, Fisher J, Robinson H, Ashby. Improving access to clinical information in after hours community palliative care. Australian Journal of Advanced Nursing, 24(1):27-32.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **ID Number** | **Interview Type** | **Status** | **Sex** | **Location** | **Practice IT System** | **OOH Inolvement** |  |
| HP001 | Telephone | GP | Male | Grampian | Adastra | Full time |  |
| HP002 | Telephone | GP | Male | Grampian | EMIS | Yes |  |
| HP003 | Telephone | GP | Male | Grampian | EMIS | Yes |  |
| HP004 | In-person | GP | Female | Grampian | Vision | No |  |
| HP005 | Telephone | GP | Female | Moray | Vision | No |  |
| HP006 | In-person | Nurse | Female | Grampian | EMIS | No |  |
| HP007 | In person | Nurse | Female | Grampian | EMIS | No |  |
| HP008 | In person | Nurse | Malee | Grampian | EMIS | No |  |
| HP009 | In person | GP | Male | Grampian | EMIS | No |  |
| HP010 | In person | Practice Manager | Female | Grampian | EMIS | No |  |
| HP011 | In person | GP | Male | Grampian | EMIS | Yes |  |
| HP012 | Telephone | GP | Female | Lothian | EMIS | Yes |  |
| HP013 | Telephone | GP | Female | Lothian | GPASS | No |  |
| HP014 | In person | GP | Male | Grampian | GPASS | Yes |  |
| HP015 | Telephone | GP | Female | Lothian | EMIS | No |  |
| HP016 | Telephone | GP | Female | Lothian | GPASS | Full time |  |
|  |  |  |  |  |  |  |  |
|  |  |  |  |  |  | **Awareness of ePCS** | **Experience of Out-of-hours care** |
| P001 | In person | Patient | Male | Moray |  | None | None |
| P002 | Telephone | Patient | Female | Lothian |  | None | None |
| C001 | In person | Carer | Female | Moray |  | None | None |
| C002 | Telephone | Carer | Female | Lothian |  | Aware | Good |
| C003 | Telephone | Carer | Male | Grampian |  | Aware | Good |
| C004 | Telephone | Carer | Female | Grampian |  | Aware | Good |

**Table 1: Characteristics of Interview Participants**

**FIGURE 1: Interview schedule for health professional interviews**

**Qualitative Evaluation of the Electronic Gold Standards Framework Scotland (eGSF) including Palliative Care Summary (PCS)**

Interview schedule: GPs. To be used by telephone or face-to-face

For each practice, we will want to obtain as background information:

1. any routinely collected data on use of the PCS in that practice in recent weeks or months

2. basic practice features such as numbers of patients on list, no of GPs (FT/PT), do they have a palliative care register, etc

The interviewer will first introduce herself, and ask if there are any questions GP would like to ask about the evaluation, and confirm that it would be acceptable to audio-record the interview. If the consent form has not yet been signed, it will then be done. Will explain the interview can be stopped at any time.

The following eight areas will be explored, using some of the questions below as prompts as required

**1 Introduction of ePCS within the practice**

-

- ease of introduction – was it adopted readily?

- compatibility with practice database?

**-** what was and is the role of the practice manager?

**2 Use of ePCS on a day to day basis**

- how often do you use the ePCS? How many patients/carers have you discussed it with?

- what sort of response have you received from patients/carers when you’ve sought consent for completion and use of the ePCS?

- time required, for setting up new ePCS, and for maintaining accuracy (after every patient visit?)

- is it always the GP who does this task?

- how easy is it for community/district nurse to access or update?

**3. Judgement on effectiveness and usefulness in decision-making**

- any examples of how it improved the care of specific patients

- role and value in relation to other palliative care initiatives used by the practice

**4. Ease of use, barriers to use**

- again, compatibility with database system, but also how form is laid out on screen

- how easy to save changes and make these available to others

**5. Any limitations of forms**

- are there additional features of patient care that should be included in the ePCS

- how much patient/carer input into the process?

**6. Concerns re confidentiality etc**

**7 Recommendations for change**

- future enhancements

**8. Any additional points**

GP is thanked, asked if s/he would like a summary of the results at the end of the study.

**FIGURE 2: Interview schedule for OOH staff interviews**

**Qualitative Evaluation of the Electronic Gold Standards Framework Scotland (eGSF) including Palliative Care Summary (PCS)**

**Interview schedule** for: out-of-hours workers, including call handlers, nurses, and general practitioners

- to be expanded during the interview, and individualised depending on role

The interviewer will first introduce herself, and ask if there are any questions the interviewee would like to ask, and if it would be fine to audio-record the interview. If the consent form has not yet been signed, it will then be done. Will explain the interview can be stopped at any time.

**The following areas will be explored, using the questions suggested below as prompts as necessary**

**1 Role of interviewee within service**

 **How the interviewee interacts with the ePCS, how frequently it is used, precise role**

**2. Compatibility with other OOH documents on individual patients**

Please describe how well the information in ePCS document fits in with the other information you have available for a patient? Is there overlap, or are you conscious of gaps?

**3. Use of ePCS on a day to day basis**

 **Is it helpful?**

**4. Judgement on effectiveness and usefulness in decision-making**

Has access to the patient-specific information on the ePCS been useful in enabling you to make a decision regarding patient care, whether a home-visit is required, etc? Please give examples if relevant.

**5. Ease of use, barriers to use**

 **Anything you find frustrating?**

**6. Any limitations of forms**

**7. Concerns re confidentiality etc**

**8. Recommendations for change**

**Any additional points**

The interviewee is thanked.

**FIGURE 3: Interview schedule for patient/carer interviews**

**Qualitative Evaluation of the Electronic Gold Standards Framework Scotland (eGSF) including Palliative Care Summary (PCS)**

**Interview schedule: patients and/or carers**

The interviewer will first introduce herself, and ask if there are any questions the patient and or carer would like to ask, and if it would be fine to audio-record the interview. If the consent form has not yet been signed, it will then be done. Will explain the interview can be stopped at any time.

**The following areas will be explored in the evaluation, using the questions below as prompts as necessary**

**1. Communication with local general practice**

Do you feel that the staff at your own practice know about you, your situation, and your particular illness and have a plan for supporting and looking after you? [How do you know this? Have they talked about forward planning with you? Who is involved in your care? Do they leave notes in the house? Do they read them/write in them?]

**2. Availability of support from practice**

Who would you contact if you wanted help from your local practice? Who deals with any problems or concerns you have? How? Are you happy with this?

**3. Palliative Care Summary**

Has your GP discussed out of hours (evenings/nights/weekends) with you? Has your GP discussed with you what information is shared or made available to other NHS colleagues for out of hours care?

**4. Completing the ePCS consent**

Have you participated in completing any forms recording your health needs, or wishes for care? How well did you understand the reason for this request? What was your response? Were you surprised to be asked? Does it make you feel more confident/less worried about needing to contact OOH?

**5. Recent use of out of hours service**

Have you ever had to phone up out-of-hours? What happened? Did it go well? Why? Did you have any worries? Why? Do you know when/why/how/who to contact if you have worries out-of-hours?

**6. Knowledge of OOH staff of your circumstances**

How confident were you that the person on the phone knew your individual circumstances? Did they ask about your medication, or any recent GP visits? Did they ask questions you wish they had already known the answer to?

**7. Acknowledgement of carer role**

Have you/your carer been offered emotional/practical support? Who/how/when/why/who raised/did it work well? Is he/she encouraged, and supported to play as full a role as they wish in your care? Can they access the information they want both about your care and about support for themselves?

If appropriate, was bereavement support offered? What was it? Who offered and how? Did you find it helpful? Why/why not?

**8. Is there anything else you would like to say?**

How could you be cared for better?

The patient /carer are then thanked. If the interviewer has any concern that they might have upset the patient, she will seek permission to inform the GP about this, and ask the GP to contact the patient.