Palliative care management system

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**Abstract.** Due to the complexity of the end of life care industry, around 92,000 patients are not given adequate palliative care due to shortage of specialist trained staff and funding. There is a need to use socio-economic and demographic characteristics of population areas to improve delivery of training and staffing to care providers. The research aims to understand the current data needs in the industry and develop a Palliative Care Management System that can be used to analyse a combination of open source data to enable evidence-based interventions. Systems engineering methods were used to enable product development by Stonehaven Technology and system roll out.

1. Introduction

This paper outlines some elements of the systems-based measurement and development process of a Palliative Care Management System (PCMS) that uses multiple data sources to improve patient experience. Approximately 470,000 people in the UK die every year of which 355,000 receive end of life care [1]. UK demographics mean that over the next 20 years there will be an increasing demand for palliative care services. However, end of life care is complex in which there are multiple settings such as: acute hospitals, hospices, care homes and home-based care. This care and its support are commissioned by various authorities from the statutory, voluntary and private sectors which increases the complexity further. In order to improve these services by using data analytics, the National Palliative Care Intelligence Network was established. As a result, a considerable amount of data is available on mortality and the conditions under which they occurred. As part of this strategy, Public Health England is working with National Council for Palliative Care and Hospice UK to improve national data collection in end of life care [2]. The aim of this programme is to enable the effectiveness of quality improvement incentive programmes to be measured thereby identifying and leveraging service integration and co-operation across care settings. However, there are gaps in knowledge of demographics, quality, patient experience, and access to some primary care and social care data. By integration of these data with other sources, there is an opportunity to allow hospices, general practitioners, and other health providers to be better equipped to improve care to patients. The data would allow relevant authorities to assess the need for palliative care and track its delivery.

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2. Methods outline
An iterative systems engineering method was used to uncover the requirements for the PCMS which was further developed using stakeholder analysis, requirements capture, systems architecture, systems design, implementation of a demonstrator and its validation and verification. Systems-based measurement is used in all of these processes though only stakeholder analysis and requirements capture are considered in this paper. However, the systems architecture of the system implemented can be seen in figure 1 below.

![Figure 1. Palliative Care Management System Architecture.](image)

The content and relationships contained within the system architecture were themselves captured via iterative interviews with system developers (Stonehaven Technology, UK) and its principal customer for this work (St Helena’s Hospice, UK).

3. Identifying stakeholders and their requirements
Primary stakeholders are those who are ultimately affected by the PCMS, that is those who expect to benefit from or be adversely affected by the developed system and as a consequence need to interact directly with it. In this category stakeholders defined for this system are patients and their carers, NHS hospices, independent hospices and general practitioners. Secondary stakeholders are those with an intermediary role in the development or use of the PCMS. They may need to interact indirectly with the system by providing ‘input to’ or ‘output from’ it. Secondary stakeholders include the local funding bodies among others – clinical commissioning groups, primary care trusts, local authorities, NHS Hospitals, private hospitals, the National Palliative Care Intelligence Network. Tertiary stakeholders are those who are not involved or affected by the PCMS, but can influence opinions either for or against system design options. Stakeholders in this category include government Departments for Health and Social Services, and the charity sector in palliative care.

For simplicity in this paper requirements are distinguished into operational requirements and functional requirements, where the former is a top-level statement of intent. The operational requirement for the PCMS is “to integrate available data sources to provide purposeful interventions in a defined local catchment area”. Note that the interventions are equally applicable to patients and their
carers in the form of (say) increased quality of care, as well as to the people who provide the care (say) in identification of training opportunities and its funding.

After an interview with a clinical director of a non-NHS hospice, a set of system attributes were developed – see table 1 below for an excerpt.

Table 1. Top-level functional requirements for the demonstrator.

| Primary Function                  | Sub-Function                                      |
|-----------------------------------|---------------------------------------------------|
| Upload data                       | Upload open source data                           |
| Analyse data                      | Generate map location of care providers           |
|                                   | Display & compare data in selected care provider's area |
|                                   | Compare/Overlap maps                              |
| Manage interventions              | Create interventions                              |
|                                   | Communicate interventions                         |
|                                   | Perform interventions                              |

Although the attributes for data types and functionality set by the customer is specific to a hospice environment, the requirements above are generic for the PCMS regardless of the user. This will increase the flexibility of the system and enhance the utility of the demonstrator. There are three primary software functions: upload data – upload and validate open source data, analyse data – analysis of the open source data to determine interventions, and, manage interventions – perform required interventions based on evidence derived from analysis. The generalised primary functions are elaborated to a further level of detail in the above diagram.

4. Discussion

Multiple surveys have shown that 64% of terminally ill patients would prefer to die at home and only 1% wish to die in hospital as shown in table 2.

Table 2. Preferred place of death [3].

| % Choice of preferred place of death | Home | Hospital | Care home | Hospice |
|-------------------------------------|------|---------|-----------|---------|
|                                     | 64%  | 1%      | 6%        | 29%     |

However as seen in table 3, 47% of patients died in hospital. There is a far greater cost associated with the NHS when a palliative care patient enters hospital for end of life care rather than being treated at home or in care homes: it costs nearly £2,000 per week for an NHS bed in comparison to around £560 per week in residential care [1].

Table 3. Actual place of death [4].

| Number of Deaths | Home | Hospital | Care home | Hospice | Total |
|------------------|------|---------|-----------|---------|-------|
| 105,356          | 108,987 | 27,087 | 470,541 |
| % of Total Deaths| 22%  | 47%     | 23%       | 6%      |
access and higher deprivation has been reported in other studies in terms of access to hospice at home [6-8]. To address these issues the PCMS demonstrator makes use of a geographic information system as one of its data resource streams whose mapping facility can be used in conjunction with (say) location of general practitioner surgeries, hospices and levels of deprivation.

5. Conclusions
Stakeholders have been identified by background literature search and interviews with hospice staff, general practitioners and software developers. Requirements were elicited via interviews with key stakeholders, including a Director of a hospice and software developers. Brainstorming techniques were used to uncover funding relationships as well as suggest data source filters used in the user interface of the PCMS demonstrator. Primary research suggests that the use of nationally available open source data such as depravity scores, population size, and ethnicity help hospice’s understand the human issues of the catchment areas that they sit in. Further exploration of the literature indicated that bespoke local measurements that are targeted to meet the needs of specific care providers could be made more effective by the use of a dedicated PCMS. However issues remain such as ethical considerations, patient confidentiality, and informed consent [9].

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