

An approach to the design of internet delivered services for those near the end of life

Abstract

Introduction

For people near the end of life, as well as those who look after them, the coordination of care and support services is vital. The ongoing work of the Leadership Alliance for the Care of Dying People has begun to identify key themes that are central to the provision of high-quality care for this group within Society. There is an emphasis in these and many other policy documents on the role that technology enabled care should play in this regard. This abstract describes one approach to the development of such a system, focused on the identified needs of those with life limiting illnesses.

Objectives

To use a structured approach to define the needs of people near the end of life and their lay and professional carers. To translate these into a scalable, secure electronic service offering.

Method

Focus groups were used to capture the views of patients, lay and professional carers.

Results

120 people took part in these events, which to reduce bias were held at a total of 6 locations across England. Service users, individuals with life limiting illness of varying types (malignant and non-malignant disease), were all currently within a hospice care (outpatient) environment; lay carers were either currently or previously in a carer role and professional carers were working for a hospice charity. Individual comments regarding previous or current experience of care, gaps in care and opportunities for improvement were captured verbatim for subsequent analysis. Comments made were reviewed by multiple assessors to identify the underlying need being expressed. These "needs" were resolved into a total of 13 core "themes" that drove the design of the electronic solution. The three most prevalent themes were the need to instil a true "service" orientation to healthcare services, the need to use digital services to engage a wider range of carers than is normally seen to be the case, including those with lay and professional backgrounds and the need to listen to signals from the patient and customise the care response to their expressed needs. There was universal recognition of the benefit seen following engagement with hospice services and an equally clear description of the size of the gap between this and "standard" care. A prescribable, personalised digital healthcare delivery platform was designed in responding to the identified service requirements and the resulting prototype was reviewed by service users and carers prior to initiating a formal solution build phase. The product is being made available across three geographical locations for in-service evaluation.

Conclusion



A digital services solution has been designed in response to the formally captured needs of those requiring end of life support - and their carers. This will be subjected to limited roll out and independent evaluation over the coming year.

This work was supported by a grant from the SBRI, administered by Health Enterprise East.

Location

United Kingdom

Year

2014

Related Integrated Care keywords

- DIGITAL HEALTH: ICT (INFORMATION AND COMMUNICATION TECHNOLOGY) SOLUTIONS, DEVICES, MONITORING
- PERSONALISED CARE

Pervasiveness

Small scale in a local jurisdiction

Status

Completed

Links

Schulte A, Pope R, Picken S, Hogston S. An approach to the design of internet delivered services for those near the end of life. International Journal of Integrated Care. 2014;14(8):None. DOI: <http://doi.org/10.5334/ijic.1826>

<https://www.ijic.org/articles/abstract/10.5334/ijic.1826/>