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Conference Abstract

## Digital patient-controlled records in end of life care

*Lloyd Humphreys, Patients Know Best, United Kingdom*

*Mohammad Al-Ubaydli, Patients Know Best, United Kingdom*

Correspondence to: **Lloyd Humphreys**, Patients Know Best, United Kingdom, E-mail: [lloyd@patientsknowbest.com](mailto:lloyd@patientsknowbest.com)

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### Abstract

In the UK over half a million people die each year, with an average of 12 healthcare professionals and multiple agencies involved in end of life care. The Government strategy for end of life care published in 2008 highlighted that key areas for improvement were involving people as much as they want in plans around their death, including their preferences for care, and the coordination and provision of high quality care.

Yet, coordinating care through organisational integration does not necessarily lead to integrated care as experienced by the patient (Curry and Ham 2010). It is further suggested that the successful development of integrated care is possible only if it comes from the 'bottom up' through 'micro-level' interventions by a small number of providers (Goodwin et al 2014).

The enabler of this is seen as both the patient and technology. For example, the importance of a shared electronic medical record and integrated IT system to support implementation and delivery is seen as essential to enable connected care (Bodenheimer 2008; Ham 2010; Hofmarcher et al 2007; Øvretveit 2011). But it is the patient that can be the true facilitator of coordinated care, being able to overcome issues of information sharing, governance and consent. Furthermore, when they are in control of their records they can more explicitly share their wishes for their own end of life care preferences.

Patients Know Best is a secure online patient controlled record, used in multiple CCGs, hospital Trusts and specialist centres across the UK, which has the ability to connect to any NHS and social care IT system, telehealth device and third party apps, to consolidate all of a patient's information in one record that can be shared by the patient with whoever they trust. PKB has used the lessons learnt from deployments in innovative areas such as Torbay and South Devon NHS Foundation NHS Trust and has worked with leading national and international hospice organisations to create a bespoke patient platform for end of life care.

The digital patient-controlled record incorporates digital care plans that can be created by the individual, and shared and endorsed by healthcare professionals, for managing their end of life care, such as advanced care directives, care preferences, what happens when they die, and legal, financial and digital estate planning. As the record is owned by the patient, it travels with them, and with a bracelet containing a unique pin number, provides emergency medical workers immediate access to essential information.

This paper details the latest technological advances and philosophical approaches to patient-led integrated services and includes descriptions of initiatives in the UK and Ireland with hospice organisations. It will also draw on patient and relatives early experiences, where appropriate, of using the system. Lastly, it will detail a research process that can evidence effectiveness at fulfilling the NHS Mandate on delivering the highest possible care for people at the end of life.

## **Keywords**

**patient-controlled records; end of life care; patient-led services; telehealth**

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