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The acceptability and usefulness of 'My Healthcare Passport' to young people with life-limiting conditions.

Duration of project: 24 months

Start Date: 01/01/2017

Budget: £111,025.79

Abstract

Background

Nearly 50,000 children and young people in the UK have life-limiting conditions, with growing numbers living into adulthood. Fragmentation of health, social and voluntary services, and difficulty moving from children's to adult services makes communication between young people, families and professionals challenging. There is consensus that young people should be fully involved in care planning, including decisions to limit treatment.

However, young people and families report having to repeat their story to numbers of professionals, and significant difficulties with advance care planning (ACP) for future and end-of-life care. Limited research on ACP shows most young people want to share in decision-making and find ACP helps communication with their families about end-of-life care. ACP is associated with improvements in mood, better decision-making, treatment in line with advance directives, and death at home rather than hospital. 'My Healthcare Passport' is a new patient-held record (PHR) for people facing life-limiting illness. This paper document is kept by the patient and contains information on family and healthcare contacts, medical condition, medications, and level of independence, with a section on care preferences if the person's condition worsens, or if they are at the end of life. An online equivalent is 'A Better Plan' (ABP), developed with and for the NHS. ABP also has a section devoted to ACP.

Aims

To evaluate the acceptability and usefulness of the Passport/ABP PHRs to young adults with life-limiting conditions; and to identify organisational and intervention factors that influence successful implementation.

Methods

We will invite 25 young people aged 16-24 years living in Northern Ireland with life-limiting conditions, their families, and service providers to take part. Young people can use either or both of the PHRs for up to nine months. We will interview the young people, 15 family members and 15 professionals about their experiences using the PHRs. We will also ask young people to keep a diary of their experiences, to give short telephone interviews at three and six months, and – if they wish – to let us see how they have used their PHRs.

How the results will be used

Development of a model for successful implementation of a PHR in relation to intervention components, organisational settings, and the characteristics of the individuals involved; with a view to conducting a future definitive evaluation of the impact of a PHR on the well-being of young people with life-limiting conditions and their families.