Background

• There are a growing number of children and young people (CYP) with chronic health needs, life-limiting conditions and complex disabilities, who are faced with the transition from children’s services, to more fragmented adult services.

• The use of a patient-held record (PHR) is one potential strategy for improving young people’s health advocacy skills, which in turn will help with communication.

• PHRs contain key information regarding the patient’s communication, medical and support needs and are completed by the patient or by those who support them, such as a parent or carer.

• However, implementation of PHRs has proved difficult due to technical, organisational, and professional barriers.

Review methodology

• Papers were included if they addressed the evaluation of PHRs for use with children and young people aged 0 years to 24 years old, with any medical condition.

Review Objectives

1. To identify the dominant programme theories in relation to PHRs.
2. To identify factors that may help or hinder the implementation of PHRs.
3. To construct context-mechanism outcome configurations to explain how the PHR may work.

Theoretical model of how patient-held records are thought to work with children and young people (CYP)

Training on use of PHR: for healthcare staff and CYP to include clarification of the purpose and potential benefits of the PHR, technical knowledge on how to use, and data security arrangements (if electronic). (I)

Usage of the PHR: A PHR that enables collaboration in disease tracking, encourages CYP to think about preferred options for care, provides access to credible information and/or access to health records, information about current health status, and enables communication with healthcare providers outside of regular appointments. (I)

CYP has improved understanding and knowledge of healthcare condition or disease process, increased feeling of control over condition and more active engagement in their healthcare. CYP has improved confidence to manage and share information about their condition, ask questions and initiate conversations about their care. (M)

Healthcare staff and CYP are aware of purpose & benefits of PHR, and have the knowledge on how to use it. CYP are reassured about confidentiality issues. (M)

Lack of organisational support including staff training (C)

CYP has high levels of concern about confidentiality (C)

CYP has low level of need for PHR & desire for self-management (C)

Low level of usage by CYP leading to decreased motivation of healthcare professionals & vice versa (C)

Improved self-advocacy and communication for CYP. PHR facilitates communication between CYP and healthcare provider, leading to improved relationships with healthcare providers and facilitation of multi-disciplinary care, and shared decision making. Improved long-term health outcomes for CYP. (O)

Conclusion

• PHRs have the potential to bring multiple benefits to children and young people. However, organisational support must be in place to ensure longer-term sustainability. Clear definitions of which children and young people would benefit from using a PHR must be established.