



# An e-health intervention to support the transition of young people with long-term illnesses to adult healthcare services: Design and early use



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## ABSTRACT

**Objective:** Co-design information and website to support adolescents and young adults with long-term illnesses in their transition to adult healthcare.

**Methods:** A participatory iterative process involving a survey (n=207), twenty-one interviews, six participatory workshops, six video recordings, two advisory groups, and a co-design group to identify needs and preferences for e-health and information provision, was used to develop an appropriate intervention.

**Results:** Adolescents and young people expressed preferences for information that was trustworthy, empowering, colorful, easily downloaded online and written using non-patronizing language. They desired video testimonials of experiences from young adults who had transitioned to adult healthcare and wanted advice about becoming more independent, managing their condition, preparing for the transition, and information about medications and the differences between child and adult healthcare. They also wanted information about the location and configuration of adult healthcare, key hospital personnel, and frequently asked questions.

**Conclusion:** The participatory iterative process led to the development of an online resource specifically tailored to the adolescents and young people's transition needs and information preferences. Preliminary feedback indicates that it is a valued resource.

**Practice implications:** The [www.SteppingUP.ie](http://www.SteppingUP.ie) website has the potential to help prepare its target population group for the transition to adult healthcare.

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## 1. Introduction

Health information communication technology (HICT) has the potential to promote self-care in the management of chronic conditions as it appears to improve communication through the efficient delivery and synthesis of information [1,2]. Improvements in knowledge [3], problem-solving and self-management [4,5] and HbA1c levels [6] have been reported for young people with diabetes using HICT. Adolescents and young adults (AYAs) are frequent users of the Internet, and are commonly seen as the 'digital native generation' due to their familiarity and ease with digital technology from an early age. Consequently digital technologies are increasingly being used to share information and engage AYAs in their healthcare [7,8]. Finding ways to promote

and empower AYAs' participation in self-care is essential as it enhances chronic illness management and contributes to a successful transition from children's healthcare to adult healthcare [9]. This paper describes the development of a web-based health information intervention to support and prepare AYAs with chronic conditions for transition to adult healthcare.

Medical advances are enabling more than 85% of children born today with chronic conditions to reach adulthood with many transferring to adult healthcare [10]. In Ireland and worldwide, the numbers of young adults with congenital heart disease (CHD) [11], cystic fibrosis (CF) [12], and Type 1 diabetes (T1D) [13] are increasing rapidly. A successful transition is defined as a: "purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults as they grow up learning to live with their lifelong health condition" [14]. This shifts the focus of transition from the negotiation of structural boundaries between services to the developmental needs of adolescents and young adults. A well planned transition appears to lead to improved adherence to appointments [15,16], improved patient satisfaction [17–19] and

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parent satisfaction [19], stable or improved disease control [20], improved relationships with health care professionals (HCPs) [21,22] and promotion of autonomy [21]. Inappropriate or inadequate transition is associated with poor clinic attendance [23], loss to follow-up, increased non-adherence to treatment, increased morbidities, increased emergency/hospital admissions [24] and adverse health outcomes [25–27]. Therefore effective transitional care can prevent deterioration in young people's health and their disengagement with healthcare [28,29].

Research indicates that many AYAs feel unprepared, lack knowledge about transition and development of self-management skills and receive limited information about adult services [9,30,31]. A review of AYAs with CHD transition experiences concluded that AYAs needed education on the implications of their condition, the differences between pediatric and adult healthcare, and self-care management [32]. A review AYAs with T1D transition experiences found that AYAs needed to develop independent self-management and self-advocacy skills to navigate the transition and adult healthcare, but some were inadequately prepared for this [23]. Clearly young people require better support and preparation to make a successful transition from child to adult healthcare. We wanted to find an innovative way of information provision beyond traditional formats (leaflets). The intention was to co-create an e-health intervention which would be user-led and user-friendly and yielded a co-designed website and information resource called [www.SteppingUP.ie](http://www.SteppingUP.ie) to address information and preparation needs prior to transition.

## 2. Methods

The aim was to co-develop an e-health information intervention to support young people with long-term illnesses transitioning to adult healthcare.

The objectives were:

1. To co-design materials and a website with AYAs to reflect their knowledge needs for transition.
2. To ensure that AYAs with long-term illnesses were involved in every stage from inception to the final product.
3. Enable the personalization of the content so that AYAs can save, share, view offline or download as an application.
4. Include interactivity to help memory recall of key information about transition.
5. Optimise the website so that it can be downloaded as an application for smartphones and tablets.

**Table 1**  
Phases of the research.

Phase 1 Consultation and cooperation with relevant stakeholders	Collate AYAs information needs on transition from TRYCIS project. Identify AYAs e-health communication preferences and transition requirements. Establish a co-design group of AYAs with chronic conditions. Establish advisory group of stakeholders from disease & voluntary organizations.
Phase 2 Experimentation	Conduct participatory workshops with AYAs. Develop the information materials. Co-design the website with AYAs. Populating the website with relevant information
Phase 3 Contextualisation and iterative development	Test demos with users & providers. Test out alternative designs. Modification in response to evaluation.
Phase 4 Consultation and cooperation with relevant stakeholders	Launch of website with AYAs and stakeholders. Dissemination of information on website. Evaluation of intervention.

### 2.1. Research design

The study used a participatory approach viewing AYAs' input as a central element in the design and development of the website and its content. The participatory approach involves co-learning and reciprocal transfer of expertise, shared decision-making and mutual ownership of process and products of the enterprise [33]. It was underpinned by four key principles: consultation and cooperation with relevant stakeholders; experimentation with alternative designs; contextualisation (testing with users and providers); and iterative development (modification in response to evaluation) [34]. The study comprised four phases (see Table 1).

### 2.2. Sample

This study builds upon the findings of a transition project (called TRYCIS) which investigated the transition experiences of AYAs (with CHD, CF, T1D), parents and healthcare professionals [35]. Data on information needs and preferences for e-health technologies were obtained through a postal survey (n=207) and interviews (n=21) with AYAs aged 14–25 years old with T1D, CF or CHD. The e-health survey statements and interview questions are outlined in Table 2.

The sample for the development of the website was recruited via email invitations to those who had taken part in the TRYCIS project, promotion through voluntary organisations for each of the three conditions and calls 'of interest' on social media. The final sample comprised: the co-design group of experienced AYA consumers of healthcare aged 15–25 years (n=5), telephone interviews (n=4) and participatory workshops (n=12). The AYAs received a €20 gift voucher as a token of appreciation for their participation.

### 2.3. Ethical considerations

Ethical approval for the study was obtained from the Faculty Research Ethics Committee, Trinity College Dublin. Informed consent was gained from all participants and parents where adolescents were under 18 years.

## 3. Results

### 3.1. Phase 1: consultation and cooperation with relevant stakeholders

#### 3.1.1. Identify information needs and preferences

The TRYCIS survey data revealed that almost 6 in 10 young people (57.1%) believed that a website would be quite or very useful

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