



# Transition From Child to Adult Care – ‘It’s Not a One-Off Event’: Development of Benchmarks to Improve the Experience

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The transition from child to adult services is a crucial time in the health of young people who may potentially fall into a poorly managed ‘care gap’. A multi-site, multi-staged study was undertaken to identify the key aspects of a transitional programme of care for young people. Through a process of mapping, which involved drawing on primary and secondary data, a clinical practice-benchmark tool was developed. Benchmarks are a health care quality performance measurement ‘tool’. They provide clinical teams with standards that services can measure themselves against to see how they are doing. They are used in a comparing and sharing activity, using a structured and systematic approach, to share best practice. They offer a mechanism to look at processes, and provide an opportunity to analyse skills and attitudes, which may be the hidden narrative in benchmarking. This paper describes steps in the development of benchmarks for transition to adult care, often associated with low patient and family satisfaction. Qualitative data were collected through focus groups, workshops and interviews from 13 young people with long-term health conditions, 11 parents, 36 professionals and 21 experts leading on transition within the United Kingdom. Transcripts were analysed using qualitative content analysis. For young people and their parents/carers to experience timely and effective transition, eight factors and their associated indicators of best practice were developed from the primary and secondary data and refined through an iterative process. We recommend their use to clinical teams to inform system level strategies as well as evaluation programmes.

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## Background

AN INCREASING NUMBER of children with long-term health conditions are now surviving into adulthood (Hagell, Coleman, & Brooks, 2013). Thus, there are a growing

number of children with long-term health needs or complex disabilities who will require on-going specialised care. The provision of health care for this group has been the focus of attention for some time, with numerous reports over the past decade highlighting the need for improvement in order to better meet the needs of young people (e.g. Department of Health [DH], 2006; Department of Health, 2008; Royal College of Nursing [RCN], 2013; Royal College of Physicians of Edinburgh, 2008).

The journey through adolescence to adulthood is a challenging time of psychological, physical and social change (Colver & Longwell, 2013). Young people with a long-term health condition can face even greater challenges as they deal with complex and important changes in the care they need and the way it is provided. The role of the young person, and also their parents/carers, will evolve with the young person often wanting and being expected to exercise greater independence in the management of their condition (While et al., 2004). Health service provision, which fails to meet the needs of young people and families at this time of significant change, may result in deterioration in health or disengagement with services which can have negative long-term consequences (Nakhla, Daneman, To, Paradis, & Guttmann, 2009; Watson, 2000). Thus, the transfer of adolescents from child to adult services is a crucial time in the health of young people who may potentially fall into a poorly managed ‘care gap’.

Transition services aim to bridge the ‘gap’ between child and adult services. ‘Transition’ can be defined as “a multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health care system” (Blum et al., 1993 p.573). Unfortunately, many young people have a very different experience of transition, which does not meet the aspirations of this definition, despite the availability of many policy documents guiding service planners in the delivery of transitional care (Gleeson & Turner, 2012). To address this problem we undertook a multi-site, multi-staged study to identify the key aspects of a transitional programme of care for young people. Through a process of mapping, which involved drawing on primary and secondary data we developed a clinical practice-benchmark tool. Reported here is a summary of the steps taken, with a focus on the final stage, development and refining of the benchmarks.

## Review of the Literature

Numerous research studies have reported that some young people experience the transfer to adult care as disjointed and more of a one-off transfer, rather than a process of preparation in which they are involved (e.g. Kirk, 2008; McCann, Kearney, & Wengstrom, 2014; Shaw, Southwood, & McDonagh, 2004; Wray & Maynard, 2008). Such experiences seem to resonate across young people with different diagnoses. A review focusing on the qualitative literature on transition by Fegran, Hall, Uhrenfeldt, Aagaard, and Ludvigsen (2014)

described themes relating to experiences of loss of relationships with the child care team combined with insecurity and a feeling of being unprepared for what was ahead.

Lack of ‘being prepared’ was also a finding from the recent report on transition from the Care Quality Commission in the United Kingdom (UK) (CQC, 2014). Here only 54% of young people described preparation for transition that had enabled them to be involved in the process as much as they wanted to be and 80% of pre-transition case notes reviewed had no transition plans for health (CQC, 2014). There are examples of services where successful transitional care programmes have been implemented (see Crowley, Wolfe, Lock, & McKee, 2011) and the CQC (2014) reported that what works well was often associated with specialist services, such as those receiving care for cystic fibrosis and cardiac conditions, and in essence this consisted of: having consistent staff members who know about the conditions and young person’s history, good communication and good information about what to expect.

The priorities set by the CQC (2014) includes the recommendations that:

1. Commissioners and providers must listen to, involve and learn from young people and their families and understand what they want from their care.
2. Existing good practice guides must be followed to ensure young people are properly supported through transition.
3. General Practitioners (GPs) should be more involved at an earlier stage, in planning for transition.
4. Adolescence/young adulthood should be recognised across the health service as an important developmental phase.

## Benchmarks for Transition

Benchmarking originates from within industry. The basic principle of benchmarking is that a point for comparison is identified (a benchmark) against which all can compare (Codling, 1992). This identified benchmark reflects best practice, traditionally identified from leaders in the field, so that users of benchmarks can identify how their performance compares. Examples of the use of benchmarking in the UK health service appear in the literature from the mid to late 1990s (Ellis, 2006): described as ‘pivotal to current government policy in healthcare in the UK’ and elsewhere (Northcott & Llewellyn, 2006, p. 420). Clinical practice benchmarking focuses on the provision of best possible care for patients; and includes not only the desired outcomes but the structures and processes that support achieving those outcomes (Ellis, 2000). Developing benchmarks for clinical practice involves drawing on a number of different types of evidence including published research, reports and professional consensus. In the UK, the Department of Health (DH 2010) has published a benchmarking tool kit, ‘Essence of Care’ to support quality improvement activity related to fundamental aspects of care that are considered vital to the quality of a patient’s experience of health care (e.g. communication). The Essence of Care benchmarks also include the opinions, experiences and expectations of patients and carers, who could be considered to be the

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