

# Facilitating the transition of young people with long-term conditions through health services from childhood to adulthood: the Transition research programme

Allan Colver,<sup>1,2\*</sup> Tim Rapley,<sup>2</sup> Jeremy R Parr,<sup>3,4,5</sup>  
Helen McConachie,<sup>2</sup> Gail Dovey-Pearce,<sup>1,2</sup>  
Ann Le Couteur,<sup>2,5</sup> Janet E McDonagh,<sup>6,7</sup>  
Caroline Bennett,<sup>8</sup> Jennifer Hislop,<sup>9</sup>  
Gregory Maniatopoulos,<sup>2</sup> Kay D Mann,<sup>2</sup>  
Hannah Merrick,<sup>2</sup> Mark S Pearce,<sup>2</sup> Debbie Reape<sup>1</sup>  
and Luke Vale<sup>9</sup>

<sup>1</sup>Child Health Department, Northumbria Healthcare NHS Foundation Trust, North Shields, UK

<sup>2</sup>Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK

<sup>3</sup>Institute of Neuroscience, Newcastle University, Newcastle upon Tyne, UK

<sup>4</sup>Great North Children's Hospital, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK

<sup>5</sup>Complex Neurodevelopmental Disorders Service, Northumberland, Tyne and Wear NHS Foundation Trust, Newcastle upon Tyne, UK

<sup>6</sup>Arthritis Research UK Centre for Epidemiology, Centre for Musculoskeletal Research, Faculty of Biology, Medicine and Health, University of Manchester, Manchester, UK

<sup>7</sup>National Institute for Health Research (NIHR) Manchester Biomedical Research Centre, Manchester University NHS Foundation Trust, Manchester, UK

<sup>8</sup>Council for Disabled Children, London, UK

<sup>9</sup>Health Economics Group, Newcastle University, Newcastle upon Tyne, UK

\*Corresponding author [allan.colver@ncl.ac.uk](mailto:allan.colver@ncl.ac.uk)

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## Scientific summary

### **The Transition research programme**

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# Scientific summary

## Background

As young people with long-term conditions move from child-centred to adult-oriented health services (transition), their health may deteriorate and their social participation may reduce. Chronic illnesses, such as diabetes mellitus, may be more difficult to control. Conditions such as cerebral palsy give rise to symptoms, such as pain or spasticity, that interfere with daily living, and for which health needs may not be met. Few young adults with autism spectrum disorder (ASD) attain their potential for participation in society.

Despite guidance over the past 10 years from government, the voluntary sector and the National Institute for Health and Care Excellence in 2016 on how to improve transition, it has been difficult to persuade commissioners and providers of health services to specify arrangements for transitional health care because much of the guidance has little evidence to support it.

The number of young people in transition is increasing; many children with long-term conditions that once commonly caused death in childhood now live into adulthood. Every year, in a typical NHS Trust serving a population of 270,000, approximately 100 young people with a long-term condition needing secondary care reach the age of 16 years. As transition takes place over about 7 years, the number in transition at any time in a typical trust is approximately 700.

## Objectives

The overall purpose of the research programme was to promote the subjective well-being and health of young people with long-term conditions by generating evidence to enable NHS commissioners and health-care providers to facilitate successful transition.

The programme had three objectives:

1. to work with young people with long-term conditions to determine what is important in their transitional health care
2. to identify the effective and efficient features of transitional health care
3. to determine how transitional health care should be commissioned and provided.

## Methods

Three separate work packages (WPs) addressed each of the above objectives.

- Work package 1.1 formed a young people's advisory group, United Progression (UP), which met monthly over the 5-year programme.
- Work package 1.2 explored the usefulness of patient-held health information ('health passports') in a project co-led by UP.
- Work package 1.3 explored the importance young people attached to different elements of transitional health care by undertaking a Q-sort study.
- Work package 2.1 assessed whether or not nine proposed beneficial features (PBFs) of transitional health care contributed to improved outcomes for young people with type 1 diabetes mellitus, cerebral palsy, or ASD and an associated mental health problem. We conducted a prospective study of 374 young people,

who were visited four times, 1 year apart, by research assistants. Outcomes covered participation, well-being, satisfaction with services and condition-specific measures. Young people with diabetes mellitus were recruited from five NHS Trusts in north, south-west and south-east England and Greater London. Those with ASD were recruited from four NHS Trusts in north and south-west England. Those with cerebral palsy were recruited from one NHS Trust in south-east England and two regional population registers in north England and Northern Ireland (covering 17 trusts).

- Work package 2.2 investigated how young people with long-term conditions experienced transition by undertaking in-depth interviews with 13 young people, their families and health professionals.
- Work package 2.3 examined the relative efficiency of illustrative models of transition. It involved a discrete choice experiment, estimating NHS costs, assessing health-related quality of life and modelling cost-effectiveness. This used a Markov model that compared a transition service with a PBF with a service containing no such feature. The model simulated outcomes for a hypothetical cohort of 14-year-olds over a 10-year time horizon, with discounting at 3.5% per annum.
- Work package 3.1 identified the factors enabling or inhibiting the introduction of developmentally appropriate health care (DAH) by undertaking an ethnographic study in three NHS Trusts. We then compiled a toolkit to assist the introduction of DAH.
- Work package 3.2 identified the factors that enabled or inhibited commissioning for effective transition. It involved a literature review, in-depth interviews and site visits.
- Work package 3.3 synthesised learning from the programme on 'what' and 'how' to commission, drawing on meetings with commissioners.

## Results

### *Work package 1.1: involving the UP group*

UP was involved in most WPs and a wide range of activities, such as advising the research team, developing video materials, disseminating results to other young person groups and co-leading a workshop at the final conference.

We forged other patient and public involvement links that included shared project work with the Council for Disabled Children, the Association of Young People's Health and The Health Foundation. Parents, young people and the voluntary sector were represented on the External Advisory Board.

### *Work package 1.2: health passport work*

UP found a lack of conceptual clarity about what a 'health passport' was.

In its survey, UP found that many young people thought that a health passport was a good idea, but that, even if they owned one, they rarely used it.

### *Work package 1.3: Q-sort study*

The Q-sort study identified four interaction styles that young people adopted when approaching transition: 'laid back', 'anxious', 'autonomy seeking' and 'socially oriented'.

Discussing preferences about transition with young people should help clinicians and young people develop personalised planning.

### *Work package 2.1: longitudinal study (quantitative)*

Services provided the nine PBFs very variably. Fewer than half stated that they provided an 'age-banded clinic', 'written transition plan', 'transition manager for clinical team', 'protocol for promotion of young person's confidence in managing their health condition ('health self-efficacy') and 'holistic life-skills training'.

There was a striking mismatch between the features that a service said it provided and the features young people reported that they had experienced. For example, across the three conditions, agreement was 30% for 'written transition plan' and 49% for 'key worker'. Agreement was better at 77% for 'appropriate parent involvement', 77% for 'age-banded clinic' and 80% for 'promotion of health self-efficacy'.

The well-being scores for each condition group remained similar over time. For those with diabetes mellitus or cerebral palsy, their average well-being was similar to that of the general population; those with ASD reported significantly lower well-being. Average satisfaction with services was reasonable at baseline; it remained steady for those with type 1 diabetes mellitus but worsened for those with cerebral palsy or ASD. For participation in life activities, there were significant differences between the three conditions, with young people with type 1 diabetes mellitus in a more independent phase than those with cerebral palsy or ASD. All made progress over time.

Average condition-specific outcomes worsened over the course of the study for those with type 1 diabetes mellitus or cerebral palsy. For those with ASD, average condition-specific outcomes remained the same between baseline and the final visit.

The features of services for transitional health care associated with better outcomes were 'appropriate parent involvement', 'promotion of health self-efficacy' and 'meeting the adult team before transfer'.

'Having a key worker' was inconsistently associated with better outcomes. Features with no evidence of association with better outcomes were 'transition plan', 'age-banded clinic', 'co-ordinated team', 'being part of a service with a transition manager for clinical team' and 'having access to holistic life-skills training'.

### **Work package 2.2: longitudinal study (qualitative)**

Transition and transfer of health care were disorientating and disrupting for young people and their families, in part because hard-earned knowledge about how best to navigate the children's health-care system was lost. Health professionals are in a position to help young people and families adjust to and mitigate these disruptions through actions such as being clear in discussions and documents about processes, explaining how procedures in adults' and children's health care differ and arranging meetings with members of the adult team before transfer.

Although it is important to support young people to become responsible for their health care, family members remain important in this process. Such involvement is normal, not dysfunctional. Family members can be helped to modify their roles so that there is partnership and sharing of care with their son or daughter.

### **Work package 2.3: discrete choice experiment and economics analysis**

Preference for current care was strong, and even stronger for those who had not transferred to an adults' service. Having clinics that welcomed parental involvement was the second most important attribute chosen.

Young people valued clinics in which information was passed on to the right person, parental involvement was welcomed, staff allowed young people to make decisions about their care and the same staff were seen at each appointment. Young people valued seeing the same staff at each appointment more than having a key worker.

In modelling health care, we found the following:

- Differences in health-related quality of life between health conditions, as measured by the EuroQol 5-Dimensions (Youth) (EQ-5D-Y). For those with type 1 diabetes mellitus, the median utility score was 0.94 (0 = worst possible health, 1 = best health) and the sumscore was 5.2 (lower score = better health); the corresponding scores for ASD were 0.76 and 7 and for cerebral palsy were 0.70 and 7. There was a trend towards lower scores after transfer.

- The median annual NHS cost of appointments, medication and investigations for an individual with type 1 diabetes mellitus was £7003, with cerebral palsy was £2934 and with ASD was £2350.
- The cost-effectiveness results suggested that provision of 'having a key worker' and 'promotion of health self-efficacy' represented better value for money. 'Having a written transition plan' and 'having a transition manager for clinical team' represented poorer value for money.
- Implementing features of transitional health care is unlikely to reduce NHS costs over a 10-year time horizon. Therefore, a judgement is needed regarding whether or not the development of a service with, for example, 'appropriate parental involvement', 'promotion of health self-efficacy' and 'meeting the adult team before transfer' would be worth the cost, given that they may increase engagement with services and prevent deterioration in health in the long term.

### **Work package 3.1: barriers to and facilitators of the introduction of developmentally appropriate health care**

Despite different understandings of DAH in the literature, and across clinical and managerial staff, we identified common themes that led to a working definition:

*DAH recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms, DAH focuses on health-care professionals' approach to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.*

Organisational barriers to introducing DAH were (1) no single group in a NHS Trust was responsible for young people, (2) there was perceived (incorrectly) to be a small number of young people attending hospital, (3) the mindset and skill set of many staff were often not ready and (4) good practices led by enthusiasts in one child specialty rarely generalised to other child health specialties or to adult specialties. Organisational solutions to introducing DAH were (1) buy-in and formal support resting at chief executive and board level, and with senior managers in both adults' and children's services; (2) planning that engaged, from the outset, adults' and children's services; and (3) a trust-wide strategy on, and training about, DAH.

We developed a toolkit to assist the introduction of DAH ([www.northumbria.nhs.uk/?s=dahtoolkit](http://www.northumbria.nhs.uk/?s=dahtoolkit)).

### **Work package 3.2: commissioning for transition**

Commissioners and providers of adults' services regarded transition as the responsibility of commissioners and providers of children's services to deal with and improve. This is inappropriate given that transition extends to approximately the age of 24 years.

Many commissioners did not regard transition as a priority.

Transition was not usually monitored by commissioners, partly because there were no nationally agreed outcome and quality indicators.

## **Strengths**

A young person's advisory group was involved throughout the 5 years of the programme.

The sample for the longitudinal study generated the largest study of its kind.

The young people invited to join the longitudinal study were representative of all young people with one of the three chosen conditions, and appeared to remain representative after analysis of non-participation and attrition. In Northern Ireland, there was a small effect of deprivation on the attrition of those with cerebral palsy.

Our study did not include young people with a learning disability, so the results cannot be generalised to this group.

The research into commissioning for transition is the first work of its kind.

The trusts varied greatly in the number and variety of the PBFs they offered. Thus, there was sufficient variety to examine the effects of these features on outcomes, without the analysis being dominated by a combination of features from a few sites.

## Limitations

There was uncertainty about whether or not the regions and trusts in the longitudinal study were representative; however, we recruited from 27 trusts, widely spread over England and Northern Ireland, and the trusts varied greatly in the number and variety of proposed beneficial features offered.

The quality of delivery of each PBF was not assessed.

Owing to the nature of the data, the economic modelling had to be exploratory rather than following a strict, formal approach. Therefore, the economic conclusions should be interpreted with caution.

## Implications for transitional health care

Our results suggest the following:

1. There is an important role for commissioners of adults' services to commission transitional health care, in addition to commissioners of children's services with whom responsibility for transitional health care currently lies.
2. 'Developmentally appropriate health care' is a crucial aspect of transitional health care. Our findings indicate the importance of health services being commissioned to ensure that providers deliver DAH across all health-care services, and that this will be facilitated by commitment from senior provider and commissioner leaders.
3. It is important for NHS Trusts to adopt a trust-wide approach to implementing transitional health care. Setting up a Transition Steering Committee in a NHS organisation is an effective way to improve service quality.
4. Joint planning between adult health-care providers, children's health-care providers and primary care is likely to improve both the transfer of individual young people and the further adoption of ways of working that improve care for this population.
5. Adults' and children's health-care providers could explore with a young person how they approach transition, thereby personalising their clinical approach. We found that young people adopted one of four interaction styles when approaching transition: 'laid back', 'anxious', 'autonomy seeking' or 'socially oriented'.
6. We found that three service features were associated with better outcomes – 'appropriate parent involvement', 'promotion of young person's confidence in managing their health condition' and 'ensuring young people and parents meet the adult team before transfer'. These findings provide practical content to be considered in NHS commissioning specifications.
7. Maximal service uptake would be achieved by a service that encouraged appropriate parental involvement, emphasised the importance of good communication with young people and encouraged young people to make decisions about their care. A service involving 'appropriate parental involvement' and 'promotion of a young person's confidence in managing their health condition' may offer good value for money. A service involving a 'transition manager for clinical team' or an 'age-banded clinic' is unlikely to offer value for money.

## Recommendations for research

1. What are the most effective and efficient ways for the findings of the programme to be introduced and implemented by health commissioners and health-care organisations?
2. What are the most effective and efficient ways for primary health-care services to be involved in improving transition, and in following up young people after transfer (whether or not they meet criteria for adults' services)?
3. What are the most effective and efficient methods of enabling young people with long-term conditions to successfully manage their own health?

## Study registration

This study is registered as UKCRN 12201, UKCRN 12980, UKCRN 12731 and UKCRN 15160.

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