

Impact case study (REF3)

Institution: Newcastle University		
Unit of Assessment: UoA 2		
Title of case study: Improving the transition of young people with long-term health conditions from child- to adult-oriented healthcare		
Period when the underpinning research was undertaken: 2015-2018		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Allan Colver	Professor of Community Child Health, Chief Investigator	1997-2012 honorary contract; 2012-2017 full contract.
Professor Jeremy Parr	Professor of Paediatric Neurodisability, Principal Investigator	2012-present
Professor Luke Vale	Professor of Health Economics	2011-present
Professor Helen McConachie	Professor of Child Clinical Psychology	1998-2017, emerita 2017-present
Professor Ann Le Couteur	Professor of Child and Adolescent Psychiatry	2016-2019, emerita 2019-present
Dr Tim Rapley	Lecturer	2002-2020
Professor Mark Pearce	Professor of Applied Epidemiology	1995-present
Dr Gregory Maniatopoulos	Senior Research Associate	2007-2020
Dr Kay Mann	Research Associate	2010-2018
Dr Hannah Merrick	Research Assistant	2012-2017, PhD student
Ms Jenni Hislop	Research Associate	2017-present 2012-2017
Period when the claimed impact occurred: 2016 onwards		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>Each year, over 25,000 young people with long-term health conditions undergo transition from childhood to adulthood. These young people require specific continuous care, but transition is not always appropriately or adequately provided. Poor transition increases rates of morbidity, including compromised social participation and employment opportunities. A longitudinal Newcastle study with young people in transition, as well as in-depth interviews with health and social care commissioners, identified seven key recommendations. These included encouraging appropriate parental involvement and offering young people the chance to make decisions about their care. These findings have underpinned national policy and guidelines, such as the 2018 Healthcare Quality Improvement Partnership Audit for Transition and the 2019 NHS Long-Term Plan, which are widely used in practice.</p>		
2. Underpinning research		
<u>Background and unmet need</u>		
<p>In the UK, over 25,000 young people with long-term health conditions undergo transition from child-centred to adult-centred healthcare each year (R2). Although they require specific continuous care, it is sometimes not appropriately or adequately provided by either children's or adult services during this transition period; and the transfer between services is often poorly managed. Poor transition and transfer compromise further education and employment, and increase long-term healthcare costs¹.</p>		
<u>Newcastle research: the five-year NIHR-funded Transition Research Programme</u>		
<p>Newcastle research began with a study of 40 young people with long-term health conditions to determine factors important to them during transition (R1). This study was the first in its field to use Q methodology, combining qualitative and quantitative methods to identify the range of</p>		

¹Colver et al. 2020 DOI: [10.7861/clinmed.2019-0077](https://doi.org/10.7861/clinmed.2019-0077)

viewpoints on an issue. The main findings were that young people had a preferred interaction style and valued being seen as an individual.

Subsequently, exploratory work was undertaken with commissioners and providers to identify their perspectives (R2 and R3). In R2, the first study to contribute evidence on commissioning for transition, 29 commissioners were interviewed and data were analysed using the framework approach. In R3, semi-structured in-depth interviews were carried out with 30 commissioners and providers. The main findings were: 1) transition should be personalised, coordinated and collaborative; 2) transition should be realised through building universal services, i.e. available to all of these young people; and 3) integration of commissioning was key.

The next two studies within the Programme were R4 and R5. R4 was a four-year observational longitudinal cohort study of 374 young people - the first study at this scale. Recruitment started in 2012 and took place across England and Northern Ireland. Participants had one of three highly representative long-term conditions: 150 with type 1 diabetes; 118 with autism spectrum disorder and additional mental health problems; and 106 with cerebral palsy. R4 found that three particular features of transition had significant positive associations with better outcomes. These were: “appropriate parent involvement”; “promotion of health self-efficacy”; and “meeting the adult team before transfer”. However, a mixed-methods study including qualitative interviews (R5) showed that implementation of these features was inconsistent. Together, R4 and R5 showed that the essence of good transitional care is good developmentally appropriate healthcare, but that this is not always consistently provided.

Finally, a scoping study (R6) found that use of the term “Developmentally Appropriate Healthcare” (DAH) in the literature was inconsistent. In a consequent ethnographic study (R7), 65 semi-structured interviews of healthcare professionals and managers explored their definitions and concepts of DAH. The five dimensions identified showed similarities with those found in R4 and R5, including “acknowledgement of young people as a distinct group” and “empowerment of the young person by embedding health education and health promotion.”

The findings of these studies were synthesised into seven key recommendations for policy and practice:

1. Transitional healthcare should be jointly commissioned by adults’ and children’s health service commissioners (R2, R3), rather than just children’s commissioners as at present.
2. It is essential to ensure that DAH is delivered across all services as it recognises the changing biopsychosocial developmental needs of young people (R2, R3, R6, R7).
3. NHS Trusts should adopt a Trust-wide approach to implement transitional healthcare (R2, R3, R7).
4. GPs, adult and childhood clinicians must plan transition procedures together (R2, R3).
5. The preferred interaction style of the young person should be identified and adopted to personalise communication (R1, R7).
6. Transition services should implement three specific features: 1) parental involvement, suiting parent and young person; 2) promotion of a young person’s confidence in managing their health; and 3) meeting the adult team before transfer (R5, R7).
7. Services uptake and value for money would be improved by encouraging appropriate parental involvement, staff continuity and offering young people the chance to make decisions about their care (R4, R5, R7).

3. References to the research

SciVal field-weighted citation impact (FWCI) as of December 2020. Newcastle researchers in **bold**.

- R1. **Hislop J**, Mason H, **Parr JR**, **Vale L**, **Colver A**. (2016) Views of Young People With Chronic Conditions on Transition From Pediatric to Adult Health Services. *Journal of Adolescent Health*. 59(3):345-53. DOI: 10.1016/j.jadohealth.2016.04.004. FWCI: 1.99.
- R2. **Kolehmainen N**, **McCafferty S**, **Maniatopoulos G**, **Vale L**, **Le Couteur A**, **Colver A** on behalf of the Transition Collaborative Group. (2017) What constitutes successful

commissioning of transition from children's to adults' services for young people with long-term conditions, and what are the challenges? An interview study. *BMJ Paediatrics Open*. 1:e000085. DOI: 10.1136/bmjpo-2017-000085. FWCI: 0.52.

- R3. **Maniatopoulos G, Le Couteur A, Vale L, Colver A.** (2018). Falling through the gaps: exploring the role of integrated commissioning in improving transition from children's to adults' services for young people with long-term health conditions in England. *Journal of Health Services Research & Policy*. 23(2):107-15. DOI: 10.1177/1355819617752744. FWCI: 1.08.
- R4. **Colver A, McConachie H, Le Couteur A, Dovey-Pearce G, Mann KD, McDonagh JE, Pearce MS, Vale L, Merrick H, Parr JR** on behalf of the Transition Collaborative Group. (2018) A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC Medicine*. 16(1):111. DOI: 10.1186/s12916-018-1102-y. FWCI: 6.86.
- R5. **Colver A, Pearse R, Watson RM, Fay M, Rapley T, Mann KD, Le Couteur A, Parr JR, McConachie H** on behalf of the Transition Collaborative Group. (2018) How well do services for young people with long term conditions deliver features proposed to improve transition? *BMC Health Services Research*. 18(1):337. DOI: 10.1186/s12913-018-3168-9. FWCI: 1.67.
- R6. Farre, A, **Wood V, Rapley T, Parr JR**, Reape D, McDonagh JE. (2015) Developmentally appropriate healthcare for young people: a scoping study. *Archives of Disease in Childhood*. 100(2):144–51. DOI: 10.1136/archdischild-2014-306749. FWCI: 1.79.
- R7. Farre, A, **Wood V**, McDonagh JE, **Parr JR**, Reape D, **Rapley T** on behalf of the Transition Collaborative Group. (2016) Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. *Archives of Disease in Childhood*. 101(7):628-33. DOI: 10.1136/archdischild-2015-309473. FWCI: 3.29.

N.B. R6 and R7 are a product of the Transition Research Programme. Both studies feature Parr as an author and were co-ordinated and overseen by Professor Allan Colver, Newcastle University, the Chief Investigator of the Programme.

4. Details of the impact

Impact on policy and guidelines

Newcastle research has had a direct impact on several high-level policy documents. First, findings from R6 directly informed definition of the term “developmentally appropriate care” in the 2016 NICE guideline NG43 (EV1).

This NICE guidance in turn informed the 2018 Royal College of Paediatrics and Child Health Standards document (EV2), providing the reference for the statement on page 32: “Service planners must ensure that services are jointly planned for all young people making a transition from children's to adults' services and that the necessary supporting infrastructure...is in place”. In addition, a toolkit developed by Newcastle (see below) is given as a practice example on page 34.

Secondly, the seven key recommendations put forward by Newcastle are directly given in the standards and guidelines for the 2018 Healthcare Quality Improvement Partnership Audit for Transition (EV3, page 3) under the section “Implication for Transition Services - Newcastle Transition Research Group”.

In 2019, Newcastle researchers were invited by the National Clinical Director for Children, Young People and Transition to Adulthood, NHS England, to submit research evidence to support proposals for improving transition. These proposals directly informed the 2019 NHS 10-year Long Term Plan (EV4) as follows:

Page 46: “The NHS plays a crucial role in improving the health of children and young people: from pregnancy, birth and the early weeks of life; through supporting essential physical and cognitive development before starting school; to help in navigating the demanding transition to adulthood.”

Page 51: “A new approach to young adult mental health services for people aged 18-25 will support the transition to adulthood.”

Page 52: “Keyworker support will also be extended...including to young people in transition to adult services.”

Page 55: “Selectively moving to a ‘0-25 years’ service will improve children’s experience of care, outcomes and continuity of care... By 2028 we aim to move towards service models for young people that offer person-centred and age appropriate care for mental and physical health needs, rather than an arbitrary transition to adult services based on age not need.”

Page 119: “The NHS, together with partners at national and local level, will commit to improve outcomes for our most vulnerable children...by improving access to targeted support for these children, especially during transition to adult services.”

The previous National Clinical Director for this area provided a letter of endorsement (EV5) citing R1-2, R4-5 and R7. The letter confirms that “this research informed the statements about Transition in the January 2019 NHS 10-year Long Term Plan.” The new National Clinical Director was briefed at his request by the Newcastle Research Group in June 2020 (EV6) to inform the Children and Young People’s Transformation Programme. This resulted in publication of the NHS England National Framework For Transition in December 2020, which was informed both generally and specifically by Newcastle research as follows:

Page 11: “There should be co-production with the child or young person and their families at all stages of the care model... Parents/carers should be involved in a way that suits both the young person and the parent/carer,” directly citing R5.

Page 19 cites the Developmentally Appropriate Healthcare model as an exemplar local model of care.

Impact on practice

A toolkit to assist with implementation of Developmentally Appropriate Healthcare was created by the Programme co-investigators (including Parr and Colver) and is downloadable from www.northumbria.nhs.uk/dahtoolkit.

In June 2020, a survey was distributed around users of the DAH toolkit, including NHS Trusts and commissioners, across England and Northern Ireland. From the 48 responses, the following main findings were seen, broadly showing that the seven key recommendations put forward by Newcastle were being adopted into practice (EV7):

- 57% stated that their Trusts recognised young people as a distinct group regarding healthcare and provision.
- 60% stated that their Trust had a policy for promoting a young person’s confidence in managing their own health.
- 75% stated that their Trust had adapted environments in which young people are seen.
- 76% stated that their Trust had policies and processes in place to support transition.
- 92% agreed that parents and young people were involved in a manner which aims to suit them both during consultations.
- 96% agreed that children’s clinicians plan transition processes jointly with adults’ clinicians in their Trust.
- 100% discussed transition with the young person and provide them with written information.

These results indicate that commissioners are starting to provide appropriate transition services for young people with long-term health conditions. Together with the recognition of the importance of successful transition in the NHS Long-Term Plan, there is clear evidence that Newcastle research is improving the way in which these young people undergo transition.

5. Sources to corroborate the impact

EV1. NICE 2016 Guideline NG43: Transition from children's to adults' services for young people using health or social care services. See page 16 for direct reference to R6. Available at <https://www.nice.org.uk/guidance/ng43>

EV2. Royal College of Paediatrics and Child Health March 2018: Facing the Future: Standards for children with ongoing health needs. Available at

https://www.rcpch.ac.uk/sites/default/files/2018-04/facing_the_future_standards_for_children_with_ongoing_health_needs_2018-03.pdf

EV3. Healthcare Quality Improvement Partnership August 2018: Addressing child to adult transition in national clinical audit – A guide. Appendix II, available at

<https://www.hqip.org.uk/wp-content/uploads/2018/08/Appendix-II-Transition-Final-2.pdf>

EV4. NHS 10-year Long Term Plan 2019. Available at

<https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>

EV5. Letter from the previous National Clinical Director, Children, Young People and Transition to Adulthood, NHS England.

EV6. Letter from Policy Manager, Children's and Young People's Transformation Team, NHS England and NHS Improvement.

EV7. Data from Qualtrics survey 31st July 2020, available on request.