

Transition of Care Programme

Final Report 2018





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With thanks to Queen's Nurse Carrie James, Transition Case Manager, Walsall Health Care NHS Trust and the young people on their activity afternoon who consented to be photographed for the project. © Kate Stanworth



Foreword

It has been a privilege to chair the Advisory Group of The Queen’s Nursing Institute’s Transition of Care Programme - managing the transition from children’s to adults’ community services.

I would like to personally thank the Burdett Trust for Nursing for supporting this project, Dr Candice Pellett OBE, QN, for leading this work and our colleagues on the advisory group. This project has shown how listening to and working with young people, their families and health care professionals can make a huge difference to quality of care. They have all been a fundamental part of this journey.

A special mention should go to Hannah Phillips who has been an amazing advocate, travelling the length and breadth of the country to spread the word and also to the team in Walsall who contributed so much to the project and the film. What has been achieved is second to none, with outputs including the literature review, online resources and the conference. The feedback we have received has been extremely positive and I would encourage all nurses involved with caring for children and young people to use them.

The conference held in 2017 was a highlight of the programme. The professional speakers and poster presentations provided a great insight into what can and should be achieved. The networking during the day and subsequent to it has shown the impact that this learning event has already had. The day elicited profound emotions and provided everyone with so many issues to reflect on.

There are a number of words that came to mind when I reflect on that day and what has been achieved with this project: insightful, inspirational, all-inclusive, and equitable. It also encapsulated the nursing philosophy I aspire to within my clinical practice: safe, secure, accepted and informed.

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Introduction

Moving from children’s to adults’ services is a pivotal moment in the lives of young people living with long term health conditions. It is the point where, if engagement is not on their terms, they can be lost in a fragmented healthcare system, which can be detrimental to their long term health and wellbeing.

The Queen’s Nursing Institute (QNI) identified that there is a limited understanding of the importance of this ‘transition’ process in primary and community care, where the majority of care takes place. In addition, many existing models of transition focus on the hospital environment rather than on the community setting. However with advances in treatment, more young people with complex health needs are now surviving into adulthood and require nursing support from District and General Practice Nurses, which would not have been the case relatively few years ago.

The QNI applied for funding in 2015 from the Burdett Trust for Nursing to deliver a new programme to support best practice in the experience of children and young people transitioning from children’s to adult community health services. The programme focused on providing evidence based information and guidance to District Nurses, General Practice Nurses and Nurse Educators, to enable them to support young people more effectively through this challenging time and to improve and develop the services and systems.

Nurses involved with the project initially reported that they were committed to supporting young people through the process, but felt that they were not well equipped in terms of the specialist knowledge to do so. The project was designed to equip nurses with the knowledge and skills required to engage with and support young people, whilst enabling the young person’s voice to be heard. The project sought complementary knowledge from relevant specialists such as learning disability nurses, community children’s nurses, nurses working in child and adolescent mental health services (CAMHS) and school nurses. Critically, there was strong engagement with young people and their parents throughout the life of the project.

To support the delivery of the project, the QNI formed an Advisory Group of experts in the care of children and young people. The Advisory Group supported the project team to improve the health and wellbeing of young adults, through the enhancement of the skills and knowledge of community nurses. The nine Advisory Group members, chaired by a QNI Fellow, were primarily Queen’s Nurses from a range of clinical disciplines relevant to the transition project and a young adult who provided a view on the young person’s experience of transition to adult services. The group met formally on four occasions during the two years of the project. They also gave ongoing support and advice to the project team and were actively involved with the development of the online learning resource.

The NICE Quality Standard QS140 (2016) ‘Transition from children’s to adults’ services’ were used as a framework for the project.





Summary Outcomes

The QNI project resulted in the following outcomes:

- A national network of 470 Transition Nurse Champions has been established;
- Learning resources have been developed specifically for nurses working in the District Nursing service, in General Practice and in Higher Education, who have pledged to use the resulting learning resource to further their own knowledge and to cascade this to teams and organisations;
- A National Conference was held and attended by over 250 people in November 2017;
- A literature review was undertaken addressing key questions linked to transition, with a primary care and community nursing focus.
- More than 1000 nurses have been in contact with the QNI and shared their learning from the project;
- Close to 500 responses were received to the online surveys, which informed the development of the resource;
- 10 focus groups were held, involving 200 nurses, young people and their parents
- Universities have pledged to develop Transition of Care as a module or course component for the first time; the QNI learning resource will be used as a framework within the curriculum;
- Pilot sites of District Nursing teams, General Practice Nurses and Nurse Educators have been supported to use the learning resource to improve their knowledge and skills and provide engagement with young people;

One of the most positive additional outcomes of the QNI project was the level of engagement from young people and nurses. Their willingness to work together to achieve solutions to questions and challenges was inspirational.

Project Development

The development of the project can be broken down into five stages, as follows:

1. Stakeholder engagement
2. Review of current education and training opportunities
3. Resource development
4. Clinical champion and network development
5. Dissemination of good practice.

Stakeholder Engagement

Focus Groups

Throughout the first phase of the project, ten focus groups were delivered in different areas of the country in order to gain an understanding of the issues for young people, their parents and the nurses involved in their care through the transition period. Originally it was planned to hold six events but the interest was so overwhelming that this number was increased.

All focus groups were facilitated by the QNI project manager working with a young person who set the scene by describing her experience of transition. Eight focus groups were convened for nurses from practice, policy, education and commissioning, all of whom were involved in supporting the care of young people with complex long term conditions and life-limiting illnesses. In addition, one focus group was dedicated to parents and one to young people themselves. It must be noted that many of the nurses were also keen to relate their own experiences of being a parent of a young person going through the transition process.

Comments included:

'Everyone in the room wanted to make a difference for young people and their families. The networking has been inspiring and I will be communicating with several nurses I have met today to see how we are all progressing with our transition pathways.'



'In my experience as a General Practice Nurse, the transition process is not well coordinated between children's services and adult community services. The young person is often left without knowing who they are to contact if an issue arises and the families are left worried, anxious and frustrated.'

'I would have liked the transition process to have been much more organised. Communication is a massive barrier throughout the health service and that makes life very difficult for parents. IT systems must be put in place in order for community adult services to be joined up with children's services. The Practice Nurse had no idea of my son's health needs when we arrived for an appointment – there was nothing on the GP system to say what was going on with my son.'

'I know a family with a vulnerable young daughter who should be transitioning to adult community services but our District Nursing service does not accept any referral until the person is 18 years old and she is 17'. The feedback from the focus groups has been analysed and the summary can be found on the QNI website at: <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>.

Surveys

To enable a wide reach to relevant stakeholder groups, three online surveys were developed in consultation with Queen's Nurses, nurse educators and a young adult with personal experience of the transition process. The three surveys identified the issues around transition of care from the perspective of:

- Community and primary care nurses
- Nurse educators
- Young people and their carers

The surveys were open to responses between March and September 2016 and 499 responses were received across the three surveys. The data were collated and informed the content of the online learning resource.

In total 397 people from mixed clinical disciplines responded to the community and primary care nurses' survey. Many comments received highlighted the fact that the transition from children's to adult health services is a time of physical, emotional, social and psychological change for young people and often an anxious time for families, carers and professionals. Young people are faced with adapting to adult healthcare services that are very different from the services they have used as a child.

Comments included:

'Main concern is that they are poor attenders and in adult services we are limited in the time available to chase up and provide more accessible services.'

'Adult community nurses do not carry out the same role as us and so sometimes find there are gaps where there are things we would normally do for a family that District Nurses don't have capacity for.' (Community Children's Nurse, Community Health NHS Trust)

'Huge gaps - the young person just "appears" without any support to them, the family or community services. There is no support with this from our community Trust – The General Practice Nurses struggle as well.' (District Nurse, Community Health NHS Trust)

Literature Review

The QNI undertook a literature search at the beginning of the project to identify relevant published research in relation to the transition of care and community and primary care nursing; a review of relevant policies and best practice guidance was also included.



Overall, the literature review has reinforced the view that there is a lack of robust research available on transitional care, in particular relating to effective practice in community and primary care settings. A gap remains in the evidence available to date of the role of community nurses, including the district nurse and the general practice nurse, in supporting young people's transition from children's to adult health services.

The literature was reviewed throughout the project as new evidence became available. It is hosted on the QNI website at: <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/> .

An article on the findings of the literature review was published in the British Journal of Community Nursing (BJCN), January 2017. The link to the abstract can be found at: <http://www.magonlinelibrary.com/doi/10.12968/bjcn.2017.22.1.668>

Resource development

An online learning resource was developed in the first year of the project. The content incorporated the feedback and data collated from the ten focus groups and the three online surveys in addition to discussions and visits to a number of service and education providers throughout England during 2016.

To ensure the online learning resource contained the most relevant content, three professional reference groups were formed to review the Introduction and the three modules, including experts from District Nursing, General Practice Nursing, nursing education and the Chair of the Advisory Group.

The resource has four parts:

- Introduction including a 'talking heads' film
- Module 1 for District Nursing Teams
- Module 2 for General Practice Nurses
- Module 3 for Nurse Educators.

The resource was piloted with an online questionnaire, to capture feedback once the modules had been completed. The feedback gathered from approximately 1000 users, including nurses, young people and their parents, has provided evidence of the benefit of the resource in supporting young people during transition. The response from nurses who have used the resource has been overwhelmingly positive.

All three modules include a workbook that can be used with the resource to reflect on practice and will provide evidence of professional development for NMC revalidation.

The resource can be accessed on the Queen's Nursing Institute website at: https://www.qni.org.uk/child_to_adult/index.php

A summary of the feedback is available here: <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>

Comments included:

'The learning resource is a great place to build confidence in how to access services in the adult arena.'

'Love the way the modules are cross-referenced. Nursing students find the comprehensive bibliography and references so useful for their assignments.'

'Good resource, challenging as individual staff do not deal with transitions regularly.'

The resource is linked on external websites including Great Ormond Street Hospital, London and Alderhey Children's Hospital, Liverpool.





Clinical Champions and Network Development

There was an overwhelming level of interest from nurses across all community and primary care specialties, resulting in the designation of over 470 new 'Nurse Champions'. Nurses were invited to declare what actions they were taking to support young people and their families; during the life of the project three online newsletters were produced to engage with the nurse champions and these contained case studies, policy updates and examples of best practice during 2017.

Dissemination of Good Practice

Nurses were encouraged to volunteer their team or organisation to be a pilot site for the Transition of Care resource, to test if it enabled nurses to enhance the transition experience for young people in their care.

Six groups were identified to review and improve their approach to the Transition of Care process. The groups reflected a wide range and size of organisations – from General Practice to a District Nursing Service. Nurse educators were also supported within the pilot groups, with visits to eight universities over a 12 month period. To ensure diversity of approach the groups selected were:

1. A large inner city District Nursing team and a large rural District Nursing team supporting student nurses on their practice placements.
2. A hospice was also supported to use the resource. The hospice has subsequently held a transition conference and is now using the resource as part of their in-house training.
3. Two universities were supported to use the resource with their Specialist Practitioner Qualification students (District Nursing).
4. A further six universities invited the project manager to discuss the learning resource with their specialist practitioner (District Nursing) students.
5. Engagement with Clinical Commissioning Groups (CCGs) commenced at the start of the project and continued through their representation at focus groups and attendance at the Transition of Care conference in November. One CCG is planning to incorporate the learning resource into its workforce learning strategy from 2018.
6. General Practice Nurses (GPNs) were generally more challenging to engage due to time restraints in their practice day; however the GPN on the QNI advisory group shared the learning resource with GPNs throughout Cambridgeshire.

The resource was enthusiastically welcomed by nurses working to support young people making the transition journey.

A District Nurse commented:

'Myself, clinical sister, two Band 5 nurses and a student have complete the module and the main element was the lack of understanding how the individual being transferred may feel, especially after being under a nursing team for so long. I think the scenarios helped them relate to this and when they were completing the module I could hear them passing comments to each other on how they would introduce themselves and to acknowledge a level of understanding with the individual, and being able to guide them to be more independent with their medical need.

'I do feel from completing the module that there is gap in this transfer and when we accept referrals it appears that their parents conduct a lot of care, therefore I have realised it is obtaining that understanding with them so we can offer the right level of support without their parents feeling that we are interfering.'

Completed feedback can be found here: <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>



Promotion and Dissemination of the Project

In year two of the project several universities invited the project manager to present sessions to groups of nursing associates, pre-registration nursing students and registered nurses undertaking the Specialist Practitioner Qualification (District Nursing). In total, approximately 500 students were reached in the classroom setting over the course of the project. These events were well received by the nursing students and university staff and feedback was excellent.

The project manager presented at three conferences during 2016 and four conferences in the final year. The work has been promoted and discussed at all QNI events, which led to more people becoming involved in the project. The project was also presented and discussed at Queen’s Nurse regional meetings.

A blog about the transition project was posted on Public Health England ‘Week of Action’ in November 2016 and this created a great deal of positive feedback on Twitter and Facebook. Further blogs are on the QNI Transition of care webpage <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/> . The project manager also worked with the Preparing for Adulthood Programme delivered by the National Development Team for Inclusion at NHS England.

In 2017 four published articles featured the project:

- 20 March – 2 April 2017, Independent Nurse, p. 35, ‘Managing the Transition from Children’s to Adults’ Community Services
- 20 March 2017, Together for Short Lives e-Bulletin, Transition Resource
- 14 March 2017, Nursing Standard (RCNi) , Transition Resource
- 14 March 2017, www.nursingtimes.net , Transition Resource

Final Conference

Planning began in year two for a final conference for the project. This was held in London at The Royal College of General Practitioners on 10th November 2017 and attracted over 250 delegates. The audience comprised a mixed group of clinical staff, allied health professionals, educators and nursing students. A summary of the presentations can be found here: <https://www.qni.org.uk/news-and-events/events/transition-care-conference/>

Poster presentations were invited from nurses working in the community and primary care to promote any area of their clinical practice which reflected the conference theme of Transition of Care.

Recommendations

The NICE Quality Standard QS140 (2016) ‘Transition from children’s to adults’ services’ were used as a framework for the QNI project and it is recommended that organisations use these Standards for all transition pathways.

This Quality Standard covers the period before, during and after a young person moves from children’s to adults’ services in all settings where transitions from children’s to adults’ health or social care services take place. It covers all young people (aged up to 25) who are using children’s health and social care services that are due to make the transition to adults’ services. This includes young people with mental health problems, disabilities and long-term, life-limiting or complex needs, those in secure settings or under the care of local authorities. It describes high-quality care in priority areas for improvement.



The Quality Standard includes five Quality Statements:

Quality Statement 1: Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Quality Statement 2: Young people who will move from children's to adults' services have an annual meeting to review transition planning.

Quality Statement 3: Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.

Quality Statement 4: Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.

Quality Statement 5: Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' service and given further opportunities to engage.

Reference: <https://www.nice.org.uk/guidance/qs140>

Summary

Making the transition from a structured and supportive paediatric environment to adult health services can be a bewildering and distressing experience. Nurses working in community and primary care have a huge contribution to make in improving this experience for young people. There are many aspects to a successful transition process, including the provision of skilled and informed nursing support to young people and their parents to enable greater independence in taking responsibility for and making decisions about their own health, while supporting parents to 'let go' of managing their child's health.

Nurses can engage positively with young adults and support their transition from paediatric to adult services, helping them to negotiate multiple pathways and agencies, to achieve the same level of service that was provided through a 'joined up' children's service,

In 2018, the QNI plans to re-visit the six pilot groups to review evidence of the impact of the resource and explore how nurses have addressed the concerns of young people, to ensure they experience a smooth transition of care.



Acknowledgements

With thanks to all the nurses, educators, young people and families who contributed at all stages of this project.

Advisory Group Members:

- Sue Boran QN, Education Representative
- Debbie Bromley QN, Specialist Nurse for Looked After Children Representative
- Lizzie Chambers, Executive Director, Transition Taskforce, Together for Short Lives
- Ruth Foster QN, District Nursing Representative
- Janet Gower QN, Nurse Practitioner (GPNs) Representative
- Carrie James QN, Health Transition Specialist Case Manager Representative
- Sandra Lawton OBE, QN, QNI Fellow (Chair)
- Anne Pearson, Director of Programmes, QNI
- Dr Candice Pellett OBE, QN, Project Manager
- Hannah Phillips, Patient Voice Representative
- Sheila Thomas QN, School Nursing Representative





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