

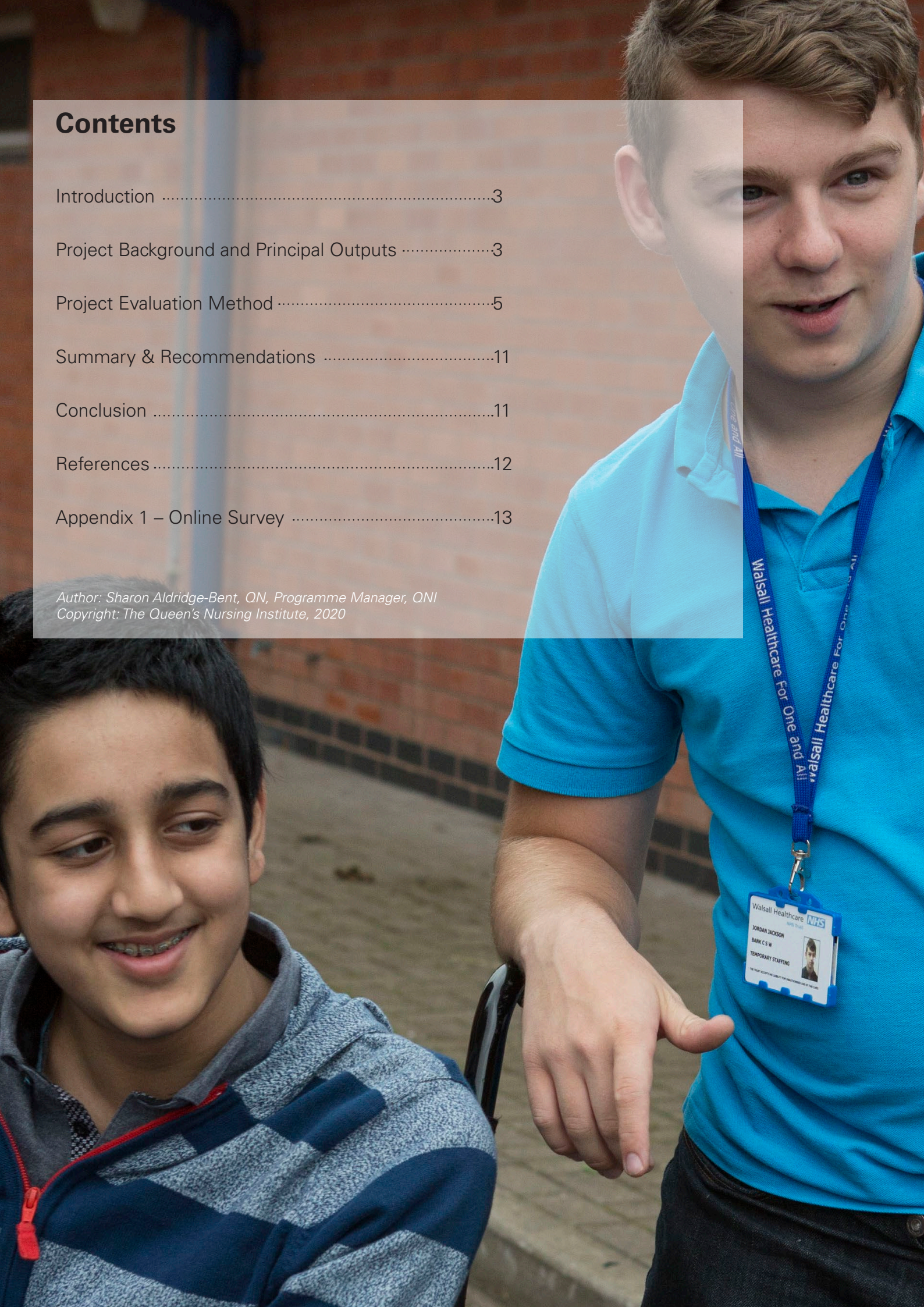
# Transition of Care Programme EVALUATION



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Once people reach young adulthood, they are normally required to transition to mainstream adult health services. This process can be stressful and confusing for young people and their families if there are gaps in communication.



## Introduction

The Queen’s Nursing Institute (QNI) was funded by the Burdett Trust for Nursing in 2016 to deliver a programme of work to improve the experience of young people transitioning from children’s services to adult community services, with a specific focus on District Nursing, General Practice Nursing and Nurse Educators.

This report evaluates the impact of the learning resource developed as part of the programme and how nurses have used the learning from the resource to address the concerns of young people to ensure they experience a smooth transition of care. This report was finalised at the time of the Covid-19 pandemic and gave the QNI the opportunity to disseminate the resource to all Higher Education Institutions involved with nurse education as a free online learning resource. The majority of university-based classes for nurse education in 2020/21 are currently online and this resource has never been more useful to students and educators.

Key stakeholders were consulted to obtain their views, perceptions and experiences of young people transitioning into adult community services for the purposes of this report. The report makes four recommendations for practice going forward to underpin the sustainability of the work performed to date.

## Project Background and Principal Outputs

The QNI undertook a two-year project funded by the Burdett Trust for Nursing, to deliver a comprehensive programme to help community nurses empower young people to transition smoothly between Children’s Services and Adult Community Services.

People who are born with, or who have been diagnosed with a long-term health condition during childhood are supported by dedicated children’s services often delivering an intensive, individualised care management programme as well as working with, and supporting, their parent(s) or guardian(s). Once people reach young adulthood, they are normally required to transition to mainstream adult health services. This process can be stressful and confusing for young people and their families if, for example, there are gaps in communication and understanding or a lack of joined up working. This can lead to omissions in care delivery and potentially to adverse health impacts.

Information about the development and outputs of the project are collated on the QNI’s website here: <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>

## Delivery of the Project

The QNI initially carried out a comprehensive literature review which confirmed that there was a lack of robust research available on transitional care, particularly relating to effective practice in primary and community care settings which was reiterated by Colver A., et al (2018)

During the two years of the project, three online surveys were also developed in consultation with a range of Queen’s Nurses, Nurse Educators and a young adult with personal experience of the transition process from children’s to adult community services. The three online surveys were intended to identify the key issues around transition of care from the perspective of:

- i) Young people and their carers
- ii) Community and Primary Care Nurses
- iii) Nurse Educators

In addition ten focus groups were organised in different parts of England. Each was attended by around 25 participants. More information about the focus groups is given in the original Project Manager’s report on the QNI website.

Six pilot sites/groups were also identified to participate in the project and supported to review their approach to the Transition of Care process. These pilot site/groups reflected a wide range and size of organisation, from a General Practice Nursing team to a District Nursing Service. Nurse Educators were also involved with the pilot site/groups with visits undertaken to several universities over a period of 12 months.

To ensure that diverse nursing settings and populations were included, the pilot site/groups selected were:

1. An inner-city District Nursing team with a large number of patients on the caseload and a rural District Nursing team with an equally large caseload. In both these groups there was an intake of student nurses undertaking their practice placements as part of their courses;
2. General Practice Nurses (GPNs) in Cambridgeshire were provided with the draft learning resource (see below), a process facilitated by a GPN member of the project advisory group;
3. A medium-sized hospice in Surrey was also supported to use the resource; the hospice has since held a transition conference and is now using the resource as part of its in-house training;
4. Two universities, in London and Lancashire were supported to use the resource with their District Nurse Specialist Practitioner Qualification students;
5. An additional six universities invited the project manager to talk to their students about the development and implementation of the learning resource;
6. Engagement with Clinical Commissioning Groups (CCGs) took place throughout the project, including their representation at focus groups and attendance at the QNI's Transition of Care conference in November 2017.

### **The Transition of Care Learning Resource**

Following on from the pilot site evaluations, an online learning resource was developed over several months and published in 2017. The content was written following the feedback and data collated from the ten focus groups and three online surveys referred to above.

Feedback that informed the development of the resource was gathered from a total of over 850 people from a range of sources including The Queen's Nurse Network, the Association of District Nurse Educators (ADNE), District Nurses, General Practice Nurses, Community Nurses, Nurse Educators, Nursing Students (pre and post registration), Hospital Nurses, Doctors, and Young People.

The resource can be accessed on the QNI's website here: <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>. It includes a short video recording of the views of young people in transition from children's to adult services and of practitioners working in the field.

The resource is structured in four parts:

- Introduction, which includes a 'Talking Heads' film
- Module 1 for District Nursing Teams
- Module 2 for General Practice Nurses
- Module 3 for Nurse Educators.

### **Transition of Care Conference**

In November 2017, the Queen's Nursing Institute held a national 'Transition of Care' conference to discuss the journey that young people take from children's services into adult services and to enable them to share their experiences directly. The audience of over 200 delegates included healthcare professionals, educators and nursing students.

More information about the conference including the delegate guide and some of the key presentations can be found on the QNI website: [www.qni.org.uk/news-and-events/events/transition-care-conference/](http://www.qni.org.uk/news-and-events/events/transition-care-conference/) The conference was well evaluated with over 85 responses to the online evaluation received after the event.

The passion and commitment of the project manager cannot be overstated and this dedication clearly contributed to the success of the programme's objectives of benefiting patients.



Responses were extremely positive and can be summarised in a selection of the quotes below:

*'An inspirational conference. Very well organised. All speakers were excellent. Together with the transition resource, everyone was equipped to make a positive difference to practice in the future. Thank you to all.'*

*'An excellent day, listening to all the wonderful work that is being done to facilitate transition from children to adult services. I intend to engage with the work on the QNI website to help develop my knowledge further.'*

*'... this subject is relevant to all care givers regardless of professional proximity. It was really worthwhile attending the conference: a great opportunity to network with colleagues and a particular privilege to listen to the young adults. I have since reflected on my previous awareness in the context of new-found knowledge with a view to influencing leadership, management and practice development in my own area of specialist practice. Thank you QNI and the Burdett Trust for providing this wonderful event!'*

### **Project Evaluation Method**

This evaluation report was informed utilising a range of methods:

- Meeting with previous Project Manager
- Telephone call with the Chair of the Project Advisory Group
- Meeting with Patient Voice Representative
- Meeting with the National Lead Nurse, Burdett National Transition Nursing Network
- Meeting with an Education Representative
- District Nursing Pilot Site Feedback
- Feedback from Director of Programmes, 'Together for Short Lives' charity
- Feedback from a Specialist Nurse for Looked after Children.
- Online survey – eighteen responses received

### **Meeting with previous Project Manager**

Meeting with the previous project manager was of fundamental importance in order to get an overview of the details and scale of the project. The discussion provided crucial information to ensure the accuracy and continuity of the evaluation process, which had been considered at the outset of the project and was also part of the final programme report, where a further review of the impact of the resource had been recommended.

The passion and commitment of the project manager cannot be overstated and this dedication clearly contributed to the success of the programme's objectives of benefiting patients, families and communities. The project manager went on to take up a nursing role with the Roald Dahl charitable foundation, Roald Dahl's Marvellous Children's Charity, focussing on Transition work and utilising the knowledge and skills developed during this project. This may be viewed as an additional successful outcome of the QNI project, in sharing and spreading the learning and the resource developed during this project further into the voluntary sector. The project lead has also remained available throughout the duration of this evaluation and has attended a further meeting when a more in-depth scrutiny of the data was required.

### **Telephone call with the Chair of the Advisory Group**

The Chair of the Advisory group provided invaluable insight into the work of this expert panel and she was enthusiastic about how cohesive and productive the group became throughout the duration of the project.

She wrote, *'It has been a privilege to chair the Queen's Nursing Institute's Transition of Care Programme. This project has shown how listening to and working with young people, their families and health care*



As I've grown older within the healthcare system, I've realised how the profile of young patients can be non-existent in healthcare services.



*professionals can make a huge difference. They have all been a fundamental part of this amazing journey. What has been achieved is second to none with the literature review, online resources and the conference. There are a number of words that came to mind when reflecting on what has been achieved with this project: insightful, inspirational, all-inclusive, and equitable, safe, secure and accepted.'*

### **Meeting with the Patient Voice Representative**

Whilst meeting with the patient representative for the programme, she provided the reviewer with a very personal and lived experience of how she became involved with the project.

At six months old she contracted meningitis and was later diagnosed with an incurable heart condition. This meant she had to spend a lot of her childhood in and out of hospital undergoing many operations and treatment regimes. As she entered her teenage years and had to move from children's to adult care, her negative experiences of transition fuelled her with the energy to influence and advocate for changes to be made in the way that services are delivered and integrated with one another.

The representative wanted young patients' voices to be heard with a principal aim of helping them to avoid the kind of negative experiences she had undergone during her transition to adult services. Her comments for the purposes of this evaluation included:

*'As a child I felt like a human – as an adult I felt like a number.'*

*'The transition process wasn't an easy one for me. As I've grown older within the healthcare system, I've realised how the profile of young patients can be non-existent in healthcare services. All of a sudden, we go from playrooms and schools, to big white rooms and restricted visiting hours.'*

She decided to dedicate her time to work as an effective advocate of the QNI project, following a conversation with her father who encouraged her to 'find her voice.' She wrote:

*"Touring' with the QNI during this project has been such an eye-opening experience. Whilst it's been a real pleasure to share my story and provide nurses with a deeper understanding of what it's like from a patient's perspective, the richness for me has come from those who have participated. Nurses from all backgrounds and experience, who recognise the problems, and who are passionate about patient care.'*

*'This Transition project has given me a national voice to speak about the challenges from a patient's perspective. It has helped me to speak with health and social care professionals across the system.'*

Since the completion of the project, the patient representative has continued to undertake campaigning, education and advocacy work. Recently she has had an article published in a new publication dedicated to this area of healthcare practice, the Journal of Transition Medicine, which can be accessed at: <https://www.degruyter.com/view/journals/jtm/2/1/article-20200004.xml>

### **Meeting with the National Lead Nurse, Burdett National Transition Nursing Network**

The nurse lead was involved with the QNI project towards the end of its delivery and attended the QNI Transition conference.

Once the lead nurse became aware of the QNI resource, she recommended its use to her colleagues and wider education and practice networks. She is currently in the process of developing a national network of nurses working in transition services and intends to promote the use of the resource within this network,

which will encompass both primary and secondary care.

The Burdett Trust for Nursing funded national lead nurse has also offered her assistance with any further developments or update of the QNI resource.

### **Meeting with the Education Representative**

The education representative provided an overview of how the resource had been received in the education sector, which included Higher Education Institutions (HEIs), Community Education Provider Networks (CEPNs) and Training Hubs in England. She explained that the resource benefited academics when delivering programmes and was also used in order to direct learners to additional reading material.

Practice areas also stated that students on placement and nurses on post graduate courses had accessed the online resource.

*'...a really excellent resource - very comprehensive. I have cascaded this email to the practice teachers in our area and also with the students so that they can see this resource and hopefully draw upon it.'* - Email from a Practice Educator

This comment illustrates how renewed awareness of the QNI resource has been raised with educators during the process of this evaluation, which also suggests that further promotion of the resource in the future will be beneficial to its uptake by academics and students.

### **District Nursing Pilot Site Feedback**

The six pilot site contacts were emailed and telephoned for feedback, but unfortunately due to re-structuring in several of the organisations, the sites were no longer functioning as identifiable entities. Feedback was however received from one District Nursing area, where the Locality Lead commented, *'Myself, clinical sister and two Band 5 nurses and a student have completed 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.'* - Locality Lead District Nursing

This comment and the restructuring referred to, underscore how important it is to continue to actively promote the QNI resource in order to put it 'front of mind' to current practitioners and those who may be new to community settings.

### **Director of Programmes - Together for Short Lives**

Together for Short Lives is a national charity that works to ensure that seriously ill children and their families can make the most of the time they have together. The charity operates a membership body for healthcare professionals working in palliative care and related disciplines. The Director of Programmes of the charity commented, *'Together for Short Lives has shared the resource with colleagues across the children's and adults' palliative care sector, with those working in transition with young people with the most complex, life-limiting conditions. The QNI Transition of Care Programme fills the gap between children's community nursing and district nursing, where there has always been a lack of join-up and potential for young people to go without vital support in the community.'*

The palliative care community is different from NHS services in that many palliative care services are offered by small to medium sized independent charities and other organisations working in specific geographical locations. Hence it is of significance that the QNI resource is being shared and having an impact across these organisations.



The QNI Transition of Care Programme fills the gap between children’s community nursing and district nursing, where there has always been potential for young people to go without vital support in the community.



### **Specialist Nurse for Looked After Children Representative**

In England and Wales the term ‘looked after children’ is defined in law under the Children Act 1989. A child is looked after by a local authority if he or she is in their care or is provided with accommodation for more than 24 hours by the authority. Nurses have an important role in supporting and promoting the health and wellbeing of looked after children. The term Nurse Specialist denotes a nurse with additional knowledge skill and experience in working with looked after children responsible for assessing and promoting wellbeing in the looked after child population. Named Nurses have an important role in promoting good practice within the provider organisation. The Named Nurse is the principal health contact for Social Care, improving the health outcomes for Looked After Children and Care Leavers by working with the individual, their carers, the corporate family and the wider community.

The Nurse Specialist interviewed for this report described her dissemination of the QNI resource as informing colleagues through presentation at meetings, speaking directly to groups of District Nurses and making Practice Educators aware of the resource. She commented, *‘I have reflected on the transition work generated over the past two years and have really enjoyed being part of it. Thank you for asking me to be part of this project - you have done a fantastic job! Below is a list of ways which I have shared the work/information across the region:*

- emails to colleagues/managers/communications team within Leicestershire Partnership Trust regarding the project - detailing that I have been part of the Advisory Board, what the remit is and where the project will feed in to
- information and links to posters/surveys/conference embedded in Trust weekly e-newsletter
- liaison with Trust SEND (Special Educational Needs and Disability) Lead/Designated Clinical Officer and Transition Lead regarding project and conference
- liaison with local District Nurses/signposting to online resource
- liaison with Diana Service (children’s community nurses) and signposting to online resource
- sharing of posters across the Trust
- feedback at QNI regional meetings regarding progress of project
- specific discussion with DN Educators and sharing of resources.’

### **Online Survey**

The QNI hosted an online survey about the use of the resource using the SurveyMonkey platform. The results from the survey had representation and responses from all the nursing disciplines and stakeholders involved with the original resource development. All aspects of the resource have been deemed to be useful when delivering care to young adults making the transition to adult community health services. The full results of the online survey are given in Appendix 1.

### **Evaluation Summary**

This evaluation has highlighted that there is good evidence of the positive and far reaching impact of the Transition of Care Programme when supporting best practice in the experience of children and young people transitioning from children to adult community health services.

This has been evident in the data collected through a range of methods used, including online survey results, meetings with collaborators, patient representatives and members of the advisory group. There has also been representation and feedback from a variety of specialist nurse disciplines, an educationist as well as District and General Practice Nursing.



Whilst there is a real sense that the messages around young people transitioning are being heard, there remains more work to be done to raise awareness of the challenges faced.



### Recommendations

Through a systematic approach to engagement and consultation with a wide range of key stakeholders and in particular the feedback from the patient representative, this evaluation concludes by making recommendations in order to develop and sustain the positive impact of the QNI's Transition of Care Programme:

- **Continue to listen to young people in order to inform nursing practice.** Whilst there is a real sense that the messages around young people transitioning are being heard, there remains more work to be done to raise awareness of the challenges faced. These challenges include expanding communication networks between the various health and social care professionals involved and a wider and ongoing dissemination of the QNI's Transition of Care Programme.
- **Update the existing QNI materials.** The online learning resource was developed in 2016 and requires updating as changes in policy and practice dictates, in order to keep it current and relevant. This update may take the format of other QNI Transition resources that have been accessed widely and are very well evaluated (<https://www.qni.org.uk/nursing-in-the-community/transition-community-nursing/>). In addition, the technology used to host the QNI resource online is now becoming dated and the QNI has been advised that significant updates will be needed in the near future. The current opportunity for the learning resource to be updated and disseminated to every university offering nursing programmes in the UK should not be missed.
- **Consideration of an independent wider longitudinal study** of the QNI's Transition of Care Programme to inform and offer increased validity to the outcomes and impacts of this innovative work.
- **The development of a national standardised data collection and data set** around transitioning from children's to adult services, so that there is a stronger case that demonstrates the value of supporting and sustaining this vital work associated with better outcomes for young people with long-term conditions.

### Conclusion

The QNI would like to take this opportunity to thank the Burdett Trust for Nursing for funding this project which has benefited young people and their parents and informed nurses in their day to day practice in communities across England, Wales and Northern Ireland since 2016.

The work being undertaken is clearly as significant as ever and there is a need to continue to promote the importance of smooth transition to adult services in order to assure continuous awareness and improvement in as many provider organisations as possible. This evaluation acknowledges that all health and social care professionals need to keep young people at the centre of all decisions that impinge upon their health when learning about best practice. All practitioners, employers and those designing services have a duty to ensure that moving from children's to adult community health services is a positive experience.

Throughout this work, healthcare staff themselves have demonstrated that they are absolutely committed to the values that lie at the heart of this project – of patient choice, of personalised and person-centred care. However in a healthcare system that always needs more resources to meet growing patient need and which constantly has to face new challenges, this will always be an ongoing mission.

Self-care lies at the heart of the NHS Long Term Plan but in the case of some of the most dependent young people making the transition to adult health services, they cannot do it alone and will always require intensive support from health workers who they know and trust. Building effective and properly resourced partnerships will be key to ensuring that these young people are enabled to live the most healthy lives possible as they transition to adulthood.

## References / Further Reading

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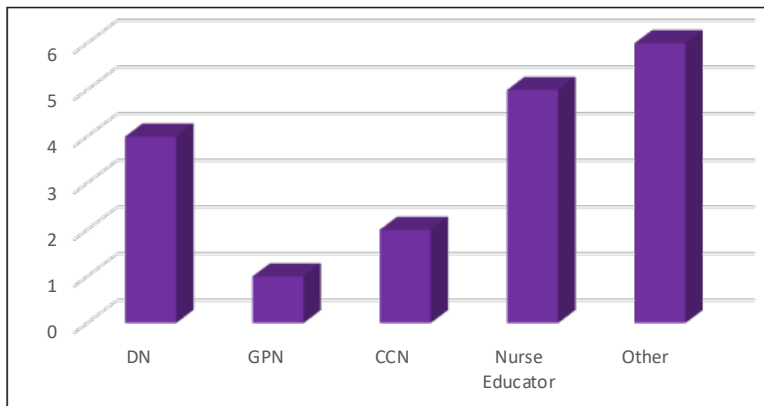
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## Appendix 1: Transition of Care Programme Evaluation Online Survey

A selection of representative answers from the survey is given below.

### 1. What is your role?

Answer choices	Responses	
DN	22.22%	4
GPN	5.56%	1
CCN	11.11%	2
Nurse Educator	27.78%	5
Other (please specify)	33.33%	6
	<b>Answered</b>	<b>18</b>
	<b>Skipped</b>	<b>0</b>



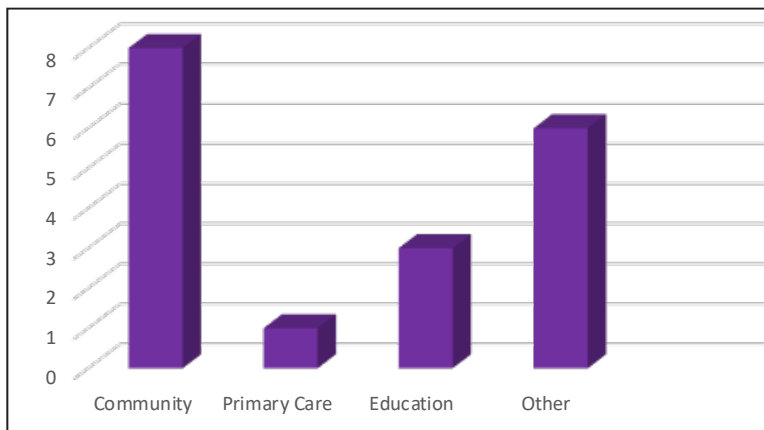
Other roles included:

- Transition Development Coordinator
- Diabetes specialist nurse
- Director of Nursing
- Occupational health manager and educator
- Adult care diabetes specialist nurse
- Lead Nurse Transition Team

The responses indicate that a broad range of professional groups were represented in the survey sample.

### 2. What area of practice do you work in?

Answer choices	Responses	
Community	44.44%	8
Primary Care	5.56%	1
Education	16.67%	3
Other (please specify)	33.33%	6
	<b>Answered</b>	<b>18</b>
	<b>Skipped</b>	<b>0</b>



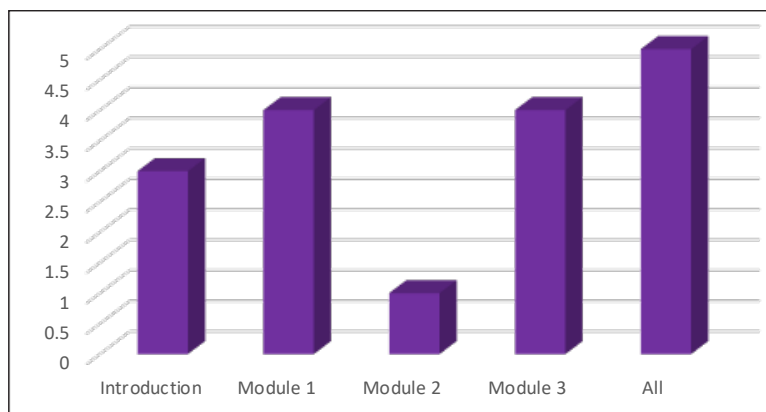
Other areas of practice included:

- Paediatric independent sector community
- Secondary care
- Hospital
- Secondary care diabetes specialist nursing
- Hospice
- Acute Children's and Adult Hospital Services

As above, the respondents were drawn from a broad cross section of healthcare settings.

### 3. Which element of the resource did you access?

Answer choices	Responses	
Introduction including the 'talking heads film'	17.65%	3
Module 1 - for District Nursing Teams	23.53%	4
Module 2 - for General Practice Nurses	5.88%	1
Module 3 - for Nurse Educators	23.53%	4
All	29.41%	5
	Answered	17
	Skipped	1



The responses to the survey reflect the balance of the professionals who completed the survey. All parts of the resource were used.

### What was the most useful part of the resource? E.g. policies, resources, film cross reference or workbooks.

Respondents mentioned the resources, the workbooks, the policies, the spoken film content and combinations of all of these. They also mentioned that taken together, the resource was useful to be able to signpost colleagues to. One respondent commented, *'to have an online resource with multiple resources is very helpful.'*

### Have you found the resource helpful when considering the care that you deliver to young adults making the transition to adult services?

Answer choices	Responses	
Yes	83.33%	15
No	0	0
Comments		8
	Answered	15

The response to this question was mostly positive. Comments included:

*'Policy and resources are useful for students to engage with when considering a young person's transition to adult services. The film is very powerful and can be used in discussion and in conjunction with their own experiences in practice.'*

*'It's helpful to have the resources for staff to assist in creating better transitions for/with Young People.'*

*'We used these to support a project between ourselves, as an adult hospice, together with the local children's hospice.'*

*'Good information for when transition period takes place and ensuring patient is well supported.'*

**Whilst reflecting on your practice have you been able to utilise the learning to assist you when writing your reflections for NMC revalidation?**

Answer choices	Responses	
Yes	55.56%	10
No	38.89%	7
Comments		4
	<b>Answered</b>	<b>17</b>

Well over half of responses were positive. Given that not all respondents would have been actively writing reflections for revalidation at any given time, this is even more significant. Comments included: *'[I am] able to reflect on how transition was possible and to ensure all information given to patient to ensure they feel well supported.'*

**Was there any aspect of the resource that you would like to see changed or amended in any way?**

Answer choices	Responses	
Yes	11.11%	2
No	77.78%	14
Comments		6
	<b>Answered</b>	<b>16</b>

One respondent said all the information in the resource was relevant for their needs. Of those who provided criticism, one wrote, *'... it may need to be in a different format - a transition resource in the style of other QNI transition resources.'* This is one of the recommendations of this report, given above. In addition another reviewer commented that more could be done to increase ongoing dissemination of the resource and connectivity with General Practice resources, which reflects a common desire among all health professionals to have integrated sources of information.

[Additional Comments and Learning](#)

Respondents were also asked if they had any other additional comments, given anonymously.

**A parent and practitioner**

One nurse who is also a parent of a young adult with a long term health condition commented that they had used the resource to support the transition of their daughter from child to adult mental health services. With other patients, they had used the information in the resource in order to find out more about what support could be available, which is in essence one of the principal aims of the resource.

**An educator**

*'It was great to be involved and to involve my students at the time the resource was introduced. It was an area of practice that I had not previously taught in any detail and I had not realised the importance of it and the impact this has on young people. It can be a very traumatic time for them and their families. It's helpful to have the resource; the challenge is ensuring it's used by staff.'*

