# The Burdett National Transition Nursing Network

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**Completed on behalf of the project team**

# Project Purpose

To improve the experience and outcomes of all young people and families when moving from children's into adult services.

## Aims

1. To achieve the best possible long term health outcomes for young people with long term conditions
2. To provide an uninterrupted, coordinated approach to healthcare across the transition pathway including across organisational boundaries
3. To drive change within organisational cultures to embrace and embed developmentally appropriate care, understanding and meeting the unique needs of young people
4. To affect change and establish best practice transition pathways that are cost effective, safe, and sustainable

## How we set out to achieve these aims

- Mapping where transition is currently happening
- Support organisations through the Model of Transition Quality Improvement (QI) process developed and tested in Leeds Teaching Hospitals NHS Trust (see Appendix 1) to improve transition pathways and the transition experience of young people and families
- Encourage transition work across organisational boundaries through collaborative working
- Influence cultural change to provide developmentally appropriate healthcare for all
- Promote the use of transition leads and champions to ensure work is sustainable
- Work with NHS Improvement and NHS England to remove some of the barriers to transition implementation
- Evaluate the effectiveness of the project work

## Geographical scope

Working across four regions of England, host organisations were selected through a competitive selection process to host the Regional Nurse Advisor (RNA) roles.

**Host organisations**

North - Alder Hey Children's NHS Foundation Trust

Midlands - University Hospitals Birmingham Foundation Trust

London - Imperial College Healthcare Trust

South - Taunton and Somerset NHS Foundation Trust

# Project process

The Regional Nurse Advisors (RNAs) worked with provider organisations, Clinical Commissioning Groups (CCGs) / Integrated Care Boards (ICBs) and NHS England (NHSE) regional teams to identify all healthcare organisations in their regions who had services which had or required transition pathways for patients with Long Term Conditions (LTCs).

When organisations were identified, the RNAs found key personnel to work with in a 'Train the trainer' coaching approach to talk through the key principles of transition, and the steps within the Transition QI process.

Building on the work with transition contacts, regional transition networks were formed. Regional transition meetings were held on a 3-monthly basis to connect like minded individuals to educate, train and share examples of good practice, and collaboratively problem solve any transition issues raised. Community of Practice (COP) events were developed in year 2 of the project, each region hosted one COP event per year using their regional focus. These included, End of Life and Palliative Care, complex needs transition into General Practice, patient experience and engagement, Learning Disabilities and Autism, and Systemwide working. The aim of these events was to facilitate a more in-depth knowledge exchange, using the principle that everyone is a teacher, and everyone is a learner. The aim of these sessions was to stimulate a discussion around a topic proposed by the expert guest facilitator, to engage the audience in a learning process and captivate their imagination to drive real change and action.

The National Lead Nurse's role was to work alongside the transition leaders within NHS England to highlight the high-level barriers to transition being implemented. There were:

- Time
- Money
- Knowledge / understanding
- Data collection and monitoring

Working in partnership with NHS England, the following workstreams were developed:

- National Framework – supporting the design of transition pathways that reduce health inequalities and improve health outcomes for all young people

- Core Capabilities for the care and transition of young people - Enabling staff to carry out an assessment of the knowledge, skills and behaviors required when caring for young people

- Community Currencies for Transition – establish funding steams for transition, alongside the creation of transition SNOWMED codes, to enable the identification and tracking of patients through the three stages of transition, and provide assurances that no young person is lost in the gap

# Project impact

Measuring the impact and influence the network has had was carried out incrementally. Data was gathered in May of each year from pre project to year 3. There were eight measures chosen to illustrate engagement with, and improvement of, provider organisations over the course of the project (Figure 1). The measures were as follows;

1. Number of transition lead roles for a whole organisation
2. Number of organisations working through the Transition QI process
3. Number of organisations with a transition contact
4. Number of organisations with an executive lead
5. Number of QI transition pathways completed
6. How many health-based youth workers are in post in England to support transition
7. Number of organisations with a process in place to use feedback from young people to support service improvement
8. Number of organisations with transition governance processes in place e.g., transition board, steering group, organisational policy, and reporting

Figure 1 shows that there was an increase in all measures, indicating that provider organisations had heard and acted on information communicated by the Burdett National Transition Nursing Network, regarding the key drivers for change in transition.

Through the network teams' experience, and documented research evidence, it was evident that to create sustainable change for transition, organisations would benefit from a whole organisation Transition Lead, who would have a global view of transition, moving away from the historical siloed working. The Transition Lead could coordinate improvement across services, ensuring consistency of approach and joined up working. The Transition Lead is a key role in maintaining momentum, standards and providing assurance data, and maintaining sustainability over time.

To ensure the work of the Transition Lead is effective, there needs to be engagement and support at the most senior levels within organisations, therefore having an Executive Lead for transition is crucial to its success. The Executive Lead can support and help to remove barriers to implementation and delivery of transition pathways for the Transition Lead.

The Transition Lead, when trained in Quality Improvement (QI) specific to transition, can support services to map the current and future state pathways for transition. Having a Transition Lead coaching staff through the QI process, facilitates staff and services to take ownership of their transition pathway or offer to young people and families, encouraging staff to maintain continual improvement processes.

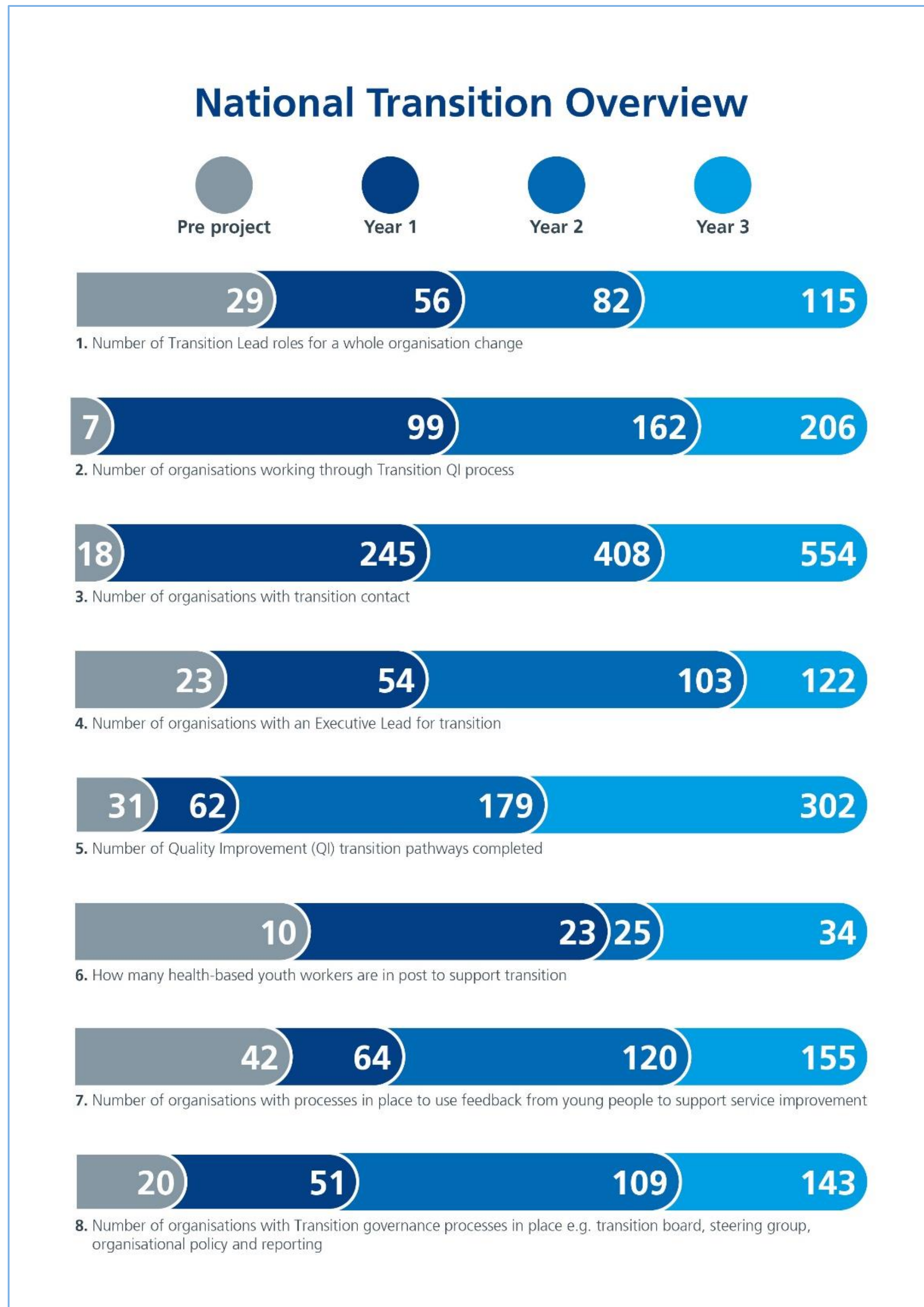


**Figure 1 Overview of project measures**

In relation to the points discussed above, Figure 1 demonstrates that measures 1, 4 & 5, had some of the most significant increases, which may indicate that the message was not only relayed by the RNAs to the providers but that they were able to support the organisations to establish and embed this management model in place.

Figure 2 shows the same measures broken down per region. Differences in growth in measures between regions seemed to have some link to how established the ICBs were, as over the course of the project there was a move from CCGs to ICBs, mainly in years 1 and 2. The Midlands and the North were observed by the network to establish ICBs most rapidly, starting to take on roles to support the delivery of healthcare transition in a systemwide approach.

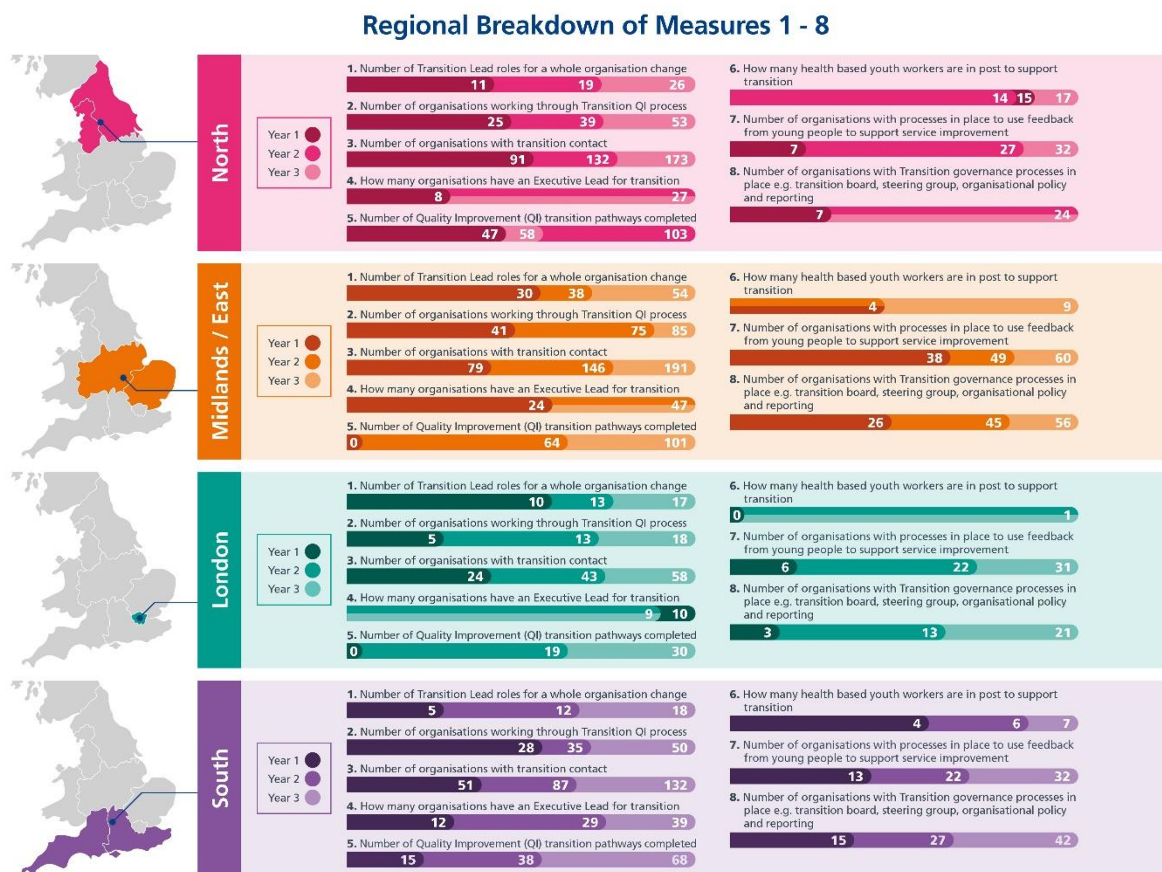


**Figure 2 Regional breakdown of project measures**

Figure 3 illustrates the network's impact on the scaling up and the spread of transition work across whole organisations. The graph shows pre-project and year three data only. Data is captured on where transition pathways should be in place with support delivered to young people and families. In Figure 3, 0%

represents no transition work happening in an organisation. At the outset of the project, the network found there weren't any organisations who had more than a quarter (25%) of an organisation with transition pathways in place.  For example an organisation with a total of 4 services who have transition patients (young people with long term conditions requiring the move from children's into adult services) would require 4 transition pathways, one for each service, if they only had 1 transition pathway set up and running  for 1 of their services they would have a quarter or 25% of the organisation with effective transition. An increase was seen by year three, 100 organisations had between 25-100% of the organisation with transition pathways in place and being delivered. The fact that there was an increase over the course of the project in 0% organisations, was due to the RNAs finding more organisations they were not aware of at the pre-project stage which were not delivering any transition pathways.

These findings also link to measure 5 in Figure 1, with the number of transition pathways completed. These figures are particularly impressive when the network team know that the QI process to develop and deliver the transition pathway takes a minimum of 7 months to complete for each individual service.

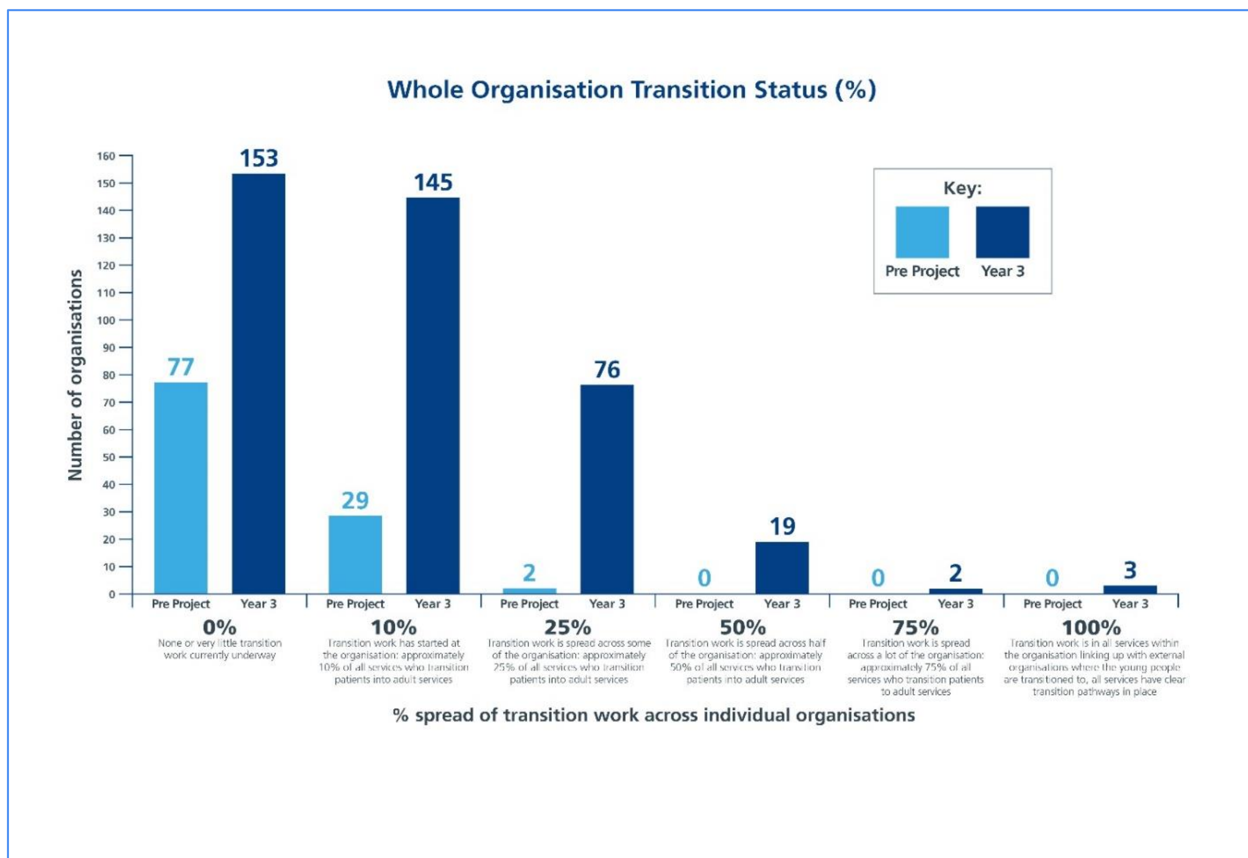


**Figure 3 Percentage spread of transition across an organisation**

# The Burdett National Transition Nursing Network Conference

We held our network conference in March 2023 and was the networks first time of running a hybrid event. It was lovely to see over 400 people who joined us join online or in person. Despite a few technical issues, we are pleased to report that the conference evaluated extremely well. It was great for our RNAs to share some examples of work from their regions, at varying stages in development and in the QI process.

**405 attendees**

Mentimeter was used to gather information from attendees on the day, we would like to share some of the Menti results from the day.

## We asked: What one aspect of transition needs to change to have maximum impact for young people going forward?

Figure 4 Mentimeter results word cloud

**Figure 4 Mentimeter results professional commitment**

Stakeholder groups attending the conference included: young people, Nurses, Doctors, Youth Workers, Allied Health Professionals, Transition Leads, Executive Leads, Commissioners, NHS England Policy and Transformation teams, Parents, General practitioners, Charities, Hospices and Educators.

Topics covered included: The national direction of transition, support for transition, Systemwide approaches, transition pathways and QI journeys, impact of the transition network on RNA host organisations and individual staff, young people's ask of staff for transition, information from the transition section of the youth summit, Transition passports and timelines etc.

The conference had an incredible response to the menti questions asked, some of the results can be seen in Figures 4 and 5. The results of the conference are currently being written up in a peer review article for publication, to show how wide engagement with young people, health professionals and policy makers is possible.

# Next Steps

The mapping work carried out by the Burdett National Transition Nursing Network has been shared with NHS England's national and regional teams, Support for provider organisations wishing to improve transition can be found via ICB leads NHS England's regional CYP leads and from the information and link found in Appendix 1. The Burdett National Transition Nursing Network Research team will continue with the evaluation of the project with written publications coming out over the course of the next year their work will conclude December 2024.

# Conclusion

At this stage in the project, prior to the research evaluation, there is clear evidence of change and influence. Measures used (Figure 1) facilitated reporting of data that can be used by organisations to map and audit their transition services. Data supports the significance of a triad of factors essential to have in place for this change to be most effective and sustainable:

- Whole organisation transition roles
- Executive Leads for transition
- Transition pathways implemented

The Burdett National Transition Nursing Network has forged change, even through challenging times, showcasing what can be achieved, ensuring a sustained focus on transition over that last three years. The network team urges NHSE to pick up where the network has left off, building on the mapping work, and seeking to target support to ICBs and provider organisations using assurance data gathered at regional levels through data dashboards. Increases in these key areas, helps to create sustainable change for transition and provides a solid foundation to maintain the work that has already been undertaken. Furthermore, with the push to gain assurance data to measure and monitor performance and success on an ongoing basis, these will be key drivers for change.

Funding has now ended to support the network. Evaluation of the network continues, and will be reported end of 2024. Further learning will be available in a final report.

## Appendix 1

## QI process

The quality improvement model takes learning from industry using processes already being used in healthcare. The Burdett model has been designed specifically for transition pathway improvement. It is easy to use and encourages the full multidisciplinary involvement in pathway formation, implementation, and delivery. Bringing together children's and adult teams to form a collaborative working joined up pathway.

To use the improvement model, follow the next steps in order:

Stakeholders

Diagnostic

Solution design

Implementation

Sustainability

How to guides can be found on the link below;

**Stakeholders (leedsth.nhs.uk)**