

# Transition care consumer experiences report

What young people and carers shared about  
transitioning from paediatric to adult health services

March 2024

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## In brief

- A [rapid evidence check](#) of transition organisational models of care conducted by the Transition Care Network in 2022 highlighted a need to increase the 'voice' of young people in transition research, build the transition evidence base and share learning across jurisdictions.
- A mixed methods approach (i.e. survey questionnaire and interviews) was used to gather transition experiences from young people in NSW (aged 18 years or older) with any chronic condition, and their parents or carers, as they move from paediatric to adult health services. It is believed this is the first time this approach has been used in NSW.
- Ethics approval was granted by the Sydney Children's Hospitals Network Human Ethics Research Committee (SCHN HREC) 2021/ETH11969. Consumer representatives (e.g. young people and carers with transition experience) were involved in all aspects of the project, including governance, study design, data collection, analysis and reporting.
- This report provides the findings from the survey questionnaire and interviews. Triangulation will occur with other evidence sources (e.g. an evidence check of peer-reviewed literature and experiential insights from health providers) to identify opportunities for statewide improvement of transition processes in NSW.
- A total of 29 respondents completed the survey questionnaire between 23 February 2022 and 11 May 2022. In addition to completing the questionnaire, three carers opted for a follow-up 45-minute interview in June 2022.
- The analyses identified that:
  - more than half of the respondents were aware of their transition process; however, few knew about the ACI Transition Care Service, and even fewer had accessed the web resources available through the ACI Transition Care Network
  - most transition discussions occurred between the ages of 16 and 18 years
  - a large proportion of respondents felt prepared to transition from paediatric to adult services.
  - only a small proportion of respondents reported having a transition plan
  - most respondents indicated they had a general practitioner while transitioning from paediatric to adult services; however, only a few indicated their general practitioners were involved in transition processes
  - parents and carers provided feedback that transition is an at-risk time; young people may present to an emergency department when left with no other support options.
- The findings were discussed and interpreted with the ACI Transition Care Network Executive on 10 October 2022. Opportunities were identified and these are explored in the discussion section of the report.

## At a glance

### Transition care consumer experiences report: What young people and carers shared about transitioning from paediatric to adult health services

#### Who took part?

**29** total respondents



#### What we found

**51%** were aware of the transition process

**69%** felt prepared or somewhat prepared for transition

**52%** were involved in transition discussions

**62%** had all the information/documents needed for their first appointments in the adult system

**52%** felt their psychosocial needs were considered

**45%** said that they were the primary coordinator of transition (rather than the healthcare team)

**24%** had a formal transition plan

**24%** said their GP was involved in their transition process

#### What will the ACI Transition Care Network do next?

1. Use the survey findings and consumer feedback to improve transition experiences in NSW for young people and carers
2. Drive systems change and quality improvement across the 7 key transition principles

## Background

The Agency for Clinical Innovation (ACI) [Transition Care Network](#) works with clinicians, managers, young people, parents and carers to improve the continuity of care for young people (aged 14 to 25 years) with chronic health conditions and disability in NSW as they move from paediatric to adult health services.

The Network completed a [rapid evidence check](#) in May 2022 to identify organisational models of care that have been shown to improve the transition of care from paediatric to adult health service.<sup>1</sup> Findings from the evidence check suggested that the age for transition can start as early as 12 years. Often the duration and complexity of the illness, rather than age, had an impact on readiness for transition to adult services.<sup>2</sup> A systematic review reported that the transfer of care was the most prominent intervention feature of transition service models. The studies also identified transition enablers, such as coordinated and tailored transitional care, transparent transition processes, care delivered in partnership, careful documentation of transition in the medical record, and the use of transition policies. Several studies highlighted the need for more 'voice' of young people in transition research; their views could differ from quantitative data missing from the reviewed studies. The findings also suggested a need to build the transition evidence base and share learning across jurisdictions.<sup>3</sup>

Gathering experiential evidence was considered important by the ACI Transition Care Network, given several peer-reviewed studies identified a gap in consumer voice. As a result, the ACI Transition Care Network launched a quality improvement project to gather and describe transition experiences (moving from paediatric to adult health services) of young people with a chronic condition or disability (aged 18 years or older), their parents and carers in NSW. Gathering experiential evidence was considered important by the ACI Transition Care Network given several peer-reviewed studies identified a gap in consumer voice. Triangulation will occur with other evidence sources (e.g. evidence check of peer-reviewed literature and experiential insights from health providers) to identify opportunities for state-wide improvement of transition processes in NSW. It is believed this is the first time such a project has been conducted in NSW.

This report will be shared with respondents who provided their details and through the same channels used to recruit participants and through ACI professional networks.

## Methods

### Design

A mixed-methods approach was used to gather transition experiences from young people with chronic conditions or disability aged 18 years or older and their parents or carers in NSW.

### Setting

In 2014, the ACI Transition Care Network developed [Key Principles for Transition](#) in partnership with the Sydney Children’s Hospitals Network (SCHN) [Trapeze](#) transition service. The ACI Transition Care Network also runs a [Transition Care Service](#), which provides practical support with transition planning for young people, their parents and carers, and health professionals.

**Figure 1: The key principles for transition care**

<p>PRINCIPLE 1</p>  <p>A formal transition process</p>	<p>PRINCIPLE 2</p>  <p>Early preparation</p>	<p>PRINCIPLE 3</p>  <p>Empower, encourage and enable young people to self-manage</p>
<p>PRINCIPLE 4</p>  <p>Identify a local transition coordinator or facilitator</p>	<p>PRINCIPLE 5</p>  <p>Good communication and shared responsibility</p>	<p>PRINCIPLE 6</p>  <p>Individual transition plan</p>
<p>PRINCIPLE 7</p>  <p>Follow-up and evaluation</p>		

## Framing question

How do young people, their parents and carers experience the transition from paediatric to adult health services in NSW and how does this relate to the seven transition principles?

## Recruitment and participant group

A purposive sampling approach was used<sup>4</sup> with the following inclusion criteria:

- Young people with a chronic condition or disability in NSW aged 18 and older who are in the process of transitioning or have transitioned to adult health services within the last three years (from 2018)
- Family members, parents and carers of young people who are in the process of transitioning or have transitioned to adult health services within the last three years (from 2018).

Invitations to participate were sent between 23 February and 11 May 2022 to relevant professional networks, including local health districts (LHDs), specialty health networks (SHNs), consumer organisations, non-government organisations, academic institutions, ACI clinical networks and not-for-profit organisations. The link to complete the questionnaire was also disseminated through four posts from ACI organisational accounts on [Twitter](#) and [LinkedIn](#). Responses were anonymous; however, respondents were given the option to leave their name and contact details to receive a copy of the final report and/or participate in a semi-structured interview. A web page was created with links to participant information sheets (including an easy-read version) and the questionnaires.

## Data collection

Data were collected from respondents using an online questionnaire administered through the Quality Audit Reporting System<sup>5</sup> from 23 February 2022 to 11 May 2022. There were two questionnaires: 1) for young people over 18 years and 2) for parents and carers. The questionnaires were developed with inputs from members of the ACI Transition Care Network Executive (n=23), the project team and four ACI Transition Care Network consumer members. Testing of the questionnaire was conducted between December 2021 and January 2022. Four ACI Transition Care Network consumer members assisted with the refinement of the question sets. Follow-up interviews were conducted with participants between 6 June and 20 June 2022.

## Data analysis

All free text responses and interview data were analysed together using a qualitative framework approach: familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation.<sup>6</sup> Data were coded line-by-line using a deductive approach, and the seven Key Principles for Transition (below and Figure 1) were used as the thematic framework:

1. A formal transition process
2. Early preparation
3. Empower, encourage and enable young people to self-manage
4. Identify a local transition coordinator or facilitator

5. Good communication and shared responsibility
6. Individual transition plan
7. Follow-up and evaluation.

Descriptive statistics were used to describe the dataset, and the findings were mapped back to the Key Principles for Transition.<sup>1</sup> The findings were discussed and interpreted with the ACI Transition Care Network Executive on 10 October 2022.

## Young people (consumer) involvement

Consumer representatives (i.e. young people and carers with transition experience) were involved in all aspects of the project, including governance, study design, data collection, analysis and reporting. One consumer representative provided oversight and governance of the project alongside two ACI Transition Care Network members. The consumer representative was a study investigator and was actively involved in developing the study protocol (including ethics submission), developing and testing the questionnaire, as well as reviewing the findings and the report. Four consumer members of the ACI Transition Care Network tested and provided feedback on the question sets.

## Ethics

Ethics approval was granted by the SCHN HREC: 2021/ETH11969.

## Limitations

The consultation has several limitations. It is a self-selected sample, and response rates were low. Data are not available on the number of young people who transition from paediatric to adult health services each year, therefore it is unclear what the potential sample size across NSW should be. The respondents represented people from metropolitan, regional and rural NSW but were not representative in terms of gender and indigeneity.

While the sample was not adequately representative, it did provide some direct insights from young people, their parents and carers about their transition experiences. However, these findings cannot be generalised or claimed to be a NSW-wide account. Given the questionnaire was confidential, it is unclear if the young people and carers who responded were connected.

There were no direct incentives or benefit, including remuneration to participate in the survey questionnaire or interviews, which could have had an impact on the response rate.

It is also essential to highlight the likely impacts of the COVID-19 pandemic on transition processes for clinicians, young people and carers. Many adult services could not take on new referrals during the pandemic.

## Findings

A total of 29 respondents completed the questionnaire between 23 February 2022 and 11 May 2022: 7 young people and 22 parents and carers. Respondents did not answer all questions, and there were some blank responses. In addition to completing the questionnaire, three carers opted for a follow-up 45-minute interview in June 2022.

Chronic conditions identified by the respondents included neurological conditions, cerebral palsy, arthritis, skin conditions, autism, spinal cord injury, diabetes, mental health conditions, cardiac conditions, neurofibromatosis, neuromuscular conditions, and genetic conditions.

All respondents accessed healthcare from the public health system and 58% (n=17) also accessed private healthcare. In addition, 48% (n=14) had accessed services through the National Disability Insurance Scheme.

The majority of respondents (58%, n=17) had transitioned from paediatric to adult health services. Nine respondents (31%) were transitioning to adult health services. Three respondents did not answer the corresponding question.

Thirteen (45%) respondents lived in metropolitan NSW, five (17%) in rural and eight (27%) in regional NSW, spanning 11 LHDs. A total of 11 respondents (38%) were currently accessing care outside their LHD of residence. Three respondents did not answer the corresponding question.

The analysis identified experiences against the key principles for transition detailed in Figure 1 as follows:

1. **A formal transition process.** More than half of the respondents (51%, n=15) were aware of their transition process. However, few respondents (6%, n=2) knew about the ACI Transition Care Service, and even fewer had accessed the web resources available through the ACI Transition Care Network (3%, n=1).
2. **Early preparation.** A large proportion of respondents (69%, n=20) felt prepared or somewhat prepared to transition from paediatric to adult services. Most transition discussions occurred between the ages of 16 and 18 years.
3. **Empower, encourage, and enable young people to self-manage.** The majority of young people and family members/carers were either very (52%, n=15) or occasionally (28%, n=8) involved in transition discussions.
4. **Identify a local transition coordinator or facilitator.** There was uncertainty around who was the transition coordinator/facilitator, with 45% of family members/carers (n=10 of 22) and 29% of young people (n=2 of 7) indicating that they were the primary coordinator of care. This principle is intended to highlight the importance of the young person, parent or carer NOT being the transition coordinator or facilitator.
5. **Good communication and shared responsibility.** Most respondents (62%, n=18) indicated they had all the healthcare information and documents they needed for their first appointments with adult health services. Across all respondents, 86% (n=25) had a general practitioner while transitioning from paediatric to adult services, and only 24% (n=6) said their general practitioners were involved in the transition processes.

6. **Individual transition plan.** Only 24% of all respondents (n=7 of 29) reported having a transition plan. Over half of the respondents (52%, n=15) felt that their psychosocial needs were considered when planning for transition.
7. **Follow-up and evaluation.** Few responses were mapped to this principle however, one respondent suggested a need to improve the feedback loop between paediatric and adult services: *“It would have been nice if the previous team followed up on the transition.”*

Parents and carers provided feedback that transition is an at-risk time, and potentially young people can ‘fall off the health system’ and present to an emergency department as their only option. Contributing factors included not being aware of the transition process or services available, service capacity, a lack of referral and follow-up, and costs. One respondent said:

*“I find it very hard to comprehend [that] we come from a very structured and supported network to nothing. Also, I have found the expense to transition is astronomical as I was under the understanding, I needed to connect with all specialists privately at a very costly expense.”*

The qualitative analysis suggested the feedback sentiment was mostly negative, and this mainly related to not meeting key principles 1, 2, 5 and 6 (see Table 1). The findings suggested there was little awareness of the transition process, no early preparation for the transition, and poor communication at various levels.

**Table 1: Overview of transition principles and selected quotes**

Transition principle	Selected respondent quote
1. A formal transition process	“Every time he went, by the time he was about 16 you were holding your breath every time thinking: ‘Are they going to say this is the last time we’re going, or are they going to start talking about this transition process?’”
2. Early preparation	“We haven’t received any information or letters about transitioning, so we feel ill-equipped for the transition and are worried there will be a big gap in the medical needs of my child. We are very unsure and unprepared for the transition as we don’t have any information. We only received word about transitioning this year as my child turned 18.”
5. Good communication and shared responsibility	“There has been no communication regarding the transition which leads to feelings of neglect, lack of support and potential gaps in continuing healthcare.”
6. Individual transition plan	“It is hard to find a team that will take on my complex issues.”

## Discussion

The experiential insights provide one source of evidence to help identify opportunities to improve the transition experience from paediatric to adult services in NSW. The discussion points were identified through a discussion with the ACI Transition Care Network Executive. Triangulation will occur with other evidence sources (e.g. an evidence check of peer-reviewed literature and experiential insights from health providers).

The feedback from 29 respondents with a transition experience in NSW signalled an opportunity for systems and quality improvement across the seven key principles for transition (see Figure 1).

One likely area for quality improvement is increasing awareness and knowledge of formal transition processes and the ACI Transition Care Service. In addition, there is a need to promote further resources, such as the transition factsheets and principles, to different audiences using a range of formats. The ACI Transition Care Network could host specialty forums for clinicians, young people and their carers to increase awareness and knowledge of transition processes for their primary health condition and the support available in NSW.

Another point to consider is the optimal age to begin the transition process. Some peer-reviewed evidence recommends 12 years, while the Transition Care Network Key Principles suggest 14 years. The experiences gathered from the questionnaire indicated that transition in NSW currently takes place between the ages of 16 and 18 years. This is too late to begin planning and preparing, especially for young people with complex needs. Internationally, the Templestar Transition Model of Care identified the need for transition to start at 12 years<sup>2</sup> and On TRAC implemented stages of transition care based on the developmental stages and capabilities of each individual.<sup>7</sup>

The ACI Transition Care Network could also explore ways of helping paediatric and adult clinicians, together with general practitioners, to run joint clinics as part of the transfer of care. Findings suggested that 38% of respondents accessed services outside their LHD. While this is understandable as not all specialist services are available in every LHD, and there are some statewide speciality services, all attempts must be made to access care locally. If transition planning commences early, it is possible to use a transition plan to map out the services required and engage with the adult services able to accept care.

Only a small number of respondents had a transition plan, which signals a need to increase awareness of and access to transition facilitators to ensure transition plans are developed with clinicians, young people and their carers. Not all young people with chronic conditions and disabilities will access a specific transition support service like Trapeze or the ACI Transition Care Service.

Other areas for improvement and further work could include increasing the involvement of general practitioners in transition processes. However, there are challenges in accessing general practitioners (e.g. wait times, physical accessibility and affordability). The ACI Transition Care Network could explore ways to identify general practitioners interested in providing care to young people with chronic conditions and disabilities to improve access.

## Conclusion

Transition experiences were gathered from young people (aged 18 years or older) with a chronic condition and their parents or carers to help identify opportunities for statewide improvement of transition processes in NSW. The findings signalled an opportunity for improvements across the key principles for transition published by the ACI Transition Care Network.

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