



Transitions of Care

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Transition of Care is defined as ‘the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults ...as they grow up learning to live with their lifelong health condition’.

Dovey-Pierce & Christie, 2013





September 2023

- ❑ Discussed website development
- ❑ Described our work on a standards document for Transition of Care
- ❑ Launched national YVM survey





Survey results





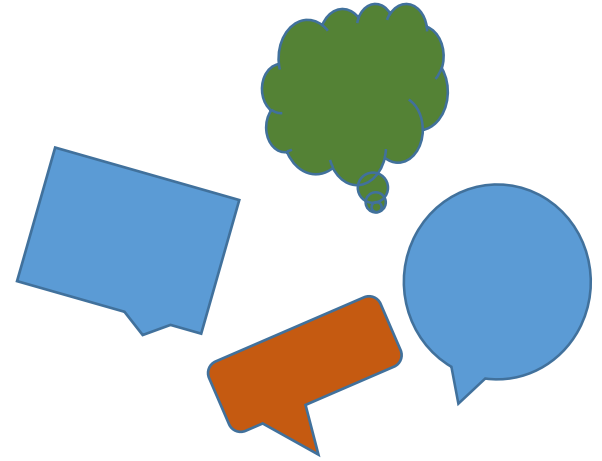
Survey was **co-designed** with healthcare staff and Young People (YP) representatives to **capture the lived experience** of YP and their families and carers with respect to the current transition of care from paediatric to adult services





Who answered the survey?

- Family members 76
- Young people (age 14 to 26) 40
 - Not transitioned -14
 - Transitioned - 26



118

Completed surveys

Young people who had transitioned to Adult services

Lived in **14 different counties**

Accessed **services across 21 different specialties:**

Psychiatry, Dermatology, Urology, Respiratory, Cardiology, Gastroenterology, Ophthalmology, Endocrinology, Rheumatology, Craniofacial, Orthopaedic, Neurology, Immunology, Gynaecology, Ear Nose and Throat, Genetics, Pain management, Metabolic, Oncology, Nephrology, Dentistry.

Almost all (96% n=23) had **transitioned by 18 years old**

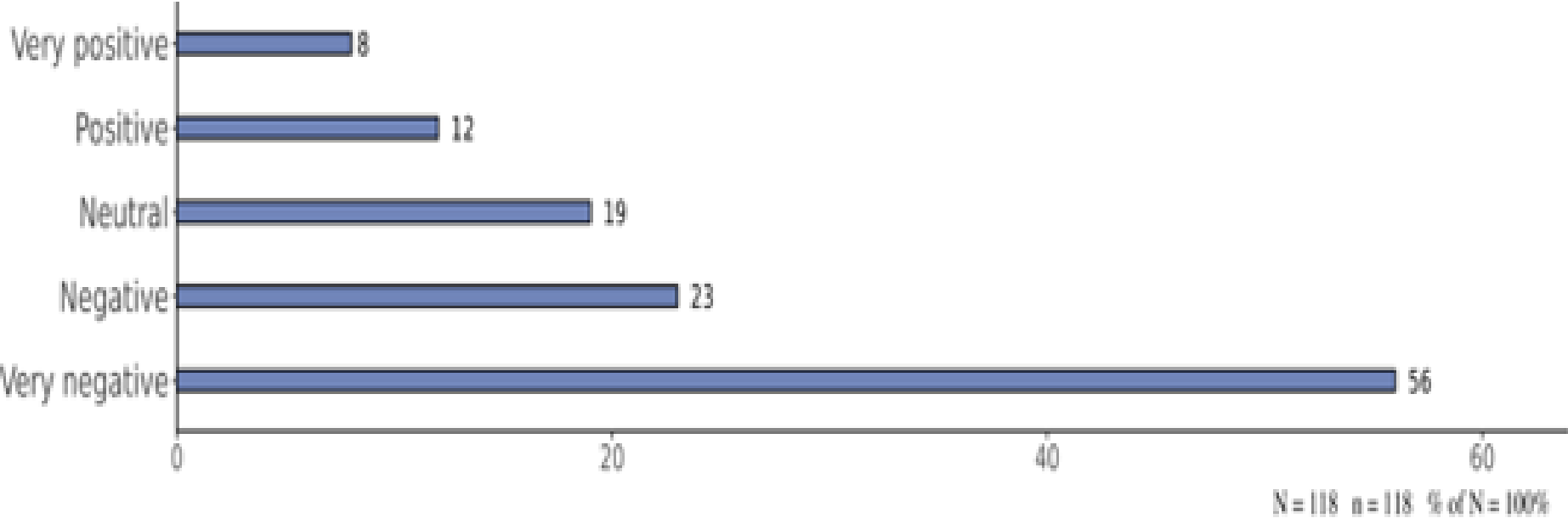
Around **half (n=14) felt transition should happen at 19+ years**

21
specialties

14
counties

67%
Negative experience

67% (n=79) described the transition as negative or very negative





Key Findings

YVM survey 2024



YP wanted to be treated with kindness but many felt forgotten and alone

“Simply being there for your patient and showing nothing but kindness and warmth is ultimately the most important thing I needed more than any certain facility or plan.” [Young person]

“I was 18 when I transferred and was a very difficult time, felt very alone and clueless at adult service.” [Young person]

The transition was an **anxious** time

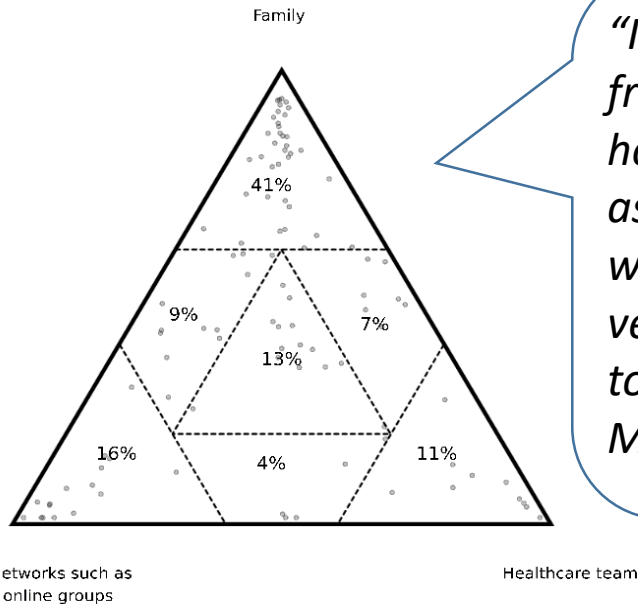
“I’m worried about dealing with a new team, a new hospital... and a million more things... major concerns about being cut out as we move to adult care... it will be a huge upheaval for us as a family and I’m already worried.”

[Parent/carer]

“I’m very nervous when my mam can’t ring like she does now to get my care and get me seen when I run into a problem.” [Young person]

80% (n=76) felt unsupported by the healthcare team. YP relied on their parent/carer.

4. During the move from child to adult care, I felt supported by:



"I'm 14 nearly 15. My mam is helping me with a lot from school to all my medical appointments at the hospital and in the disability office. No one has asked mam or me about the future ... Mam says we will have to start the planning now ourselves. It's very hard. Mam knows what to do. She try very hard to try and get it right for me. I ask people to ask Mam." [Young person]

What does support look like from the service user perspective?

✓ Emotional support i.e. Feeling cared for

✓ Informational support

“The nurse spends lots of time with my son - nothing rushed. Lots of information re the future with things we never thought of...” [Parent/carer]

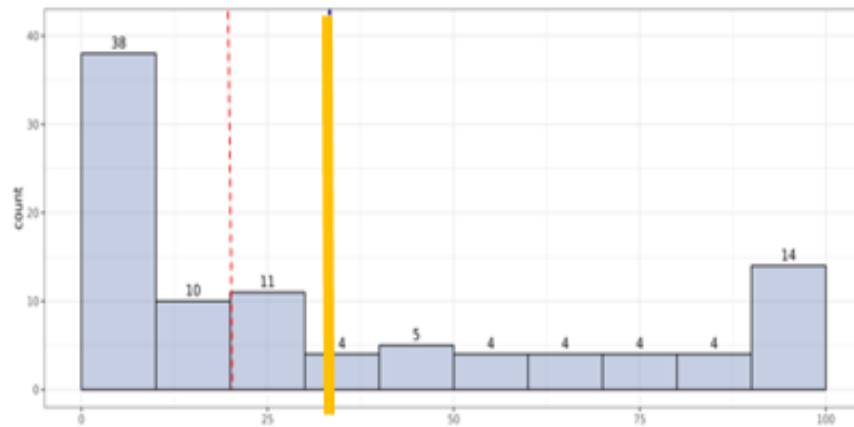
99% wanted more information

Information in general and specifically on the teams and contacts was necessary for a positive experience

“I have received no guidance preparation or help with this and don't know where to look for information. I have been asked to have my questions ready for my next appointment as it will be my last. I am anxious about this as I have no idea what I should be asking, yet feel that it is important that I ask the right questions.” [Young person]

Communication was often too little, unclear and difficult to understand

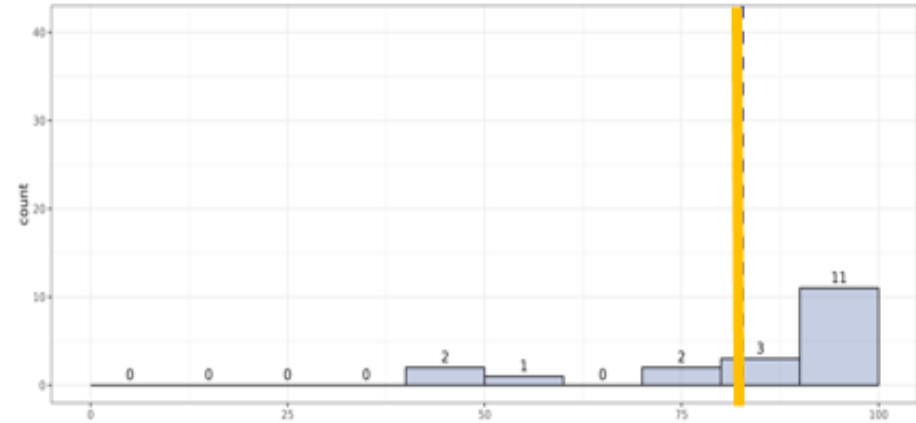
Communication was...



Unclear and difficult

Clear and easy

Overall response



Unclear and difficult

Clear and easy

Positive experiences

There was a lack of continuity of care

GPs often lacked the knowledge and resources to adequately care for YP with rare or complex conditions

Adult services had

- fewer appointments
- longer waiting times
- reduced services particularly mental health services

Patients medical history was often not transferred

“You go from having all the help, guidance and information in the world to getting a phone call visit every now and then.”

[Young person]

Adult clinics, wards and EDs were felt to be unsuitable environments for young adults

“My child is 19 years old... non-verbal and mentally and physically disabled with a rare life limiting condition. Going into an adult hospital A&E with my child who is small and vulnerable has been horrific. My son wears a size 9-10 pyjamas...” [Parent/carer]



How do we improve Transition of Care ?

Use the Survey findings to
identify areas of service
improvement for further
research and investigation

Start with the key themes





What can we do now to make transition of care better?



By the end of 2024

- ❖ National Transition of care standards and resource links document
- ❖ HSE web page dedicated to Transition of Care

By the end of 2025

- ❖ Build Transition of Care into every clinical programme



Thank you

The Transition of Care Working Group

Patient advocacy groups and clinicians who provided valuable feedback on the TOC document.

Aoife Collins and Adèle deVries from Your Voice Matters

Jen Davies and Victiry Nwabu from the HSE webpage team

Youth Advisory Council (YAC)

