

Learnings from a Transition Pilot from Paediatric to Adult Palliative Care Services: **During A Pandemic**

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Managing transition of young adults with life-limiting conditions from paediatric to adult services has become a global health and social care issue. Suboptimal transitions from paediatric to adult services can lead to measurable adverse outcomes.

PPWH and CHAS have committed to a year long transition pilot for 9 identified individuals to learn what helped and what got in the way of a successful transition. The pilot will close in January 2022.

- O'Connell A, Petty J (2018) Preparing young people with complex needs and their families for transition to adult services. Evidence & Practice/ Transition of Care Nursing Children and Young People. Royal College of Nursing
- The Principles of Good Transition 3 (2017) Scottish Transition Forum ARC Scotland




The Prince & Princess
of Wales Hospice



Children's Hospices Across Scotland

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This poster is part of
the SPPC Poster
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All Change!

Creating Pilot Aims – our Thought Cloud

Breaking down barriers - Stigma and fear

Support to guide them through the process

Smooth and equitable process

Planned and co-ordinated care

Early interventions

Recognition and characterisation of those in need

Promote overall wellbeing

Ensure better outcomes

Transition across all health and social care

Timely health service co-ordination

Formalise the process of transition

Clearer new pathway, locally and nationally

Working pathway benefiting those not known to CHAS

Hearing the YA's voice

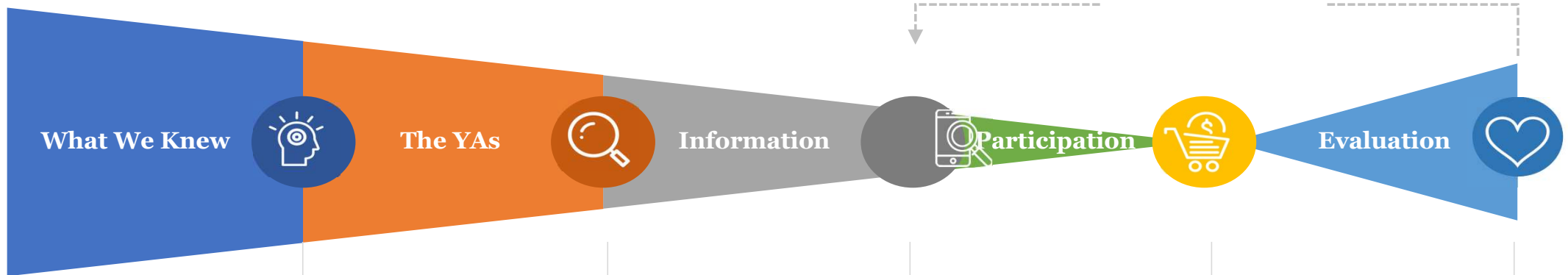
Supporting them now so they live well into the future

YA and person-centred

**Measurable outcomes:
GIRFEC & SHANARRI**



CHAS PPWH Transition Pilot Journey Map



- Children with life limiting conditions are living longer
- Change in the upper age limit at CHAS
- Lack of a coordinated transition pathway locally
- Lack of coordinated MDT care in adult services

- ACT categorisation used to identify those who would benefit from transfer from child to adult hospice services
- 9 young adults identified by CHAS: 18-20 years old, Undiagnosed genetic conditions, complex neurodisability and neuromuscular.

Development of Leaflets:

- 1. 'What is Transition'?
- 2. 'The Transition Pilot' Information Leaflet
- 3. 'Getting to Know the Prince & Princess of Wales Hospice' The difference between child and adult services.

- CHAS First assessment with young adult
- First Joint Transition Clinic Appointment
- Ongoing Transition Appointments
- Full transition to PPWH with 6/12 medical support from CHAS
- Joint MDTs and Evaluation meetings

- Ongoing co-production through evaluation by YA and their families:
 - QR code
 - SurveyMonkey
 - Paper
 - Verbal
 - You Said We Did
- Continuous model of improvement

Expectations of the pilot

- Every young adult would be **ON** the Transition Pathway following completion of the pilot
- Young adults, families and carers would be keen to engage with the pilot process and would offer constructive feedback
- We would be better placed to understand the Transition Pathway what influences it and what gets in the way
- Resources would be sufficient to successfully manage the transition caseload

Outcome of the Pilot

- Two young adults fully transitioned to PPWH
- One young adult in the process of being transitioned to local hospice with support from PPWH
- One family visited the PPWH
- Information about the pilot shared with other YA's, their family/carer identified as part of the pilot

Reality of the pilot

- Transitioning Young adults, families and carers can be fraught with difficulties. During a Pandemic the difficulties are even greater as they appear reluctant to transition from what they know, especially as the future of healthcare and services remains uncertain
- Inadequate resources for the pilot as all team members have additional roles and work outwith the pilot. – relying heavily on 'good will' for those involved
- Lacking of understanding around the need for an administrative role. The pilot team members spent excessive amount of time phoning, emailing and lettering individuals
- The team naïve in the amount of time that would be required to transition the individual's involved
- Extension of the 12 month pilot will be needed if we are to support the remaining 6 individuals who will require transition from paediatric to adult services including the potential of adult palliative care.

