

GRIT: Getting it Right In Transition – empowering young people with congenital heart disease

Introduction

A Success Story

Congenital heart disease is a great medical success story: now 90% of children with congenital heart disease survive to adulthood¹.

Transfer from paediatric to adult care is a hugely important step in the patient journey, made often at a time when a young person faces challenges in many aspects of life.

The numbers of patients transferring to adult care are increasing:

⇒ There were 176 attendances by 16-18 year olds in Oxford Paediatric Cardiology in 2012, rising to 249 in 2022: an increase of over 40%.

The Challenge

When transition is done well:

- ⇒ the process empowers young people to take shared responsibility, make healthy lifestyle choices, and use healthcare services appropriately and wisely.
- ⇒ patients can be supported to achieve a level of independence which maximises their quality of life.

Getting it wrong can be a disaster:

- ⇒ more than 26% of congenital heart disease patients experience interruptions in care at the time of transition²
- ⇒ Patients can be lost to follow-up and suffer preventable complications as a result³
- ⇒ disengagement with healthcare providers; non-adherence to medications
- ⇒ lost opportunities for preventative strategies
- ⇒ failure to provide holistic care for complex needs

The objectives

To improve the OUH congenital heart disease transition service and empower young patients by

- Improving patient satisfaction
- Improving our performance measured against the Burdett Trust benchmarks for transition⁴
- Reducing number of patients lost to follow-up



Step 1: Stakeholder engagement and data gathering

A. Patient engagement

- Patient experience questionnaires (underway)
 - Pre, during and post-transition
 - Based on Burdett Trust benchmarks⁴
 - To identify priorities for transition service
 - To identify strengths/ areas for improvement
- Somerville Foundation collaboration - Sharing results of their focus groups on transition to identify priorities

B. Learning from others

- Best practice from other specialties – eg Diabetes
- National Transition Evaluation Study

C. Stakeholder meetings

- Including adult and paediatric clinical, specialist nursing, psychology, admin, management teams
- Wider network transition discussions
- Audit of achievement of Burdett Trust benchmarks for transition (underway)

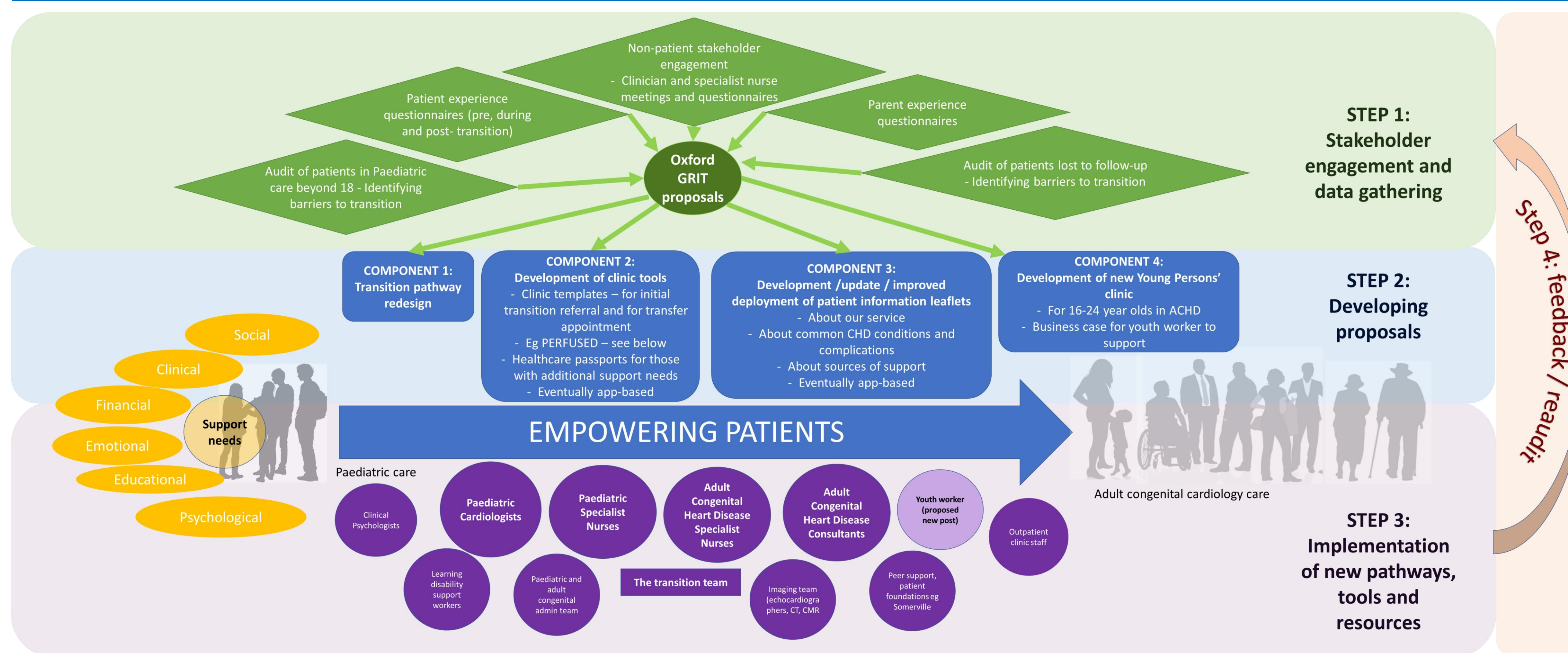
D. Clinical data

- Audits identifying barriers to transition (underway)
 - of patients lost to follow up at transition
 - of patients who remain under paediatric care beyond 18

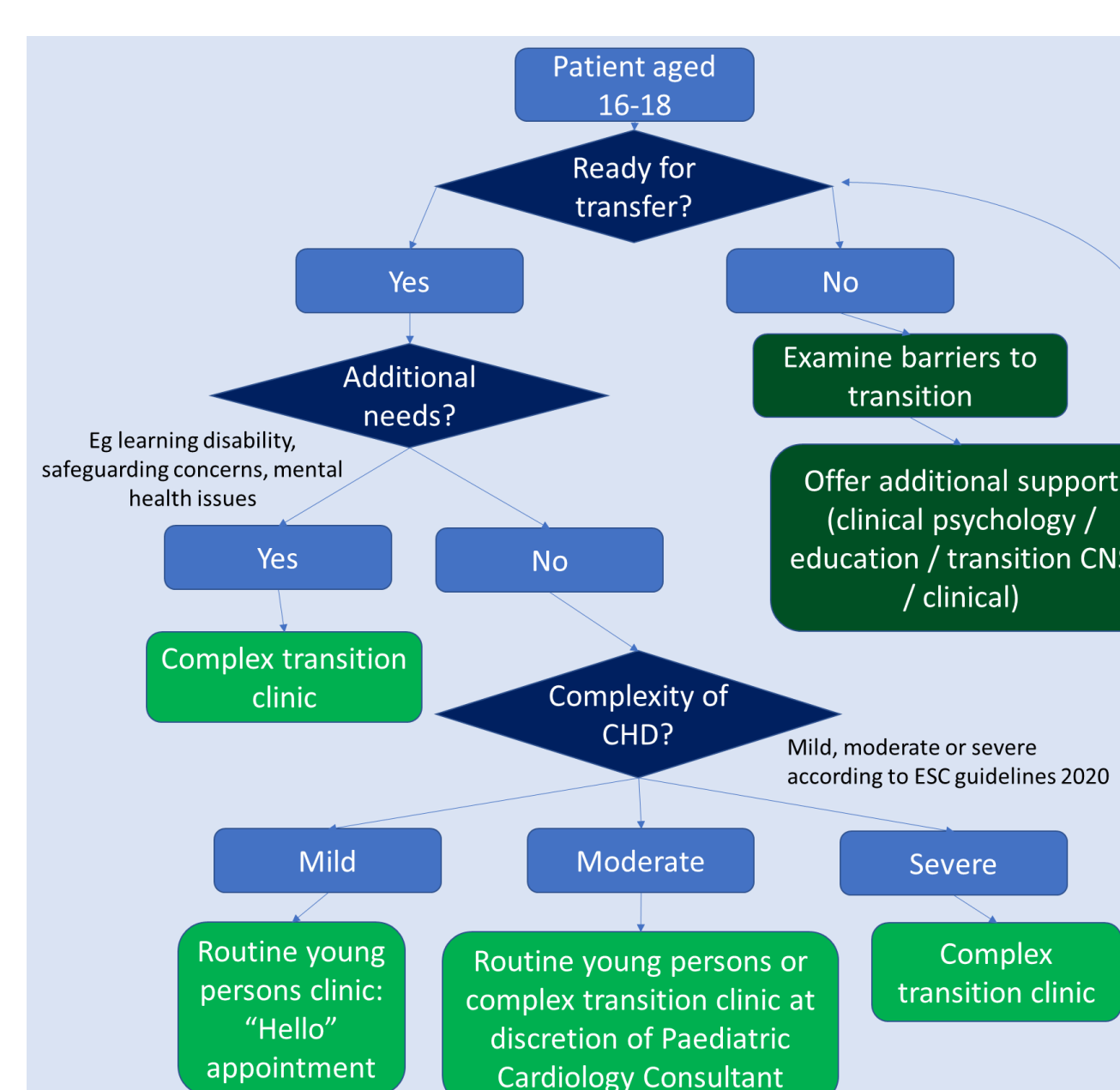
Key points from initial feedback:

- Need for clearer transition pathways
- Key is ability to tailor for individual patient needs
- Generic transition tools too unwieldy in CHD clinics
- Need for clinic templates / tools to simplify process, ensure comprehensive coverage of specific issues
- Need for coordination of care with other specialties

FIGURE 1: THE ANATOMY OF THE GRIT PROJECT: key steps, components, stakeholders and needs



Step 2: Developing proposals for feedback and discussion



Component 1: Proposal for transition pathway redesign

This will be presented to stakeholders including patients for feedback

- Aim to reduce number of patients lost to follow-up
- Aim to offer complex support where needed but recognise capacity limitations and provide simpler transition arrangements where appropriate
- Simple but with scope for flexibility to remain patient-focused

The proposal includes component 4: new young persons clinic:

Feedback from other specialties and patients that adult services not well-tailored to support younger patients

- Can be delivered within current job plans by repurposing general clinic
- Requires admin support for set-up.
- Youth worker key in other specialties – can visit patients at home / other care settings and support more holistically – possible part funding from charity sources

Step 2 continued:

Component 2: Development of clinic tools

Initial discussions have highlighted the need for simple tools tailored to young people with congenital heart disease

- A template for referral to adult services which collates key information about each patient
- A tool to guide discussion in the complex transition / young people's clinic

We have developed the clinic tool proposal "PERFUSeD" which forms the basis of a draft clinic letter template to ensure key topics have been addressed :

- Positive lifestyle choices (exercise, diet, smoking, drugs advice)
- Endocarditis prophylaxis
- Reproductive counselling
- Future prognosis
- Understanding of condition
- Support sources
- Employment / education
- Drugs / medications

Step 4: Measuring outcomes

- Reaudit of patients lost to follow-up
- Repeat Burdett Trust benchmarking
- Repeat patient questionnaires based on targets identified in the international consensus statement on transition³ (figure below adapted from targets in this paper)



Conclusions

- Getting it Right In Transition is of great importance to patients and the congenital heart disease service
- The GRIT project will evolve with feedback from patients and other stakeholders
- We plan to deliver measurable improvements in care for young patients with congenital heart disease

References

1. Mandalenakis et al J Am Heart Assoc 2020;9:e017704
2. Moons et al J Am Heart Assoc 2021;10:e019552
3. Moons et al Eur Heart J 2021 Nov 1;42(41):4213-4223
4. Burdett Trust benchmarks available at: gosh-benchmarksfortransitionfromchildtoadultservices-2015.pdf (yhscn.nhs.uk)