

Promoting Open Research Throughout the Evaluation of the Development of Burdett National Transition Nursing Network

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Introduction

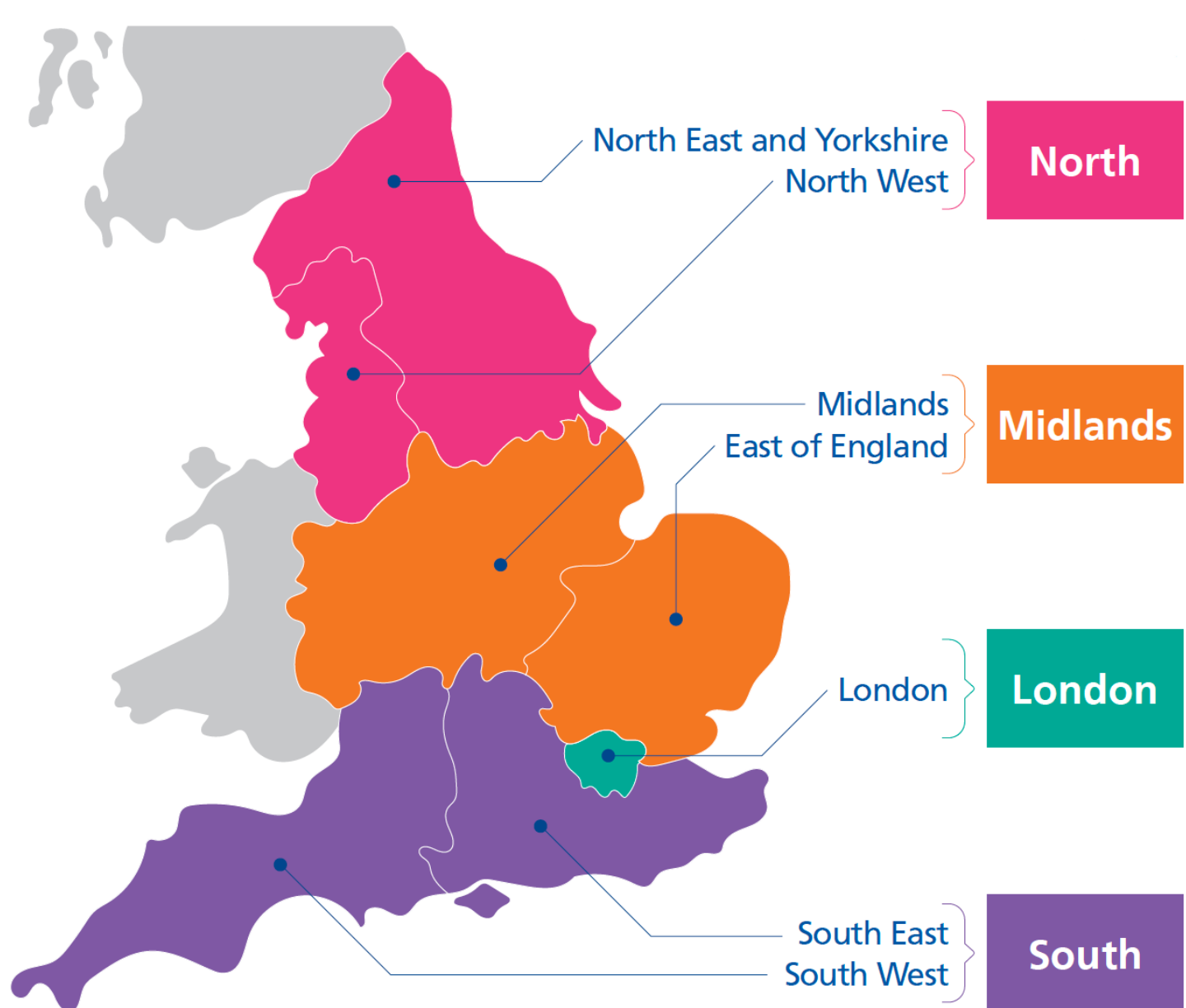
The transition from child/adolescent services into adult services is a crucial time in the health of young people with a long-term health condition, yet processes are disjointed and often fall short of what is required for effective transition.

Following the successful development of an exemplar Model of Care for Transition at Leeds Teaching Hospital Trust (LTHT; **Figure 1**), a National Transition Nursing Network is being implemented across England (**Figure 2**).

Figure 1: The Model of Care for Transition



Figure 2: National Transition Nursing Network Implementation in four regions across the UK



A formal evaluation of this quality improvement model for transition will be conducted by a research team at The University of Surrey, in partnership with LTHT, funded by the Burdett Trust for Nursing.

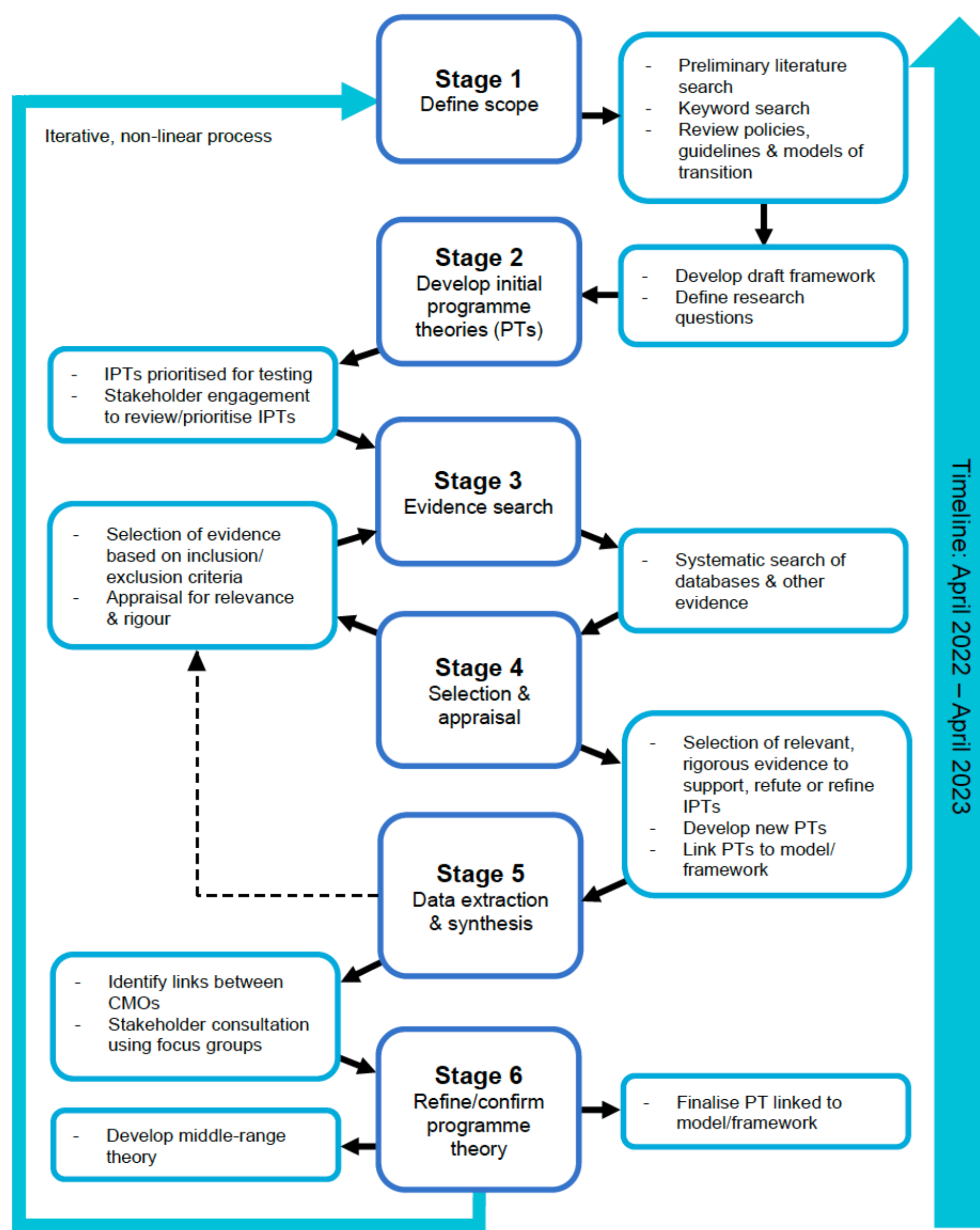
Proposed methods

A three phase multi-centre concurrent mixed methods design will be utilised including:

- Qualitative interviews/case studies
- Quantitative descriptive surveys

Participants will include young people, parents, and professionals involved in the young person's transition journey.

This study also includes a realist synthesis of the literature to understand what works for whom, under what circumstances, and how/why it works during young people's transition from child/adolescent services into adult services (**Figure 3**).



Adapted from: Kantilal et al (2020) doi:10.1136/bmjopen-2020-037636; Power et al. (2019) doi: 10.1136/bmjopen-2018-022084
Abbreviations: IPTs – Initial programme theories; PTs – programme theories; CMOs – Context, Mechanisms, Outcomes

Figure 3: Stages of Realist Synthesis

Proposed Open Research practices:

Promoting Open Research, the study team will work in partnership with lead professionals from the National Transition Nursing Network throughout. This includes:

- Open collaboration on the Realist Synthesis with members of the National Transition Nursing Network, including early protocol registration, and joint authorship on both the protocol and final realist synthesis publications.
- Young people's involvement to steer the study, with a Transition Advisory Group already established.
- Digital newsletters and social media platforms for the sharing of study information.
- Regular updates publicly available on LTHT's website to share emerging findings and new learning.
- Joint, open access publications with key stakeholders throughout the study.
- Study registration on the International Standard Randomised Controlled Trial Number Registry, in line with the HRA's 'Make It Public' Transparency Strategy.
- Research outputs will be deposited in the University's Open Research repository.



This study is funded by the Burdett Trust for Nursing

Promoting Inclusion:

The study team is acutely aware of potential barriers to some young people and families being able to participate. This study aims to be as inclusive as possible including:

- Offering digital *and* paper surveys
- Easy read versions of participant facing documents for those with intellectual disability or low literacy levels
- Translation of study materials, as required
- The provision of interpreters, as required
- Investigation of the provision of electronic devices to facilitate survey completion at participating sites for those without access to the internet or without a device

Requested feedback:

The study team would be grateful for feedback or advice on:

- Increasing study visibility
- Suggestions of methods to share emerging and ongoing findings
- Ideas for wider dissemination at the end of the study
- Additional methods to promote inclusion
- Sharing qualitative data e.g., excerpts from framework analysis

References:

1. Health Research Authority. Make it public: transparency and openness in health and social care research 2021; <<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/make-it-public-transparency-and-openness-health-and-social-care-research/>>
2. ISRCTN registry <<https://www.isrctn.com/>>
3. Kantilal et al. Realist review protocol for understanding the real-world barriers and enablers to practitioners implementing self-management support to people living with and beyond cancer. BMJ Open 2020;10:e037636. doi:10.1136/bmjopen-2020-037636