




# BMJ Open Transition of young people from children's into adults' services: what works for whom and in what circumstances – protocol for a realist synthesis

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## ABSTRACT

**Introduction** The process of transitioning young people from children's or adolescents' health services into adults' services is a crucial time in the lives and health of young people and has been reported to be disjointed rather than a process of preparation in which they are involved. Such transitions not only fail to meet the needs of young people and families at this time of significant change, but they may also result in a deterioration in health, or disengagement with services, which can have deleterious long-term consequences. Despite the wealth of literature on this topic, there has yet to be a focus on what works for whom, in what circumstances, how and why, in relation to *all* young people transitioning from children's into adults' services, which this realist synthesis aims to address.

**Methods and analysis** This realist synthesis will be undertaken in six stages: (1) the scope of the review will be defined; (2) initial programme theories (IPTs) developed; (3) evidence searched; (4) selection and appraisal; (5) data extraction and synthesis; and (6) finally, refine/confirm programme theory. A theory-driven, iterative approach using the 'On Your Own Feet Ahead' theoretical framework, will be combined with an evidence search including a review of national transition policy documents, supplemented by citation tracking, snowballing and stakeholder feedback to develop IPTs. Searches of EMBASE, EMCARE, Medline, CINAHL, Cochrane Library, Web of Science, Scopus, APA PsycINFO and AMED will be conducted from 2014 to present, supplemented with grey literature, free-text searching (title, abstract and keywords) and citation tracking. Data selection will be based on relevance and rigour and extracted and synthesised iteratively with the aim of identifying and exploring causal links between contexts, mechanisms and outcomes. Results will be reported according to the Realist And Meta-narrative Evidence Syntheses: Evolving Standards Quality and Publication Standards.

**Ethics and dissemination** This realist synthesis forms part of the National Transition Evaluation Study, which has received ethical and regulatory approval (IRAS ID: 313576). Results will be disseminated through peer-review publication, conference presentations and working with healthcare organisations, stakeholder groups and charities.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Realist methodology will be used to explore contextual factors and underpinning causal mechanisms of young people's effective transition from children's into adults' healthcare.
- ⇒ Using the 'On Your Own Feet Ahead' theoretical framework is a novel approach for the initial development and continuous refinement of the programme theories in realist methodology.
- ⇒ Continuous refinement of programme theories is guided by key stakeholders, including young people, ensuring applicability to the real world.
- ⇒ Findings will inform practice and future policy.
- ⇒ A limitation is that only evidence in the English language will be included.

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## INTRODUCTION

The journey through adolescence into adulthood is a challenging time of physical, psychological, emotional and social changes. Young people with a long-term health condition can face even greater challenges as they deal with complex and important changes in the healthcare that they need and in the way that it is provided. The role of the young person, and also their parents/carers, will evolve with the young person often wanting and being expected to exercise greater independence in the management of their health condition, as much as they are cognitively able.

'Transition' can be defined as "a multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health care system".<sup>1(p.573)</sup> Unfortunately, for many



young people, their experience of transition does not always meet the aspirations of this definition. The Care Quality Commission (CQC) described a health and social care system that is letting down many young people who are desperately ill at a time of life where decisions are crucial.<sup>2</sup> It is well known that “young people are at risk of experiencing poorer health outcomes when transition between children’s and adults’ services is not coordinated and planned”,<sup>3(p.32)</sup> Research studies have reported that some young people experience a disjointed transfer into adults’ services which is more of a one-off transfer event, rather than a process of preparation and support in which they are involved; such experiences seem to be comparable across young people with different diagnoses.<sup>4</sup> Consequently, health service provision, which fails to meet the needs of young people and families at this time of significant change, may result in deterioration in health or disengagement with services, which can have negative long-term consequences.

The National Institute for Health and Care Excellence’s Quality Standard for Transition recommends that health and social care service managers in children’s and adults’ services should provide an integrated, collaborative approach to ensure a smooth and gradual transition for young people.<sup>5</sup> The transition from children’s into adults’ services is a crucial time in the health of young people who may potentially fall into what has been described as a poorly managed ‘care gap’. We know already that transition processes or programmes of preparation and support need to smooth this journey and bridge this ‘care gap’, but this process is not yet fully understood. We also know that current practices across the UK and elsewhere are varied, creating an ad hoc, often chaotic approach to young people’s transition, meaning that there is a need to understand these processes and this care gap further, which is the focus of this realist synthesis.

We chose realist methodology over the more traditional systematic review methodology because traditional methods focus on evidence without considering the context; we know already that context is key to transition. Also, realist methodology is theory driven, aiming to establish what works for whom in what circumstances, how and why. While there are numerous reviews into ‘evidence’ surrounding the issue of healthcare transition, the outcomes invariably conclude that there is not enough evidence. Furthermore, most reviews only consider one specific intervention and/or a specific patient group, the results are then neither applicable to all young people or transferable to all disease groups nor to complex interventions such as transition programmes that consist of numerous different elements. Finally, realist methodology has been applied in the field of transition, healthcare in the context of young adults with life-limiting conditions.<sup>6,7</sup>

The first of these studies focused on the evaluation of eight interventions which can help prepare young people with life-limiting conditions and healthcare services for a successful transition. Kerr *et al* reported three of the eight

interventions were validated: early start to the transition process; developing adolescent/young adult autonomy; and the role of parents/carers, with partial support for the remaining five. Effective communication between health-care professionals and young people and their parents/carers was identified as an additional intervention of importance.<sup>6</sup> Contextual factors affecting successful transition were highlighted including those related to staff knowledge and attitudes and a lack of time to provide young person-centred transition services.<sup>6</sup> Mechanisms that were supported include the young person’s decision-making and gaining confidence in relationships with service providers.<sup>6</sup>

The second of these studies reported the following elements as vital to the successful transition of young people with life-limiting conditions: early planning; collaboration between children’s and adult healthcare providers; and an emphasis on increasing the young person’s confidence in making decisions and engaging with adult services.<sup>7</sup> Kerr *et al* advocated that “interventions should be tailored to their context and focused not only on organisational procedures but on equipping young adults, parents/carers and staff to engage with each other effectively”.<sup>7(p.1)</sup> We acknowledge the contribution these studies make to the transition field. We seek to add additional knowledge through expansion of patient populations, using the same realist methodology, and consider *all* young people transitioning from children’s into adults’ services. This realist synthesis will be inclusive of young people with long-term conditions and complements the research being undertaken as part of the National Transition Evaluation Study, which formally evaluates the implementation of the Burdett National Transition Nursing Network and the Model of Improvement for Transition (<https://www.leedsth.nhs.uk/burdett-national-transition-nursing-network/>).

## METHODS AND ANALYSIS

Realist methodology uses a theory-driven paradigm to “explore how context such as cultural norms and values, economic conditions, geographical characteristics or national policy interacts with various mechanisms to produce outcomes”.<sup>8(p.2)</sup> This study aims to produce important information about the relative effectiveness of transition intervention components taking into consideration different conditions, needs and associated complexities, ages of young people, differences in healthcare personnel and service provision in different healthcare contexts. The realist approach acknowledges that interventions may work in some contexts but not others, with a key principle being the notion that interventions are context bound. A realist synthesis focuses on causation and is represented as context+mechanism=outcome.<sup>9,10</sup>

*Context* pertains to the ‘backdrop’ of programmes and research.<sup>11</sup> In our study, this pertains to ways in which services are configured and how transition processes and pathways are constructed to provide or support the

**Table 1** Study PICOH

PICOH	
P—Population	<ol style="list-style-type: none"> <li>1. Child health clinicians (doctors—including GPs, nurses, allied health professionals) preparing and supporting young people's transition from child into adult services.</li> <li>2. Adult clinicians (doctors—including GPs, nurses, allied health professionals) supporting and engaging young people in the adult service during the process of transition.</li> <li>3. Youth workers, key workers and support staff (MDT co-ordinators, play specialists, administrative support in both child and adult setting).</li> <li>4. Young people's perspectives on transition into adults' services (age 12–25 years).</li> <li>5. Parent/caregiver perspectives on their child's transition into adults' services.</li> </ol>
I—Intervention	Interventions related to successful transition of young people from children's into adults' services <sup>5 12</sup> : <ol style="list-style-type: none"> <li>1. Start the transition process early, by the young person's 14th birthday at the latest (unless diagnosed after).</li> <li>2. Make a developmentally appropriate transition plan that takes into account each young person's capabilities, needs and hopes for the future.</li> <li>3. Children's and adults' services working in partnership through effective communication and collaboration.</li> <li>4. Orientation of the young person to adults' services (joint clinic appointments with both children's and adult healthcare professionals in both settings, preparation visits to the adult centre, discussion of adult service processes).</li> <li>5. The engagement of a transition co-ordinator (or named worker).</li> <li>6. Interdisciplinary and interagency joint working.</li> <li>7. Developing the young person's autonomy throughout the transition process.</li> <li>8. Service providers demonstrating a person-centred approach to care.</li> <li>9. Involvement of parents/carers (as much as the young person wishes them to be), with a parallel transition programme of support.</li> <li>10. Opportunity for the young person to be seen alone for all or part of the consultation or without usual caregiver.</li> </ol>
C—Comparator	None
O—Outcomes	Outcomes will vary according to the intervention, but may include: <ol style="list-style-type: none"> <li>1. Measurable adverse outcomes such as non-adherence to treatment, loss to follow-up, adverse social and educational outcomes, morbidity and mortality.<sup>23</sup></li> <li>2. Measurable favourable outcomes such as increasingly taking responsibility for engaging with services providers, adherence to treatment strategies and contributing to their disease management plan.<sup>12</sup></li> <li>3. Attendance at appointments, understanding of condition and its self-management.</li> <li>4. Self-reported readiness for the transfer into adults' services and self-advocacy.</li> </ol>
H—Healthcare context	Any healthcare setting that is involved with the transition of young people from child into adults' services including but not limited to primary, secondary and tertiary care centres, community healthcare providers, mental health services, learning disability services and social care within or outside the NHS.
GP, general practitioner; MDT, multidisciplinary team; NHS, National Health Service.	

transition of young people from children's into adults' services. This would include both child and adult healthcare providers and all healthcare settings, as described in the study's population, intervention, comparator, outcomes and healthcare context (table 1). Context can be understood as any condition that triggers or modifies a mechanism<sup>11</sup> and includes concepts such as how services are funded, cultural norms and values and pre-existing relationships between child and adult healthcare settings or between healthcare providers and young people and their families.<sup>8</sup>

*Mechanism* concerns the causal force, triggered in particular contexts, that leads to outcomes. Mechanisms explain why and how observed outcomes occur and usually comprise two parts: the 'resources' offered by an intervention and the cognitive or emotional decisions ('reasoning') and behaviour of people, in this case the behaviour of young people, their parents or carers

and healthcare professionals involved in the transition of young people to adults' services.<sup>8</sup> Jagosh *et al* identify that mechanisms advance the synthesis beyond describing 'what happened' to theorising 'why it happened, for whom and under what circumstances' based on participant reasoning or reaction,<sup>11</sup> which is key to understanding the intricacies related to young people's effective transition into adults' services.

*Outcomes* are either intended or unintended/unexpected and are defined as either intermediate or final.<sup>11</sup> Examples of outcomes related to young people's transition include young people's increased engagement in their health management, increased knowledge of their condition(s), treatment and medication. Examples of outcomes related to transition-related interventions include improved health outcomes, increased adherence to treatment strategies or contributing to their disease management plan.<sup>12</sup>

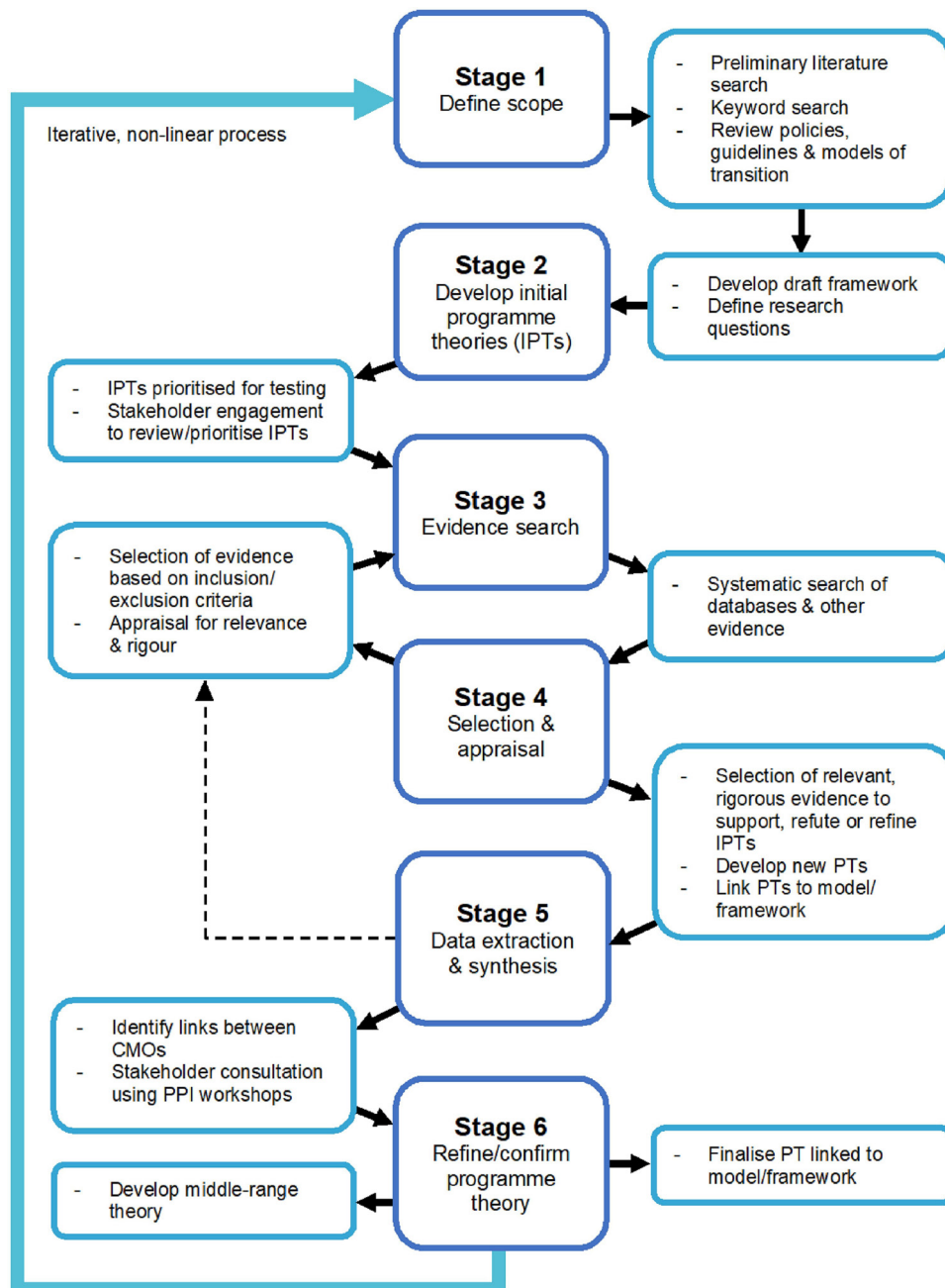
## Realist synthesis

An interpretative theory-driven approach will be used to synthesise evidence from a broad range of sources including quantitative and qualitative published studies, policy documents, grey literature, free-text searching using title, abstract and keywords. Publications in the English language will be included. Pawson *et al* have proposed a method for conducting realist reviews,<sup>13</sup> however we have interpreted this method to include six stages rather than Pawson's five steps, emphasising the iterative process of requiring programme theory to be refined and confirmed accordingly: (1) the review's scope will be defined, (2) initial programme theories

(IPTs) will be developed, (3) evidence search, (4) selection and appraisal, (5) data extraction and synthesis and (6) refine/confirm programme theory. This study commenced in July 2022 and completion is planned for July 2024. **Figure 1** provides an overview of the realist synthesis design. Due to the iterative process of a realist synthesis, the sequential stages may be repeated or run in parallel as the study progresses

### Stage 1: define scope

The scope of the review was clarified through preliminary literature searching, keyword searching and review of transition-related policies, guidelines and models



**Figure 1** Overview of realist synthesis design. Adapted from Kantilal *et al.*<sup>8</sup> CMOs, context mechanisms outcomes; PPI, patient and public involvement; PTs, programme theories.



of transition. Subsequently, IPTs were developed (as described below), providing the framework for synthesis of the evidence.

### Stage 2: develop IPTs

A theory-driven, iterative approach using the ‘On Your Own Feet Ahead’ theoretical framework, which includes care co-ordination, continuity of care, psychosocial care, self-management, parent involvement and future-oriented care,<sup>14</sup> was combined with an informal literature search. This included a review of national transition policy documents, supplemented by additional search methods, such as citation tracking and snowballing.

‘On Your Own Feet Ahead’ theoretical framework, developed in 2008, incorporates eight key elements of good healthcare transition care, divided into three core categories:

1. Interventions to improve the organisation of care.
2. Interventions to stimulate independence and self-management of adolescents.
3. Collaboration with young people (and their families) and within the multidisciplinary team of professionals, working both in paediatric care and adult care.<sup>14</sup>

This evidence-based theoretical framework was chosen to guide this research due to the well-documented success of its use over the last 15 years in the Netherlands.<sup>14–16</sup> Furthermore, this framework directly promotes young people’s voices being heard in matters that directly affect them<sup>16 17</sup> and emphasises the collaboration of all relevant stakeholders for healthcare transition success<sup>14</sup>, elements crucial to understand further in the context of published work.

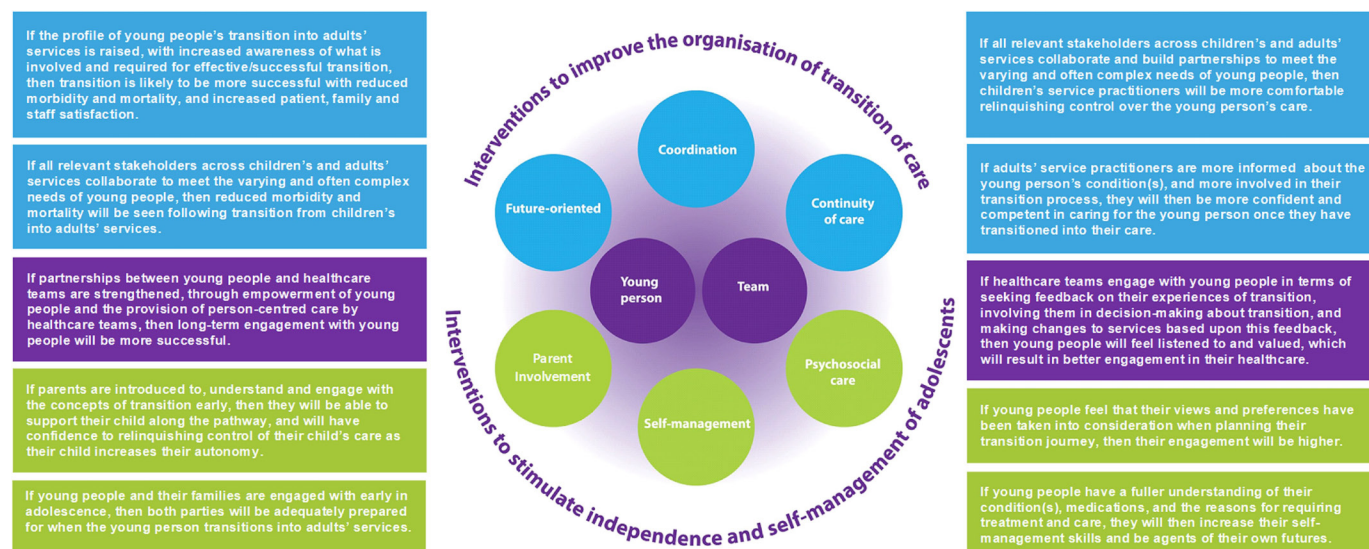
As a starting point, IPTs linking to the different elements of the theoretical framework were formulated by the research team. Prior to commencing the formal searches, these IPTs were presented at a workshop with two leading experts on the transition of young people from children’s into adults’ services, namely, the National

Lead Nurse for Transition and the National Advisor for Transition who advised on the Burdett National Transition Nursing Network implementation project. The IPTs were refined through discussion with the experts, who imparted their knowledge from their extensive clinical and specialty specific experience, with a final consensus being reached as to the applicability and appropriateness of each IPT. **Figure 2** presents examples of the IPTs, which are colour coded according to which aspect of the framework they relate to. It is important to note that IPTs can relate to more than one dimension within the framework. An example of this is, ‘if all relevant stakeholders across children’s and adults’ services collaborate and build partnerships to meet the varying and often complex needs of young people, then children’s service practitioners will be more comfortable relinquishing control over the young person’s care’ relates to ‘future-orientated, ‘co-ordination’ and ‘continuity of care’. This process enabled the formulation of the research questions. The selection of relevant, rigorous evidence will be applied to these IPTs in subsequent stages of this realist synthesis so that they can be supported, refuted or refined.

### Realist synthesis research questions

- ▶ What range of interventions are associated with an effective transition from children’s into adults’ services for young people with long-term health conditions?
- ▶ What are the contextual factors that facilitate an effective transition into adults’ services?
- ▶ What mechanisms are triggered by the interventions that support an effective transition into adults’ services?
- ▶ How might this influence future clinical practice, research and policy?

To fully understand the process to be taken, it was necessary to commence stages 1 and 2 of the realist synthesis prior to publication of the protocol, so that the IPTs could be developed and applied to the theoretical



**Figure 2** Initial programme theories applied to the ‘On Your Own Feet Ahead’ theoretical framework.

framework, which would then inform the subsequent stages of this research.

### Stage 3: evidence search

A search of EMBASE, EMCARE, Medline, CINAHL, Cochrane Library, Web of Science, Scopus, APA PsycINFO and AMED (online supplemental files 1-9) will be conducted from 2014 to present, to capture the architecture of service provision following the CQC's 'from the pond into the sea' children's transition to adults' health services document that was published in June 2014<sup>2</sup>, a significant policy document in the UK from which change in practice was started to be reported. Searches will be supplemented with grey literature, free-text searching using title and abstract keywords and citation tracking for broad inclusion of all study designs, publications or policy documents. Publications in the English language will be included.

Data will be exported from the databases into Covidence web-based collaboration software platform for subsequent selection and appraisal.<sup>18</sup> Data selection will be based on relevance and rigour and will be extracted and synthesised iteratively with the aim of identifying and exploring causal links between contexts, mechanisms and outcomes. Results will be reported according to the Realist And Meta-narrative Evidence Syntheses: Evolving Standards Quality and Publication Standards (RAMESES).<sup>19</sup>

### Inclusion

- ▶ All study designs.
- ▶ Non-empirical sources of evidence—grey literature: policy documents, guidelines, books, opinion papers, editorials, dissertations, blogs and additional sources identified by the review team and stakeholder groups.
- ▶ Evidence from 2014 to present to capture the architecture of service provision following the CQC's 'from the pond into the sea' children's transition to adults' health services document (June 2014).<sup>2</sup>

### Exclusion

- ▶ Evidence not written in the English language.
- ▶ Publications involving young people with life-limiting conditions.

### Stage 4: selection and appraisal

Documents will be initially screened against the inclusion and exclusion criteria: by title and abstract and then by full-text screening by two reviewers using Covidence. Disagreements will be resolved through discussion with the realist synthesist research team ensuring consistency in document inclusion.

The quality of studies will be assessed on relevance to contributing to theory development and/or testing and rigour in terms of credibility and trustworthiness. Included evidence will be appraised using the 'Appraisal Form Template'<sup>20</sup> which examines:

- ▶ Usefulness/relevance of the evidence to the research questions.

- ▶ How the evidence is relevant to the candidate programme theories, if at all.
- ▶ Strengths/weaknesses of the evidence, whether there are any 'red flags'.
- ▶ Connection(s) between the outcomes and the process (C+M=O).
- ▶ Any unintended positive/negative impacts and their mechanism link to the outcomes.

The quality of a 10% sample of studies will be independently checked by a second reviewer, with disagreements resolved by discussion with the realist synthesis team to ensure quality and consistency in study inclusion.

The RAMESES quality and publication standards will be applied at the full-text screening stage.<sup>19</sup> These will be used to guide the assessment of the quality of selected studies. Selected full texts will be coded in two ways: inductive codes originating from the studies and deductive codes originating from the programme theory. Using an iterative process, coded text will be selected based on the following:

- ▶ Is the evidence referring to context (C), mechanism (M) or outcome (O)?
- ▶ What is the context mechanisms outcome (CMO) configuration?
- ▶ Is there a link within or between the CMO configurations?
- ▶ In light of the CMO configurations, does the programme theory need to be amended?
- ▶ Are there any other trustworthy and rigorous criteria that should be considered?

### Stage 5: data extraction and synthesis

Data extraction will be performed within Covidence with the formulation of a data extraction table within the software. Data will be organised according to the 'On Your Own Feet Ahead' framework's<sup>14</sup> measures: (1) evidence that relates to interventions to improve the organisation of transition and (2) evidence that relates to interventions to stimulate independence and self-management of young people. Data will also be organised according to a third measure, that is, evidence that relates to the young person's experience of transition.

Evidence will be extracted and synthesised iteratively with the aim of identifying and exploring causal links between contexts, mechanisms and outcomes (C+M=O) and the extracted codes will be synthesised according to the relationship between contexts, mechanisms and outcomes (intended and unintended/unexpected). The synthesis will include the following steps:

- ▶ Organising the extracted information from various sources of evidence.
- ▶ Identifying themes and patterns or demi-regularities across the codes among context, mechanism and outcomes, as we seek confirming and disconfirming evidence.
- ▶ Linking the patterns or demi-regularities to refine IPTs to develop formal programme theory.

- ▶ Reflection and discussion within the realist synthesis team.

### Stage 6: refine/confirm programme theory

The reliability of the programme theory, adjudication between competing theories and implications of different contexts to the same programme theories will be considered. Programme theories will be compared with practical experiences of young people's, parents' and carers', and healthcare professionals' experience of young people's transition from children's into adults' services through patient and public involvement (PPI) workshops with the respective stakeholder groups. Realist synthesis findings and programme theories will be presented at the respective workshops, allowing for programme theory to be confirmed, refuted or refined, or, if required, even alternate theories developed using an iterative process. The refined and finalised theory, called middle-range theory, will be the final output of the review, aiming to clarify the current gap in knowledge.

Searching and purposive sampling of additional documents to test and examine emerging programme theory will be performed, as necessary. Finalised programme theory will describe the intervention strategies, steps and the contexts that need to be present to support the successful transition of young people from children's health services into adults' services.

### Expected challenges of using realist methodology in this context

There are several challenges that may arise with the use of realist methodology. First, opposed to the relatively simple evaluation of clinical treatments through randomised controlled trials, realist synthesis of the literature on service interventions may be challenging due to epistemological complexity and methodological diversity.<sup>21</sup> This may mean that the search has not only breadth but also depth and will require time to conduct. The research team would consider the search to be complete when no new information is added to the theory being evaluated, which is called 'theoretical saturation', a concept borrowed from qualitative grounded theory.<sup>22</sup>

Second, due to the nature of this realist synthesis including young people with a wide range of long-term health conditions, challenges may arise when considering the same theory applied to young people with different long-term conditions in comparative settings.<sup>21</sup> A further complexity may be applying the same theory to different locations, where care provision varies. To overcome these challenges, one approach could be to group services so that the theory can be compared across services that operate more closely (demonstrating where they align) or, conversely, more distantly (demonstrating where they differ).<sup>21</sup> It is acknowledged that, until the evidence is gathered and the theories have been developed, this cannot be predicted.

Finally, due to the diversity and complexity of this realist synthesis, drawing meaningful conclusions and framing

recommendations that will have an impact on practice, research and policy will be a challenge.<sup>21</sup> Emphasis is placed on the involvement of key stakeholders and experts on the transition of young people from children's into adults' services, in addition to experts by experience (young people who have commenced or completed their transition from children's health services into adults' services).

### Patient and public involvement statement

Extensive patient and public involvement has been undertaken prior to conception of the Burdett National Transition Nursing Network and the implementation of the Model of Improvement for Transition, the National Transition Evaluation Study and this realist synthesis. This included liaison with the 'Transition Advisory Group', made up of young people to advise on the implementation of the Burdett National Transition Nursing Network and on this study, a National Transition Steering Group and an Advisory Group, both formed of key stakeholders and professionals who are consulted on matters relating to the overall implementation project, the study, and the realist synthesis.

### ETHICS AND DISSEMINATION

This realist synthesis forms part of the National Transition Evaluation Study, which has received ethical and regulatory approval (IRAS ID: 313576). Results will be disseminated through peer-review publication, conference presentations and working with healthcare organisations, stakeholder groups and charities. This realist synthesis is registered on PROSPERO (registration number: CRD42023388985).

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critically reviewed the subsequent drafts of the manuscript providing comments for improvement. All authors have read and approved the final manuscript.

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