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The transition of young people from children's into adults' services – what works for whom in what circumstances: a realist synthesis

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4 **whom in what circumstances: a realist synthesis**
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The transition of young people from children's into adults' services – what works for whom in what circumstances: a realist synthesis

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 it works, 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 developed; (3) evidence searched; (4) selection and appraisal; (5) data extraction and synthesis; (6) finally, refine/confirm programme theory. A theory-driven, iterative approach utilising 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 initial programme theories. 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**). The study is registered on

ClinicalTrials.gov (**Identifier: NCT05867745**). Results will be disseminated through peer-review publication, conference presentations and through working with healthcare organisations, stakeholder groups, and charities. This realist synthesis is registered on PROSPERO (**Registration number: CRD42023388985**).

Article Summary

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.
- Utilising 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.

Introduction

The journey through adolescence into adulthood is a challenging time of physical, psychological emotional and social change. 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" (p.573)[1]. 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 [2]. It is well known that 'young people are at risk of experiencing

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3 poorer health outcomes when transition between children's and adults' services is not
4 coordinated and planned' [3], p32. Research studies have reported that some young
5 people experience a disjointed transfer into adults' services which is more of a one-off
6 transfer event, rather than a process of preparation and support in which they are involved:
7 such experiences seem to be comparable across young people with different diagnoses
8 [4]. Consequently, health service provision, which fails to meet the needs of young people
9 and families at this time of significant change, may result in deterioration in health or
10 disengagement with services, which can have negative long-term consequences.
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18 The National Institute for Health and Care Excellence's Quality Standard for Transition
19 recommends that health and social care service managers in children's and adults'
20 services should provide an integrated, collaborative approach to ensure a smooth and
21 gradual transition for young people [5]. The transition from children's into adults' services
22 is a crucial time in the health of young people who may potentially fall into what has been
23 described as a poorly managed 'care gap'. Transition processes or programmes of
24 preparation and support need to smooth the journey and bridge this 'gap' between
25 children's and adults' services, but this process is not yet fully understood. However,
26 current practices across the United Kingdom are varied, creating an ad hoc, chaotic
27 approach to young people's transition, meaning that there is a need to understand these
28 processes, and this gap in understanding further, which will be explored through this realist
29 synthesis. Realist methodology has been applied to healthcare transition in the context of
30 young adults with life-limiting conditions [6, 7], however there has yet to be a focus on
31 what works for whom, in what circumstances, how and why it works, in relation to *all* young
32 people transitioning from children's into adults' services. This realist synthesis will be
33 inclusive of young people with long term conditions, and complements the research being
34 undertaken as part of the National Transition Evaluation Study, which formally evaluates
35 the implementation of the Burdett National Transition Nursing Network and the Model of
36 Improvement for Transition ([https://www.leedsth.nhs.uk/burdett-national-transition-nursing-
37 network/](https://www.leedsth.nhs.uk/burdett-national-transition-nursing-network/)).

54 **Methods and analysis**

55 Realist methodology uses a theory-driven paradigm to "explore how context such as
56 cultural norms and values, economic conditions, geographical characteristics or national
57 policy interacts with various mechanisms to produce outcomes" p2 [8]. This study aims to
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3 produce important information about the relative effectiveness of transition intervention
4 components taking into consideration different conditions, needs and associated
5 complexities, ages of young people, differences in healthcare personnel and service
6 provision in different healthcare contexts. The realist approach acknowledges that
7 interventions may work in some contexts but not others, with a key principle being the
8 notion that interventions are context-bound. A realist synthesis focuses on causation and
9 is represented as context+mechanism=outcome [9, 10].
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17 **Context** “pertains to the ‘backdrop’ of programs and research” [11]. In our study, this
18 pertains to ways in which services are configured, and how transition processes and
19 pathways are constructed to provide or support the transition of young people from
20 children’s into adults’ services. This would include both child and adult healthcare
21 providers, and includes all healthcare settings, as described in the study’s PICOH (Table
22 1). Context can be understood as any condition that triggers or modifies a mechanism [11],
23 and includes concepts such as how services are funded, cultural norms and values, and
24 pre-existing relationships between child and adult healthcare settings, or between
25 healthcare providers and young people and their families [8].
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34 **Mechanism** concerns the causal force, triggered in particular contexts, that leads to
35 outcomes. Mechanisms explain why and how observed outcomes occur and usually
36 comprise two parts: the ‘resources’ offered by an intervention and the cognitive or
37 emotional decisions (‘reasoning’) and behaviour of people, in this case the behaviour of
38 young people, their parents or carers, and healthcare professionals involved in the
39 transition of young people to adults’ services [8]. Jagosh *et al* identify that mechanisms
40 advance the synthesis beyond describing ‘what happened’ to theorising ‘why it happened,
41 for whom, and under what circumstances’ based on participant reasoning or reaction [11],
42 which is key to understanding the intricacies related to young people’s effective transition
43 into adults’ services.
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Table 1: Study PICOH

PICOH	
P - Population	<p>Child health clinicians (doctors - including GPs, nurses, allied health professionals) preparing and supporting young people's transition from child into adult services.</p> <p>Adult clinicians (doctors – including GPs, nurses, allied health professionals) supporting and engaging young people in the adult service during the process of transition.</p> <p>Youth workers, key workers, and support staff (MDT coordinators, play specialists, administrative support in both child and adult setting)</p> <p>Young people's perspectives on transition into adults' services (age 12-25 years)</p> <p>Parent/caregiver perspectives on their child's transition into adults' services</p>
I – Intervention	<p>Interventions related to successful transition of young people from children's into adults' services [12]:</p> <ol style="list-style-type: none"> 1. Start the transition process early, by the young person's 14th birthday at the latest (unless diagnosed after) 2. Children's and adults' services to working in partnership through effective communication and collaboration 3. Orientation of the young person to adults' services 4. The engagement of a transition coordinator (or named worker) 5. Interdisciplinary and interagency joint working 6. Developing the young person's autonomy throughout the transition process 7. Service providers demonstrating a person-centred approach to care 8. Involvement of parents/carers (as much as the young person wishes them to be), with a parallel transition programme of support 9. Opportunity for the young person to be seen alone for all or part of the consultation or without usual caregiver
C – Comparator	None
O – Outcomes	<p>Outcomes will vary according to the intervention, but may include:</p> <p>Measurable adverse outcomes such as: nonadherence to treatment, loss to follow up, adverse social and educational outcomes, morbidity and mortality [13]</p> <p>Measurable favourable outcomes such as: increasingly taking responsibility for engaging with services providers, adherence to treatment strategies and contributing to their disease management plan [12]</p> <p>Attendance at appointments, understanding of condition and its self-management.</p> <p>Self-reported readiness for the transfer into adults' services and self-advocacy.</p>
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.

Abbreviations: GP – General Practitioner; MDT – Multi-disciplinary team NHS – National Health Service

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3 **Outcomes** are either intended or unintended/unexpected and are defined as either
4 intermediate or final [11]. Examples of outcomes related to young people's transition
5 include young people's increased engagement in their health management, increased
6 knowledge of their condition(s), treatment and medication. Examples of outcomes related
7 to transition-related interventions include improved health outcomes, increased adherence
8 to treatment strategies or contributing to their disease management plan [12].
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14 **Realist synthesis**

15 An interpretative theory-driven approach will be utilised to synthesise evidence from a
16 broad range of sources including quantitative and qualitative published studies, policy
17 documents, grey literature, free text searching using title, abstract and keywords.
18 Publications in the English language will be included. Pawson *et al* have proposed a
19 method for conducting realist reviews [14], however we have interpreted this method to
20 include six stages rather than Pawson's five steps, emphasising the iterative process of
21 requiring programme theory to be refined and confirmed accordingly: (1) The review's
22 scope will be defined, (2) initial programme theories will be developed, (3) evidence
23 search, (4) selection and appraisal, (5) data extraction and synthesis and (6)
24 Refine/confirm programme theory. Figure 1 provides an overview of the realist synthesis
25 design. Due to the iterative process of a realist synthesis the sequential stages may be
26 repeated or run in parallel as the study progresses.
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39 **Figure 1: Overview of realist synthesis design**

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43 44 45 **Stage 1: Define scope**

46 The scope of the review was clarified through preliminary literature searching, keyword
47 searching, and review of transition-related policies, guidelines and models of transition.
48 Subsequently, initial programme theories (IPTs) were developed (as described below),
49 providing the framework for synthesis of the evidence.
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56 **Stage 2: Develop initial programme theories**

57 A theory-driven, iterative approach utilising the 'On Your Own Feet Ahead' theoretical
58 framework, which includes care coordination, continuity of care, psychosocial care, self-
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3 management, parent involvement, and future-oriented care [16], was combined with an
4 informal literature search. This included a review of national transition policy documents,
5 supplemented by additional search methods, such as citation tracking and snowballing.
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7 Initial programme theories (IPTs) linking to the theoretical framework were formulated.
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9 Prior to commencing the formal searches, these were presented at a stakeholder
10 workshop with experts on the transition of young people from children's into adults'
11 services. The IPTs were refined through discussion and final consensus amongst the
12 group. Figure 2 presents the IPTs, which are colour coded according to which aspect of
13 the framework they relate to. It is important to note that IPTs can relate to more than one
14 dimension within the framework, for example, 'If all relevant stakeholders across children's
15 and adults' services collaborate and build partnerships to meet the varying and often
16 complex needs of young people, then children's service practitioners will be more
17 comfortable relinquishing control over the young person's care' relates to 'Future-
18 orientated, 'Co-ordination', and 'Continuity of care'. This process enabled the formulation
19 of the research questions.
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31 **Figure 2: Initial programme theories applied to the 'On Your Own Feet Ahead' theoretical**
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38 **Realist synthesis research questions**

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- 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?

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55 **Stage 3: Evidence search**

56 A search of EMBASE, EMCARE, Medline, CINAHL, Cochrane Library, Web of Science,
57 Scopus, (APA) PsycINFO, and AMED will be conducted from 2014 to present, to capture
58 the architecture of service provision following the Care Quality Commission's 'From the
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3 Pond into the Sea' children's transition to adults' health services document that was
4 published in June 2014 [2]. Searches will be supplemented with grey literature, free text
5 searching using title and abstract keywords, and citation tracking for broad inclusion of all
6 study designs, publications, or policy documents. Publications in the English language will
7 be included.
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13 Data will be exported from the databases into Covidence web-based collaboration
14 software platform for subsequent selection and appraisal [17]. Data selection will be based
15 on relevance and rigour, and will be extracted and synthesised iteratively with the aim of
16 identifying and exploring causal links between contexts, mechanisms and outcomes.
17 Results will be reported according to the Realist And Meta-narrative Evidence Syntheses:
18 Evolving Standards Quality and Publication Standards [15].
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24 25 **Inclusion**

- 26 • All study designs
- 27 • Non-empirical sources of evidence – grey literature: policy documents, guidelines,
28 books, opinion papers, editorials, dissertations, blogs, additional sources identified
29 by the review team and stakeholder groups
- 30 • Evidence from 2014 to present to capture the architecture of service provision
31 following the Care Quality Commission's 'From the Pond into the Sea' children's
32 transition to adults' health services document (June 2014) [2].
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41 42 **Exclusion**

- 43 • Evidence not written in the English language
- 44 • Publications involving young people with life-limiting conditions
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48 49 **Stage 4: Selection and appraisal**

50 Documents will be initially screened against the inclusion and exclusion criteria; by title
51 and abstract, then by full text screening by two reviewers using Covidence. Disagreements
52 will be resolved through discussion with the realist synthesist research team ensuring
53 consistency in document inclusion.
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3 The quality of studies will be assessed on relevance to contributing to theory development
4 and/or testing and rigour in terms of credibility and trustworthiness. Included evidence will
5 be appraised using the 'Appraisal Form Template' [18] which examines:

- 6 • Usefulness/relevance of the evidence to the research questions
- 7 • How the evidence is relevant to the candidate programme theories, if at all
- 8 • Strengths/weaknesses of the evidence; whether there are any 'red flags'
- 9 • Connection(s) between the outcomes and the process (C+M=O)
- 10 • Any unintended positive/negative impacts and their mechanism link to the outcomes.

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

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18 The RAMESES quality and publication standards (Wong *et al.*, 2022) will be applied at the
19 full text screening stage. These will be used to guide the assessment of the quality of
20 selected studies. Selected full texts will be coded in two ways: inductive codes originating
21 from the studies and deductive codes originating from the programme theory. Using an
22 iterative process, coded text will be selected based on the following:

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

28 29 30 **Stage 5: Data extraction and synthesis**

- 31 • Data extraction will be also performed within Covidence with the formulation of a data
32 extraction table within the software. Data will be organised according to the 'On your
33 own feet ahead' framework [16]: 1) evidence that relates to interventions to improve the
34 organisation of transition; 2) evidence that relates to interventions to stimulate
35 independence and self-management of young people. Data will also be organised
36 according to a third measure: 3) evidence that relates to the young person's experience
37 of transition.
- 38 • Evidence will be extracted and synthesised iteratively with the aim of identifying and
39 exploring causal links between contexts, mechanisms and outcomes (C+M=O) and the

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3 extracted codes will be synthesised according to the relationship between contexts,
4 mechanisms and outcomes (intended and unintended/unexpected). The synthesis will
5 include the following steps:
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- 8 ○ Organising the extracted information from various sources of evidence.
- 9
- 10 ○ Identifying themes and patterns or demi-regularities across the codes among
- 11 context, mechanism and outcomes, as we seek confirming and disconfirming
- 12 evidence.
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- 14 ○ Linking the patterns or demi-regularities to refine programme theory
- 15
- 16 ○ Reflection and discussion within the realist synthesis team.
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20 **Stage 6: Refine/confirm programme theory**

21 The reliability of the programme theory, adjudication between competing theories, and
22 implications of different contexts to the same programme theories will be considered.

23 Programme theories will be compared to practical experiences of young people's, parents'
24 and carers', and healthcare professionals' experience of young people's transition from
25 children's into adults' services through Patient and Public Involvement engagement
26 workshops with the respective stakeholder groups. Realist synthesis findings and
27 programme theories will be presented at the respective workshops, allowing for
28 programme theory to be confirmed, refuted or refined, or, if required, even alternate
29 theories developed using an iterative process. The refined and finalised theory, called
30 middle-range theory, will be the final output of the review, aiming to clarify the current gap
31 in knowledge.
32

33 Searching and purposive sampling of additional documents to test and examine emerging
34 programme theory will be performed, as necessary. Finalised programme theory will
35 describe the intervention strategies, steps and the contexts that need to be present to
36 support the successful transition of young people from children's health services into
37 adults' services.
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39 **Patient and Public Involvement Statement**

40 Extensive patient and public involvement has been undertaken prior to conception of the
41 Burdett National Transition Nursing Network and the implementation of the Model of
42 Improvement for Transition, The National Transition Evaluation Study and this realist
43 synthesis. This includes liaison with the 'Transition Advisory Group', made up of young
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3 people to advise on the implementation of the Burdett National Transition Nursing Network
4 and on this study, a National Transition Steering Group, and an Advisory Group, both
5 formed of key stakeholders and professionals who are consulted on matters relating to the
6 overall implementation project, the study and the realist synthesis.
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10 11 **Author Contributions**

12 PS, FG and SA contributed to the conceptualisation of the realist synthesis. PS wrote the
13 protocol and first draft of the manuscript. All authors critically reviewed the subsequent
14 drafts of the manuscript providing comments for improvement. All authors have read and
15 approved the final manuscript.
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26 27 **Competing interests**

28 None declared.
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42 this article are those of the author(s) and not necessarily those of the NIHR, or the
43 Department of Health and Social Care.
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52 53 **Data sharing statement**

54 When data is available for this research, this will be available through the University of
55 Surrey's Open Research Platform (<https://www.surrey.ac.uk/library/open-research>).
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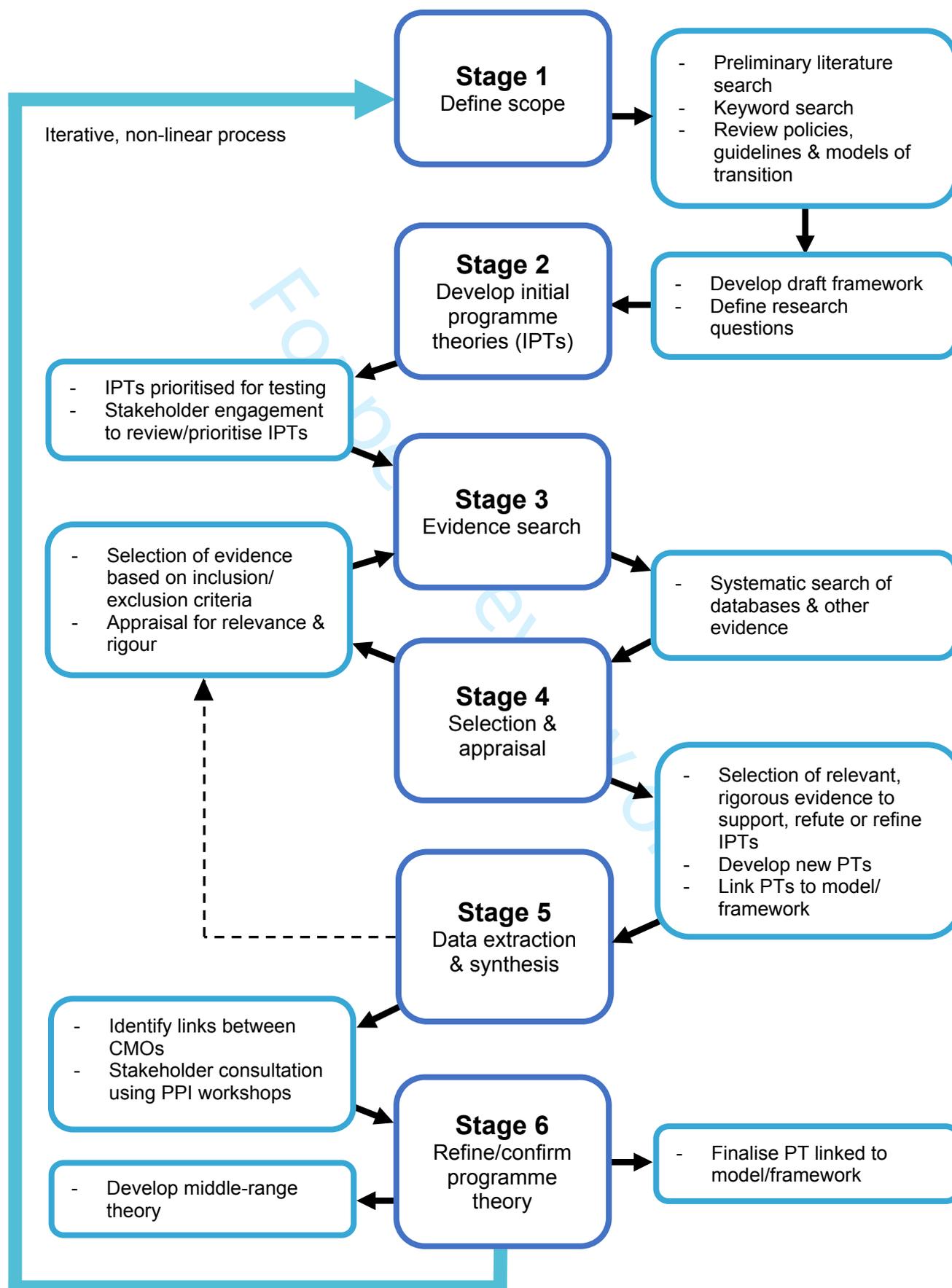
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Stages of Realist Synthesis



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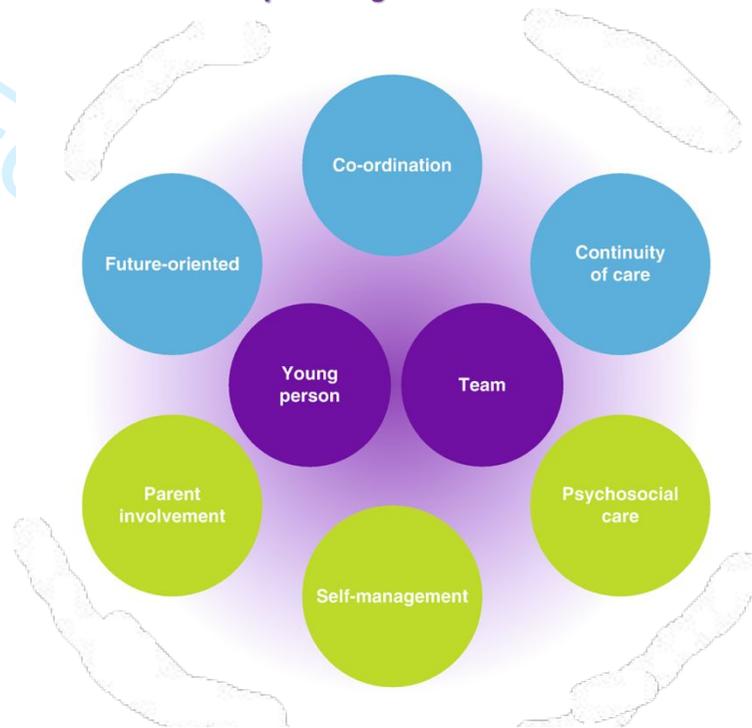
If the profile of young people's transition into adults' services is raised, with increased awareness of what is involved and required for effective/successful transition, then transition is likely to be more successful with reduced morbidity and mortality, and increased patient, family and staff satisfaction.

If all relevant stakeholders across children's and adults' services collaborate to meet the varying and often complex needs of young people, then reduced morbidity and mortality will be seen following transition from children's into adults' services.

If parents are introduced to, understand and engage with the concepts of transition early, then they will be able to support their child along the pathway, and will have confidence to relinquishing control of their child's care as their child increases their autonomy.

If young people and their families are engaged with early in adolescence, then both parties will be adequately prepared for when the young person transitions into adults' services.

Interventions to improve organisation of transition of care



Interventions to stimulate independence and self-management of adolescents

If 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.

If children's service practitioners are more informed about the young person's condition(s), and more involved in their transition process, they will then be more confident and competent in caring for the young person once they have transitioned into their care.

If young people feel that their views and preferences have been taken into consideration when planning their transition journey, then their engagement will be higher.

If young people have a fuller understanding of their condition(s), medications and care, they will then increase their self-management skills and be agents of their own futures.

BMJ Open

The transition of young people from children's into adults' services – what works for whom in what circumstances: protocol for a realist synthesis

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Manuscripts

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3 **The transition of young people from children's into adults' services – what works for**
4 **whom in what circumstances: protocol for a realist synthesis**
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24 **Word count: 3742**
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The transition of young people from children's into adults' services – what works for whom in what circumstances: protocol for a realist synthesis

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 it works, 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 developed; (3) evidence searched; (4) selection and appraisal; (5) data extraction and synthesis; (6) finally, refine/confirm programme theory. A theory-driven, iterative approach utilising 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 initial programme theories. 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**). The study is registered on

ClinicalTrials.gov (**Identifier: NCT05867745**). Results will be disseminated through peer-review publication, conference presentations and through working with healthcare organisations, stakeholder groups, and charities. This realist synthesis is registered on PROSPERO (**Registration number: CRD42023388985**).

Article Summary

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.
- Utilising 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.

Introduction

The journey through adolescence into adulthood is a challenging time of physical, psychological emotional and social change. 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" (p.573)[1]. 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 [2]. It is well known that 'young people are at risk of experiencing

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3 poorer health outcomes when transition between children's and adults' services is not
4 coordinated and planned' [3], p32. Research studies have reported that some young
5 people experience a disjointed transfer into adults' services which is more of a one-off
6 transfer event, rather than a process of preparation and support in which they are involved:
7 such experiences seem to be comparable across young people with different diagnoses
8 [4]. Consequently, health service provision, which fails to meet the needs of young people
9 and families at this time of significant change, may result in deterioration in health or
10 disengagement with services, which can have negative long-term consequences.
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18 The National Institute for Health and Care Excellence's Quality Standard for Transition
19 recommends that health and social care service managers in children's and adults'
20 services should provide an integrated, collaborative approach to ensure a smooth and
21 gradual transition for young people [5]. The transition from children's into adults' services
22 is a crucial time in the health of young people who may potentially fall into what has been
23 described as a poorly managed 'care gap'. We know already that transition processes or
24 programmes of preparation and support need to smooth this journey and bridge this 'care
25 gap', but this process is not yet fully understood. We also know that current practices
26 across the United Kingdom (UK) and elsewhere are varied, creating an ad hoc, often
27 chaotic approach to young people's transition, meaning that there is a need to understand
28 these processes, and this care gap further, which is the focus of this realist synthesis.
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39 We chose realist methodology over the more traditional systematic review methodology
40 because traditional methods focus on evidence without considering the context: we know
41 already that context is key to transition. Also, realist methodology is theory-driven, aiming
42 to establish what works for whom in what circumstances, how and why it works. While
43 there are numerous reviews into "evidence" surrounding the issue of healthcare transition,
44 the outcomes invariably conclude that there is not enough evidence. Furthermore, most
45 reviews only consider one specific intervention and/ or a specific patient group, the results
46 are then not applicable to all young people or transferable to all disease groups; nor to
47 complex interventions such as transition programmes that consist of numerous different
48 elements. Finally, realist methodology has been applied in the field of transition, healthcare
49 in the context of young adults with life-limiting conditions [6, 7].
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3 The first of these studies focused on the evaluation of eight interventions which can help
4 prepare young people with life-limiting conditions and healthcare services for a successful
5 transition. Kerr et al., reported three of the eight interventions were validated: early start to
6 the transition process; developing adolescent/young adult autonomy; and the role of
7 parents/carers; with partial support for the remaining five. Effective communication
8 between healthcare professionals and young people and their parents/carers was
9 identified as an additional intervention of importance [6]. Contextual factors affecting
10 successful transition were highlighted including those related to staff knowledge and
11 attitudes, and a lack of time to provide young person-centred transition services [6].
12 Mechanisms that were supported include the young person's decision-making, and gaining
13 confidence in relationships with service providers [6].
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24 The second of these studies reported the following elements as vital to the successful
25 transition of young people with life-limiting conditions: early planning; collaboration
26 between children's and adult healthcare providers; an emphasis on increasing the young
27 person's confidence in making decisions and engaging with adult services [7]. Kerr et al.,
28 advocated that "interventions should be tailored to their context and focused not only on
29 organisational procedures but on equipping young adults, parents/carers and staff to
30 engage with each other effectively" [7](page 1). We acknowledge the contribution these
31 studies make to the transition field. We seek to add additional knowledge through
32 expansion of patient populations, using the same realist methodology, and consider *all*
33 young people transitioning from children's into adults' services. This realist synthesis will
34 be inclusive of young people with long-term conditions, and complements the research
35 being undertaken as part of the National Transition Evaluation Study, which formally
36 evaluates the implementation of the Burdett National Transition Nursing Network and the
37 Model of Improvement for Transition ([https://www.leedsth.nhs.uk/burdett-national-
38 transition-nursing-network/](https://www.leedsth.nhs.uk/burdett-national-transition-nursing-network/)).
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51 **Methods and analysis**

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53 Realist methodology uses a theory-driven paradigm to "explore how context such as
54 cultural norms and values, economic conditions, geographical characteristics or national
55 policy interacts with various mechanisms to produce outcomes" p2 [8]. This study aims to
56 produce important information about the relative effectiveness of transition intervention
57 components taking into consideration different conditions, needs and associated
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3 complexities, ages of young people, differences in healthcare personnel and service
4 provision in different healthcare contexts. The realist approach acknowledges that
5 interventions may work in some contexts but not others, with a key principle being the
6 notion that interventions are context-bound. A realist synthesis focuses on causation and
7 is represented as context+mechanism=outcome [9, 10].
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13 **Context** “pertains to the ‘backdrop’ of programmes and research” [11]. In our study, this
14 pertains to ways in which services are configured, and how transition processes and
15 pathways are constructed to provide or support the transition of young people from
16 children’s into adults’ services. This would include both child and adult healthcare
17 providers, and includes all healthcare settings, as described in the study’s PICOH (Table
18 1). Context can be understood as any condition that triggers or modifies a mechanism [11],
19 and includes concepts such as how services are funded, cultural norms and values, and
20 pre-existing relationships between child and adult healthcare settings, or between
21 healthcare providers and young people and their families [8].
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31 **Mechanism** concerns the causal force, triggered in particular contexts, that leads to
32 outcomes. Mechanisms explain why and how observed outcomes occur and usually
33 comprise two parts: the ‘resources’ offered by an intervention and the cognitive or
34 emotional decisions (‘reasoning’) and behaviour of people, in this case the behaviour of
35 young people, their parents or carers, and healthcare professionals involved in the
36 transition of young people to adults’ services [8]. Jagosh *et al.*, identify that mechanisms
37 advance the synthesis beyond describing ‘what happened’ to theorising ‘why it happened,
38 for whom, and under what circumstances’ based on participant reasoning or reaction [11],
39 which is key to understanding the intricacies related to young people’s effective transition
40 into adults’ services.
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Table 1: Study PICOH

PICOH	
P - Population	<p>Child health clinicians (doctors - including GPs, nurses, allied health professionals) preparing and supporting young people's transition from child into adult services.</p> <p>Adult clinicians (doctors – including GPs, nurses, allied health professionals) supporting and engaging young people in the adult service during the process of transition.</p> <p>Youth workers, key workers, and support staff (MDT coordinators, play specialists, administrative support in both child and adult setting)</p> <p>Young people's perspectives on transition into adults' services (age 12-25 years)</p> <p>Parent/caregiver perspectives on their child's transition into adults' services</p>
I – Intervention	<p>Interventions related to successful transition of young people from children's into adults' services [5, 12]:</p> <ol style="list-style-type: none"> 1. Start the transition process early, by the young person's 14th birthday at the latest (unless diagnosed after) 2. Make a developmentally appropriate transition plan that takes into account each young person's capabilities, needs and hopes for the future 3. Children's and adults' services working in partnership through effective communication and collaboration 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) 5. The engagement of a transition coordinator (or named worker) 6. Interdisciplinary and interagency joint working 7. Developing the young person's autonomy throughout the transition process 8. Service providers demonstrating a person-centred approach to care 9. Involvement of parents/carers (as much as the young person wishes them to be), with a parallel transition programme of support 10. Opportunity for the young person to be seen alone for all or part of the consultation or without usual caregiver
C – Comparator	None
O – Outcomes	<p>Outcomes will vary according to the intervention, but may include:</p> <p>Measurable adverse outcomes such as: nonadherence to treatment, loss to follow up, adverse social and educational outcomes, morbidity and mortality [13]</p> <p>Measurable favourable outcomes such as: increasingly taking responsibility for engaging with services providers, adherence to treatment strategies and contributing to their disease management plan [12]</p> <p>Attendance at appointments, understanding of condition and its self-management.</p> <p>Self-reported readiness for the transfer into adults' services and self-advocacy.</p>
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.

Abbreviations: GP – General Practitioner; MDT – Multi-disciplinary team NHS – National Health Service

Outcomes are either intended or unintended/unexpected and are defined as either intermediate or final [11]. 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 [12].

Realist synthesis

An interpretative theory-driven approach will be utilised 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 [14], 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 will be developed, (3) evidence search, (4) selection and appraisal, (5) data extraction and synthesis and (6) Refine/confirm programme theory. 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.

Figure 1: Overview of realist synthesis design

[Insert Figure 1 here]

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

Stage 2: Develop initial programme theories

A theory-driven, iterative approach utilising the 'On Your Own Feet Ahead' theoretical framework, which includes care coordination, continuity of care, psychosocial care, self-

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3 management, parent involvement, and future-oriented care [15], was combined with an
4 informal literature search. This included a review of national transition policy documents,
5 supplemented by additional search methods, such as citation tracking and snowballing.
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10 'On Your Own Feet Ahead' theoretical framework, developed in 2008, incorporates eight
11 key elements of good healthcare transition care, divided into three core categories:
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- 14 1. Interventions to improve the organisation of care;
- 15 2. Interventions to stimulate independence and self-management of adolescents; and
- 16 3. Collaboration with young people (and their families) and within the multidisciplinary
17 team of professionals, working both in paediatric care and adult care [15].
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23 This evidence-based theoretical framework was chosen to guide this research due to the
24 well-documented success of its use over the last 15 years in The Netherlands [15-17].
25 Furthermore, this framework directly promotes young people's voices being heard in
26 matters that directly affect them [17, 18], and emphasises the collaboration of all relevant
27 stakeholder for healthcare transition success [15]: elements crucial to understand further in
28 the context of published work.
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34 As a starting point, initial programme theories (IPTs) linking to the different elements of the
35 theoretical framework were formulated by the research team. Prior to commencing the
36 formal searches, these IPTs were presented at a workshop with two leading experts on the
37 transition of young people from children's into adults' services, namely the National Lead
38 Nurse for Transition, and the National Advisor for Transition who advised on the Burdett
39 National Transition Nursing Network implementation project. The IPTs were refined
40 through discussion with the experts, who imparted their knowledge from their extensive
41 clinical and specialty specific experience, with a final consensus being reached as to the
42 applicability and appropriateness of each IPT. Figure 2 presents examples of the IPTs,
43 which are colour coded according to which aspect of the framework they relate to. It is
44 important to note that IPTs can relate to more than one dimension within the framework.
45 An example of this is, 'If all relevant stakeholders across children's and adults' services
46 collaborate and build partnerships to meet the varying and often complex needs of young
47 people, then children's service practitioners will be more comfortable relinquishing control
48 over the young person's care' relates to 'Future-orientated', 'Co-ordination', and 'Continuity
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of care'. This process enabled the formulation of the research questions. The selection of relevant, rigorous evidence will be applied to these IPT's in subsequent stages of this realist synthesis so that they can be supported, refuted or refined.

Figure 2: Initial programme theories applied to the 'On Your Own Feet Ahead' theoretical framework

[Insert Figure 2 here]

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 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 will be conducted from 2014 to present, to capture the architecture of service provision following the Care Quality Commission's 'From the Pond into the Sea' children's transition to adults' health services document that was published in June 2014 [2]: a significant policy document in the UK from which change in practice was starting 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.

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3 Data will be exported from the databases into Covidence web-based collaboration
4 software platform for subsequent selection and appraisal [19]. Data selection will be based
5 on relevance and rigour, and will be extracted and synthesised iteratively with the aim of
6 identifying and exploring causal links between contexts, mechanisms and outcomes.
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8 Results will be reported according to the Realist And Meta-narrative Evidence Syntheses:
9 Evolving Standards Quality and Publication Standards [20].
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15 Inclusion

- 16 • All study designs
- 17 • Non-empirical sources of evidence – grey literature: policy documents, guidelines,
18 books, opinion papers, editorials, dissertations, blogs, additional sources identified
19 by the review team and stakeholder groups
- 20 • Evidence from 2014 to present to capture the architecture of service provision
21 following the Care Quality Commission's 'From the Pond into the Sea' children's
22 transition to adults' health services document (June 2014) [2].
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30 Exclusion

- 31 • Evidence not written in the English language
- 32 • Publications involving young people with life-limiting conditions
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38 Stage 4: Selection and appraisal

39 Documents will be initially screened against the inclusion and exclusion criteria; by title
40 and abstract, then by full text screening by two reviewers using Covidence. Disagreements
41 will be resolved through discussion with the realist synthesist research team ensuring
42 consistency in document inclusion.
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48 The quality of studies will be assessed on relevance to contributing to theory development
49 and/or testing and rigour in terms of credibility and trustworthiness. Included evidence will
50 be appraised using the 'Appraisal Form Template' [21] which examines:

- 51 • Usefulness/relevance of the evidence to the research questions
- 52 • How the evidence is relevant to the candidate programme theories, if at all
- 53 • Strengths/weaknesses of the evidence; whether there are any 'red flags'
- 54 • Connection(s) between the outcomes and the process (C+M=O)
- 55 • Any unintended positive/negative impacts and their mechanism link to the outcomes.
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5 The quality of a 10% sample of studies will be independently checked by a second
6 reviewer, with disagreements resolved by discussion with the realist synthesis team to
7 ensure quality and consistency in study inclusion.
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11 The RAMESES quality and publication standards (Wong *et al.*, 2022) will be applied at the
12 full text screening stage. These will be used to guide the assessment of the quality of
13 selected studies. Selected full texts will be coded in two ways: inductive codes originating
14 from the studies and deductive codes originating from the programme theory. Using an
15 iterative process, coded text will be selected based on the following:
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- 20 • Is the evidence referring to context (C), mechanism (M) or outcome (O)?
 - 21 • What is the CMO configuration?
 - 22 • Is there a link within or between the CMO configurations?
 - 23 • In light of the CMO configurations, does the programme theory need to be amended?
 - 24 • Are there any other trustworthy and rigorous criteria that should be considered?
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30 **Stage 5: Data extraction and synthesis**

- 31 • Data extraction will be performed within Covidence with the formulation of a data
32 extraction table within the software. Data will be organised according to the 'On your
33 own feet ahead' framework [15]: 1) evidence that relates to interventions to improve the
34 organisation of transition; 2) evidence that relates to interventions to stimulate
35 independence and self-management of young people. Data will also be organised
36 according to a third measure: 3) evidence that relates to the young person's experience
37 of transition.
38
 - 39 • Evidence will be extracted and synthesised iteratively with the aim of identifying and
40 exploring causal links between contexts, mechanisms and outcomes (C+M=O) and the
41 extracted codes will be synthesised according to the relationship between contexts,
42 mechanisms and outcomes (intended and unintended/unexpected). The synthesis will
43 include the following steps:
44
 - 45 ○ Organising the extracted information from various sources of evidence.
 - 46 ○ Identifying themes and patterns or demi-regularities across the codes among
47 context, mechanism and outcomes, as we seek confirming and disconfirming
48 evidence.
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- 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 to 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 engagement 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. Firstly, 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 [22]. This may mean that the search has not only breadth but 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 [23].

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3 Secondly, due to the nature of this realist synthesis including young people with a wide
4 range of long-term health conditions, challenges may arise when considering the same
5 theory applied to young people with different long-term conditions in comparative settings
6 [22]. A further complexity may be applying the same theory to different locations, where
7 care provision varies . To overcome these challenges, one approach could be to group
8 services so that the theory can be compared across services that operate more closely
9 (demonstrating where they align) or, conversely, more distantly (demonstrating where they
10 differ) [22]. It is acknowledged that, until the evidence is gathered, and the theories have
11 been developed, this cannot predicted.

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20 Finally, due to the diversity and complexity of this realist synthesis, drawing meaningful
21 conclusions and framing recommendations that will have an impact on practice, research
22 and policy will be a challenge [22]. Emphasis is placed on the involvement of key
23 stakeholders and experts on the transition of young people from children's into adults'
24 services, in addition to experts by experience (young people who have commenced or
25 completed their transition from children's health services into adults' services).

26 27 28 29 30 31 32 **Patient and Public Involvement Statement**

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

41 42 43 44 45 46 47 48 49 **Author Contributions**

50 PS, FG and SA contributed to the conceptualisation of the realist synthesis. PS wrote the
51 protocol and first draft of the manuscript. All authors critically reviewed the subsequent
52 drafts of the manuscript providing comments for improvement. All authors have read and
53 approved the final manuscript.

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4
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6 **Competing interests**

7
8 None declared.
9

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32 **Data sharing statement**

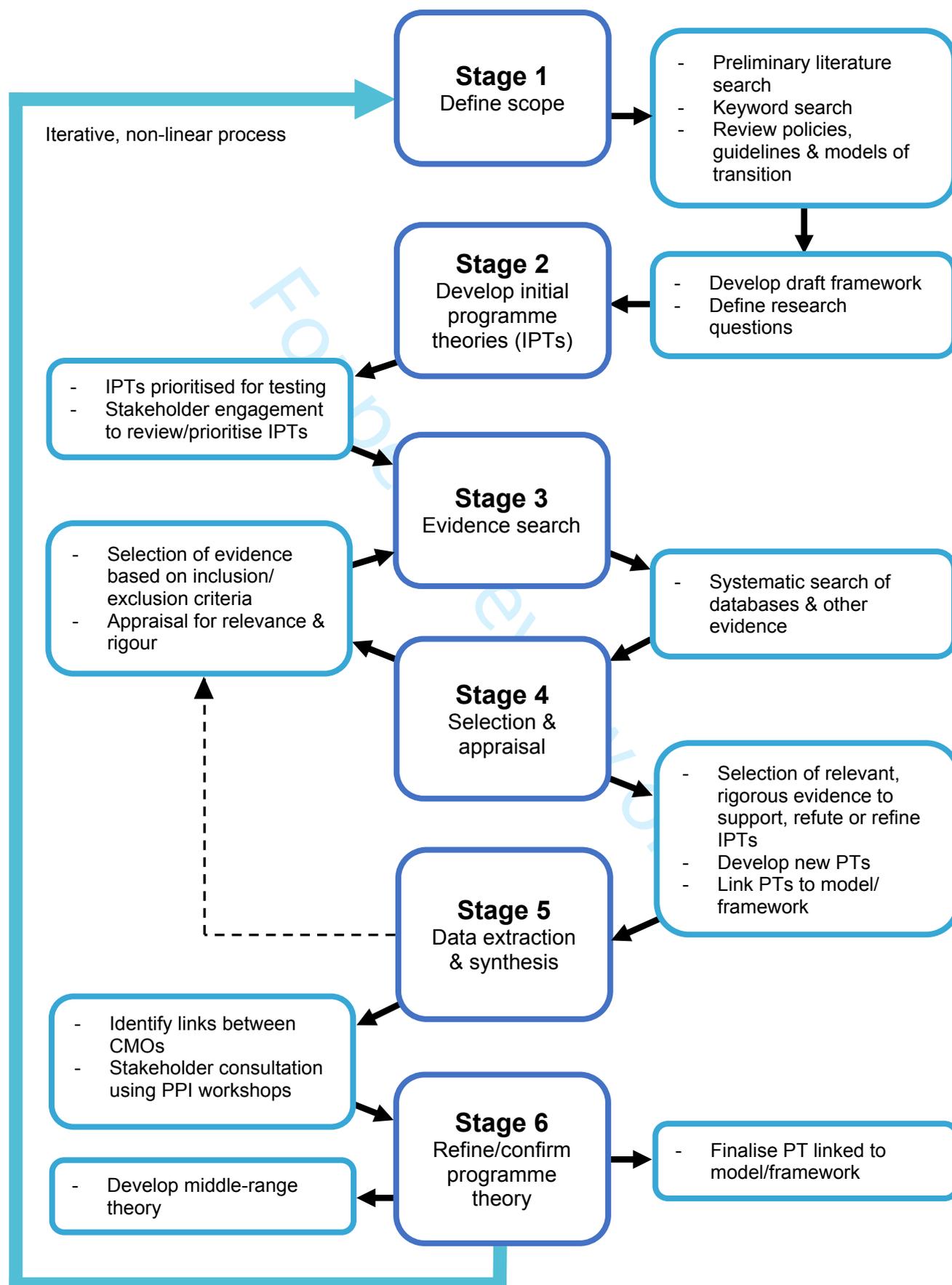
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34 When data is available for this research, this will be available through the University of
35 Surrey's Open Research Platform (<https://www.surrey.ac.uk/library/open-research>).
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Stages of Realist Synthesis



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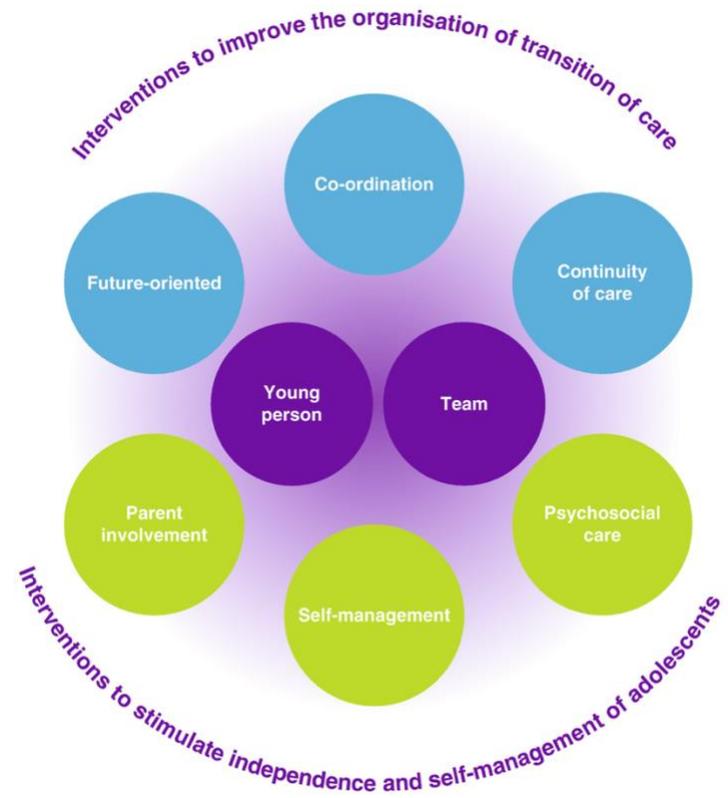
If the profile of young people's transition into adults' services is raised, with increased awareness of what is involved and required for effective/successful transition, then transition is likely to be more successful with reduced morbidity and mortality, and increased patient, family and staff satisfaction.

If all relevant stakeholders across children's and adults' services collaborate to meet the varying and often complex needs of young people, then reduced morbidity and mortality will be seen following transition from children's into adults' services.

If partnerships between young people and healthcare teams are strengthened, through empowerment of young people and the provision of person-centred care by healthcare teams, then long-term engagement with young people will be more successful.

If parents are introduced to, understand and engage with the concepts of transition early, then they will be able to support their child along the pathway, and will have confidence to relinquishing control of their child's care as their child increases their autonomy.

If young people and their families are engaged with early in adolescence, then both parties will be adequately prepared for when the young person transitions into adults' services.



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.

If all relevant service practitioners are more informed about the young person's condition(s), and more involved in their transition process, they will then be more confident and competent in caring for the young person once they have transitioned into their care.

If healthcare teams engage with young people in terms of seeking feedback on their experiences of transition, involving them in decision-making about transition, and making changes to services based upon this feedback, then young people will feel listened to and valued, which will result in better engagement in their healthcare.

If young people feel that their views and preferences have been taken into consideration when planning their transition journey, then their engagement will be higher.

If young people have a fuller understanding of their condition(s), medications, and the reasons for requiring treatment and care, they will then increase their self-management skills and be agents of their own futures.

BMJ Open

The transition of young people from children's into adults' services – what works for whom in what circumstances: protocol for a realist synthesis

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3 **The transition of young people from children's into adults' services – what works for**
4 **whom in what circumstances: protocol for a realist synthesis**
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The transition of young people from children's into adults' services – what works for whom in what circumstances: protocol for a realist synthesis

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 it works, 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 developed; (3) evidence searched; (4) selection and appraisal; (5) data extraction and synthesis; (6) finally, refine/confirm programme theory. A theory-driven, iterative approach utilising 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 initial programme theories. 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**). The study is registered on

ClinicalTrials.gov (**Identifier: NCT05867745**). Results will be disseminated through peer-review publication, conference presentations and through working with healthcare organisations, stakeholder groups, and charities. This realist synthesis is registered on PROSPERO (**Registration number: CRD42023388985**).

Article Summary

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.
- Utilising 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.

Introduction

The journey through adolescence into adulthood is a challenging time of physical, psychological emotional and social change. 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" (p.573)[1]. 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 [2]. It is well known that 'young people are at risk of experiencing

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3 poorer health outcomes when transition between children's and adults' services is not
4 coordinated and planned' [3], p32. Research studies have reported that some young
5 people experience a disjointed transfer into adults' services which is more of a one-off
6 transfer event, rather than a process of preparation and support in which they are involved:
7 such experiences seem to be comparable across young people with different diagnoses
8 [4]. Consequently, health service provision, which fails to meet the needs of young people
9 and families at this time of significant change, may result in deterioration in health or
10 disengagement with services, which can have negative long-term consequences.
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18 The National Institute for Health and Care Excellence's Quality Standard for Transition
19 recommends that health and social care service managers in children's and adults'
20 services should provide an integrated, collaborative approach to ensure a smooth and
21 gradual transition for young people [5]. The transition from children's into adults' services
22 is a crucial time in the health of young people who may potentially fall into what has been
23 described as a poorly managed 'care gap'. We know already that transition processes or
24 programmes of preparation and support need to smooth this journey and bridge this 'care
25 gap', but this process is not yet fully understood. We also know that current practices
26 across the United Kingdom (UK) and elsewhere are varied, creating an ad hoc, often
27 chaotic approach to young people's transition, meaning that there is a need to understand
28 these processes, and this care gap further, which is the focus of this realist synthesis.
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39 We chose realist methodology over the more traditional systematic review methodology
40 because traditional methods focus on evidence without considering the context: we know
41 already that context is key to transition. Also, realist methodology is theory-driven, aiming
42 to establish what works for whom in what circumstances, how and why it works. While
43 there are numerous reviews into "evidence" surrounding the issue of healthcare transition,
44 the outcomes invariably conclude that there is not enough evidence. Furthermore, most
45 reviews only consider one specific intervention and/ or a specific patient group, the results
46 are then not applicable to all young people or transferable to all disease groups; nor to
47 complex interventions such as transition programmes that consist of numerous different
48 elements. Finally, realist methodology has been applied in the field of transition, healthcare
49 in the context of young adults with life-limiting conditions [6, 7].
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3 The first of these studies focused on the evaluation of eight interventions which can help
4 prepare young people with life-limiting conditions and healthcare services for a successful
5 transition. Kerr et al., reported three of the eight interventions were validated: early start to
6 the transition process; developing adolescent/young adult autonomy; and the role of
7 parents/carers; with partial support for the remaining five. Effective communication
8 between healthcare professionals and young people and their parents/carers was
9 identified as an additional intervention of importance [6]. Contextual factors affecting
10 successful transition were highlighted including those related to staff knowledge and
11 attitudes, and a lack of time to provide young person-centred transition services [6].
12 Mechanisms that were supported include the young person's decision-making, and gaining
13 confidence in relationships with service providers [6].
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24 The second of these studies reported the following elements as vital to the successful
25 transition of young people with life-limiting conditions: early planning; collaboration
26 between children's and adult healthcare providers; an emphasis on increasing the young
27 person's confidence in making decisions and engaging with adult services [7]. Kerr et al.,
28 advocated that "interventions should be tailored to their context and focused not only on
29 organisational procedures but on equipping young adults, parents/carers and staff to
30 engage with each other effectively" [7](page 1). We acknowledge the contribution these
31 studies make to the transition field. We seek to add additional knowledge through
32 expansion of patient populations, using the same realist methodology, and consider *all*
33 young people transitioning from children's into adults' services. This realist synthesis will
34 be inclusive of young people with long-term conditions, and complements the research
35 being undertaken as part of the National Transition Evaluation Study, which formally
36 evaluates the implementation of the Burdett National Transition Nursing Network and the
37 Model of Improvement for Transition ([https://www.leedsth.nhs.uk/burdett-national-
38 transition-nursing-network/](https://www.leedsth.nhs.uk/burdett-national-transition-nursing-network/)).
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50 51 **Methods and analysis**

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53 Realist methodology uses a theory-driven paradigm to "explore how context such as
54 cultural norms and values, economic conditions, geographical characteristics or national
55 policy interacts with various mechanisms to produce outcomes" p2 [8]. This study aims to
56 produce important information about the relative effectiveness of transition intervention
57 components taking into consideration different conditions, needs and associated
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3 complexities, ages of young people, differences in healthcare personnel and service
4 provision in different healthcare contexts. The realist approach acknowledges that
5 interventions may work in some contexts but not others, with a key principle being the
6 notion that interventions are context-bound. A realist synthesis focuses on causation and
7 is represented as context+mechanism=outcome [9, 10].
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13 **Context** “pertains to the ‘backdrop’ of programmes and research” [11]. In our study, this
14 pertains to ways in which services are configured, and how transition processes and
15 pathways are constructed to provide or support the transition of young people from
16 children’s into adults’ services. This would include both child and adult healthcare
17 providers, and includes all healthcare settings, as described in the study’s PICOH (Table
18 1). Context can be understood as any condition that triggers or modifies a mechanism [11],
19 and includes concepts such as how services are funded, cultural norms and values, and
20 pre-existing relationships between child and adult healthcare settings, or between
21 healthcare providers and young people and their families [8].
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31 **Mechanism** concerns the causal force, triggered in particular contexts, that leads to
32 outcomes. Mechanisms explain why and how observed outcomes occur and usually
33 comprise two parts: the ‘resources’ offered by an intervention and the cognitive or
34 emotional decisions (‘reasoning’) and behaviour of people, in this case the behaviour of
35 young people, their parents or carers, and healthcare professionals involved in the
36 transition of young people to adults’ services [8]. Jagosh *et al.*, identify that mechanisms
37 advance the synthesis beyond describing ‘what happened’ to theorising ‘why it happened,
38 for whom, and under what circumstances’ based on participant reasoning or reaction [11],
39 which is key to understanding the intricacies related to young people’s effective transition
40 into adults’ services.
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50 **Outcomes** are either intended or unintended/unexpected and are defined as either
51 intermediate or final [11]. Examples of outcomes related to young people’s transition
52 include young people’s increased engagement in their health management, increased
53 knowledge of their condition(s), treatment and medication. Examples of outcomes related
54 to transition-related interventions include improved health outcomes, increased adherence
55 to treatment strategies or contributing to their disease management plan [12].
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Table 1: Study PICOH

PICOH	
P - Population	<p>Child health clinicians (doctors - including GPs, nurses, allied health professionals) preparing and supporting young people's transition from child into adult services.</p> <p>Adult clinicians (doctors – including GPs, nurses, allied health professionals) supporting and engaging young people in the adult service during the process of transition.</p> <p>Youth workers, key workers, and support staff (MDT coordinators, play specialists, administrative support in both child and adult setting)</p> <p>Young people's perspectives on transition into adults' services (age 12-25 years)</p> <p>Parent/caregiver perspectives on their child's transition into adults' services</p>
I – Intervention	<p>Interventions related to successful transition of young people from children's into adults' services [5, 12]:</p> <ol style="list-style-type: none"> 1. Start the transition process early, by the young person's 14th birthday at the latest (unless diagnosed after) 2. Make a developmentally appropriate transition plan that takes into account each young person's capabilities, needs and hopes for the future 3. Children's and adults' services working in partnership through effective communication and collaboration 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) 5. The engagement of a transition coordinator (or named worker) 6. Interdisciplinary and interagency joint working 7. Developing the young person's autonomy throughout the transition process 8. Service providers demonstrating a person-centred approach to care 9. Involvement of parents/carers (as much as the young person wishes them to be), with a parallel transition programme of support 10. Opportunity for the young person to be seen alone for all or part of the consultation or without usual caregiver
C – Comparator	None
O – Outcomes	<p>Outcomes will vary according to the intervention, but may include:</p> <p>Measurable adverse outcomes such as: nonadherence to treatment, loss to follow up, adverse social and educational outcomes, morbidity and mortality [13]</p> <p>Measurable favourable outcomes such as: increasingly taking responsibility for engaging with services providers, adherence to treatment strategies and contributing to their disease management plan [12]</p> <p>Attendance at appointments, understanding of condition and its self-management.</p> <p>Self-reported readiness for the transfer into adults' services and self-advocacy.</p>
H – Healthcare context	<p>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.</p>

Abbreviations: GP – General Practitioner; MDT – Multi-disciplinary team NHS – National Health Service

Realist synthesis

An interpretative theory-driven approach will be utilised 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 [14], 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 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.

Figure 1: Overview of realist synthesis design

[Insert Figure 1 here]

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

Stage 2: Develop initial programme theories

A theory-driven, iterative approach utilising the 'On Your Own Feet Ahead' theoretical framework, which includes care coordination, continuity of care, psychosocial care, self-management, parent involvement, and future-oriented care [15], 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:

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- 2
- 3 1. Interventions to improve the organisation of care;
- 4
- 5 2. Interventions to stimulate independence and self-management of adolescents; and
- 6
- 7 3. Collaboration with young people (and their families) and within the multidisciplinary
- 8 team of professionals, working both in paediatric care and adult care [15].
- 9

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11 This evidence-based theoretical framework was chosen to guide this research due to the
12 well-documented success of its use over the last 15 years in The Netherlands [15-17].
13 Furthermore, this framework directly promotes young people's voices being heard in
14 matters that directly affect them [17, 18], and emphasises the collaboration of all relevant
15 stakeholder for healthcare transition success [15]: elements crucial to understand further in
16 the context of published work.
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24 As a starting point, initial programme theories (IPTs) linking to the different elements of the
25 theoretical framework were formulated by the research team. Prior to commencing the
26 formal searches, these IPTs were presented at a workshop with two leading experts on the
27 transition of young people from children's into adults' services, namely the National Lead
28 Nurse for Transition, and the National Advisor for Transition who advised on the Burdett
29 National Transition Nursing Network implementation project. The IPTs were refined
30 through discussion with the experts, who imparted their knowledge from their extensive
31 clinical and specialty specific experience, with a final consensus being reached as to the
32 applicability and appropriateness of each IPT. Figure 2 presents examples of the IPTs,
33 which are colour coded according to which aspect of the framework they relate to. It is
34 important to note that IPTs can relate to more than one dimension within the framework.
35 An example of this is, 'If all relevant stakeholders across children's and adults' services
36 collaborate and build partnerships to meet the varying and often complex needs of young
37 people, then children's service practitioners will be more comfortable relinquishing control
38 over the young person's care' relates to 'Future-orientated', 'Co-ordination', and 'Continuity
39 of care'. This process enabled the formulation of the research questions. The selection of
40 relevant, rigorous evidence will be applied to these IPT's in subsequent stages of this
41 realist synthesis so that they can be supported, refuted or refined.
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56 **Figure 2: Initial programme theories applied to the 'On Your Own Feet Ahead' theoretical**
57 **framework**

58 [Insert Figure 2 here]
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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 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 (supplementary files 1-9) will be conducted from 2014 to present, to capture the architecture of service provision following the Care Quality Commission's 'From the Pond into the Sea' children's transition to adults' health services document that was published in June 2014 [2]: a significant policy document in the UK from which change in practice was starting 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 [19]. 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 [20].

Inclusion

- All study designs

- Non-empirical sources of evidence – grey literature: policy documents, guidelines, books, opinion papers, editorials, dissertations, blogs, additional sources identified by the review team and stakeholder groups
- Evidence from 2014 to present to capture the architecture of service provision following the Care Quality Commission's 'From the Pond into the Sea' children's transition to adults' health services document (June 2014) [2].

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, 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' [21] 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 [20]. 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

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3 and deductive codes originating from the programme theory. Using an iterative process,
4 coded text will be selected based on the following:

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6 • Is the evidence referring to context (C), mechanism (M) or outcome (O)?
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8 • What is the CMO configuration?
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10 • Is there a link within or between the CMO configurations?
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12 • In light of the CMO configurations, does the programme theory need to be amended?
13
14 • Are there any other trustworthy and rigorous criteria that should be considered?
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16 **Stage 5: Data extraction and synthesis**

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18 • Data extraction will be performed within Covidence with the formulation of a data
19 extraction table within the software. Data will be organised according to the 'On your
20 own feet ahead' framework [15]: 1) evidence that relates to interventions to improve the
21 organisation of transition; 2) evidence that relates to interventions to stimulate
22 independence and self-management of young people. Data will also be organised
23 according to a third measure: 3) evidence that relates to the young person's experience
24 of transition.
25
26 • Evidence will be extracted and synthesised iteratively with the aim of identifying and
27 exploring causal links between contexts, mechanisms and outcomes (C+M=O) and the
28 extracted codes will be synthesised according to the relationship between contexts,
29 mechanisms and outcomes (intended and unintended/unexpected). The synthesis will
30 include the following steps:
31
32 ○ Organising the extracted information from various sources of evidence.
33
34 ○ Identifying themes and patterns or demi-regularities across the codes among
35 context, mechanism and outcomes, as we seek confirming and disconfirming
36 evidence.
37
38 ○ Linking the patterns or demi-regularities to refine IPTs to develop formal
39 programme theory
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41 ○ Reflection and discussion within the realist synthesis team.
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55 **Stage 6: Refine/confirm programme theory**

56 The reliability of the programme theory, adjudication between competing theories, and
57 implications of different contexts to the same programme theories will be considered.
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59 Programme theories will be compared to practical experiences of young people's, parents'
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3 and carers', and healthcare professionals' experience of young people's transition from
4 children's into adults' services through Patient and Public Involvement engagement
5 workshops with the respective stakeholder groups. Realist synthesis findings and
6 programme theories will be presented at the respective workshops, allowing for
7 programme theory to be confirmed, refuted or refined, or, if required, even alternate
8 theories developed using an iterative process. The refined and finalised theory, called
9 middle-range theory, will be the final output of the review, aiming to clarify the current gap
10 in knowledge.
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18 Searching and purposive sampling of additional documents to test and examine emerging
19 programme theory will be performed, as necessary. Finalised programme theory will
20 describe the intervention strategies, steps and the contexts that need to be present to
21 support the successful transition of young people from children's health services into
22 adults' services.
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29 **Expected challenges of using realist methodology in this context**

30 There are several challenges that may arise with the use of realist methodology. Firstly,
31 opposed to the relatively simple evaluation of clinical treatments through randomised
32 controlled trials, realist synthesis of the literature on service interventions may be
33 challenging due to epistemological complexity and methodological diversity [22]. This may
34 mean that the search has not only breadth but depth, and will require time to conduct. The
35 research team would consider the search to be complete when no new information is
36 added to the theory being evaluated, which is called 'theoretical saturation', a concept
37 borrowed from qualitative grounded theory [23].
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46 Secondly, due to the nature of this realist synthesis including young people with a wide
47 range of long-term health conditions, challenges may arise when considering the same
48 theory applied to young people with different long-term conditions in comparative settings
49 [22]. A further complexity may be applying the same theory to different locations, where
50 care provision varies. To overcome these challenges, one approach could be to group
51 services so that the theory can be compared across services that operate more closely
52 (demonstrating where they align) or, conversely, more distantly (demonstrating where they
53 differ) [22]. It is acknowledged that, until the evidence is gathered, and the theories have
54 been developed, this cannot be predicted.
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5 Finally, due to the diversity and complexity of this realist synthesis, drawing meaningful
6 conclusions and framing recommendations that will have an impact on practice, research
7 and policy will be a challenge [22]. Emphasis is placed on the involvement of key
8 stakeholders and experts on the transition of young people from children's into adults'
9 services, in addition to experts by experience (young people who have commenced or
10 completed their transition from children's health services into adults' services).
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16 **Patient and Public Involvement Statement**

17 Extensive patient and public involvement has been undertaken prior to conception of the
18 Burdett National Transition Nursing Network and the implementation of the Model of
19 Improvement for Transition, The National Transition Evaluation Study and this realist
20 synthesis. This includes liaison with the 'Transition Advisory Group', made up of young
21 people to advise on the implementation of the Burdett National Transition Nursing Network
22 and on this study, a National Transition Steering Group, and an Advisory Group, both
23 formed of key stakeholders and professionals who are consulted on matters relating to the
24 overall implementation project, the study and the realist synthesis.
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34 **Ethics and Dissemination**

35 This realist synthesis forms part of the National Transition Evaluation Study, which has
36 received ethical and regulatory approval (**IRAS ID: 313576**). The study is registered on
37 ClinicalTrials.gov (**Identifier: NCT05867745**). Results will be disseminated through peer-
38 review publication, conference presentations and through working with healthcare
39 organisations, stakeholder groups, and charities. This realist synthesis is registered on
40 PROSPERO (**Registration number: CRD42023388985**).
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48 **Author Contributions**

49 Pippa Sipanoun contributed to the conceptualisation of the realist synthesis, wrote the
50 protocol, and lead the writing of the manuscript. Susie Aldiss, Faith Gibson, Sue Morgan,
51 Louise Porter and Emma Powell contributed to the conceptualisation of the realist
52 synthesis and protocol, and critically reviewed the subsequent drafts of the manuscript
53 providing comments for improvement. All authors have read and approved the final
54 manuscript.
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Competing interests

None declared.

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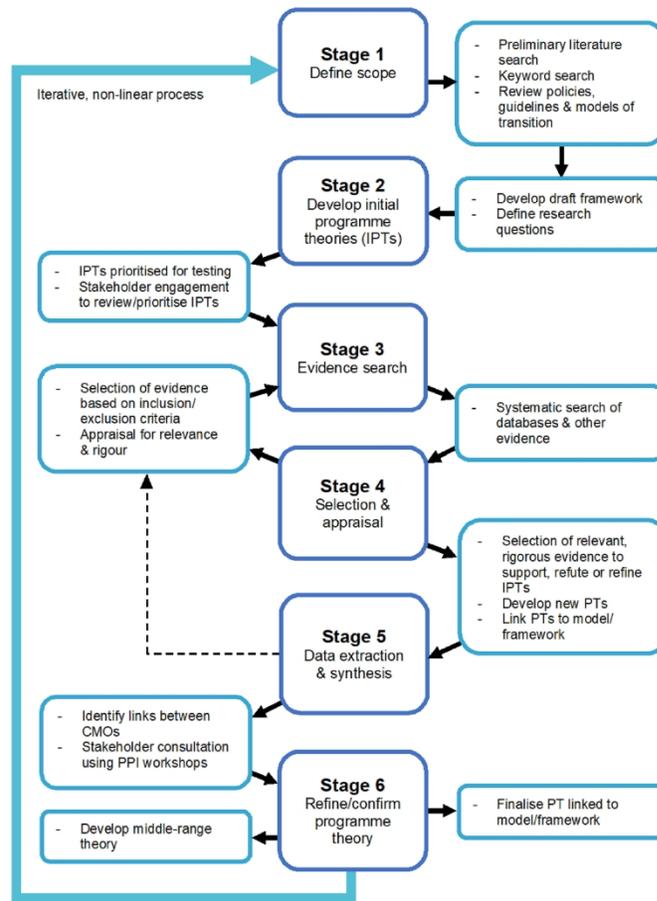
Data sharing statement

When data is available for this research, this will be available through the University of Surrey's Open Research Platform (<https://www.surrey.ac.uk/library/open-research>).

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- Adolescents During Hospital Consultations: A Mixed Methods Study.* Journal of Pediatric Nursing-Nursing Care of Children & Families, 2015. **30**(5): p. 757-775.
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Adapted from: Kantlilal et al (2020) doi:10.1136/bmjopen-2020-037636
Abbreviations: IPTs – Initial programme theories; PTs – programme theories; CMOs – Context, Mechanisms, Outcomes

Figure 1: Overview of realist synthesis design

1590x1590mm (96 x 96 DPI)

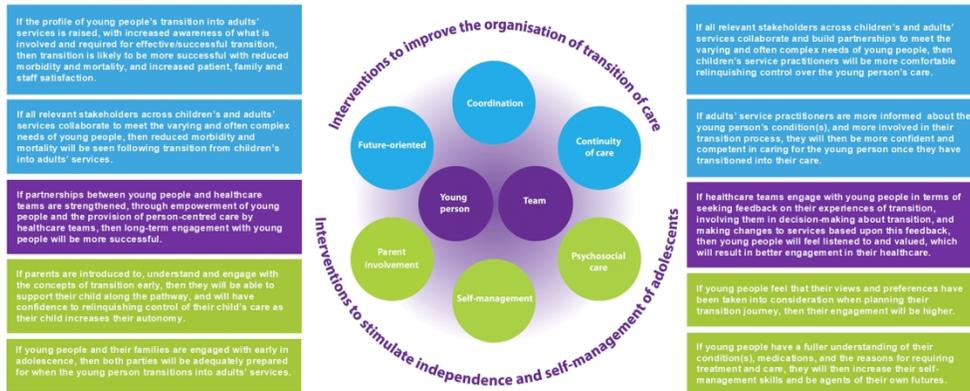


Figure 2: Initial programme theories applied to the On Your Own Feet Ahead theoretical framework

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OVID Embase Search Strategy <1980 to 2022 Week 27>

1 adolescent/ or hospitalized adolescent/ or institutionalized adolescent/
1629618

2 young adult/ 464835

3 pediatrics/ 82024

4 parent/ or father/ or mother/ or single parent/ 197287

5 caregiver/ 100220

6 family/94820

7 health care personnel/ or advanced practice provider/ or care coordinator/ or
clinician/ or mental health care personnel/ 227430

8 exp nurse/ 197441

9 health educator/ 2117

10 exp medical staff/ 38249

11 exp nursing staff/ 71751

12 hospital personnel/ 23613

13 physiotherapist/ 24781

14 pediatrician/ 24892

15 physician/ or general practitioner/ or hospital physician/ or psychiatrist/
441814

16 psychotherapist/ 6973

17 pharmacist/ or clinical pharmacist/ or community pharmacist/ or hospital
pharmacist/ 88339

18 occupational therapist/ 7673

19 social worker/ 13308

20 dietitian/ 14945

21 patient/ 1482249

22 patient attendance/ 1570

23 (young person* or young people* or adolescen* or teen* or youth* or young
adult* or p?ediatric* or child*).ti,ab,kf. 2512778

24 patient*.ti,ab,kf. 10798005

25 (family or families or parent* or father* or mother* or carer* or caregiver* or
care giver*).ti,ab,kf. 2067984

26 (doctor* or physician* or p?ediatrician* or general practitioner* or GP? or
health care professional* or healthcare professional* or health care personnel* or
healthcare personnel* or clinician* or case manager*).ti,ab,kf. 1398375

27 (youth worker* or transition champion* or transition coordinator* or transition
co-ordinator*).ti,ab,kf. 316

28 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 14665402

29 hospital/ 388579

30 primary health care/72475

31 (hospital* or hospice* or primary care* or primary health care* or primary
healthcare* or secondary care* or secondary health care* or secondary healthcare*
or tertiary care* or tertiary health care* or tertiary healthcare* or NHS or national
health service).ti,ab,kf. 2541933

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33 transition to adult care/ or transitional care/ 6838

34 transition*.ti,ab,kf. 509571

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3 36 28 and 32 and 35 31682
4 37 perception/ 140996
5 38 exp attitude to health/ or attitude/ 185100
6 39 health personnel attitude/ 82841
7 40 catastrophizing/ 4430
8 41 (perception* or experience* or perspective* or challenge* or information need*
9 or support need* or barrier* or facilitator* or attitude* or expectation* or opinion* or
10 satisfaction* or view* or empowerment or shared decision-making).ti,ab,kf. 4476321
11 42 37 or 38 or 39 or 40 or 41 4607367
12 43 36 and 42 14256
13 44 limit 43 to (yr="2014 -Current" and "humans only (removes records about
14 animals)") 9946
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For peer review only

OVID Emcare Search Strategy 1995 to present

- 1 adolescent/ or hospitalized adolescent/ or institutionalized adolescent/
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- 2 young adult/ 86080
- 3 pediatrics/ 28310
- 4 parent/ or father/ or mother/ or single parent/ 120001
- 5 caregiver/ 58296
- 6 family/20367
- 7 health care personnel/ or advanced practice provider/ or care coordinator/ or
clinician/ or mental health care personnel/ 109490
- 8 exp nurse/ 172849
- 9 health educator/ 1961
- 10 exp medical staff/ 14224
- 11 exp nursing staff/ 26879
- 12 hospital personnel/ 9447
- 13 physiotherapist/ 13435
- 14 pediatrician/ 11176
- 15 physician/ or general practitioner/ or hospital physician/ or psychiatrist/
229101
- 16 psychotherapist/ 3777
- 17 pharmacist/ or clinical pharmacist/ or community pharmacist/ or hospital
pharmacist/ 31388
- 18 occupational therapist/ 7821
- 19 social worker/ 10993
- 20 dietitian/ 6340
- 21 patient/ 657335
- 22 patient attendance/ 566
- 23 (young person* or young people* or adolescen* or teen* or youth* or young
adult* or p?ediatric* or child*).ti,ab,kf. 852013
- 24 patient*.ti,ab,kf. 2381929

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3 25 (family or families or parent* or father* or mother* or carer* or caregiver* or
4 care giver*).ti,ab,kf. 569972
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6 26 (doctor* or physician* or p?ediatrician* or general practitioner* or GP? or
7 health care professional* or healthcare professional* or health care personnel* or
8 healthcare personnel* or clinician* or case manager*).ti,ab,kf. 460105
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10 27 (youth worker* or transition champion* or transition coordinator* or transition
11 co-ordinator*).ti,ab,kf. 235
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13 28 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
14 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 3660684
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22 or tertiary care* or tertiary health care* or tertiary healthcare* or NHS or national
23 health service).ti,ab,kf. 716781
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25 32 29 or 30 or 31 738427
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27 33 transition to adult care/ or transitional care/ 2614
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31 35 33 or 34 93186
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33 36 28 and 32 and 35 10333
34
35 37 perception/ 96593
36
37 38 exp attitude to health/ or attitude/ or health personnel attitude/ 41683
38
39 39 catastrophizing/ 1999
40
41 40 (perception* or experience* or perspective* or challenge* or information need*
42 or support need* or barrier* or facilitator* or attitude* or expectation* or opinion* or
43 satisfaction* or view* or empowerment or shared decision-making).ti,ab,kf. 1432813
44
45 41 37 or 38 or 39 or 40 1454284
46
47 42 36 and 41 5449
48
49 43 limit 42 to yr="2014 -Current" 3793
50
51 44 limit 43 to "humans only (removes records about animals)" 3789
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CINAHL Search strategy 12.7.22

#	Query	Limiters/Expanders	Results	Action
S32	S19 AND S23 AND S26 AND S30	Limiters - Publication Year: 2014-2022 Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	3,678	EditS32
S31	S19 AND S23 AND S26 AND S30	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	5,437	EditS31
S30	S27 OR S28 OR S29	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	1,261,876	EditS30
S29	TI (perception* or experience* or perspective* or challenge* or "information need*" or "support need*" or barrier* or facilitator* or attitude* or expectation* or opinion* or satisfaction* or view* or empowerment or "shared decision-making") OR AB (perception* or experience* or perspective* or challenge* or "information need*" or "support need*" or barrier* or facilitator* or attitude* or expectation* or opinion* or satisfaction* or view* or empowerment or "shared decision-making")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	1,205,143	EditS29
S28	(MH "Attitude of Health Personnel") OR (MH "Attitude") OR (MH "Attitude to Health") OR (MH "Catastrophization")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	113,428	EditS28
S27	(MH "Perception")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	31,465	EditS27
S26	S24 OR S25	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	66,688	EditS26
S25	TI transition* OR AB transition*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	66,125	EditS25
S24	(MH "Transitional Care")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	3,099	EditS24
S23	S20 OR S21 OR S22	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	756,802	EditS23
S22	TI (hospital* or hospice* or "primary care*" or "primary health care*" or "primary healthcare*" or "secondary care*" or "secondary health care*" or "secondary healthcare*" or "tertiary care*" or "tertiary health care*" or "tertiary healthcare*" or NHS or "national health service") OR AB (hospital* or hospice* or "primary care*" or "primary health	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	678,861	EditS22

CINAHL Search strategy 12.7.22

	care*" or "primary healthcare*" or "secondary care*" or "secondary health care*" or "secondary healthcare*" or "tertiary care*" or "tertiary health care*" or "tertiary healthcare*" or NHS or "national health service")			
S21	(MH "Primary Health Care")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	71,114	EditS21
S20	(MH "Hospitals+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	131,053	EditS20
S19	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	3,851,513	EditS19
S18	TI ("youth worker*" or "transition champion*" or "transition coordinator*" or "transition co-ordinator*") OR AB ("youth worker*" or "transition champion*" or "transition coordinator*" or "transition co-ordinator*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	191	EditS18
S17	TI (nurs* or "occupational therapist*" or pharmacist* or physiotherapist* or "physical therapist*" or psychotherapist* or psychologist* or psychiatrist* or dietician* or nutritionist* or "social worker*") OR AB (nurs* or "occupational therapist*" or pharmacist* or physiotherapist* or "physical therapist*" or psychotherapist* or psychologist* or psychiatrist* or dietician* or nutritionist* or "social worker*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	682,072	EditS17
S16	TI (doctor* or physician* or p#ediatician* or "general practitioner*" or GP or GPs or "health care professional*" or "healthcare professional*" or "health care personnel*" or "healthcare personnel*" or clinician* or "case manager*") OR AB (doctor* or physician* or p#ediatician* or "general practitioner*" or GP or GPs or "health care professional*" or "healthcare professional*" or "health care personnel*" or "healthcare personnel*" or clinician* or "case manager*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	410,584	EditS16
S15	TI (family or families or parent* or father* or mother* or carer* or caregiver* or "care giver*") OR AB (family or families or parent* or father* or mother* or carer* or caregiver* or "care giver*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	505,373	EditS15
S14	TI patient* OR AB patient*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	2,029,431	EditS14

CINAHL Search strategy 12.7.22

1	S13	TI ("young person*" or "young people*" or adolescen* or teen* or youth* or "young adult*" or p#ediatric* or child*) OR AB ("young person*" or "young people*" or adolescen* or teen* or youth* or "young adult*" or p#ediatric* or child*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	801,837	EditS13
7	S12	(MH "Patients") OR (MH "Inpatients") OR (MH "Outpatients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	139,297	EditS12
9	S11	(MH "Psychotherapists")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	3,652	EditS11
12	S10	(MH "Pediatricians")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	3,809	EditS10
15	S9	(MH "Physicians, Family")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	22,394	EditS9
17	S8	(MH "Nursing Staff, Hospital")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	23,740	EditS8
20	S7	(MH "Case Managers") OR (MH "Health Personnel") OR (MH "Dietitians") OR (MH "Health Educators") OR (MH "Occupational Therapists") OR (MH "Physical Therapists") OR (MH "Social Workers") OR (MH "Medical Staff+") OR (MH "Nurses+") OR (MH "Pharmacists") OR (MH "Physicians")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	408,570	EditS7
26	S6	(MH "Family")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	46,538	EditS6
29	S5	(MH "Caregivers")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	40,697	EditS5
31	S4	(MH "Fathers") OR (MH "Mothers") OR (MH "Single Parent")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	40,419	EditS4
34	S3	(MH "Pediatrics")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	21,564	EditS3
36	S2	(MH "Young Adult")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	279,872	EditS2
39	S1	(MH "Adolescent, Hospitalized") OR (MH "Adolescent Health Services") OR (MH "Adolescence")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	584,568	

Cochrane Search Strategy

Search Name: Cochrane 12th July

Date Run: 12/07/2022 15:48:01

Comment:

ID	Search	Hits
#1	MeSH descriptor: [Adolescent] this term only	110346
#2	MeSH descriptor: [Adolescent, Hospitalized] this term only	9
#3	MeSH descriptor: [Adolescent, Institutionalized] this term only	1
#4	MeSH descriptor: [Young Adult] this term only	72670
#5	MeSH descriptor: [Pediatrics] this term only	675
#6	MeSH descriptor: [Parents] this term only	3714
#7	MeSH descriptor: [Fathers] this term only	223
#8	MeSH descriptor: [Mothers] this term only	2193
#9	MeSH descriptor: [Single Parent] this term only	45
#10	MeSH descriptor: [Caregivers] this term only	2582
#11	MeSH descriptor: [Family] this term only	1619
#12	MeSH descriptor: [Health Personnel] this term only	1183
#13	MeSH descriptor: [Case Managers] this term only	16
#14	MeSH descriptor: [Health Educators] this term only	28
#15	MeSH descriptor: [Medical Staff] explode all trees	345
#16	MeSH descriptor: [Nurses] explode all trees	1322
#17	MeSH descriptor: [Nursing Staff] explode all trees	684
#18	MeSH descriptor: [Personnel, Hospital] this term only	188
#19	MeSH descriptor: [Medical Staff, Hospital] this term only	278
#20	MeSH descriptor: [Nursing Staff, Hospital] this term only	466
#21	MeSH descriptor: [Physical Therapists] this term only	157
#22	MeSH descriptor: [Physicians] this term only	1008
#23	MeSH descriptor: [General Practitioners] this term only	342
#24	MeSH descriptor: [Pediatricians] this term only	25
#25	MeSH descriptor: [Physicians, Family] this term only	462
#26	MeSH descriptor: [Physicians, Primary Care] this term only	177
#27	MeSH descriptor: [Psychotherapists] this term only	5
#28	MeSH descriptor: [Pharmacists] this term only	721
#29	MeSH descriptor: [Occupational Therapists] this term only	11
#30	MeSH descriptor: [Social Workers] this term only	30
#31	MeSH descriptor: [Nutritionists] this term only	56
#32	MeSH descriptor: [Patients] this term only	403
#33	MeSH descriptor: [Inpatients] this term only	1100
#34	MeSH descriptor: [No-Show Patients] this term only	11
#35	MeSH descriptor: [Outpatients] this term only	1388
#36	(young person* or young people* or adolescen* or teen* or youth* or young adult* or p?ediatric* or child*):ti,ab,kw	339085
#37	(patient*):ti,ab,kw	1076849
#38	(family or families or parent* or father* or mother* or carer* or caregiver* or care giver*):ti,ab,kw	109119
#39	(doctor* or physician* or p?ediatrician* or general practitioner* or GP? or health care professional* or healthcare professional* or health care personnel* or healthcare personnel* or clinician* or case manager*):ti,ab,kw	112066

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2
3 #40 (nurs* or occupational therapist* or pharmacist* or physiotherapist* or physical
4 therapist* or psychotherapist* or psychologist* or psychiatrist* or dietician* or
5 nutritionist* or social worker*):ti,ab,kw 68463
6
7 #41 (youth worker* or transition champion* or transition coordinator* or transition
8 co-ordinator*):ti,ab,kw 279
9 #42 {OR #1-#41} 1306481
10 #43 MeSH descriptor: [Hospitals] explode all trees 3996
11 #44 MeSH descriptor: [Primary Health Care] explode all trees 8394
12 #45 MeSH descriptor: [Adolescent Health Services] this term only 177
13 #46 (hospital* or hospice* or primary care* or primary health care* or primary
14 healthcare* or secondary care* or secondary health care* or secondary healthcare*
15 or tertiary care* or tertiary health care* or tertiary healthcare* or NHS or national
16 health service):ti,ab,kw 291726
17 #47 {OR #43-#46} 292877
18 #48 MeSH descriptor: [Transition to Adult Care] this term only 25
19 #49 MeSH descriptor: [Transitional Care] this term only 83
20 #50 (transition*):ti,ab,kw 11635
21 #51 {OR #48-#50} 11635
22 #52 MeSH descriptor: [Perception] this term only 1684
23 #53 MeSH descriptor: [Attitude] this term only 1188
24 #54 MeSH descriptor: [Attitude of Health Personnel] this term only 2024
25 #55 MeSH descriptor: [Attitude to Health] explode all trees 37736
26 #56 MeSH descriptor: [Catastrophization] this term only 201
27 #57 (perception* or experience* or perspective* or challenge* or information need*
28 or support need* or barrier* or facilitator* or attitude* or expectation* or opinion* or
29 satisfaction* or view* or empowerment or shared decision-making):ti,ab,kw
30 306622
31 #58 {OR #52-#57} 319149
32 #59 #42 AND #47 AND #51 AND #58 with Publication Year from 2014 to 2022, in
33 Trials 1403
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3 OVID AMED (Allied and Complementary Medicine) Search Strategy <1985 to June
4 2022>
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6
7 1 adolescent/ or adolescence/ 6499
8 2 pediatrics/ 748
9 3 parents/ or fathers/ or mothers/ 2418
10 4 caregivers/ 3313
11 5 Family/ 2833
12 6 health personnel/ or exp nurses/ or exp nursing staff/ or occupational
13 therapists/ or physiotherapists/ 5460
14 7 physicians/ 1030
15 8 exp patients/ 2656
16 9 (young person* or young people* or adolescen* or teen* or youth* or young
17 adult* or p?ediatric* or child*).ti,ab. 26710
18 10 patient*.ti,ab. 80684
19 11 (family or families or parent* or father* or mother* or carer* or caregiver* or
20 care giver*).ti,ab. 19854
21 12 (doctor* or physician* or p?ediatrician* or general practitioner* or GP? or
22 health care professional* or healthcare professional* or health care personnel* or
23 healthcare personnel* or clinician* or case manager*).ti,ab. 18096
24 13 (nurs* or occupational therapist* or pharmacist* or physiotherapist* or physical
25 therapist* or psychotherapist* or psychologist* or psychiatrist* or dietician* or
26 nutritionist* or social worker*).ti,ab. 19931
27 14 (youth worker* or transition champion* or transition coordinator* or transition
28 co-ordinator*).ti,ab. 4
29 15 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 131991
30 16 exp Hospitals/ 1490
31 17 exp Primary health care/ 1019
32 18 (hospital* or hospice* or primary care* or primary health care* or primary
33 healthcare* or secondary care* or secondary health care* or secondary healthcare*
34 or tertiary care* or tertiary health care* or tertiary healthcare* or NHS or national
35 health service).ti,ab.20425
36 19 16 or 17 or 18 21169
37 20 transition*.ti,ab. 2725
38 21 15 and 19 and 20 321
39 22 Perception/ 2751
40 23 Attitude/ 2096
41 24 (perception* or experience* or perspective* or challenge* or information need*
42 or support need* or barrier* or facilitator* or attitude* or expectation* or opinion* or
43 satisfaction* or view* or empowerment or shared decision-making).ti,ab. 54373
44 25 22 or 23 or 24 56176
45 26 21 and 25 165
46 27 limit 26 to yr="2014 -Current" 56
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3 OVID MEDLINE(R) ALL Search Strategy <1946 to July 11, 2022>
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- 7 1 Adolescent/ or adolescent, hospitalized/ or adolescent, institutionalized/ or
8 Young Adult/ or Pediatrics/ 2686951
9
- 10 2 parents/ or fathers/ or mothers/ or single parent/ 132227
11
12 3 Caregivers/ 46292
13
14 4 Family/ 82752
15
- 16 5 health personnel/ or case managers/ or health educators/ or exp medical staff/
17 or exp nurses/ or exp nursing staff/ or personnel, hospital/ or medical staff, hospital/
18 or nursing staff, hospital/ or physical therapists/ or physicians/ or general
19 practitioners/ or pediatricians/ or physicians, family/ or physicians, primary care/ or
20 psychotherapists/ 377568
21
22
- 23 6 Pharmacists/ 20407
24
25 7 Occupational Therapists/ 566
26
27 8 Social Workers/ 961
28
29 9 Nutritionists/ 1633
30
- 31 10 patients/ or inpatients/ or no-show patients/ or outpatients/ 66921
32
33 11 (young person* or young people* or adolescen* or teen* or youth* or young
34 adult* or p?ediatric* or child*).ti,ab,kf. 2085766
35
- 36 12 patient*.ti,ab,kf. 7648258
37
38 13 (family or families or parent* or father* or mother* or carer* or caregiver* or
39 care giver*).ti,ab,kf. 1701694
40
- 41 14 (doctor* or physician* or p?ediatrician* or general practitioner* or GP? or
42 health care professional* or healthcare professional* or health care personnel* or
43 healthcare personnel* or clinician* or case manager*).ti,ab,kf. 1031087
44
- 45 15 (nurs* or occupational therapist* or pharmacist* or physiotherapist* or physical
46 therapist* or psychotherapist* or psychologist* or psychiatrist* or dietician* or
47 nutritionist* or social worker*).ti,ab,kf. 614580
48
- 49 16 (youth worker* or transition champion* or transition coordinator* or transition
50 co-ordinator*).ti,ab,kf. 186
51
- 52 17 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
53 11799493
54
- 55 18 exp Hospitals/ 305779
56
57 19 exp Primary Health Care/ 184156
58
- 59 20 Adolescent health services/ 5844
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3 21 (hospital* or hospice* or primary care* or primary health care* or primary
4 healthcare* or secondary care* or secondary health care* or secondary healthcare*
5 or tertiary care* or tertiary health care* or tertiary healthcare* or NHS or national
6 health service).ti,ab,kf. 1733153
7
8
9 22 18 or 19 or 20 or 21 1905305
10
11 23 transition to adult care/ or transitional care/ 3048
12
13 24 transition*.ti,ab,kf. 484217
14
15 25 23 or 24 484546
16
17 26 17 and 22 and 25 20543
18
19 27 Perception/ 41631
20
21 28 attitude/ or "attitude of health personnel"/ or exp attitude to health/ or
22 catastrophization/ 613115
23
24 29 (perception* or experience* or perspective* or challenge* or information need*
25 or support need* or barrier* or facilitator* or attitude* or expectation* or opinion* or
26 satisfaction* or view* or empowerment or shared decision-making).ti,ab,kf. 3588560
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28 30 27 or 28 or 29 3906756
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30 31 26 and 30 10276
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32 32 limit 31 to (yr="2014 -Current" and "humans only (removes records about
33 animals)") 7083
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APA PsycInfo Search Strategy <1806 to July Week 2 2022>

1 exp adolescent health/ 2912
 2 pediatrics/ or chronically ill children/ 29489
 3 parents/ or fathers/ or mothers/ or single parents/ 94818
 4 caregivers/ or child care/ 41105
 5 exp Family/ 328505
 6 health personnel/ 19445
 7 clinicians/ 12337
 8 exp Mental Health Personnel/ 55616
 9 exp Nurses/ 35665
 10 medical personnel/ or health personnel/ or physical therapists/ or physicians/
 11 or clinicians/ or mental health personnel/72104
 12 exp Physical Therapists/ 625
 13 exp Pediatricians/ 1604
 14 physicians/ or family physicians/ or general practitioners/ or psychiatrists/
 15 42533
 16 pharmacists/ or pharmacy/ 2582
 17 exp patients/ 103671
 18 (young person* or young people* or adolescen* or teen* or youth* or young
 19 adult* or p?ediatric* or child*).ti,ab,id. 1021091
 20 patient*.ti,ab,id. 775209
 21 (family or families or parent* or father* or mother* or carer* or caregiver* or
 22 care giver*).ti,ab,id. 703206
 23 (doctor* or physician* or p?ediatrician* or general practitioner* or GP? or
 24 health care professional* or healthcare professional* or health care personnel* or
 25 healthcare personnel* or clinician* or case manager*).ti,ab,id. 240484
 26 (youth worker* or transition champion* or transition coordinator* or transition
 27 co-ordinator*).ti,ab,id. 480
 28 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
 29 or 17 or 18 or 19 or 20 2130230
 30 exp hospitals/ 26703
 31 exp Primary Health Care/ 20201
 32 (hospital* or hospice* or primary care* or primary health care* or primary
 33 healthcare* or secondary care* or secondary health care* or secondary healthcare*
 34 or tertiary care* or tertiary health care* or tertiary healthcare* or NHS or national
 35 health service).ti,ab,id. 224017
 36 22 or 23 or 24 228856
 37 transition*.ti,ab,id. 84116
 38 21 and 25 and 26 3916
 39 exp Perception/ 458547
 40 attitudes/ 29733
 41 exp Health Personnel Attitudes/ or exp Health Attitudes/ 37091
 42 exp Catastrophizing/ 965
 43 (perception* or experience* or perspective* or challenge* or information need*
 44 or support need* or barrier* or facilitator* or attitude* or expectation* or opinion* or
 45 satisfaction* or view* or empowerment or shared decision-making).ti,ab,id. 1883939
 46 28 or 29 or 30 or 31 or 32 2132644
 47 27 and 33 2340
 48 limit 34 to (human and yr="2014 -Current") 1250

1
 2
 3 36 exp adolescent health/ 2912
 4 37 pediatrics/ or chronically ill children/ 29489
 5 38 parents/ or fathers/ or mothers/ or single parents/ 94818
 6 39 caregivers/ or child care/ 41105
 7 40 exp Family/ 328505
 8 41 health personnel/ 19445
 9 42 clinicians/ 12337
 10 43 exp Mental Health Personnel/ 55616
 11 44 exp Nurses/ 35665
 12 45 medical personnel/ or health personnel/ or physical therapists/ or physicians/
 13 or clinicians/ or mental health personnel/72104
 14 46 exp Physical Therapists/ 625
 15 47 exp Pediatricians/ 1604
 16 48 physicians/ or family physicians/ or general practitioners/ or psychiatrists/
 17 42533
 18 49 pharmacists/ or pharmacy/ 2582
 19 50 exp patients/ 103671
 20 51 (young person* or young people* or adolescen* or teen* or youth* or young
 21 adult* or p?ediatric* or child*).ti,ab,id. 1021091
 22 52 patient*.ti,ab,id. 775209
 23 53 (family or families or parent* or father* or mother* or carer* or caregiver* or
 24 care giver*).ti,ab,id. 703206
 25 54 (doctor* or physician* or p?ediatrician* or general practitioner* or GP? or
 26 health care professional* or healthcare professional* or health care personnel* or
 27 healthcare personnel* or clinician* or case manager*).ti,ab,id. 240484
 28 55 (youth worker* or transition champion* or transition coordinator* or transition
 29 co-ordinator*).ti,ab,id. 480
 30 56 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
 31 or 50 or 51 or 52 or 53 or 54 or 55 2130230
 32 57 exp hospitals/ 26703
 33 58 exp Primary Health Care/ 20201
 34 59 (hospital* or hospice* or primary care* or primary health care* or primary
 35 healthcare* or secondary care* or secondary health care* or secondary healthcare*
 36 or tertiary care* or tertiary health care* or tertiary healthcare* or NHS or national
 37 health service).ti,ab,id. 224017
 38 60 57 or 58 or 59 228856
 39 61 transition*.ti,ab,id. 84116
 40 62 56 and 60 and 61 3916
 41 63 exp Perception/ 458547
 42 64 attitudes/ 29733
 43 65 exp Health Personnel Attitudes/ or exp Health Attitudes/ 37091
 44 66 exp Catastrophizing/ 965
 45 67 (perception* or experience* or perspective* or challenge* or information need*
 46 or support need* or barrier* or facilitator* or attitude* or expectation* or opinion* or
 47 satisfaction* or view* or empowerment or shared decision-making).ti,ab,id. 1883939
 48 68 63 or 64 or 65 or 66 or 67 2132644
 49 69 62 and 68 2340
 50 70 limit 69 to (human and yr="2014 -Current") 1250
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4 Web of Science 12.7.22

5 8

6 **#6 AND #2 AND #3 AND**

7 **#4 and 2014 or 2015 or 2016 or 2017 or 2019 or 2018 or 2020 or 2021 or 2022 (Publ**
8 **ication Years)**

9 [6,198](#)

10 Add to query

11 7

12 **#6 AND #2 AND #3 AND #4**

13 [8,331](#)

14 Add to query

15 6

16 **#5 OR #1**

17 [11,887,744](#)

18 Add to query

19 5

20 **TS=(("young person*" or "young people*" or adolescen* or teen* or youth* or**
21 **"young adult*" or p\$ediatric* or child*))**

22 [2,858,002](#)

23 Add to query

24 4

25 **(perception* or experience* or perspective* or challenge* or "information**
26 **need*" or "support need*" or barrier* or facilitator* or attitude* or expectation***
27 **or opinion* or satisfaction* or view* or empowerment or "shared decision-**
28 **making") (Topic)**

29 [7,790,995](#)

30 Add to query

31 3

32 **transition* (Topic)**

33 [1,954,616](#)

34 Add to query

35 2

36 **(hospital* or hospice* or "primary care*" or "primary health care*" or "primary**
37 **healthcare*" or "secondary care*" or "secondary health care*" or "secondary**
38 **healthcare*" or "tertiary care*" or "tertiary health care*" or "tertiary**
39 **healthcare*" or NHS or "national health service") (Topic)**

40 [1,602,881](#)

41 Add to query

42 1

43 **(patient* (Topic) or (family or families or parent* or father* or mother* or carer***
44 **or caregiver* or "care giver*") (Topic) or (doctor* or physician* or p\$ediatrician***
45 **or "general practitioner*" or GP or GPs or "health care professional*" or**
46 **"healthcare professional*" or "health care personnel*" or "healthcare**
47 **personnel*" or clinician* or "case manager*") (Topic) or (nurs* or "occupational**
48 **therapist*" or pharmacist* or physiotherapist* or "physical therapist*" or**
49 **psychotherapist* or psychologist* or psychiatrist* or dietician* or nutritionist***

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3 or "social worker*") (Topic) or ("youth worker*" or "transition champion*" or
4 "transition coordinator*" or "transition co-ordinator*") (Topic)
5 [10,232,180](#)
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For peer review only

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Scopus search strategy 12.7.22

((TITLE-ABS-KEY ("young person*" OR "young
 people*" OR adolescen* OR teen* OR youth* OR "young
 adult*" OR pediatric* OR paediatric* OR child*) OR TITLE-ABS-
 KEY ((patient*)) OR TITLE-ABS-
 KEY ((family OR families OR parent* OR father* OR mother* OR carer* OR
 caregiver* OR "care giver*")) OR TITLE-ABS-
 KEY ((doctor* OR physician* OR pediatrician* OR paediatrician* OR "general
 practitioner*" OR gp OR gps OR "health care professional*" OR "healthcare
 professional*" OR "health care personnel*" OR "healthcare
 personnel*" OR clinician* OR "case manager*")) OR TITLE-ABS-
 KEY ((nurs* OR "occupational
 therapist*" OR pharmacist* OR physiotherapist* OR "physical
 therapist*" OR psychotherapist* OR psychologist* OR psychiatrist* OR dietician
 * OR nutritionist* OR "social worker*")) OR TITLE-ABS-KEY (("youth
 worker*" OR "transition champion*" OR "transition coordinator*" OR "transition
 co-ordinator*")))) AND (TITLE-ABS-
 KEY ((hospital* OR hospice* OR "primary care*" OR "primary health
 care*" OR "primary healthcare*" OR "secondary care*" OR "secondary health
 care*" OR "secondary healthcare*" OR "tertiary care*" OR "tertiary health
 care*" OR "tertiary healthcare*" OR nhs OR "national health
 service"))) AND (TITLE-ABS-KEY (transition*)) AND (TITLE-ABS-
 KEY ((perception* OR experience* OR perspective* OR challenge* OR "infor
 mation need*" OR "support
 need*" OR barrier* OR facilitator* OR attitude* OR expectation* OR opinion*
 OR satisfaction* OR view* OR empowerment OR "shared decision-
 making"))) AND (LIMIT-TO (PUBYEAR , 2022) OR LIMIT-
 TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-
 TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-
 TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-
 TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014))