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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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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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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

poorer health outcomes when transition between children's and adults' services is not coordinated and planned' [3], p32. Research studies have reported that some young people experience a disjointed transfer into adults' services which is more of a one-off transfer event, rather than a process of preparation and support in which they are involved: such experiences seem to be comparable across young people with different diagnoses [4]. Consequently, health service provision, which fails to meet the needs of young people and families at this time of significant change, may result in deterioration in health or disengagement with services, which can have negative long-term consequences.

The National Institute for Health and Care Excellence's Quality Standard for Transition recommends that health and social care service managers in children's and adults' services should provide an integrated, collaborative approach to ensure a smooth and gradual transition for young people [5]. The transition from children's into adults' services is a crucial time in the health of young people who may potentially fall into what has been described as a poorly managed 'care gap'. Transition processes or programmes of preparation and support need to smooth the journey and bridge this 'gap' between children's and adults' services, but this process is not yet fully understood. However, current practices across the United Kingdom are varied, creating an ad hoc, chaotic approach to young people's transition, meaning that there is a need to understand these processes, and this gap in understanding further, which will be explored through this realist synthesis. Realist methodology has been applied to healthcare transition in the context of young adults with life-limiting conditions [6, 7], however 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. This realist synthesis will be inclusive of young people with long term conditions, and complements the research being undertaken as part of the National Transition Evaluation Study, which formally evaluates the implementation of the Burdett National Transition Nursing Network and the Model of Improvement for Transition (https://www.leedsth.nhs.uk/burdett-national-transition-nursing-network/).

Methods and analysis

Realist methodology uses a theory-driven paradigm to "explore how context such as cultural norms and values, economic conditions, geographical characteristics or national policy interacts with various mechanisms to produce outcomes" p2 [8]. This study aims to

produce important information about the relative effectiveness of transition intervention components taking into consideration different conditions, needs and associated complexities, ages of young people, differences in healthcare personnel and service provision in different healthcare contexts. The realist approach acknowledges that interventions may work in some contexts but not others, with a key principle being the notion that interventions are context-bound. A realist synthesis focuses on causation and is represented as context+mechanism=outcome [9, 10].

Context "pertains to the 'backdrop' of programs and research" [11]. In our study, this pertains to ways in which services are configured, and how transition processes and pathways are constructed to provide or support the transition of young people from children's into adults' services. This would include both child and adult healthcare providers, and includes all healthcare settings, as described in the study's PICOH (Table 1). Context can be understood as any condition that triggers or modifies a mechanism [11], and includes concepts such as how services are funded, cultural norms and values, and pre-existing relationships between child and adult healthcare settings, or between healthcare providers and young people and their families [8].

Mechanism concerns the causal force, triggered in particular contexts, that leads to outcomes. Mechanisms explain why and how observed outcomes occur and usually comprise two parts: the 'resources' offered by an intervention and the cognitive or emotional decisions ('reasoning') and behaviour of people, in this case the behaviour of young people, their parents or carers, and healthcare professionals involved in the transition of young people to adults' services [8]. Jagosh *et al* identify that mechanisms advance the synthesis beyond describing 'what happened' to theorising 'why it happened, for whom, and under what circumstances' based on participant reasoning or reaction [11], which is key to understanding the intricacies related to young people's effective transition into adults' services.

Table 1: Study PICOH

PICOH	
P - Population	Child health clinicians (doctors - including GPs, nurses, allied health professionals) preparing and supporting young people's transition from child into adult services. Adult clinicians (doctors – including GPs, nurses, allied health professionals) supporting and engaging young people in the adult service during the process of transition. Youth workers, key workers, and support staff (MDT coordinators, play specialists, administrative support in both child and adult setting) Young people's perspectives on transition into adults' services (age 12-25 years) Parent/caregiver perspectives on their child's transition into adults' services
I – Intervention	Interventions related to successful transition of young people from children's into adults' services [12]: 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	Outcomes will vary according to the intervention, but may include: Measurable adverse outcomes such as: nonadherence to treatment, loss to follow up, adverse social and educational outcomes, morbidity and mortality [13] 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] Attendance at appointments, understanding of condition and its self-management. Self-reported readiness for the transfer into adults' services and self-advocacy.
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-

management, parent involvement, and future-oriented care [16], 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. Initial programme theories (IPTs) linking to the theoretical framework were formulated. Prior to commencing the formal searches, these were presented at a stakeholder workshop with experts on the transition of young people from children's into adults' services. The IPTs were refined through discussion and final consensus amongst the group. Figure 2 presents the IPTs, which are colour coded according to which aspect of the framework they relate to. It is important to note that IPTs can relate to more than one dimension within the framework, for example, 'If all relevant stakeholders across children's and adults' services collaborate and build partnerships to meet the varying and often complex needs of young people, then children's service practitioners will be more comfortable relinquishing control over the young person's care' relates to 'Future-orientated, 'Co-ordination', and 'Continuity of care'. This process enabled the formulation of the research questions.

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?

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]. 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 [17]. 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 [15].

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

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

Stage 5: Data extraction and synthesis

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

extracted codes will be synthesised according to the relationship between contexts, mechanisms and outcomes (intended and unintended/unexpected). The synthesis will include the following steps:

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

Patient and Public Involvement Statement

Extensive patient and public involvement has been undertaken prior to conception of the Burdett National Transition Nursing Network and the implementation of the Model of Improvement for Transition, The National Transition Evaluation Study and this realist synthesis. This includes liaison with the 'Transition Advisory Group', made up of young

people to advise on the implementation of the Burdett National Transition Nursing Network and on this study, a National Transition Steering Group, and an Advisory Group, both formed of key stakeholders and professionals who are consulted on matters relating to the overall implementation project, the study and the realist synthesis.

Author Contributions

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

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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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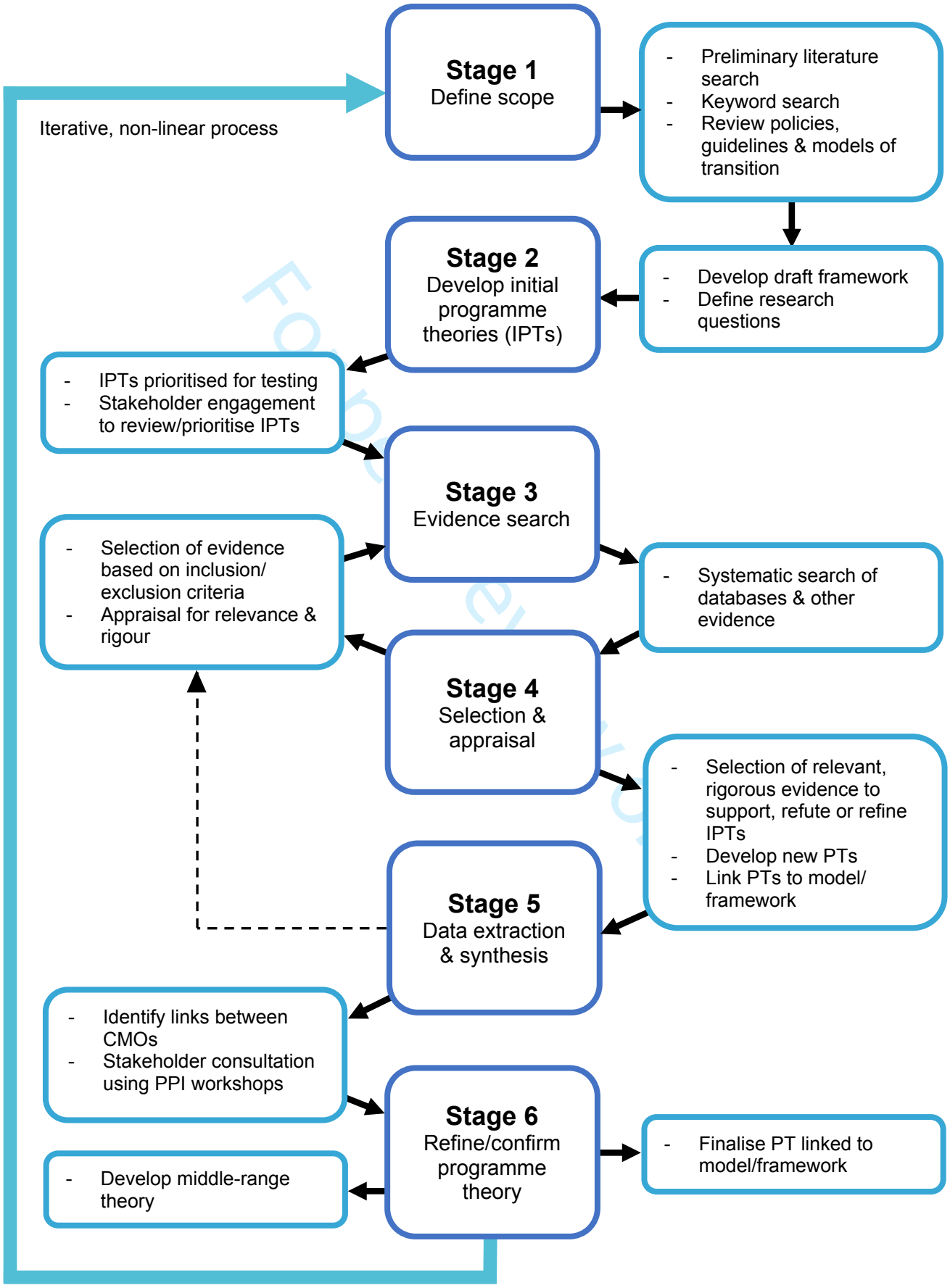
Stages of Realist Synthesis



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

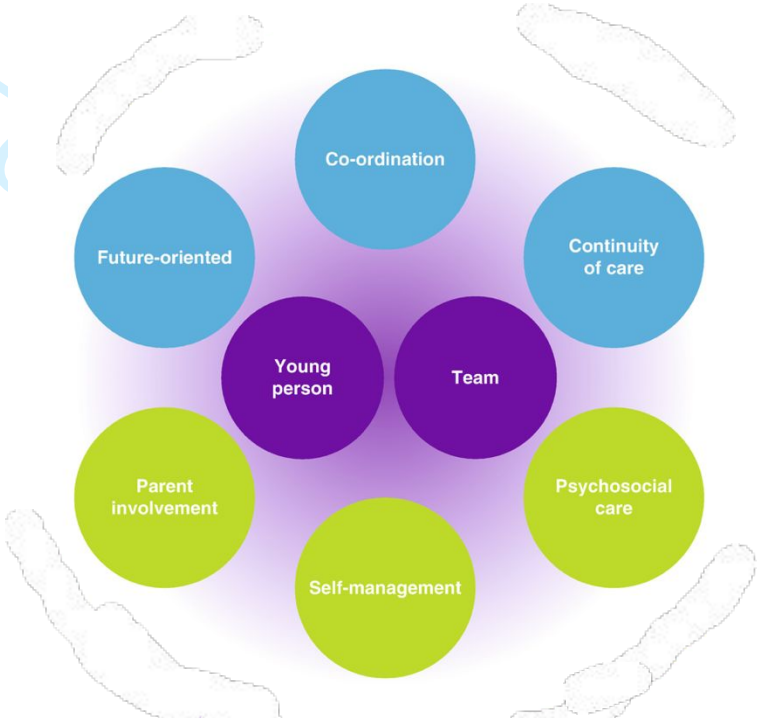
If the profile of young people's transition into adults' services is raised, with increased awareness of what is involved and required for effective/successful transition, then transition is likely to be more successful with reduced morbidity and mortality, and increased patient, family and staff satisfaction.

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 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 children's and adults' 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 aware of their own futures.

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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

poorer health outcomes when transition between children's and adults' services is not coordinated and planned' [3], p32. Research studies have reported that some young people experience a disjointed transfer into adults' services which is more of a one-off transfer event, rather than a process of preparation and support in which they are involved: such experiences seem to be comparable across young people with different diagnoses [4]. Consequently, health service provision, which fails to meet the needs of young people and families at this time of significant change, may result in deterioration in health or disengagement with services, which can have negative long-term consequences.

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

We chose realist methodology over the more traditional systematic review methodology because traditional methods focus on evidence without considering the context: we know already that context is key to transition. Also, realist methodology is theory-driven, aiming to establish what works for whom in what circumstances, how and why it works. While there are numerous reviews into "evidence" surrounding the issue of healthcare transition, the outcomes invariably conclude that there is not enough evidence. Furthermore, most reviews only consider one specific intervention and/ or a specific patient group, the results are then not applicable to all young people or transferable to all disease groups; nor to complex interventions such as transition programmes that consist of numerous different elements. Finally, realist methodology has been applied in the field of transition, healthcare in the context of young adults with life-limiting conditions [6, 7].

The first of these studies focused on the evaluation of eight interventions which can help prepare young people with life-limiting conditions and healthcare services for a successful transition. Kerr et al., reported three of the eight interventions were validated: early start to the transition process; developing adolescent/young adult autonomy; and the role of parents/carers; with partial support for the remaining five. Effective communication between healthcare professionals and young people and their parents/carers was identified as an additional intervention of importance [6]. Contextual factors affecting successful transition were highlighted including those related to staff knowledge and attitudes, and a lack of time to provide young person-centred transition services [6]. Mechanisms that were supported include the young person's decision-making, and gaining confidence in relationships with service providers [6].

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

Methods and analysis

Realist methodology uses a theory-driven paradigm to "explore how context such as cultural norms and values, economic conditions, geographical characteristics or national policy interacts with various mechanisms to produce outcomes" p2 [8]. This study aims to produce important information about the relative effectiveness of transition intervention components taking into consideration different conditions, needs and associated

complexities, ages of young people, differences in healthcare personnel and service provision in different healthcare contexts. The realist approach acknowledges that interventions may work in some contexts but not others, with a key principle being the notion that interventions are context-bound. A realist synthesis focuses on causation and is represented as context+mechanism=outcome [9, 10].

Context "pertains to the 'backdrop' of programmes and research" [11]. In our study, this pertains to ways in which services are configured, and how transition processes and pathways are constructed to provide or support the transition of young people from children's into adults' services. This would include both child and adult healthcare providers, and includes all healthcare settings, as described in the study's PICOH (Table 1). Context can be understood as any condition that triggers or modifies a mechanism [11], and includes concepts such as how services are funded, cultural norms and values, and pre-existing relationships between child and adult healthcare settings, or between healthcare providers and young people and their families [8].

Mechanism concerns the causal force, triggered in particular contexts, that leads to outcomes. Mechanisms explain why and how observed outcomes occur and usually comprise two parts: the 'resources' offered by an intervention and the cognitive or emotional decisions ('reasoning') and behaviour of people, in this case the behaviour of young people, their parents or carers, and healthcare professionals involved in the transition of young people to adults' services [8]. Jagosh *et al.,* identify that mechanisms advance the synthesis beyond describing 'what happened' to theorising 'why it happened, for whom, and under what circumstances' based on participant reasoning or reaction [11], which is key to understanding the intricacies related to young people's effective transition into adults' services.

Table 1: Study PICOH

PICOH	
P - Population	Child health clinicians (doctors - including GPs, nurses, allied health professionals) preparing and supporting young people's transition from child into adult services. Adult clinicians (doctors – including GPs, nurses, allied health professionals) supporting and engaging young people in the adult service during the process of transition. Youth workers, key workers, and support staff (MDT coordinators, play specialists, administrative support in both child and adult setting) Young people's perspectives on transition into adults' services (age 12-25 years) Parent/caregiver perspectives on their child's transition into adults' services
I – Intervention	Interventions related to successful transition of young people from children's into adults' services [5, 12]: 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	Outcomes will vary according to the intervention, but may include: Measurable adverse outcomes such as: nonadherence to treatment, loss to follow up, adverse social and educational outcomes, morbidity and mortality [13] 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] Attendance at appointments, understanding of condition and its self-management. Self-reported readiness for the transfer into adults' services and self-advocacy.
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-

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:

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

This evidence-based theoretical framework was chosen to guide this research due to the well-documented success of its use over the last 15 years in The Netherlands [15-17]. Furthermore, this framework directly promotes young people's voices being heard in matters that directly affect them [17, 18], and emphasises the collaboration of all relevant stakeholder for healthcare transition success [15]: elements crucial to understand further in the context of published work.

As a starting point, initial programme theories (IPTs) linking to the different elements of the theoretical framework were formulated by the research team. Prior to commencing the formal searches, these IPTs were presented at a workshop with two leading experts on the transition of young people from children's into adults' services, namely the National Lead Nurse for Transition, and the National Advisor for Transition who advised on the Burdett National Transition Nursing Network implementation project. The IPTs were refined through discussion with the experts, who imparted their knowledge from their extensive clinical and specialty specific experience, with a final consensus being reached as to the applicability and appropriateness of each IPT. Figure 2 presents examples of the IPTs, which are colour coded according to which aspect of the framework they relate to. It is important to note that IPTs can relate to more than one dimension within the framework. An example of this is, 'If all relevant stakeholders across children's and adults' services collaborate and build partnerships to meet the varying and often complex needs of young people, then children's service practitioners will be more comfortable relinquishing control over the young person's care' relates to 'Future-orientated, 'Co-ordination', and 'Continuity

of care'. This process enabled the formulation of the research questions. The selection of relevant, rigorous evidence will be applied to these 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.

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

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

Stage 5: Data extraction and synthesis

- Data extraction will be performed within Covidence with the formulation of a data extraction table within the software. Data will be organised according to the 'On your own feet ahead' framework [15]: 1) evidence that relates to interventions to improve the organisation of transition; 2) evidence that relates to interventions to stimulate independence and self-management of young people. Data will also be organised according to a third measure: 3) evidence that relates to the young person's experience of transition.
- Evidence will be extracted and synthesised iteratively with the aim of identifying and exploring causal links between contexts, mechanisms and outcomes (C+M=O) and the extracted codes will be synthesised according to the relationship between contexts, mechanisms and outcomes (intended and unintended/unexpected). The synthesis will include the following steps:
    - Organising the extracted information from various sources of evidence.
    - Identifying themes and patterns or demi-regularities across the codes among context, mechanism and outcomes, as we seek confirming and disconfirming evidence.

- Linking the patterns or demi-regularities to refine IPTs to develop formal programme theory
- Reflection and discussion within the realist synthesis team.

Stage 6: Refine/confirm programme theory

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

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

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

Patient and Public Involvement Statement

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

Author Contributions

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

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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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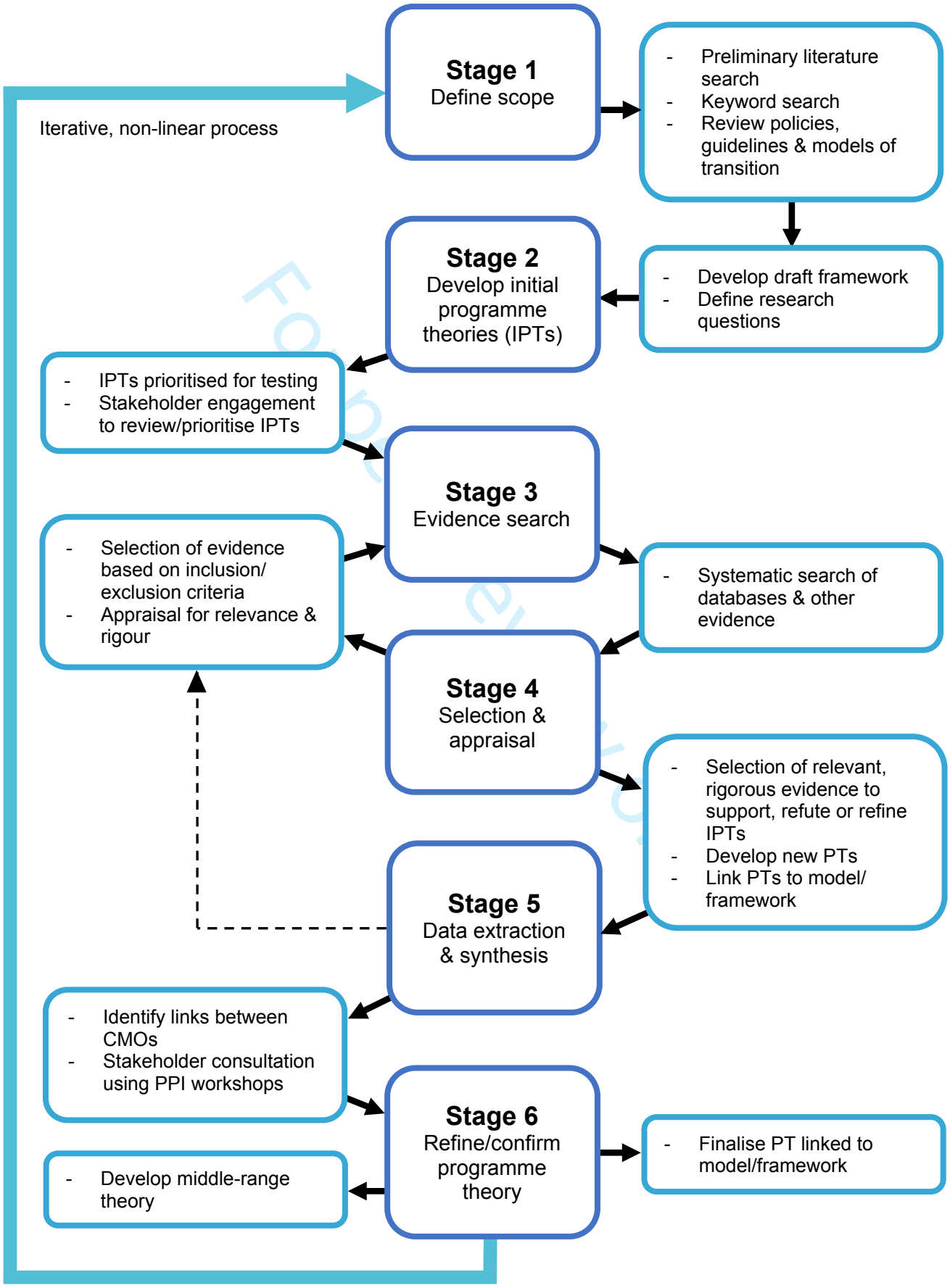
Stages of Realist Synthesis



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

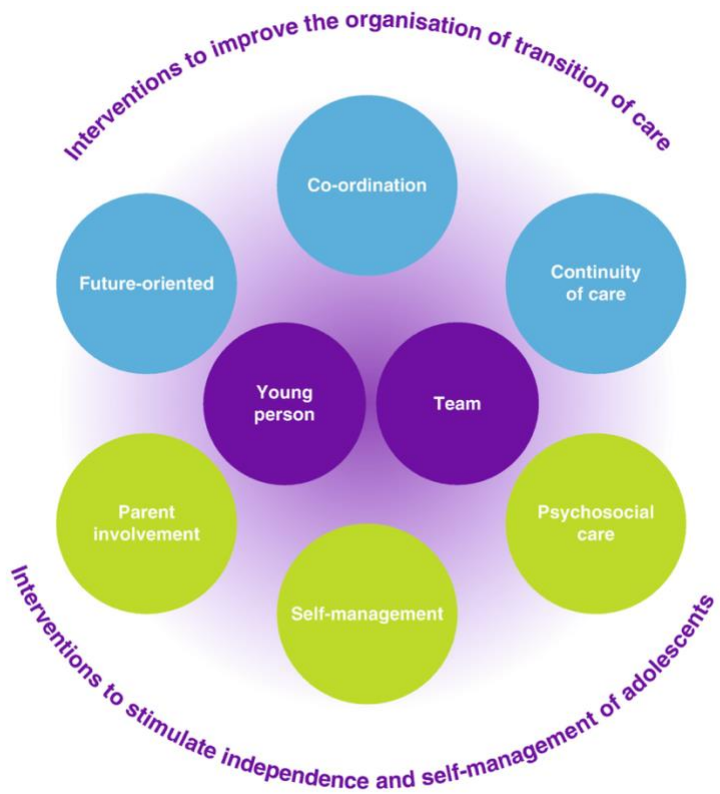
If the profile of young people's transition into adults' services is raised, with increased awareness of what is involved and required for effective/successful transition, then transition is likely to be more successful with reduced morbidity and mortality, and increased patient, family and staff satisfaction.

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 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 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.

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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

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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

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Abstract

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

poorer health outcomes when transition between children's and adults' services is not coordinated and planned' [3], p32. Research studies have reported that some young people experience a disjointed transfer into adults' services which is more of a one-off transfer event, rather than a process of preparation and support in which they are involved: such experiences seem to be comparable across young people with different diagnoses [4]. Consequently, health service provision, which fails to meet the needs of young people and families at this time of significant change, may result in deterioration in health or disengagement with services, which can have negative long-term consequences.

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

We chose realist methodology over the more traditional systematic review methodology because traditional methods focus on evidence without considering the context: we know already that context is key to transition. Also, realist methodology is theory-driven, aiming to establish what works for whom in what circumstances, how and why it works. While there are numerous reviews into "evidence" surrounding the issue of healthcare transition, the outcomes invariably conclude that there is not enough evidence. Furthermore, most reviews only consider one specific intervention and/ or a specific patient group, the results are then not applicable to all young people or transferable to all disease groups; nor to complex interventions such as transition programmes that consist of numerous different elements. Finally, realist methodology has been applied in the field of transition, healthcare in the context of young adults with life-limiting conditions [6, 7].

The first of these studies focused on the evaluation of eight interventions which can help prepare young people with life-limiting conditions and healthcare services for a successful transition. Kerr et al., reported three of the eight interventions were validated: early start to the transition process; developing adolescent/young adult autonomy; and the role of parents/carers; with partial support for the remaining five. Effective communication between healthcare professionals and young people and their parents/carers was identified as an additional intervention of importance [6]. Contextual factors affecting successful transition were highlighted including those related to staff knowledge and attitudes, and a lack of time to provide young person-centred transition services [6]. Mechanisms that were supported include the young person's decision-making, and gaining confidence in relationships with service providers [6].

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

Methods and analysis

Realist methodology uses a theory-driven paradigm to "explore how context such as cultural norms and values, economic conditions, geographical characteristics or national policy interacts with various mechanisms to produce outcomes" p2 [8]. This study aims to produce important information about the relative effectiveness of transition intervention components taking into consideration different conditions, needs and associated

complexities, ages of young people, differences in healthcare personnel and service provision in different healthcare contexts. The realist approach acknowledges that interventions may work in some contexts but not others, with a key principle being the notion that interventions are context-bound. A realist synthesis focuses on causation and is represented as context+mechanism=outcome [9, 10].

Context "pertains to the 'backdrop' of programmes and research" [11]. In our study, this pertains to ways in which services are configured, and how transition processes and pathways are constructed to provide or support the transition of young people from children's into adults' services. This would include both child and adult healthcare providers, and includes all healthcare settings, as described in the study's PICOH (Table 1). Context can be understood as any condition that triggers or modifies a mechanism [11], and includes concepts such as how services are funded, cultural norms and values, and pre-existing relationships between child and adult healthcare settings, or between healthcare providers and young people and their families [8].

Mechanism concerns the causal force, triggered in particular contexts, that leads to outcomes. Mechanisms explain why and how observed outcomes occur and usually comprise two parts: the 'resources' offered by an intervention and the cognitive or emotional decisions ('reasoning') and behaviour of people, in this case the behaviour of young people, their parents or carers, and healthcare professionals involved in the transition of young people to adults' services [8]. Jagosh *et al.,* identify that mechanisms advance the synthesis beyond describing 'what happened' to theorising 'why it happened, for whom, and under what circumstances' based on participant reasoning or reaction [11], which is key to understanding the intricacies related to young people's effective transition into adults' services.

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

Table 1: Study PICOH

PICOH	
P - Population	Child health clinicians (doctors - including GPs, nurses, allied health professionals) preparing and supporting young people's transition from child into adult services. Adult clinicians (doctors – including GPs, nurses, allied health professionals) supporting and engaging young people in the adult service during the process of transition. Youth workers, key workers, and support staff (MDT coordinators, play specialists, administrative support in both child and adult setting) Young people's perspectives on transition into adults' services (age 12-25 years) Parent/caregiver perspectives on their child's transition into adults' services
I – Intervention	Interventions related to successful transition of young people from children's into adults' services [5, 12]: 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	Outcomes will vary according to the intervention, but may include: Measurable adverse outcomes such as: nonadherence to treatment, loss to follow up, adverse social and educational outcomes, morbidity and mortality [13] 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] Attendance at appointments, understanding of condition and its self-management. Self-reported readiness for the transfer into adults' services and self-advocacy.
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

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:

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

This evidence-based theoretical framework was chosen to guide this research due to the well-documented success of its use over the last 15 years in The Netherlands [15-17]. Furthermore, this framework directly promotes young people's voices being heard in matters that directly affect them [17, 18], and emphasises the collaboration of all relevant stakeholder for healthcare transition success [15]: elements crucial to understand further in the context of published work.

As a starting point, initial programme theories (IPTs) linking to the different elements of the theoretical framework were formulated by the research team. Prior to commencing the formal searches, these IPTs were presented at a workshop with two leading experts on the transition of young people from children's into adults' services, namely the National Lead Nurse for Transition, and the National Advisor for Transition who advised on the Burdett National Transition Nursing Network implementation project. The IPTs were refined through discussion with the experts, who imparted their knowledge from their extensive clinical and specialty specific experience, with a final consensus being reached as to the applicability and appropriateness of each IPT. Figure 2 presents examples of the IPTs, which are colour coded according to which aspect of the framework they relate to. It is important to note that IPTs can relate to more than one dimension within the framework. An example of this is, 'If all relevant stakeholders across children's and adults' services collaborate and build partnerships to meet the varying and often complex needs of young people, then children's service practitioners will be more comfortable relinquishing control over the young person's care' relates to 'Future-orientated, 'Co-ordination', and 'Continuity of care'. This process enabled the formulation of the research questions. The selection of relevant, rigorous evidence will be applied to these 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 (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

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

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

Stage 5: Data extraction and synthesis

- Data extraction will be performed within Covidence with the formulation of a data extraction table within the software. Data will be organised according to the 'On your own feet ahead' framework [15]: 1) evidence that relates to interventions to improve the organisation of transition; 2) evidence that relates to interventions to stimulate independence and self-management of young people. Data will also be organised according to a third measure: 3) evidence that relates to the young person's experience of transition.
- Evidence will be extracted and synthesised iteratively with the aim of identifying and exploring causal links between contexts, mechanisms and outcomes (C+M=O) and the extracted codes will be synthesised according to the relationship between contexts, mechanisms and outcomes (intended and unintended/unexpected). The synthesis will include the following steps:

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

Stage 6: Refine/confirm programme theory

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

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

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

Patient and Public Involvement Statement

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

Ethics and Dissemination

This realist synthesis forms part of the National Transition Evaluation Study, which has received ethical and regulatory approval (**IRAS ID: 313576**). 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**).

Author Contributions

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

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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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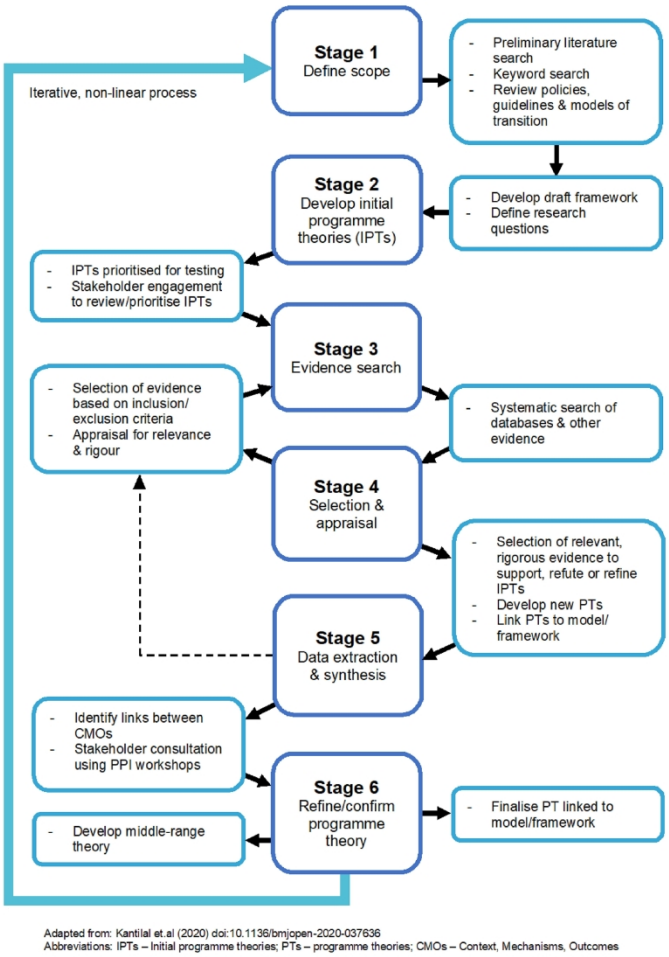

Figure 1: Overview of realist synthesis design

1590x1590mm (96 x 96 DPI)

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

899x792mm (144 x 144 DPI)

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
32 29 or 30 or 31 2665081
33 transition to adult care/ or transitional care/ 6838
34 transition*.ti,ab,kf. 509571
35 33 or 34 510600

36 28 and 32 and 35 31682
37 perception/ 140996
38 exp attitude to health/ or attitude/ 185100
39 health personnel attitude/ 82841
40 catastrophizing/ 4430
41 (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).ti,ab,kf. 4476321
42 37 or 38 or 39 or 40 or 41 4607367
43 36 and 42 14256
44 limit 43 to (yr="2014 -Current" and "humans only (removes records about animals)") 9946

OVID Emcare Search Strategy 1995 to present

1 adolescent/ or hospitalized adolescent/ or institutionalized adolescent/ 377532

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

25 (family or families or parent* or father* or mother* or carer* or caregiver* or care giver*).ti,ab,kf. 569972

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. 460105

27 (youth worker* or transition champion* or transition coordinator* or transition co-ordinator*).ti,ab,kf. 235

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 3660684

29 hospital/ 138101

30 primary health care/ 28020

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. 716781

32 29 or 30 or 31 738427

33 transition to adult care/ or transitional care/ 2614

34 transition*.ti,ab,kf. 92720

35 33 or 34 93186

36 28 and 32 and 35 10333

37 perception/ 96593

38 exp attitude to health/ or attitude/ or health personnel attitude/ 41683

39 catastrophizing/ 1999

40 (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).ti,ab,kf. 1432813

41 37 or 38 or 39 or 40 1454284

42 36 and 41 5449

43 limit 42 to yr="2014 -Current" 3793

44 limit 43 to "humans only (removes records about animals)" 3789

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#ediatrician* 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#ediatrician* 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

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
S12	(MH "Patients") OR (MH "Inpatients") OR (MH "Outpatients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	139,297	EditS12
S11	(MH "Psychotherapists")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	3,652	EditS11
S10	(MH "Pediatricians")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	3,809	EditS10
S9	(MH "Physicians, Family")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	22,394	EditS9
S8	(MH "Nursing Staff, Hospital")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	23,740	EditS8
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
S6	(MH "Family")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	46,538	EditS6
S5	(MH "Caregivers")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	40,697	EditS5
S4	(MH "Fathers") OR (MH "Mothers") OR (MH "Single Parent")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	40,419	EditS4
S3	(MH "Pediatrics")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	21,564	EditS3
S2	(MH "Young Adult")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	279,872	EditS2
S1	(MH "Adolescent, Hospitalized") OR (MH "Adolescent Health Services") OR (MH "Adolescence")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	584,568	

CINAHL Search strategy 12.7.22

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

#40 (nurs* or occupational therapist* or pharmacist* or physiotherapist* or physical therapist* or psychotherapist* or psychologist* or psychiatrist* or dietician* or nutritionist* or social worker*):ti,ab,kw 68463
#41 (youth worker* or transition champion* or transition coordinator* or transition co-ordinator*):ti,ab,kw 279
#42 {OR #1-#41} 1306481
#43 MeSH descriptor: [Hospitals] explode all trees 3996
#44 MeSH descriptor: [Primary Health Care] explode all trees 8394
#45 MeSH descriptor: [Adolescent Health Services] this term only 177
#46 (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,kw 291726
#47 {OR #43-#46} 292877
#48 MeSH descriptor: [Transition to Adult Care] this term only 25
#49 MeSH descriptor: [Transitional Care] this term only 83
#50 (transition*):ti,ab,kw 11635
#51 {OR #48-#50} 11635
#52 MeSH descriptor: [Perception] this term only 1684
#53 MeSH descriptor: [Attitude] this term only 1188
#54 MeSH descriptor: [Attitude of Health Personnel] this term only 2024
#55 MeSH descriptor: [Attitude to Health] explode all trees 37736
#56 MeSH descriptor: [Catastrophization] this term only 201
#57 (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):ti,ab,kw 306622
#58 {OR #52-#57} 319149
#59 #42 AND #47 AND #51 AND #58 with Publication Year from 2014 to 2022, in Trials 1403

OVID AMED (Allied and Complementary Medicine) Search Strategy <1985 to June 2022>

1 adolescent/ or adolescence/ 6499
2 pediatrics/ 748
3 parents/ or fathers/ or mothers/ 2418
4 caregivers/ 3313
5 Family/ 2833
6 health personnel/ or exp nurses/ or exp nursing staff/ or occupational therapists/ or physiotherapists/ 5460
7 physicians/ 1030
8 exp patients/ 2656
9 (young person* or young people* or adolescen* or teen* or youth* or young adult* or p?ediatric* or child*).ti,ab. 26710
10 patient*.ti,ab. 80684
11 (family or families or parent* or father* or mother* or carer* or caregiver* or care giver*).ti,ab. 19854
12 (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. 18096
13 (nurs* or occupational therapist* or pharmacist* or physiotherapist* or physical therapist* or psychotherapist* or psychologist* or psychiatrist* or dietician* or nutritionist* or social worker*).ti,ab. 19931
14 (youth worker* or transition champion* or transition coordinator* or transition co-ordinator*).ti,ab. 4
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
16 exp Hospitals/ 1490
17 exp Primary health care/ 1019
18 (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. 20425
19 16 or 17 or 18 21169
20 transition*.ti,ab. 2725
21 15 and 19 and 20 321
22 Perception/ 2751
23 Attitude/ 2096
24 (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).ti,ab. 54373
25 22 or 23 or 24 56176
26 21 and 25 165
27 limit 26 to yr="2014 -Current" 56

OVID MEDLINE(R) ALL Search Strategy <1946 to July 11, 2022>

1 Adolescent/ or adolescent, hospitalized/ or adolescent, institutionalized/ or Young Adult/ or Pediatrics/ 2686951

2 parents/ or fathers/ or mothers/ or single parent/ 132227

3 Caregivers/ 46292

4 Family/ 82752

5 health personnel/ or case managers/ or health educators/ or exp medical staff/ or exp nurses/ or exp nursing staff/ or personnel, hospital/ or medical staff, hospital/ or nursing staff, hospital/ or physical therapists/ or physicians/ or general practitioners/ or pediatricians/ or physicians, family/ or physicians, primary care/ or psychotherapists/ 377568

6 Pharmacists/ 20407

7 Occupational Therapists/ 566

8 Social Workers/ 961

9 Nutritionists/ 1633

10 patients/ or inpatients/ or no-show patients/ or outpatients/ 66921

11 (young person* or young people* or adolescen* or teen* or youth* or young adult* or p?ediatric* or child*).ti,ab,kf. 2085766

12 patient*.ti,ab,kf. 7648258

13 (family or families or parent* or father* or mother* or carer* or caregiver* or care giver*).ti,ab,kf. 1701694

14 (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. 1031087

15 (nurs* or occupational therapist* or pharmacist* or physiotherapist* or physical therapist* or psychotherapist* or psychologist* or psychiatrist* or dietician* or nutritionist* or social worker*).ti,ab,kf. 614580

16 (youth worker* or transition champion* or transition coordinator* or transition co-ordinator*).ti,ab,kf. 186

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 11799493

18 exp Hospitals/ 305779

19 exp Primary Health Care/ 184156

20 Adolescent health services/ 5844

21 (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. 1733153

22 18 or 19 or 20 or 21 1905305

23 transition to adult care/ or transitional care/ 3048

24 transition*.ti,ab,kf. 484217

25 23 or 24 484546

26 17 and 22 and 25 20543

27 Perception/ 41631

28 attitude/ or "attitude of health personnel"/ or exp attitude to health/ or catastrophization/ 613115

29 (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).ti,ab,kf. 3588560

30 27 or 28 or 29 3906756

31 26 and 30 10276

32 limit 31 to (yr="2014 -Current" and "humans only (removes records about animals)") 7083

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/ or clinicians/ or mental health personnel/ 72104
11 exp Physical Therapists/ 625
12 exp Pediatricians/ 1604
13 physicians/ or family physicians/ or general practitioners/ or psychiatrists/ 42533
14 pharmacists/ or pharmacy/ 2582
15 exp patients/ 103671
16 (young person* or young people* or adolescen* or teen* or youth* or young adult* or p?ediatric* or child*).ti,ab,id. 1021091
17 patient*.ti,ab,id. 775209
18 (family or families or parent* or father* or mother* or carer* or caregiver* or care giver*).ti,ab,id. 703206
19 (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,id. 240484
20 (youth worker* or transition champion* or transition coordinator* or transition co-ordinator*).ti,ab,id. 480
21 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 2130230
22 exp hospitals/ 26703
23 exp Primary Health Care/ 20201
24 (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,id. 224017
25 22 or 23 or 24 228856
26 transition*.ti,ab,id. 84116
27 21 and 25 and 26 3916
28 exp Perception/ 458547
29 attitudes/ 29733
30 exp Health Personnel Attitudes/ or exp Health Attitudes/ 37091
31 exp Catastrophizing/ 965
32 (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).ti,ab,id. 1883939
33 28 or 29 or 30 or 31 or 32 2132644
34 27 and 33 2340
35 limit 34 to (human and yr="2014 -Current") 1250

36 exp adolescent health/ 2912
37 pediatrics/ or chronically ill children/ 29489
38 parents/ or fathers/ or mothers/ or single parents/ 94818
39 caregivers/ or child care/ 41105
40 exp Family/ 328505
41 health personnel/ 19445
42 clinicians/ 12337
43 exp Mental Health Personnel/ 55616
44 exp Nurses/ 35665
45 medical personnel/ or health personnel/ or physical therapists/ or physicians/ or clinicians/ or mental health personnel/ 72104
46 exp Physical Therapists/ 625
47 exp Pediatricians/ 1604
48 physicians/ or family physicians/ or general practitioners/ or psychiatrists/ 42533
49 pharmacists/ or pharmacy/ 2582
50 exp patients/ 103671
51 (young person* or young people* or adolescen* or teen* or youth* or young adult* or p?ediatric* or child*).ti,ab,id. 1021091
52 patient*.ti,ab,id. 775209
53 (family or families or parent* or father* or mother* or carer* or caregiver* or care giver*).ti,ab,id. 703206
54 (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,id. 240484
55 (youth worker* or transition champion* or transition coordinator* or transition co-ordinator*).ti,ab,id. 480
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 or 50 or 51 or 52 or 53 or 54 or 55 2130230
57 exp hospitals/ 26703
58 exp Primary Health Care/ 20201
59 (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,id. 224017
60 57 or 58 or 59 228856
61 transition*.ti,ab,id. 84116
62 56 and 60 and 61 3916
63 exp Perception/ 458547
64 attitudes/ 29733
65 exp Health Personnel Attitudes/ or exp Health Attitudes/ 37091
66 exp Catastrophizing/ 965
67 (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).ti,ab,id. 1883939
68 63 or 64 or 65 or 66 or 67 2132644
69 62 and 68 2340
70 limit 69 to (human and yr="2014 -Current") 1250

Web of Science 12.7.22

8
#6 AND #2 AND #3 AND #4 and **2014** or **2015** or **2016** or **2017** or **2019** or **2018** or **2020** or **2021** or **2022** (Publication Years)
6,198
Add to query

7
#6 AND #2 AND #3 AND #4
8,331
Add to query

6
#5 OR #1
11,887,744
Add to query

5
TS=(("young person*" or "young people*" or adolescen* or teen* or youth* or "young adult*" or p$ediatric* or child*))
2,858,002
Add to query

4
(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") (Topic)
7,790,995
Add to query

3
transition* (Topic)
1,954,616
Add to query

2
(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") (Topic)
1,602,881
Add to query

1
(patient*) (Topic) or **(family or families or parent* or father* or mother* or carer* or caregiver* or "care giver*")** (Topic) or **(doctor* or physician* or p$ediatrician* 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*")** (Topic) or **(nurs* or "occupational therapist*" or pharmacist* or physiotherapist* or "physical therapist*" or psychotherapist* or psychologist* or psychiatrist* or dietician* or nutritionist***

or "social worker*") (Topic) or **("youth worker*" or "transition champion*" or "transition coordinator*" or "transition co-ordinator*")** (Topic)
10,232,180

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 "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"))) 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))