# Implementing a transition pathway developed to improve services for young people with long-term conditions moving between children's and adult health care services: A Realist Evaluation

Julie Louise Feather July 2021

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

Edge Hill University

# Declaration

This thesis is entirely my own work and has not been submitted, in full, or in part, for the award of a higher degree at any other educational institution. Sections of this thesis have already been published and presented at conferences. The details of publications, reports and conference presentations are listed below:

### Publication

FEATHER, J. L., 2018. Developing programme theories as part of a realist evaluation of a healthcare quality improvement programme. *International Journal of Care Coordination* [online]. 21 (3), pp. 68-72.

#### Report

FEATHER, J., KIERNAN, J., LYNES, D., ROGERS, J., BROOK, L and KAEHNE, A., 2020. *An evaluation of the implementation of the 10-steps transition pathway to adult services at Alder Hey Children's Hospital* [online]. Available from: https://research.edgehill.ac.uk/en/publications/an-evaluation-of-the-implementation-of-the-10-steps-transition-pa [Accessed 9 May 2021].

#### Conferences

FEATHER, J, 2017. 'Implementing a transition pathway developed to improve service for young people with complex healthcare needs moving between children's and adult healthcare services: A Realist Evaluation'. Poster presented at Postgraduate Research Symposium, Edge Hill University.

FEATHER, J, 2017. 'Implementing a transition pathway developed to improve service for young people with complex healthcare needs moving between children's and adult healthcare services: A Realist Evaluation'. Poster presented at Edge Hill University's Cutting Edge Postgraduate Research Conference.

FEATHER, J, 2017. 'Implementing a transition pathway developed to improve service for young people with complex healthcare needs moving between children's and adult healthcare services: A Realist Evaluation'. Poster presented at Transforming Transition in the North West Conference, Warrington. FEATHER, J, 2017. 'Implementing a transition pathway developed to improve service for young people with complex healthcare needs moving between children's and adult healthcare services: A Realist Evaluation'. Poster presented at Public Health PGR Symposium, University of Liverpool.

FEATHER, J, 2018. 'What's in the black box?' Using realist evaluation to open the black box of programme implementation in healthcare. Oral presentation presented at Postgraduate Research Symposium, Edge Hill University.

FEATHER, J, 2019. Preliminary findings from a Realist Evaluation of the implementation of the 10 Steps Transition Pathway at Alder Hey Children's Hospital. Oral presentation presented at Transforming Transition in the North West Conference, Warrington.

FEATHER, J, 2019. Implementing a transition pathway into a Paediatric Hospital in England: A Realist Evaluation. Poster presentation presented at HSRUK 2019, University of Manchester.

FEATHER, J, 2021. An Evaluation of the implementation of the 10 Steps Transition Pathway at Alder Hey Children's NHS Foundation Trust. Oral presentation presented at Transforming Transition in the North West Conference [Online].

# Acknowledgements

I would like to express my sincerest thanks to the participants who took part in this research, taking precious time out of their busy work schedules to share their experiences of transition and implementation with me. I would specifically like to thank Jacqui Rogers and Dr Lynda Brook for all of their guidance and support. Their dedication and perseverance to improve transition practice is truly inspirational and without their contribution this research would not have been possible.

I would also like to thank my supervisory team at Edge Hill University: Dr Axel Kaehne, Dr Joann Kiernan and Dr Dave Lynes. From the very beginning of my PhD journey until the end your unwavering support has enabled me to complete this thesis. I have had a few wobbles along the way but your patience, understanding and encouragement has kept me going. I am extremely grateful to you all for providing me with valuable learning experiences and supporting my development as a researcher.

Thank you to my wonderful parents and sister Lisa for always believing in me and giving me the time to complete this thesis by providing extra childcare support.

Finally, I would like to thank my partner Neil for his endless support over the past five years. Thank you for taking good care of our daughter to allow me time to complete this thesis. You can both have me back soon.

## Dedication

I would like to dedicate this thesis to my darling daughter Phoebe Nyasha Chuma who was born halfway through this PhD research. You are and will always be my greatest achievement in life.

# Abstract

## Background and research aim

Delivering well-planned and co-ordinated transition processes for young people with long-term conditions has become a key priority for healthcare organisations. Within the existing literature transition programmes to improve this process have mostly been evaluated using outcome-based methods. This approach to evaluation fails to acknowledge the complex systems in which health transition programmes are implemented and, the agency of implementers. This study proposes an alternative approach to the evaluation of transition programmes, utilising realist evaluation to examine the processes that exist within a transition programme's implementation and identifies the contexts which influence or hinder implementation processes and outcomes.

#### Methods

The study used a single qualitative embedded case study design informed by a realist evaluation approach. Data were collected through a review of programme documentation and semi-structured interviews with programme designers and implementers. Thematic analysis and context, mechanism, outcome (CMO) analysis were used to analyse the data.

## Findings

The findings of this study suggest that the outcomes of programme implementation are influenced by the complex interaction of macro, meso and micro processes and contexts. Features of the context which facilitated the successful implementation of the transition programme included the active participation of implementers in the change process, having well-established inter-organisational social networks and fostering a collective commitment and coordinated behaviour change from professionals across children's and adult services. However, findings further highlight contextual barriers that affect implementation.

## Conclusion

Through its application of a realist evaluation framework this study identifies the role that context and human agency play in facilitating or hindering the successful implementation of transition programmes. It demonstrates how formal theories of implementation and organisational behaviour can be used to understand the processes and contexts that exist within the implementation of complex transition programmes.

## Key words

Transition programme, healthcare organisations, implementation, realist evaluation.

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# **Glossary of abbreviations**

С	Context		
CBU	Clinical Business Units		
СМО	Context Mechanism Outcome		
СМОС	Context Mechanism Outcome Configuration		
EHU	Edge Hill University		
GDPR	General Data Protection Regulations		
GTI	General Theory of Implementation		
НСР	Health Care Professional		
іт	Informational Technology		
М	Mechanism		
MDT	Multi-Disciplinary Team		
NPT	Normalisation Process Theory		
0	Outcome		
РТ	Programme Theory		
RAMESES II	Realist and Meta-narrative Evidence Synthesis: Evolving Standards		
RCT	Randomised Controlled Trial		
RIPT	Rough Initial Programme Theory		

## Preface

'Everybody seems to want to do the right thing, but there seems to be a missing link. No one seems to work together' (CQC, 2014: 10).

I first read the Care Quality Commission (CQC, 2014) report on children's transition to adult health services in 2015. At the time I was working as an adult's social worker in a community team and had secured a secondment to work as a transition coordinator across children, family and adult services. This was a new role developed as a result of the Care Act (2014) which emphasised the importance of early and comprehensive identification of young people who may require transition to adult services. My early experiences of transition as a newly qualified social worker were somewhat discouraging. It appeared to be the norm that adult services did not engage in supporting young people during their transition until just before they turned 18. However, I always felt this was too late as I had no time to develop a relationship with the young person and their family or to effectively plan with involvement from children's services. This caused much uncertainty for the young people and often resulted in delays to future care, support and placement.

Although the transition coordinator role was not clearly defined the objective of the post was to assess the transition protocols and policies that were in place within the local authority and make recommendations to senior managers of how these could be improved. To do this I worked closely with frontline social worker's across children, family and adult services asking them to share their lived experience of transition to support change. What they told me closely resonated with my experience. Social workers across children's and adult social care services were striving to ensure that young people had a successful transition to adult services. However quite often they were working in a fragmented way with a lack of joint systems in place to support them. There appeared to be a significant gap between children's and adult services and many practitioners were unaware that there was an organisational policy which informed transition. Children's practitioners reported feeling anxious about transition, not knowing when and how to refer young people to adult services. Whereas adult

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practitioner's reported feeling rushed and unable to effectively plan transition in partnership with young people.

The learning and experience acquired during this time informed my decision to apply for a PhD Studentship. In 2016, I found the ideal opportunity to undertake a piece of research which focused on improving healthcare transition practice. As a social worker, undertaking research in healthcare provided an opportunity to offer a different perspective. By speaking to a range of different healthcare professionals I have been able to consider transition practice from both a health and social care viewpoint.

In undertaking this research study, it is clear that practitioners in both health and social care face similar challenges relating to transition. The aspiration to 'do the right thing' by ensuring that young people are supported to have successful transition has always been evident. However, practitioners are frequently faced with barriers many of which are described in this study, that impact on their ability to 'work together'. The quote above refers to the missing link as being the failure of professionals to work together. However, it fails to acknowledge the systems and processes that affect collaborative working. As a social work practitioner with experience of transition practice I have always been mindful of these challenges, and to an extent this has shaped my research approach. Throughout this research I have met many incredible healthcare professionals who are passionate about transition and work tirelessly to make changes to improve transition practice. It is my hope that this thesis accurately conveys their voices in highlighting the fantastic work that they do as well as the challenges that they face.

# **Chapter 1: Introduction**

This chapter introduces the PhD study and provides important background information to the research, highlighting the context of the research and the study aims. The chapter begins by exploring the wider context of healthcare transition more generally before focusing specifically on evaluations of transition programmes in healthcare organisations. The 10 Steps Transition Pathway is then described, and a rationale is provided for using realist evaluation to evaluate the implementation of the pathway. The chapter concludes with the relevance for the research, the aim and research questions and an outline of what each chapter includes.

## **1.1 Introduction to the study**

This PhD study is a complex systems (realist) evaluation of a person-centred children and young person's transition programme. It explores how a transition programme is implemented by professionals in a paediatric healthcare organisation. Although there is a focus on healthcare transition, in particular transition programmes, this study in a broader sense also considers how organisational behaviour shapes implementation processes and decisions. It highlights transition and its challenges from an organisational perspective rather than a patient perspective. However, factors that affect transition for young people are considered within the background section of this chapter. This study is therefore aligned to organisational and implementation research and aims to contribute new knowledge to these important fields. In order to situate the study, the next section of this chapter will discuss transition within its wider context.

## **1.2 Transition in healthcare**

To set the context for the study this section of the chapter will provide important background information relating to the current context of transitional healthcare services for young people with long term conditions in the UK. Although the chapter draws mostly on literature from the UK, it recognises the impact that delayed transition has on young people globally and the challenges faced by both young people, their families and healthcare organisations worldwide. The section begins by providing a working definition of transition.

#### 1.2.1 What is healthcare transition?

Transition has been described as a:

'Purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic physical, neurodevelopmental and medical conditions as they move from child-centred to adult-oriented health-care' (Colver et al., 2019: xxi).

Transition is an all-encompassing, multi-faceted process, experienced differently by individuals based upon their life experiences and needs (Moore Hepburn et al., 2015). Transitioning from adolescence into adulthood can be a challenging time for all young people, however for those young people who have long term conditions the journey can be even more problematic due to changes in the delivery of their care (RCN, 2013; Campbell et al., 2016). During the period of adolescence young people with long term conditions further experience several different transitions which occur at the same time (CQC, 2014). These may include transition from school to college or specialist further education, transition from children's to adult social care services and transition from children's to adult health care services. As stated in the preface to this thesis, the challenges faced by young people, their families and professionals during the process of transition are applicable to service transitions which fall outside of healthcare. However, whilst recognising the multiple transitions a young person makes during this period of their lives and the challenges encountered, this study focuses on the transition of young people, aged between 14-25, with long term conditions, from children's to adult healthcare services.

# **1.2.2** Which groups are most likely to experience healthcare transition?

Young people who have a long-term condition, which is defined as 'a condition that cannot currently be cured but can be controlled with medication and/or other therapies' (Colver et al., 2019: xix), are more likely to require continuing health care upon entering adulthood. In line with Colver et al. (2019) this study uses the term young people with a 'long-term condition' to encompass the range of young people who experience healthcare transition. However, it is important to highlight that within the literature the term young people with 'complex health needs' is often used when referring to

transition. In a previous study Colver et al. (2013: 676) defined young people with complex health needs as 'those with a physical, mental or health impairment that has the potential for a substantial and long-term adverse effect on their ability to carry out day-to-day activities'. Colver et al. (2019) later argue that the term 'complex health needs' better describes a smaller cohort of young people with very complex needs whilst 'long-term condition' covers a larger patient population. The decision to use 'long-term condition' instead of 'complex health needs' was thus informed by the work of Colver et al. (2019) who uses contemporary language which is more reflective of the larger patient population. 'Long-term condition' also better reflects the health needs of the cohort of young people for whom the transition programme being evaluated was designed.

#### 1.2.3 Why is healthcare transition important?

Over the past two decades changing demographics and advances in medical care have resulted in more young people with long-term conditions surviving into adulthood (Davis et al., 2014). Consequently, as more young people enter adult healthcare systems improving the healthcare of young people is a key priority of governments in both the UK and internationally (Viner, 2008; DOH, 2008; Campbell et al., 2016; Colver et al., 2019). Health care services globally have recognised their failure to meet the demand of changing healthcare needs within this population (Campbell et al., 2016). Such failures have often resulted in delayed transitions for young people which has a significant impact on their health outcomes. Thus, the process of transition for young people with long-term conditions has been recognised and prioritised as requiring urgent improvement (DOH/DFE, 2006; DOH, 2008; Kime et al., 2013; CQC, 2014; NICE, 2016).

#### 1.2.4 What do we know about healthcare transition?

Transition occurs during the years of adolescence, which is a transitional stage resulting in rapid change physically, psychologically, emotionally and socially (Singh et al., 2010; Colver et al., 2013). For young people who additionally have ongoing health needs this period in their lives can further be compounded by difficulties associated with their long-term condition (DOH, 2008; Royal College of Physicians, 2008). Research suggests that young people who experience poor transitions

between children's and adult health care services, suffer physically, emotionally, socially and educationally in the long term (DOH/DFE, 2006; Colver et al., 2019). Furthermore, poorly planned and delivered transitions are associated with discontinuity of care (Dogba et al., 2014), risk of non-adherence to treatment (DOH/DFE, 2006), poor clinical outcomes and increased health care costs (Kime et al., 2013; Moore Hepburn et al., 2015) and negative consequences relating to morbidity and mortality (DOH/DFE, 2006). Effective transitions on the other hand, have been evidenced to lead to improved experiences and long-term outcomes (CYPHOS, 2012).

Healthcare transition is largely dependent on collaboration and joint working between paediatric and adult organisations. However, there are several factors which impact on this. Viner (2008) suggests that differences between paediatric and adult care are largely historical and adolescents have been an undervalued and neglected group. Paediatric services in the UK were historically focused on meeting the needs of infants and young children (Viner, 2008). Although, adolescents now make up a substantial proportion of the paediatric patient population, Viner (2008) argues that the training and mindset of paediatricians remains fixed on supporting young children. A similar pattern is apparent in adult services with adult health care professionals often lacking the knowledge and training required to support young people with complex, long-term health conditions (Brown et al., 2020). There is also a lack of responsibility for transition on the part of adult providers with commissioners viewing transition to be the responsibility of paediatric providers (Colver et al., 2019).

Paediatric and adult organisations further adopt different models and approaches to patient care which can create barriers to transition. These different approaches are displayed in figure 1 below. Paediatric services have been described as child and family centred (Kime et al., 2013; Brown et al., 2020) and developmentally focused (Allen et al., 2010), whilst adult services focus more on the individual and their condition (Brown et al., 2020) and promote autonomous decision making (RCPE, 2008). The ethos of independence that underpins adult services can be intimidating for young people and their parents who have always played an active role in decision making (Allen et al., 2010). Tysbina et al. (2012) argue that paediatric services need to do more to prepare young people for the move to adult services by supporting them

to develop self-advocacy and self-determination skills. Inadequate preparation and poor, inconsistent information provided by paediatric professionals to young people and their families can result in a lack of understanding about the transition process and increased anxiety (CQC, 2014; Zhou et al., 2016).



Figure 1: Different approaches to paediatric and adult patient care (Source: Brown et al., 2020: 7).

The paternalistic, family-centred culture of paediatric services and the close relationships developed between young people, their parents and paediatric professionals can create feelings of 'reluctance to let go' for all parties during the process of transition (Allen et al., 2010; CQC, 2014; Together for Short Lives, 2015; Coyne et al., 2017). There is also a distrust of adult services (Allen et al., 2010) based on differences in care provision, a potential decline in care quality (Coyne et al., 2017) and concerns expressed by paediatric professionals as well as parents regarding the appropriateness of adult services (Campbell et al., 2016; Zhou et al., 2016). A recent report by Brown et al. found that 'parents commonly viewed transition as a loss of the entire professional support network... and emotional support from professionals who

had known their family for many years' (Brown et al, 2020: 15). Parental concerns about transition are further influenced by a lack of equivalent adult services and strict eligibility criteria (Colver et al., 2019). A lack of co-ordination and management of transition further creates feelings of uncertainty and anxiety for young people and their parents (CQC, 2014; Campbell et al., 2016; Brown et al., 2020).

#### 1.2.5 What should healthcare transition involve?

In response to the increasing focus on improving healthcare services for young people with long-term conditions, several UK reports and policies stipulate standards of best practice for transition services (DOH/DFE, 2006; DOH, 2008; DOH, 2011; CQC, 2014; NICE, 2016). However, Colver et al. (2019) argue that despite guidance from the government and NICE on how to improve transition there has been limited support from commissioners and healthcare providers due to a lack of evidence underpinning the guidance. Coyne et al. (2017: 17) suggest that guidelines are 'based on expert clinical experience and a best practice approach rather than strong evidence from empirical studies'. Nevertheless, healthcare providers nationally have started to develop transition programmes based on good practice guidance. However, it is still unclear as to whether these transition programmes are successful and there is still no universal 'model or template for how transition should be implemented' (Kime et al., 2013: 4).

The main guidance documents on transition similarly emphasise the importance of several key principles which should inform transition programmes (Brown et al., 2020). These key principles are displayed in table 1.1 below.

Table 1.1 Key principles of transition



More recently, the NHS Long Term Plan (2019) emphasises the importance of transition to adult services being driven by need rather than age and discusses a move to a '0-25 years' service.

# **1.3 Implementing and evaluating transition programmes in healthcare**

The first section of this chapter discussed healthcare transition generally highlighting some of the challenges experienced by young people, their families and healthcare organisations. The subsequent sections will focus specifically on evaluations of transition programmes in healthcare organisations to further situate the study within the existing evidence base. Whilst transition guidance provides best practice recommendations on what good transition should involve, there remains a lack of formal evaluation of implementation of the guidance and outcomes of transition programmes (QNI, 2017). As will be demonstrated in Chapter 2, studies which attempt to evaluate the effectiveness of transition programmes have failed to establish a sufficient evidence base (Allen et al., 2010; Crowley et al., 2011; Chu et al., 2015; Campbell et al., 2016). Evidence relating to the successful implementation of transition programmes is also lacking, with few studies taking into consideration how implementation affects the success or failure of transition programmes. Nevertheless, Viner (2008) argues that it is critical for healthcare providers to start to make positive changes to improve transition processes and they need not wait for rigorous evaluation evidence before doing so. Transition guidance and research points to several beneficial features of transition services, with some evidence to suggest an improvement in health outcomes (Colver et al., 2018). These features have been collated from published research and are presented in table 1.2 below.

Table 1.2 Main features of transition programmes

#### Main features of transition programmes

- Education programmes to promote health self-efficacy.
- Written transition plans.
- Age-specific transition clinics.
- Joint-transition clinics between paediatric and adult services.
- Appropriate parental involvement.
- Holistic life-skills training.
- Key worker/transition co-ordinator.

(Sources: DOH/DFE, 2006; DOH, 2008; Allen et al., 2010; Crowley et al., 2011; Lewis and Noyes, 2013; Huang et al., 2014; Wafa and Nakhla, 2015; Campbell et al., 2016; NICE, 2016; Colver et al., 2018).

However, a recent study by Colver et al. (2018) highlighted a gap between what health services say they provide and what is experienced by young people themselves. They found that services often reported delivering beneficial features of transition to young people, such as written transition plans, whilst the implementation data from young people suggested otherwise (Colver et al., 2018).

### **1.4 The 10 Steps Transition Pathway to Adult Services**

Despite a lack of rigorous evaluation evidence to support the implementation and outcomes of transition guidance, organisations have used national good practice guidance and standards to inform the development of their own quality improvement programmes. One of these quality improvement programmes is based at Alder Hey Children's NHS Foundation Trust, which is a National Children's Hospital and NHS Trust in the UK. Alder Hey Children's NHS Foundation Trust, which is a National Children's Hospital and NHS Alder Hey Children, young people and their families every year' (Rogers, Brooks, Aizelwood & Kaehne, 2019: 2).

Over the past few decades, much work has been done by professionals at Alder Hey to develop and provide good transitional care services, with cystic fibrosis in particular being recognised as an exemplar (Rogers & Brook, 2017; Rogers et al., 2019). More recently, since 2014 Alder Hey Children's NHS Foundation Trust has embarked on a journey to improve the process of transition for young people with long-term health conditions moving between children's and adult services. This work stemmed from a Care Quality Commission (CQC) inspection undertaken in May 2014 which identified the need for improvement to transitional services at Alder Hey (CQC, 2014). Whilst recognition was given to transition arrangements in specific specialties, a lack of leadership and responsibility for overall transitional care services was raised as a concern and recommendations were made to improve transitional services (CQC, 2014; Rogers & Brook, 2017; Rogers et al., 2019).

This led to the development of the 10 Steps Transition Pathway (Figure 2), which is a multi-disciplinary, collaborative pathway consisting of multiple interventions aimed at both supporting and facilitating transition for young people, their parents and carers and professionals in both children's and adult healthcare services. The pathway

incorporates key standards of good practice in transition services (DOH, 2008; NICE, 2016), and aims to standardise transition practice across the trust, improving the process of transition for young people and their families and leading to improved long-term health outcomes. The 10 Steps Transition Pathway was developed alongside a trust transition policy through a detailed literature review and trust wide consultation and engagement with young people, parents and professionals during 2015 (Rogers and Brook, 2017; Rogers et al., 2019). Programme designers consulted young people, parents and professionals through a one-day workshop which used focus groups and the world café model to explore key aspects of transition (Rogers and Brook, 2017; Rogers et al., 2019). This was followed by a series of 17 roadshows with staff across the trust to further explore issues and concerns regarding transition (Rogers et al., 2019). Programme designers wanted to 'develop a simple, generic transition pathway, based on best practice evidence, flexible enough to be able to support highly complex patients but simple and clear enough to be equally applicable for more simple transitions' (Rogers and Brook, 2017: 2).



Figure 2 The 10 Steps Transition Pathway to Adult Services (Source: Rogers and Brook, 2017: 2).

The 10 Steps Transition Pathway incorporates some of the main features of transition programmes as highlighted in good-practice guidance. Key components of the pathway include transition education and preparation, a written transition plan, multidisciplinary team working, identification of a keyworker to co-ordinate transition and joint transition reviews between children's and adult services. Specific details of what each step involves are provided in figure 3 below.

Steps 1 to 10	Suggested Action	Expectations
Steps 1 & 2: Recognising the need to move on & empower the young person through support and guidance.	To have a dedicated person in both children's and adult services to assist with transition. To identify a lead to communicate with and coordinate all specialities to ensure transition happens. For the 10-step pathway to be mandatory, and provide Trust Transition preparation programme training to support implementation of this, also to consider Young person's clinics.	It was identified that the family and YP should be confident in transition, not fearful and that the quality of care is maintained. Also, a % of all 14+ year olds with a long-term condition to commence the transition preparation programme, and that a % of all 14+ year olds with a long-term condition have a keyworker. Lastly, that a % of adult and paediatric trusts who will have an identified lead for Learning disabilities and transition.
Step 3: Start transition plan.	That a Lead consultant identified with time and commitment, and a Keyworker should be identified. (Model 1 – dedicated keyworker role from a team of keyworkers. Model 2 – keyworker is professional already involved with family but with dedicated time allocated for transition).	It was identified that a number of Trusts would be signed up and committed to the transition pathway. That a % of inappropriate Alder Hey admissions would reduce, feedback from families was also suggested.
Step 4: Review circle of support.	That a lead consultant identified with time and commitment, also that a Keyworker is identified. (Model 1 – dedicated keyworker role from a team of keyworkers. Model 2 – keyworker is professional already involved with family but with dedicated time allocated for transition).	In order to achieve these consultants would need to have additional allocated PA's in job plans, and therefore there should be an increase in the % of YP with an identified keyworker and an increase in % of YP with a personalised transition plan.
Step 5: Refer on to lead adult medical service.	There needs to be improved communication between adult and paediatric services e.g. adults writing to say they have received referral and are taking over YP's care. During the transition preparation process the differences	Positive feedback from families is a measure of a good quality service and patient journey, feedback also from professionals around

	between paediatric and adult services will need to be acknowledged, discussed and addressed with families, the process should be gradual, so the family and professionals are confident and ready to say goodbye to children's services. Joint funded posts between paediatrics and adult services were identified to be a solution to improve communication and the transition process, and the possibility of a transition hub was highlighted. Identification of staff to take on the role of transition champions within adult and paediatric trusts were considered to be an important role, and lastly which was considered very important was a "One stop shop" clinic model for complex patients.	confidence in transition would be a firm indicator. The % of GP's getting patients to FUP and taking it. A % of staff trained in appropriate communication techniques and strategies with adolescents was an important outcome measure, and the feeling of joint working between children's to adult services with no avoidable complications.
Steps 6 & 9: Joint clinics in children's services & joint clinics in adult services.	A defined end point is needed, with robust forward planning and clear criteria – system for flagging up patients for transition. Joint clinics with attendance from lead consultants and keyworkers from adult and paediatric were also considered to be good solutions, with of course increased GP involvement.	Positive feedback from families is a measure of a good positive outcome, as well as feedback from professionals – satisfaction of a job well done. The number of joint clinics successfully held and attended, including Measurable data in terms of age of attendance at joint transition clinics for individual patients. A concrete measurable data set of the age of transition and the number of YP over the age of 18 who still attend Alder Hey is a sure measure of success.
Step 7: Identify a route into urgent care.	To empower the GP and community service by having strategies in place to escalate care if needed. An adolescent link person in AED with the option of an orientation visit to adult AED	A number of potential A&E admissions managed in the community or a dedicated adolescent unit, and a measurement of the number of calls made to out of hours contact.

	for the YP. Out of hours contact numbers for advice was highlighted as key to success and for information to be shared and visible in adult and paediatrics with shared care plans for patients and community teams. Again, a measure of feedback from patients and families was discussed.	Again, patient feedback was also recognised as a good measure.
Step 8: Young person (16+ years) confident to move to adult services.	Holding focus groups to ascertain YP's wishes, and exploring and managing the expectations for the YP and their family, also acknowledging that staff members need appropriate skillset to deal with YP in adult setting – specialist adolescent wing was discussed and to include GP's empowering them to support families.	Outcomes should be measured using a formal transition tool similar to AQUA's "Bridging the Gap" or "Ready Steady Go".
Step 10: Young person (18+ years) confident in adult services.	The service should be age appropriate and YP should be well prepared on what to expect. YP should have a keyworker to troubleshoot any problems the YP might encounter, and their Transition should be flexible and individualised. Communications and regular updates from MDT's so professionals are kept aware of how things are progressing was identified as much needed and it was acknowledged that services should embrace technology to support transition e.g. Facebook, transition APPs etc.	It was identified that more joined up working between specialities and services were required and the need for feedback from professionals – ownership by both sides was highlighted. Feedback from patients and families was considered a good outcome measure. As is the number of patients over the age of 18 years still accessing services at Alder Hey.

Figure 3 Break down of the 10 Steps Transition Pathway (Source: Rogers et al., 2019: 7).

Implementation of the 10 Steps Transition Pathway commenced in 2016. The transition team which consists of a Trust Clinical Lead for Transition and a Trust Transition Service Nurse Lead, adopted a phased approach to implementation of the 10 Steps Transition Pathway with early implementation efforts being initially focussed to four identified specialities within the trust. In the first twelve months, the transition team worked with Clinical Business Units (CBU) transition leads and transition champions to facilitate implementation. Implementation was then extended with the support of the transition team and transition champions to additional specialities within the trust between 2017-2019. Implementation of the 10 Steps Transition Pathway was monitored by the trust transition steering group chaired by the Medical Director and Executive Lead for Transition (Brook and Rogers, 2020).

This is the first study to undertake an independent evaluation of the 10 Steps Transition Pathway. The study aimed to investigate how the 10 Steps Transition Pathway was being implemented by healthcare professionals across Alder Hey Children's NHS Foundation Trust.

#### **1.5 Realist Evaluation**

In considering the best approach to evaluate the implementation of the 10 Steps Transition Pathway, it was important to examine the existing evidence base for empirical evaluations of healthcare transition programmes. Chapter 2 explores this in detail. It highlights how theory-driven evaluations may be a more appropriate fit due to limited knowledge on the role that implementation processes and contexts play in determining the success or failure of transition programmes. To examine the processes that existed within the 10 Steps Transition Pathway's implementation and the contexts which influenced or hindered implementation processes and outcomes, the study employed a realist evaluation framework.

Realist evaluation is a theory-driven approach, which seeks to understand and explain how and why complex programmes work, for whom and in what contexts (Astbury, 2013; Wong et al., 2017). It stems from the work of Pawson and Tilley (1997) who argue that programmes themselves do not produce change (outcomes), rather it is the reasoning of stakeholders to the resources offered by the programme (mechanisms) and the appropriateness of social and cultural conditions (contexts). Realist evaluation recognises the role that human agency plays in determining the success or failure of programme implementation. Implementation of the 10 Steps Transition Pathway was dependent on how healthcare professionals reasoned with the resources offered by the pathway which would then influence the outcomes of implementation. Implementation of the transition pathway was further context-dependent, and the evaluation would need to understand how contextual features affected implementation processes. Realist evaluation allowed an exploration of these important factors and was thus regarded to be a suitable evaluation framework to guide the study design. Chapter 3 provides an overview of the underlying assumptions of realist evaluation which informed the design of the study.

#### **1.6 Research rationale**

Ensuring that young people with long-term conditions experience a positive transition and continue to access adequate healthcare provision upon entering adult services is a key priority for healthcare organisations. Although national guidance has highlighted guiding principles for transition and recommended some important features of transition programmes, these are largely based on best practice. Whilst there remains a paucity of formal evaluations of transition programmes and their implementation, studies which do formally evaluate transition programmes are mostly outcomefocused and fail to acknowledge the agency of implementers and participants and the context of programme implementation (Moore et al., 2015). This study uses realist evaluation to examine the processes and contexts within the pathway's implementation and their relationships to implementation outcomes. It seeks to address identified gaps within the transition programme research evidence by providing important insight into how and why implementation processes and contexts affect the success or failure of transition programmes. In doing so, it adds new knowledge and insight into the processes and contexts through which transition programmes function and offers a broader understanding of organisational behaviour and how it affects programme implementation.

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### 1.7 Study aim and research questions

To advance knowledge and understanding of transition programme implementation specifically, and healthcare programme implementation more generally, this research aims to examine the processes that exist within the 10-step transition pathway's implementation and the contexts which influence or hinder implementation processes and outcomes. It seeks to answer the main research question:

To what extent do implementation processes and contexts affect the success or failure of transition programmes?

The main research question will be answered by focusing on the following research sub-questions:

1. What are the contexts, mechanisms and outcomes that exist within the programme's implementation?

2. How do contexts influence or hinder implementation mechanisms and outcomes?

3. How does organisational behaviour affect programme implementation?

4. How useful is realist evaluation as a framework to evaluate programme implementation?

## **1.8 Thesis outline**

The thesis is structured around seven individual chapters which are described below:

#### **Chapter 1: Introduction**

The introduction provides the background to the study, including an overview of the current context of healthcare transition and introductions to the 10 Steps Transition Pathway and how this was evaluated using a realist evaluation framework. A rationale for the study is provided alongside the study aim and research questions. The chapter concludes with an outline of the overall thesis.

# Chapter 2: A narrative literature review of current health transition programme evaluations

This chapter provides a narrative overview and synthesis of the existing literature on evaluations of transition programmes in healthcare. The literature review describes and summarises current knowledge relating to evaluations of healthcare transition programmes, and highlights gaps in the existing evidence base. These are used to inform the research aim and questions which are presented at the end of this chapter.

#### **Chapter 3: Methodology**

This chapter describes the different ways in which evaluation can be approached and the philosophical assumptions underpinning different evaluation frameworks. The rationale for choosing critical realism and realist evaluation as an evaluation framework is provided. A critical account of the key tenets of critical realism and realist evaluation is considered, alongside a description of how they shaped the study design.

#### Chapter 4: Methods

The methods chapter describes the stages of realist evaluation and how these supported the study. The chapter discusses the overall research design, approach to sampling, recruitment, data collection methods, data analysis and ethical considerations.

#### **Chapter 5: Findings**

This chapter presents the findings from the realist evaluation of the implementation of the 10 Steps Transition Pathway.

#### **Chapter 6: Discussion**

This chapter situates the findings that are discussed in Chapter 5 within the wider field of theory and literature on transition and programme implementation. It provides a conceptual framework of the transition pathway's implementation which is used to inform Chapter 7.

#### **Chapter 7: Conclusions and recommendations**

The final chapter summarises the research and describes how the research contributes to new knowledge. A reflection on the methodological approach is provided. The strengths and limitations of the study are discussed and recommendations for practice, policy and future research are outlined.
## **1.9 Conclusion**

This chapter outlines the current state of healthcare transition, summarising the evidence on what healthcare transition means, who it affects, why it is important and what is necessary to make transition successful. The 10 Steps Transition Pathway has been introduced and the evaluation framework utilised to evaluate its implementation has been described. The chapter highlights the paucity of formal evaluations of transition programmes and their implementation, providing a rationale for the research. The study aim and research questions have been highlighted and an outline for each chapter within the thesis given. The next chapter of this thesis will examine in more detail the existing evidence base for evaluations of transition programmes in healthcare.

# Chapter 2: A narrative literature review of current health transition programme evaluations

### 2.1 Introduction

This chapter provides a narrative overview and synthesis of the existing literature on evaluations of transition programmes in healthcare. The main purpose of this literature review is to highlight what is currently known about transition programmes and to identify gaps in the existing knowledge and evidence base relating to evaluations of healthcare transition programmes.

This chapter begins with a description of the search strategy applied to identify and retrieve relevant literature on evaluations of healthcare transition programmes. The chapter is structured according to three overarching themes identified through the literature review and analysis: multi-factorial transition interventions in healthcare, multiplicity of outcome measures and complexity of health transition programme evaluations. The first two themes highlight the diversity and variation of transition interventions and outcome measures evaluated across studies, which have had a significant impact on determining the overall effectiveness of transition programmes. The complex nature of multi-component transition programmes and difficulties associated with evaluating such complex programmes using traditional evaluation methods will be discussed throughout theme three. Studies using realist evaluation approaches will then be explored to identify and understand the value of applying a realist framework to the evaluation of complex transition programmes. The chapter concludes with the study research aim and questions which were informed by findings from this review.

## 2.2 Narrative literature reviews

Narrative literature reviews are commonly used in healthcare research to identify and summarise the knowledge relating to a certain topic, highlight gaps in the evidence and thus provide a justification for the undertaking of new empirical research (Ferrari, 2015; Noble and Smith, 2018). In contrast to systematic literature reviews which apply rigorous methods to reviewing the literature, narrative literature reviews are considered to be more selective with the materials included in the review (Cronin et

al., 2008). The primary purpose of a narrative literature review is to present a broad perspective on a specific topic (Noble and Smith, 2018) rather than answer a formulated research question (Cronin et al., 2008). The decision to undertake a narrative literature review fits with the aims of the review which were to:

- Describe and summarise what is currently known about healthcare transition programmes and;
- Review existing evaluations of healthcare transition programmes to identify any gaps or inconsistencies in the evidence base

The next section of this chapter describes the approach taken to searching the literature on evaluations of healthcare transition programmes.

## 2.3 Literature search strategy

During the period dating April 2017 to March 2021 a systematic search strategy was applied to identify and retrieve the most relevant studies carried out which related to evaluations of healthcare transition programmes. A PICO (population, intervention, comparator, outcome) table was used to focus the literature search (see table 2.1).

Population	Young people with any long-term condition
Intervention	Formal evaluation of healthcare transition programmes
Comparator	Descriptions of healthcare transition programmes
Outcome	Process and outcome transition measures

Table 2.1 PICO table

Subject specific databases were searched online including Cinahl Complete via EBSCO Host (inclusive of Medline and Psychinfo), Pub med via NCBI and Cochrane Database of Systematic Reviews. These databases were chosen as they related specifically to the area of health and nursing and contained the largest variety of journals. Search terms included: transition OR transfer AND paediatric OR pediatric

OR children AND adolescent OR "young adult" AND evaluation AND program OR programme OR pathway OR intervention. Both British and American spellings were included in the search in addition to wildcards (\*) which were applied to ensure the inclusion of alternate word endings. Grey literature was also searched via Google Scholar as well as hand searches of reference lists for included articles.

Inclusion and exclusion criteria were applied to ensure the relevance of articles to the review aims, as displayed in table 2.2. The decision to limit the search to health service transitions for young people aged 14-25 was informed by national guidance which stipulates that transition planning should begin at age 14 and continue into young adulthood (up to age 25) (DOH, 2006; DOH, 2008; CQC, 2014; NICE, 2016). Abstracts and full-text articles were initially screened by one reviewer, however decisions to include/exclude articles were discussed with the supervisory team as part of regular supervision. The process and results of the literature search are displayed in figure 4 using the PRISMA flow diagram as a guide (Moher et al., 2009). After reviewing 57 full text articles and assessing them against the inclusion/exclusion criteria a total of 32 articles were identified as meeting the inclusion criteria for this literature review. Details of the 32 included articles are presented in Appendix A.

Inclusion criteria	Exclusion criteria
Health services transition only	Other service transitions
Formal evaluation of a transition programme	Description of a transition programme
Transitions during the period of adolescence/young adulthood (14-25 years)	Transitions during different age periods
English language only	Written language other than English
Published within the last 10 years	Published prior to 2010
Any long-term condition	
Studies focusing on process and outcome transition measures	

Table 2.2: Inclusion and exclusion criteria for literature search



Figure 4: Flow chart of literature selection using PRISMA flow diagram as a guide (Source: Moher et al., 2009).

A separate search was carried out to identify empirical research that had applied realist methods of evaluation to evaluate complex healthcare programmes. The same databases and strategies were applied, however the key terms differed. Search terms included 'realist evaluation\*', 'complex\*', 'program\*' and 'health\*'. English language only inclusion criteria was applied. Abstracts were reviewed to determine the relevancy of the papers to the literature review. A total of 4 papers were included. An additional 8 papers were identified through hand searching reference lists and in discussion with the Centre for Advancement in Realist Evaluation.

Papers were critically appraised to determine their value and relevance to the narrative of the literature review. Similar themes emerging from the literature were grouped together to form overarching categories. This resulted in the identification of three overarching categories:

- Multi-factorial transition interventions in healthcare
- Multiplicity of outcome measures
- Complexity of health transition programme evaluations

## 2.4 Multi-factorial transition interventions in healthcare

A review of the literature on transition programme evaluations revealed the wide range and diversity of transition intervention types delivered within health care settings. Systematic reviews conducted by Crowley et al. (2011), Prior et al. (2014), Chu et al. (2015) and Campbell et al. (2016) were all unable to directly compare study data due to the heterogeneity of interventions and different approaches employed when measuring outcomes. Interventions evaluated varied significantly across empirical studies with the majority evaluating a number of different intervention types simultaneously (Chaudhry, Keaton and Nasr, 2013; Dogba et al., 2014; McManus et al., 2015; Nieboer et al., 2014; Okumura et al., 2014; Gravelle et al., 2015; Jensen et al., 2015; Sequeira et al., 2015).

Whilst intervention types varied greatly, the pattern emerging from the literature highlighted three different categories of intervention. These categories can be classified according to their intended target and include education based interventions directed at young people receiving transition services, the use of transition co-

ordinators, keyworkers and joint transition clinics between children's and adult services directed at healthcare professionals, and transition pathways and age specific clinics directed at the organisation of care (Crowley et al., 2011; Kingsnorth et al., 2011; Nieboer et al., 2014; Prior et al., 2014; Chu et al., 2015; Campbell et al., 2016; Zhou et al., 2016). The next part of this literature review will thus discuss the most common types of transition interventions as identified from the literature, highlighting the heterogeneity of interventions, and will debate why existing evaluations of transition interventions have so far failed to establish a sufficient evidence base (Allen et al., 2010; Crowley et al., 2011; Chu et al., 2015; Campbell et al., 2016).

#### 2.4.1 Interventions aimed at the young person

#### 2.4.1.1 Education programmes

The use of patient education programmes aimed to improve individual's knowledge of their condition and knowledge of adult health services in preparation for transition was one of the most commonly used interventions in evaluation studies (Betz, Smith and Macias, 2010; Crowley et al., 2011; Huang et al., 2014; Okumura et al., 2014; Gravelle et al., 2014; Davis et al., 2014; Sequeira et al., 2015; Wafa and Nakhla, 2015; Campbell et al., 2016; Gabriel et al., 2017).

One study evaluated a generic technology-based education programme using a randomised controlled trial (RCT) design (Huang et al., 2014). This study found significant improvements in disease and health knowledge for treatment group participants post intervention at two- and eight-month intervals compared to control group participants (Huang et al., 2014). Evidence for the effectiveness of disease-specific patient education programmes were found in two systematic reviews carried out by Crowley et al. (2011) and Campbell et al. (2016) and a further literature review carried out by Wafa and Nakhla (2015). Campbell et al. (2016) found in three out of four included studies, that education programmes designed to support individuals with diabetes mellitus resulted in slight improvements in transitional readiness. Crowley et al. (2011) similarly found that in four out of ten included studies, disease specific education programs improved patient's knowledge and self-management of their conditions. These findings are supported by Wafa and Nakhla (2015) who reported improvements to diabetes management knowledge following a structured transition

programme in one study. However, statistically significant differences were found in only one of several measurable outcomes within six out of ten studies included by Crowley et al. (2011), all of which were condition specific measures of HbA1c found in patients with diabetes mellitus. Therefore, although these studies identified slight improvements in two measurable outcomes the overall effectiveness of educational programmes reviewed within these studies could not be assessed.

In addition, a RCT carried out by Betz et al. (2010), a retrospective evaluation by Gravelle et al. (2014), a cross-sectional study by Okumura et al. (2014) and a case control study by Sequeira et al. (2015) evaluated disease specific education programmes targeted at young people with spina bifida, cystic fibrosis and diabetes. Whilst authors suggested that interventions were well received by participants none of these studies found statistically significant improvements in measurable outcomes for young people post intervention. The evidence for the effectiveness of patient education programmes appears to be limited. Most studies have tested specific conditions with results showing only slight improvements in transitional readiness and disease specific measures. Allen et al. (2010) conclude that an insufficient evidence base for the overall effectiveness of education programmes makes it impossible to recommend the implementation of a specific model.

### 2.4.2 Interventions aimed at staff

#### 2.4.2.1 Transition co-ordinators

Transition co-ordinators/key workers and joint transition clinics between paediatric and adult services were the two most common types of staff interventions evaluated in the literature. 12 studies in total evaluated the use of transition co-ordinators/key workers (Allen et al., 2010; Crowley et al., 2011; Kingsnorth et al., 2011; Chaudhry et al., 2013; Dogba et al., 2014; Steinbeck et al., 2014; Chu et al., 2015; Egan, Corrigan and Shurpin, 2015; Jensen et al., 2015; McManus et al., 2015; Sequeira et al., 2015; Wafa and Nakhla, 2015) and eight studies evaluated the use of joint transition clinics (Allen et al., 2010; Crowley et al., 2011; Chaudhry et al., 2013; Lewis and Noyes, 2013; Shaw et al., 2013; Gravelle et al., 2015; Stringer et al., 2015; Wafa and Nakhla, 2015).

A systematic review carried out by Crowley et al. (2011) found that transition coordinators were used in three out of ten included studies, however only two of these studies were shown to be successful in improving outcomes and these results could not be attributed to the use of a transition co-ordinator due to the multiple interventions evaluated within these studies. Similarly, a systematic review carried out by Chu et al. (2015) found in all five included studies that interventions incorporated nurse case managers, care co-ordinators and lead physicians. However, increased rates of transfer could not be causally attributed to the use of keyworkers as programme designs encompassed multiple components of interventions (Chu et al., 2015). Similar findings were highlighted in five additional studies which each evaluated the use of transition co-ordinators simultaneously to other intervention types, thus failing to demonstrate what part of the overall programme led to improved outcomes (Chaudhry et al., 2013; Dogba et al., 2014; Egan et al., 2015; McManus et al., 2015; Sequeira et al., 2015). However, it is important to acknowledge that programme components may be difficult to disentangle, and it may not be possible to determine which component led to which outcome as components may only work to produce outcomes in the context of the whole programme (Moore et al., 2015).

A pilot RCT study carried out by Steinbeck et al. (2014) which evaluated a diabetes transition programme consisting of a trial transition co-ordinator and standardised telephone communication support over a 12-month period found no significant difference in rates of transfer between treatment and control groups. Only one case-control study carried out by Jensen et al. (2015) individually evaluated the effectiveness of a social worker as transition co-ordinator in a paediatric rheumatology clinic in America. Although Jensen et al. (2015) found increased rates of satisfaction and transfer for young people exposed to this intervention, results of the study were not statistically significant and could not be generalised to other settings and populations due to the small sample, the non-validated questionnaire used to assess satisfaction, the narrow definition of transfer and lack of information for control group participants (Jensen et al., 2015).

Despite a lack of statistically significant findings for the overall effectiveness of transition co-ordinators, the importance of this specific role to building and maintaining relationships with patients, working in partnership and improving continuity for young

people moving into adult services were highlighted in a mixed method study by Allen et al. (2010) and a qualitative study by Kingsnorth et al. (2011). However, Allen et al. (2010) suggest that depending on a single individual such as a transition co-ordinator to facilitate service transitions for young people is unrealistic. This argument is supported by a scoping review carried out by Watson et al. (2011) who found that there was an over-reliance on single transition co-ordinators and transition champions across services. They found that these individuals were responsible for the implementation of transition services and questioned the sustainability of services if such individuals were to leave their positions (Watson et al., 2011).

#### 2.4.2.2 Joint transition clinics

Evidence for the effectiveness of jointly facilitated transition clinics were found in a mixed method study by Allen et al. (2010), a systematic review by Crowley et al. (2011), a qualitative comparative embedded case study by Lewis and Noyes (2013) and a literature review by Wafa and Nakhla (2015). However, whereas Lewis and Noyes (2013) identified multi-disciplinary working as being the most effective component of transition clinics, Allen et al. (2010) suggested that young people in their study preferred simple consultations over multi-disciplinary clinics due to experiences of confusion when attending such clinics. Both studies also found evidence of young people and parents disengaging when joint clinics failed to involve young people's perspectives (Lewis and Noyes, 2014), and when careful consideration was not given to the accessibility of joint clinics for young people and their families (Allen et al. 2010). To draw conclusions from these studies is problematic due to the variation in the composition of transition clinics and the limited number of evaluation studies carried out within specific settings for specific conditions. Definitions of transition clinics were further inconsistent and varied greatly across different studies. Shaw et al. (2013) found that 21% of clinics in one UK paediatric and neighbouring adult hospital defined a joint clinic as point of handover. Similarly, both Allen et al. (2010) and Lewis and Noyes (2013) distinguished between the use of 'single, handover clinics' which predominantly focused on 'transfer' and jointly facilitated clinics which were attended by both children's and adult professionals and occurred over a period of time.

A case-control study carried out by Chaudhry et al. (2013) and a retrospective evaluation by Gravelle et al. (2015) evaluated condition specific joint transition clinics as part of a wider programme evaluation. Measuring patient satisfaction pre-and-post intervention using a comparison group, Chaudhry et al. (2013) reported a statistically significant difference in patient satisfaction following a structured transition programme for intervention group participants. Gravelle et al. (2015) also reported an improvement in patient knowledge for young adults with cystic fibrosis following a pre-graduation workshop which incorporated the use of a joint transition clinic. However, these findings were not statistically significant. A case report study carried out by Stringer et al. (2015) reported improved patient satisfaction post transition clinic intervention, however these findings were similarly not statistically significant. All of these studies were limited by small sample sizes, use of non-validated measurement instruments, limited long term follow up and a lack of control group in two out of three studies (Gravelle et al., 2015; Stringer et al., 2015).

#### 2.4.3 Interventions aimed at the organisation of care

#### 2.4.3.1 Age specific transition clinics

Five studies in total evaluated interventions that targeted service delivery and the organisation of care (Allen et al., 2010; Crowley et al., 2011; Price et al., 2011; Gravelle et al., 2015; Walter et al., 2018). The use of age specific transition clinics were evaluated in a systematic review carried out by Crowley et al. (2011) and a mixed method study carried out by Allen et al. (2010). Crowley et al. (2011) found that improved outcomes were associated with specific young adult clinics in three out of four studies, whilst Allen et al. (2010) highlighted the importance that simultaneous adolescent and young adult clinics facilitated longitudinal continuity between services. However, Allen et al. (2010) further identified failures in the delivery of age specific clinics to fully prepare young people for the move to adult services. Poor delivery of the processes involved as part of age specific clinics were identified by participants as having a negative impact on their experiences (Allen et al., 2010). These included standardised transition clinics which failed to address individual need, lack of ageappropriate consultation styles and poor interpersonal skills of staff delivering the intervention (Allen et al., 2010). This finding highlights the role that individual staff members play in facilitating and delivering effective transition services, which is

supported by similar findings taken from a qualitative study by Kingsnorth et al. (2011) and a scoping review by Watson et al. (2011).

#### 2.4.3.2 Transition pathways and processes

Transition pathways and structured healthcare transition processes were described in four separate studies (Price et al., 2011; Gravelle et al., 2015; Walter et al., 2018; Jones et al., 2019). However, only three of these studies reported findings relating to the effectiveness of these intervention types (Price et al., 2011; Gravelle et al., 2015; Walter et al., 2018). A qualitative study carried out by Price et al. (2011) evaluated a transition pathway which consisted of four separate sessions delivered to young people in their final year in paediatric diabetes services in one UK hospital. Their findings suggest that young people did not differentiate between sessions delivered as part of the transition pathway and normal clinical sessions delivered as part of routine care (Price et al., 2011). A cross-sectional observational study by Walter et al. (2018) evaluated a clinical transition pathway, for young people with juvenile-onset rheumatic and musculoskeletal diseases, which was made up of several different elements with the main focus being on use of an individual transition plan. They reported high patient satisfaction and self-efficacy scores following transfer to an adolescent or adult clinic. Additionally, Gravelle et al. (2015) retrospectively evaluated a generic transition clinical care pathway (TCCP) implemented in a paediatric hospital in Canada. Due to low sample size, statistical analysis was not performed and findings could not be generalised. However, the authors reported difficulties with implementing a generic transition pathway for young people with complex cystic fibrosis conditions, resulting in the development of a disease specific transition pathway (Gravelle et al., 2015). An evaluation of the disease specific pathway is yet to be carried out, and findings about the effectiveness of transition pathways therefore remain limited at this time.

#### 2.4.4 Disease specific versus generic transition interventions

Diabetes specific transition interventions appeared to be evaluated most frequently. Systematic reviews carried out by Crowley et al. (2011), Davis et al. (2014), Prior et al. (2014), Chu et al. (2015), Campbell et al. (2016) and Gabriel et al. (2017) and a literature review carried out by Wafa and Nakhla (2015) reported 36 studies involving

the evaluation of diabetes specific transition interventions. An additional six studies included in this literature review evaluated diabetes specific interventions (Allen et al., 2010; Price et al., 2011; Steinbeck et al., 2014; Egan et al., 2015; Sequeira et al., 2015; Little et al., 2017). Rheumatology specific transition interventions were evaluated in three studies (Jensen et al., 2015; Stringer et al., 2015; Walter et al., 2018), cystic fibrosis in three studies (Chaudhry et al., 2013; Okumura et al., 2014; Gravelle et al., 2015) and a range of different conditions across the remaining studies (Betz et al., 2010; Lewis and Noyes, 2013; Dogba et al., 2014; Price et al., 2014; Campbell et al., 2016). Only four studies included in this literature review evaluated generic transition interventions for a range of different conditions (Kingsnorth et al., 2011; Huang et al., 2014; Nieboer et al., 2014; Jones et al., 2019).

The dominance of disease specific transition interventions, in particular diabetes, within the existing literature base on transition programme evaluations makes it difficult to determine the effectiveness of such interventions for different health conditions, in particular for those young people with very complex health needs (Crowley et al., 2011; Chu et al., 2015; Campbell et al., 2016). Support for the effectiveness of transition interventions further comes mainly from diabetes specific transition interventions measuring mostly disease specific outcomes (HbA1c) (Crowley et al., 2011; Gabriel et al., 2017). Only one RCT study carried out by Huang et al. (2014) demonstrated statistically significant improvements in disease management and health related self-efficacy following a generic technology based intervention, however only three different patient groups were involved in this trial (cystic fibrosis, diabetes, and inflammatory bowel disease).

This section of the literature review has highlighted the ways in which existing evaluation research has attempted to measure the effect of different transition interventions on improving health outcomes for young people. However, the heterogeneity of transition intervention types has made it difficult to make a direct comparison between studies to determine which intervention has the most successful outcomes. A lack of evidence on what works best when it comes to healthcare transition has created difficulties for healthcare providers who wish to develop and implement evidence-based transition programmes. The next section of this literature review will continue to identify the gaps in the current research base through exploring

the multiple outcome measures that are used to evaluate healthcare transition programmes.

#### 2.5 Multiplicity of outcome measures

A similar pattern was identified across studies relating to the variability of measures and instruments used to evaluate transition programmes (Crowley et al., 2011; Watson et al., 2014; Davis et al., 2014; Prior et al., 2014; Chu et al., 2015; Campbell et al., 2016; Gabriel et al., 2017). Empirical research aimed at evaluating transition programmes attempted to evaluate their effectiveness by measuring a range of process and outcome measures. Both process and outcome measures were included within the literature search. Process measures within transition refer to the way in which transitional care is delivered, whereas outcome measures refer to the change that occurs as a result of an intervention (Chu et al., 2015). A review of the literature on transition programme evaluations revealed that the most frequently used measurements to determine programme effectiveness were measures of 'transfer of care' (process measure), 'transitional readiness', 'patient/parental satisfaction with care', 'health related quality of life' and 'disease specific' (outcome measures).

#### 2.5.1 Transfer of care

Transfer of care was the most frequently reported process measure identified across evaluation studies. Nine studies in total measured attendance rates post transition at an adult hospital to determine whether young adults had transferred and ultimately transitioned successfully (Crowley et al., 2011; Davis et al., 2014; Okumura et al., 2014; Chu et al., 2015; Egan et al., 2015; Jensen et al., 2015; Sequeira et al., 2015; Campbell et al., 2016; Zhou et al., 2016). Many of these studies defined successful transfer as young adult's having attended at least one health care visit at an adult hospital within the last 12 months (Jensen et al., 2015; Okumura et al., 2014; Chu et al., 2015; Sequeira et al., 2015; Campbell et al., 2016). Four studies in total reported improvements in rates of transfer post transition intervention (Okumura et al., 2014; Chu et al., 2015; Egan et al., 2015; Jensen et al., 2015). A case-control study by Jensen et al. (2015) found that a higher proportion of patients, who had been exposed to a paediatric rheumatology transition programme transitioned successfully compared to a control group who had not received the programme. Similarly, a cross

sectional study by Okumura et al. (2014) found increased attendance rates 6-12 months post transfer for adolescents receiving structured transition interventions. However, these findings did not show statistical significance and were constrained by small sample sizes, short term follow up and lack of a comparison group (Okumura et al., 2014; Jensen et al., 2015). Only one systematic review carried out by Chu et al. (2015) and one prospective cohort study carried out by Egan et al. (2015) reported findings that were statistically significant.

In contrast, a systematic review by Campbell et al. (2016) found no significant difference in rates of transfer following a comprehensive transition programme for adolescents with diabetes. In a case-control study Sequeira et al. (2015) similarly reported no significant difference in transfer rates between participants receiving a structured diabetes transition programme and control group participants receiving standard care. An integrative review carried out by Zhou et al. (2016) found that systematic evaluations of transfer measures were weak across studies due to a lack of tracking mechanisms post transfer and incomplete transition records. They found evidence of low clinic attendance and loss to follow up post transfer across four studies included in their review (Zhou et al., 2016).

Systematic reviews by Crowley et al. (2011) and Campbell et al. (2016) highlighted a lack of information pertaining to how timing of transfer to adult services was decided for young people. Both Crowley et al. (2011) and Davis et al. (2014) argue that findings across studies included in their reviews were also compounded by the narrow definition of 'transfer' as an indicator of successful transition. In a systematic review, Chu et al. (2015) suggest that 'transfer of care' as a process measure is inconsistently assessed and reported in evaluation studies due to different interpretations and definitions of what constitutes a successful transition. This argument is supported in a cross-sectional study by Shaw et al. (2013) who found a considerable variation in how transition services were delivered in 23 different clinics in one UK paediatric and neighbouring adult hospital. Their findings suggest that many services consist of a 'transfer/handover clinic' rather than a structured transition programme (Shaw et al., 2013).

Definitions of transfer varied greatly in the studies included in this literature review, with the majority measuring clinic attendance up to a maximum of 12 months post transfer from paediatric services. None of the included studies carried out long term follow up of patients and were therefore unable to identify whether 'successful transfer' resulted in improvement to long term health outcomes. Chu et al. (2015) state that the relationship between improved outcomes and successful transfer is yet to be definitively established, which raises questions regarding the validity of studies which use 'transfer' as an outcome measure. Longitudinal studies that follow participants over a period of several years' post transition may provide more insight into the relationship between 'successful transfer' on long term health outcomes. However, these study designs remain limited in the area of transition at the current time (Campbell et al., 2016; Tysbina et al., 2012).

#### 2.5.2 Transitional readiness

Transitional readiness refers to an individual's awareness and knowledge of their own condition and their ability to manage their condition, as well as the level of their communication and self-advocacy skills (Campbell et al., 2016). This literature review revealed that transitional readiness is a common outcome measure used in transition programme evaluations, with eight studies in total reporting findings related to transitional readiness following a transition intervention (Betz et al., 2010; Huang et al., 2014; Okumura et al., 2014; Steinbeck et al., 2014; Gravelle et al., 2015; Campbell et al., 2016; Little et al., 2017; Jones et al., 2019). However, the instruments used to measure transitional readiness varied greatly, with the Transition Readiness Assessment Questionnaire (TRAQ) being used more commonly in studies carried out by Huang et al. (2014), Okumura et al. (2014) and Little et al. (2017).

An RCT carried out by Huang et al. (2014), a cross-sectional study by Okumura et al. (2014) and a quantitative study by Little et al. (2017) all assessed the effectiveness of TRAQ in determining transitional readiness in young people with a range of complex health needs. Huang et al. (2014) reported significant improvements in performance of health-related self-efficacy and disease management tasks for intervention group participants compared to control group participants following a technology programme. In contrast, Okumura et al. (2014) reported no statistically significant

differences in self-advocacy and self-management scores between intervention and control groups pre-and post-intervention. Little et al. (2017) similarly found no significant relationship between high TRAQ scores and effective disease management.

An integrative review carried out by Zhang et al. (2014) which evaluated the psychometric properties of transition readiness assessment tools in young people with chronic disease, highlighted the strengths of TRAQ. These strengths included positive scores for content, good construct validity and TRAQ's ability to assess less common diseases where disease specific tools had not been developed (Zhang et al., 2014). However, TRAQ was developed and implemented in the USA which has a significantly different health care system to the UK, thus raising questions as to its applicability to other health care settings (Campbell et al. 2016).

A retrospective evaluation by Gravelle et al. (2015) adapted the 'AM I ON TRAC' questionnaire to measure young people's perceptions of readiness to transfer to an adult hospital environment. They found improvements in post-test scores following a cystic fibrosis education intervention. However, these findings were not statistically significant and sample size of participants was extremely small (n=6) (Gravelle et al., 2015). The application of the 'AM I ON TRAC' tool has also been criticised for relying too much on self-report which allows individuals to express their own capabilities, thus allowing for possible over-estimation or under-estimation of skills and abilities (Moyhihan et al., 2014). The tool is further only available in the English language and has only been tested in Canada with small samples, which impacts on the application of the tool to other settings and generalisation of its findings (Gravelle et al., 2015).

Two further RCT studies used different instruments including the Denyes self-care practice instrument (DSCPI-90) (Betz et al., 2010) and a readiness to transfer checklist with the validated Harter self-perception profile (Steinbeck et al., 2014) to measure transitional readiness in adolescent's post transition intervention. Betz et al. (2010) reported little or no difference in transitional readiness outcomes (Campbell et al., 2016), whilst Steinbeck et al. (2014) failed to report transitional readiness scores at 12 months follow up (Campbell et al., 2016). A lack of available empirically tested transitional readiness instruments were however recognised as a limitation by Betz et

al. (2010), who argued that tools used within their study did not have the correct level of sensitivity and specificity required. An integrative review by Zhang et al. (2014) supports this argument highlighting the lack of well-established and tested transitional readiness assessment tools. Findings from their integrative review suggest that no 'gold standard' measure of transitional readiness has been established, and whilst TRAQ has been evaluated as the most valid tool, limitations as to its applicability to other health care settings and culturally diverse populations remain (Zhang et al., 2014).

#### 2.5.3 Patient/parental satisfaction with care

Patient/parental satisfaction with care was frequently reported as a transition outcome measure within the literature base. Eight studies in total used different instruments to measure patient/parental satisfaction before, during and/or following a transition intervention (Chaudhry et al., 2013; Shaw et al., 2013; Davis et al., 2014; Nieboer et al., 2014; Prior et al., 2014; Jensen et al., 2015; Stringer et al., 2015; Walter et al., 2018). A systematic review by Gabriel et al. (2017) reported statistically significant outcomes for patient satisfaction in seven out of ten studies. However, both Gabriel et al. (2017) and Prior et al. (2014) found that the range of instruments used across studies included in their systematic reviews varied greatly, with few instruments being validated and no common measurement framework being applied.

The most frequently used instrument was the 'Mind the GAP scale' (Shaw et al., 2013; Nieboer et al., 2014). This instrument worked by measuring the difference between patients and parent's perceptions of 'actual care' and 'best care' (Shaw et al., 2013). A cross-sectional study carried out by Shaw et al. (2013) found no significant difference in satisfaction between young people who had received the transition programme, compared to those who had not. However, they did find a statistically significant difference between parental satisfaction with parents whose children had received the transition programme rating the service higher than those whose children had not received the programme (Shaw et al., 2013).

A prospective cohort study by Nieboer et al. (2014) reported statistically significant improvements in patient's experiences of care delivery in two areas on the 'Mind the

GAP scale', adolescents being seen alone during clinic appointments and deciding who should be present during consultations, following a structured transition programme. In their systematic review Campbell et al. (2016) further argue that the concept of 'usual care' applied within the 'Mind the GAP scale' is open to interpretation due to the inconsistency and variation in transitional care across different services. Furthermore, in Shaw et al's. (2013) study problems with duplication arose with some confusion over the definitions of 'usual care' and 'best care'.

A cross sectional observational study by Walter et al. (2018) used the 'on your own feet transfer experience scale' (OYOF-TES), which is a validated tool, to measure patient experience and satisfaction for two groups of adolescents following transfer to an adolescent or adult clinic. They reported high scores on the satisfaction scale for both groups (Walter et al., 2018). However, the response rate for adolescents who had transferred to an adult clinic was low (36%) as compared to those who had transferred to an adolescent clinic (61%) and adolescents in both groups had only transferred to one institution which influenced the external validity of the study (Walter et al., 2018).

Other studies measuring patient/parental satisfaction used non-validated, self-devised questionnaires (Chaudhry et al., 2013; Jensen et al., 2015; Stringer et al., 2015). A case-control study by Chaudhry et al. (2013) found that patients with cystic fibrosis who had participated in a formal transition programme were more likely to have higher satisfaction rates than those who had not participated. Similarly, a case-control study by Jensen et al. (2015) used a self-devised ten item satisfaction questionnaire determining that 81% of their sample rated high satisfaction with a transition programme in a Rheumatology clinic. A case report study by Stringer et al. (2015) additionally reported improved levels of overall satisfaction following a transition clinic intervention. However, differences within these studies were not statistically significant and authors across all three studies agreed that due to the limited focus on condition specific groups findings did not generalise to other patient groups (Chaudhry et al., 2013; Jensen et al., 2015). Loss of control group participants (Jenson et al., 2015), difficulties with patient recall (Chaudhry et al., 2013) and low response rates associated with the use of self-report instruments across studies compromise the validity of findings (Prior et al., 2014).

#### 2.5.4 Health related quality of life

Eight studies in total reported findings on health-related quality of life outcomes following the implementation of a transition intervention (Betz et al., 2010; Davis et al., 2014; Huang et al., 2014; Prior et al., 2014; Egan et al., 2015; Sequeira et al., 2015; Campbell et al., 2016; Gabriel et al., 2017). Two RCT studies carried out by Betz et al. (2010) and Huang et al. (2014) found no significant improvement in health-related quality of life for intervention group participants compared to control group participants following structured transition interventions. Only one case-control study carried out by Sequeira et al. (2015) reported statistically significant improvements in global wellbeing for intervention group participants compared to control group participants at 12 months follow up. However, no significant improvement was reported on life satisfaction. Additionally, a prospective cohort study by Egan et al. (2015) found no significant difference to health-related quality of life for adolescents with diabetes following a structured transition intervention. However, they did find a statistically significant reduction in diabetes-related distress post transition intervention, thus suggesting that a structured transition programme may be effective in reducing diabetes-related distress (Egan et al., 2015). Whilst health-related quality of life is measured frequently across evaluation studies of transition programmes, findings that support improvements to health-related quality of life following a structured transition programme remain limited. A systematic review by Prior et al. (2014) suggests that quality of life measures may not be suitable when measuring the impact of an intervention as compared to measuring the overall quality of health care.

#### 2.5.5 Disease specific measures

Disease specific outcome measures were reported in ten different studies included within the literature review (Crowley et al., 2011; Watson et al., 2011; Davis et al., 2014; Prior et al., 2014; Chu et al., 2015; Egan et al., 2015; Wafa and Nakhla, 2015; Campbell et al., 2016; Gabriel et al., 2017; Little et al., 2017). A systematic review by Prior et al. (2014) found that disease specific measures were viewed as the primary outcome measure in 13 studies evaluating transition interventions for diabetes mellitus. Similarly, systematic reviews carried out by Crowley et al. (2011), Watson et al. (2011), Davis et al. (2014), Chu et al. (2015), Campbell et al. (2016) and Gabriel et al. (2017) found that transition programmes evaluated for individuals with diabetes

mellitus had used disease specific measures of HbA1c control as a primary outcome measure to determine transition success.

Only one study reported significant improvements in disease specific measures post transition intervention (Crowley et al., 2011). A systematic review by Crowley et al. (2011) found statistically significant improvements in outcomes following transition interventions in six out of ten studies which were all specific to diabetes mellitus. Although these studies had examined several outcome measures, only one measure showed statistical significance (HbA1c) (Crowley et al., 2011). In their systematic review, Gabriel et al. (2017) reported a decline in HbA1c levels in eight studies, however they do not report on whether these results were statistically significant. In contrast, four studies reported no significant difference in HbA1c levels post transition intervention (Chu et al., 2015; Egan et al., 2015; Campbell et al., 2016; Little et al., 2017).

However, although there is some evidence of improvement in HbA1c levels for individuals with diabetes mellitus who have been exposed to a transition intervention, there is little evidence to demonstrate whether this improvement was a result of an intervention or other external factors that adolescents experience during transition. Forbes et al. (2001) suggest that interventions themselves may not lead directly to improved clinical outcomes when taking into consideration adolescent problems that may affect HbA1c levels. These findings are thus open to interpretation and may not fully determine the impact of an intervention on improved outcomes. Due to these studies predominantly focusing on diabetes mellitus, it is difficult to relate these findings to other long-term conditions (Prior et al., 2014). Comparisons across different conditions and populations thus cannot be made as the same interventions may lead to different outcomes for individuals without diabetes mellitus.

## 2.5.6 Methodological challenges of health transition programme evaluations

As highlighted throughout the first section of this literature review the interventions and outcomes used to measure the effectiveness of transition programmes vary greatly, with no standardised approach to evaluation. Existing evaluation studies of transition programmes are further fraught with methodological weaknesses (Watson et al., 2011;

Davis et al., 2014; Prior et al., 2014; Wafa and Nakhla, 2015; Campbell et al., 2016). Instruments designed to measure outcomes ranging from patient satisfaction to transitional readiness vary greatly, with no one tool or outcome measure being evidenced as any more effective than the other (Davis et al., 2014). Most instruments further relate to specific conditions which limits the generalisation of findings when applied to other groups of people with differing health conditions. Additionally, most instruments have not been validated and have very little evidence to back up their overall effectiveness (Zhang et al., 2014). Although much research, policy and good practice guidance agrees on what transition processes should include (Colver et al., 2013), a lack of well-defined, accepted outcome measures relating to transition success continues to create barriers to support the development of transition programmes (Davis et al., 2014). Consequently, there remains a lack of evidence in the existing literature base to support the effectiveness of transition programmes in improving health outcomes for young people.

Empirical evidence for the effectiveness of transition programmes is further limited by a lack of rigorously evaluated interventions (Crowley et al., 2011; Watson et al., 2011; Chu et al., 2015; Campbell et al., 2016). Systematic reviews by Crowley et al. (2011), Watson et al. (2011) and Gabriel et al. (2017) highlight the paucity of objective evaluations of transition programmes in the current literature base, with the majority of studies instead providing descriptive accounts. Study designs also vary greatly ranging from randomised controlled trials (Betz et al., 2010; Huang et al., 2014; Steinbeck et al., 2014) to prospective cohort studies (Nieboer et al., 2014; Egan et al., 2015) and gualitative study designs (Kingsnorth et al., 2011; Price et al., 2011; Lewis and Noyes, 2013). However, systematic reviews carried out by Crowley et al. (2011), Chu et al. (2015) and Campbell et al. (2016) highlight significant limitations relating to the robustness of such study designs. These limitations include non-randomisation (Crowley et al., 2011; Chu et al., 2015; Sequeira et al., 2015), limited blinding (Campbell et al., 2016), lack of comparison groups (Crowley et al., 2011; Shaw et al., 2013; Davis et al., 2014; Prior et al., 2014; Wafa and Nakhla, 2015), and problems associated with using 'usual care' as a control for comparison studies (Campbell et al., 2016) or pre-existing data from patients who transitioned before the implementation of a structured transition programme (Davis et al., 2014).

Sample sizes across studies also vary greatly with the majority using small samples of between 11 (Price et al., 2011) to 165 participants (Chu et al., 2015). Many studies highlighted limitations associated with using small samples including an inability to generalise study findings (Price et al., 2011; Chaudhry et al., 2013; Okumura et al., 2014; Egan et al., 2015; Gravelle et al., 2015; Jensen et al., 2015; Wafa and Nakhla, 2015; Gabriel et al., 2017), a lack of statistically significant findings (Okumura et al., 2014) and failure to compare clinical outcomes as a proxy measure of transition success (Sequeira et al., 2015). Both Steinbeck et al. (2014) and Chu et al. (2015) highlight challenges with recruiting participants within the age range of 16-21 when transition takes place. Slow recruitment of participants had a significant impact on sample size used in Steinbeck et al's (2014) pilot RCT study.

Additionally, studies which evaluate long term health outcomes and provide long term outcome data are currently few in the existing literature base (Crowley et al., 2011; Davis et al., 2014; Egan et al., 2015; Campbell et al., 2016). Follow up periods used across studies range from 4 months (Campbell et al., 2016) to 18 months (Okumura et al., 2014). Systematic reviews by Crowley et al. (2011) and Campbell et al. (2016) argue that such brief periods of follow up fail to demonstrate the impact of transition programmes on the long-term health status of young adults. In their RCT study, Betz et al. (2010) found that the period to evaluate a transition intervention for adolescents with spina bifida was insufficient in measuring changes to long term outcomes which extend for many years beyond the intervention itself. A greater understanding of how and to what extent transition programmes improve long term health outcomes for young adults is thus vital to future research within this area (Crowley et al., 2011; Campbell et al., 2016).

Furthermore, a mixed method study carried out by Allen et al. (2010) and systematic reviews by Crowley et al. (2011), Chu et al. (2015) and Campbell et al. (2016) highlight the complex nature of transition programmes which consist of multiple, concurrent components making analysis of findings difficult to demonstrate due to the lack of homogeneity. Only one case-control study included in this literature review evaluated an individual transition intervention (Jensen et al., 2015), with the remaining studies evaluating multiple components of transition programmes simultaneously, thus failing to demonstrate which aspect of the programme led to observable outcomes (Chu et al., 2015). Therefore, whilst some evaluation studies reported slight improvements to

outcomes post intervention (Crowley et al., 2011; Shaw et al., 2013; Huang et al., 2014; Sequeira et al., 2015) they failed to explore and explain in depth how and why these changes had occurred.

#### 2.6 Complexity of health transition programme evaluations

A recurring, overarching theme apparent throughout the literature on evaluations of transition programmes related to complexity. Complexity was highlighted as existing within the process of transition itself (Allen et al., 2010; Stewart et al., 2014; Egan et al., 2015; Campbell et al., 2016), the complex nature and composition of transition interventions (Allen et al., 2010; Crowley et al., 2011; Lewis and Noyes, 2013; Davis et al., 2014; Chu et al., 2015; Campbell et al., 2016; Le Roux et al., 2017), and the complex systems into which interventions are developed and implemented and their interaction with context (Kingsnorth et al., 2011; Watson et al., 2011; Chu et al., 2015; Moore et al., 2015; Kerr et al., 2017). Drawing on a wider literature base which supports and informs the narrative of complexity identified across the literature, the next section of this review will explore the complex nature of health transition programmes and challenges of using traditional evaluation methods to evaluate complex transition programmes. Alternative methods for evaluating complex interventions in healthcare will be discussed and critically analysed to determine their relevance and value to the evaluation of complex transition programmes.

#### 2.6.1 Complexity of transition

Transition from paediatric to adult health care is just one element of a wider transition process that young people with long-term conditions experience throughout their transition from childhood to adulthood (Campbell et al., 2016). During this critical stage in their development young people with long-term conditions may experience multiple transitions simultaneously encompassing health, educational and social care settings, employment and housing. As part of these transitions young people with long-term conditions often require multiple supports, which exist within various interacting systems, thus creating a level of complexity (Stewart et al., 2014; Egan et al., 2015). Although the term complexity is often used when referring to the process of transition itself, studies reviewed do not provide a definition of complexity relating to

transition interventions. Complexity within the process of transition is thus under theorised within the existing literature base. However, for the purpose of this literature review it is important to begin to explore why transition processes may be viewed as complex.

A number of studies included in this literature review highlighted the multidimensional, complex and fluid nature of transition (Meleis et al., 2000; Allen et al., 2010; Hudson, Corner and Whichello, 2012; Stewart et al., 2014; Egan et al., 2015; Campbell et al., 2016). A literature review carried out by Hudson et al. (2012) exploring transitional care processes for older people aged 65 years and over moving from acute care settings back into the community, noted important similarities between transition and 'wicked problems'.

The concept of 'wicked problems' was first coined by Rittel and Webber (1973) who stratified problems into 'tame problems' versus 'wicked problems'. The authors described 'tame problems' as those which have a definitive solution and 'wicked problems' as those which are complex and tied up in inter-dependent social systems (Rittel and Webber, 1973). 'Tame problems' were linked to the natural sciences in which problems are separable and definable which may result in findable solutions, whereas 'wicked problems' were linked to governmental planning which was seen as ill-defined and reliant upon political judgement (Rittel and Webber, 1973). The concept of 'wicked problems' has since been used in the realm of healthcare to examine and evaluate complex interventions.

Findings from Hudson et al's. (2012) literature review suggest that 'transitional care' and interventions developed to improve 'transitional care' for older people are influenced by contradictory agendas of stakeholders and multifaceted political, economic and societal stimuli. A mixed method study by Allen et al. (2010) supports this argument stating that transition has been constructed as a problem through political discourses which favour a set of solutions that fit young people into pre-existing service structures. However, transitional care interventions exist within complex, interacting open systems which are constantly evolving in a dynamic social context (Hudson et al., 2012). They are further influenced by the perspectives, values and lived experience of individuals who are directly or indirectly involved in their

development and implementation (Head, 2008). Transition and interventions to improve transition processes are therefore viewed as ambiguous problems that cannot be solved in the same way as 'tame problems' (Rittel and Webber, 1973). Therefore, whilst traditional evaluations which focus on measuring quantitative outcomes may be useful in evaluating linear models to demonstrate cause and effect relationships, their ability to evaluate more complex, non-linear programmes linked to transition and wicked problems has been contested (Head, 2008; Hudson et al., 2012).

#### 2.6.2 Evaluating complex transition programmes

A review of the literature on evaluations of transition programmes highlighted the complex, multi-component designs of transition interventions and the complex social systems into which interventions are implemented which have created additional challenges for evaluators (Allen et al., 2010; Crowley et al., 2011; Colver et al., 2013; Lewis and Noyes, 2013; Davis et al., 2014; Nieboer et al., 2014; Chu et al., 2015; Moore et al., 2015; Campbell et al., 2016; Le Roux et al., 2017). Moore et al. (2015) suggest that complex interventions are defined as those which contain multiple interacting components operating on multiple levels (Moore et al., 2015). Whereas, complexity features within the implementation of interventions and their interaction with the wider context (Moore et al., 2015). Whilst these two interacting areas of complexity are not isolated, for the purpose of this literature review they will be discussed as individual themes within an overarching theme of complexity apparent across the reviewed literature.

Part one of this literature review commented on the diversity of transition interventions and difficulties associated with evaluating the effectiveness of complex and multicomponent transition programmes (Allen et al., 2010; Crowley et al., 2011; Lewis and Noyes, 2013; Davis et al., 2014; Chu et al., 2015; Campbell et al., 2016). As discussed, most transition programmes consist of multiple individual components, with the majority of studies failing to carry out separate evaluations of individual programme components (Crowley et al., 2011; Davis et al., 2014; Huang et al., 2014; Nieboer et al., 2014; Chu et al., 2015; Sequeira et al., 2015; Campbell et al., 2016). An RCT carried out by Huang et al. (2014), a prospective cohort study by Nieboer et al. (2014) and a case-control study by Sequeira et al. (2015) all emphasise the limitations of their study findings in being able to attribute improved outcomes to individual programme components. In their systematic review, Chu et al. (2015) argue that understanding the contribution that individual programme components have on resulting outcomes is essential to evidencing the overall effectiveness of transition programmes. However, as discussed throughout this literature review most evaluation studies of transition programmes use outcome-based evaluation methods, which have failed to evaluate the individual aspects of an intervention which enable change and to provide detailed understandings of how and why interventions work or fail to work (Chu et al., 2015; Moore et al., 2015; Campbell et al., 2016). Moore et al. (2015) suggest that evaluations of complex interventions need to evaluate not only whether an intervention works by measuring outcomes but how the intervention may work within different environments. Evaluation studies that recognise the complex nature of transition programmes and the need for evaluations to uncover the underlying aspects of what makes an intervention work are however rarely done in transitional care research (Colver et al., 2013; Campbell et al., 2016).

Only three studies applied alternative evaluation methods to measure and evaluate the individual components of transition programmes which contributed to programme effectiveness (Allen et al., 2010; Price et al., 2011; Lewis and Noyes, 2013). Price et al. (2011) evaluated a transition pathway in a paediatric diabetes service and adult service in the UK using semi-structured interviews with young people receiving the transition pathway. They found that improved satisfaction related more to the quality of young people's interactions with healthcare professionals involved in their transition than structural components of the transition pathway itself (Price et al., 2011).

For participants in this study what worked best was being treated by healthcare professionals as an individual which enabled a higher level of engagement and interaction with the transition pathway (Price et al., 2011). This finding is supported by a mixed methods study carried out by Allen et al. (2010) and a qualitative comparative embedded case study by Lewis and Noyes (2013) who applied realist evaluation methods to evaluate transition programmes in diabetes and epilepsy services in the UK. Allen et al's. (2010) study suggests that relationships with healthcare professionals who know the young person's needs and treat them as an individual are valued more by young people than the mechanical aspects of transition programmes. Lewis and Noyes (2013) further found in their study that disengagement from adult

services was partly a behavioural response of young people triggered by a lack of facilitative and person-centred communication skills provided by healthcare professionals. These findings are supported by Donabedian (2003) who argues that the patient-practitioner relationship is the vehicle by which technical care is implemented and effectiveness of care is thus enhanced.

Therefore, studies which have used alternative evaluation methods to evaluate transition programmes have provided more in depth and detailed descriptions of key mechanisms that explain how and why transition programmes work or fail to work. However, these studies tend to focus on condition specific transition programmes (Allen et al., 2010; Lewis and Noyes, 2013) and fail to examine the implementation and context of implementation of the transition programme itself. Allen et al's (2010) study focused specifically on Forbes et al's (2001) framework of continuity, failing to consider key programme mechanisms existing outside of continuity that contributed to programme outcomes. Additionally, Lewis and Noyes (2013) study addressed specifically two areas within the transition programme: enabling information exchange and developing self-care skills. Realist evaluation was only partially applied during the data analysis stage of this study rather than being used as a framework to guide theory development and testing as recommended by Pawson and Tilley (1997).

#### 2.6.3 Complexity related to programme implementation

Whilst transition programmes may be complex because of multiple interacting components, they are also developed and implemented into complex inter-related social systems which shape the way in which individuals receive and engage with them (Allen et al., 2010; Moore et al., 2015). Moore et al. (2015) argue that traditional evaluation methods, such as outcome focused evaluations used to evaluate complex programmes, fail to acknowledge the agency of implementers and participants and the context of programme implementation. This is supported by a realist review of transition processes for young adults with life-limiting conditions undertaken by Kerr et al. (2017). Kerr et al. (2017) suggest that human motivation and organisational and social contexts highly influence the implementation of complex transition interventions. Findings from their review suggest that transition intervention outcomes are dependent on how stakeholders use human agency to interact with programme resources

(mechanisms), and the presence of enabling contextual factors such as the availability of resources to support programme activities (Kerr et al., 2017).

As programme implementation is both shaped and informed by contextual factors, Moore et al. (2015) argue that the success or failure of programmes is dependent on the context in which they are implemented. Therefore, to examine outcomes in isolation of the context of the programme may lead to flawed results (Donabedian, 2003; Allen et al., 2010). Donabedian (2003), Moore et al. (2015) and Kerr et al. (2017) all agree that in order to fully understand how and why complex programmes lead to certain outcomes evaluations need to fully understand the functioning of the programme by examining the mechanisms through which the programme is implemented and its relationship with context. Abhyankar et al. (2013) suggest that programmes represent the theories and ideas of those individuals who develop and implement them. Therefore, evaluation studies should capture the theories of how the programme is designed to work in order to test the implementation of complex programmes (Pawson and Tilley, 1997).

A review of the literature on health transition programme evaluations revealed that few studies had fully examined how implementation, processes and contexts of transition programmes had influenced outcomes for young people (Watson et al., 2011; Davis et al., 2014; Chu et al., 2015; Kerr et al., 2017). Eleven studies in total referred to programme implementation (Allen et al., 2010; Kingsnorth et al., 2011; Watson et al., 2011; Lewis and Noyes, 2013; Dogba et al., 2014; Okumura et al., 2014; McManus et al., 2015; Hergenroeder et al., 2016; Kerr et al., 2017; Little et al., 2017; Jones et al., 2019). However, with the exception of Kerr et al. (2017) who undertook a realist review, these studies provided usually descriptive accounts of facilitators and challenges to implementation in comparison to actual evaluations of programme implementation. Common facilitators to implementation identified across the literature included commitment by staff and transition champions to drive forward implementation (Allen et al., 2010; Kingsnorth et al., 2011; Watson et al., 2011; Hergenroeder et al., 2016; Jones et al., 2019), resources invested into transition programmes (Dogba et al., 2014; Hergenroeder et al., 2016; Kerr et al., 2017) and the receptiveness and commitment of adult service providers (Hergenroeder et al., 2016). Common challenges to programme implementation included differences between services in organisational

policies (Kingsnorth et al., 2011; McManus et al., 2015) and reluctance of staff to implement transition processes without identified adult providers where patients could be transferred to (McManus et al., 2015; Hergenroeder et al., 2016).

Whilst these findings provide an important evidence base related to the facilitators and challenges of transition programme implementation, with the exception of Kerr et al. (2017), they provide little insight into the relationship between mechanisms and contextual factors which influence and shape transition programme implementation (Moore et al., 2015). They fail to explain how and why the implementation of transition programmes influence resulting outcomes. Study designs of existing transition programme evaluations are thus limited in their ability to investigate factors and conditions that exist within programmes which influence outcomes (Marchal et al., 2012). Alternative approaches to evaluation could therefore support the evidence base by providing more in-depth explanations of how and why complex transition programmes work or fail to work (Moore et al., 2015) through investigating the context in which complex programmes are implemented. The final section of this literature review draws on empirical studies that have used realist evaluation, which is a theorydriven approach, as a framework to evaluate complex healthcare programmes. In doing so, it highlights the strengths and value of utilising realist evaluation as an alternative approach to evaluate the implementation of complex transition programmes.

## 2.6.4 Alternative approaches to evaluating complex transition programmes in healthcare

This literature review has so far identified that there is a lack of empirical evidence to support the effectiveness of transition interventions in improving health outcomes for young people. This stems from the variation of different interventions and outcome measures used across evaluation studies which make it difficult to compare data to determine which transition interventions are most effective (Allen et al., 2010; Crowley et al., 2011; Chu et al., 2015; Campbell et al., 2016).

Additionally, approaches used to evaluate transition programmes have predominantly focused on assessing the effectiveness of programmes through measuring specific

outcomes to evidence cause and effect relationships (Allen et al., 2010; Crowley et al., 2011; Lewis and Noyes, 2013; Chu et al., 2015; Campbell et al., 2016). In doing this, they have failed to acknowledge that transition programmes are in fact complex, as they are made up of 'multiple interrelated and interdependent components and their effectiveness is highly context dependent' (Kerr et al., 2017: 2). Existing studies have further failed to consider how the success or failure of transition programmes are to an extent shaped by the context in which they are implemented. Commentators have thus debated the appropriateness of outcome-focused evaluations when dealing with complex programmes, such as transition programmes, due to their failure to explain how and why such programmes work or fail to work for different individuals across different contexts (Astbury and Leeuw, 2010; Abhyankar et al., 2013). To address these gaps within the literature, future evaluations of transition programmes should therefore consider which evaluation frameworks are most likely to be able to account for these factors.

Over the past two decades, theory-driven evaluation approaches have gained increasing popularity in healthcare research as they offer an alternative approach to the evaluation of complex programmes (Marchal et al., 2012; Salter and Kothari, 2014). According to Astbury and Leeuw (2010) theory-driven evaluations attempt to unpack programmatic 'black boxes' to uncover how effects are produced and to explain how and why programmes work or fail to work. Whilst traditional evaluation methods focus solely on outcomes, theory-driven evaluation approaches additionally examine possible causes and contextual factors associated with outcomes (Salter and Kothari, 2014). Realist evaluation is positioned within theory-based evaluation approaches and stems from the original work of Pawson and Tilley (1997). Pawson and Tilley (1997) contend that it is not the programme which leads to outcomes, but the response of the people who receive and interact with the resources invested into the programme which are further dependent on the context in which they work (Abhyankar et al., 2013). Therefore, realist evaluation attempts to answer 'what works, for whom, how and in what contexts' by examining underlying mechanisms that exist within a programme which interact with various contextual factors in which the programme operates to produce intended and unintended outcomes (Pawson and Tilley, 1997).

As discussed in the previous section, whilst few studies have used realist evaluation to evaluate complex transition programmes, an increasing number of empirical studies have utilised realist evaluation as a framework for evaluating complex programmes in other areas of healthcare (Greenhalgh et al., 2009; Marchal, Dedzo and Kegels, 2010; Rycroft-Malone et al., 2010; Abhyankar et al., 2013; Salter and Kothari, 2014; McConnell et al., 2015; Haynes et al., 2017). These studies include evaluations of health service transformation programmes (Greenhalgh et al., 2009), healthcare management approaches (Marchal, Dedzo and Kegels, 2010), protocol-based care interventions (Rycroft-Malone et al., 2010), a complex programme to support normal birth (Abhyankar et al., 2013), an end-of-life care pathway (McConnell et al., 2015) and a programme designed to increase research use capacity in health services (Haynes et al., 2017).

Authors of these studies described the programmes being evaluated as complex, multi-component interventions implemented into uncontrolled, context rich healthcare settings (Salter and Kothari, 2014; Haynes et al., 2017). Abhyankar et al. (2013) argue that organisations which deliver healthcare services are in a constant state of change suggesting that any evaluation of complex healthcare interventions should fully consider the interaction of interventions with the contexts in which they are implemented. Greenhalgh et al. (2009) found from their study that local contexts and the wider policy environment had a significant influence on how transformation interventions were implemented across different services. What worked in some services was not necessarily feasible across other services due to contextual differences within the institution, profession, cultural and economic climate (Greenhalgh et al., 2009). McConnell et al. (2015) further identified facilitation as an important resource input in an end-of-life care pathway which helped to increase the successful implementation of the pathway across services. The main strength of realist evaluation for these studies was thus its ability to deconstruct complex interventions to expose underlying mechanisms and contextual factors, which contributed to programme outcomes (Marchal et al., 2012).

However, whilst these studies highlighted the value of realist evaluation in evaluating the implementation of complex programmes, they also recognised some of the limitations of realist evaluation. These included difficulties with identifying, defining and differentiating between mechanisms and contexts within a programme (Greenhalgh et

al., 2009; Astbury and Leeuw, 2010; Rycroft-Malone et al., 2010; Marchal et al., 2012; Salter and Kothari, 2014), separating mechanisms from intervention strategies (Haynes et al., 2017), difficulties in generating hypothesis about context, mechanism, outcome configurations (CMOCs) (Abhyankar et al, 2013; Salter and Kothari, 2014) and different interpretations of the philosophical foundations on which realist evaluation is contingent (Marchal, Dedzo and Kegels, 2010; Marchal et al., 2012). More importantly, a lack of methodological and practical guidance was a common problem identified across studies which according to Marchal et al. (2012) led to realist evaluation being operationalised differently in different studies. Recent reporting and quality standards for realist evaluation have now been produced by Wong et al. (2016) and Greenhalgh et al. (2017) which may help address these methodological limitations in future realist evaluation designs.

This final section has highlighted the value of using realist evaluation as a framework to evaluate the implementation of complex transition programmes. Whilst realist evaluation has some limitations, which are discussed above, its focus on the relationship between programme contexts and mechanisms provides a more detailed understanding of the processes and factors that influence programme implementation outcomes.

## 2.7 Conclusion

The aim of this literature review was to examine research related to evaluations of healthcare transition programmes to identify any gaps or inconsistencies in the evidence base. By exploring the current empirical evidence base of transition programme evaluations this literature review found that evaluations of transition programmes vary greatly both in terms of the diversity of interventions and the selected outcomes to measure programme effectiveness. The range and diversity of interventions and outcomes used across studies had a significant impact on their findings, with many failing to establish a sufficient evidence base for the effectiveness of transition programmes. There is a lack of empirical evidence to support the effectiveness of transition programmes in improving health outcomes for young people. This continues to create barriers to support the development of transition programmes in healthcare.

Furthermore, many existing studies have used outcome-focused approaches to evaluate transition programmes. The argument presented in theme three of this literature review is that transition programmes and the systems into which they are implemented are complex. Transition is a process that is dependent on multiple stakeholders, services and organisations working together. Transition programmes are therefore made up of several interrelated and interacting components. They are implemented within and across multiple social systems. Frameworks used to evaluate transition programmes need to be equipped to account for this complexity. This literature review argues that traditional evaluation methods are not equipped to do this, and an alternative approach known as realist evaluation may be a more suitable fit to the evaluation of complex transition programmes.

Finally, this literature review has highlighted that there is a lack of focus within existing evaluations on how programmes are implemented and how components interact to make programmes successful rather than focusing solely on whether programmes work. Whilst a number of studies have identified factors that influence implementation (Allen et al., 2010; Kingsnorth et al., 2011; Watson et al., 2011; Hergenroeder et al., 2016) the role of context and its influence on programme implementation has not been fully explored. Furthermore, evidence on which specific aspects of transition programmes are most effective remains to be seen. The literature review has thus identified a significant gap in the transition programme evaluation field relating to why and how implementation processes and contexts determine the success or failure of transition programmes. This important finding informed the research aim and questions for this study, which are described below:

#### 2.7.1 Research aim

To examine the processes that exist within the 10-step transition pathway's implementation and the contexts which influence or hinder implementation processes and outcomes.

#### 2.7.2 Research question

To what extent do implementation processes and contexts affect the success or failure of transition programmes?

#### 2.7.2.1 Research sub-questions

1. What are the contexts, mechanisms and outcomes that exist within the programme's implementation?

2. How do contexts influence or hinder implementation mechanisms and outcomes?

3. How does organisational behaviour affect programme implementation?

4. How useful is realist evaluation as a framework to evaluate programme implementation?

## **Chapter 3: Methodology**

## **3.1 Introduction**

The previous chapter established that there remain significant gaps within the existing literature on healthcare transition programme evaluations relating to how and why implementation processes and contexts can influence the success or failure of programmes. To address this gap this study aimed to examine the processes that exist within the 10 Steps Transition Pathway's implementation and the contexts which influence or hinder implementation processes and outcomes. It thus required an approach to evaluation which allowed a closer examination of the programme's implementation. This chapter begins with a discussion about different ways in which evaluation can be approached and the philosophical assumptions underpinning different evaluation frameworks. The reasoning behind choosing critical realism and realist evaluation as an evaluation framework is provided. This is followed by a critical account of the key tenets of critical realism and realist evaluation, and how they shaped the study design.

## 3.2 Evaluation research

As discussed in Chapter 2, traditional evaluation methods which focus on measuring outcomes to assess the effectiveness of programmes using experimental or quasi experimental designs, have historically been regarded as the gold standard in evaluation research (Lathlean, 2015; Robson and McCartan, 2016). However, recently there has been a shift towards understanding the processes involved in the operation of programmes to explain what enables a programme to succeed or fail (Pawson and Tilley, 1997; Lathlean, 2015; Moore et al., 2015). Supporting the stance of the previous chapter, a case will be made for using theory-driven evaluation, in particular realist evaluation underpinned by the philosophy of Bhaskar's critical realism (Bhaskar, 1978, 1979).

## 3.2.1 Outcome evaluation

In outcome-based evaluations the focus is on measuring the outputs of a programme to evidence the relationship between the programme and its effects (Stame, 2004). This type of evaluation is aligned to positivism which is influenced by an empiricist epistemology (Stame, 2004; Cruickshank, 2012). Positivists suggest that there is a
real external world and we come to know about this through direct observation and experimentation (Wong et al., 2017).

Bhaskar (1978) criticises positivist thinking for promoting the 'epistemic fallacy' of reducing questions about being (ontology) to questions about knowing (epistemology) (Bhaskar, 1978; Danermark et al., 2001; Fletcher, 2017). A positivist theory of causal explanation places emphasis on how we come to know (epistemology), and it is argued that knowledge of the world is acquired through what we experience and observe (Outhwaite, 1987; Wainwright, 1997; Cruickshank, 2011). Positivism tends to assume that 'A' is always the cause of 'B' as where 'B' is observed, 'A' is observed as its precursor (Outhwaite, 1987; Blaikie, 2007; Connelly, 2007; Porter and O'Halloran, 2012; Robson and McCartan, 2016). Hence, we know what exists because through experimentation we infer that relationships are formed between variables thus suggesting that there is a causal association (Proctor, 1998; Cruickshank, 2012; Williams, Rycroft-Malone and Burton, 2017).

Bhaskar (1978; 1979) rejects the notion that reality can be defined according to 'fixed empirical regularities that are closed to the possibility of change' (Cruickshank, 2011: 7). He coins this definition of reality a 'closed systems ontology' (Cruickshank, 2012) in which experimentation creates the right conditions to produce a constant conjunction of events (Bhaskar, 1978; Bhaskar, 1979; Outhwaite, 1987; Sayer, 2010). Whilst a positivist account of explanation may be able to predict whether or not an event is going to occur, there is a risk that it fails to provide a causal explanation for why that event occurred (Keat and Urry, 2011; Porter and O'Halloran, 2012). In evaluation research, this oversimplified view of causality (Fletcher et al., 2016) has been referred to as the 'black box problem' (Stame, 2004; Astbury and Leeuw, 2010; Chen, 2013). This can be defined as 'viewing social programmes primarily in terms of effects, with little attention paid to how those effects are produced' (Astbury and Leeuw, 2010: 364). Whilst the evaluation may tell us whether programme implementation was successful or not, it tells us little about what caused programme implementation to work or fail (Pawson and Tilley, 1997). It is on this basis that process, and theory-driven evaluations have been developed to delve deeper into the black box to further explain programme implementation.

As discussed in Chapter 2, existing evaluations of transition programmes have mostly been informed by a positivist account of causation. These evaluations have been unsuccessful in demonstrating what it is about an intervention that causes its effects. This study required an approach which allowed a more extensive examination of the perceived causative agents existing within the programme's implementation (Walsh and Evans, 2014). Critical realism and realist evaluation were therefore chosen over positivism and outcome-based evaluation due to their shared understanding of causality. Both critical realism and realist evaluation share a generative view of causality 'which assumes that not all causal forces are observable' (The RAMESES II project, 2017a: 1). In order to understand and explain what is experienced and observed we require knowledge of the underlying, unobservable mechanisms and structures that exist at a different level to observable outcomes (Keat and Urry, 2011; Westhorp, 2014). The generative model of causation utilised by critical realism and realist evaluation utilised by critical realism and realist evaluation utilised by critical realism and realist evaluation is discussed in the next section of this chapter.

#### 3.2.2 Process evaluation

Process evaluations aim to provide a more comprehensive understanding of implementation by investigating and explaining what actually happens within a programme (Moore et al., 2015; Robson and McCartan, 2016). There is an underlying belief that social programmes work through a process of human reasoning (Pawson and Tilley, 1997). The job of the evaluator is thus to explore how and why ideas underpinning a programme have changed individual reasoning to cause certain effects (Pawson and Tilley, 1997). This approach to evaluation is aligned to constructivism which argues that reality is socially constructed (Berger and Luckmann, 1966) and knowledge of the world is interpreted through the human brain (Wainwright, 1997; Cruickshank, 2011; Wong et al., 2017). Evaluation and inquiry should therefore seek to understand the actions and meanings of individuals receiving the programme (Wainwright, 1997; Williams, Rycroft-Malone and Burton, 2017).

The main criticism of constructivism and thus process evaluation is its failure to recognise the existence of social structures and mechanisms which act to enable or constrain individual reasoning (Wainwright, 1997; Pawson and Tilley, 1997). Pawson and Tilley (1997) argue that there is more to social programmes and policies then just the choices, expectations and beliefs of individuals. Social structures and

mechanisms exist independently of human reasoning and are imbued with power which can affect how individuals' reason with the programme (Pawson and Tilley, 1997). This is of relevance to the transition programme being evaluated within this study. Implementation of healthcare interventions involve an interplay between structure and human agency (McEvoy and Richards, 2003). It was therefore important to choose a method which combined both structural and agential approaches. Critical realism and realist evaluation were thus chosen over constructivism and process evaluation due to the emphasis placed on the interplay of structure and agency existing in social programmes (Williams, Rycroft-Malone and Burton, 2017).

#### 3.2.3 Theory-driven evaluation

Theory-driven or theory-informed evaluation attempts to overcome some of the limitations, as identified above, of outcome and process evaluations (Blamey and Mackenzie, 2007). They suggest that every programme has an underpinning theory (Pawson and Tilley, 1997; Hewitt, Sims and Harris, 2012; Westhorp, 2014) and it is the absence of programme theory which generates the 'black box problem' (Stame, 2004). To investigate the black box and seek answers regarding what makes a programme or implementation of the programme work (Pawson and Tilley, 1997), programme theory should be used as a conceptual framework to guide evaluation (Hewitt, Sims and Harris, 2013). Programme theory is used to inform the evaluation design and is tested through empirical data collection (Walshe, 2007).

The two main approaches to theory-driven evaluation used in the UK are theories of change and realist evaluation (Blamey and Mackenzie, 2007). Both use programme theory to understand and explain how and why programme outcomes or outcomes of implementation are influenced by intervention activities and contextual features (Blamey and Mackenzie, 2007). However, theories of change focus more on implementation processes and less on how individuals respond to interventions which is an important aspect of realist evaluation (Weiss, 1997; Blamey and Mackenzie, 2007). The key distinguishing feature of realist evaluation from other theory-driven approaches is its application of realist philosophy to its evaluation design (Hewitt, Sims and Harris, 2012; Astbury, 2013; Westhorp, 2014). Programme theory is constructed

using realist concepts of context-mechanism-outcome (CMO) configurations (Clarke, 1999; Stame, 2004) and the CMO framework is used to guide the evaluation.

The philosophical foundations of realist evaluation and key realist concepts will be discussed in detail in the next section of this chapter. However, at this stage it is important to identify why realist evaluation was viewed as a better fit to the evaluation design of this study over theories of change. The reasoning behind this decision rests with realist evaluation's distinct realist philosophy which recognises that the way in which a programme works is dependent on how people respond to the resources it provides (Pawson and Tilley, 1997). In realist evaluation terms resources may consist of material, social, emotional or political properties that are offered to individuals by the programme (The RAMESES II project, 2017a). Individuals interact with and interpret these resources in different ways (The RAMESES II project, 2017a). This understanding of social programmes and the role of human agency was seen to be important to this study. The implementation of the transition programme being evaluated was dependent on how healthcare professionals reasoned with resources which would then influence outcomes of implementation. It was therefore critical to choose an evaluation design which allowed for the analysis of structure and agency. Realist evaluation provided a framework which encompassed both of these elements.

## 3.3 Realism and Realist Evaluation

Like positivism and constructivism, realism is a methodological orientation (Pawson, 2006) which comprises different strands of realism informed by different philosophical thinkers. However, realist philosophers mutually agree that causality is generative, and attention should be paid to the mechanics of explanation (Pawson and Tilley, 1997). It has been argued that Bhaskar's critical realism laid the foundations for realist evaluation (Porter and O'Halloran, 2012; Astbury, 2013; Porter, 2015; Fletcher et al., 2016; Williams, Rycroft-Malone and Burton, 2017). According to Porter and O'Halloran (2012), Astbury (2013), Fletcher et al. (2016) and Williams, Rycroft-Malone and Burton (2017) realist evaluation adopts a critical realist ontology and a generative understanding of causality (Marchal et al., 2012; Wong et al., 2017). To explain causality critical realists analyse objects by their nature, their interactions and their causal powers and liabilities (Kazi, 2003). Evaluation approaches which reflect critical realist assumptions can thus 'shed light on the processes essential to the success and

sustainability of those interventions processes that remain in the dark to the experimental scientist' (Porter and O'Halloran, 2012: 26). Critical realism and generative causation will be considered in more detail in the next section of this chapter. However, it is important to discuss the commonalities and differences shared between realist evaluation and critical realism to clarify the philosophical approach which underpins the design of this study.

Although realist evaluation and critical realism share a number of similarities, most importantly the same understanding of causality, Pawson and Tilley (1997) and later Pawson (2006) disagree with Bhaskar on their conceptualisation of social mechanisms (Marchal at el., 2012; De Souza, 2013; Dalkin et al., 2015; Porter, 2015). Bhaskar (1978, 1979) argues that causal mechanisms are found in the structural element of the social world (Dalkin et al., 2015). Whereas, Pawson and Tilley (1997) argue that mechanisms involve an interaction between human reasoning and resources that exist structurally (Porter, 2015). Pawson (2006) thus argues that realist evaluation practices a type of scientific realism which seeks to develop realism as an empirical method (Marchal et al., 2012; De Souza, 2013).

Julnes, Mark and Henry (1998) suggest that when considering realism as a foundation for evaluation it is essential to choose the most appropriate fit to the study's aims and objectives. As already highlighted in Chapter 2 existing evaluations of transition programmes have a narrow focus on outcomes. It is not known which transition interventions are most successful as evaluations have not focused on the contexts needed for programmes to be effectively implemented. Therefore, research on what constitutes effective implementation of transition programmes remains limited. This evaluation aimed to reveal the mechanisms and processes at play in the implementation of a transition programme and the contexts which affected implementation. In order to do this, it required an approach which recognised the complex nature of healthcare programmes and the contingent

relationship between mechanisms, contexts and outcomes. Critical realism was believed to be the most appropriate fit to the study's aims and objectives due to its understanding of causality. However, it is recognised that whilst realist evaluation shares many of the same beliefs as critical realism including a model of generative causation, it differs in its understanding of what constitutes social mechanisms. The approach to evaluation taken in this study was therefore informed by both Bhaskar's critical realism and Pawson and Tilley's definition of social mechanisms.

## 3.4 Critical realism: Questions of ontology and epistemology

Critical realism draws on elements from both positivism and constructivism to propose an alternative account of ontology (the theory of being) and epistemology (the theory of knowledge) (Wainwright, 1997; Fletcher, 2017; Williams, Rycroft-Malone and Burton, 2017). This account emphasises the importance of ontology and claims that in order to understand how scientific knowledge is possible (epistemology), we must first define what constitutes social reality (ontology) (Bhaskar, 1979; Bhaskar and Lawson, 1998; Connelly, 2007; Cruickshank, 2011). In making this claim critical realism switches the focus on epistemology, in both positivism and constructivism, back to ontology (Outhwaite, 1987; Wainwright, 1997; Cruickshank, 2012; Fletcher, 2017).

For critical realists, social reality cannot be investigated using a closed systems science as proposed by positivism as reality is complex, messy and open to change (Pawson 2006; Cruickshank, 2011; Cruickshank, 2012). There is an underlying belief that reality exists independently of human cognition (Bhaskar, 1978; Sayer, 1999; Danermark et al., 2001; Houston, 2001, cited in Williams et al., 2017; Blaikie, 2007; Sayer, 2010) and structures creating the world are thus not accessible to immediate observation (Wainwright, 1997; Danermark et al., 2001). Bhaskar (1978; 1979) offers an alternative explanation of reality in which the world is regarded as a stratified open system (Cruickshank, 2012; Robson and McCartan, 2016) and reality is far greater than what we observe empirically (Spencer, 1995, cited in Williams, Rycroft-Malone and Burton, 2017; Sayer, 1999; De Souza, 2014). Reality is defined by Bhaskar to be an open system because it is exposed to change at the level of observable events (Cruickshank, 2011). Critical realism makes a distinction between three overlapping domains of reality: the real, the actual and the empirical (Outhwaite, 1987; Wainwright, 1997; Bhaskar and Lawson, 1998; Proctor, 1998; De Souza, 2014; Walsh and Evans, 2014), with the real domain being what science seeks to reveal (Bhaskar, 1975;1979, cited in Connelly, 2007). This is depicted in figure 5 below and explained further under the real, actual and empirical domain headings.



Figure 5 An iceberg metaphor for Critical Realism ontology (Source: Fletcher, 2017: 183)

## 3.4.1 The real domain

For Bhaskar (1978; 1979) it is the nature of the real and what exists within the real domain that explains the social world (Connelly, 2007; Williams, Rycroft-Malone and Burton, 2017). The social world is said to have ontological depth and is much more than a pattern of events as contended by positivism (Sayer, 1999). The real domain consists of real objects and structures containing causal or generative mechanisms which when activated produce events or changes in objects at the empirical level of observation (Pawson, 2013; De Souza, 2014; Fletcher, 2017). Generative mechanisms have causal powers and liabilities, or the ability to behave in certain ways (Bhaskar, 1978; Sayer, 1999). They exist and act independently of human knowledge and experience and consequently the events that they generate (Bhaskar, 1978; Wainwright, 1997; Williams, 2018). According to Bhaskar (1978; 1979; 1998) mechanisms are the intransitive objects of knowledge. A fundamental distinction is made between transitive objects of knowledge which are established facts or theories

produced by man and intransitive objects of knowledge which are the objects of science that exist and act independently of man (Bhaskar, 1978; 1979; 1998; Sayer, 1999). Mechanisms are believed to be intransitive objects as they are not dependent on human activity (Bhaskar, 1998). They exist and will continue to work in the same way regardless of whether they are observed or not. This understanding can be applied to the laws of gravity which would still work without man or a falling tree which would still fall and make a sound even if there was no one to observe its occurrence.

Whilst generative mechanisms are not directly observable (Danermark et al., 2001; Cruickshank, 2011); and we may not necessarily understand their nature (Sayer, 1999), they are regarded as real due to their effects (Outhwaite, 1987; Bryman, 2001, cited in Walsh and Evans, 2014; De Souza, 2014). Westhorp (2014) suggests that if something can produce real effects then it must be real. In critical realism, what we experience and observe is thus a result of causal powers in generative mechanisms that operate in the real domain (Bhaskar, 1978; Pawson, 2006; Connelly, 2007; Sayer, 2010; Pawson, 2013; Walsh and Evans, 2014; Robson and McCartan, 2016). Understanding and explaining how generative mechanisms function and produce observable events is therefore the primary purpose of critical realism (Outhwaite, 1987; Sayer, 1999; McEvoy and Richards, 2003; Cruickshank, 2011; Keat and Urry, 2011; De Souza, 2014; Robson and McCartan, 2016).

To further explain the nature of causal or generative mechanisms critical realism looks to the interplay between agency and structure (McEvoy and Richards, 2003; Connelly, 2007; Cruickshank, 2012; Williams, Rycroft-Malone and Burton, 2017). A critical realist ontology suggests that social structures emerge from the actions of individuals (Cruickshank, 2012) and provide the necessary resources to enable people to act (McEvoy and Richards, 2003). However, structures cannot determine individuals' behaviour, they can only condition it (Carter and New, 2004; Cruickshank, 2012). This is because people have agency such as the ability to reason (Sayer, 2010) and therefore act back on and change structures (Cruickshank, 2012). As different structures can influence human behaviour in different ways, reality is held to be an open system exposed to change at the empirical level (Cruickshank, 2011; Cruickshank, 2012).

However, in an open system there exist multiple generative mechanisms working concurrently (De Souza, 2014). Not all mechanisms will be activated to produce events in the actual level of reality (see figure 5) (Sayer, 1999; De Souza, 2014). The activation of a mechanism is dependent on whether the conditions needed to make it work are present (Connelly, 2007; Sayer, 2010; De Souza, 2014). Pawson (2013) uses the example of fireworks exploding to illustrate the contingent relationship between mechanisms and their effects. He suggests that what we observe in the empirical domain (i.e. an exploding firework) results from a sequence of events in the actual domain (i.e. fireworks explode in the presence of a flame) which is activated by a causal mechanism in the real domain (i.e. the chemical composition of gunpowder causes the firework to explode in the presence of a flame) (Pawson, 2013). In other words, the causal mechanism (the chemical composition of gunpowder) will only be activated if the conditions are right (a flame is present) which causes the firework to explode. This can alternatively be explained as 'given a generative mechanism (M) and a conducive context (C) for its triggering we can expect to see and measure specific observations (O) and events' (Connelly, 2007: 936).

#### 3.4.2 The actual and empirical domains

Generative mechanisms which are activated under the right conditions produce a sequence of events in the actual domain (see figure 5) (Sayer, 1999; Pawson, 2013; De Souza, 2014). These events occur regardless of whether or not we interpret or experience them (Walsh and Evans, 2014; Fletcher, 2017) and can be different to what is observed in the empirical domain (Danermark et al., 2002, cited in Fletcher, 2017). This is because what we observe is always filtered through the lens of human interpretation and experience (Fletcher, 2017). Thus, the empirical domain relates to our experiences of the world and what we observe to exist (see figure 5) (Pawson, 2013; De Souza, 2014; Walsh and Evans, 2014). These epistemological assumptions are interpretivist and although critical realism is less concerned with epistemology (Outhwaite, 1987), it shares with interpretivism the view that meaning is understood through an interpretive lens (Sayer, 1999; Blaikie, 2007). Critical realism is therefore informed by an interpretivist epistemology as it seeks to interpret how mechanisms operate in an open system (Cruickshank, 2012). In order to do this, it uses theory. The role of theory in critical realism and realist evaluation will be discussed in detail in the next section of this thesis.

## **3.5 The Realist Evaluation Framework**

Realist evaluation applies a realism-based approach to evaluation (Julnes, Mark and Henry, 1998) underpinned by a critical realist understanding of the nature of reality (ontology) and how we acquire knowledge (epistemology) (Westhorp, 2018). In this respect it is more than just an approach to evaluation; 'it is a type of applied realism' (Westhorp, 2018: 43) or a way of thinking about the social world (Pawson and Tilley, 2004; Westhorp, 2014). Using a model of generative causation as described by critical realism, realist evaluation seeks to understand and explain how and why complex programmes work, for whom and in what contexts (Astbury, 2013; Wong et al., 2017). It proposes its own terminology and definitions of realist concepts (Pawson, 2013) and it is these which drive the evaluation study design (Pawson and Tilley, 2004). The subsequent section of this chapter will outline some of the key assumptions and features of realist evaluation. Realist concepts shaping the evaluation design of this study will be defined and discussed in detail. Further advantages of utilising a realist approach to evaluate the implementation of complex, social programmes will be emphasised to justify its use within this study.

#### 3.5.1 A realist understanding of social programmes

Realist evaluation recognises the complex social reality in which programmes exist and operate (Julnes, Mark and Henry, 1998; Dalkin et al., 2017). In line with critical realism, the world is defined as an open system (Connelly, 2007). Thus, social programmes by their very nature are assumed to be complex interventions introduced into complex social systems (Sayer, 1999; Pawson, 2006; Pawson, 2013). Health care interventions and health systems are defined as social and thus complex (Walshe, 2007; Marchal, Kegels and Van Belle, 2018) due to their multi-component designs (Mukumbang et al., 2018) and the challenging social, political and institutional contexts in which they are delivered (Davidoff et al., 2015). The complex nature of health transition programmes and complexity related to programme implementation have already been discussed in Chapter 2 of this thesis. Therefore, it is not the intention of this chapter to repeat this argument. However, the aim is to briefly summarise the underlying assumptions of realist evaluation which informed the design of this study. A realist understanding of social programmes argues that interventions are always sensitive to context (Greenhalgh et al., 2015; Mukumbang et al., 2018) and their success or failure is thus dependent on the context in which they are implemented (Hickey et al., 2016; Rycroft-Malone et al., 2018). The importance of context to programme implementation and outcomes was recognised by Pawson and Tilley (1997) who critiqued evaluations using experimental design for failing to account for this. Realist evaluation provides a framework which considers how context shapes and constrains causal mechanisms (Wong et al., 2017) hence making it more appropriate to evaluations of complex healthcare programmes.

Pawson (2006) argues that social programmes and policies are active interventions delivered to active subjects. Active interventions generate change only when active subjects reason with the resources offered by the intervention (Pawson and Tilley, 1997; Pawson, 2006). Individuals involved with the intervention are thus seen to be the vehicles of change which contribute to the end outcome. Interventions are further open to change and are consequently implemented and interpreted quite differently by different stakeholders (Pawson, 2006). Realist evaluation thus seeks to understand how different individuals interact with and interpret interventions to explain outcomes of implementation (Ritchie and Lewis, 2003, cited in Haynes et al., 2017). This is of particular relevance to this study which recognises that implementation of the transition programme is dependent on how healthcare professionals interpret and reason with the resources provided. Implementation of the transition programme is further context-dependent, and an understanding of how contextual features affect implementation processes is thus essential. Realist evaluation allows an exploration of how and why implementation decisions made by healthcare professionals in reallife contexts can affect the success or failure of programme implementation (Adams et al., 2016). It is therefore very suitable as an evaluation framework to guide the design of this study.

#### 3.5.2 Theory and Retroduction

Central to realist evaluation is the assumption that interventions are theories (Pawson, 2006; Dalkin et al., 2017) or 'theories incarnate' as defined by Pawson and Tilley (1997). Whilst these theories may not be explicit (Hewitt, Sims and Harris, 2012; Wong

et al., 2017), they are theories because they are based on a hypothesis that if a programme is delivered or managed in a particular way then it will result in an improved outcome (Pawson, 2006; Hewitt, Sims and Harris, 2012). Pawson (2013) and Dalkin et al. (2017) thus argue that scientific enquiry should be led by theory as it is theory which provides explanation about the nature of programmes. According to Emmel et al. (2018: 4) this way of thinking tips the hierarchy of evidence, which places experimental design at the top, onto its side as it recognises 'that the key is not some arbitrary measure of methodological rigour but the utility of insight in crafting theory'. Realist evaluation therefore begins and ends with theory (Dalkin et al., 2017; Van Belle, Rifkin and Marchal, 2017).

The type of theory that realist evaluation attempts to elicit is programme theory. Programme theories encompass the ideas and assumptions about how the intervention is expected to work, for whom and in what conditions (Dalkin et al., 2017). Based on a generative model of causation programme theories articulate the underlying mechanisms within the intervention and the contexts which are needed to realise the goals of the intervention (Pawson and Tilley, 1997; Leeuw and Donaldson, 2015; Van Belle, Rifkin and Marchal, 2017). In realist evaluation programme theories are presented as conjectured context-mechanism-outcome (CMO) configurations or 'if-then' propositions (Dalkin et al., 2017). These realist concepts will be discussed in more detail later in this chapter. Programme theories are detailed hypothesis which are tested and refined throughout the evaluation (Van Belle, Rifkin and Marchal, 2017). They are used to inform the whole research process including the research questions, research design and data collection and analysis (Dalkin et al., 2017). Initial programme theories are tested and revised through empirical data collection resulting in a refined programme theory or set of programme theories as an end product (Dalkin et al., 2017; Emmel et al., 2018).

To construct theories or hypothetical models about how the programme is expected to work realist evaluation uses a process of retroduction (The RAMESES II project, 2017c). Retroduction involves identifying or theorising the underlying mechanisms existent within a programme that are thought to produce observed patterns (Bhaskar, 1979; Proctor, 1998; Kazi, 2003; Blaikie, 2007; The RAMESES II project, 2017c). Retroduction uses both inductive and deductive reasoning to move between theory building and testing propositions through empirical data collection (Astbury and Leeuw, 2010; The RAMESES II project, 2017c). The researcher can also use informed imagination, hunches, experience, expertise and common sense to build programme theories (The RAMESES II project, 2017c; Astbury, 2018). This is reflective of critical realism and the generative model of causation that realist evaluation adopts.

#### 3.5.3 Mechanisms

The concept of mechanisms is fundamental to realist explanations of how and why change occurs (Pawson, 2006; The RAMESES II project, 2017a). As previously discussed, critical realism proposes that generative mechanisms exist within the real domain and contain causal powers and liabilities (Bhaskar, 1978; Sayer, 1999). However, Pawson and Tilley (1997) put forward their own definition of what constitutes a mechanism. Whilst they agree with Bhaskar on certain assumptions they differ in the belief on where social mechanisms are located (Dalkin et al., 2015). Yet, Pawson and Tilley are unable to offer a fixed definition of mechanism (Feather, 2018) and instead explain mechanisms in terms of key characteristics (Pawson and Tilley, 1997). The broad definition offered by Pawson and Tilley has thus contributed to difficulties when attempting to operationalise realist evaluation (Feather, 2018). Defining, identifying and locating mechanisms has been reported as one of the most problematic areas in realist evaluation research (Marchal et al., 2012; Lacouture et al., 2015; Wong et al., 2017) with different authors providing different definitions of mechanism (Westhorp, 2018). Westhorp (2018) argues that any construct of mechanism can be utilised in the research design. However, it must be consistent with the fundamental realist explanation of mechanisms (Westhorp, 2018).

As this study is informed by critical realism as a philosophical orientation and realist evaluation as a framework, it recognises both positions and explanations of mechanism. From a critical realist perspective, a mechanism is hidden and operates at a different level to the outcomes it generates (Astbury and Leeuw, 2010; Lacouture et al., 2015; Westhorp, 2018). It is unobservable to the eye and to identify it the evaluator needs to look beneath the surface and into the inner workings of the programme (Pawson and Tilley, 1997; Pawson, 2006; The RAMESES II project, 2017a). Mechanisms are causal processes or forces (Westhorp, 2018) that have the

ability to behave in certain ways (Bhaskar, 1979; Sayer, 1999; Pawson and Tilley, 1997). Realist evaluation essentially agrees with these key features. However, Pawson and Tilley (1997) introduce an additional characteristic of mechanisms. For Pawson and Tilley mechanisms are a combination of the resources offered by the programme and the reasoning in response from recipients (Pawson, 2006; Lacouture et al., 2015). Thus, social programmes work by providing opportunities and resources to individuals (Wong et al., 2017) who have agency to reason with and choose whether or not to make use of the resources. Identifying mechanisms in realist evaluation thus involves a weaving process of binding resources and reasoning together (Pawson and Tilley, 1997; Dalkin et al., 2015). Dalkin et al. (2015) provide a useful framework for how mechanisms can be identified by separating resources and reasoning and considering the role that context plays. They suggest that 'intervention resources are introduced in a context, in a way that enhances a change in reasoning. This alters the behaviour of participants, which leads to outcomes' (Dalkin et al., 2015: 4). This definition of mechanism was found to be most useful during the process of data analysis and thus underpinned the study.

Westhorp (2018) warns realist evaluators to be careful of the 'resources and reasoning' construct as not all programmes aim to change individual reasoning. However, she does recognise that most social programmes will involve an element of human decision making and if this is the case then Pawson and Tilley's construct is likely to be useful (Westhorp, 2018). Yet, Westhorp (2018) advises that realist evaluators need to ensure that their understanding of mechanisms is reflective of the underlying principles of realism. Therefore, when searching for and identifying mechanisms that existed in the implementation of the transition programme under evaluation, this study was guided by a critical realist understanding of generative causality as well as Dalkin et al's (2015) framework for defining a mechanism (Feather, 2018).

#### 3.5.4 Contexts

Realist evaluation shares with critical realism the same belief that the relationship between causal mechanisms and outcome patterns is contingent on context (Pawson and Tilley, 1997; Pawson, 2006; Sayer, 2010; Astbury and Leeuw, 2010). The

mechanisms that exist within a programme are always conditioned by the context in which the programme operates (Pawson and Tilley, 1997). Therefore, the success of a programme is restricted by features of the context which effect the mechanism (Pawson, 2006). Pawson and Tilley (1997: 70) suggest that:

'programs are always introduced into pre-existing social contexts and ... these prevailing social conditions are of crucial importance when it comes to explaining the successes and failures of social programs.'

Identifying and understanding how pre-existing social contexts can shape and affect the operation of mechanisms and thus resulting outcomes is essential to realist evaluation. Pawson and Tilley (1997) argue that one of the greatest omissions of evaluation research is failing to account for contextual features that exist and endure within programmes. Failure to acknowledge the context of transition programme implementation and its effect on programme outcomes was highlighted as one of the key limitations of experimental evaluation design in Chapter 2. Realist evaluations inclusion and understanding of context thus makes it an appropriate fit to the aims and objectives of this study.

The definition of context provided by Pawson and Tilley is somewhat clearer then constructs of mechanism. However, a more up-to-date definition based on Pawson and Tilley's original work has been provided by the RAMESES II project (2017b) which has produced quality and reporting standards, resources and training materials for realist evaluation:

'For policies and programmes context describes those features of situations into which programmes are introduced that affect the operation of programme mechanisms' (The RAMESES II project, 2017b: 1).

Contexts can include but are not limited too social, material, psychological, economic, organisational and technical situational features (The RAMESES II project, 2017b). They are believed to operate at all levels of the system with different contextual features interacting and influencing others across different levels (The RAMESES II project, 2017b). Pawson (2006; 2013) highlights four contextual layers within a system

that contain contextual features. He coins these the four I's and suggests that realist evaluators may wish to use these as an aide memoir. These include: the individual layer which contains the individual characteristics and capacities of key stakeholders, interpersonal relationships that support the programme, institutional settings including the norms, customs and rules local to the programme and infrastructure defined as the wider economic, social and cultural setting of the programme (Pawson, 2006; Pawson, 2013). Pawson's approach to identifying contexts at different levels within a system was found to be most useful during the process of data analysis. This definition of context was used to inform the overall study.

One of the challenges identified in the realist evaluation literature pertains to identifying which features of context are most relevant and should thus be explored during the evaluation (The RAMESES II project, 2017b). Astbury (2013) advises that it is impossible to consider all potential contexts and realist evaluation permits evaluators to prioritise what is most important in shaping the operation of mechanisms. Furthermore, contexts can sometimes be intertwined with mechanisms and there have been reported difficulties in differentiating between the two concepts (Byng, Norman and Redfern, 2005; Greenhalgh et al., 2009; Dalkin et al., 2015; Punton, Vogel and Lloyd, 2016; The RAMESES II project, 2017b; Feather, 2018). Guidance from the RAMESES II project (2017b) suggests that this can be overcome by thinking about context in relation to the causal mechanism and treating it as an interconnected element of the CMO configuration rather than a separate entity. This will be discussed in more detail in the ensuing section of this chapter.

#### 3.5.5 Outcomes

The realist concept of outcome or outcome-patterns make up the third component of Pawson and Tilley's context-mechanism-outcome model. The objective of realist evaluation is to explain how and why programme outcomes or, for the purpose of this study, outcomes of implementation are caused and it looks to mechanisms and contexts to provide this explanation (Pawson and Tilley, 1997). Realist evaluation asserts that outcomes always follow from mechanisms acting in contexts (Pawson and Tilley, 1997). Outcomes are examined in a theory testing role whereby they are analysed according to their conjectured mechanism-context theories to confirm their

relationship (Pawson and Tilley, 1997). It is argued that multiple mechanisms and contexts can exist within a social programme and therefore any programme can have mixed outcome-patterns (Pawson and Tilley, 1997; Pawson and Tilley, 2004). Outcome-patterns thus 'comprise the intended and unintended consequences of programmes, resulting from the activation of different mechanisms in different contexts' (Pawson and Tilley, 2004: 8). As this study evaluates programme implementation rather than programme impact, this part of Pawson and Tilley's definition was modified to fit the aims and objectives of the study. The intended and unintended consequences of programmes was changed to the intended and unintended consequences of programmes was used to guide the evaluation.

#### 3.5.6 Context-Mechanism-Outcome configuration (CMOC)

Context, mechanism and outcome are the fundamental building blocks of realist analysis and explanation (Pawson and Tilley, 1997; Marchal, Kegels and Van Belle, 2018; Pawson, 2018). These concepts are brought together to form contextmechanism-outcome configuration's (CMOC) which represent programme theories. Pawson and Tilley (1997: 57) argue that 'programmes work (have successful 'outcomes') only in so far as they introduce the appropriate ideas and opportunities ('mechanisms') to groups in the appropriate social and cultural conditions ('contexts')'. A CMOC is thus a testable hypothesis or a proposition that states which mechanisms and contexts lead to which outcomes (Pawson and Tilley, 1997; Pawson, 2013). It has been referred to as a heuristic device (Emmel et al., 2018) which guides analysis to generate causative explanations about programme outcomes (Jagosh et al., 2015; Marchal, Kegels and Van Belle, 2018). It helps to demonstrate the interconnectedness and contingent relationship between contexts, mechanisms and outcomes (Pawson, 2013; Emmel et al., 2018). Conjectured CMOC are used to display initial programme theories at the beginning of the evaluation. They are exposed to a process of testing and refinement through empirical data collection (Pawson and Tilley, 1997). The refined CMOC are then presented as the findings of the evaluation (Pawson and Tilley, 1997).

The propositional function of the CMO configuration has however been greatly misunderstood by different authors conducting realist research (Pawson and Manzano-Santaella, 2012; Pawson, 2013). Some authors have analysed and presented CMOs as separate and disconnected entities (Pawson, 2013). This is viewed as problematic by Pawson and Manzano-Santaella (2012) and Emmel et al. (2018) as unconfigured CMOs do not provide an explanation of the social processes being evaluated which is the main objective of realist evaluation. Other authors have adapted and developed Pawson and Tilley's original CMOC framework to fit their research design (Dalkin et al., 2015; Mukumbang et al., 2018). Mukumbang et al. (2018) suggest using 'if-then-because' statements to represent mechanisms, outcomes and contexts. Whereas Dalkin et al. (2015) propose a reconceptualization of the CMOC framework which distinguishes between resources and reasoning which make up mechanisms. They argue that whilst Pawson and Tilley do account for resources and reasoning in their description of mechanisms, they fail to include this within the CMOC formula (Dalkin et al., 2015). This has resulted in some evaluators choosing one concept over the other when identifying mechanisms (Dalkin et al., 2015). Dalkin et al. (2015: 4) thus present a reconceptualised CMOC framework which claims that 'intervention resources are introduced in a context, in a way that enhances a change in reasoning. This alters the behaviour of participants, which leads to outcomes'. This is presented as M (Resources) + C --- M (Reasoning) = O (Dalkin et al., 2015). Disaggregating mechanisms into resources and reasoning and recognising how context shapes human decision making made it easier to identify mechanisms and differentiate between mechanism and context (Feather, 2018). Dalkin et al.'s (2015) reconfigured CMOC framework was therefore used to support theory development, testing and refinement (Feather, 2018). This will be discussed in more detail in the next chapter.

#### 3.5.7 CMOC and Middle-range theory

Pawson and Tilley (1997) suggest that programme theories represented as CMO configurations can help to develop transferrable lessons from research. In realist evaluation the unit of analysis is the programme theory, not the programme itself (Pawson and Tilley, 2004, cited in Hewitt, Sims and Harris, 2012). Therefore, it is the set of ideas (Pawson and Tilley, 1997) or understandings of 'what works, for whom, in

what contexts and how', that are transferable and can be used to better inform the development and evaluation of social programmes and policies (Astbury and Leeuw, 2010; Westhorp, 2014). Realist evaluation thus makes generalisations using explanatory theory (Pawson and Tilley, 2004; Astbury, 2018). Fundamental to this explanation is generative causation and mechanisms of change (Astbury and Leeuw, 2010; Astbury, 2018). It is recognised that whilst programme theory will always be partial and capable of being corrected, the explanation it produces through its focus on mechanisms can facilitate generalisation beyond the scope of the initial evaluation (Astbury, 2018). Generalisation hence rests at the level of mechanism (Astbury, 2018).

Furthermore, mechanisms are perceived to be portable as they can be used for middle-range programme theorising, which may be transferrable to different settings and policy areas (Astbury and Leeuw, 2010). Realist evaluation attempts to generalise about programmes using CMO configurations to develop middle-range theories (Pawson and Tilley, 1997; Emmel et al., 2018). Pawson and Tilley (1997) refer to this as cumulation which they describe as a theory development model. Middle-range theories, as developed by Merton (1949), are formal theories that operate at a different level of abstraction to programme theories (Marchal, Kegels and Van Belle, 2018). They offer analytic frameworks that can be used to interpret differences and similarities between programmes (Pawson and Tilley, 1997). They can serve different purposes in evaluation research (Pawson, 2013). One such purpose is to use existing middlerange theory as a conceptual lens for explaining how programmes work (Astbury, 2018). This involves working through a process of abstraction whereby the evaluator continually moves between the empirical and the theoretical to develop understanding and transferrable knowledge (Pawson and Tilley, 1997). Pawson and Tilley (2004) argue that by operating at the middle-range there is greater opportunity for transferring evaluation findings.

## **3.6 Conclusion**

This chapter has provided a detailed account of the philosophical assumptions that underpin this study's design. A case for using critical realism and realist evaluation as a framework to evaluate the implementation of the transition programme has been made. Alternative approaches to evaluation and their ensuing philosophical positions have been discussed, whilst evidencing throughout the chapter why critical realism and realist evaluation acted as a more appropriate fit to the study's aims and objectives. The next chapter will continue to explore how critical realism and realist evaluation informed the chosen data collection methods.

# **Chapter 4: Methods**

## 4.1 Introduction

The previous chapter explored how critical realism and realist evaluation were used as a framework within the study to evaluate the implementation of the transition programme. Following a similar narrative this chapter will consider how critical realism and realist evaluation informed the study design and choice of data collection methods. The chapter begins by describing the different stages of realist evaluation and how these featured within the context of this study. This is followed by a discussion of the research design, approach to sampling, recruitment, data collection methods, data analysis and ethical considerations.

## 4.2 Stages of a realist evaluation

Realist evaluation involves three broad stages: developing programme theory, testing programme theory and refining programme theory (Pawson and Tilley, 1997). The objective of the first stage is to elicit an initial programme theory or theories which reflect the assumptions of how the programme or implementation of the programme is expected to work (Westhorp, 2014). Programme theory is then tested in the second stage to see if it holds (Manzano, 2016). The final stage of realist evaluation involves analysis and interpretation to refine the programme theory and address the initial research question of 'what works, for whom, under what circumstances, why and how?' (Jagosh et al., 2015).

The first section of this chapter will briefly discuss how realist evaluation informed and guided the different stages of data collection and analysis for this study. A timeline showing the completion of each stage is provided below.

Stage 1: Programme theory development	July – November 2017
Stage 2: Testing programme theory	December 2017 – February 2019
Stage 3: Refining programme theory	March 2019 – January 2021

Table 4.1: Study timeline

#### 4.2.1 Programme theory development

Pawson (2006, 2013) proposes that social programmes always start out as theories. These theories or hypotheses are understood to be based upon the ideas of programme designers, policy makers and stakeholders about how delivering or implementing a programme in a particular way should lead to some improved outcomes (Pawson, 2006; Greenhalgh et al., 2015; Leeuw and Donaldson, 2015; Wong et al., 2017). Therefore, the starting point of realist evaluation is to articulate and make explicit the theories underpinning the programme (Pawson and Tilley, 1997; Wong et al., 2017), or for the purpose of this study theories supporting implementation of the programme. These theories are referred to as 'initial rough theory' (Shearn et al., 2017), 'initial tentative programme theory' (Wong et al., 2017) or in this study 'rough initial programme theories'. They encompass the general assumptions, intentions and cognitive processes of programme designers and implementers towards the programme under investigation (Leeuw and Donaldson, 2015; Marchal, Kegels and Van Belle, 2018). This provides the realist evaluator with an informed understanding of what is being implemented and why (Wong et al., 2017).

Realist evaluation does not stipulate an exact formula for the development of initial programme theories (Rycroft-Malone et al., 2013) and various qualitative and quantitative data collection methods can be used independently or combined in an iterative process (Pawson and Tilley, 2004; The RAMESES II project, 2017d; Marchal, Kegels and Van Belle, 2018). However, initial programme theories must reflect a realist understanding of causation (The RAMESES II project, 2017d) and should always be re-cast in realist terms using the context + mechanism = outcome framework (Wong et al., 2017). One approach to building realist programme theory recognised by Shearn et al. (2017) focuses on extracting 'tacit theories' directly from policymakers using programme documentation, interviews and brainstorming. According to Pawson and Tilley (1997) policymakers' accounts of how the programme is expected to be implemented provide a vital source of testable theory. Documents concerning the development and operation of the programme are key sources of data that provide rich contextual information (Williams et al., 2012; Westhorpe, 2014; Moore et al., 2015; McHugh et al., 2016) whereas qualitative interviews with policymakers

help to explore participants reasoning about programme implementation (mechanisms) (McHugh et al., 2016), underlying motives and intentions (Robson and McCartan, 2016), contextual conditions (context) that may impact on programme implementation (Williams et al., 2012) and expected/unexpected outcomes of implementation (Pawson and Tilley, 1997).

To elicit the initial programme theories of how and why the transition programme was expected to be implemented by health care professionals two different methods were used. Firstly, an analysis of the transition programme documentation was undertaken, including policy documents, consultation reports and national guidelines. This was followed by six semi-structured interviews with a purposive sample of stakeholders involved in the development and implementation of the transition programme. Qualitative data was analysed using thematic analysis and the context-mechanism-outcome (CMO) configuration analysis tool which is aligned with realist evaluation (Pawson and Tilley, 1997). This resulted in five 'rough' initial programme theories which are reported in Chapter 5. The process for eliciting the 'rough' initial programme theories (stage one) is presented in figure 6 and described in detail in the next sections of this chapter. This is further described in a paper published in the International Journal of Care Co-ordination in 2018 (Appendix B).

To avoid what Pawson (2013: 161) refers to as 'a potential overabundance of theories to choose from' or a 'swamp', this study adopted a pragmatic perspective when deciding which initial programme theories to focus on. This view was informed by which aspects of programme implementation were most important to policymakers and what the organisation needed to know about programme implementation (Punton et al., 2016; Astbury, 2018). In taking a pragmatic stance the preliminary analysis of CMOs to develop initial programme theories was more manageable and only those CMOs considered to be useful to the purpose of the evaluation were tested (Westhorp, 2014).



Figure 6 The realist evaluation cycle adapted from Pawson, 2013; Mukumbang et al., 2016a and Gilmore et al., 2019.

## 4.2.2 Testing programme theory

The second stage of a realist evaluation involves testing the initial programme theories using the best available evidence (The RAMESES II project, 2017d). A theory-driven approach should inform choice of data collection methods and the realist evaluator should purposely select 'the best tools to uncover patterns and regularities about the programme' (Manzano, 2016: 348). As discussed in the previous chapter, context plays a key role in realist evaluation and the initial hypothesis should be tested by collecting data across a range of different contexts. To achieve this, the second stage of this study used a single qualitative embedded case study design (Yin, 2018) informed by realist evaluation. Data were collected through semi-structured interviews with a purposeful sample of twenty healthcare professionals involved in implementing the transition programme across the hospital. The process for testing the programme

theories (stage 2) is illustrated in figure 7 and described in detail in the following sections of this chapter.

## 4.2.3 Refining programme theory

The testing and refinement stages of realist evaluation follow an iterative process (Manzano, 2016). In the third stage of a realist evaluation initial programme theories are gradually revised and presented as refined programme theories at the end of the evaluation cycle (Pawson, 2013; Shearn et al., 2017; Wong et al., 2017). Programme theory refinement involves searching for demi-regularities or semi-predictable patterns across the data (Gilmore et al., 2019). Explanatory theories from the social, behavioural and policy sciences are drawn on to explain CMOs underlying programmes and policies (Leeuw and Donaldson, 2015). To refine initial programme theories data collected in the second stage of this study were analysed using thematic analysis followed by CMO analysis. CMO configurations were interpreted using the existing literature and formal theories. This resulted in seven refined programme theories which are presented and discussed in Chapter 6. The process for refining programme theories is depicted in figure 7 below and described in detail in the data analysis section of this chapter.



Figure 7 The realist evaluation cycle adapted from Pawson, 2013; Mukumbang et al., 2016a and Gilmore et al., 2019.

## 4.3 Case study design

As mentioned in the previous section, stages two and three of this study adopted a single qualitative embedded case study design (Yin, 2018) informed by realist evaluation methodology. Case study design was chosen due to its compatibility with critical realism and realist evaluation, its consideration of context and its argument for the use of multiple data collection methods. The following section of this chapter will discuss the relationship between case study, critical realism and realist evaluation providing a rationale for its use within this study. Different types of case study design will then be explored, and an argument put forward for the appropriateness of a single qualitative embedded case study design. This will be followed by an examination of the connections between case study, realist evaluation and theoretical generalisability.

#### 4.3.1 Case study, critical realism and realist evaluation

Case study design is commonly used to investigate and explore phenomena (cases) 'in depth and within their real-world context' to provide descriptive and explanatory accounts of how and why questions (Yin, 2018: 15). This focus on description and explanation rather than prediction reinforces the philosophical and epistemological assumptions of critical realism described within this thesis (Easton, 2010; Walsh and Evans, 2014). Although case study design shows no preference to a particular philosophical orientation, Yin (2018) suggests that much case study research is aligned with a realist perspective. For critical realists, causality is realised through the interaction of structures and human reasoning (generative mechanisms) that are unobservable, existing beneath the empirical level (Bhaskar, 1975; Sayer, 2010). To provide descriptive and explanatory accounts case study design attempts to uncover generative mechanisms to identify and explain the cause of events (Easton, 2010; Walsh and Evans, 2014). It is this recognition of generative causation across case study design, realist evaluation and critical realism which informed this study's chosen research design.

Case study design supported the study due to its focus on the relationship between contextual factors and phenomena (Stake, 1995; Yin, 2018). Contextual factors are significant to critical realism and realist evaluation's understanding of generative causation (Sayer, 2010; Pawson and Tilley, 1997). The use of an embedded case study design which contains multiple sub-units of analysis supported a more detailed investigation of the operation of generative mechanisms across different sub-units (Yin, 2018). This helped to determine whether the same generative mechanisms were activated across different contexts for different groups of healthcare professionals who were implementing the transition programme (Greenhalgh et al., 2009; Rycroft-Malone et al., 2010).

Additionally, Yin (2018) suggests that case study design benefits from the development of 'theoretical propositions', otherwise known as 'programme theories' or 'CMOCs' within realist evaluation, to guide processes of data collection and analysis within the research cycle. Realist evaluation is thus compatible to case study design as it helps to strengthen the internal validity of the study through the process of theory

development and refinement (Pawson and Tilley, 1997). The use of multiple methods of data collection advocated by both methodologies further helped to enhance the credibility and rigour of the study (Yin, 2018).

#### 4.3.2 Single or multiple case study design

Yin (2018) differentiates between single (holistic) and single (embedded) case study design. The difference lies in the unit of analysis with single (holistic) being the only unit of analysis and single (embedded) containing multiple units of analysis (Yin, 2018). Single case study design is mostly used where the case represents a critical test of theory (Yin, 2018). The single case can be used to develop and test theory by confirming, challenging or extending theoretical propositions (Yin, 2018). Alternatively, there is multiple case study design which similarly contains either single or multiple units of analysis (Yin, 2018).

The decision to use a single embedded case study design was part pragmatic and part theoretically driven. The transition programme which was the focus of this study was unique to the paediatric organisation and at the time only being implemented within a single organisation. There were also considerable differences between the size of participant samples in the services that were implementing the transition programme. This limited opportunities to explore replication across multiple cases. However, there was a need to examine how and why implementation processes and mechanisms acted differently in different contexts. Therefore, the case study design needed to contain multiple sub-units of analysis to allow for a comparison of CMOs across different services within the organisation. A single embedded case study design was thus deemed to be a more suitable fit to the aims and objectives of the study.

#### 4.3.3 Case study, realist evaluation and generalisability

Stake (1995) suggests that the objective of case study research is not to form generalisations but to instead establish particularisations. Case study research involves examining a particular case in depth to better understand what it is and what it does (Stake, 1995). However, Yin (2018) argues that case study research is generalisable to theoretical propositions. He uses the term 'analytic generalisation' to

explain how 'findings from one case can be generalised to a broader variety of other situations' (Yin, 2018: 38). Realist evaluator's including Pawson and Tilley (1997) and Astbury (2018) put forward a similar argument. Astbury (2018) suggests that in realist evaluation generalisation happens through causal explanation. It is the explanation or sets of ideas informing the programme theories that facilitate generalisation beyond the immediate context of the case (Pawson and Tilley, 1997; Easton, 2010; Astbury, 2018). Key to this is the causal mechanism. According to Punton et al. 'mechanisms are not unique to a particular setting' (2016: 2). The same mechanism may be present in different settings given that the context is supportive which may result in similar outcomes (Punton et al., 2016). 'CMO configurations are therefore portable' (Punton et al., 2016: 2). However, Astbury (2018) argues that the problem of generalisability should be approached with caution by realist evaluators. This is because there is always the possibility that within any study relevant mechanisms may remain unidentified whilst incorrect mechanisms may be revealed (Astbury, 2018). CMO configurations must therefore be tested and refined in a continuous cycle to enable 'the accumulation of knowledge about how programmes work in different contexts over time' (Punton et al., 2016: 2).

#### 4.4 Defining and bounding the case

Yin (2018) highlights the importance of both defining and bounding the case. In this study the case is defined as the implementation of the transition programme as the objective of the study is to capture the processes and contexts that influence the success or failure of programme implementation. The case study site was pre-selected based on the transition programme being implemented within one paediatric organisation in England. The organisation wanted to understand how the transition programme was being implemented by healthcare professionals. This provided a unique opportunity for the researcher to evaluate the implementation of a newly developed transition programme. Crowe (2011) argues that case studies can be selected on their own merits and decisions are often influenced by factors including the uniqueness of the case and what is of interest to the researcher.

Within a single embedded case study design sub-units of analysis are utilised as they provide opportunities for extensive analysis, identification of differences in contextual

conditions and enhance understandings of the single case (Yin, 2018). Embedded units or sub-units of analysis must sit within the original single case and can be selected through different sampling techniques (Yin, 2018). In this study, sub-units of analysis were purposively selected to be services within the paediatric organisation in which the transition programme was being implemented. Services were selected based on their early adoption of the transition programme. In total seven services were selected to be sub-units of analysis within the single case.

#### 4.5 Purposive sampling

Purposive sampling was chosen as the most appropriate sampling approach for this study. It allowed for participants to be involved based on their knowledge and experiences of the development and implementation of the transition programme (Hunt and Lathlean, 2000; Palinkas et al., 2015). In stage one, participants who had been involved in developing the transition programme, referred to as programme designers, were identified and recruited through gatekeepers. Their understanding and knowledge of the programme and how it was expected to be implemented was important to the initial programme theory development stage. Existing documents pertaining to the development and implementation of the transition programme were also purposively selected.

In the theory testing stage, healthcare professionals from a range of disciplines within the seven selected services (sub-units of analysis) were identified and, again, recruited through gatekeepers based on their involvement in implementing the transition programme. Pawson and Tilley (1997: 161) suggest that 'practitioners translate programme theories into practice' and therefore have considerable knowledge of the mechanisms, contexts and outcomes of programme implementation. Participants were thus selected based on their ability to cast light on the rough initial programme theories (The RAMESES II project, 2017e). Different participant viewpoints were deemed to be necessary to investigate implementation patterns and unintended outcomes (The RAMESES II project, 2017e). It was therefore important to include professionals across the multi-disciplinary domain to test whether implementation of the transition programme worked in the same way for different

groups of practitioners (Emmel et al., 2018). The inclusion and exclusion criteria for participants included:

#### Inclusion criteria:

• Any relevant internal and external written documentation relating to the development and implementation of the transition programme.

• All transition steering group members or professionals identified in consultation with gatekeepers, who had specialist knowledge of the development and implementation of the transition programme.

• Healthcare professionals across seven services within the paediatric organisation who had direct experience and knowledge of implementing the transition programme.

#### Exclusion criteria:

• Any written internal or external written documentation which did not specifically relate to the development and implementation of the transition programme.

• Any professional who was not a member of the transition steering group or did not have specialist knowledge of the development and implementation of the programme.

• Healthcare professionals who did not work within the seven identified services and who did not have direct experience of implementing the transition programme.

A total of seven documents were analysed and six participants were interviewed in the first stage of the study to develop the initial programme theories. To test the initial programme theories twenty participants within the seven identified services were interviewed (see table 4.2 below). The sample size for stages one and two of the study were determined by the quality, depth and detail of experiential and contextual information provided by participants about the transition programme (Ritchie et al., 2014). Data were collected and analysed iteratively.

Service (sub-unit)	Number of participants
Service A	5
Service B	5
Service C	2
Service D	1
Service E	2
Service F	3
Service G	2

Table 4.2 Number of participants in each service (sub-unit)

## 4.6 Recruitment

Two separate phases of recruitment supported Pawson and Tilley's realist evaluation cycle. To elicit the initial programme theories (stage one), healthcare professionals involved in the development and implementation of the transition programme were recruited from the transition steering group based at the paediatric organisation in which the study was undertaken. This stage of recruitment began in July 2017 and concluded in November 2017. To test the initial programme theories (stage two), healthcare professionals involved in implementing the transition programme within the seven identified services (sub-units) were again recruited through gatekeepers based within the paediatric organisation. This stage of recruitment began in December 2017 and concluded in February 2019.

Permission to attend the transition steering group was gained via the transition lead nurse for the programme. The transition steering group was made up of 50 members who met on a regular basis (bi-monthly). The transition steering group was attended to discuss the aims and objectives of the study. To ensure all transition steering group members were aware of the study further meetings were attended and written information about the study was provided. Written information was also disseminated via email through the transition lead nurse to all active group members seeking expressions of interest. Further participants who were not steering group members but had specialist knowledge in the development of the transition programme were identified and approached through the transition lead for the programme. Approval to

access relevant internal documentation relating to the development and implementation of the programme was further made to the transition lead nurse for the programme

A standard invitation letter (Appendix C) with the researcher details included was sent via secure email to the transition service lead nurse based within the organisation, who acted as the main gatekeeper. The main gatekeeper disseminated the study information to transition steering group members and healthcare professionals across seven identified services to seek expressions of interest. Participants who responded to the study invitation received from the researcher were sent a participant information sheet (Appendix D) and consent form (Appendix E) via secure email. Suitable dates and times for semi-structured interviews to be undertaken were arranged flexibly to meet the needs of participants.

## 4.7 Data collection methods

Critical realism recognises that multiple methods may be required to address different research questions, and therefore offers flexibility in choosing what is most appropriate (Proctor, 1998; McEvoy and Richards, 2003). Similarly, realist evaluation and case study design recommend a multi-method approach (Crowe et al., 2011; Pawson, 2013; Yin, 2018; Mukumbang et al., 2018). According to Yin (2018: 127), when undertaking an 'in depth study of a phenomenon in its real-world context' it is vital to use different sources of evidence (data triangulation) to provide both in depth and contextual information. Realist evaluation likewise advocates for use of data triangulation to develop and test programme theories (Mukumbang et al., 2018). The choice of data collection methods used in this study were informed by the study's aims and objectives.

Documentary analysis and semi-structured interviews with healthcare professionals involved in the development and implementation of the transition programme were considered to be the most appropriate methods to support the development of initial programme theories. Semi-structured interviews with healthcare professionals from the seven identified services who had experience of implementing the transition

programme were considered to be the most suitable method to test the programme theories. The study thus applied multiple qualitative methods to collect data.

#### 4.7.1 Analysis of transition programme documentation

Documentary analysis was used to inform the development of the initial programme theories. Existing documents are important sources of qualitative evidence that can be drawn upon to develop initial programme theories as part of a realist evaluation (The RAMESES II project, 2017d). They often provide insight into the objectives and purpose of a programme and may reveal any facilitators or barriers to programme implementation (Clarke, 1999). Existing documents reflect the social, economic, historical and political circumstances in which they were developed, which helps to enhance the researcher's insight into the complex social systems and structures in which programmes are developed and implemented (Miller and Alvarado, 2005). Yin (2018) suggests that documentation is mostly used in case study research to confirm and strengthen evidence from other sources. In this study existing documents were used to firstly gather important historical and contextual information about the transition programme and to identify areas that required further investigation during participant interviews.

Existing and available, written documentation which had been produced for the purpose of the development and implementation of the transition programme were purposively selected. Documents included published and non-published reports, minutes from transition steering group meetings, audit reports, strategy documents, organisational transition policy and any other resources that pertained to the transition programme. Relevant internal documents were identified and accessed through regular discussion and consultation with gatekeepers. External publicly available documents including local and national good practice guidance and policy were further accessed to provide contextual information (McHugh et al., 2016). Documents were limited to those that would enable initial programme theory development (Miller and Alvarado, 2005). In total seven documents were identified and analysed. These are displayed in table 4.3 below.

Documents selected	Document type	Purpose of documents
Transition to adult services	Organisation policy	The purpose of this document is to
(2016)	(internal)	provide the trust with a standard
		transition policy/processes for all
		specialities and staff to follow when
		working with young people of
		transition age. It introduces the
		transition programme and provides
		information on how it is to be followed
		and implemented.
Transition consultations:	Organisation report on	The purpose of this document is to
transition roadshows, online	staff consultations	evidence what work has been done to
transition survey and full day	(internal)	improve transitional services since the
transition workshop (2015)		CQC inspection in 2014. Also, to
		develop a trust transition policy and to
		further develop the transition
		programme.
Transition to adult services:	PowerPoint	This presentation was intended to
core training (2017)	presentation on	provide staff with information to
3(1),	transition training for	improve knowledge of transition, the
	staff (internal)	trust transition policy and the
		transition programme.
Transition programme	PowerPoint	This presentation provides an
development and	presentation delivered	overview of the work that has been
implementation (2017)	to the North West	undertaken at the paediatric
	Regional Transition	organisation since 2014 to develop
	Conference 2017	and improve transition services. Its
	(internal)	intention was to share information.
		knowledge and best practice on
		transition with colleagues from
		different organisations (health, social
		care education).
Transition promise to you	Information leaflet	Gives written information to young
(2015)	(internal)	people and their parents and carers
	,	on what to expect from the paediatric
		organisation during their transition to
		adult services. Describes key aspects
		of the transition programme.
2016-2017 CQUIN: Planned	Organisation report	Discusses the final development and
transition to adult services for	(internal)	implementation of the transition
specialised paediatric patients	,	programme in four identified
		specialities and the trust wide
		transition policy.
Transition from children's to	National report	This report provides guidance and
adults' services for young	(external)	recommendations for the
people using health or social	(	development of transition
care services. NICE guidelines		improvement programmes in health
(2016)		and social care organisations. It
		informed the development of the
		transition programme being evaluated
		in this study.

Table 4.3 Documents included in the document revi
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To establish the accuracy and authenticity of documents (Miller and Alvarado, 2005; Moule, 2015) a data collection form for each document was developed (Appendix F). Documentation which included personal information was treated, as per study protocol, with confidentiality (Miller and Alvarado, 2005). Data collected from documents were used to create an initial framework of common mechanisms, contexts and outcomes. This informed the development of the topic guide (Appendix G) used to inform the semi-structured interviews with programme designers.

#### 4.7.2 Semi-structured interviews

Semi-structured, face to face and telephone interviews were the main method of data collection adopted for use in both stage one and two of the study. Yin (2018) argues that interviews are one of the most important methods employed in case study research. They can help to offer explanations of key events (Yin, 2018) and obtain multiple views of the single case (Stake, 1995). Furthermore, interviews can help to validate certain findings that have previously been established (Yin, 2018). Interviews are compatible with critical realism as they support the researcher to collect in-depth, 'richly textured accounts of events, experiences and underlying conditions or processes, which represent different facets of a complex and multi-layered social reality' (Smith and Elger, 2012: 14). They further allow the researcher to explore with participants the causal mechanisms existing within programme implementation that are unobservable to the eye. The decision to use interviews over other qualitative methods such as naturalistic observations, was therefore informed by the study's methodological approach. Although naturalistic observations support researchers to observe and make sense of everyday routines of practice (Green and Thorogood, 2014), they do not allow for the collection of in-depth, interpretive data (Fletcher, 2017) based on participants direct views and experiences. It is however important to note that during the early stages of programme theory development the researcher did collect field notes when observing transition steering groups. This was not considered as part of formal data collection, however it supported the researcher to make sense of the programme under investigation.

In line with realist evaluation, semi-structured interviews were informed by the 'realist interview technique' in which the researcher's theory is the subject matter (Pawson,
1996; Manzano, 2016; Mukumbang et al., 2016b; Mukumbang et al., 2018). In a theory-driven interview, programme theories are used to guide the interview and the role of participants is to confirm, falsify and refine the programme theory (Pawson, 1996). Realist interviews pursue the programme's story and in doing so can illuminate implementation mechanisms and contexts and various outcomes (The RAMESES II project, 2017e). Pawson (1996) identifies two key processes involved in theory driven interviews: 1. The teacher-learner function and 2. The conceptual refinement process. The teacher-learner function involves the researcher teaching the participant about the conceptual structure of the subject matter which enables the participant to make sense of the questions posed (Pawson, 1996). The conceptual refinement process focuses on the reasoning of the participants to the programme which helps the researcher to uncover explanatory mechanisms (Pawson, 1996). The transparency of the theoretical framework throughout the interview process according to Pawson (1996) allows participants to make an informed, critical account of the subject under investigation. Figure 8 below depicts the information flow in theory-driven interviews (Pawson, 1996). This was used to guide semi-structured interviews during stages one and two of the study.





Structured interview topic guides were developed for both stages of data collection (see appendix G and appendix H). The topic guide used for stage one interviews was informed by the initial findings from the analysis of documentation. Resources provided by the RAMESES projects were further used to develop initial interviewing questions (Westhorp and Manzano, 2017). Questions included within the first topic guide were exploratory and focused on information relating to relevant contexts, potential mechanisms, and key outcomes of implementation (Mukumbang et al., 2018). The topic guide used for stage two interviews was informed by the initial CMO analysis undertaken following stage one of data collection.

Although the topic guides were structured it was important to make them flexible to allow for modifications during the interview resulting from discussion and inquiry (McHugh et al., 2016; Robson and McCartan, 2016). Information sheets and consent forms were given to participants prior to the interview, and issues of confidentiality and anonymity were fully explained to participants (Mathers et al., 2000). Participants were further given the opportunity to become familiar with the topic guide prior to the commencement of the interviews (Mathers et al., 2000). This followed Pawson's (1996) teacher-learner function ensuring that participants were familiar enough with the developing theories to give a considered response (McEvoy and Richards, 2003).

Interviews were audio recorded with the permission of participants. Taking into consideration the existing demands on clinicians and health care professionals, interviews were kept to 45 minutes each during both stages (Robson and McCartan, 2016). Consideration was also given to convenience of place for healthcare professionals. Interviews were transcribed verbatim, and field notes were taken following the interview to take account of non-verbal cues and interpreted meanings that were later explored during data analysis (Spencer et al., 2014).

Several steps were taken to ensure that the conduct of interviews provided opportunities for participants to offer open and honest perspectives on their experiences of implementing the transition programme. Although interviews were undertaken within the workplace for reasons of convenience to participants, the researcher ensured that, where possible, private rooms were booked to allow a safe environment for participants to openly discuss their experiences. Interview topic guides were used to structure and steer interviews. However, these were not rigidly applied in a formal manner as it was important to allow open conversations between the researcher and participants. Interviews were thus participant-led and sensitive to the individual needs of each participant. Furthermore, before commencing interviews the researcher provided information to participants on how their data would be confidentially and anonymously treated, stored and reported on. Participants were further informed that the researcher was independent to the organisation. This acted to support participants to feel more comfortable about openly sharing their experiences (both positive and negative) of programme implementation.

### 4.8 Data analysis

Pawson and Tilley (2004: 11) argue that realist evaluation is not suited to 'one single analytic method' and 'the design of data analysis is a matter of subtlety of the proposed theories and the availability of the data'. The overall approach taken to data analysis is retroductive with the researcher moving between inductive and deductive processes (Greenhalgh et al., 2017). Realist evaluation studies adopt different approaches to analysis with thematic analysis (Hickey et al., 2016; Jeffries et al., 2017) and framework analysis (Abhyankar et al., 2013; Adams et al., 2016) being the most popular. Most studies however lack details on the actual process of data analysis (Feather, 2018; Gilmore et al., 2019). However, what is clear is that data analysis in realist evaluation studies must apply a realist philosophical 'lens' with the CMO heuristic being used as the main analytical tool (Mukumbang et al., 2016b). Data analysis in this study consisted of two distinct stages. Firstly, Braun and Clarke's (2006) stages of thematic analysis were used to manage and organise the complex dataset into overarching themes. This supported the researcher to make sense of the processes underlying implementation of the transition programme in general. Data within themes were then coded against rough initial programme theories using Dalkin et al's (2015) reconceptualised CMOC framework as a guide. The following section of this chapter describes the separate stages of analysis. Figure 10 provides a visual illustration of the data analysis process.

#### 4.8.1 Thematic analysis

Thematic analysis was used in the early stages of data analysis for both stages within the study and supported the researcher to identify, analyse and organise data into overarching themes (Braun and Clarke, 2006). It was selected as the most appropriate approach for qualitative analysis due to its theoretical flexibility (Braun and Clarke, 2006; Nowell et al., 2017; Braun and Clarke, 2020). Thematic analysis is not aligned with any specific philosophical or theoretical assumptions and can be used across a range of epistemologies and research questions (Nowell et al., 2017; Braun and Clarke, 2020). Previous realist evaluation studies have found it to be compatible with critical realism and realist evaluation as it can be adapted to generate realist concepts of 'mechanisms', 'contexts' and 'outcomes' to identify frequent patterns of CMO configurations emerging across data sources (Pawson and Tilley, 1997; Braun and Clarke, 2006; Hickey et al., 2016; Jeffries et al., 2017). It is further compatible with both deductive and theoretical approaches to research (Braun and Clarke, 2020) and was thus of value to this study which involved a cycle of theory generation, theory testing and theory refinement (Pawson and Tilley, 1997).

Initial data analysis in both stages of the study followed the first five steps of thematic analysis as emphasised by Braun and Clarke (2006). These include familiarisation, generate codes, generate initial themes, review initial themes and define and name themes (Braun and Clarke, 2006). To familiarise oneself with the data the researcher conducted and transcribed all interviews. Interview transcripts were read a number of times and interesting points were highlighted by the researcher. A reflective diary was kept throughout the data analysis process to make a note of potential codes and reflect on any assumptions made in the data (Braun and Clarke, 2006). This was completed for the whole dataset with the preliminary codes acting as the initial blocks in the next stage of coding (Braun and Clarke, 2013). Regular supervisions with the researcher's supervisory team further supported the analytical process.

The next step of data analysis involved generating codes for the whole dataset. Braun and Clarke (2006) define a code as a label that captures something interesting in the data. They differentiate between semantic codes which are based on the surface meaning of the data and latent codes which use pre-existing theories to interpret the

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data (Braun and Clarke, 2006). The researcher used inductive thematic analysis and semantic coding to identify anything of importance to implementation of the transition programme. Three coding sweeps were undertaken with some codes being merged together, some deleted and some renamed. Visual maps were used to identify codes and memos were created for each code to offer further explanation.

The third step of thematic analysis involved generating initial themes (Braun and Clarke, 2006). To achieve this, similar codes were grouped together using visual thematic themes. An example of a thematic map is provided in Appendix I. During this stage coded data were re-visited which helped to identify the initial themes (Braun and Clarke, 2006). Two codes which did not fit into the initial themes were collated into a miscellaneous category and eventually following discussions with the supervisory team were placed into existing themes. Initial themes were then reviewed by the researcher as part of step four. This involved re-visiting the whole dataset to ensure that all important data had been captured and that there were enough data to support the overall theme (Braun and Clarke, 2006). Themes were then further refined and named as part of step five. It resulted in three main themes: working together, barriers to implementation and clinical autonomy and agency. To support the next stage of analysis individual themes were split into four different levels: individual, service, organisational and inter-organisational levels with supportive or constraining features identified.

To ensure the rigour of the data several practices were used as recommended by Nowell et al. (2017). The researcher actively engaged with the data during each stage of analysis. As previously mentioned a reflective and theoretical journal was kept to document thoughts and initial codes. Raw data were archived using a secure drive. A coding framework was used to generate codes and a clear audit trail of how those codes had been generated was kept by the researcher (Nowell et al., 2017). The supervisory team were able to view analysis and discuss as part of the supervisory process. Visual thematic maps (Appendix I) were used to make sense of theme connections and themes were explored and agreed upon with the supervisory team. Information provided in this chapter and within the attached appendices clearly describe in detail the process of coding and analysis undertaken in the study.

### 4.8.2 CMO analysis

The above section of this chapter has described how the first five steps of thematic analysis were used to develop three overarching themes. The next section of this chapter will explain how CMO analysis was used to test and refine initial programme theories.

Step six of data analysis within the study involved coding each individual theme for CMOs mapped against initial programme theories. Within each theme sub-units were coded individually to allow for comparison. This stage of analysis involved returning to the original data and code maps. Definitions of contexts, mechanisms and outcomes as stated in Chapter 3 were used to guide this stage of analysis. In addition to differentiating between CMOs programme components were added as an additional coding category which helped to differentiate between interventions and resources (Astbury, 2018; Marchal, Kegels and Van Belle, 2018). Dalkin et al.'s (2015) reconceptualised CMOC framework (as displayed in figure 9) was used to develop the CMOC coding framework used in this study. Dalkin et al's (2015) framework was particularly useful as it disaggregates mechanisms into resources and reasoning offering an alternative way of thinking about CMOs. Dalkin et al. (2015) suggest that 'intervention resources are introduced in a context, in a way that enhances a change in reasoning. This alters the behaviour of participants, which leads to outcomes' (Dalkin et al., 2015: 4). This is presented as M (Resources) + C - M (Reasoning) = O (Dalkin et al., 2015).



Figure 9 Dalkin et al.'s (2015) reconceptualised CMOC framework

A coding spreadsheet was created for each sub-unit using Microsoft Excel (see example in Appendix J). Once this had been completed for all sub-units and themes CMOs relating to a specific programme component or set of programme components were brought together to help to configure CMOs for each individual sub-unit. An example of this can be seen in Appendix K. This helped the researcher to develop causal configurations in line with realist analysis ensuring that CMOs were connected which is a common failure of some realist evaluation studies reported on by Pawson and Manzano-Santaella (2012).

Step seven of data analysis involved synthesising and refining CMOCs within each sub-unit (Gilmore et al., 2019). These supported the refinement of initial programme theories into final programme theories. All CMOCs and their supporting evidence for each sub-unit were collated into tables using Microsoft Word. Where the data was not enough data to support CMOCs within sub-units, then at this stage they were disregarded. In step eight CMOCs within each sub-unit were further synthesised by searching for semi-predictable patterns or demi-regularities across all sub-units (Gilmore et al., 2019). This process is referred to by Yin (2018) as cross-case comparison and although it is mainly recommended for multiple case study design it

was a useful technique in this study as it helped to identify patterns and variations (Crowe et al., 2011) of CMOCs across sub-units which fed back into programme theory refinement (Flynn et al., 2019). This process resulted in four final CMOCs. The findings of this stage of analysis are reported in Chapter 5.



Figure 10 Illustration of the data analysis process

The final CMOCs identified within the data across sub-units were then reviewed in relation to the existing literature and formal theories and synthesised back into the initial programme theories (Gilmore et al., 2019). This resulted in seven final programme theories. Chapter 6 of this thesis discusses the process of developing the final programme theories.

### 4.9 Ethical considerations

### 4.9.1 Ethical approval processes

The study was granted ethical approval from Edge Hill University Faculty of Health and Social Care Research Ethics Committee (FREC) on the 17<sup>th</sup> July 2017. Ethical approval was also gained from the Health Research Authority (HRA) on the 7th July 2017 (IRAS ID: 227709). As part of the HRA approval process the researcher completed training on 'an introduction to good clinical practice' (secondary care) on the 8<sup>th</sup> April 2017. Confirmation of capacity and capability to conduct research at the paediatric NHS Foundation Trust was permitted from the 16<sup>th</sup> July 2017. The researcher was supervised throughout the study by three experienced researchers from Edge Hill University. Additional supervision support relating to recruitment and data collection was provided by lead clinicians involved in implementing the transition pathway within Alder Hey Children's Hospital.

### 4.9.2 Obtaining informed consent

Accessing participants through gatekeepers had potential ethical implications for the study because of the power that gatekeepers can exercise over participants and the intentions that they may have for the research (Webster, Lewis and Brown, 2014). When working with gatekeepers the researcher ensured that all potential participants were given the opportunity to participate or decline and sufficient accessible information (see Appendix D) was provided to participants to allow them to make an informed decision (Webster et al., 2014; EHU, 2016).

Careful consideration was given to the approach taken by the study to gain informed consent from participants (DOH, 2005; EHU, 2016). The researcher was guided by Edge Hill University's research governance framework for health and social care (EHU, 2016) and the University's code of practice for the conduct of research (EHU,

2014). To gain informed consent participants were sent information sheets (see Appendix D) detailing the nature and purpose of the study, any potential risks and benefits of the study, what participating would involve, details of who was carrying out the study and who to contact if the participant wished to complain about the research (Webster et al., 2014; Moule, 2015). Participants were given time to consider the information to make an informed decision about whether they wished to participate (Webster et al., 2014; EHU, 2016). Participants were further informed of their right to withdraw their data from the study up to 14 days after interviews had taken place (Maltby et al., 2013; Webster et al., 2014; Moule, 2015). Contact details for the researcher were given to participants in case they required further information. Participants were given access to an additional contact from the University should they wish to discuss issues relating to the conduct of the study.

#### 4.9.3 Maintaining confidentiality and anonymity

A researcher has a duty of care to protect participants and to prevent them from experiencing any intentional harm resulting from research (EHU, 2012; Maltby et al., 2013; Moule, 2015). This duty includes the right for participants to have their information treated and stored confidentially and anonymously (Webster et al., 2014; Moule, 2015; Robson and McCartan, 2016). In line with the General Data Protection Regulations (GDPR, 2018), Edge Hill University's Code of practice for the conduct of research (EHU, 2014), the Framework for Research Ethics (EHU, 2016) and Research Data Management Guidelines (EHU, 2013) the researcher ensured that all participant data was managed and stored confidentially and securely as stipulated in the data management plan. Consent forms, interview transcripts, field notes and written documentation were anonymised and stored electronically into password protected, labelled files using the University's secure Z storage drive which is regularly backed up. All data transcripts from interviews had personal information (such as names and identifiers) removed to ensure anonymity and confidentiality of participant data. Copies of hard data (consent forms and field notes) were stored in a secure, lockable cupboard at Edge Hill University until they were scanned electronically onto the secure Z drive. Once scanned hard data were disposed of using the University's confidential waste bin and later shredded by the University. Participants were advised about how their information would be stored and used in accordance with Edge Hill University's

policy on open access (Webster et al, 2014; EHU, 2012). Participants were however made aware in the participant information sheet (Appendix D) that confidentiality may be breached if information pertaining to the safety and protection of vulnerable people was disclosed during the research (Maltby et al., 2013; EHU, 2016).

### 4.10 Patient and public involvement

It is was very important to involve patients and the public where possible in the planning, development, undertaking and dissemination of the research (NIHR, 2016). The researcher took several steps to ensure patient and public involvement. All briefing and consent documentation were developed in partnership with transition steering group members by attending transition steering group meetings and gathering feedback. An outline of the research and supporting documentation which included participant information sheets and consent forms were further sent to Edge Hill University's Service User and Carer group via secure email to request feedback on design and content. This resulted in some minor changes being made to the participant information sheet. Study findings were disseminated throughout the research to peers through attending and presenting at regional transition conferences.

### 4.11 Conclusion

This chapter has provided a detailed account of how the study was undertaken and how the research design, choice of data collection methods and analysis were informed by critical realism and realist evaluation. The different stages of the study have been outlined followed by a rationale for the use of a single qualitative embedded case study design. The approach taken to defining and bounding the case has been highlighted as well as the process for recruiting participants. The methods used to collect and analyse qualitative data have been described in detail as well as the difficulties encountered by the researcher during the data analysis process. Consideration has been given to how the researcher ensured that the study followed ethical guidelines and how patients and the public were involved in the development of the research. The next chapter presents the CMO findings from the study.

### **Chapter 5: Findings**

### 5.1 Presentation of findings

As discussed in previous chapters the aim of this study was to examine the processes that exist within the implementation of the 10 Steps Transition Pathway and the contexts which affect implementation efforts and outcomes. The initial stage of programme theory development, which consisted of documentation analysis and semi-structured interviews with programme designers, elicited four 'rough initial programme theories' presented as 'if...then...because' statements in table 5.1. Rough initial programme theories were tested and refined during the second stage of data collection using data derived from semi-structured interviews with programme implementers. This resulted in four refined CMOCs (context, mechanism, outcome configurations) which are presented within this chapter as the findings of the evaluation from the programme's implementation.

Each section of the chapter (four sections in total) begins with a brief summary of the rough initial programme theory. This is followed by a discussion of the main contexts, mechanisms and outcomes identified across all sub-units (services within the organisation) with evidence from the data to support CMOCs. Similarities and differences between CMOCs within each sub-unit (service) are highlighted within the main and summary sections of the chapter. The final CMOC is presented which resulted from a synthesis of the CMOCs in each sub-unit of the case (implementation of the transition programme). Figures showing both positive and negative outcome patterns are used to illustrate how the same contexts can be both supportive and unsupportive affecting the activation of mechanisms in some services. The chapter concludes with a brief summary of the final CMO configurations which are presented in table 5.2. CMO findings are further discussed and explained in the discussion chapter of this thesis in the context of existing literature and theory.

### Table 5.1 Rough initial programme theories presented as 'if.... then...because' statements

1. IF paediatric healthcare professionals are motivated and committed to improving transition (C) and receptive to organisational change (C),

THEN the transition pathway is more likely to be adopted and implemented by paediatric healthcare professionals (O),

BECAUSE paediatric healthcare professionals can use the transition pathway flexibly alongside existing transition processes to meet the needs of different patient groups. Paediatric healthcare professionals see the benefit that implementation of the transition pathway has to your page and the exprises in which the your level. (A)

the transition pathway has to young people and the services in which they work (M). 2. IF paediatric health care professionals are given dedicated time to use transition preparation tools with young people (C) and have flexibility to adapt transition preparation tools to meet the needs of their own patient group (C),

THEN paediatric health care professionals are more likely to integrate a transition preparation tool into transition planning for young people (O),

BECAUSE they see the benefit the use of the tool in transition planning has for a young person (M).

3. IF there is an identified adult service to transition young people to (C), motivated professionals in both paediatric and adult services who are committed to improving transition (C) and additional capacity to hold joint transition reviews (C),

THEN paediatric health care professionals are more likely to implement joint transition reviews (O),

BECAUSE by working together in partnership with adult services, paediatric health care professionals have an improved sense of trust and confidence in their adult service counterparts (M).

4. IF transition training facilitates open communication between the transition team and paediatric healthcare professionals (C),

THEN paediatric healthcare professionals' knowledge of transition and the pathway will improve, they will have a greater understanding of their roles and responsibilities and take ownership for their individual patients (O),

BECAUSE paediatric healthcare professionals feel that their professional views and experience have been considered and valued by the transition team (M).

### 5.2 Rough Initial Programme Theory One

During development of the transition pathway programme designers intended to, firstly, ensure that all young people were supported through transition from paediatric to adult health services, and, secondly, to give all people involved in transition a clearer focus on what needs to be done at each stage to achieve good service transition. One of the main informational resources established was a diagram with accompanying literature which described ten different steps to good transition to adult services. Early implementation efforts were focused on disseminating this information to professionals across the trust, with an initial focus on targeting those who showed more interest and motivation for transition and would be more likely to receive change positively. Rough

Initial Programme Theory One (box 1) thus hypothesised that paediatric healthcare professionals who were motivated, committed and receptive to organisational change would be more likely to adopt and implement the transition pathway. Programme designers theorised that in this context the implementation of the pathway would work because healthcare professionals would be able to use the pathway flexibly alongside existing processes to meet the needs of their patient groups and would 'see the benefit' of programme implementation to young people and the services in which they work.

IF paediatric healthcare professionals are motivated and committed to improving transition (C) and receptive to organisational change (C),
THEN the transition pathway is more likely to be adopted and implemented by paediatric healthcare professionals (O),
BECAUSE paediatric healthcare professionals can use the transition pathway flexibly alongside existing transition processes to meet the needs of different patient groups. Paediatric healthcare professionals see the benefit that implementation of the transition pathway has to young people and the services in which they work (M).

### Box 1 Rough Initial Programme Theory One

This rough initial programme theory was tested during data collection with healthcare professionals involved in implementing the transition pathway. The section below discusses the key contexts, mechanisms and outcomes developed from the data across sub-units (services) of the case study. This is followed by a discussion in the summary section related to how the rough initial programme theory was further refined. The final CMOC for this programme theory is illustrated in figures 11a and 11b.

### 5.2.1 CMOC 1

### 5.2.1 Well-established, existing transition processes (context)

To test rough initial programme theories data were collected from programme implementers within seven different services (defined as sub-units) across the trust. Six out of seven services reported having existing transition processes in place prior to the introduction of the transition pathway. There appeared however wide variation between services in terms of how established existing transition processes were. Services B and C appeared to have well-established transition processes that had been in place for many years and were firmly integrated into routine practice:

"... We've got a pretty good transition pathway in place particularly for [condition] patients. I think we were one of the earlier adopters of transition in this trust. So, we've been doing transition for about twenty years to the adult, particularly on [condition] because our patients are so complex. Because it's needed. It's well integrated into [condition] care. So, there's nothing really in the [transition pathway] that is anything different from what we already do" (Service B, HCP9).

In service C, having robust transition processes was a requirement resulting from the condition's service specification:

"So, it's basically the [condition] service it's part of the specification for the service that we deliver anyway to have a transition process. And there is a national service specification document that was published.... Ooh I can't quite remember the date it was published. So, I guess we already had... you know we already had our own requirements to make sure that we had a robust transition process" (Service C, HCP22).

Participants in services B and C described their own transition processes as being very similar and thus compatible with the newly developed transition pathway. As an implication of this, participants reported none or fewer changes to their transition practice resulting from the introduction of the transition pathway:

"You can badge it as the [transition pathway] because essentially, it's what we're doing. And you can say that we're adhering to the [transition pathway] or more or less but it's.... I don't think it's really going to change anything we're doing" (Service B, HCP9).

In these circumstances existing transition processes acted as a supportive context for programme implementation (see figure 11a) with healthcare professionals continuing to use their own comparable processes. However, existing transition processes played a dual role within these services as they further created barriers to implementation of the transition pathway. Whilst participants in services B and C communicated that they were applying most of the steps within the transition pathway to their practice, joint transition reviews (step 9 of the pathway) were reported to not be implemented. This

is discussed in more detail under section CMOC 3. Furthermore, in service B existing transition processes similar to the newly developed transition pathway were only being used for one patient group not all.

Service D was the only service to report having no existing transition processes prior to the introduction of the transition pathway. In this service the fact that transition processes were not well-established within the service acted as a supportive context and the newly developed transition pathway was reported to have a significant impact on practice:

"No. I don't, well as you say there are certain circumstances where it's been set up and it's been set up for a long time and it's well established, and I think that works really well. I think the departments that didn't have, like ours, I don't think anything would be happening if this hadn't been highlighted as a need" (Service D, HCP5).

Whilst services A, E, F and G described having existing transition processes these did not appear to be as well-established and integrated as services B and C. The extent to which these processes were being used for all young people varied greatly as well as the willingness of participants in these services to adopt and implement the newly developed transition pathway. Uptake of the transition pathway was affected by additional constraining contexts which are discussed below and displayed in figure 11b. The data suggested that where existing transition processes were still relatively new and not well-established, not all services were implementing the newly developed transition pathway:

"But I don't think the [transition pathway] has changed anything in that sense. We don't use it (pauses)" (Service F, HCP14).

A similar pattern emerged across services B, C, E and F, with participants maintaining that they felt they were already applying steps within the new transition pathway to their practice. As discussed above, in services B and C where existing transition processes were well-established, step 9 of the transition pathway (joint transition reviews) were not being implemented. In services E and F, where existing transition

processes were not well-established, it was also evident that not all steps were being implemented as initially commented by participants.

### 5.2.2 Inter-organisational commonalities and differences (context)

Across all services, participants described key similarities and differences between paediatric and adult health organisations which either helped or hindered programme mechanisms. Similar to the above context, inter-organisational commonalities and differences further played a dual role (as displayed in figures 11a and 11b) in different services. In addition to having existing, well-integrated transition processes in services B and C, paediatric and adult services had a similar set up for the delivery of care. This appeared to have been influenced by the nature of these condition groups and treatment requirements in adulthood:

"Everybody in the UK with [condition] is supposed to be seen at a specialist service.... we did undertake a piece of pre and post transition work about fifteen years ago. We identified the key anxieties and concerns and key themes for the young people and their parents before transition and then went back to them after. And the youngsters to a main were absolutely fine and the parents. Every one of them. Their fears had been ameliorated by the similarities in the way that the team worked" (Service B, HCP18).

Having a similar set-up across paediatric and adult services made it easier for healthcare professionals to transition young people and supported programme implementation. However, in other services participants expressed that interorganisational differences outweighed commonalities and thus acted as a barrier to successful implementation of the transition pathway. Services A, D, E, F and G did not have similar set ups to their adult counterparts. Participants across these services commonly highlighted differences between paediatric and adult organisational infrastructure as being a hindrance to programme implementation. In particular, difficulties in transitioning patients from a tertiary to non-tertiary hospital were reflected on by participants:

"I think if we also follow this pathway... I think they will never want to leave paediatrics because really, it's quite.... If you were to tell them the truth of what it's going to be like in adult's... so, from our chronic condition it would be purely looking at [condition] at the (pauses) tertiary centre... And everything else can't go there, and they won't refer anyone on... And all of a sudden you would have had a G.P. right through child life and in a complex child that will say go to [paediatric hospital] ... And then all of a sudden you will have the [adult hospital] saying you need to go see the G.P. about that" (Service E, HCP19).

Additionally, differences between paediatric and adult care provision featured heavily in the data, with some adult services not being available to young people as part of their transition:

"We just knew certainly from a physiotherapy point of view that there's no real physiotherapy services available in adult's so... and that's something that we just kind of accept really" (Service D, HCP5).

Participants further described differences in the approaches taken by paediatric and adult healthcare professionals to supporting patients. Paediatric services were defined by participants to be more 'nurturing', 'protective' and 'supportive' than adult services. There were also differences between how often young people would be seen in adult services which impacted on professional decision making around implementation of the transition pathway:

"Whereas I know the adult [consultant] cross country will see that patient once and then discharge them. So, there is no point in going through all the whole big transition rigour of the [pathway] for that patient as I know that even when I've done my total best the adult team will say 'pfft why am I seeing that one?'... you know, it's just (pauses)" (Service A, HCP11).

In some cases, the context 'inter-organisational differences' affected how participants reasoned with the transition pathway and resulted in a different outcome pattern (see figure 11b). This is discussed in detail in sections 6.2.5 and 6.2.7 of this chapter.

### 5.2.3 Healthcare professionals' perceptions of transition (context)

In services A, D, E, F and G participants' perceptions of transition, transition programmes and adult services had some negative connotations attached. Previous experiences of using different transition pathways that were viewed negatively affected how some participants regarded the new transition pathway:

"I think we're very aware of transition. We're doing it well... but over the years we've had a number of sort of enthusiastic processes that have been developed where really there is a philosophy that has come out of them which I've tried to take on but the practicalities have become a little bit... what's the word....a little bit strict and a little bit like a strait jacket really and we haven't found that very user friendly... So, I think we don't... we're not very keen just to adapt and use it but we very much value the focus on it" (Service A, HCP11).

The influence that individuals' past experiences have on their willingness to adopt and implement something new was taken into consideration by programme designers. The quote below taken from an earlier stage of data collection with programme designers highlights this:

"Similarly, to that you will have people who are much more likely to go with it and I suspect that that won't necessarily be as influenced by experience. Some of it will be but some of it will be how responsive they are to change and how they feel about taking on something new" (HCP7).

Inflexibility of care between paediatric and adult health systems for adolescents was further perceived negatively by participants in some services. Participants highlighted the tension between meeting organisational demands in terms of moving young people on to adult care within the given timescales whilst balancing this with patient quality of care:

"I don't think... if they weren't able to do their own diet and their own supplements and blood testing that we would transfer them... because I feel like we have to. We don't really have a choice if they're not ready. Unless there is a real kind of issue or it's unsafe to transfer them" (Service F, HCP14).

In services D and E participants described feelings of frustration due to what they perceived to be a lack of engagement from adult services in relation to transition. For the participant below, feeling that adult services were not on board with the transition pathway impacted negatively on their own decision making about implementation:

"We would love to see... I would be more than happy to use this (points to transition pathway) ... and even though it's come from high above... NHS England... you know filtered down from management and everything... until we get adult services on board my personal opinion is that it's not going to work" (Service E, HCP19).

Within service E, this was further exacerbated by participants perceived negative reactions from senior clinical team members to the newly developed transition pathway. Participants described difficulties around getting all professionals in their own service on board with the transition pathway. They suggested that the transition pathway had not been received positively by senior clinical team members and this directly affected how they implemented the pathway:

"Will it be adopted? (Pauses). I have to say (pauses)... not by our [senior clinical team members]. I would sadly lay a wager on it because of their reaction.... So, [lead transition service nurse] attended the meeting with the [senior clinical team members] and talked through... one of them got up and walked out. The other one just argued the whole point about how busy he was, and one didn't show actually. No two didn't show. And one just sat quiet and I know his beliefs so... Yeah, I just don't think that he was going to get into an argument about it because he... his belief is he is doing transition" (Service E, HCP19).

### 5.2.4 Use of professional autonomy and agency to benefit young people (mechanism)

Across all seven services participants highlighted the importance of ensuring that the young person was at the centre of their transition planning. Participants described how transition had to be tailored to each individual due to differences between individual

health needs, cognitive capacities and the impact of other life changes on the young person's health:

"It's dependent on the individual and I actually think that's right because I think the patient, and it should always be patient focused, is different. So, their needs are very different, their co-morbidities, their intellectual understanding, their confidence are all very different. So, I think it is appropriate and it should be as flexible as it can be. That's my view" (Service A, HCP11).

Decisions about whether and when to implement different steps within the transition pathway appeared to be influenced by professionals' perceptions of individual patient's needs rather than the transition process itself. Perceptions of individual needs were however informed by information provided by the young person themselves and their families as well as professionals' knowledge and understanding of the young person's condition:

"I think you have to be flexible and you have to be fluid, you know. Things change all the time you know. So, I don't think you can be rigid in saying right were going to start this at fourteen. Some children aren't ready, but yet some are ready to go at sixteen. So, for those you have an idea and you can start things earlier. So, fourteen would be ideal for them. I just think you have to take each individual child and family and adapt it to them. I think it has to be. You can't be rigid with it because it won't work" (Service D, HCP5).

On the whole, participants across services felt that the transition pathway could be adapted and used flexibly to meet the needs of individual patients. This supports Rough Initial Programme Theory One which hypothesised that one of the key mechanisms through which implementation would work would be the 'flexibility' of the transition pathway and the ability for professionals to adapt it to meet the individual needs of their own patient groups:

"So, there are things again that have to be bespoke to the speciality and the needs of the young person and so all those things that can make it harder to be clear and consistent across the trust. But that's certainly what we're intending to do. So, these are the guiding principles. This is what we would like you to work towards and with as an overarching structure. So, we're all pointing in the same direction. But we absolutely recognise that different specialities will have different patterns of care need and intervention and we have to be sensitive to that and we can't possibly expect one size to fit all" (HCP7).

Data collected to test this rough initial programme theory further suggested that when making implementation decisions participants exercised their professional autonomy and agency. As theorised in Rough Initial Programme Theory One, professionals must 'see the benefit' that the implementation has for the young person (see box 1). This hypothesised mechanism was supported by the data as it was evident that professional decision making was influenced by the perceived value that implementation of the transition pathway would bring to patient care. In instances where participants did not 'see the benefit' to patient quality of care, they used their professional autonomy to decide not to implement certain steps within the transition pathway. This is highlighted in the excerpt below from a participant describing their feelings around use of the transition exception register, which was one of the resources within the transition pathway:

"No. I don't see an advantage to it. I think it's just an additional exercise to collect information which I don't think will bring value to the patient's care.... I think fundamentally that if a clinician has made a judgment not to transition for whatever those reasons are. At a day to day with the patient, I don't see a value to having the register" (Service A, HCP8).

### 5.2.5 Feelings of 'self-defeat' (mechanism)

In cases where the contexts of 'inter-organisational differences' and 'healthcare professionals' perceptions of transition' were unsupportive, a different mechanism was activated. Participants in services D and E described feelings of 'self-defeat'. In service D this appeared to be more as a result of adult services not being able to transition some young people:

"I just think a lot of professionals' feel disheartened by the lack of services and I think you just feel it's too hard. Who do you speak too? Who are the right people? And I think you rely on managers and people at higher level to do that sort of, that fight for you and then you can you know. Once the services are there and you can engage with them, you know. You can do your job. You can do your bit, but I think it just seems too hard and nobody quite knows the right people to speak too to try and make a difference" (Service D, HCP5).

In service E, feelings of 'self-defeat' were instead connected more with participants' frustrations about what they perceived to be a lack of engagement from adult services and from senior clinical team members within their own service:

"I know it may seem that I have been very negative about them, but I don't... it's not that... It's about our service. Well not even our service it's (pauses) the whole.... I don't think it's the children's services. I think our [senior clinical team members], as much as they are a unique bunch, could be swayed to do these things. I think it... and I might be doing them a big injustice, but I think it's purely adult services that's... and I think the only way that you would get them to hear and to understand is to say if you don't do these then you don't get paid for this service" (Service E, HCP19).

These features of the context affected how participants reasoned with the new transition pathway. As a result, some participants described being unable to 'see the benefit' that implementation had for young people and their own services as initially hypothesised in Rough Initial Programme Theory One (box 1). The feeling that not everybody was on board with implementation of the new transition pathway directly affected how participants interacted with the pathway:

"If I've gone through all of this with the family [points to transition pathway]. You know you want to know that there is something at the end of it for them don't you (laughs). You know you have invested.... We have invested time and effort with that family to get them to that point. Now what's going to happen to them and it's that... that link that's just not there.... isn't it really to carry that on for them" (Service E, HCP20).

This resulted in a different outcome-pattern which is discussed in detail below and displayed in figure 11b.

# 5.2.6 Adapt and use transition pathway flexibly to meet individual needs (positive outcome)

As displayed in figure 11a, where the context was supportive in that existing transition processes were either well-integrated or did not exist prior to the new transition pathway and there were similarities between paediatric and adult services, participants used their professional autonomy and agency when making implementation decisions. This resulted in professionals across most services adapting and using the transition pathway flexibly to meet the individual needs of young people:

"I think because we've got a pathway, we know what the end result is. Does it really matter you know how they get there or at what age they get there? You know as long as you are, as the family are happy, and you are adjusting the pathway to suit them I think that's, you know I think that's fine. Because as long as. At the end of the day they're supported here, and they're supported once they leave here that's got to be your ultimate aim" (Service D, HCP5).

## 5.2.7 Acceptance that there is nothing more that they can do to change transition in their service (negative outcome)

Alternatively, in cases where the context was constraining as displayed in figure 11b, a different mechanism 'feeling of self-defeat' was activated which resulted in participants accepting that there was nothing more they could do to change transition in their service. This was only evident in services D (for some young people not all) and E where the context was less supportive:

"You do just accept because you kind of feel like there's nothing you can do.... And the other thing people just seem you know really busy and it's easier just to say there's nothing more for me to offer to you.... You know, goodbye and good luck sort of thing" (Service D, HCP5).

### 5.2.8 Summary of CMOC 1

Rough Initial Programme Theory One (box 1) hypothesised that paediatric healthcare professionals who were motivated, committed and receptive to organisational change would be more likely to adopt and implement the transition pathway. This theory was based on the premise of programme designers that paediatric healthcare professionals would 'see the benefit' of implementation to young people and the services in which they work whilst being able to use the transition pathway flexibly alongside their existing transition processes to meet the needs of their patients.

Data collected to test this rough initial programme theory partially supports this. In services where existing transition processes were well-established participants highlighted key similarities between their own transition processes and the new transition pathway. This supported professionals to identify which aspects of the transition pathway they were already implementing and facilitated a flexible approach to implementation of the pathway. Professionals were able to continue to use their own transition processes where they were similar to the new transition pathway. However, this context was not always supportive since, although professionals recognised that they were not implementing the transition pathway in its entirety, they did not appear to see the need to change aspects of their practice. Changes to practice appeared to be more prominent in services which had no existing transition processes prior to the pathway being introduced.

Inter-organisational commonalities and differences were similarly found to play a dual role acting in both a supportive and unsupportive capacity. Where paediatric and adult services had a similar organisational set up implementation of the transition pathway was made easier for professionals. However, differences between paediatric and adult services infrastructure, care provision and approaches to supporting young people were more likely identified as significant barriers to programme implementation. Furthermore, healthcare professionals' perceptions of transition, transition programmes and the role that adult services played in transition were reported to be negative, which affected how participants regarded the new transition pathway. Rough Initial Programme Theory One did not fully consider the effects of such contexts on

professionals' receptiveness to organisational change. This is reflected in the refined CMOC (table 5.2) for Rough Initial Programme Theory One.

Where the context was supportive (as displayed in figure 11a) the initial theorised mechanism was partially supported by the data. Participants across all services felt that the transition pathway should and could be used flexibly to meet the needs of each individual patient. There was a recognition that young people were at different stages in their transition journey and implementation of steps within the pathway should be determined by the individual needs of each young person. In making implementation decisions participants therefore used their professional autonomy and agency. Decision making about what steps and when to implement them for each young person were influenced by the perceived value that implementation would bring to patient quality of care. This supports the initial mechanism of 'seeing the benefit' as it reinforces the idea that professionals' are more likely to implement processes if they see the benefit implementation brings to patient care. The data further highlighted that where participants did not 'see the benefit' implementation would bring to the patient; they were less likely to implement the pathway.

Furthermore, where the context was unsupportive (as displayed in figure 11b) a secondary mechanism 'feelings of self-defeat' was activated in services D and E. Features of the context including inter-organisational differences and perceived negative perceptions of adult services affected how participants regarded the transition pathway. This resulted in a different outcome-pattern with participants accepting that there was nothing more they could do to change transition in their service for some young people. This was not originally accounted for in the rough initial programme theory.

### 5.2.9 Final CMOC 1

**Context:** Implementation of the transition pathway is supported by existing, wellestablished transition processes that are similar to the newly developed pathway and inter-organisational commonalities between paediatric and adult services. Existing transition processes, inter-organisational differences and healthcare professionals' perceptions of transition also act as barriers to programme implementation.

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**Mechanism:** Paediatric healthcare professionals use their professional autonomy and agency when making implementation decisions based on perceived individual needs and the value implementation brings to patient quality of care. Where the context is unsupportive paediatric healthcare professionals experience feelings of 'self-defeat'.

**Outcome:** Paediatric healthcare professionals adapt and use the transition pathway flexibly to meet individual patient needs. Where the context is unsupportive and professionals experience feelings of 'self-defeat' there is an acceptance that nothing more can be done to change transition within services.



Figure 11a Final CMO 1 configuration displaying positive outcome



### 5.3 Rough Initial Programme Theory Two

The first three steps within the transition pathway focus on preparing young people and their parents for transition through a process of education, empowerment and support. Transition preparation tools and transition documents play an important role in this process. Rough Initial Programme Theory two (box 2) was based on the views of programme designers that, if professionals were given dedicated time to use transition preparation tools and felt that they could adapt the tool to their patient groups, they would be more likely to integrate the tool into transition planning because they would see the benefit to the young person.

2. IF paediatric health care professionals are given dedicated time to use transition preparation tools with young people (C) and have flexibility to adapt transition preparation tools to meet the needs of their own patient group (C), THEN paediatric health care professionals are more likely to integrate a transition preparation tool into transition planning for young people (O), BECAUSE they see the benefit the use of the tool in transition planning has for a young person (M).

### Box 2: Rough Initial Programme Theory Two

Following the same process as outlined above Rough Initial Programme Theory Two was tested during data collection. The section below discusses the main contexts, mechanisms and outcomes developed from the data across sub-units (services) of the case study. This is followed by a discussion in the summary section about how the rough initial programme theory was further refined. The final CMOC for this programme theory is illustrated in figures 12a and 12b.

### 5.3.1 CMOC 2

### 5.3.1 Shared professional values (context)

In services A, B, C, E and F professionals regarded the education and preparation stage of transition to be an integral part of routine adolescent care. Participants demonstrated a shared set of professional values about transition preparation across the organisation, which acted as a receptive context to support implementation of the pathway. Many professionals reported that transition preparation was already being undertaken with young people from an early age as part of standard clinical care:

"Their transition is part of their routine care because it goes on for a number of years.... we need to see them from a clinical point of view and so I don't think it's.... I don't see it as a different thing as it's part of their routine care" (Service B, HCP16).

However, it was apparent that discussions with young people about transition which formed part of the preparation stage were done informally most of the time and not always recorded in a meaningful way as part of a transition plan or by using a transition preparation tool:

"...and you think well I might have discussed some of these things but actually for a plan. A rigid plan to be put in place. I'll be honest and say that I haven't done that. I discuss things and I put in my letter that things have been discussed but as far as... going for a plan" (Service E, HCP20).

As described by one participant who was interviewed in the first stage of data collection, use of transition preparation tools as recommended in the transition pathway were intended to:

"provide a sort of, bit of an opportunity to have a series of discussions over a period of time.... so, the idea of the preparation tool is, it's not just a one off... so, it's building on it over a period of time" (HCP7).

It was evident from the data that professionals were having these discussions with young people as part of their transition planning over a period of time; yet they were not always using transition preparation tools as part of their formal transition process. Professionals' ability to implement transition preparation tools were partly hindered by a secondary context of time constraints which features within this CMOC and is discussed below.

### 5.3.2 Time constraints (context)

Difficulties in using transition preparation tools and transition documents were often associated with time constraints. Participants from services A, D, E, F and G commonly reported that the use of transition preparation tools generated extra paperwork which required additional time resources that were not available to support implementation:

"We're not given any additional time. Again, from the consultant point of view, I don't think that they get any extra allowances for that at all. So, it's just supposed to be absorbed into your normal workload which is quite hard" (Service A, HCP15).

During clinics, priority was given to discussing the medical aspects of a young person's condition with them over transition preparation which impacted on professionals' use of transition preparation tools:

"...we have the resource that we have. Inevitably that resource has limitations and for example in my own role when I meet a young person with their parents/carers, to deliver the medical aspects of the consultation is challenging. To then factor in the information gathering specifically relating to ten steps and the ready steady go I'm going to find incredibly difficult" (Service A, HCP8).

The context of time constraints triggered a change in how professionals positioned themselves vis-a-vis transition preparation tools and transition documents.

"... it's such a massive implication on our time and resources. I think that's quite difficult... if we were having to do that on a more regular basis with some of our bigger caseloads, that would be quite hard. It would be quite a big resource for us" (Service A, HCP15).

### 5.3.3 Unsupportive technology (context)

During later interviews with participants in services A, E and G, it became apparent that the implementation of the transition pathway had moved forward, and transition documents had been built into the organisation's internal computer system. An earlier interview with a participant in Service A highlighted an expectation that making transition documents electronic would make it easier for professionals to complete them with young people. However, later interviews suggested that technology acted

as a barrier to implementation of transition documents and professionals reported difficulties associated with locating and using documents:

".... and it's difficult to find the transition documents.... It's not giving any real information. It's not asking a question 'what does the patient need to know?', 'how prepared are they?', 'what have they already done at this stage?'.... I just feel it could be a little bit more in depth about what the patient needs" (Service A, HCP26).

Lack of training provided by IT on how to access and complete transition documentation on the internal computer system was also frequently cited as problematic by professionals across services A, E and G:

"I'm confused at how to fill in the documentation.... I didn't learn anything new. It was very much how to use it on the computer.... but I don't really understand" (Service G, HCP24).

This affected some services more than others. For example, in Service E, the mechanism 'perception of individual need' did not fire as the context was not conducive. This is presented in figure 12b and discussed in more detail in the summary for CMOC 2.

### 5.3.4 Perception of individual need (mechanism)

Across services A, B, C, D, F and G professionals commented on the relevance of transition preparation tools and transition documents to those young people who had fewer complex needs. Many professionals reasoned that not all young people would require a transition preparation tool and decisions to use the tool should be determined by the needs of the individual:

"I think it's going to be difficult to apply them all to every patient because partly I think some patients don't need, we have a spectrum of cases/conditions and I'm not sure that, I'm not sure that all patients would need every step in my practice. I think there are others who do." (Service A, HCP8). The use of transition documents that were built onto the internal computer system at a later stage of implementation was also perceived by professionals as less relevant for more independent young people:

"Because all they really need to know is, how we have always done this, is advice about things like sexual health and the impact of drugs and alcohol, how to get their new prescriptions. Those sorts of things....so, having to work through what is actually quite lengthy and not relevant we just... we're not doing that" (Service G, HCP23).

The context of time constraints featured significantly within the data and underlined professional decision making around using transition preparation tools and transition documents with young people:

"It's the ideal world scenario isn't it. I think, in theory I think they should be achievable but it's, you know we don't practice in an ideal world. To me fundamentally it does come back to the limited resource that we have. That we're just trying to allocate it into priority areas" (Service A, HCP8).

This resulted in professionals prioritising the use of the transition preparation tool and transition documents with young people who they perceived to be most in need of transitioning to adult services.

In services B and C, Ready, Steady, Go was perceived by participants as not being condition-specific enough to their patient group and they continued to use their own transition preparation tools or used it alongside their own tools:

"We've looked at using Ready, Steady, Go... it's too... we feel it's a bit too generic for our needs...." (Service C, HCP12).

Data partially support the rough initial programme theory as the intention of programme designers was for professionals to either use their own transition preparation tools or start to implement Ready, Steady, Go. The capacity for professionals to adapt transition preparation tools to meet the needs of their own patient group was fully considered as discussed by one participant interviewed during the first stage of data collection below:

"... as long as we can show them that it will work and integrate with the condition specific and it's flexible enough to meet the needs of their patients, they will jump on it" (HCP7).

However, the mechanism 'seeing the benefit' as theorised in the rough initial programme theory appeared differently when it came to implementing transition preparation tools and transition documents, due to different contextual factors as discussed above. Professionals reported seeing the benefit of using transition preparation tools with some young people, but not all. Therefore, professional decision making was influenced by their own understanding of the needs of each individual and whether they felt use of the tool would be of benefit to the individual. The outcome was thus different in that professionals took a prioritisation approach and did not use a transition preparation tool for all young people.

### 5.3.5 Adaptation and prioritisation (outcome)

Using transition preparation tools flexibly and adapting Ready, Steady, Go to better meet the needs of young people were commonly reported by professionals in services A, B and F:

"It just needs to be adapted to their understanding or adapted to how they are best going to you know (pauses) understand what's going on and sort of things. But I think it needs to be brought to their level" (Service F, HCP21).

However, as discussed above, professionals did not feel that transition preparation tools and transition documents were always relevant for some young people:

"The ready, steady, go programme itself and the paperwork with that I think is really good. Particularly for our patients with chronic problems who are going to need a lot of input in adult services" (Service G, HCP23). Professionals in services A, D and G reported taking a prioritisation approach whereby transition preparation tools and transition documents would be used with young people whose needs were more complex and who they felt would benefit more from the tool:

"I think to do it across the board is probably impossible with our current resource and I suspect we'll start to identify priority patients to focus with initially" (Service A, HCP8).

In service G, one professional explained how they had requested additional time to hold planned transition appointments in which transition documents would be completed with young people whose needs were more complex:

"And then just sort of saying 'can I have an hour?' And that is counted and its booked as a planned transition appointment. And then I'm sort of planning on seeing them, dependent on what they need, every few month's (Service G, HCP23).

Adapting transition preparation tools and operating a priority approach were important outcomes in five out of seven services within the organisation. However, in services C and E the outcome was different due to the context which affected the operation of the mechanism. Figure 12b illustrates key factors evident in services C and E which hindered the CMO. These are also described in the section below.

### 5.3.6 Summary of CMOC 2

As previously discussed, Rough Initial Programme Theory Two (box 2) hypothesised that if professionals were given dedicated time to use transition preparation tools and felt that they could adapt the tools to their patient groups, then they would be more likely to integrate a tool into transition planning because they would see the benefit to the young person. Data collected to test this theory partially support it. Most professionals did feel that they could use the tool flexibly and adapt it to better meet the needs of their patient group. They also saw the benefit that using the tool had for young people and in some instances did use either Ready, Steady, Go or an alternative transition preparation tool with young people.
However, different contexts affected how professionals across services interacted with transition preparation tools and transition documents. Shared professional values relating to transition and adolescent care supported implementation of transition preparation tools across services A, B, C and F. Nevertheless, time constraints were commonly reported across services A, D, E, F and G as impacting on professionals' ability to fully implement transition preparation tools and transition documents with all young people. In later interviews, when implementation had evolved further and transition documents were integrated into the internal computer system, professionals in services A, E and G described the difficulties they were experiencing when attempting to find and use transition documents.

Data showed that in five out of seven services the mechanism of 'perception of individual need' was significant. When considering using a transition preparation tool and transition documents, professional decision making was influenced by how relevant they felt the tool was to the needs of each individual patient. Contextual features including time constraints and unsupportive technology affected the way professional's reasoned with resources. This resulted in professionals choosing to take a prioritisation approach and only use transition preparation tools and transition documents with young people who had the most complex health needs.

Yet, in services C and E the outcome was very different due to contextual variations in both services which hindered CMOC 2. Service C had a well-established transition pathway which encompassed a structured education programme that covered all aspects of transition. Transition had been treated as a priority for many years and transition preparation was already embedded into working practices, with the education programme being delivered to all young people in the service. Therefore, the mechanism 'perception of individual need' did not trigger as it did for other services. Professionals in service C continued to use their own processes and documentation and the transition pathway had little impact on this service. On the other hand, professionals in service E displayed negative attitudes towards transition preparation tools and transition documents introduced by the transition pathway. They communicated that there was some conflict between their own definitions of what transition should be and the thoughts and actions of other professionals within the same service. Data suggested that there was a lack of consensus between professionals within this service which shaped participants' negative perceptions of the transition pathway. This resulted in professionals deciding not to use transition preparation tools and transition documents with their patients and continuing to follow existing processes which were disconnected from the transition pathway.

# 5.3.7 Final CMOC 2

**Context:** Paediatric healthcare professionals share a set of values in which transition preparation is seen to be a fundamental part of normal adolescent care. However, transition preparation tools and transition documents are not always used with young people due to time constraints and difficulties in using technology.

**Mechanism:** Professionals choose to use transition preparation tools and transition documents based on their perceptions of the needs of each individual patient and the perceived relevancy and benefit use of the tool/documents has for the individual.

**Outcome:** Professionals adapt the tool/documents to meet the needs of individual patients and prioritise who to use the tool/documents with.

The CMO is hindered where there is a lack of consensus between professionals on what transition should entail, negative attitudes about transition preparation tools and documents and pre-existing transition processes.



Figure 12a Final CMO 2 configuration displaying positive outcome



Figure 12b Final CMO 2 configuration displaying negative outcome

# 5.4 Rough Initial Programme Theory Three

Joint transition reviews between paediatric and adult services feature as steps six and nine of the transition pathway. Rough Initial Programme Theory Three (box 3) was based on the premise of programme designers that paediatric healthcare professionals would be more likely to implement joint transition reviews if there was an identified adult service to transition young people to, additional capacity to hold joint reviews and motivated and committed professionals in both services. By working together in partnership with each other, it was assumed that paediatric healthcare professionals would have an improved sense of trust and confidence in their adult colleagues which would support implementation.

3. IF there is an identified adult service to transition young people to (C), motivated professionals in both paediatric and adult services who are committed to improving transition (C) and additional capacity to hold joint transition reviews (C), THEN paediatric health care professionals are more likely to implement joint transition reviews (O), BECAUSE by working together in partnership with adult services, paediatric health care professionals have an improved sense of trust and confidence in their adult service counterparts (M).

Box 3: Rough Initial Programme Theory Three

Rough Initial Programme Theory Three was tested during data collection with paediatric healthcare professionals responsible for implementing the transition pathway. The main contexts, mechanisms and outcomes developed from the data across sub-units (services) of the case study are discussed in detail below. This is followed by a discussion in the summary section about how Rough Initial Programme Theory Three was further refined. The final CMOC for this programme theory is illustrated in figures 13a and 13b.

## 5.4.1 CMOC 3

# 5.4.1 Geographical proximity of paediatric and adult hospitals (context)

In six out of seven services participants agreed that implementation of joint transition reviews was dependent on the area in which the young person would be receiving their care as an adult. Geographical proximity of paediatric and adult hospitals thus acted as both a supportive and unsupportive context. When paediatric and adult hospitals were within proximity to one another, joint transition reviews were more likely to be implemented by health care professionals. The proximity of adult services to paediatric services made it easier and more probable for professionals to come together to undertake joint reviews:

"There's just that one clinic. The nurses and the consultants will pop out because they are only down the road. They will come before that to meet most of the patients who are transitioning from our hospital" (Service B, HCP16).

However, the context was not as receptive for those young people who were transitioning to out-of-area adult hospitals:

".... but it only works for the transition to these teams. Because of course other patients come from out of the area" (Service A, HCP25).

Not having established links with key professionals in out-of-area adult hospitals was the main reason given by participants as to why it was more difficult to implement joint transition reviews:

"The only thing we have got is we have only got the [adult hospital], but we have got other children that may go to like [area], or you know other places that we haven't got that contact and that link with yet. So, but I think what we need is we need to structure the [adult hospital] first and then cascade them out to other hospitals we have" (Service B, HCP17).

Consequently, it appeared that geographical proximity of services supported the operation of the mechanism 'trust and confidence' leading to the positive outcome of 'partial implementation of joint transition reviews'. However, the same context also negatively affected the operation of the mechanism 'trust and confidence' resulting in an unexpected outcome 'joint transition reviews not being implemented'. This is described by one participant below:

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"I think... we've mentioned it already the postcode lottery. Joint reviews number six (step six). That only happens for in area patients. So, that is you know it's an aspiration" (Service A, HCP11).

Figures 13a and 13b further demonstrate how the same context resulted in different outcome patterns. Variations in CMO patterns are also described in more detail in the summary section for CMOC 3.

### 5.4.2 Funding (context)

Implementation of joint transition reviews were further affected by the wider financial context of adolescent care. Services B and C were the only services to have funding in place to support joint transition reviews between paediatric and adult services. Services A, D, E, F and G did not have funding for transition. Participants in these services encountered greater difficulties in terms of implementing joint reviews with adult services. This context again both supported and constrained the operation of the mechanism 'trust and confidence' resulting in different outcome patterns as displayed in figures 13a and 13b.

In services A, D, E, F and G, where there was no funding in place to support transition, pre and post joint transition reviews (steps 6 and 9 of the transition pathway) could not always be implemented. Pre-transition reviews were more likely to be implemented by health care professionals for young people transitioning to local adult hospitals. However, lack of funding affected how often joint reviews could take place and were often dependent on the good will of individual health care professionals in both services:

"At the moment, the only ones that occur here are for them two centres and they only come here. So, the consultants come here. Funding is difficult because what they're saying is... because one of them has said he can come monthly, and it is part of his contract that he can do these. But they don't get funded for it. That's the thing. Whereas, the other consultant it's not part of her. So, she does one every three months and for her to do more will be difficult and she will have to put that forward because she's just not funded for it" (Service A, HCP25).

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In services B and C where there was funding to support joint transition reviews, participants reported more positive implementation outcomes. Joint transition reviews (steps 6 and 9 of the transition pathway) were more likely to happen as adult professionals received funding and transition was integrated into their job roles:

"It's been quite a robust process since 2014/2015. And that's been more around the fact that before then it was sort of done on good will. Whereas now we actually have funding for the adult teams to come and join us for those clinics. So, it's quite... you know it's a very definite thing now. So, they turn up for the clinics now (laughs). Whereas, before it was a little bit more whether they could fit it in. Which is fair enough from their point of view because you know if it's not in their job plans then it's difficult isn't it?" (Service C, HCP22).

However, although service B had funding for joint transition reviews, participants reported difficulties in implementing post-transition reviews (step 9 of the transition pathway) due to resource implications for consultants:

"...consultants they are interested in it, but you know, they are all working beyond you know what they should be doing. They are busy. They've got clinic. They've got hot weeks. They just haven't got the time" (Service B, HCP16).

Lack of capacity within teams to implement post-transition reviews (step 9 of the transition pathway) was also evident in services A, D and E. Data collected from programme designers to develop rough initial programme theories show that services would require additional time for joint transition reviews and implementation would partly depend on this:

*"It is recognised by the transition steering group that additional capacity for lead consultants, and possibly in some specialities specialist nurses, will need to be identified to support the implementation of transition preparation clinics" (Document 1).* 

However, data collected from semi-structured interviews with programme implementers across the trust suggest that the additional resources required to support implementation of joint transition reviews were not in place.

### 5.4.3 Professionals motivation and interest in transition (context)

The individual motivations of professionals in both children and adult sectors were viewed by programme designers as vital to the successful implementation of the transition pathway. Rough Initial Programme Theory Three was developed from the ideas of programme designers that professionals would be more likely to implement joint transition reviews if they were motivated and committed to improving transition (see box 3):

"The will to make it happen both sides. So, where I'm aware of things that go well and have worked well.... it's very often because there is an adult clinician who is interested in this and wants to reach into children's services" (HCP7).

Data collected from programme implementers to test Rough Initial Programme Theory Three supports this context. In services A, B, D and F participants emphasised the importance of having key professionals from both sides who were interested in transition and motivated to improve transition services. The quote below taken from a participant in service D describes how joint transition reviews are reliant on one individual health care professional from the adult sector who has a special interest in transition:

"Yeah, and if that person wasn't to be there, I'd, I don't know whether the service would continue. I'm not sure who else would have an interest. It's through communication from this side and a special relationship really and I don't know who else I could go to. It's not a team, it's one person. So, you know it could potentially fall down" (Service D, HCP5).

The motivations of individual health care professionals acted as a supportive context in four out of seven services enabling the mechanism of 'trust and confidence' as discussed in more detail below.

# 5.6.4 Trust and confidence gained through well-established, collaborative relationships between individual professionals (mechanism)

The strength in relationship between individual practitioners from both children and adult sectors featured as a key resource in the data across services A, B, C, D and G. Relationships between individual professionals were better established when paediatric and adult hospitals were in geographical proximity to one another. Professionals from services A, B, C and G had developed good relationships with their adult colleagues in local hospitals that pre-dated the introduction of the transition pathway. Service D was the only service that did not have an existing relationship with adult professionals, and the introduction of the transition pathway helped them to establish this vital relationship. For services B and C funding for joint transition reviews had strengthened relationships between professionals over a number of years:

"I think we are probably one of the only teams in the trust that have quite a good relationship with the other team. You know, we have got a very good relationship with them. So, you know that's a good thing" (Service B, HCP17).

For services that did not have funding to support transition (A, D and G), relationships were driven more by the individual motivations and interests of health care professionals in children's and adult sectors:

"And this team because they are doing these meetings they are. This is what they want to do. They want to transition these patients. They want to get them over there, and it be appropriate for them. They're really putting a lot into this" (Service A, HCP25).

Whilst individual relationships were seen to be essential to the implementation of joint transition reviews, participants recognised the dangers in relying on singular individuals. A participant described how joint transition reviews in their service are not always possible as they are contingent on the availability of one consultant in one adult service:

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"We've only had a couple of clinics. We've had one in the adult's; I think and one or two over here. The consultants off sick at the moment in the adult service so we're waiting for her return. We did have one due in September. Times ticking on, which is why I'm concerned. If it falls down, I don't know where to go from here" (Service D, HCP5).

Additionally, the context of geographical proximity of paediatric and adult hospitals' was not always supportive when young people were transitioning to out-of-area adult hospitals. Relationships with adult professionals from out-of-area were not well-established which affected the mechanism 'trust and confidence':

"... there are odd consultants in outreach areas that (pauses). Maybe relationships aren't as great (long pause) and they do have the odd issues, don't they" (Service A, HCP26).

Participants from services E and F were the only services to report poor or strained relationships with adult health care professionals. Poor or strained relationships were often linked to a lack of communication, of partnership working from adult professionals, and a lack of capacity in adult teams:

"It's a bit of a long story. They say that they haven't got capacity, but they do it for other centres. Just not for here and I think it's... it's historical really. So, I don't really know. I don't want to go into that side of things.... Yeah. It's a difficult one. It works in other centres they just don't want to come over here and they will have their own reasons for that" (Service F, HCP14).

In these services, the mechanism 'trust and confidence' did not trigger as the context was unsupportive resulting in a negative outcome. This is displayed in figure 13b and discussed in more detail in the summary section for CMOC 3.

The importance of working collaboratively and in partnership to ensure young people receive a good transition, was also described by some participants as essential to the operation of joint transition reviews:

"And then sort of working together to collaborate to get better care. So, that should be what it is. It should be more about working together so it's seamless" (Service B, HCP17).

Participants from services who reported having good, well-established relationships with their adult counterparts further communicated how they were able to use joint transition reviews to work collaboratively with their adult colleagues. Joint transition reviews supported the sharing of information between professionals, education, contact and engagement, which in turn resulted in paediatric health care professionals having an increased sense of confidence and trust in their adult colleagues:

"It's key. Yeah. Because you know that you've got the confidence. You've looked after that child since they have been what two or three and they are sixteen and you are passing them over. You've kept them safe. You know the mums have kept them safe. If you can give the parents that confidence because you've got confidence in that team, then that will help... So, we've got that good relationship. So, I think... and good communication with them. So, that is a massive part of it. It's like we're a team but you're just going to have your hospital admission in another hospital. So, it is really good you know. The relationship we've got with the other team, the other nurses and that. And you know I think that if we didn't have that and you know if they thought they were a bit naff you wouldn't have the confidence then to be sending them yourself. They are like your babies aren't they, and you are letting them go, you know" (Service B, HCP17).

For some participants having trust and confidence in adult health care professionals sent out a good message to young people and their parents supporting them to develop trust and confidence in adult services:

"It sends out a good message to parents and children that you're both roughly on the same sort of hymn sheet and singing the same songs and you know sort of the overall standard of care is a good standard. If they see that you've got a good relationship with the adult services, then that's a healthy thing really. And it gives them trust in the services" (Service B, HCP9). Data collected from programme implementers to test Rough Initial Programme Theory Three support the mechanism of 'trust and confidence'. As presented in box 3, the implementation of joint transition reviews was expected to work through a 'partnership approach' which would instil 'trust and confidence' in paediatric health care professionals. This idea is described in the quote below which is taken from the first stage of data collection:

"The great thing is that because it starts from children's services and goes through to adult services if our adult colleagues can see the steps of preparation that have already happened before, they get involved, hopefully that will give them again that trust and confidence. And if we can see the steps that will continue as the young person moves in adult services, again hopefully that will give that trust and confidence" (HCP7).

However, the data further suggest that relationships between individual practitioners across children and adult sectors were instrumental to paediatric health care professionals having 'trust and confidence' in their adult colleagues. In services E and F, where relationships between professionals were poor or strained, the mechanism of 'trust and confidence' was missing. Additionally, the context (as discussed above) sometimes supported the mechanism of 'trust and confidence' and at other times constrained the mechanism which resulted in a different outcome pattern. Figures 13a and 13b demonstrate how the same context affected the mechanism which in turn resulted in different outcomes. This is described below in more detail.

# 5.4.5 Joint transition reviews are partially implemented for some young people (positive outcome)

In services A, B, C, D and G pre-transition joint reviews (step 6 of the transition pathway) were being implemented by health care professionals for young people transitioning within the local area:

"At the moment, the only ones that occur here are for them two centres and they only come here" (Service A, HCP25).

Participants in services A, B, C and G commented that pre-transition joint reviews had been in place within their services prior to the introduction of the transition pathway, although they did not always refer to them as joint transition reviews:

"It's not classed as a transition clinic. It's a clinic that's full of adolescents but his... Again, his main priority is seeing them from a clinical perspective. We will identify patients, and then sometimes we will do a joint, where we are both sitting in together and we'll discuss part of the transition as well" (Service G, HCP23).

Most services expressed difficulties in implementing post-transition joint reviews (step 9 of the transition pathway) due to lack of capacity within teams of consultants:

*"Joint reviews with adult services leading (step 9). That doesn't happen" (Service B, HCP9).* 

Service D was the only service to report implementation of post-transition joint reviews (step 9 of the transition pathway) for young people transitioning in-area. However, as previously discussed these did not always happen as there was no funding in place to support implementation and the running of joint transition reviews were dependent on the good will and availability of individual adult health care professionals.

# 5.4.6 Joint transition reviews are not implemented for all young people (negative outcome)

Participants across all seven services agreed that joint transition reviews could only be implemented for young people transitioning to in-area adult hospitals. For those young people wishing to receive their care in an adult hospital out-of-area, joint transition reviews were not possible. Similarly, joint transition reviews were only being implemented for young people with specific conditions. Participants reported greater difficulties in implementing joint transition reviews for those young people with more rare conditions:

"Joint reviews. And that's not always going to be possible. You can do that for certain conditions. For our 'condition' the 'condition' nurses come along and meet our patients here or we go over there. But when you've got one patient going here with our more complex diseases which are rarer and are therefore going to just kind of be one person going here and one person going there. A joint review whilst optimal is not going to be practically possible" (Service B, HCP16).

A number of participants expressed their frustrations relating to not having an appropriate adult service to transition young people to, and this resulted in young people either remaining in paediatric services or being discharged to their G.P:

"There seems to be huge stumbling blocks and there are still a lot of children that either remain in paediatrics long after they should, or there are still young adult's that I'm discharging without any, any input in the adult's side because it's just not available" (Service D, HCP5).

Where the context was unsupportive (i.e. out-of-area adult hospitals, lack of funding for transition) the mechanism 'trust and confidence' did not activate and joint transition reviews could not be implemented by paediatric health care professionals for all young people. Therefore, many young people did not receive a joint transition review and were instead transferred through a letter of referral:

"No, I wouldn't say we transition them. I would say I write a letter to 'Dear condition consultant' at whatever hospital they are going to and I write a letter which isn't really a transition process. That's transferring their care" (Service B, HCP16).

## 5.4.7 Summary of CMOC 3

Rough Initial Programme Theory Three (box 3) hypothesised that paediatric health care professionals would be more likely to implement joint transition reviews if there was an identified adult service to transition young people to, additional capacity to support implementation and motivated, committed professionals in both paediatric and adult services. Under the right conditions, successful implementation of joint transition reviews would work through a 'partnership approach' which would increase the 'trust and confidence' that paediatric health care professionals had in their adult counterparts.

Data collected to test this theory partially support it. The motivations of individual health care professionals across children and adult sectors were recognised by participants as an important contextual feature which supported implementation of joint transition reviews. Having an appropriate adult service to transition young people to and additional capacity to hold joint transition reviews were further considered by participants to be essential to successful implementation. However, these contexts were not always present, and participants reported difficulties in fully implementing joint transition reviews due to a lack of capacity across senior medical teams and no destination service being available.

Additional contexts of geographical proximity between paediatric and adult hospitals' and 'funding' also featured heavily in the data and the mechanism 'trust and confidence' was contingent on whether these contexts were supportive or unsupportive. As figure 13a shows the context was most supportive when hospitals were in geographical proximity to one another, there was funding in place to support implementation of joint transition reviews and/or professionals across both services where motivated and interested in improving transition. In these instances, relationships between individual health care professionals across children's and adult sectors were strong and this influenced the reasoning of paediatric health care professionals. Paediatric health care professionals had 'trust and confidence' in their adult sector colleagues and, as a result, pre-transition joint reviews, and in service D only, post-transition joint reviews were more likely to be implemented.

However, figure 13b shows a different CMO pattern as the context did not always act to support the mechanism. Participants across all seven services expressed difficulties in implementing joint transition reviews for young people transitioning to out-of-area hospitals. Contacts and relationships between individual health care professionals had not been established out-of-area which affected the mechanism 'trust and confidence' resulting in a different outcome to what was expected. Only two services (B and C) had funding for transition which helped to support implementation of joint transition reviews. Other services did not have funding in place, and this negatively affected implementation efforts.

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In services E and F, relationships between individual health care professionals were poor or strained. The context was not as supportive in these services and the mechanism 'trust and confidence' was not activated. Additional features of the context which acted to constrain the mechanism included poor communication between paediatric and adult services, and negative attitudes towards implementing the transition pathway. In these services joint transition reviews were not being implemented and young people were being transferred to an adult service through a letter of referral.

#### 5.4.8 Final CMOC 3

**Context:** When paediatric and adult hospitals are within geographical proximity to one another and there is funding attached to service transition, joint transition reviews are more likely to be implemented by paediatric health care professionals. For services that do not have funding attached to service transition, implementation of joint transition reviews depend on the motivations of individual health care professionals across both paediatric and adult services.

**Mechanism:** Good, collaborative relationships between individual health care professionals in children's and adult sectors improves paediatric health care professionals 'trust and confidence' in their adult counterparts.

**Outcome:** Joint transition reviews are partially implemented for some young people transitioning within the local area.

This CMO is hindered by the area in which the young person is transitioning to, the nature of the young person's condition and whether they require transition to multiple services. The CMO is also hindered where communication between paediatric and adult services is poor or/and negative attitudes towards implementation of the pathway.



Figure 13a Final CMO 3 configuration displaying positive outcome



# 5.5 Rough Initial Programme Theory Four

Transition training was an important intervention delivered by programme designers to programme implementers to support implementation of the transition pathway. Programme designers hoped that transition training would improve healthcare professional's knowledge of transition and the pathway, help them understand their roles and responsibilities in transition and facilitate appropriate multi-disciplinary team (MDT) transitional care ownership. Rough Initial Programme Theory Four (box 4) hypothesised that, to achieve these outcomes, relationships and communication between programme designers (transition team) and programme implementers (paediatric healthcare professionals) would need to be supportive ensuring that programme implementers felt their views and experiences had been considered and valued by the transition team.

4. IF transition training facilitates open communication between the transition team and paediatric healthcare professionals (C), THEN paediatric healthcare professionals' knowledge of transition and the pathway will improve, they will have a greater understanding of their roles and responsibilities

and take ownership for their individual patients (O), BECAUSE paediatric healthcare professionals feel that their professional views and experience have been considered and valued by the transition team (M).

#### Box 4: Rough Initial Programme Theory Four

Following the same process as detailed throughout this chapter Rough Initial Programme Theory Four was tested during the second stage of data collection with programme implementers. The main contexts, mechanisms and outcomes developed from the data across sub-units (services) of the case study are discussed in detail below. This is followed by a discussion in the summary section about how Rough Initial Programme Theory Four was further refined. The final CMOC for this programme theory is illustrated in figures 14a and 14b.

## 5.5.1 CMOC 4

## 5.5.1 Inclusive/partnership approach (context)

Relationships between programme designers (transition team) and programme implementers (paediatric healthcare professionals) were in most instances described by participants as supportive. This appeared to be influenced by the approach taken by the transition team during the development of the transition pathway, delivery of

transition training and support around implementation. Participants across services A, B, C, D and F felt that the transition team, and in particular the lead transition service nurse for the trust, had worked in partnership with them considering their knowledge and experiences of transition. Participants in services B and C, where robust transition processes had been in place for many years and transition appeared to be working well, commented most on the inclusive/partnership approach adopted by the lead transition service nurse:

"So, anyone who is interested in transition has talked to us and [lead transition service nurse] has been very inclusive, I think. She has done a massive piece of work that's looked at the needs of different patient groups around the hospital and tried to identify who the key people are and what would be the key... what are the key steps in the transition process. And I think that the [transition pathway] is the result of all of that work really" (Service, B, HCP18).

In service A, a participant described how the lead transition service nurse had worked alongside a consultant within their service to support implementation of the pathway. The perseverance and dedication of the lead transition service nurse was recognised by many participants as key to moving implementation of the pathway forward:

"I think (pauses)... I think they've got a hard job. I think they have really really pushed it with all the different teams to get people on board. To get meetings. So, they have pushed us definitely. They have moved things forward. I couldn't tell you about other teams but definitely with our team. They have got us moving things forward. They have got the team thinking about it.... they're pretty much capturing everyone aren't they? So, but if it hadn't been for [lead transition service nurse] ... I think that we would just be again continuing as it had before. 'Oh, we've got a patient. They're about to turn eighteen. Perhaps we had better get them in the transition clinic'. And that's what has happened in the past. Because some consultants just like to keep hold of patients and then realise suddenly what age they are. I definitely think they have pushed and pushed and pushed but they have had a hard slog to do it" (Service A, HCP25). Furthermore, the approach taken by the transition team to the development of the pathway and delivery of transition training was recognised by a participant in service D who was a member of the transition steering group. They described how they were involved in the early stages of programme development, providing feedback on the transition policy and pathway:

".... And it was a case of coming to the meetings and discussing about our own practice and (pauses). I think it just, drafts were coming out and it was a case of just looking through them and seeing does this fit in" (Service D, HCP5).

The transition steering group and key professionals within each speciality were recognised by programme designers as important resources within the theory development stage of data collection. The quote below from a programme designer highlights the approach taken by the transition team to adoption and implementation of the pathway:

"But the idea is that we are trying to do it in a phased, staged, planned way with named links across the whole trust, with the transition steering group and working speciality to speciality to get them on board. And then to start using the specialities that have been early adopters to help become a resource for the next phase and then the next phase. So, it's very much intended and expected to be that we are working mostly with the more enthusiastic people at this stage, but you know that's being sensible" (HCP7).

Data collected from programme implementers partially supports Rough Initial Programme Theory Four. By working in partnership with key professionals in each speciality and transition steering group members to develop and implement the pathway, most participants described feeling 'supported', 'valued' and 'encouraged' to move transition practice forward and make changes to improve transition in their service. Taking an inclusive/partnership approach to programme development and implementation therefore facilitated adoption and implementation of the pathway in most services (see figure 14a). However, the data suggested that this was not the case for participants across all services (see figure 14b).

The size and availability of the transition team was commonly reported by participants in services A, E and G as a hindrance. Participants in these services felt that the team, which at the time of data collection consisted of two professionals, were too small for the amount of work needed to support professionals within both children and adult sectors:

".... and again, I understand the reason why it's not happening. It's because it's ridiculously... you know it's a huge piece of work for two people to do and one of which who that's not even full time. So, I understand it and it's not criticism. It's more an observation. And it needs to be at least a team of people" (Service E, HCP19).

Additionally, in services A, B and E it was evident that there was some resistance from professionals to fully engage with transition training and implementation of the transition pathway:

"I don't know really because I mean [lead transition service nurse] has tried to open up teaching sessions to all areas. I don't think everyone's necessarily taken them up on that. I know some of my colleagues in therapies have gone to her training and they found it very useful. (Pauses). But I think there is still quite a number of people at the trust who feel that this is too much and it's going to be too difficult to implement and as a result I feel there is still a little bit of resistance there" (Service A, HCP15).

# 5.5.2 Service specific key professionals to co-ordinate transition (context)

Identifying a key professional to support and co-ordinate transition within and across services was identified by participants as both a supportive and unsupportive feature of the context. The transition pathway (step 4) and transition training delivered to programme implementers emphasised the importance of this. However, difficulties in identifying who the keyworker would be were commonly reported across most services.

Services B and D were the only services who had service specific key professionals to co-ordinate transition. In service B, specialist nurses took the lead on co-ordinating transition and this arrangement had been in place prior to the introduction of the new transition pathway. However, whilst it was supportive to have a key professional for transition, participants highlighted the limitations around not having much input from the medical and therapy teams:

"Review the multi-disciplinary team. Again, with [condition] that's where it has been going wrong because it has been the nurses leading it without any involvement from the medical team or the physio team. It needs to be a multi-disciplinary approach" (Service B, HCP16).

In service D, identification of a key professional to support and co-ordinate transition was a direct result of implementation of the transition pathway. It appeared to be working well within this service. However, in comparison to other services, service D had small numbers of people requiring transition and was a specialist service:

"I think in my department, because they know that someone's taken it on, I think they're aware of it and they're keen for it to happen. Perhaps not for them to be involved but they know someone, you know they know that I'm leading it. So, I'm getting letters to book patients on to the transition clinics. So, I think certainly in my department, I think it's working quite well" (Service D, HCP5).

Participants from other services suggested that it was unclear who the transition keyworker should be, and how that would work when multiple services across the trust where involved in supporting young people. Participants commonly reported that transition was still done separately in each speciality and it would be very difficult to identify a professional to lead on transition for more complex young people:

"No, No. There is absolutely not... and I just don't feel when they are under multiple teams, which all of the complex one's are, that we've really got (pauses). No-one really knows... but again, it's like who is leading that? And it's just that confusion (sighs)" (Service G, HCP23). In cases where the context was unsupportive, the mechanism 'active engagement and reflection on practice' was not activated and did not result in the same positive outcomes. This is displayed in figure 14b and described in more detail below.

#### 5.5.3 Active engagement and reflection on practice (mechanism)

The inclusive/partnership approach adopted by the transition team enabled programme implementers across most services to feel 'supported', 'valued' and 'encouraged' to move transition practice forward and make changes to improve transition within their own services. Transition training delivered by programme designers supported paediatric healthcare professionals to actively engage with the transition pathway, think more about transition and reflect on their practice to identify where the gaps were within their services:

"Definitely. It's reenergised me in terms of delivery of transition or trying to improve how we do it. It's made me think much more about transition. It's made me (pauses)... it's made me reflect on current practice, which has been I think, to identify and to begin transition care... I think we've begun too late for many of our patients" (Service A, HCP8).

For those services that had pre-existing, well-established transition processes that they continued to use, it was reported that transition training had a positive effect. Participants in these services reported that transition training helped them identify what they needed to improve on:

"But... I think like you say... like I sort of said already really it just highlighted the fact that we need to be better as a team, not just from a medical point of view... and sort of combining bits... you know... sort of the documentation. Whereas now we're all doing separate bits which is often a waste of time and actually trying to do it together would be better... sort of things. And that was probably the key thing" (Service B, HCP13).

However, the mechanism 'active engagement and reflection on practice' was not activated across all services due to the context being unsupportive (see figure 14b).

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This was most apparent in service E with participants highlighting the size and availability of the transition team as being a barrier to implementation. Participants in this service describe feeling 'deflated' after their transition training and that they had been given 'false hopes' by programme designers:

"... and I felt that we were promised some things that are just not.... also, not going to happen. So, just contact us and we'll sort it type suggestion.... yeah. If we don't get the replies which just makes you not do it in the end if you've tried that" (Service E, HCP19).

"I was quite deflated to be honest when I came out... because I thought you know these people have done so much work clearly around transition... you know putting things in place but actually it's not (pauses)... well it's not workable (laughs) for us. You know for other people it might work very well but you know actually having a kind of one size fits all doesn't always work... and I did feel quite deflated when I came out because we were like well 'it's never going to happen' (laughs)" (Service E, HCP20).

This resulted in a different outcome pattern whereby participants became disengaged and did not make changes to their transition practice. This is displayed in figure 14b and discussed in more detail in the next section of this chapter.

# 5.5.4 Improved knowledge and changes to transition practice (outcomes)

Where the context was supportive and the mechanism 'active engagement and reflection on practice' was activated participants frequently reported that training had made them more aware of transition thus improving their knowledge and helping them to make changes to their transition practice:

"Yes. I think so. Partly through education really. (Pauses). Both for the patient and for the staff as well. Because we're all very much more aware of how it should be done, and people are now starting to take steps to make that happen. So, I think it's made us very much more aware" (Service A, HCP15). Improved knowledge was commonly reported as an outcome across services A, B, D and F. In service A two participants suggested that their knowledge of a young person's route into urgent care (step 4 of the pathway) had improved as a result of the training offered:

"So, I think a real essential is the route into urgent care. That's really important. I don't think anyone discusses it. It's something that came about in the transition pathway which is really important" (Service A, HCP11).

In service D, improved knowledge was described as having a better understanding of where young people fit in to transition and what healthcare professionals should be doing to ensure that young people are fully involved:

"I think it was just being made aware of how you need to try and give more ownership to the young person if it's possible. I think here you often treat the adult's... the parents... more or equal to the children you know. Your dealing with them all the time. Your speaking to them. You're getting information from them more often then you are the child because they can't communicate... a lot of our children can't communicate. So, the training just brought that all to mind really and the fact that you're meant to be addressing clinic letters to young person as well. I have to say we don't always do that but if they have... if they have some communication and we've had a detailed conversation with them then you know I will address it to them if it's appropriate" (Service D, HCP5).

The data support the outcomes hypothesised in Rough Initial Programme Theory Four. The intentions of programme designers were to improve healthcare professionals' knowledge of transition and the pathway, to better understand their roles and responsibilities and to facilitate appropriate MDT transitional care ownership. The quote below from a programme designer illustrates this:

"I think what we're trying to do with the training is again raise awareness of transition in general. Raise awareness of why it's important and encouraging people to take ownership of it for their patients... but also be aware of the fact that it is going to be happening for the young person across all spheres of life and whatever it is... and provide a bit more information and signposting towards resources, guidance and us as a transition team so that they know where to go and were all working closely together" (HCP7).

However, the data further demonstrate that in most services (excluding service E), when the context was supportive and the mechanism 'active engagement and reflection on practice' was active, changes to practice were made by participants. One of the most common changes reported by participants across services A, D, F and G was starting to identify and prepare young people for transition at an earlier age:

"Yeah. It has highlighted it... because if we get a patient who is diagnosed with [condition] at the age of fourteen, or they are starting on medication at that age... I would never have talked about transition. It wouldn't have even entered my head to think about 'let's talk about when you get to adult services and what we'll be doing over the next few years to transition you... making you more independent'. It wouldn't have... I wouldn't have even mentioned it. So, because we've got the [transition pathway] and it is you know... they are trying to push it... I now... when I educate... I also start the initial transition assessment, if they're that age... at fourteen" (Service A, HCP26).

In services A, B and G transition training had further supported them to either establish joint transition clinics or change the way in which they were delivered. Participants in service B had identified the need to make their transition clinics more MDT focused, whilst in service G one participant had requested additional time for transition clinics. In service A joint transition clinics were changed in order for adult sector professionals to take more of a leading role:

"It's been part of the reason why we've changed how we practice in the transition clinic that I'm involved with which we've largely flipped. So, instead of the paediatrician leading with the adult team in the background we've actually flipped it such that the adult team lead and the paediatrician's in the background. It's felt more appropriate and better for the young person to do that. And I think for the facilitating paediatrician to perhaps just let go of the patient a bit sooner" (Service A, HCP8).

Furthermore, participants in services B and D highlighted that as a result of transition training they had changed the structure of their appointments with young people to ensure that young people were offered the opportunity to be seen without their parents in preparation for adulthood:

"I have had a couple who I have asked their parents to leave the room and have a conversation which I think is amazing... that's not really happened before and it's not something I would have sort of thought to have suggested... and... but it has sort of come from them... and, you tend to... now I'm sort of addressing the person more than the parent now. So, that's changed my practice a bit" (Service D, HCP5).

Participants in service C reported fewer changes to their practice due to having preexisting, well-established transition processes which they continued to use. However, they did suggest that their informal processes had become more entrenched as a result of transition training and the pathway:

"As far as I know yeah... and [lead transition service nurse] has pulled it all together and refined it... and you know there were certain aspects of the [transition pathway] we were already using informally... yeah... that have become more entrenched because it's now a part of the care processes within the hospital" (Service C, HCP12).

For some participants, particularly those in service E, making changes to their transition practice was more difficult due to the context being less supportive. A different outcome pattern was evident in which healthcare professionals became disengaged and changes to practice did not take place (see figure 14b). Participants further reported challenges to changing their practice in line with the transition pathway due to normal patterns of working which had become ingrained in their everyday practice:

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"So, there is no reason why we shouldn't... but we just aren't programmed to do that I suppose you know... it's not something we've normally done" (Service B, HCP13).

#### 5.5.6 Summary of CMOC 4

Rough Initial Programme Theory Four (box 4) hypothesised that if transition training facilitated open communication between the transition team (programme designers) and paediatric healthcare professionals (programme implementers) then healthcare professionals' knowledge of transition and the pathway would improve. Consequently, they would have a greater understanding of their roles and responsibilities and facilitate appropriate MDT transitional care ownership. Programme designers hoped that the partnership working approach taken to development, training and implementation would support healthcare professionals to feel valued and they were thus more likely to implement changes.

Data collected to test this theory partially support it. Most participants felt that their professional knowledge and experiences had been considered by the transition team during the development, training and implementation phases of the transition pathway. Participants highlighted how the transition team, in particular the lead transition service nurse, had worked in partnership with them in an inclusive way, supporting and encouraging them to move transition practice forward within their own services. Additionally, having service specific key professionals to co-ordinate transition featured in the data as a supportive context. However, whilst these contexts were supportive in some services in other services, they acted to constrain the mechanism 'active engagement and reflection on practice' (see figure 14b). Participants across services A, B, E and G reported that it was not clear who the key professional should be within each service and it was not always possible to identify a lead professional when multiple services were involved in transition. The size and availability of the transition team and resistance from healthcare professionals to access and engage in transition training and the pathway further hindered the firing of the mechanism.

In most cases participants communicated that they felt valued and supported by the transition team thus supporting the original mechanism in Rough Initial Programme

Theory Four. However, this was refined during data collection and analysis as the data highlighted that transition training worked by supporting healthcare professionals to actively engage with the transition pathway. Transition training helped participants think more about transition and reflect on their own practice to identify where the gaps were in order for them to start to make changes. In services where the context was supportive and the mechanism 'active engagement and reflection on practice' was activated the hypothesised outcomes were partially achieved. Healthcare professionals' knowledge of transition and the pathway improved and changes to transition practice were made by most participants across most services. This is illustrated in figure 14a which shows a positive outcome pattern.

However, the theorised outcomes were not achieved for all participants in all services as the context affected the activation of the mechanism. Some participants reported that they did not fully understand their role and responsibilities when it came to who should be co-ordinating transition in the key worker role. This in turn affected who took ownership for individual patients. In service E, the mechanism 'active engagement and reflection on practice' did not activate due to an unsupportive context. Participants in this service described feeling 'deflated', that 'things would never change' and that they had been 'given false hopes' by the transition team. This resulted in a different outcome pattern as presented in figure 14b with healthcare professionals becoming disengaged and not making changes to practice.

#### 5.5.7 Final CMOC 4

**Context:** An inclusive/partnership approach to development, delivery of training and early implementation efforts between programme designers (transition team) and programme implementers (paediatric healthcare professionals) supports adoption and implementation of the transition pathway. Identifying service specific key professionals to co-ordinate transition further supports early implementation efforts.

**Mechanism:** Transition training supports paediatric healthcare professionals to actively engage with the transition pathway, think more about transition and reflect on current practice to identify service gaps.

**Outcome:** Paediatric healthcare professionals' knowledge of transition and the pathway improves, and changes are made to transition practice.

This CMO is hindered by the size and availability of the transition team and resistance from some professionals to access and engage in transition training. As a result, healthcare professionals can become disengaged and fail to make changes to their transition practice.



Figure 14a Final CMO 4 configuration displaying positive outcome



#### **CMOC 1:**

**Context:** Implementation of the transition pathway is supported by existing, wellestablished transition processes that are similar to the newly developed pathway and inter-organisational commonalities between paediatric and adult services. Existing transition processes, inter-organisational differences and healthcare professionals' perceptions of transition also act as barriers to programme implementation.

**Mechanism:** Paediatric healthcare professionals use their professional autonomy and agency when making implementation decisions based on perceived individual needs and the value implementation brings to patient quality of care. Where the context is unsupportive paediatric healthcare professionals experience feelings of 'self-defeat'.

**Outcome:** Paediatric healthcare professionals adapt and use the transition pathway flexibly to meet individual patient needs. Where the context is unsupportive and professionals experience feelings of 'self-defeat' there is an acceptance that nothing more can be done to change transition within services.

#### **CMOC 2:**

**Context:** Paediatric healthcare professionals share a set of values in which transition preparation is seen to be a fundamental part of normal adolescent care. However, transition preparation tools and transition documents are not always used with young people due to time constraints and difficulties in using technology.

**Mechanism:** Professionals choose to use transition preparation tools and transition documents based on their perceptions of the needs of each individual patient and the perceived relevancy and benefit use of the tool/documents has for the individual.

**Outcome:** Professionals adapt the tool/documents to meet the needs of individual patients and prioritise who to use the tool/documents with.

The CMO is hindered where there is a lack of consensus between professionals on what transition should entail, negative attitudes about transition preparation tools and documents and pre-existing transition processes.

#### **CMOC 3:**

**Context:** When paediatric and adult hospitals are within geographical proximity to one another and there is funding attached to service transition, joint transition reviews are more likely to be implemented by paediatric health care professionals. For services that do not have funding attached to service transition, implementation

of joint transition reviews depend on the motivations of individual health care professionals across both paediatric and adult services.

**Mechanism:** Good, collaborative relationships between individual health care professionals across children's and adult sectors improves paediatric health care professionals 'trust and confidence' in their adult counterparts.

**Outcome:** Joint transition reviews are partially implemented for some young people transitioning within the local area.

This CMO is hindered by the area in which the young person is transitioning too, the nature of the young person's condition and whether they require transition to multiple services. The CMO is also hindered where communication between paediatric and adult services is poor or/and negative attitudes towards implementation of the pathway.

#### CMOC 4:

**Context:** An inclusive/partnership approach to development, delivery of training and early implementation efforts between programme designers (transition team) and programme implementers (paediatric healthcare professionals) supports adoption and implementation of the transition pathway. Identifying service specific key professionals to co-ordinate transition further supports early implementation efforts.

**Mechanism:** Transition training supports paediatric healthcare professionals to actively engage with the transition pathway, think more about transition and reflect on current practice to identify service gaps.

**Outcome:** Paediatric healthcare professionals' knowledge of transition and the pathway improves, and changes are made to transition practice.

This CMO is hindered by the size and availability of the transition team and resistance from some professionals to access and engage in transition training. As a result, healthcare professionals can become disengaged and fail to make changes to their transition practice.

Table 5.2 Summary of final CMO configurations
## 5.6 Conclusion

This chapter has presented the findings from the evaluation of the implementation of the transition programme. It has identified how rough initial programme theories developed from documentary analysis and semi-structured interviews with programme designers were tested during the second stage of data collection, which consisted of semi-structured interviews with programme implementers across seven services (sub-units of analysis) within the paediatric organisation. The chapter demonstrates how the use of sub-units (services) within the case under study (transition programme) enabled CMOCs to be built upon and refined over time. Identifying demi-regularities between sub-unit CMOCs helped to provide an explanation of how the transition programme was being implemented overall within the trust. Differences between CMO patterns across sub-units and probable reasons as to why this may be are further accounted for and will be discussed in more detail in the discussion chapter. The chapter concludes with a summary of the four CMO configurations that were identified from the data to answer the research question as to what are the contexts, mechanisms and outcomes that exist within the transition programme's implementation? The next chapter will discuss the main CMO findings in the context of the existing theoretical literature.

## **Chapter 6: Discussion**

## 6.1 Introduction

This chapter will discuss the main CMOC findings and their implications for the wider field of theory and literature to identify what new contribution to knowledge the study makes. In doing so, it will answer the main research question and sub-questions:

1. To what extent do implementation processes and contexts affect the success or failure of transition programmes?

1a. What are the contexts, mechanisms and outcomes that exist within the programme's implementation?

1b. How do contexts influence or hinder implementation mechanisms and outcomes?

1c. How does organisational behaviour affect programme implementation?1d. How useful is realist evaluation as a framework to evaluate programme implementation?

In realist evaluation, CMOC demi-regularities are synthesised back into programme theories either during or following analysis (Gilmore et al., 2019). This study adopted the latter approach. Rough initial programme theories will be re-visited in this chapter and discussed alongside CMOC demi-regularities and theory and literature in order to refine programme theories. The chapter will present the refined programme theories which are situated within existing formal theories. As the aim of realist evaluation is to produce policy-relevant findings at a level of abstraction that can be transferred across settings (Salter and Kothari, 2014; Fletcher et al., 2016), final programme theories will be practical recommendations that can be generalised to programme implementation in other contexts. Final programme theories will inform the concluding chapter of this thesis which will discuss the strengths and limitations of the study, the original contribution to knowledge and recommendations for future research, policy and practice.

#### 6.2 Realist evaluation and theory

The important role that theory plays in realist evaluation has been discussed in the methodology chapter. However, as this current chapter draws on existing formal theories to situate and discuss CMOC findings, this section will re-visit the different types of theories used in this study to clarify their purpose. May's (2013) General Theory of Implementation (GTI) is partly relevant in offering explanation of CMOC findings and is discussed throughout this chapter. However, GTI does not provide a comprehensive understanding of the study's findings and alternative formal theories are drawn on to give wider explanations.

In the findings chapter, programme theories represented as CMO configurations from across all sub-units (services) were presented and discussed. Programme theories pertain to specific interventions (Kislov et al., 2019) and focus on the 'assumptions about (behavioural, social, economic) mechanisms underlying a program or intervention (or policy) that are believed to help realise the goals of an intervention or program' (Leeuw and Donaldson, 2015: 468-469). In realist evaluation, the CMO formula is used as a heuristic device to demonstrate the interrelatedness of contexts, mechanisms and outcomes that make up programme theories. Whilst programme theories are useful in explaining what it is about a specific programme that works, for whom and in what contexts (Pawson and Tilley, 1997), explanation cannot be transferred to different programmes or settings from programme theories alone (Leeuw and Donaldson, 2015). Instead, realist evaluation encourages researchers to use existing middle-range theory to explain how programmes (or in this study programme implementation) work (Astbury, 2018). Leeuw and Donaldson (2015: 472) argue that 'working with tested and robust explanatory theories from the (social, behavioural and policy) sciences adds crucial insights about mechanisms and contexts underlying policies and programs'. Operating at the middle-range further provides greater opportunities for the transferability of CMOC findings to different contexts (Pawson and Tilley, 2004). This discussion chapter therefore uses existing formal theories, that offer the highest explanatory potential (Kislov et al., 2019), to situate CMOC findings and provide plausible explanations (Marchal, Kegels and Van Belle, 2018) that can be generalised to programme implementation in other contexts.

Nilsen (2015) suggests that classic theories which originate from psychology, sociology and organisational theory offer detailed understanding and explanation of aspects of programme implementation. One such theory is a 'general theory of implementation' (GTI) which links Normalisation Process Theory (NPT) with constructs from sociology (social network theories) and psychology (social cognitive theories) 'to provide a more comprehensive explanation of the constituents of implementation processes' (May, 2013: 18). A diagram of how higher level and middle-range theories inform GTI is provided in [Appendix L]. May's (2013) GTI incorporates four core constructs: potential, capacity, capability and contribution. Each of these constructs contain core components which are displayed in Appendix M. May (2013: 18) describes and explains implementation processes as:

'interactions between 'emergent expressions of agency' (the things that people do to make something happen and the ways that they work with different components of a complex intervention to do so) and as 'dynamic elements of context' (the social structural and social cognitive resources that people draw on to realise that agency)'.

The role of professional agency (capability and contribution) and influence of wider contextual factors (potential and capacity) strongly featured in the CMOC findings. Hence, GTI provides a useful framework for explaining implementation processes (Segrott et al., 2017), the interactions between human agency (decision-making agents) (Chandler et al., 2016) and the contexts which shape, influence and constrain decision making. As it combines multiple theoretical approaches it further offers a more comprehensive explanation of programme implementation (May, 2013; Nilsen, 2015). Its ability to explain the CMOC findings was therefore considered to be meaningful.

However, the core constructs and their related components were not always sufficient in offering explanations of CMOC findings in the present case. This is why middle-range theories which underpin GTI were often referred back to as in some cases they offered more meaningful explanations. Wider formal theory and literature was further drawn on to situate CMOC findings. Whilst GTI recognises that dynamic elements of the context exist across different levels of the social system, the framework it uses fails to differentiate between the micro, meso and macro level contexts and how these interact and influence each other. The

interaction between contexts within and across different levels of the healthcare system and their relationships with implementation mechanisms and outcomes was relevant to this study's findings. The structure of the discussion chapter therefore reflects this and categorises contexts identified across all CMOCs according to the level of the healthcare system in which they operate. Definitions of micro, meso and macro level contexts are provided below alongside a discussion relating to the importance of context to this study's findings.

## 6.3 Structure of the chapter

Identifying and understanding how pre-existing contextual features shape and affect the operation of mechanisms and outcomes is essential to realist evaluation. For Pawson and Tilley (1997), mechanisms are conditioned by the contexts in which the programme operates. Therefore, to understand and explain mechanisms and outcomes one firstly needs to recognise the importance of context. Context played a vital part in this study. As discussed in the findings chapter, context adopted a dual role in both facilitating and constraining implementation in some services. It further featured within and across different levels of the healthcare system which interact and influence one another. Fulop and Robert (2015: 31) suggest that it is 'the dynamic relationships between different contextual factors, both within and between levels' which impacts on the success and sustainability of quality improvement efforts. They argue that little attention has been paid to the interaction of multiple levels of context and how they impact on the effectiveness of quality improvement. Whilst this study does not evaluate the effectiveness of the transition programme, it does evaluate the effectiveness of programme implementation and the multiple contexts which facilitate and/or hinder implementation efforts.

The chapter is therefore broken down into the macro, meso and micro level contexts that featured across all CMOC findings. Existing literature, guidance, policy and theory relating to transition and programme implementation is used to interpret CMOC findings and better understand their meaning. Consideration has been given to both Pawson's (2006; 2013) definition of contextual layers which was applied during data analysis to identify and differentiate contexts, and Fulop and Robert's (2015) definitions of macro, meso and micro

level contexts. Fulop and Robert's (2015) definition of context levels was deemed to be more suitable to structuring the discussion of findings. The following definitions are thus applied:

- Macro contextual factors are located at the system level
- Meso contextual factors are located at the organisational level
- Micro contextual factors are located at the team or individual professional

The subsequent section of the chapter begins with a recap of the main CMOC findings before discussing the macro, meso and micro level contexts across CMOCs against the wider literature and theory base. This is followed by a discussion of the mechanisms and outcomes which are again interpreted using existing theory, literature, policy and guidance. The chapter ends with a final summary, the refined programme theories and the study's original contribution to knowledge

## 6.4 CMOC findings

The previous chapter highlighted and examined four CMO configurations which were evident across different sub-units (services) within the organisation. CMOC 1 emphasised the importance of well-established, existing transition processes, inter-organisational commonalities and differences and healthcare professional's perceptions of transition. In CMOC 2, shared professional values, time constraints and unsupportive technology were significant contextual factors. Geographical proximity of paediatric and adult hospitals, funding and professional's motivation and interest in transition were key elements of the context in CMOC 3. CMOC 4 indicated that an inclusive/partnership approach and service-specific key professionals to co-ordinate transition were important. The relevance of these findings is discussed in the following sections of this chapter using existing theory, literature, policy and guidance to offer further explanation.

## 6.5 Macro level contexts

As discussed above, macro level contexts operate within the system level of the organisation (Fulop and Robert, 2015). Fulop and Robert's (2015) definition of macro contextual factors and Pawson's (2006; 2013) definition of contextual layers at the infra-structural level were

used to determine the macro level contexts within this study that facilitated or hindered the mechanisms within the transition programme.

The findings chapter highlighted three dominant macro-level contexts that were identified across CMOCs. These were inter-organisational commonalities and differences, geographical proximity of paediatric and adult hospitals and funding. The following section of this chapter discusses these contexts against the wider field of literature and theory. Descriptions of macro level contexts are refined taking into consideration their meaning for transition and programme implementation. As previously highlighted whilst there is some discussion of mechanisms and outcomes in this section, the main analysis takes place in subsequent sections of the chapter.

# 6.5.1 The structural and cultural divide between children's and adult services

Implementation of the transition pathway across services within the paediatric organisation was both facilitated and impeded by similarities and differences between the paediatric and multiple adult healthcare organisations. Similarities and differences exist in the structure and delivery of services as well as differences between organisational culture. For example, in paediatric organisations services tend to be under the 'same roof' whilst in adult organisations services are spread out across different hospitals. Culturally, children's services may be more child and family-centred and offer a holistic, supportive approach to care, whereas adult services are more independence-orientated (Kime et al., 2013; Brown et al., 2020). This argument is well recognised in the healthcare transition policy and literature field and can create additional challenges for young people moving between services (Allen et al., 2010; Huang et al., 2011; NICE, 2016; Kerr et al., 2017; Brown et al., 2020). Findings from this study suggest that structural and cultural differences between children's and adult services also affect implementation processes.

In some paediatric services where existing transition processes were well-integrated and relationships with adult services were established, services had a similar set up for the delivery of care. In these services, similar ways of working had been built on over the years and appeared to be motivated by the nature of young people's conditions and their treatment requirements in adulthood. In this context, inter-organisational commonalities supported professional decision making on implementation of the pathway. Existing transition processes within these services were similar to, and thus compatible with, the new pathway and participants felt that they were already applying many of the steps to their practice. This finding is supported by Kingsnorth et al. (2011) who found that the fit and compatibility between paediatric and adult organisations acted as a key enabler to support implementation of a new transition model.

However, across the remaining paediatric services participants highlighted important interorganisational differences which affected how health care professionals responded to the transition pathway. This study found that inter-organisational structures were not always in place to support full implementation. A lack of equivalent adult services, moving between tertiary to non-tertiary hospitals and different approaches taken to supporting patients were commonly raised by participants as barriers to transition.

Allen et al. (2010) indicate that many of these challenges result from the cultural differences that exist between paediatric and adult services. As found in this study, the nurturing, family-orientated ethos of paediatric services can conflict with the independence-oriented ethos of adult services (Allen et al., 2010). This can create barriers for both professionals, young people and parents who may perceive adult services as offering a lesser quality experience (Rogers et al., 2019). Young people may also be seen less frequently in adult services and there may be no follow-up for those who fail to attend their appointments (Allen et al., 2010). This was reported by healthcare professionals in this study to be a common worry which at times impacted on their decision making with regards to implementation.

Findings from this study suggest that cultural differences between paediatric and adult services can affect how paediatric health care professionals use their professional autonomy and agency when making implementation decisions. For some participants, implementing steps within the transition pathway within their own services was considered to be futile if their adult counterparts were not equally on board with implementation, and/or inter-organisational structures were absent.

According to Greenhalgh et al. (2004: 608) 'an important influence on an organisation's decision to adopt is whether a threshold proportion of comparable (homophilous) organisations have done so or plan to do so'. Although the focus of this evaluation was on the early implementation of the transition pathway across seven services within the paediatric organisation, it was evident that many participants felt that full implementation of the pathway was dependent on uptake from adult organisations. Transition between paediatric and adult services involves collaboration and inter-agency working between a number of different organisations. However, participants in several services within the paediatric organisation commented that connections with adult services were not always established which impacted on their ability to work together to support implementation. Social network theory, which is one of several mid-range theories which underpin and inform May's (2013) GTI, may help to explain how and why similarities/differences between organisations affected implementation of the transition pathway.

A key argument within this theory is that adoption and implementation of innovations by individuals, are influenced by the structure and guality of their social networks (Greenhalgh et al., 2004). 'Social networks represent ties between individuals' (West et al., 1999: 634) and are 'important antecedent conditions for implementation processes, because they provide relational contexts for the reciprocal chains of interactions and flows of information that form social systems' (May, 2013: 5). Findings from this study suggest that interorganisational social networks were strong in some services yet lacking in others. Participants capacity to co-operate and co-ordinate their actions to implement the transition pathway were constrained by weak inter-organisational social networks. Structural and cultural differences between children's and adult services in terms of material resources such as funding and infrastructure, and conflicting social norms further created barriers for paediatric healthcare professionals when making implementation decisions. Some participants described feelings of frustration at not knowing the right people to contact in adult services and not having adult services fully on board to continue good transition practice through implementation of the pathway. In these instances, the ability for participants to 'see the benefit' that implementation would bring to young people and their own services, as hypothesised in the initial programme theory, was hindered. Instead,

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participants expressed feelings of 'self-defeat' and an acceptance that there is nothing more they can do to change transition processes in their service.

Having well-established inter-organisational social networks and 'buy in' from adult organisations were critical to full implementation of the transition pathway. This is an important finding from this study as it highlights how lack of inter-organisational social networks affect how paediatric health care professionals choose to implement transition programmes. In services where inter-organisational networks were strong, professionals were more likely to implement steps within the pathway if they were not already doing so as part of their own transition processes. Comparably, in services where inter-organisational networks were lacking, professionals were less likely to implement steps within the pathway. Policymakers should therefore consider the structure and quality of their social networks with adult organisations when developing and implementing new transition programmes.

However, structural and cultural differences between children's and adult services affected the development of inter-organisational social networks. Similarities and differences in the way services were structured and delivered either supported or hindered the formation of inter-organisational social networks. Findings from this study further support Allen et al. (2010) who suggest that more needs to be done to bridge the 'cultural gap' between paediatric and adult services. Whilst the existing healthcare transition literature evidences the difficulties young people face when transitioning due to 'cultural differences' between services, this study further indicates that 'cultural differences' influence the decisions that paediatric health care professionals make when implementing transition programmes.

#### 6.5.2 Proximity and social networks

Proximity and availability of adult services are frequently cited in the healthcare transition literature as both a facilitator and barrier to transition (Bryon and Madge, 2001; Viner, 2009; Kingsnorth et al., 2011; Kerr et al., 2017). Although availability of adult services was recognised as significant to programme implementation in Rough Initial Programme Theory Three, findings from this study suggest that implementation of joint transition reviews were further influenced and/or constrained by the geographical proximity of paediatric and adult organisations. Joint transition reviews were more likely to occur where paediatric and adult

services were in geographical proximity to one another. For young people receiving their adult care out of area, joint transition reviews were less likely to be implemented. Participants suggested joint transition reviews were more feasible and easier to organise where services were in geographical proximity. Inter-organisational social networks were also more established between paediatric and adult services that were closely located. Findings from this study highlight how geographical proximity of services influences social proximity.

Viner (2009) suggests that geographical proximity of services does not translate into a close professional relationship. However, findings from this study highlight the importance of proximity to inter-organisational social networks and relationships between healthcare professionals. In CMOC 3, the mechanism 'relationships' was contingent on how closely located paediatric and adult organisations were to one another. Services that were in geographical proximity to one another had established strong social networks over the years. Within these social networks, individual paediatric and adult health care professionals had developed 'trust and confidence' in one another, and this helped to support implementation of the joint transition reviews. This finding suggests that both proximity of services and social network contexts interacted with one another to support implementation of joint transition reviews.

In comparison, social networks and relationships with out-of-area adult hospitals and key professionals were not as well established. Health care professionals' capacity to co-operate and co-ordinate their actions (May, 2013) when attempting to implement joint transition reviews were directly affected by disconnected 'physical systems'. In this context, 'geographical proximity' acted to constrain the mechanism and joint transition reviews did not happen for young people receiving their adult care out of area. Instead, young people's care was transferred to the adult organisation by a referral letter between professionals.

It is important to highlight that findings from this study are not reflective of the changes brought about by the COVID-19 pandemic. Since March 2020, healthcare organisations have started to implement virtualised care (Webster, 2020) including remote consultations as part of the response to coronavirus (NHS England and NHS Improvement, 2020). At the time of writing this thesis, there are no known studies that have specifically focused on how virtualised care has affected transition and in particular the facilitation of joint transition reviews. Studies that focus on the usefulness of virtual clinics more generally, have shown them to be a more convenient and cost-effective option for patients (Lavin et al., 2020). However, in a recent discussion paper published in the Lancet, Webster (2020) argues that a permanent move to virtualised care would risk diminishing the quality of clinical care. In this study, there was an absence of data to support the use of digital technology to facilitate joint transition reviews for patients transitioning out-of-area. However, the move to virtualised care as a response to coronavirus may have provided opportunities for paediatric and adult professionals to embrace innovation and implement better ways of working. It also offers potential to conveniently bring the MDT together to convene joint transition reviews. As there are no published studies on this to date, it is difficult to know what impact use of digital technology has had on transition. Therefore, future research which evaluates the impact of virtual clinics on transition for young people with long-term conditions is vital.

#### 6.5.3 The wider funding agenda for transition

In this study, implementation processes and outcomes were further affected by whether there was funding in place to support joint transition reviews with adult services. Lack of funding for transitional health care is a national issue which has implications on paediatric organisations when attempting to improve transition services. A recent study undertaken by Colver et al. (2019) argues that little has changed over the past ten years despite national guidance on how to improve transition. Although national guidance has been welcomed, there is little evidence to support it which impacts on levels of commitment and investment from commissioners and providers of health services (CQC, 2014; Colver et al., 2019). It is still not clear where responsibility for funding transitional health care arrangements sits, with commissioners and providers of adults' services viewing it to be the responsibility of children's services (Colver et al., 2019). Although this study did not extend to adult services, findings indicate that the wider funding agenda for transition clearly affected paediatric professional's ability to implement specific aspects of the transition pathway.

In two paediatric services within the organisation participants communicated that adult services were funded to attend joint transition reviews and transition was integrated within adult professionals' job roles. As a result, joint transition reviews were more likely to be implemented in services that had existing funding for transition. In contrast, participants in services that did not have funding were less likely to implement joint transition reviews and implementation was dependent on the 'good will' and 'motivation' of individual healthcare professionals across both services. This finding supports the work of Baines (2009) and McManus et al. (2015) who suggest that lack of funding for added transition work affects adherence to policy standards and the sustainability of programme implementation.

Although, programme designers recognised the need for additional capacity to implement joint reviews, findings from this study suggest that material resources including additional time and funding were not always in place. A lack of social-structural resources available to health care professionals affected their potential to translate capacity into action (May, 2013). However, in some services, healthcare professionals showed high levels of individual and shared commitment (May, 2013) to implement joint transition reviews. Micro level contexts including 'motivation and interest in transition' interacted with macro level contexts in meaningful ways. This is discussed in more detail under the micro level contexts section of this chapter.

## **6.6 Meso level contexts**

Meso level contexts operate at the organisational level. Fulop and Robert's (2015) definition of meso contextual factors and Pawson's (2006; 2013) definition of contextual layers at the institutional level were used to determine the meso level contexts within this study that facilitated or hindered the mechanisms within the transition programme. Well-established, existing transition processes, shared professional values, time constraints, unsupportive technology, inclusive/partnership approach and service-specific key professionals to coordinate transition were the main meso-level contexts identified across CMOCs during analysis. These are discussed in detail below against the background of the wider theory, literature, guidance and policy. Descriptions of meso-level contexts have similarly been refined to take into consideration their meaning for transition and programme implementation.

#### 6.6.1 Habituation and existing ways of working

Existing transition processes were well-established and integrated into usual care in some services but not others. Many participants viewed the new transition pathway as being very similar to and compatible with their own transition processes. In fact, the transition pathway had been developed taking into account existing transition processes in services that were considered to be good exemplars of transition practice. Programme designers intended for the new pathway to be used flexibly alongside existing transition processes and to be adapted to meet the needs of different patient groups. However, findings from this study showed that whilst some healthcare professionals were more willing to use the pathway flexibly alongside their own processes, others did not believe that they needed to change their practice and continued to use their own transition processes.

May's (2013) GTI helps to situate this finding within the wider context of programme implementation in healthcare organisations. May (2013) views organisations or services within an organisation as social systems that are emergent. They are emergent because 'they are shaped, over time and across space, by both endogenous and exogenous factors' (May, 2013: 3). Within these social systems are existing delivery systems (May, 2013) or, for the purpose of this study, existing ways of delivering transition within individual services. The new transition pathway was expected to operate within these existing systems to implement and embed it into routine practice (May, 2013). Essential to this is the theoretical construct of capability. May (2013) indicates that the capability of health care professionals to enact the transition pathway is dependent on both its workability and integration into standard practice. In this study, the flexible design of the transition pathway offered a high degree of workability and integration. Yet, although many participants agreed that the pathway was flexible and could be adapted and used alongside existing processes, this was not always operationalised in practice.

A systematic review carried out by Geerligs et al. (2018) on barriers and facilitators to implementation processes in hospital-based interventions uncovered a similar pattern. They suggest that interventions that are compatible with existing hospital systems and ways of working are more likely to be implemented by healthcare professionals (Geerligs et al.,

2018). However, contrary to this they found evidence that healthcare professionals were less likely to adopt the changes required for effective implementation if they 'felt they were already equipped to address the issue targeted by the intervention' (Geerligs et al., 2018: 10). The theoretical construct of 'contribution' in May's (2013) GTI offers a more comprehensive explanation of this finding.

May (2013) suggests that participants invest sense-making, commitment, effort and appraisal into implementation of new practices over time. How participants understand and make sense of a practice or, as May (2013) terms it, 'coherence or sense-making' is key to how they move forward with implementation. Differentiation is seen to be an important aspect of coherence (May and Finch, 2009). A study undertaken by Sutton et al. (2018) which explored sense-making in implementation of an enhanced recovery after surgery programme, found that professionals had to be able to differentiate the new practice favourably from the old practice in order to invest in implementation. Furthermore, professionals had to believe in the new practice both as an individual and as a team (Sutton et al., 2018). Professionals thus considered the meaning of implementing the new practice by assessing its value, benefits and importance to patient care and linking it to personal norms and values (Sutton et al., 2018). Coherence or sense-making may help to explain how the context 'existing transition processes' both supported and hindered the mechanism of 'professional autonomy and agency to benefit young people' in CMOC 1.

As discussed above, many participants commented on the similarities between the new transition pathway and their existing processes. In doing so, participants were attempting to differentiate between existing ways of delivering transition and the new approach. Where professionals viewed the new pathway as being 'no different' to their own processes, they were less likely to make changes to their practice, even though they recognised that certain steps within the pathway were not being implemented. In Sutton et al's. (2018) study, many participants stated that the new programme had formalised practice that was already being enacted rather than creating major changes. For others, the introduction of the new programme had resulted in significant changes to their practice (Sutton et al., 2018).

Similar findings were uncovered in this study. In services with well-established existing transition processes participants suggested that the new pathway had formalised transition practice across the trust and they continued to use their own practices. In services with less established or no existing processes there were some changes resulting from implementation of the new pathway. However, further contexts across the macro, meso and micro levels of the system affected implementation mechanisms and outcomes across different services.

Results from this study further indicate that professionals considered the value, benefits and importance which implementation of steps within the pathway would bring to patient care as part of their 'sense-making' process. Findings supported the theorised mechanism 'seeing the benefit' in Rough Initial Programme Theory One. Professionals were able to see the benefit and value that implementation of the pathway would bring to each individual patient. Where professionals were unable to 'see the benefit' they were less likely to implement steps within the pathway. Sanders et al. (2011) support this finding suggesting that a failure to demonstrate coherence to implementers is frequently reported as a barrier to implementation. Professionals are more reluctant to implement new ways of working if they perceive them unfavourably (Sanders et al., 2011). However, in some instances although participants perceived the transition pathway favourably, it was evident that they found it difficult to deviate from their existing practices.

Habituation or habit theory offers valuable insights into why healthcare professionals were reluctant to implement new ways of working and make changes to current practice. Nilsen et al. (2012: 53) define habit as a 'behaviour that has been repeated until it has become more or less automatic, enacted with purposeful thinking, largely without any sense of awareness'. Nilsen et al. (2012: 57) argue that healthcare professionals are 'prone to developing efficient and automatically activated habits' as their daily practice is primarily habitual by nature. Implementing change can be more difficult where practices are well-established and healthcare professionals may be more predisposed to familiar ways of working (Davidoff, 2015). This is supported by Rycroft-Malone et al. (2013) who argue that healthcare organisations become habituated as existing ways of working are embedded and institutionalised within systems so that standard practice becomes the acceptable norm. In

Rycroft-Malone et al's (2013) study professionals considered traditional ways of working to offer them more stability and familiarity. Findings from this study support the findings of Nilsen et al. (2012), Rycroft-Malone et al. (2013) and Davidoff (2015) by highlighting how healthcare professionals form habitual behaviours which impact on how and to what extent they choose to engage with the implementation of new practices. This helps to explain why in some services healthcare professionals failed to implement certain interventions within the pathway even though they differed to their own processes. However, it is important to note that additional contexts on the macro, meso and micro levels presented equal challenges for programme implementation across services within the trust. These are discussed in more detail in the following sections of this chapter.

#### 6.6.2 Norms of practice

Shared professional values acted as a supportive context in this study. Healthcare professionals across services shared a set of professional values about transition preparation in which it was seen to be an integral part of routine adolescent care. For some participants in this study, adolescent care involved providing young people with age and developmentally appropriate healthcare information. Developmentally appropriate healthcare is well-recognised in transition policy and guidance (NICE, 2016; Colver et al., 2019). Good practice guidance suggests that transition support should be developmentally appropriate, considering the 'changing biopsychosocial developmental needs' of young people (Colver et al., 2019: 21). Within this study, transition preparation fell into the category of routine or developmentally appropriate adolescent care. Price et al. (2011) report a similar finding from their study which explored the implementation of a transition pathway in a Diabetes Service from the perspectives and experiences of young people. Young people did not perceive the transition pathway as being separate from their normal clinical care (Price et al., 2011). Instead, they viewed it to be a standard element of their general healthcare experience (Price et al., 2011). Whilst participants in this study reported that conversations to prepare young people for transition were happening from an early age, it was evident that transition preparation was being done informally most of the time rather than being recorded using a transition preparation tool or transition plan.

Habituation once again offers some insight into why some healthcare professionals in this study failed to change their practice to accommodate the new transition pathway. Although professionals were preparing young people for transition by having conversations as part of their normal adolescent care, this formed part of their existing transition processes. The use of transition preparation tools and transition plans was not new to services as many had their own preparation tools which were more specific to their patient groups. However, the new pathway incorporated transition preparation tools and transition professionals would use these tools as part of transition planning. In this sense, there was an expected change to current practice, yet in some services participants continued to use existing practices which had become habituated.

Changing practitioner habits or existing ways of working can be challenging and is recognised as one of many barriers to the implementation of clinical guidelines in practice (Fischer et al., 2016, Cotterill et al., 2019). Organisations and professionals working in them have established social or clinical norms that govern their behaviour (McDonnell Norms Group, 2006). These can be implicit or explicit and are often informal rules that are used to determine values, attitudes and beliefs (Cotterill et al., 2019). In this study, professionals expressed that they were already working with young people to prepare them for transition. Working with young people in age and developmentally appropriate ways was an established norm of practice, although this was mainly done informally. Therefore, changing practice by making this more formal through recording information using a transition preparation tool or plan, was not always seen to be necessary. In this instance social norms and established habits shaped the way in which professionals responded to implementation of the transition guidelines. Research by the McDonnell Norms Group (2006) suggests that organisations must align desired changes with existing norms to support understanding and adoption of new practices. Findings from this study support this by demonstrating that there is a relationship between established norms of practice and non-adherence to clinical guidelines. Policymakers should take this into consideration during the early development stages of new initiatives.

#### 6.6.3 Lack of resources

In CMOC 2, the context of 'time constraints' affected how professionals engaged with transition preparation tools and documents. Whilst having additional time to use transition preparation tools with young people was recognised as vital in the initial programme theories, findings from the study suggested that additional time resources were not in place to support implementation. This is by no means unexpected. Lack of resources such as time restrictions and heavy workload are commonly reported within the literature as barriers to the implementation of clinical guidelines and interventions (Fischer et al., 2016, Geerligs et al., 2018).

Professionals in this study also described having to prioritise the medical aspects of young people's care over the transition aspects due to time constraints. A lack of additional time given to focus on the biopsychosocial needs of young people during their transition meant that there was an over-reliance on the medical model of care. Farre and Rapley (2017) highlight how the biopsychosocial model is integral to understanding the health and care needs of adolescents. However, integrating this model of working into healthcare practice remains challenging (Farre and Rapley, 2017). Furthermore, transitional care is not always prioritised by commissioners and managers (Kime et al., 2013, Colver et al., 2019) and this was commented on by many participants in this study. This relates to the wider funding agenda for transition and how commissioners and providers of health services are reluctant to invest resources into transition due to a lack of evidence to support good practice guidance (Colver et al., 2019). A lack of time to complete additional paperwork resulting from the new pathway made it difficult for professionals to implement transition preparation tools and documents.

Professionals' capacity to implement transition preparation tools and documents was affected by lack of material resources (i.e. time) that were necessary for implementation (May, 2013). Lack of material resources in turn were reported to compromise the workability and integration of the transition pathway into routine practice (May, 2013). However, in some services healthcare professionals were able to make transition preparation tools and documents workable and attempt to integrate them into their practice by using them flexibly, adapting and prioritising their use based on their perception of individual patient need. This

is discussed in more detail below in relation to the third interrelated context 'unsupportive technology' which underpinned CMOC 2.

#### 6.6.4 Information Technology Systems

Towards the latter stages of semi-structured interviews with healthcare professionals it was apparent that the implementation of the pathway had advanced and transition documents, which were key resources offered by the pathway, had been integrated into the hospital's internal electronic system. A number of participants highlighted the difficulties they faced in relation to accessing and using relevant documents with young people. It is important to note that this finding was not representative of the whole sample of participants, as in earlier interviews transition documents were still in paper format and participants did not have the same experiences with technology. However, it was significant to the overall findings of this study as it provided a more comprehensive understanding of the organisational contexts which presented barriers to full implementation of the transition pathway.

Challenges associated with implementation involving IT systems is recognised within the wider programme implementation literature (Gotlib Conn et al., 2015; Geerligs et al., 2018). Gotlib Conn et al. (2015) found that many implementation champions struggled with electronic systems integration resulting from the new programme. Successful operationalisation of the programme was however supported by positioning electronic aspects of the programme within existing systems which would be easily seen by professionals and seamlessly integrated (Gotlib Conn et al., 2015). In this study, participants experienced difficulties in locating transition documents which would suggest that transition documents were not easily accessible. Issues of accessibility within IT systems are similarly highlighted as a barrier to the implementation of new interventions in Geerligs et al's (2018) systematic review.

Additionally, in this study professionals reported that transition documents were difficult to use and were not specific enough to what the patient needed to know about transition. Training offered by the IT department to support professionals to use transition documents did not have its desired effect. Professionals who had accessed the training stated that they

found it confusing and it had not provided them with the skills they required to effectively use transition documents.

According to May's (2013) GTI, material resources such as information and knowledge of IT systems and how to use them, are important contexts that support participants to implement and embed new practices. In this study, unsupportive technology and time constraints (material resources) affected how healthcare professionals operationalised transition preparation tools and documents. Professional's capability to enact tools and documents depended on their workability and integration into routine practice (May, 2013). Although, professionals were challenged by a lack of additional time and difficulties accessing and using transition tools and documents, a majority were able to make transition tools and plans work and integrate them into routine practice by using them flexibly. However, decisions to use tools and documents with young people were influenced by professionals understanding of the needs of each individual and whether they felt use of the tool/document would benefit the young person.

## 6.6.5 Active participation and organisational readiness for change

The involvement and active participation of professionals in the stages of programme development and implementation are considered to be vital to the success of long-term adoption and enactment within the wider programme implementation literature (Fernandez and Rainey, 2006; Geerligs et al., 2018). Rough Initial Programme Theory Four indicates that active participation and involvement of professionals was taken into account by programme designers who deemed this to be important to implementation of the pathway. Professionals across different specialties were consulted with and their knowledge and experiences of transition was drawn upon by programme designers to develop the pathway. A transition steering group was also formed with key professionals identified across specialities within the organisation to support early implementation efforts. Data collected from programme implementers supported Rough Initial Programme Theory Four and further demonstrated just how significant a collaborative approach was to professional commitment to adopt and implement the pathway.

Findings from this study suggest that the active participation of healthcare professionals in the change process facilitated high levels of commitment to implement the pathway by some participants, but not all. Organisational readiness for change is an organisation level theory which helps to situate this finding within the wider context of programme implementation research (Weiner, 2009; Weiner, Lewis and Linnan, 2009). It underpins and informs the construct of 'potential' in May's (2013) GTI. There are two aspects to the concept of 'potential' presented by May (2013). These are individual intentions and shared commitments. May (2013) argues that the theory of organisational readiness for change is valuable in helping to explain collective processes.

Weiner (2009) suggests that levels of commitment to implement change are determined by change valence (defined as how much professionals value the changes implementation will bring) and change efficacy (defined as whether the changes are achievable). In this study, participants who were actively involved in the development and early stages of implementation either through the transition steering group or more general consultation, spoke positively about the transition pathway and placed value on the potential changes it would bring (change valence). The flexibility offered by the pathway further created more opportunity for professionals to implement the changes that they felt were achievable for patients in their individual services (change efficacy). This supported an increased sense of shared commitment by healthcare professionals to implement change (May, 2013).

This finding shares similarities with a study undertaken by Thomas, Bendtsen and Krevers (2015) who found that levels of participation in the intervention development phase influenced positive attitudes to change which was a pre-condition for implementation. In this study, the transition team, and in particular the lead transition service nurse, was seen to be instrumental to facilitating the active participation of healthcare professionals in the change process. Both Kingsnorth et al. (2011) and Colver et al. (2019) highlight the critical role that trust-wide transition co-ordinators have in terms of realising organisation-wide commitment to improve transition. The key difference in Kingsnorth et al's (2011) study is that the transition co-ordinator held a position that bridged paediatric and adult services. In contrast, in this study the lead transition service nurse was employed by the paediatric organisation and worked to develop relationships with key professionals from adult organisations.

As transition spans organisational boundaries and implementation of the pathway was thus dependent on active engagement from both paediatric and adult organisations there were some disadvantages to this. It was more difficult to build relationships and involve adult healthcare professionals in the change programme. However, the transition team and lead transition service nurse more specifically worked tirelessly to build important relationships, engage paediatric professionals from an early stage and learn from professionals about current practices and how they were working. This approach encouraged active participation and supported implementation processes. Gotlib Conn et al. (2015) similarly found that time dedicated to understanding current practices, high levels of engagement work, raising awareness and reviewing evidence with colleagues supported cognitive participation.

Furthermore, support for the transition pathway from senior leadership was recognised as important in this study and noted in studies undertaken by Nickel et al. (2013) and McManus et al. (2015). Weiner (2009: 69) suggests that 'consistent leadership messages and actions generate a shared sense of readiness'. Membership of senior managers in the transition steering group demonstrated support for, and belief in, the transition pathway, and participants received this more positively. However, there appeared to be a lack of support and 'buy-in' from senior managers in adult organisations, which impacted on how paediatric professionals interacted with the transition pathway.

The size and availability of the transition team further acted as a barrier in some services. Fernandez and Rainey (2006) suggest that support and commitment from senior management is crucial to implementation success. If there is limited support from senior management in the change process, then little is accomplished (Fernandez and Rainey, 2006). Findings from this study suggest that lack of 'buy-in' and support for the transition pathway from senior management in adult organisations and lack of resources within the transition team, acted as a barrier to implementation of the pathway. This impacted on professionals' shared commitment to implement the pathway.

Armenakis and Harris (2009: 130) suggest that without active participation in the change process 'genuine buy in to sustainable change is unlikely'. This study identified important

gaps in relation to active participation and 'buy-in' from adult organisations in the development and implementation of the transition pathway. This directly affected how paediatric healthcare professionals chose to engage with implementation. Future planning around developing and implementing transition improvement programmes should account for the active participation of adult organisations from a very early stage. In order for change to be sustainable there needs to be involvement and active participation from both paediatric and adult healthcare professionals within and across organisations. Consideration should also be given to the support of the transition programme from senior leaders across both paediatric and adult organisations.

#### 6.6.6 Co-ordinating transition

The importance of the transition co-ordinator/key worker role is well-recognised within the transition literature and is one of the most common interventions evaluated (Holmes-Walker et al., 2007; McDonagh et al., 2007; Allen et al., 2010; Crowley et al., 2011; Kingsnorth et al., 2011; Chaudhry et al., 2013; Dogba et al., 2014; Steinbeck et al., 2014; Chu et al., 2015; Egan, Corrigan and Shurpin, 2015; Jensen et al., 2015; McManus et al., 2015; Sequeira et al., 2015; Wafa and Nakhla, 2015; Hergenroeder et al., 2015; Kerr et al., 2017). Having a professional to co-ordinate transition is also at the centre of good practice guidance and policy on transition (DOH, 2006, RCN, 2013, NICE, 2016).

In Kerr et al's (2017) realist review of the transition literature they identified that engagement of a key worker supports young people to build confidence and develop trust in the therapeutic relationship. This in turn facilitates continuing engagement with adult services (Kerr et al., 2017). Few studies focus on the influence of the transition co-ordinator/key worker role to implementation processes and outcomes. Only one study conducted by Hergenroeder et al. (2015) found that uptake of a programme's implementation increases when a key worker has been identified and given extra time for transition in their job role. Good practice guidance developed by the Department of Health (2006) and the Royal College of Nursing (2013) recommends that tasks related to co-ordinating transition should form part of a person's job description and they should be allocated enough time to complete such tasks. Findings from this study add to the existing transition programme implementation literature by highlighting how the transition co-ordinator/key worker role influences implementation processes and outcomes. The role of the keyworker as described in the hospital's transition policy (Brook and Rogers, 2020) included educating, empowering and supporting young people through transition and working closely with consultants and transition keyworkers in adult services. The need for additional capacity to implement the pathway was recognised by programme designers. However, the material resources of extra time and key worker capacity within the team were not in place to support the role. Thus, in most services participants expressed difficulties in identifying who exactly the key worker would be, particularly when multiple services were involved in the young person's transition. Only two services had identified key workers who would be responsible for co-ordinating transition. In these services, transition was more defined as part of their job roles, however they were not given any additional time for transition. There were also key differences between these services and others including smaller numbers and existing transition processes which made the key worker role more achievable.

The transition key worker role was closely linked to motivation and interest in transition which is a micro-level context that is discussed in the next section of this chapter. As highlighted by Geerligs et al. (2018) if staff feel that a) the intervention is not part of their job role and b) they are unclear as to who should fulfil this role, then their motivation to adopt changes required for implementation is less evident. Participants in this study, were more reluctant to take on the key worker role when it was not formally part of their job role and time was not allocated for transition tasks. They also suggested that it was not clear in the transition pathway who should take on responsibility for this.

Thus, whilst the transition co-ordinator/key worker role is an important intervention within transition programmes which has been shown to improve transition outcomes for young people (Kerr et al., 2017), consideration must be given to ensuring that key working is either formally built into existing job roles or a separate role is created to specifically undertake this work. Support for the creation of dual roles that span paediatric and adult services comes from the existing transition literature (DOH, 2008) as well as this study. For those with complex needs whose care crosses into multiple services, a transition co-ordinator who

works within multiple services and between paediatric and adult organisations would be most valuable. Consideration should also be given to the role that adult healthcare professionals can play in facilitating co-ordination. However, as discussed in the previous section of this chapter, responsibility for transitional care arrangements is often aligned to children's services rather than a joint responsibility, due to lack of funding in adult services (CQC, 2014; Colver et al., 2019). More needs to be done to address the funding gaps and to ensure that transitional care arrangements are a joint responsibility between children's and adult services.

#### 6.7 Micro level contexts

Micro-level contexts operate at the level of the team and individual professionals. They relate to the 'interactions between people and processes' (Chandler, 2016: 464). Fulop and Robert's (2015) definition of micro contextual factors and Pawson's (2006; 2013) definition of contextual layers at the individual and interpersonal relationship levels were used to determine the micro level contexts within this study that facilitated or hindered the mechanisms within the transition programme. The two most important micro-level contexts identified across CMOCs and highlighted in the findings chapter were healthcare professionals' perceptions of transition and professional's motivation and interest in transition. These micro-level contexts are discussed in detail below alongside the wider theory, literature, guidance and policy base.

#### 6.7.1 Joint responsibility for transition

Fulop and Robert (2015) argue that different contextual factors, within and between levels of the system, are not independent. It is the interaction of these contextual factors within and across levels of the system that ultimately impacts on the overall effectiveness of interventions (Fulop and Robert, 2015). Findings from this study demonstrate the relationship between contextual factors within and across different levels of the system. Healthcare professionals' perceptions of transition, in particular adult services, appeared to be influenced by the structural and cultural divide between children's and adult services and the wider funding agenda for transition. Differences in infrastructure, approaches to care and funding informed and shaped how participants regarded adult professionals and the role

they played in transition. A perceived lack of joint responsibility for transition and collaborative working between children's and adult services were commonly communicated by participants as barriers to implementation of the pathway. This is by no means uncommon. National guidance and policy on transition all point to the importance of joint responsibility for transition and collaboration between children's and adult services (DOH, 2006, DOH, 2008, CQC, 2014, NICE, 2016). However, this continues to be problematic and disjointed (Colver et al., 2019).

Joint responsibility for transition and collaborative working are essential pre-conditions for the successful implementation of transition programmes (Hergenroeder et al., 2015, Colver et al., 2019). Good practice guidance by the Department of Health (2006: 23) suggests that 'a transition programme can only be successful if organised with the active participation and interest of the receiving adult service'. Research by Hergenroeder et al. (2015) found that paediatric staff were more likely to be receptive to transition planning if adult providers had firstly been identified, and secondly were interested and qualified in transition. There was a reluctance to begin transition planning with young people in services where specific adult providers had not been identified (Hergenroeder et al., 2015). This study similarly found a reluctance from some paediatric healthcare professionals to implement the transition pathway where no adult equivalent service had been identified. This had been taken into consideration by programme designers in Rough Initial Programme Theory Three. However, what became more evident during the second stage of data collection was that this reluctance to implement was further influenced by negative perceptions of adult services. Even where there was an identified adult provider, some paediatric healthcare professionals felt that adult services were disengaged. This affected the extent to which they choose to engage with and implement the pathway.

Joint responsibility for transition extends outside of healthcare into the domains of social care and education. Young people receiving healthcare in a paediatric setting may also be receiving support from children's social services and specialist education providers. They will be experiencing a number of service transitions which often happen separately from their health service transition. The importance of integration and joined up working between health and social care is recognised in both the Care Act (2014) and the Children and

Families Act (2014) as well as research and guidance on transition (CQC, 2014; NICE, 2016). Although this is an important aspect of transition and should be taken into consideration when developing and implementing transition programmes it was only commented upon by one participant in this study. This participant suggested that the transition pathway did not fully take into consideration the social and financial aspects of transition such as information around changes to welfare benefits and how to signpost parents and young people to appropriate services. Healthcare policymakers need to take these wider factors into consideration when developing transition programmes, ensuring that healthcare professionals are equipped to respond to the wider needs of young people and their parents.

Participants' past experiences of using transition pathways which were perceived to be unhelpful further impacted on their willingness to adopt and implement the new transition pathway. Geerligs et al. (2018) suggest that staff may be reluctant to implement new ways of working if their previous experiences have been unsuccessful. In this study, past experiences of transition programmes and negative perceptions of adult providers which were based on them, affected commitment levels within different services to implement change (May, 2013). May's (2013) GTI is again useful here, in particular the construct of potential, which is informed by organisational readiness for change, in helping to make sense of these findings. Weiner (2009: 70) states that:

'past experience with change could positively or negatively affect organisational members' change valence (e.g., whether they think the change really will deliver touted benefits) and change efficacy judgements (e.g. whether they think the organisation can effectively execute and co-ordinate change related activities)'.

According to Fernandez and Rainey (2006) organisational change is dependent on the level of support from key external stakeholders. Implementation of change involves collective action between interdependent individuals, services (Weiner, 2009) and furthermore in the context of this study, between organisations. A limitation of organisational readiness for change is that it only focuses on the intra-organisational context, whereas transition programme implementation by its very nature spans organisational boundaries. Findings from this study suggest that a perceived lack of engagement and support from adult professionals and organisations at the inter-organisational level, negatively affected paediatric professionals change valence and change efficacy judgments in some services.

The effects of this context can be seen in the mechanisms for CMOC 1, 'use of professional autonomy and agency to benefit young people' and 'feelings of self-defeat'. These are discussed in more detail within the context of the wider theory and literature in the following section of this chapter. However, professionals' ability to see the value and benefit that implementation would bring to each individual (change valence) was adversely affected by their perceptions of adult providers. In services where participants perceived adult providers to be disengaged with the transition pathway, perceptions of change efficacy were low and collective commitment to implement the pathway was absent. This resulted in the mechanism 'feelings of self-defeat' whereby professionals felt disheartened by a perceived lack of engagement from adult providers which affected implementation outcomes. Weiner, Amick and Shoou-Yih (2008) argue that implementation success is dependent on collective and coordinated behaviour change by the majority of organisational members. This study builds on this and highlights that implementation success of transition programmes is dependent on collective commitment and coordinated behaviour change by both paediatric and adult organisational members.

According to May (2013), when participants implement a complex intervention they reflect on and appraise its effects within their field of agency. This is known as reflexive monitoring and underpins the construct of contribution in GTI (May, 2013). May (2013: 25) defines reflexive monitoring as the ability to 'collect and utilise information about the effects of the intervention'. This is particularly relevant to this study as participants across services commonly reported that it was difficult to monitor how effective implementation of the transition pathway would be once the young person transitioned over to adult services. There appeared to be limited reflexive monitoring in some services, although this was not the case for others who had some informal monitoring arrangements in place with adult providers. However, for those services without such arrangements a perceived lack of engagement from adult providers negatively affected reflexive monitoring which threatened the implementation of the pathway. Good practice guidance and policy states that transition should continue for several years once young people leave children's services (DOH, 2006, DOH, 2008, NICE, 2016). However, in this study there was no formal follow up once young people left the paediatric organisation even though the final step in the transition pathway (step 10) focused on young people being settled in adult services. There was no evidence to support this aspect of the transition pathway as adult professionals were not interviewed as part of the study. Ensuring that transition continues when people enter adult services is essential and policymakers should consider how young people can be followed up in adult services and whether this should be a joint responsibility between children's and adult services.

Additionally, in one service difficulties were not confined to relations between paediatric and adult professionals but also existed within the service itself. Participants' perceptions of senior clinical team members reactions to the transition pathway were often negative and there appeared to be a lack of shared values and low levels of collective commitment to implement the pathway (May, 2013). A study by Nickel et al. (2013) highlights some similarities suggesting that staff members who held more influence often lacked commitment to implementation. This was also apparent in this study. However, it is important to note that senior clinical team members in this service were not interviewed as part of this study. Findings in relation to this are based on the perceptions of other professionals within this service. Nevertheless, the data showed that in one service there was a lack of co-operation between healthcare professionals within the service which affected change valence and efficacy (Weiner, 2009). Nickel et al. (2013) further suggest that staff members show higher levels of commitment if they perceive others are committed to implement the change. In Drew et al.'s (2015) study, professionals perceived to be uncooperative were characterised by their colleagues as having 'unsupportive personalities'. Participants in one service frequently referred to the personalities of senior clinical team members as problematic. These findings may help to explain why there appeared to be more resistance in this service as compared to other services.

#### 6.7.2 Commitment to making transition work

In this study, professionals who were motivated and committed to improve transition practice within their own services were more likely to implement aspects of the transition pathway. Motivation and commitment were recognised by programme designers as important enablers to implementation in the early stages of programme theory development (Rogers et al., 2019). Interviews with programme implementers suggested that individual motivation and commitment supported implementation of the pathway overall, however, it was most significant to the implementation of joint transition reviews (CMOC 3) which involved input from adult sector professionals. This feature of the micro-level context was interconnected with 'healthcare professionals' perceptions of transition', meso level contexts of 'service-specific key professionals to co-ordinate transition' and 'well-established, existing transition processes' and macro-level contexts of 'inter-organisational commonalities' and 'funding'. The implementation of joint transition reviews was contingent on the interaction of these different contexts across the different levels of the organisation.

As previously discussed, involving key professionals from adult services who are interested in transition helps to support transition planning (Hergenroeder et al., 2015). This also related to facilitating joint transition reviews in this study. Services with well-established, existing transition processes, inter-organisational commonalities and funding to support transition work further encouraged implementation of joint transition reviews. However, the existence of these contexts were not consistent across all services within the organisation and it was evident from the data that joint transition reviews were sometimes dependent on the motivation and good will of individual healthcare professionals from both sectors.

Over-reliance on individual healthcare professionals or 'transition champions' is recognised within the existing transition literature as problematic (Allen et al., 2010; Kingsnorth et al., 2011; Watson et al., 2011). Findings from this study support the work of Allen et al. (2010) and Watson et al. (2011) who similarly found that individual transition co-ordinators and transition champions were responsible for implementation of transition interventions. In this study, some participants communicated that joint transition reviews would not happen if it were not for individual professionals from the adult sector who were committed and motivated to make changes. They questioned what would happen if such individuals were

to leave their positions. This finding suggests that individual motivation and intentions played an important role in the implementation of joint transition reviews. However, implementation of transition programmes requires collective activity and commitment from different professionals, services and organisations. Organisation-wide approaches to implementation are thus vital to establish better transitional healthcare (Colver et al., 2019).

Geerligs et al. (2018) argue that motivation and commitment are influenced by staff attitudes to the change process which impacts on how they choose to engage with implementation. In this study, the attitudes and intentions of healthcare professionals were mostly positive, and they appeared to be motivated to make changes. Most professionals were in support of the transition pathway. They saw it as being necessary and of benefit to some young people. Change valence and change efficacy were high in some services which determined their level of commitment. Additionally, there appeared to be a wider set of shared commitments in some services, in which professionals demonstrated a sense of collective readiness, and they worked to accommodate the changes that the new pathway brought (May, 2013). This can be seen in the outcomes of CMOC 1 and CMOC 2 where professionals adapted aspects of the pathway to make it work for individual patients.

However, in other services individual intentions and shared commitments were impeded by other aspects of the context including negative attitudes towards implementation, a perceived lack of engagement from adult services and poor communication between paediatric and adult services. Research undertaken by Rogers et al. (2019) prior to the development of the transition pathway highlighted good channels of communication as a facilitator to implementation. However, in some services communication with adult providers was described as 'poor' which acted as a barrier to implementation of the pathway. Change valence and change efficacy were lower in these services and collective readiness was not present.

Human motivation is defined by Le Grand (2010: 2) as 'the internal desires or preferences that incite action' and human agency as 'the capacity to undertake that action'. Le Grand (2010) suggests that both human motivation and agency are significant to the development and implementation of public policy. This was evident in this study where individual

motivation was believed to influence professional agency and decision making about implementation of the pathway. However, Le Grand (2010) differentiates between motivation and behaviour, suggesting that motivation is a psychological state that is one of many factors which determine behaviour. Competing influences may include external constraints such as financial resources and availability of time (Le Grand, 2010). For Le Grand (2010: 25) 'behaviour is the product of an interaction between motivation and constraints'. The meaning of human motivation and behaviour offered by Le Grand (2010) resonates with findings from this study. Motivation to implement change to improve transition for young people was evident across the dataset. However, motivation alone did not determine professional decision making (behaviour) as there were competing demands created by time constraints, funding, existing transition processes and negative perceptions of the transition pathway and adult providers. These features of the context shaped professional agency and determined the actions that professionals undertook when implementing the transition pathway.

#### 6.8 Mechanisms and Outcomes

The above section identified and critically discussed the main macro, meso and micro level contexts which operated across different CMOCs within this study. The subsequent section of this chapter will discuss the mechanisms and outcome patterns which resulted from the interaction of different contexts across different levels of the healthcare system. Similar to the previous section of the chapter, mechanisms and outcomes will be interpreted using existing guidance, policy, literature and theory relating to transition and programme implementation. Descriptions of mechanisms and outcomes have been refined taking into consideration their meaning for transition and programme implementation.

In realist evaluation, outcomes always follow from mechanisms acting in contexts (Pawson and Tilley, 1997). The chapter has therefore been structured in this way to identify and understand how contexts within and across different levels of the system shaped and affected the operation of mechanisms and resulting outcomes. CMOC 1 and 2 shared many similarities and are discussed collectively, followed by mechanisms and outcomes identified in CMOC 3 and CMOC 4.

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#### 6.8.1 Person-centred decision making and agency

A significant finding emerging from this study relates to professionals' ability to implement aspects of the transition pathway against the backdrop of contextual constraints within and across the macro, meso and micro levels of the system. What this shows is that the social-cognitive resources that were available to participants such as individual intentions and shared commitments, supported practitioners to overcome challenges such as a lack of social-structural resources which affected implementation. May (2013) suggests the capability of participants to operationalise a new practice is dependent on their potential to act which is broken down into individual attitudes, intentions, shared values and commitments. According to Weiner (2009), if participants value the intervention and the changes it will bring (change valence) and consider the changes to be feasible (change efficacy) then they are more likely to commit to implementation. The mechanisms in CMOC 1 'use of professional autonomy and agency to benefit young people' and CMOC 2 'perception of individual need' reflect both the individual intentions of healthcare professionals and shared commitments.

In most services, participants did see the value (change valence) of using the transition pathway with some young people, however not everyone did. Decisions to use interventions within the pathway, such as transition tools and documents with young people, were determined by healthcare professionals' perceptions of the YP's needs rather than the process itself. Individualised, person centred approaches were at the heart of professional decision making with regards to implementation.

The importance of taking a person-centred approach to transition and meeting individual need are well recognised within transition policy, guidance and literature (Price et al., 2011; Kerr et al., 2017). The Care Act (2014), Children and Families Act (2014) and NHS Long Term Plan (2019) all state that transition should be built around the individual, offering person-centred and age-appropriate care. Good practice guidance developed by the Department of Health (2008) and NICE (2016) further argue that the views and needs of each young person should be considered and they should be treated as an equal partner in the process of transition. In Price et al's (2011: 859) study, 'recognising individuality and working with it to empower young people to take control over aspects of their health care'

was an important theme. This also featured strongly in this study and underpinned professional decision making. In CMOC 1 and 2, professional decision making was influenced by the perceived value and benefit implementation of the pathway would bring to each young person (change valence). Thus, healthcare professionals exercised their professional autonomy and agency when making implementation decisions.

Educating and supporting young people to self-manage their health conditions in adulthood was also seen to be an important aspect of transition in this study. Many participants discussed how they supported young people to develop self-management skills through a process of knowledge transfer and responsibility from parent or professional to young people and helping them to develop self-management skills. Good practice guidance (DOH, 2006, NICE, 2016) recognises the importance of parental involvement and support in this process. However, recent research undertaken by Colver et al. (2019) suggests that when young people move over to adult services parental involvement is discouraged as it is considered to be 'overdependence'. Findings from this study support Colver et al.'s (2019) recommendation that professionals should continue to work with parents and carers once a young person moves over to adult services, considering what the young person wants and needs.

Although seeing the benefit (change valence) implementation would bring to young people was central to professional autonomy and agency, believing in one's capability to effectively implement the changes (change efficacy) was equally important. Bandura (2001: 10) argues that 'efficacy beliefs are the foundation of human agency'. Agents must believe that they can produce the desired results by their own actions (Bandura, 2001; Eccles and Wigfield, 2002), and they must have incentive to do so (Fishbein et al., 2001). Without this belief the incentive to act or persevere in the face of difficulties is limited (Bandura, 2001). Efficacy beliefs determine the work agents choose to undertake and how much effort and time they put into the endeavour (Bandura, 2001). Incentives to act may include physical outcomes, social outcomes or self-sanctions (Fishbein et al., 2001).

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Bandura's social cognitive theory which is one of several middle range theories that inform GTI (May, 2013) provides insight into the mechanism 'use of professional autonomy and agency to benefit young people'. In this study, contextual features at the macro, meso and micro levels acted to support or hinder the efficacy beliefs of professionals. In some services there were incentives to act such as funding, inter-professional commonalities, geographical proximity, service-specific key professional to co-ordinate transition and existing transition processes, which increased the self-efficacy beliefs of professionals. However, in other services these incentives were not established which impacted on professional's capability to effectively implement aspects within the transition pathway.

Bandura's social cognitive theory further separates human agency into personal, proxy and collective dimensions (Bandura, 2001). May's (2013) general theory of implementation is most concerned with collective agency. This is because the implementation of complex interventions is contingent on socially interdependent effort and coordination (Bandura, 2001; May, 2013). Bandura (2001: 14) defines collective agency as 'people's shared belief in their collective power to produce desired results'. Efficacy beliefs are an important aspect of collective agency and are described by Bandura (2001) as shared beliefs that relate to collective action to produce desired results.

As discussed in the above section on 'micro-level contexts', healthcare professionals' perceptions of adult providers negatively affected shared efficacy beliefs in some services. Perceptions of senior clinical team members negative reactions to the new pathway also exacerbated this in one particular service. In this service, healthcare professionals did not appear to share the same beliefs, attitudes and commitments to implementing the pathway. Participants in this service suggested that senior clinical team members regarded transition as a single event of transfer rather than a process. Good practice guidance developed by the Department of Health (2006) identifies professional and managerial attitudes towards transition as being one of the biggest obstacles to implementing change. The authors argue that a fundamental change of attitude in terms of treating transition as a process, not an event, is required (DOH, 2006). Findings from this study suggest that there are still misconceptions around what transition should entail. Training provided by the transition team
aimed to address these misconceptions, however training was not mandatory, with some professionals choosing not to attend the training that was offered.

In this study, implementation of the transition pathway was dependent on collective commitment and coordinated behaviour change both within and between paediatric and adult providers. Within the paediatric organisation 'collectives' included members of the clinical multi-disciplinary team within the service and across different services depending on who was involved in the young person's care. However, 'collectives' further extended to the involvement of key adult professionals who would be involved in the care and support of young people during and following their transition to adult services.

Differences in beliefs and attitudes towards the pathway in one service however resulted in a different mechanism and outcome. This was founded on 'feelings of self-defeat' whereby participants ability to see the benefit (change valence) and shared capability to implement changes (change efficacy) were confounded by unsupportive contextual features. In these circumstances, participants internalised 'feelings of self-defeat' which impacted on their ability to implement changes.

The mechanisms in CMOC 1 and CMOC 2 were further influenced by the context of wellestablished, existing transition processes. As previously discussed, programme designers developed the pathway with flexibility in mind, with the belief that healthcare professionals would be more likely to implement the transition pathway if they could use it flexibly alongside their existing processes to meet the needs of different patient groups. Equating this to the concept of capability in GTI, it is clear that the flexible design of the transition pathway offered a high degree of workability and integration into standard practice (May, 2013). Although agency was constrained to an extent by unsupportive features of the context (i.e. interorganisational differences, time constraints, unsupportive technology etc.), professionals used collective agency to make interventions within the pathway such as tools/documents workable and integrate them into routine practice. However, decisions to use tools/documents were based on the perceptions of each individual patient and the perceived relevancy and benefit use of the tool/document would have for the individual (change valence). To make it work professionals further adapted the pathway and prioritised which patients to use tools/documents with based on their perception of individual needs.

According to Thomas et al. (2015), adapting interventions to make them more workable is necessary to fully embed new practices. The requirement to use transition pathways flexibly and be able to adjust them to meet the needs of individuals over time is recognised within the transition literature by Allen et al. (2010). Allen et al. (2010) use the term 'flexible continuity' which refers to use of flexibility in the timing of transfer to ensure that individual needs and other life-course transitions are accounted for. Findings from this study highlight the importance of 'flexible continuity' and how this informs and underpins professional agency. In CMOC 1 and CMOC 2 professionals adapted and used the transition pathway flexibly according to their perceptions of individual need. Working against unsupportive contextual features, such as time constraints, they further adopted a priority approach to implementation of tools/documents, based on perceived relevancy and benefit to each individual (change valence). Whilst programme designers initially hypothesised that 'seeing the benefit' would be vital to implementation decisions, data collected from programme implementers further evidenced that 'seeing the benefit' was not collectively applied to all young people. 'Seeing the benefit' was instead determined by perceptions of individual need and professionals expressed their agency when deciding who to use tools/documents with. In some instances, professionals were unable to 'see the benefit' of implementation and exercised their professional autonomy by not engaging in the implementation of certain steps within the pathway.

The construct of 'contribution' in May's (2013) GTI helps to explain the actions agents take to implement a new practice. May (2013) suggests that professionals' contributions to implementing change depend on how much they invest in its meaning, their commitment, effort and appraisal. In this study, professionals' perceptions of individual need helped them to make sense of how they could best use interventions such as transition preparation tools and documents with young people. Adaptation and prioritisation of the pathway were important outcomes that were partly influenced by limited material and cognitive resources (such as time constraints and unsupportive technology) which shaped emergent expressions of agency (May, 2013). Professionals expressed their agency by choosing to use the

pathway flexibly, prioritise and adapt tools/documents based on perceived relevance and 'benefit' to each individual. The flexible design of the pathway supported the outcomes of adaptation and prioritisation. However, as previously discussed this was not universal across all services due to different contextual features which acted to constrain professional agency.

### 6.8.2 Relationships

Trust, collaboration and effective communication between paediatric and adult services are seen to be crucial to successful transition for young people (Kingsnorth et al., 2011; Kerr et al., 2017). A realist review of the transition literature undertaken by Kerr et al. (2017) highlighted the importance of inter-disciplinary and inter-agency work to establish trust between services and organisations. Creating a cohesive team who shared the same focus on the young adult and their family helped to facilitate trust, collaboration and accountability (Kerr et al., 2017). Positive and optimistic attitudes from paediatric staff, which were partly influenced by trust and a sense of collaboration, enhanced the self-efficacy beliefs of young people and their parents in relation to engaging with adult services (Kerr et al., 2017).

In this study, professionals similarly suggested that having trust and confidence in adult services sent out a positive message to young people and their parents and supported them to develop trust and confidence. Findings from Kerr et al.'s (2017) review point to the importance of cohesive team relationships rather than relationships between individual professionals, which was a key difference in this study. Whilst collective relationships were seen to be important to healthcare professionals in this study, implementation of joint transition reviews were at times dependent on the strength in relationships were, however, shaped by wider contextual features including geographical proximity, funding and the motivation and interest of individual professionals.

These contexts both acted to support and constrain the mechanism 'trust and confidence'. Relationships between professionals were better established in services where there was funding in place to support joint reviews, and where services were in geographical proximity to one another. Participants in these services had developed trust and confidence in their adult counterparts over the years and attitudes towards adult service providers were often more positive. In contrast, relationships were more strained or non-existent in services without funding and with out of area adult hospitals. Perceptions of adult service providers were frequently more negative and where relationships did exist, they were driven more by the determination of healthcare professionals in both organisations. Poor communication, a perceived lack of partnership working and a perceived lack of capacity in adult teams further hindered paediatric professionals trust and confidence in their adult counterparts. Nevertheless, across many services pre-existing relationships, and in one particular service new relationships, which resulted from the transition pathway, enabled the development of trust and confidence which supported implementation of joint transition reviews. This finding is similar to that of Kingsnorth et al. (2011) who suggest that pre-existing relationships, shared responsibility and extensive face to face contact help to develop trust and open lines of communication between different services.

The concept of 'letting go' which refers to paediatric professionals' reluctance to end their relationship with young adults further featured in this study and also guidance by the Department of Health (2006) and research by Kingsnorth et al. (2011). The relationships that paediatric professionals develop with young people and their families over the years can result in feelings of attachment which make it more difficult to 'let-go' of young people when they move over to adult services (DOH, 2006). Kingsnorth et al. (2011) found that trust and confidence in the relationship between professionals supported paediatric staff to 'let-go' of young people without feeling that they were abandoning them. Whilst this study did not find a direct link between trust and confidence and 'letting go', it was evident from the data that keeping patients within paediatric services through fear of letting them down was more commonly expressed by participants in services that did not have well-established relationships with adult services. Trust and confidence between paediatric and adult healthcare professionals may therefore play a significant role in the timing of transition for young people.

Many professionals in this study spoke about the importance of their relationships with young people and their families. They suggested that parents in particular struggle to accept the need to move young people over to adult services and develop new relationships with professionals who do not know the young person and their needs. Research by Colver et al.

(2019) makes reference to this, describing it as 'disrupting relationships of trust'. They suggest that both parents and young people develop trust over a period of time with children's healthcare professionals, learning how to navigate the health service and manage health conditions. When young people move over to adult services the relationships of trust with children's healthcare professionals end, and young people/parents are expected to start over again. Relationships between professionals, young people and their parents play an important role in how professionals engage with transition programmes and must be taken into consideration by policymakers. Although, joint transition reviews provide opportunities for young people and their parents to meet adult professionals, they are often one off events and do not happen for all young people. A longer period of contact prior to the move over to adult services would support young people and their parents to develop relationships with adult professionals which may help to break down some of the barriers currently faced during the process of transition.

Social network theory once again offers insights into the mechanism trust and confidence gained through well-established relationships. In an earlier section of this chapter, social network theory helped to explain the macro-level contexts of inter-organisational commonalities and differences and geographical proximity. Findings from this study suggest that weak inter-organisational networks affected participants capacity to co-operate and coordinate their actions to implement the transition pathway. Inter-organisational networks were also stronger where paediatric and adult services were in geographical proximity to one another. These macro-level contexts directly affected the mechanism 'trust and confidence' which operated within the micro level of the system. In most cases, interorganisational networks were a necessary pre-condition for 'trust and confidence'. However, this was not the case for all services. In one particular service, inter-organisational networks were not strong and there was no funding to support joint transition reviews. Instead, the implementation of joint reviews was dependent on individual healthcare professionals from both services who were motivated and committed to improving transition. The importance of the relationship between individual professionals was strongest here. This finding highlights the important role of key individual healthcare professionals from both services and suggests that implementation is both an outcome of the inter-organisational network and the actions of individuals themselves. The argument against the dangers of over-reliance on individual

professionals to programme implementation sustainability has already been made in this chapter. Findings from this study suggest that more attention needs to be given to the strength of relationships between inter-organisational networks and how these can support implementation, rather than relying on individual healthcare professionals.

Interestingly, in this study few participants commented on relationships with primary care, in particular General Practitioners (GP), and their role in implementation of the transition pathway. Where it was mentioned, relationships were often described as poor. Relationships with GPs was a key theme in research undertaken by Rogers et al. (2019) with paediatric professionals in the same organisation highlighting the need to involve GPs more in the transition of young people's care. As this was rarely mentioned by participants in this study it was unclear to what extent this had been actioned. The importance of GP involvement in transition is strongly emphasised in national good practice guidance and research (DOH, 2006, DOH, 2008, CQC, 2014, Colver et al. 2019). However, it remains an under-researched area (NICE, 2016). GPs are often overlooked when young people are receiving their care in paediatric services as they are able to meet all of a young person's health needs (DOH, 2006). However, they are expected to support young people when they move over to adult services. Therefore, the development of those important relationships needs to begin in paediatric services (CQC, 2014). Findings from this study identified gaps in this important area of specialist GP relationship.

#### 6.8.3 Reflective practice

As with similar mechanisms already discussed in this chapter, macro, meso and micro-level contexts across different CMOCs acted to both support and constrain the mechanism 'active engagement and reflection on practice'. In this study, participants attempted to make sense of the transition pathway and the possibilities it offered to them within their own practice through a cognitive process of reflection on practice. 'Reflection on practice' or 'reflective practice' stem from the work of Argyris and Schon (1976) and then later Schon (1983, 1987) (Fook, 2007). Schon (1983) argues that practitioners can use reflective processes to identify the theory behind their practice (what they do) rather than (what they say they do) (Fook, 2007). Reflective practice supports practitioners to recognise routines or established habits that may guide their practice (Schon, 1983), and essentially unpick these to identify ways to

improve practice (Fook, 2007). However, one's ability to reflect on practice is not a natural state and practitioners need support to enable them to engage in reflection (Schon, 1983). Group training can support reflective practice by providing opportunities for practitioners to critically evaluate current practice and share ideas with one another as a means of improving practice. In this study, transition training delivered by the transition team facilitated reflection on practice for some participants, but not all.

By actively thinking about current transition practice and comparing this with what is advocated within the transition pathway, participants reflected on what was working well, what needed to change and how resources offered by the pathway could support them to change practice. May's (2013) construct of contribution and the dimension of 'coherence/sense making' is important to this finding as it helps to explain the processes which frame how agents implement and embed new practices. Through the cognitive process of 'sense making' professionals' knowledge of transition increased, and they were able to make a number of changes in line with the transition pathway to their practice. Changes to practice were in some cases specific to each service and this was context dependent. For example, in one service transition was mainly co-ordinated by specialist nurses with little input from the multi-disciplinary team. As a result of reflecting on current practice, professionals highlighted the changes that needed to be made to ensure that their transition clinics could operate, with more of a focus on multi-disciplinary working. Other changes such as starting transition preparation earlier were more common across different services.

However, many features of the context across different CMOCs constrained the mechanism 'active engagement and reflection on practice'. The impact of this was more evident in service E where there appeared to be greater resistance of senior clinical team members to access and engage with transition training and implementation of the pathway itself. The transition training offered to healthcare professionals in this organisation was not mandatory. Whilst good practice guidance (RCN, 2013, DOH, 2006) and research (Baines, 2009) emphasises the importance of including transition in the mandatory education and training of healthcare professionals in both children's and adult services, it remains optional as to whether healthcare professionals choose to access this. Mandatory training on transition

would ensure that professionals are better informed about transition, addressing any misconceptions and facilitating an organisation-wide approach to transition.

#### 6.9 Summary of findings

Findings from the study revealed four CMOC demi-regularities that existed within the transition programme's implementation. These findings have been reviewed within this chapter using existing literature, policy, guidance and theory on transition and programme implementation. Rough initial programme theories developed at the beginning of the study have been re-visited throughout the chapter and discussed alongside CMOC findings and the wider literature and theory base.

The findings of this study evidence the important role that contextual factors within and across macro, meso and micro levels of the healthcare system have on implementation mechanisms and outcomes. The success of implementation of the transition pathway was dependent on the extent to which contextual factors either supported or hindered implementation processes. Structural and cultural differences between children's and adult services, proximity, social networks and funding for transition were important external contexts that affected how healthcare professionals engaged with the transition pathway. Social network theory was used to situate these findings and explain how the presence or absence of inter-organisational social networks affected implementation of the pathway.

Findings from the study further highlight how organisational factors, identified within the meso-level of the healthcare system, affected implementation of the transition pathway. Existing ways of working, norms of practice, lack of resources, IT systems, active participation and co-ordinating transition were key organisational features that shaped mechanisms and outcomes. May's (2013) GTI offered important insight into how organisational factors, such as the one's identified in this study, impact on professionals' ability to implement new ways of working. Findings further resonate with the theories of 'habituation' and organisational readiness for change which help to explain why implementation of the pathway was more successful in some services and not others.

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Findings further show that, contexts operating at the level of team and individual professionals similarly influenced or hindered implementation processes. These were largely shaped by external factors such as structural and cultural differences between children's and adult services. This wider debate within the area of transition directly affected how paediatric healthcare professionals, in this study, regarded adult professionals and to what extent they chose to engage with implementation of the pathway. Organisational readiness for change and May's (2013) GTI offered explanation to these findings highlighting how negative perceptions of adult providers affected participants change valence and change efficacy judgements. However, findings from this study showed that human factors such as individual motivations and intentions played an important role in facilitating programme implementation.

The contexts discussed above and within this chapter directly affected the presence of mechanisms and resulting outcomes. Findings from this study show that change valence (the perceived value and benefit implementation of the pathway would bring to young people) and change efficacy (shared capability to implement change) were important mechanisms which, if activated by supportive contexts, encouraged implementation through flexible use of the pathway and changes to transition practice. Person-centred decision making, trust and confidence in relationships with adult providers and reflection on practice also supported implementation resulting in improved knowledge and changes to transition practice. Social network theory and theories of reflective practice were useful in helping to situate these findings. However, one of the main arguments throughout this chapter and the findings chapter has been that the same contexts were found to both facilitate and hinder mechanisms and outcomes, and this was dependent on features of the paediatric service itself. Therefore, findings from this study showed that where several features of the context were unsupportive professionals described feelings of 'self-defeat' which resulted in disengaged professionals who failed to make changes to their practice. Refined programme theories thus reflect the contextual features that are necessary to support implementation of transition programmes, whilst also highlighting contextual barriers that affect implementation.

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# 6.10 From rough initial programme theories (RIPT's) to programme theories (PT's)

The rough initial programme theories for this study developed from a documentation analysis and semi-structured interviews with programme designers, consisted of four broad 'if...then...because' statements'. These were informed by the ideas of programme designers on what conditions were necessary to support paediatric healthcare professionals to implement the transition pathway within their own services. Findings from the evaluation provided a more detailed description of what supported and hindered implementation efforts and outcomes. This resulted in four refined CMOCs which are presented in the findings chapter and have been discussed throughout this chapter against the wider literature and theory base. This chapter has drawn on transition literature, policy and guidance and underlying theory including a general theory of implementation, social network theory, habit theory, organisational readiness for change and social cognitive theory, to provide understanding and explanation of the study's findings and the contribution they make to the broader evidence base. During this process, initial programme theories have been further refined resulting in final programme theories which form practical recommendations for healthcare practitioners, providers and policy makers. These are displayed in table 6.1 below, followed by an overall conceptual framework of implementation of the transition pathway (figure 15).

# 6.11 Final programme theories and conceptual framework

Table 6.1 Final programme theories

- Transition programmes that offer flexibility and can be easily integrated into standard practice, are more likely to be positively received by professionals. However, the ability to differentiate new ways of working with existing ways of working favourably through demonstrating the value, benefit and importance implementation will bring to patient care must be considered by policymakers when designing transition programmes. Seeing the benefit and value implementation will bring to individual patients (change valence) supports the flexible use and implementation of transition programmes.
- 2. Social norms and existing practices that have become routinely habituated affect the implementation of transition programmes. Aligning desired changes with existing social norms and practices supports adoption and implementation of clinical guidelines.
- Group training that offers opportunities for professionals to critically evaluate and reflect on current practice can support the unlearning of routine habits that guide their practice. Opportunities for reflection and shared learning improves professionals knowledge of transition and supports them to make changes to current practice.
- 4. Investing material resources such as additional time for transition and providing the necessary information and knowledge about IT systems supports professionals to employ and integrate new ways of working into routine practice more easily. Incorporating responsibilities and workload of the transition keyworker role into individual job descriptions and considering the establishment of dual roles across children's and adult organisations are important factors that facilitate transition.
- 5. Well-established inter-organisational social networks, joint responsibility for transition, including additional funding to facilitate transition processes across organisations, and collaborative working between children's and adult's organisations are essential pre-conditions for successful implementation of transition programmes. Active participation and support from adult organisations improves children's professionals change valence (seeing the value and benefit that implementation will bring to young people) and change efficacy (shared capability to implement change). Successful implementation of transition programmes require collective commitment and co-ordinated behaviour change by professionals within and across children's and adult organisations. Where collective commitment to implement change is lacking, change valence and change efficacy is affected and implementation is not fully realised.
- 6. Geographical proximity of children's and adult services supports the development of inter-organisational social networks and important relationships between professionals across organisations. Trust and confidence formed between children's and adult professionals are important conditions that facilitate implementation of transition programmes. Where inter-organisational social networks are absent the

individual motivations and intentions of professionals across organisations attempt to compensate for this. However, dependency on individual professionals to implement change is not sustainable and transition programmes require organisational wide approaches to implementation.

7. The active participation of implementers in the development and early implementation stages of the programme promotes change valence and change efficacy. By facilitating positive attitudes towards change through active participation of recipients, managers and policymakers can foster shared commitment to implement change. This can be strengthened by support from senior leadership across children's and adult organisations.



Figure 15 A conceptual framework of the Transition Pathway's implementation

# 6.12 Conclusion

This chapter has discussed and situated the findings of this study within the wider field of theory and literature on transition and programme implementation. The application of realist evaluation to this study's design has offered an opportunity to explore the important contextual conditions on the macro, meso and micro levels that influence and hinder implementation mechanisms and outcomes. Formal theories including a general theory of implementation, social network theory, habit theory, organisational readiness for change and social cognitive theory have offered crucial insights into this study's findings and their significance to practice, policy and research. The final concluding chapter of this thesis will describe the strengths and limitations of the study, the original contribution to knowledge and make final recommendations for practice, policy and future research.

# **Chapter 7: Conclusions and recommendations**

## 7.1 Introduction

This chapter begins with a brief summary of the research. The advantages and challenges of using realist evaluation as a framework to evaluate programme implementation are then explored through a reflection by the author. The strengths and limitations of the study are highlighted followed by the original contributions to knowledge that the study makes. The chapter concludes with recommendations for future research, practice and policy.

### 7.2 Research summary

This thesis began by exploring transition in healthcare with a specific focus on formal evaluations of transition programmes in healthcare organisations. The 10 Steps Transition Pathway, which is the focus of this evaluation, was introduced and described. A narrative review of the existing literature on evaluations of healthcare transition programmes identified gaps within the current evidence base relating to the effect that implementation processes and contexts have on the success or failure of programmes. To address this gap the study used realist evaluation to examine the processes that existed within the 10 Steps Transition Pathway's implementation and the contexts which influenced or hindered implementation processes and outcomes.

The study used a single qualitative embedded case study design informed by a realist evaluation approach to examine implementation processes across different contexts. Data were collected through a review of programme documentation and semi-structured interviews with programme designers and implementers. To analyse data thematic analysis and CMO analysis were used. Initial data analysis to develop programme theories resulted in four 'rough initial programme theories'. These were tested and refined in an additional round of data collection and analysis and resulted in four refined CMOCs which were discussed in Chapter 5.

The discussion chapter used formal theories including a general theory of implementation, social network theory, habit theory, organisational readiness for change and social cognitive

theory to explain the study's CMOC findings and refine the initial programme theories. Findings suggest that the outcomes of the programme's implementation were influenced by the complex interaction of macro, meso and micro processes and contexts. Features of the context which were found to facilitate implementation of the transition programme included the active participation of implementers in the change process, having well-established interorganisational social networks and fostering a collective commitment and coordinated behaviour change from professionals across children's and adult services. However, findings further suggest that the same contexts which facilitate implementation can also hinder mechanisms and outcomes. The previous chapter concluded with the refined programme theories and a conceptual framework of the transition pathway's implementation. The following sections of this chapter provide conclusions from the discussion beginning with a reflection on the methodological approach adopted within the study.

## 7.3 Methodological reflections

Realist evaluation was used in this study as a framework to evaluate the implementation of the transition pathway. The decision to adopt this approach to evaluation was informed by gaps within the literature relating to how existing transition programmes had been evaluated and a lack of empirical evidence concerning the role that implementation processes and contexts play in determining the success or failure of transition programmes. The aim of this study was to examine the processes that existed in the transition pathway's implementation and the contexts that influenced and hindered implementation processes and outcomes. Therefore, realist evaluation, which allowed a closer examination of the pathway's implementation and the contexts that shaped implementation outcomes, was considered to be an appropriate fit. The strengths and limitations of realist evaluation were briefly discussed in Chapters 2, 3 and 4 of this thesis. However, this concluding chapter reflects on the process of using realist evaluation within this study. It considers the value of realist evaluation as a framework to evaluate programme implementation as well as some of the challenges encountered and how these were overcome to operationalise the approach in practice. In doing so, the study adds new knowledge relating to how to operationalise realist evaluation, to the existing body of evidence.

# 7.3.1 The value of realist evaluation as a framework to evaluate programme implementation

Based on a generative model of causation, realist evaluation uses programme theory throughout the evaluation cycle to uncover the underlying mechanisms within the programme and the contexts which are needed to achieve programme outcomes (Pawson and Tilley, 1997; Leeuw and Donaldson, 2015; Van Belle, Rifkin and Marchal, 2017). In this study programme theory provided a conceptual structure to guide the evaluation of the pathway's implementation. Developing rough initial programme theories at the start of the evaluation allowed the researcher to focus on aspects of implementation that were considered to be most important to programme designers. Rough initial programme theories supported the researcher to maintain focus and informed all aspects of the research design.

Realist evaluation's recognition of the interplay between agency and structure, and resources and reasoning were particularly found to be useful to the evaluation of the transition pathway's implementation. By exploring how healthcare professionals received and interpreted resources provided by the transition pathway, the researcher was able to identify important mechanisms that existed within the implementation of the pathway. For example, relationships between individual professionals in paediatric and adult services based upon trust and confidence were highlighted as an important mechanism that supported implementation of the pathway. This finding as well as others provides insight into why programme implementation may be more successful for some services as compared to others. It adds to a better understanding of what is needed to ensure the success of transition programme implementation in healthcare organisations.

Furthermore, realist evaluation provided the researcher with the opportunity to investigate how contextual features affected the implementation of the pathway. The role that context plays in shaping implementation processes and outcomes was identified as an area within the existing evidence base in which knowledge was lacking. The CMOC formula offered by realist evaluation was used within this study to identify important contextual conditions and their relationships to implementation mechanisms and outcomes. This was particularly valuable to this study as it supported the researcher to identify how implementation decisions

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made by healthcare professionals in practice were highly affected by the contexts in which implementation took place. This important finding offers insight into which contextual conditions are necessary for implementation of transition programmes to be successful. These findings can be used to inform the development and implementation of future transition programmes.

Whilst realist evaluation was considered to be a useful framework to evaluate the implementation of the transition pathway, there were several methodological challenges that the researcher experienced, particularly during the process of data analysis. These are described in the next section of this chapter alongside the strategies that the researcher employed to overcome the challenges in order to effectively operationalise realist evaluation.

#### 7.3.2 Methodological challenges and how they were overcome

The lack of transparent methodological and practical guidance on how to operationalise realist evaluation created challenges for the researcher, particularly during the process of data analysis. The reporting and quality standards for realist evaluation developed as part of the RAMESES II project were used by the researcher to support the development of programme theory and realist interviewing techniques, and to better understand the concepts of mechanism and context. Whilst they were felt to be useful in this respect, they do not specify how realist evaluation should be operationalised in practice (Feather, 2018); or how one should analyse data using the CMOC heuristic. There are few published studies which provide detailed, transparent accounts of how data is analysed using realist methodologies.

During the first stage of data analysis studies published by Byng et al. (2005), Dalkin et al. (2015) and Punton et al. (2016) were found to be useful. In particular, Dalkin et al's (2015) paper which reconceptualises the CMOC framework by disaggregating mechanisms into resource and reasoning. Initially, differentiating between mechanisms, programme components and contexts was a challenge for the researcher. Dalkin et al's (2015) reconceptualised CMOC framework supported the researcher to identify important mechanisms within the data by examining how healthcare professionals reasoned with the resources offered by the transition pathway. This helped to firstly differentiate mechanisms

from programme components and then mechanisms from contexts. Maintaining critical realist principles and applying these to data analysis further supported the identification and differentiation of core realist concepts. Critical realism and realist evaluation are both underpinned by a model of generative causation which situates programme mechanisms within the real level of reality (Astbury, 2018). By separating mechanism into resource and reasoning using Dalkin et al's (2015) framework the researcher was able to bring to the surface 'real, yet hidden mechanisms' that existed within the transition pathway's implementation (Feather, 2018: 70). Contexts were then identified within the data using definitions provided by both Pawson (2006; 2013) and the RAMESES II project (2017b) which acted as a guide.

Although, Dalkin et al's (2015) reconceptualised CMOC framework supported the researcher to differentiate between programme mechanism, component and context, challenges again arose when considering the best way to represent initial CMO configurations. The researcher referred to the work of Mukumbang et al. (2018) who use 'if-then-because' statements to represent interconnected mechanisms, contexts and outcomes. This alternative way of presenting the contexts, mechanisms and outcomes that informed the rough initial programme theories, was found to be a more useful technique. The advantages of using 'ifthen' statements to represent programme theories are highlighted by Pearson et al. (2015). Use of 'lf-then' statements can provide a means of communicating complex information in an accessible and understandable manner and support the identification of interrelationships between programme theories (Pearson et al., 2015). In this study, they served two purposes. They supported the researcher to make connections between contexts, mechanisms and outcomes identified during initial programme theory development, and were then further integrated into final programme theories as part of the refinement process. Whilst final programme theories are not presented as 'if-then-because' statements, they played a vital role in supporting the researcher to conceptualise final programme theories and are a useful tool for realist evaluators to use during data analysis.

As data analysis progressed, Pawson's (2006; 2013) four I's aide memoir which categorises contextual features according to four contextual layers within a system, was found to be particularly useful in supporting the researcher to identify contexts across the data. Whilst

the definition of context provided by RAMESES II (2017b) initially supported the researcher to better understand the meaning of 'context', it was found to have limitations in its ability to support the researcher to identify different types of contextual features. Pawson's four I's aide memoir enabled the researcher to identify contextual features at the individual, interpersonal, institutional and infrastructural level of programme implementation. Pawson (2006) provides a description of the types of contexts that exist within each contextual layer of a system and supporting questions that can be used to guide identification of contextual features. The researcher was able to adapt Pawson's (2006) supporting questions making them more specific to the study which helped to identify contexts within the data. For example, at the individual level Pawson (2006: 39) asks the guestion: 'do the educators have the appropriate motivations, capabilities and credibility to take the intervention forward?'. This question was adapted by the researcher to: Do healthcare professionals have the appropriate motivations, capabilities and credibility to implement the transition programme? By asking this question of the data, the researcher was able to identify individual motivations and capabilities as important contexts evident across the data. As discussed above, difficulties in identifying and differentiating contexts from mechanisms is reported as a key methodological challenge for realist evaluators (Feather, 2018). Pawson's (2006; 2013) four I's aide memoir was used as a framework within this study to overcome this challenge and is a useful resource for realist evaluators to draw on to support data analysis.

Methodological difficulties were further encountered when attempting to analyse data using two different methods: thematic analysis and CMO analysis. Although, thematic analysis is theoretically flexible (Braun and Clarke, 2006; Nowell et al., 2017; Braun and Clarke, 2020) and is a popular data analysis framework used by realist evaluators, studies that report on how thematic analysis is used alongside CMO analysis in realist evaluation studies are limited. In this study, difficulties in aligning these two approaches came to the surface in the second stage of data analysis when there was a much larger proportion of data that needed to be analysed against rough initial programme theories. The researcher began the analysis process by following the first two steps of Braun and Clarke's stages of thematic analysis. This involved familiarisation with the data and initial coding. During the initial coding stage CMOs were mapped against rough initial programme theories. However, this approach felt quite restrictive with CMOs being forced to fit in with codes that had been generated. The

approach took away from the flexibility of thematic analysis. Due to the theoretical framework that was applied not all information was taken into consideration and there was a risk of losing data that might provide important insight into the implementation of the pathway. To address these difficulties the researcher decided to sequence the stages of analysis. Thematic analysis and open coding were firstly used to understand the processes underlying the pathway's implementation. The CMO heuristic was then applied to identify the main CMOs within the pathway's implementation. This process was extremely time consuming as the researcher had to go back to stage two of thematic analysis to re-examine initial codes and then complete an additional three stages of thematic analysis to identify the main themes across the data. The CMO heuristic was then re-introduced into the analysis process and used as a tool to code individual themes for CMOs. Gilmore et al's (2019) recent paper which provides a transparent account of data analysis in realist evaluation was used as a guide for the latter stages of data analysis which involved CMOC extraction and elicitation and synthesis and refinement.

On reflection, the data analysis process followed within this study was useful in that it allowed the researcher to provide a step-by-step, transparent account of each stage of analysis. However, as stated above, it took a significant amount of time and there were elements of repetition purely due to the realisation at a later stage that thematic analysis and CMO analysis could not be easily aligned. Papers that report on the process of analysis in realist evaluation such as Gilmore et al. (2019) and Dalkin et al. (2020) provide important insights into data analysis processes and would have been beneficial to the researcher if available at an earlier date. The difficulties encountered and solutions applied to overcome methodological challenges experienced earlier on in this study have already been published (see Appendix B). It is anticipated that the published paper and later findings described in this thesis will support researchers who are new to realist evaluation to better understand how to operationalise realist evaluation in practice.

It is further important to acknowledge that the researcher's own understanding of realist evaluation developed significantly over the period in which this study was undertaken. Specialist training on realist methods delivered by the centre of advancement in realist evaluation and synthesis (CARES), attendance at conferences and engaging with new publications on realist methodologies provided opportunities for the researcher to enhance her knowledge and understanding of how to operationalise realist evaluation in practice. As discussed above, the most significant learning curve occurred during the process of undertaking data analysis. Data analysis was an evolving, dynamic process which provided the researcher with a valuable learning experience. This experience and knowledge will be used by the researcher to inform the analysis process for future realist evaluation research.

## 7.4 Strengths and limitations

The previous section of this chapter discussed the advantages and limitations of using a realist evaluation approach within this study. The next section of this chapter will highlight further strengths and limitations of the study.

# 7.4.1 Strengths of the study

Undertaking an independent evaluation and being external to the paediatric organisation were considered to be key strengths. As a social worker previously involved in transitional care the researcher approached the evaluation with some existing views on the role of professionals in transition. However, the researcher had no prior knowledge or experience of healthcare transition or the programme being evaluated and offered an outsider perspective. This had several advantages. The researcher was able to reassure participants that their responses to questions during interviews were anonymous. This supported participants to feel more comfortable in the presence of the researcher and give open, honest feedback about some of the challenges that they faced when attempting to implement the transition programme. Research by Hurley, Eyk and Baum (2002) and Conley-Tylor (2005) which explores insider and outsider evaluation support this suggesting that people may be more prepared to share sensitive information and open up if the evaluator is external to the organisation. During interviews several participants also commented that the interview itself provided an opportunity for them to reflect on their transition practice and openly share their views on what needed to be improved. The researcher's impartiality and reassurance of participant anonymity supported this process and data collected reflected both positive and negative aspects of programme implementation. Data may have been different if the

researcher was internal to the organisation as participants may not have been as open and honest due to fear of repercussion.

Conley-Tylor (2005) argues that external evaluators often lack knowledge of programmes which may limit their understanding of how programmes work and the wider context in which they function. Inside evaluators may thus be at an advantage. Rather than being a limitation of this study, it may be viewed as a strength. The researcher had the time to be able to educate herself about the transition programme and how it operates. Time was spent at the beginning of the study developing relationships with key stakeholders and attending transition steering groups to better understand the programme theories the researcher spent time reviewing the programme documentation and interviewing programme designers. This gave the researcher a more comprehensive understanding of the programme, how it was expected to be implemented and wider contextual features that would potentially support or hinder implementation. The time given to complete this may not have been the same if the researcher were internal to the organisation and had competing priorities.

A further strength of this study is the inclusion of a range of multi-disciplinary professionals within the sample. Interviews were undertaken with paediatric consultants, specialist nurses, physiotherapists, dieticians, community matrons and a dual qualified nurse/social worker. Data collected is thus reflective of the different experiences of healthcare professionals across the paediatric organisation.

As this study was undertaken in one paediatric organisation and evaluated the implementation of a transition programme specific to that organisation, it is not possible to draw generalisations. However, the sets of ideas informing the final programme theories help to facilitate generalisation beyond the immediate context of the organisation (Pawson and Tilley, 1997; Easton, 2010; Astbury, 2018). The strength of this study is that it provides a degree of insight into the contextual conditions that are needed to facilitate successful implementation. Through its focus on practice and implementation, the study provides several practical recommendations for policymakers, managers and practitioners to consider

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when developing and implementing transition programmes. These are discussed in the final section of this chapter.

#### 7.4.2 Limitations of the study

As stated in the introduction to this study, the study does not include the views and experiences of young people who are recipients of the transition programme. This is because the study focused on healthcare professional's decision making around implementation of the transition programme. The decision to focus on healthcare professionals and implementation was influenced by both gaps identified in the literature, which are discussed in Chapter 2, and practical considerations relating to the organisation itself. The three-year timescale for funding of the PhD and the stage at which the organisation was at in their attempts to implement the programme meant that it would not be achievable for the study to evaluate patient outcomes. The paediatric organisation were very early on in their efforts to implement the transition programme and were adopting a phased approach to implementation across the trust. Between 2017-2019 when data collection took place the transition programme was being rolled out to targeted services within the organisation. Healthcare professionals were still familiarising themselves with the transition programme and starting to implement aspects of it within their services. Implementation of the transition programme was therefore in its infancy and programme designers wanted to find out if and how it was being implemented by professionals. Although it was not necessary or possible to include the views of young people experiencing the transition programme in this study, it is a limitation of the study. Any future evaluations of the 10 Steps Transition Pathway should include the views and experiences of the young people receiving it.

Furthermore, this study was undertaken in one paediatric organisation and was only able to collect data from paediatric professionals in specific services within that organisation. This was because implementation of the transition programme was being phased out across the trust and not all services were familiar with the transition programme. Using a single embedded case study design with multiple sub-units of analysis allowed the researcher to compare CMOs across seven services within the paediatric organisation. This was an advantage of the study as it enhanced understanding of implementation of the transition pathway and identified differences in contextual conditions across services (Yin, 2018).

However, the number of participants interviewed from each service or sub-unit ranged from one to five with some services showing more interest in participating in the study than others. This resulted in a larger dataset for certain services. This did not affect the findings of the study too much as the evaluation was not focused on implementation in individual services but implementation across services. Data were combined and synthesised across sub-units to test and refine initial programme theories.

Additionally, although programme designers planned to undertake work with adult organisations with the hope that they would adopt the transition programme, this study took place before that could happen. As the aim of the study was to investigate how the transition programme was being implemented by healthcare professionals, it was not possible to include adult healthcare professionals from external organisations within the sample. Findings are therefore based on paediatric professionals' experiences of transition programme implementation. This is considered as a limitation of the study as adult healthcare professionals' voices have not been included.

Finally, the sampling of participants used within the study is not representative of the individual experiences and perspectives of service commissioners and managers. Participating healthcare professionals worked in front-line services and therefore offered a particular perspective on implementation of the transition programme. This is a limitation of the study, as service commissioners and managers often have a more comprehensive understanding of the wider landscape which impacts (both positively and negatively) on programme implementation. The limitations of the participant population accessed within the study are thus recognised.

### 7.5 Original contributions to knowledge

Chapter 2 of this thesis identifies how existing evaluations of healthcare transition programmes have predominantly focused on measuring programme outcomes in isolation of implementation processes and contexts. In doing so, it argues that existing studies have failed to consider the important role that implementation processes and contexts, which both involve human agency, play in determining the success or failure of transition programmes.

This lack of insight into how implementation processes and contexts affect the outcomes of transition programmes highlighted the need for this study. By formally evaluating the implementation of a newly developed transition programme using a realist evaluation framework, this study provides new insight into some of the key mechanisms and contexts that influence and shape transition programme implementation. The original contribution to knowledge that this study makes sits within three main areas which are discussed below.

# 7.5.1 Insights into how and why healthcare transition programmes work or fail to work

This was the first study of its kind to formally evaluate the implementation of a newly developed transition programme (the 10 Steps Transition Pathway) within a paediatric organisation in the UK. Through its application of a realist evaluation framework, the study contributes new knowledge to the wider field of healthcare transition programmes by identifying the role that context and human agency play in facilitating or hindering successful implementation of transition programmes. Findings suggest that the outcomes of programme implementation are influenced by the complex interaction of macro, meso and micro processes and contexts. The contribution that such factors have on the success or failure of transition programmes are rarely taken into consideration by existing evaluation studies. However, this study shows that factors including structural and cultural differences between paediatric and adult organisations, proximity of services and social networks, funding, organisational behaviour, individual motivation and agency do have an effect on how transition programmes are implemented which will ultimately influence whether they succeed or fail. These important findings have been formally reported back to the paediatric organisation (see appendix N) and disseminated to staff within and outside of the organisation who are responsible for transition. This study has provided practical recommendations for transition programme implementation thus contributing to the improvement of transition practice across the trust. Findings can further be used by healthcare providers to support the development and implementation of future transition programmes.

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# 7.5.2 Organisational behaviour and programme implementation

The current literature base provides little evidence on the role that organisational behaviour plays in influencing transition programme implementation. This study provides an in-depth understanding of how organisational behaviour including habituation, culture, organisational readiness for change and professional relationships impact on professional's ability to implement new ways of working. Through its application of GTI, this study shows how formal theories of implementation and organisational behaviour can be used to understand the processes and contexts that exist within the implementation of complex transition programmes. In doing so, it contributes new knowledge to the fields of organisational and implementation research.

## 7.5.3 Realist evaluation methodology

Although the methodological challenges associated with utilising a realist evaluation framework are frequently cited by authors, few have provided detailed, transparent accounts of how these challenges have been overcome. This study provides a description of how realist evaluation can be operationalised despite the methodological challenges encountered. In chapters four and seven the researcher offers a transparent account of the strategies that were used to overcome methodological difficulties, particularly around data analysis processes. A methodological discussion paper (see Appendix B) informed by findings from this thesis was also published. This study therefore contributes new knowledge to methodological debates of realist evaluation.

# 7.6 Recommendations

# 7.6.1 Recommendations for future research

This study has highlighted how inter-organisational social networks, which are integral to the successful implementation of transition programmes, are affected by structural and cultural differences between children's and adult organisations. As this study focused specifically on the views and experiences of paediatric healthcare professionals future research should explore the impact of this in further detail through the experiences of adult healthcare professionals. A better understanding of why and how structural and cultural differences

affect implementation processes from the perspectives of both children's and adult healthcare professionals may help to improve transition practice overall.

The final programme theories presented in this study should continue to be tested and refined in line with a realist evaluation approach. It would be particularly useful to test these programme theories in an adult healthcare organisation to identify any additional contextual features specific to the adult sector that are necessary for effective implementation. This is an area of research that will be further developed by the researcher following successful completion of this thesis.

The COVID-19 pandemic has pushed healthcare organisations to implement new ways of working which include virtualised care (Webster, 2020). Little is known about the extent to which 'virtual' or 'remote' transition clinics have been used by healthcare organisations, and the impact that these may have had on transition practice. It would be beneficial to explore whether the use of 'virtual' transition clinics have improved partnership working between children's and adult organisations. There may therefore be an opportunity for the researcher to advance knowledge in this area by evaluating the impact of COVID-19 and use of virtualised care on transition practice.

This research has further been used to inform undergraduate and postgraduate health and social work education within two universities. Within social work education, transition for young people with long-term conditions is now prioritised as a key subject area. Furthermore, the researcher has been successful in gaining funding through the Cheshire and Merseyside Social Work Teaching Partnership to further explore the training needs of health and social care professionals working with adolescents transitioning between children's and adult health and social care services. The findings from this research will be used to make recommendations for health and social work education and practice.

# 7.6.2 Recommendations for policy and practice

The study findings highlight several recommendations for policy and practice which can be separated into recommendations that are specific to practice at Alder Hey Children's NHS Foundation Trust and recommendations that are more general to the wider field of healthcare

transition programmes and implementation. Guided by research undertaken by Carrieri et al. (2020), key recommendations for policy and practice are presented in table 7.1 as principles for programme implementation linked to different stakeholder groups.

#### 7.6.2.1 Recommendations for Alder Hey Children's NHS Foundation Trust

In this study, proximity and inter-organisational social networks were highlighted as important contexts which either supported or hindered the implementation of joint transition reviews. 'Virtual' or 'remote' joint transition reviews for young people transitioning to an outof-area adult service were not always being utilised by healthcare professionals at the time of data collection. This meant that joint transition reviews were less likely to happen for young people transitioning outside of the local area. Undertaking 'virtual' or 'remote' joint transition reviews for out of area transitions should be taken into consideration by the organisation. This will help to improve social networks with adult organisations outside of the local area ensuring that all young people have access to a joint transition review.

Assessing the workability of transition documents built onto the organisation's computer system should also be taken into consideration. Healthcare professionals and young people should be consulted with to explore how accessible transition documents are, and whether they are specific enough to what young people need to know about transition. To fully implement transition preparation tools and documents with young people, healthcare professionals require additional time resources. They further require additional time within their current job roles to fulfil their responsibilities as a transition key worker. Programme designers should therefore take these factors into consideration when moving forward with implementation. If feasible, a new service specific transition coordinator role which involves working across both the children's hospital and adult organisations should be developed.

Findings from this study also highlight differences between services within the organisation in relation to implementation efforts. Through consultation with healthcare professionals, programme designers should consider reviewing current internal barriers to transition within teams who do not have well-established transition processes. Programme designers should consider using a change model such as organisational readiness for change which may help to improve levels of commitment to implement change within specific services. Making transition training mandatory for professionals across the trust and extending the offer to key professionals in adult organisations may support future implementation. The earlier involvement of adult organisations in implementation of the transition programme would also be beneficial. As well as working with commissioners from adult organisations to evidence the need for additional funding to support the implementation of joint transition reviews.

These recommendations have been reported back to Alder Hey Children's NHS Foundation Trust (see Appendix N) and disseminated to healthcare professionals across the trust through a written report and oral presentations at annual transition conferences in 2019 and 2021.

# 7.6.2.2 Recommendations for wider healthcare transition programmes and implementation

When designing future healthcare transition programmes policymakers and managers should ensure that transition programmes are flexible enough to be adapted to meet the needs of different patient groups. As findings from this study showed, the greater the flexibility of the transition programme the more likely professionals are to implement it. Programme designers should also consider aligning desired changes to practice with the existing social norms and practices of the organisation. This has been shown to support understanding and adoption of new practices (McDonnell Norms Group, 2006). Providing opportunities for reflection and shared learning may also support professionals to unlearn routine habits and make changes to current practice.

The active participation of implementers in the development and early implementation stages of quality improvement initiatives are essential. Active participation and communication between programme designers and implementers can foster shared commitment to implement change and improve implementation outcomes. Support from senior leadership across both children's and adult organisations can further strengthen this. The successful implementation of transition programmes' requires the cooperation and coordination of actions from both children's and adult professionals. Dependency on individual professionals to implement change is not sustainable and transition programmes

require organisational wide approaches to implementation. Prior to implementation, programme designers should ensure that inter-organisational social networks are wellestablished and adult organisations are actively involved in implementation efforts.

The role of the transition coordinator/keyworker which is an important feature within good practice guidance and policy should be reviewed nationally. Healthcare organisations should consider incorporating the responsibilities and workload of transition coordinators/keyworkers into individual job descriptions. The establishment of dual roles across children's and adult organisations may provide a valuable opportunity.

Transition programmes should further take into consideration the wider social and financial aspects of transition that impact on young people. Thought should be given to the suitability of healthcare professionals in meeting the wider needs of young people and multidisciplinary working involving transition should be extended to include social care professionals.

Audience	Key recommendations and principles for programme implementation
Commissioners	Ensure that adult services involvement in healthcare transition is part of best practice, and funding is available to support joint transition reviews.
Programme designers	Ensure that transition programmes are flexible enough to be adapted by services who are at different stages in their transition offer, and individual healthcare professionals wanting to meet different patient needs Allow additional time for transition documents to be completed. Provide staff with comprehensive IT training and address any difficulties with IT integration. Establish a process to develop inter-professional/inter-
	service shared understandings of healthcare transition and what this should entail. Support staff to develop and maintain inter-professional/inter-service working relationships within and across organisations. Seek ongoing feedback (over a number of years) from

Table 7.1 Key recommendations and principles for programme implementation

	paediatric and adult services to establish how well the young person has settled in adult services.
	Ensure that everyone who needs to be involved in transition is through regular communication with key professionals.
Health care professionals	Actively seek out inter-professional working relationships which support you to develop trust and confidence in each other.

# 7.7 Conclusion

This study has evaluated how a healthcare transition programme is implemented by healthcare professionals within a paediatric organisation. By using realist evaluation as a framework to evaluate the programme's implementation it has revealed important contextual conditions which both support and hinder implementation. It has addressed a significant gap within the existing evidence base relating to the role that context and human agency play in facilitating or hindering the successful implementation of transition programmes. It contributes new knowledge in three domains: evidence relating to how and why healthcare transition programmes work or fail to work, organisational behaviour and programme implementation, and realist evaluation methodology. The study has made several recommendations for future research, policy and practice. Findings have been disseminated through publication, a report and both poster and oral presentations at conferences (see Appendix B and N). Recommendations have been used by programme designers at Alder Hey Children's NHS Foundation Trust to support the next stage of implementation across adult organisations.

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# Appendices

Appendix A: Table of 32 articles included in narrative literature review

Author/s and year	Country	Aims	Methodology	Target population	Main findings
Allen, D., Cohen, D., Robling, M., Hood, K., Atwell, C., Lane, C., Gregory, J., Lowes, L., Channon, S., Gillespie, D., Groves, S. & Harvey, J. (2010)	UK	To identify, map, categorise and enumerate the range of diabetes transition models in use in England. To develop a conceptual framework of models. To understand users'/carers'/providers' experiences of transition services, the processes and organisational challenges and assess costs. To make recommendations about what works best, for whom and in what circumstances. To contribute to understanding of pathways through transition.	Mixed methods (Informed by systems thinking, continuity of care and realist evaluation frameworks)	Health professionals working in paediatric and adult Diabetes services in England	Insufficient evidence based for overall effectiveness of education transition programmes. Importance of transition co- ordinator role in improving continuity for young people moving into adult services. YP prefer simple consultations over multi-disciplinary clinics. Simultaneous adolescent and young adult clinics facilitate longitudinal continuity between services. Poor delivery of age specific clinics impacts negatively on YP's experiences of transition. Highlights complex nature of transition and transition programmes.
Betz, C. L., Smith, K. & Macias, K. <b>(2010)</b>	US	To examine whether a cognitive-behavioural program of Transition Preparation Training (TPT), in combination with Spina Bifida management, leads to improved transition	Quantitative (RCT)	65 adolescents with Spina Bifida in a Children's Hospital in Los Angeles	Reported little or no significant difference in transitional readiness outcomes. No significant improvement in health-related quality of life following a structured transition intervention.

		subjective wellbeing, role mastery and self-care practice.			
Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., While, A. & Gibson, F. <b>(2016)</b>	UK	To evaluate the effectiveness of interventions designed to improve the transition of care for adolescents from paediatric to adult health services.	Systematic Review	Adolescents with any chronic condition that required ongoing clinical care, who were leaving paediatric services and entering adult healthcare units	In 3 out of 4 included studies, education programmes for patients with diabetes mellitus resulted in slight improvements in transitional readiness. No significant difference in rates of transfer following transition programme. Highlights complex nature of transition programmes
Chaudhry, S. R., Keaton, M. & Nasr, S. Z. (2013)	US	To evaluate the experiences and opinions of patients in an adult Cystic Fibrosis centre who went through a formal transition versus those who did not, to evaluate the overall process and identify means for improvement.	Quantitative (case-control study)	Adult Cystic Fibrosis patients at an adult Cystic Fibrosis centre	Reported a statistically significant difference in patient satisfaction following a structured transition programme.
Chu, P. Y., Maslow, G. R., Von Isenburg, M. & Chung, R. J. (2015)	US	To examine the current evidence regarding the effect of transition interventions on care transfer.	Systematic Review	Adolescents and young adult with chronic illness receiving a transition intervention	Reported improvement in rates of transfer post transition intervention. Increased rates of transfer cannot be causally attributed to the use of keyworkers due to multiple component design of transition interventions. Reported no significant difference in HbA1c levels post transition intervention. Importance of complex nature of transition programmes.

Crowley, R., Wolfe, I. & McKee, M. (2011)	UK	To systematically review the evidence of effectiveness of transitional care programmes in young people aged 11-25 with chronic illness (physical or mental) or disability, and identify their successful components.	Systematic Review	Young people aged 11-25 with chronic illness (physical or mental) or disability receiving a transitional care programme	In 4 out of 10 included studies, disease specific education programmes improved patients' knowledge and self-management of their conditions. Improved outcomes could not be attributed to the use of transition coordinator due to multiple component design of transition interventions. Improved outcomes are associated with specific young adult clinics. Narrow definition of transfer as an indicator for successful transition is problematic. Importance of complex nature of transition programmes.
Davis, A. M., Brown, R. F., Lounds Taylor, J., Epstein, R. A. & McPheeters, M. L. <b>(2014)</b>	US	To explore existing research on the effectiveness of transition programs.	Literature Review	Young people with special health care needs transitioning from paediatric to adult care	Narrow definition of transfer as an indicator for successful transition is problematic. There is a lack of well-defined, accepted outcome measures related to transition success. Importance of complex nature of transition programmes.
Dogba, M. J., Rauch, F., Wong, T., Ruck, J., Glorieux, F. H. & Bedos, C. (2014)	US	To evaluate a transition program for adolescents and young adults with osteogenesis imperfecta (OI) from a pediatric orthopaedic hospital to adult care.	Qualitative	Patients with OI (6), parents (4) and staff (15)	Resources invested into transition programmes facilitates implementation.
Egan, E. A., Corrigan, J. & Shurpin, K. (2015)	US	To evaluate the effectiveness of a structured transition program by measuring	Quantitative (prospective cohort study)	Young adults with type 1 Diabetes aged 18-28 years	Reported improvements in rates of transfer post transition intervention.

		clinical and psychometric properties related to transition and adherence to follow up.			Reported no significant difference to health-related quality of life for adolescents with Diabetes following a structured transition intervention. Reported a statistically significant reduction in Diabetes-related distress post transition intervention. Notes the complexity of transition.
Gabriel, P., McManus, M., Rogers, K. & White, P. (2017)	US/UK	To identify statistically significant positive outcomes in paediatric- to-adult transition studies using the triple aim framework of population health, consumer experience, and utilisation and costs of care.	Systematic Review	Youths transferring from paediatric to adult outpatient healthcare who had received a transition intervention	Reported statistically significant outcomes for patient satisfaction in 7 out of 10 studies. Reported a decline in HbA1c levels in 8 studies.
Gravelle, A. M., Paone, M., Davidson, A. G. F. & Chilvers, M. A. (2015)	Canada	To describe the evolution of a transition clinic for patients with Cystic Fibrosis into a multidimensional quality improvement transition initiative.	Quantitative (retrospective evaluation)	Young people receiving Cystic Fibrosis care at an adult CF clinic	Reported an improvement in patient knowledge following a pre- graduation workshop which incorporated the use of a joint transition clinic. Improvements in post-test scores for transitional readiness following a CF education intervention.
Huang, J. S., Terrones, L., Tompane, T., Dillon, L., Pian, M., Gottschalk, M., Norman, G. J. & Bartholomew, L. K. <b>(2014)</b>	US	To evaluate whether a generic, internet and mobile phone delivering disease management intervention would improve disease- management, self- efficacy and	Quantitative (RCT)	81 adolescents with chronic disease, aged 12-22 years old without cognitive impairment	Reported statistically significant improvements in disease and health knowledge for treatment group participants post intervention. Reported no significant improvement in health-related quality of life for intervention group participants post intervention.

		communication			
Jensen, P. T., Karnes, J., Jones, K., Lehman, A., Rennebohm, R., Higgins, G. C., Spencer, C. H. & Ardoin, S. P. (2015)	US	To assess transition outcome and satisfaction of a social-worker centred program in a paediatric rheumatology clinic.	Quantitative (case-control study)	210 adolescents and young adults receiving care in a rheumatology clinic	Reported increased rates of satisfaction and transfer for young people exposed to the intervention but these were not statistically significant.
Jones, M. R., Johnson Hooper, T., Cuomo, C., Crouch, G., Hickam, T., Lestishock, L., Mennito, S. & White, P. H. (2019)	US	To report findings from a pre-post study of a structured health care transition process implementation using the six core elements.	Mixed methods	55 practice sites from within the national healthcare transition learning network	Implementation of transition programmes require committed staff and transition champions to drive them forward.
Kerr, H., Price, J., Nicholl, H. & O'Halloran, P. (2017)	UK	To explain how intervention processes interact with contextual factors to help transition from children's to adult services for young adults with life-limiting conditions.	Systematic Realist Review	Young adults with life-limiting conditions transitioning from children's to adult services	Human motivation and organisational social contexts influence the implementation of complex transition interventions. Resources invested into transition programmes facilitates implementation. Importance of complex nature of transition programmes.
Kingsnorth, S., Lindsay, S., Maxwell, J., Tysbina, I., Seo, H., Macarthur, C. & Bayley, M. (2011)	Canada	To understand key factors in a collaborative cross-sectoral partnership by undertaking a process evaluation of stakeholder experiences.	Qualitative	18 stakeholders (health professionals, managers and senior administrators)	Importance of transition co- ordinator role to young people transitioning into adult care. Implementation of transition programmes require committed staff and transition champions to drive them forward.

					Barriers to implementation include differences between
					organisational policies.
Lewis, S. A & Noyes, J. <b>(2013)</b>	UK	To explore communication, information needs and experiences of knowledge exchange in clinical settings by young people and their parents, during transition from children's to adult epilepsy services.	Qualitative (partially informed by a realist evaluation framework)	Young people aged 13-19 receiving care for Epilepsy (30) and parents (28)	MDT working reported as an effective component of transition clinics. Importance of complex nature of transition programmes.
Little, J. M., Odiaga, J. A. & Minutti, C. Z. (2017)	US	To evaluate transition readiness for adolescents 14 years of age and older with Type- 1 diabetes to determine their self-advocacy and self-management skills.	Quantitative	Adolescents 14 years of age and older with Type-1 diabetes	Reported no significant relationship between high TRAQ scores and effective disease management.
McManus, M., White, P., Barbour, A., Downing, B., Hawkins, K., Quion, N., Tuchman, L., Cooley, W. C. & McAllister, J. W. (2015)	US	To examine the relationship between quality improvement activities within paediatric and adult primary care practices and improvements in transition from paediatric to adult care.	Quantitative (time series comparative study)	Children and young adults (14- 24 years) with chronic physical, developmental and mental health conditions	Barriers to implementation include differences between organisational policies and reluctance of staff to implement transition processes without identified adult providers.
Nieboer, A. P., Cramm, J. M., Sonneveld, H, M., Roebroeck, M. E., Van Staa, A. & Strating, M. M. H. (2014)	Netherlands	To describe the interventions implemented in a quality improvement programme to improve transitional care and evaluate its effectiveness in reducing	Quantitative (prospective cohort study)	Adolescents and professionals who participated in a quality improvement transition programme	Reported statistically significant improvements in patients' experiences of care delivery using the 'Mind the Gap Scale'.

		bottlenecks as perceived by professionals and improving chronically ill adolescents' experiences with care delivery.			
Okumura, M. J., Ong, T., Dawson, D., Nielson, D., Lewis, N., Richards, M., Brindis, C. D. & Kleinhenz, M. E. (2014)	US	To develop, implement and evaluate a theory- based programme for transition from paediatric to adult CF care.	Quantitative (cross-sectional study)	Adolescents receiving care in paediatric and adult CF clinic's	Reported increased attendance rates 6-12 months post transfer for adolescents receiving a structured transition intervention. Reported no statistically significant differences in self-advocacy and self-management between intervention and control groups pre and post intervention.
Price, C. S., Corbett, S., Lewis- Barned, N., Morgan, J., Oliver, L. E. & Dovey- Pearce, G. (2011)	UK	To evaluate a transition model in diabetes, the 'Transition Pathway' via interviews with young people who have experienced it first-hand.	Qualitative	11 young people in paediatric diabetes services who received a transition programme	Young people do not differentiate between sessions delivered as part of a transition pathway and normal clinical sessions delivered as part of routine care. Improved satisfaction relates more to the quality of young people's interactions with health care professionals involved in their transition.
Prior, M., McManus, M., White, P. & Davidson. L. (2014)	US	To examine and categorise transition measures by using the 'Triple Aim' Framework of experience of care, population health, and cost of care.	Systematic Review	Adolescents with and without chronic conditions transferring from paediatric to adult outpatient healthcare	Quality of life measures may not be suitable when measuring the impact of an intervention as compared to measuring the overall quality of healthcare.
Sequeira, P. A., Pyatak, E. A., Weigensberg, M. J., Vigen, C. P., Wood, J. R.,	US	To evaluate the efficacy of a structured transition programme compared with usual care in improving routine follow-	Quantitative (case control study design)	81 young adults in their last year of paediatric care	Reported no significant difference in transfer rates between participants receiving a structured diabetes transition programme

Ruelas, V., Montoya, L., Cohen, M., Speer, H., Clark, S. & Peters, A. L. (2015)		up, clinical and psychosocial outcomes among young adults with type 1 diabetes.			and control group participants receiving standard care. Reported statistically significant improvements in global well-being for intervention group participants at 12 months follow up.
Shaw, K. L., Watanabe, A., Rankin, E. & McDonagh, J. E. (2013)	UK	To examine the quality of transitional care in a paediatric and adult hospital by investigating (i) adherence to national transition guidance and (ii) whether implementation is associated with better patient/carer experiences.	Quantitative (cross-sectional)	Young people aged 11-21 years and parents/carers	Reported no significant difference in satisfaction between young people who had received a transition programme, compared to those who had not. Reported a statistically significant difference between parental satisfaction with parents whose children had received the transition programme, compared to those who had not.
Steinbeck, K. S., Shrewsbury, V. A., Harvey, V., Mikler, K., Donaghue, K. C., Craig, M. E. & Woodhead, H. J. (2014)	Australia	To determine if transition in type 1 diabetes mellitus is more effective with a comprehensive transition programme compared with standard clinical practice.	Quantitative (pilot RCT)	Young people (aged 16) with type 1 diabetes mellitus attending outpatient clinics	Reported no significant difference in rates of transfer between treatment and control groups.
Stringer, E., Scott, R., Mosher, D., MacNeill, I., Huber, A. M., Ramsey, S. & Lang, B. (2015)	Canada	To evaluate a paediatric rheumatology transition clinic from the perspective of young adults who attended the clinic.	Quantitative (case report study)	Young adults' who attended a paediatric rheumatology clinic	Reported improved patient satisfaction post transition clinic intervention.
Wafa, S. & Nakhla, M. (2015)	Canada	To review the literature to date on existing methods of transition care delivery for emerging adults with diabetes.	Literature Review	Emerging adults with diabetes receiving a transition programme	Reported improvements to diabetes management knowledge following a structured transition programme in one study.

Walter, M., Kamphuis, S., Van Pelt, P., De Vroed, A. & Hazes, J. M. W. (2018)	US	To evaluate the effectiveness of a clinical transition pathway; and to evaluate the experiences and satisfaction of young people with the transitional process and evaluate their perceived self-management skills.	Quantitative (cross-sectional)	Young people with any juvenile- onset rheumatic and musculoskeletal diseases (jRMD) transferring from a paediatric to adult rheumatology department	Reported high patient satisfaction and self-efficacy scores following transfer to an adolescent or adult clinic.
Watson, R., Parr, J. R., Joyce, C., May, C. & Le Couteur, A. S. (2011)	UK	To identify successful models of transitional care for young people with complex healthcare needs.	Scoping Review	Young people with cerebral palsy, autistic spectrum disorder or diabetes transferring from child to adult health services	Implementation of transition programmes require committed staff and transition champions to drive them forward. Over-reliance on single transition coordinators and transition champions.
Zhang, L. F., Ho, J. S. W. & Kennedy, S. E. <b>(2014)</b>	US	To summarise the validation of all published transition-readiness tools for adolescents (aged 11-19 years) with chronic disease.	Integrative Review	Adolescents (aged 11-19 years) with chronic disease	Reported a lack of well- established and tested transitional-readiness assessment tools.
Zhou, H., Roberts, P., Dhaliwal, S. & Della. P. <b>(2016)</b>	Australia	To provide an updated comprehensive review of the research-based evidence related to the transitions of care process for adolescents and young adults with chronic illness/disabilities since 2010.	Integrative Review	Adolescents and young adults with chronic illness/disabilities	Reported low clinic attendance and loss to follow up post transfer across 4 studies.

# Appendix B: Discussion paper published in the International Journal of Care Coordination

Developing programme theories as part of a realist evaluation of a healthcare quality improvement programme

International Journal of Care Coordination 2018, Vol. 21(3) 68–72 ! The Author(s) 2018 Article reuse guidelines: sagepub.com/journalspermissions DOI: 10.1177/2053434518779753 journals.sagepub.com/home/icp

**SAGE** 

Julie Louise Feather

# Abstract

The application of realist approaches to health services research and evaluation has continued to grow over the past two decades. However, difficulties in defining and operationalising key realist concepts of contexts, mechanisms and outcomes in healthcare settings continue to be recognised within the realist evaluation literature. Reflecting on an ongoing realist evaluation of a healthcare quality improvement programme across an inter-organisational context, this article explores some of the methodological challenges encountered by the author in the early stages of programme theory development. An individualised operationalisation and application of realist concepts are presented to demonstrate how initial programme theories can be developed despite the methodological difficulties presented.

Keywords

Health services research, quality improvement, programme development

# Introduction

Over recent years, there has been much debate regarding the appropriateness of applying experimental methods to the evaluation of complex interventions,<sup>1</sup> particularly within healthcare.<sup>2–4</sup> Experimental approaches have been subject to criticism from realist evaluators for oversimplifying causality<sup>3</sup> and failing to account for the complex, context-sensitive health systems<sup>2</sup> in which healthcare

#### Feather

programmes are implemented. This has been recognised by the UK Medical Research Council who issued guidance in 2015 on process evaluations of complex interventions, which argued that 'effect sizes alone are insufficient' and emphasised the importance of understanding how outcomes are shaped by implementation processes, causal mechanisms and contextual factors<sup>5</sup> (p. 21). Through its commitment to understanding causality within complex environments, realist evaluation has been recognised as an appropriate method for investigating complexity.<sup>3</sup> Realist evaluation offers evaluators deeper insights into the complex nature of programmes and the contexts in which they are implemented.<sup>6</sup> It seeks to explain how and why complex programmes work or fail to work, for whom and in what circumstances through examining the interaction between the mechanisms and contexts that exist within an intervention.<sup>1</sup> It has continued to influence health services research<sup>7,8</sup> with a growing number of realist evaluations being undertaken across different healthcare contexts. However, difficulties in defining realist concepts of contexts, mechanisms and outcomes and applying the contextbmechanism¼outcome (CMO) framework to health services have been reported as

#### key methodological challenges.<sup>2,6,9–15</sup>

To improve the quality of realist evaluations and address methodological issues, the RAMESES II project has recently developed reporting and quality standards for realist evaluation.<sup>6,16,17</sup> However, whilst these provide guidance on how to report realist evaluations, they do not specify how realist evaluations should be operationalised in practice. As realist evaluation is not a method, it is a way of thinking<sup>18</sup> which involves a level of inference to be made by evaluators, it has been argued that it is not possible to provide a systematic description of how to conduct realist evaluations.<sup>6</sup>

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#### Edge Hill University, UK

Corresponding author:

Julie Louise Feather, Edge Hill University, St Helens Road, Ormskirk L39 4QP, UK.

Email: featherj@edgehill.ac.uk

Reflecting on a current realist evaluation of a healthcare quality improvement programme across an inter-organisational context, this article describes how methodological problems encountered in the early stages of this project were navigated to develop initial programme theories. Dalkin et al.'s<sup>15</sup> reconceptualised contextpmechanism¼outcome configuration (CMOc) framework is used to illustrate how certain challenges were approached. Steps taken to address methodological difficulties are described and solutions are offered to demonstrate how realist concepts can be operationalised in a personalised way to conduct a valuable realist evaluation, despite methodological challenges.

# Defining and operationalising contexts, mechanisms and outcomes

Pawson and Tilley's realist evaluation is based on the premise that programmes themselves do not produce change (outcomes), rather it is the reasoning of stakeholders to the resources offered by the programme (mechanisms) and the appropriateness of social and cultural conditions (contexts).<sup>1</sup> This proposition is more commonly presented as a CMO configuration.<sup>1</sup> In their original text, Pawson and Tilley<sup>1</sup> argue that mechanisms can best be understood as theories which represent the 'potential of human resources and reasoning' (p. 68). This definition reflects a realist account of causation, which assumes that within any open social system (programme) there is a constant interaction between human reasoning and social structures (resources), and it is this interaction that generates mechanisms.<sup>1,18</sup> However, the activation of mechanisms is dependent on the context in which the programme operates. 'Context' is defined by Pawson and Tilley<sup>1</sup> as the 'prior set of social rules, norms, values and interrelationships' (p. 70) that exist within any institution/place/area. Contexts can both enable or constrain the operation of mechanisms, which affects how the programme works for different groups of stakeholders.<sup>7</sup> Variation of contexts can activate different types of mechanisms, which results in mixed outcome patterns consisting of both intended and unintended programme consequences.<sup>1</sup> Pawson and Tilley's definitions of 'mechanisms' and 'contexts' are however thought to be inconsistently applied across realist evaluation studies.<sup>6,13,14,16,19</sup> In their systematic review, Salter and Kothari<sup>13</sup> found that only 2 out of 14 realist evaluations applied Pawson and Tilley's definition of context. Similarly, disparity in definitions of mechanisms used across realist evaluation studies has also been reported over the years, particularly in health service evaluations.<sup>6,14</sup> Furthermore, difficulties with operationalising key realist concepts have been reported across realist evaluation studies.<sup>8,10,14</sup> Porter<sup>8</sup> suggests that the difficulties faced by healthcare researcher's in operationalising CMO concepts result from inconsistencies and contradictions in the philosophical and methodological foundations of realist evaluation. Operationalising realist evaluation in healthcare settings has thus proven

Although many realist evaluation studies have reported difficulties in operationalising the approach, few with the exception of Byng et al.,<sup>9</sup> Dalkin et al.<sup>15</sup> and Punton et al.<sup>22</sup> have described in detail how they resolved such issues and offered solutions to support future realist evaluators.<sup>13</sup> To address this, I will provide a detailed account of the challenges I have encountered during the early stages of my realist evaluation of a healthcare quality improvement programme. I will reflect on what informed my thinking process during initial analysis and offer solutions for novice realist evaluators to overcome methodological difficulties.

# Developing programme theories as part of an ongoing realist evaluation study

The study I reflect on is an ongoing realist evaluation of the implementation of a quality improvement programme developed to improve transition for young people with complex healthcare needs moving from paediatric to adult health services. The programme consists of multiple interventions aimed at both the young person, their families and professionals in both children's and adult healthcare services. Pawson and Tilley<sup>1</sup> assert that programme theories must be made explicit at the very beginning of an evaluation as the purpose of realist evaluation is to test and refine these programme theories to build an explanatory account of how, for whom and in what circumstances they work to bring about change. Therefore, the first stage of my evaluation which forms the discussion of this paper involved the development of initial programme theories by collecting data through documentary analysis and semi-structured interviews with programme developers. Thematic analysis was then used to analyse key programme documents and interview transcripts.

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to be problematic. Difficulties in identifying, categorising and differentiating mechanisms from both programme components and contextual conditions are some of the main challenges faced by realist evaluators.<sup>10–12,14,20,21</sup>

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During the early stages of data analysis, the main challenges I encountered were consistent with what has already been reported in the literature.<sup>10–</sup> <sup>12,14,15,21,22</sup> Firstly, differentiating programme components from programme mechanisms was

complicated as the programme I was evaluating consisted of multiple interventions that were not always explicitly defined in the documentation and interview transcripts. Guidance for process evaluations of complex interventions<sup>5</sup> recommends constructing a logic model which may help to distinguish core components of an intervention from the resources, structures and outcomes required for successful implementation. Whilst using a logic model helped me to identify key programme activities, it was not as successful in helping me to surface programme mechanisms. Adhering to the realist principle of generative causation and applying these ideas to my analysis is what supported me with this process. Whereas, programme components are visible to the eye, programme mechanisms are not directly observable as they exist beneath the empirical level.<sup>16,23</sup> Therefore, to help me uncover real, yet hidden mechanisms I applied Dalkin et al.'s<sup>15</sup> reconceptualised CMOc framework which disaggregates mechanisms into resources and reasoning. This alternative way of thinking about CMOs suggests that 'intervention resources are introduced in a context, in a way that enhances a change in reasoning. This alters the behaviour of participants, which leads to outcomes'<sup>15</sup> (p. 4). This is presented as M (Resources) + C - M (Reasoning) = O.<sup>15</sup> Separating mechanisms into resources and reasoning through the application of Dalkin et al.'s<sup>15</sup> framework helped me to differentiate unobservable programme mechanisms from observable programme components.

Furthermore, Dalkin et al.'s<sup>15</sup> framework which considers the influence of context on participant's behaviours enabled me to distinguish mechanisms (resource + reasoning) more easily from contexts. Distinguishing mechanisms from contexts was the second challenge I experienced during initial programme theory development and is commonly reported as a methodological difficulty across realist evaluation studies.<sup>9,10,15,22</sup> Part of the difficulty with making a clear distinction between mechanisms and contexts lies in the broad definitions of both concepts provided by Pawson and Tilley.<sup>1</sup> Again, returning to the philosophical foundations of critical realism and applying Dalkin et al.'s<sup>15</sup> reconfigured CMOc framework aided my understanding. Within Dalkin et

al.'s<sup>15</sup> model, the relationship between resourcescontext-reasoning is clearer and helped me to understand how resources can be received differently by stakeholders depending on contextual features. This approach to uncovering CMOs was the preferred choice over other existing models, as this way of thinking supported me to develop my initial CMO hypothesis. For example, structured training on the transition programme was identified as a vital resource offered to staff by the programme. It was envisioned by programme developers that training would increase staff confidence, which would lead to higher levels of implementation fidelity. However, the decision to attend this training was dependent on contextual conditions which included staff's interest and commitment to improving transition services. Therefore, using Dalkin et al.'s<sup>15</sup> model I hypothesised that structured transition training (i.e. resource) attended by staff with a high level of commitment to improving transition services (i.e. context) would increase staff confidence in implementing new transition processes (i.e. reasoning) leading to higher levels of implementation fidelity (i.e. outcome).

However, getting to these initial programme theories was time-consuming and involved a high level of critical thinking and reflection. Data collected from programme developers to develop initial programme theories highlighted the complex nature of the transition improvement programme and the complex environments into which it was implemented, evidencing common features of complexity in healthcare such as unpredictability, emergence and feedback loops.<sup>24,25</sup> As previously described in the literature,<sup>9,22</sup> difficulties with using linear CMO configurations (i.e. this resource introduced in this context will lead to this reasoning resulting in this outcome) to fully account for nonlinear effects was the third challenge encountered during the programme theory development phase of this study. Health care programmes developed and implemented into complex health systems often generate non-linear outcomes which cannot be fully explained using linear causal patterns.<sup>25</sup> This was apparent in the context of the transition improvement programme. Healthcare transition involves moving between paediatric and adult

healthcare services, therefore the improvement programme was inter-organisational and successful implementation was dependent on a number of different health care organisations working together. However, due to different priorities, funding streams and resource allocation between organisations' the improvement programme was not always received and acted upon in the same way by adult healthcare professionals as paediatric healthcare professionals. This had a significant impact on the desired effect of the programme and fed back into the system influencing further outcomes of policy implementation in the paediatric organisation. Thus, being able to fully capture feedback loops and non-linear effects through singular CMO configurations was the most challenging aspect of programme theory development.

However, although challenges were encountered

#### Feather

during the initial theory development phase of this study, it is important to recognise the value of using a realist approach to evaluate complex healthcare interventions. Realist evaluation supported the development of this study's programme theories by providing important insights into how and why the programme was expected to work, for whom and in which circumstances. Initial programme theories will later be tested through empirical data collection with key programme stakeholders to provide refined programme theories.

# Conclusion

This article has highlighted the challenges encountered in operationalising realist evaluation across an interorganisational healthcare context. These are (1) differentiating programme components from programme mechanisms (2) determining what constitutes mechanisms and contexts and (3) the fundamental tension between complexity and the CMO framework. These challenges reflect the methodological under determinacy of a realist evaluation approach to data analysis. Strategies adopted to overcome these methodological difficulties during my study have been discussed, and the value of adopting a realist approach to evaluating complex health care interventions has been emphasised. Although, this article focuses solely on programme theory development in realist evaluation and not programme theory testing, I hope that solutions offered will help to support novice realist researchers with their application of realist concepts to future evaluations of health service programmes.

# Acknowledgements

The author would like to thank the PhD supervisory team at Edge Hill University Dr Axel Kaehne, Dr Joann Kiernan and Dr Dave Lynes for their guidance and support. The author would also like to acknowledge Dr Lynda Brook (Trust Clinical Lead for Transition and Macmillan Consultant in Paediatric Palliative Care) and Jacqui Rogers (Trust Transition Service Nurse Lead) at Alder Hey NHS Foundation Trust.

# **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

# Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

# **ORCID** iD

Julie Louise Feather D http://orcid.org/0000-0003-1806-2405

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# Standard Email Invitation for Health Care Professionals

Dear Sir/Madam,

As part of a PhD programme with Edge Hill University I am undertaking a research study based on the 10-steps transition to adult services pathway developed at Alder Hey Children's Hospital. The study aims to investigate and evaluate how the 10steps transition pathway is implemented by conducting face to face interviews with health care professionals who have been involved in developing and delivering the 10-steps transition pathway.

If you are interested in taking part in this study and would like further information please contact Julie Feather (PhD Student) to advise her of your interest. You will then be sent a participant information sheet and consent form which explain the study in greater detail. Please could I ask that you read the participant information sheet and consent form carefully before making a decision to take part. If you have any questions or would like further information, please feel free to contact me directly on the details provided below.

This study has been reviewed and approved by the Faculty of Health and Social Care Research Ethics Committee at Edge Hill University and the Health Research Authority (HRA).

Thank you for taking the time to read this email.

Kind regards

Julie Feather MA Social Work, BSc (Hons) Psychology and Criminology, HCPC registered Graduate Teaching Assistant/PhD Studentship Room H016 Edge Hill University Faculty of Health & Social Care St Helens Road, Ormskirk L39 4QP Email: <u>Featherj@edgehill.ac.uk</u>

# Appendix D: Participant information sheet







### Introduction

I would like to invite you to take part in a study which aims to evaluate the 10-steps transition to adult services pathway developed and implemented in Alder Hey Children's Hospital. Before you make your decision, you need to understand why this study is being done and what participation in this study will involve. Please take time to read the following information carefully. If the information is not clear to you or you require further information then please feel free to ask the researcher, whose details are provided at the end of this sheet. Please take time to decide whether or not you wish to take part in this study.

### What is the purpose of this study?

The study aims to investigate and evaluate how the 10-steps transition to adult services pathway developed at Alder Hey Children's Hospital is implemented by health care professionals. This study is being undertaken as part of a PhD programme at Edge Hill University.

## Why have I been invited to take part in this study?

You have been invited to take part in this study as you are a health care professional involved in developing and/or implementing the 10-steps transition to adult services pathway to support young people's health care.

## What will happen to me if I decide to take part in this study?

You will be asked to participate in a face to face interview led by the researcher which will take no longer than 45 minutes. If you are involved in both developing and delivering the 10-steps transition pathway you may be asked to participate in an additional follow up face to face interview. This interview will take place a number of months after first stage interviews and will last approximately 30-45 minutes. Interview dates and times will be arranged with you taking into account your work schedules and commitments. Interviews will be conducted within Alder Hey Children's Hospital, at the most convenient time for you. With your consent, interviews will be audio recorded using a Dictaphone.

## Do I have to take part in this study?

No, it is entirely up to you as to whether or not you wish to be involved in this study. If you do decide to participate signed consent will be taken from you prior to the interview. Your participation in this study is voluntary and it is your right to withdraw from the study at any point before and during the interview without giving a reason. Data collected from you during the interview can also be withdrawn for up to 7 days

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after interviews have taken place. This can be achieved by contacting the researcher on the contact details provided in this information sheet.

# What are the possible disadvantages and risks of taking part in the study?

There are no recognisable disadvantages or risks posed to you when choosing to take part in this study. All data collected from you during the interview will be anonymised and treated confidentially at all times. It is not anticipated that interviews will cause you any emotional distress. However, if during the interview you do become emotionally distressed then the interview will be paused and you will be offered the opportunity to either take a break or discontinue the interview. You will further be provided with information and contact details for appropriate services who offer ongoing emotional support.

## What are the possible benefits of taking part in this study?

I cannot promise that the study will benefit you on a personal level, however the data that you share as part of the interview will be used to inform and potentially improve future transition services for young people with complex health care needs.

## Will my taking part in this study be kept confidential?

All information collected during this study will be kept strictly confidential in accordance with the Data Protection Act (1998). The researcher who is independent of Alder Hey Children's Hospital will be the only person to hear and see the information you provide during interviews. Following interviews, audio recordings will be transcribed by the researcher in to Microsoft Word documents. The Dictaphone used to record interviews will be stored in a secure, locked cupboard in the researcher's office at the University. Once transcribed audio recordings will be permanently deleted from the Dictaphone and transcribed interview scripts will be anonymised to protect your identity.

Anonymised interview transcripts will then be encrypted and stored electronically on a secure University server for up to 10 years. Signed consent forms will also be stored electronically onto the University's secure drive using an encrypted file. Paper copies of signed consent forms will be shredded using the University's confidential waste bin. Your personal details will not be shared in any reports, presentations or publications and your identity will not be revealed. With your consent, only anonymised data will be shared with other researchers if required to support future research.

If a disclosure is made during the study which constitutes illegal activity or poor professional practice the researcher will discuss this with you and may need to report this to the participating organisation and to Edge Hill University.

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# What will happen to the results of the research study?

Findings taken from this study will be presented in the researchers PhD thesis. Findings may also be published in a peer reviewed journal and presented at conferences to share knowledge and ideas with other professionals. Your anonymity will be maintained if findings are shared through publication and conferences. A summary of the studies main findings will be shared with you if you choose to participate in this study.

# Who has reviewed the study?

The study has been reviewed and approved by the Faculty of Health and Social Care Research Ethics Committee at Edge Hill University and the Health Research Authority (HRA).

# Who can I contact if I want to take part or want more information?

If you would like to take part in this study or require further information, please contact:

Julie Feather Email: Featherj@edgehill.ac.uk

# What if there is a problem?

If you have any concerns about any aspect of the study or would like more information about the study you should contact the researcher in the first instance on the details provided above.

As this study is being undertaken as part of a PhD programme at Edge Hill University the researcher has a supervisory team who oversee the study:

Dr Axel Kaehne Telephone: 01695 657233 Email: (Kaehnea@edgehill.ac.uk)

Dr Joann Kiernan Telephone: 01695 657094 Email: (<u>Kiernanj@edgehill.ac.uk</u>)

Dr Dave Lynes Telephone: 01695 657067 Email: (Lynesd@edgehill.ac.uk)

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# Is there someone independent I can talk to about the research?

If you wish to discuss the research with an independent person, please contact:

Professor Clare Austin, Associate Dean for Research and Innovation, Faculty of Health and Social Care, Edge Hill University, St Helens Road, Ormskirk. L39 4QP. Telephone: 01695 650772 Email: austincl@edgehill.ac.uk

# Thank you very much for taking the time to read this information sheet and for considering taking part in this study.

Edge Hill University





# CONSENT FORM TO PARTICIPATE IN INTERVIEWS: HEALTH CARE PROFESSIONALS

Title of Project: 'Implementing a transition pathway developed to improve services for young people with complex healthcare needs moving between children's and adult's healthcare services: A realist evaluation'

Name of Researcher: Julie Feather

#### Please initial box

I confirm that I have read the information sheet (date and version number) for the above study.

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw from the study before or during interviews without giving any reason and that it is possible to withdraw my data up to 7 days after interviews have been carried out.

I agree to the interview being digitally audio recorded.

I agree to my words being used as direct quotes in publications and presentations and that these will be anonymised so I won't be identifiable.

I understand that the information collected from me may be used to support other research in the future, and I agree for my data to be shared anonymously with other researchers.

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I understand that data collected during the study, may be looked at by individuals from regulatory authorities, the University, or from the NHS Trust, where it is relevant. I give permission for these individuals to have access to my anonymised data.	
I agree to take part in the above study.	

Name of Participant	Date	Signature	
		<b>.</b>	
Name of Person taking consent	Date	Signature	

Consent form Health Care Professionals - Version 3 - 7th June 2017 - IRAS ID: 227709

# Appendix F: Data collection form

### Documentary analysis: Data collection record

# Selection and appraisal

DOCUMENT NAME AND NUMBER:	Transition Consultation 2015: Transition Roadshows, Online Transition
	Survey and full day transition workshop (2)
Is it relevant to the research question?	Yes.
Does the content fit the conceptual framework of the study?	Yes.
AUTHENTICITY OF DOCUMENT	
Is the evidence genuine?	Yes. However, <u>take into account</u> the context of why this document was produced. It was produced as evidence to show that actions had been taken to improve transitional care services following a CQC inspection in 2014. It was produced because the trust wanted to develop a trust wide transition policy because they were under pressure by CQC to action this and they also had key deliverables as part of the CQUIN's in 2014-2015. The consultations were undertaken to educate staff about transition and to develop the transition policy. Has it been shaped to benefit the NHS
Author of document and original sources of information	Trust transition service lead nurse, clinical lead for transition and additional person whose job is not known. Information taken from three consultations that were carried out with staff based at the paediatric organisation, parents and YP (although not known how many parents and YP were involved (as below).
What are the conditions surrounding the production of the document?	Developed as a result of CQC inspection May 2014 which identified the need for improvement in transition services within the paediatric organisation. Carried out a series of trust wide engagement and consultation exercises to support the development and implementation of the trust transition policy. This document reports the outcomes from three consultation exercises: a series of roadshow meetings with individual teams and services, an online web based transition survey, and a professional's away day titled "tackling tricky transitions". 17 roadshows (170 professionals) across the paediatric organisation. 212 professionals completed the online survey. 60 professionals attended the away day.

	Additionally, in 2014 as a response to the CQC report the paediatric organisation was issued with two CQUINS (commissioning for quality and innovation) targets for 2014-2015 for YP with complex neuro-disability and CAMHS (more complex transitions). This was a further factor which led to the development of this document.
Is the evidence free from error and distortion?	This is difficult to determine as it was produced to evidence that actions
	had been taken to develop and improve transitional care services, therefore it may be written in a way that benefits the organisation. Information may have been distorted to provide a more positive picture (this is not known).
Is it accurate?	As above. The document was produced by the NHS organisation to
	evidence that actions had been taken to improve transitional care services.
	It is hoped that data is reported as staff meant it to be.
Why did the author choose to produce the document?	<ul> <li>To demonstrate and evidence that actions had been taken to improve transitional care services. To evidence consultations with staff. The aims of the consultations were to: <ul> <li>Increase staff engagement and understanding of transition amongst key professionals</li> <li>To assess professional's education and training needs with regard to transition</li> <li>To identify barriers and success to transition</li> <li>To identify markers for tricky transitions and to develop solutions to help with tricky transition and co-ordination of care e.g. lead consultant, key worker and GP</li> </ul> </li> <li>Staff recommended a clear transition pathway for any speciality, including when a YP is under multiple specialities – is essential to a seamless transition. They also identified the need for an overarching trust transition policy which was developed as a result of this document.</li> </ul>
REPRESENTATIVNESS OF THE DOCUMENT	
Is the evidence typical of its kind?	Yes, it is consistent and typical of other documents acquired from the paediatric organisation as part of this research.

Is it complete, has it been edited (comprehensive or selective)?	It is not known whether the document has been edited or whether information has been left out. However, the document may be published therefore it may have been edited and information left out.
What documents exist, which are accessible and why?	In sexists as it is part of the work that the paediatric organisation <u>have</u> completed following the CQC report in 2014 to improve transitional care services. There was a lack of evidence to support transition therefore this acts as evidence to demonstrate what work has been done since recommendations were made. It was made accessible to me by the lead transition nurse and it is accessible as the hope is to publish this report.
MEANING	
When, where and by whom was the source created?	Created in 2015 by the trust transition service lead nurse, clinical lead for transition and additional person whose job is not known. Following the CQC inspection in 2014 and CQUIN's 2014-2015.
What is the purpose of the document and who is the target audience?	Target audience is wide – commissioners, CQC, managers, staff at the paediatric organisation and across other paediatric and adult services. It is not known whether YP and parents are part of the target audience as the document appears to be addressed more to professionals working in transitional services. The purpose of the document is to evidence what work has been done to improve transitional services since the CQC inspection in 2014. Also, to develop a trust transition policy and to further develop the transition programme.
Is the evidence clear and comprehensible?	Yes.
In what social context and climate was it produced?	Following the CQC report in 2014 and CQUINS 2014/2015. The paediatric organisation had to take actions to improve services and to meet key deliverables. Economic and political climate of the NHS. May be portrayed in a light that favours and supports the NHS organisation.
What are the intentions and abilities of the documents producers?	To demonstrate what work has been done to improve transitional care services (evidence). To further develop services.

# Appendix G: Topic guide for stage one semi-structured interviews







#### Indicative Semi-Structured Interview Schedule for Health Care Professionals

Pre-amble: Thank you for agreeing to talk to me about your involvement and experiences of the 10steps transition to Adult Services pathway based at Alder Hey Children's Hospital.

#### Part 1: Background of participant

- 1. Could you tell me about your current professional role and the area in which you work?
- How have you been involved in developing or implementing the 10-steps transition pathway?

(Prompts if required: How did you become a member of the transition steering group? What is your role within the transition steering group? Do you have any previous experiences as a professional of supporting young people with complex health care needs who are moving across health care services?).

#### Part 2: Introductory question

Could you explain to me how and why the 10-steps transition pathway was developed and who it was developed for?

(Prompts if required: What did transition processes look like before the development of the 10-steps transition pathway? What is different now and why is it different? Were there any external pressures which impacted on the way in which the pathway was developed?).

4. How is the 10-steps transition pathway expected to work and who, do you feel, will benefit most?

(Prompts if required: What are your personal views of the 10-steps transition pathway? Are there any particular groups of people who you feel the 10-steps pathway will work better for? Are there any particular groups of people who you do not feel it will benefit?).

#### Part 3: Exploring Context (To explore contextual factors the interviewer will integrate the candidate programme theories into the interview schedule)

5. What, do you feel, are the main facilitators of the 10-steps transition pathway?

(Prompt for candidate programme theories: What are the key ingredients required to ensure that the 10-steps transition pathway is implemented effectively across Diabetes, Rheumatology, Cystic Fibrosis and Orthopaedics (hip and lower limb)? Are the same factors relevant to all clinical areas? If not, why not and what is different?).

 Do you anticipate any potential barriers or challenges to implementing the 10-steps transition pathway across Diabetes, Rheumatology, Cystic Fibrosis and Orthopaedics (hip and lower limb)?

(Prompt for candidate programme theories: Do all clinical areas follow the same transition procedures? If not, why not? - think about the different ways transition services have been

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carried out in the past and whether specific clinical areas have different norms and values based on how things are usually done. Could contextual factors such as the norms and values of different clinical areas, history of what has worked/not worked in the past, financial/resource constraints and existing public policy/good practice guidance for different clinical areas create challenges/barriers to implementation?).

#### Part 4: Looking for Mechanisms (To explore the mechanisms existing within the 10-steps transition pathway the interviewer will integrate the candidate programme theories into the interview schedule)

Are there any characteristics in the way staff work with young people and their parents, which you feel are important to the success of the 10-steps transition pathway?

(Prompt for candidate programme theories: relationships, trust, communication, empowerment, provision of information, staff training, person-centred practice, shared decision making, confidence, knowledge).

 How do you think the Transition Trust Policy will impact on how health care staff deliver transition services within diabetes, Rheumatology, Cystic Fibrosis and Orthopaedics (hip and lower limb?

(Prompt for candidate programme theories: Do you feel staff within all areas will follow the transition trust policy? If not, why not? Are there any resources that exist within the 10steps transition pathway that you feel will have a positive or negative effect on the way in which staff reason with and deliver services? Explore the reasoning of staff to the resources provided by the 10-steps transition pathway).

#### Part 5: Looking for intended and unintended outcomes (To explore the expected outcomes of the 10-steps transition pathway the interviewer will integrate the candidate programme theories into the interview schedule)

9. Could you tell me what the expected outcomes of the 10-steps transition pathway are for the young person, their family and the organisation?

(Prompt for candidate programme theories: continued engagement with adult care providers, improved health related quality of life, increased self-management and selfefficacy, reduction in admissions to Alder Hey A&E, discharge, seamless transitions).

 Finally, is there anything else that you would like to add about the 10-steps transition pathway?

#### Thank you for your time. Do you have any questions that you would like to ask me?

(Close the interview by informing the participant of what will happen next, timescales for receiving a summary of findings and the ability to withdraw their data from the study for up to 7 days from interview date).

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# Appendix H: Topic guide for stage two semi-structured interviews







more resources; young person – self management, engaged with adult services, continuity of care. If unexpected outcomes are identified, prompt for greater description).

9. Do you think that the outcomes have been the same for all professionals? In what ways have they been different?

(Additional questions to prompt: Do professionals have different responsibilities for transition? Are certain professionals given more time to complete transition tasks?)

10. I am curious about how the (10-steps transition pathway/element of the pathway) causes its outcomes. How do you think the (10-steps transition pathway/element of the pathway) has caused, or helped to cause (outcome identified by respondent)?

(Additional questions to prompt: What is it about the {pathway/element of the pathway} that helps to cause the outcome? Are there any specific resources within the (pathway/element of the pathway) that helps to cause the outcome?}

 Have you attended the transition training and if so, what messages did you take away from this?

(Additional questions to prompt: Has the training helped you to use the 10-steps pathway? What did the training provide that was new? Was it mainly about new skills, do you think, or new attitudes? What was the outcome of the training? Has anything changed with your practice as a result of attending the transition training? Can you provide an example of what has changed?).

12. Do you think the (10-steps transition pathway/element of the pathway) has changed the way you think or feel about transition in any way? In what ways? Can you provide examples?

(Prompt for: your role in transition, your understanding of the process, talking about transition with young person earlier, your relationship with adult services, <u>Does</u> it help your job in any way? Does this make you more likely to use it?).

13. There are lots of ideas about how the 10-steps transition pathway is meant to work, and I think it probably works differently in different specialities and for different people. One of those ideas is that the visual 10-steps pathway acts as a guide for professionals telling them what they should be doing at what stage. Its flexibility means that it can be implemented alongside existing processes and it can meet the needs of different patient groups. Has it worked at all like that for you? Can you give an example?

(Additional questions to prompt: If it hasn't worked in that way, why do you think that is? What are the difficulties with this for your particular area of work? What impacts on it's ability to work in this way? If it has worked in this way, what is it about this speciality that makes it work so well?).

14. Within the 10-steps transition pathway there is also this idea that joint transition clinics between children's and adult services better prepare the young person for their transition and help professionals to feel more confident in supporting the young person to move to adult services. Again, has it worked at all like that for you? Can you give an example?

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(Additional questions to prompt: If it hasn't worked in that way, why do you think that is? What are the difficulties with this for your particular area of work? What impacts on its ability to work in this way? If it has worked in this way, what is it about this speciality that makes it work so well?).

- 15. Are you aware of the transition exception register? What makes you more likely to use the transition exception register?
- 16. If you could change something about the 10-steps transition pathway to make it work more effectively for your service, what would you change and why?
- 17. Is there anything else that you think I need to know, to really understand how the 10-steps transition pathway has worked in your service?

Thank you for your time. Do you have any questions that you would like to ask me?

(Close the interview by informing the participant of what will happen next, timescales for receiving a summary of findings if requested (once the thesis is complete) and the ability to withdraw their data from the study for up to 7 days from interview date). Appendix I: Example of thematic map (Theme 2: Barriers to implementation)



# Appendix J: Coding spreadsheet for CMO analysis

Intervention	Code	Resource	Context (individual, interpersonal, institutional, infra-structural system)	Reasoning	Outcome	Initial CMC
			Lack of social perspective within MDT. There is a need for a professional			
Joint transition reviews	Importance of MDT working	MDT working	who can offer support and advice on wider social issues (unsupportive)	Part of how they always deliver services		CM0C5
	Support for wider social issues	There is no resource for this	Same as above			
		Direct contact/being in the same room		Helps adult HCPs get to know YP/relationship is built up over time		
	The appropriate use and transfer of information	Adult HCPs who attend joint reviews		Communicate to YP what to expect and provide written information		
			Existing shared computer software where important information is documented	Paediatric HCPs recognise the importance of good transfer of information		
			(supportive and unsupportive)	over to adult services		
				Based on whether the HCP feels the YP needs support at their first	Step 9 (joint review with adults leading) is	
	Perception of individual needs	Paediatric HCPs who attend joint reviews		appointment with adult services, do they have a complicated history?	not implemented for all patients	
		The relationship/links between paediatric HCPs and	Dependent on which area the patient lives and wishes to receive their adult care.			
		adult HCPs is the mechanism through which joint	For out of area patients there are not the same links with adult services as for in area	The relationship/links between paediatric HCPs and adult HCPs is the		
	Out of area patients	reviews work	patients (supportive and unsupportive)	mechanism through which joint reviews work	Joint reviews do not happen for all patients	
		The relationshiprlinks between paediatric HCPs		The relationship/links between paediatric HCP's and adult HCP's is the		
		and adult HCP's is the mechanism through which joint		mechanism		
		reviews work		through which joint reviews work		
	Practitioner relationships	Working closely together, regular contact and	Same as above	Vorking closely together, regular contact and communication	Joint reviews are more likely to happen	
		·····	Funding tariffs for adult HCPs to attend joint transition reviews in paediatric services		Joint reviews (step 6) happen every 3 months	
	Financial context of adolescent care	Adult HCPs who attend joint reviews	Joint reviews are definite as they are part of adult HCPs contract and job role		(alternating between two in area trusts)	
				Value one another's expertise and professional decision making		
	Working together to inform practice	Collaborative working/shared learning		Educating adult HCPs on YP's wider needs and why certain technologies are		
		Good communication (Face to Face and written),				
	Communication	regular contact	Better for in area services not out of area (supportive and unsupportive)		NO 1.1 11 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	
	1 1 M		National guidelines specify the age of transition as 18.5-19, different age criteria		I ransition discussions (steps 1 and 2) begin	
Identification of YP' needing transition	Inconsistent transition processes		For transition across different services (unsupportive)		at a later stage (i.e. between 15-16)	Additional
			I ransition discussions begin at a later stage [10-16] based on national guidelines and	HUP makes a professional judgement/decision informed by national guidelines		
			when the HCP feels the time is right for the YP. Health transition is aligned to	but also based on the perceived individual's needs - when the time is right for the		
10-steps pathway as a whole (whole programm	ne) Perception of individual needs	Visual 10-steps pathway diagram	education transition (unsupportive)	YP	Step 1 and 2 begin at a later stage for YP in Diabe	ete CMOC1
			Nature of the condition - Diabetes already have well integrated, robust transition		Continue to use their own transition processes	
			processes due to transition being seen as a priority in Diabetes, Diabetes tariff,	Feel that they are already applying the 10-steps, don't feel that they need	and	
	Nature of the condition		historical context of diabetes care etc. (unsupportive)	to change their practice	do not fully implement the 10-steps	
	Inflexibility within adolescent care between		Age of diagnosis affects the timing of transition. For example if a YP is diagnosed	nosed HCPs feel that having a cut off point is a good thing - explain this to YP and parents		
	paediatric and adult services		around 16 they will have their diagnosis/care provided by adult services			
			Use a separate sortware system that is shared with adult counterparts to record all		Do not use transition document as	
	Unsupportive technology		transition information (supportive and unsupportive to 10-steps implementation)		recommended in	
				Recognise that the 10-steps should be implemented but continue to follow their		
	Tension between theory and application of transition processes		where we can be a set of the	own transition processes - reel like they are already applying the 10-steps - no		
			Existing, well integrated transition pathways (unsupportive)	need		
	A construction of the first state of the first state of	Lead transition service nurse role - involvement in		Approach taken to work alongside HUP's and use their knowledge and expertise		
	Approach taken by the transition team	early development and implementation efforts			0	
		Viewel 10 and a show the same	Eviation and the second descendation and the second for succession (	reer that they are already applying parts of the IU-steps, conft feel that they need	Continue to use their own transition processes	
	Existing transition processes	visual IU-steps pathway diagram	Existing, weilintegrated transition pathways (unsupportive)	to change their practice	anu	
	Lack of service engagement from YP		Level of engagement from young people (unsupportive)			
	Presentation of information in the pathway	visual 10-steps pathway diagram	Vider patienal context of diabates care informs how UCDs implyment two video	I oo basic, not comprehensive enough, not condition and service specific		
			wider national context or diabetes care informs now mums implement transition			
			processes, innere are national guidelines which specify the age for transition and			
	Maximum at an interference		what should be done. This superseeds internal organisational pathways. Best			
	ivational guidelines		practice tarins			
			use a structured education programmel goals or diabetes which includes transition			
			(supportive and unsupportive). Unsupportive to ready, steady, go and 10-steps			
mpower young person/support parents	Knowledge transfer	Education/process of learning facilitated by HCP	transition assessment as HUH's continue to use their existing tool			Additional
			<ul> <li>Extends level or anyiety anous transition, strength of relationship between paediatric.</li> </ul>			
	1		Tarents lever of anxiety about cansition, strengthor relationship between paediatro			

# Appendix K: Example of configured CMOs from stage two of data analysis

#### CMOc for sub unit A

Steps 1-3 of the pathway (transition preparation) – aligns to initial draft programme theories 3 and 4

- Transition preparation tools such as ready, steady, go (resource) are introduced into an unsupportive context in which HCPs feel they do not have any additional time to use the tool with YP outside of their routine clinics in which discussions are primarily medically focused (constraining context) which makes them feel anxious and apprehensive about using the tool with all YP requiring transition and about how information collected through the tool will be shared with adult services (reasoning) leading to HCPs prioritising which YP to use the tool with initially (outcome).
- 2. Transition preparation tools such as ready, steady, go (resource) are introduced into a context where HCPs view transition preparation to be part of normal adolescent care (supportive context). However, HCPs do not feel that all YP need ready, steady, go and it should be based on the individual's needs (reasoning). Some HCPs do not perceive ready, steady, go to be relevant to their clinical responsibilities (reasoning). HCPs therefore prioritise which YP to use ready, steady, go with initially and allocate use of the tool into priority areas (outcome).
- 3. Transition documents built on to the internal computer system (resource) and IT training to support implementation (resource) are difficult for HCPs to use with YP in normal clinic time and cannot be used for out of area patients (constraining context). HCPs in later interviews had difficulties in finding and using internal transition documents. They felt that documentation was not always clear and did not fit with the YP's needs. They favoured the format of ready, steady, go which they felt was easier to use and better suited to the YP's needs (reasoning). This resulted in HCPs focusing more on ready, steady, go (outcome).
- 4. The transition exception register (resource) (missing context) is perceived by HCPs as an additional exercise which does not add any extra value to the YP's care (reasoning). HCPs therefore do not use the transition exception register as anticipated (outcome).
- 5. The transition exception register (resource) (missing context) is seen to be a 'good idea' by HCPs who see value in its use (reasoning) however whilst they recognise that they should be using it, in practice they are yet to use it. This results in inconsistent use of the transition exception register (outcome).



Appendix L: Organisation of higher level and middle range theories used to inform GTI (Source: May, 2013)



# Appendix M: GTI constructs and core components (Source: May, 2013)



Appendix N: Written report for Alder Hey Children's NHS Foundation Trust

# An Evaluation of the Implementation of the 10-Steps Transition Pathway to Adult Services at Alder Hey Children's Hospital

# Authors:

Julie Feather in collaboration with Dr Lynda Brook, Jacqui Rogers, Joann

Kiernan, Dave Lynes, and Axel Kaehne

October 2020

A report for Alder Hey Children's NHS Foundation Trust



# Acknowledgements

The evaluation of the implementation of the 10-Steps Transition Pathway was a collaborative research proposal devised in consultation with Dr Lynda Brook and Jacqui Rogers at Alder Hey Children's NHS Foundation Trust. The author would like to acknowledge the support provided by Dr Lynda Brook and Jacqui Rogers who facilitated access to participants, provided important information to inform the research design and contributed to the supervision of the project. Without their continuous support the evaluation would not have been achievable.

The author would further like to acknowledge the practitioners at Alder Hey Children's NHS Foundation Trust who made this evaluation possible by taking time out of their busy work schedules to discuss their experiences of transition and the 10-steps Transition Pathway.

# **Executive Summary**

The 10-Steps Transition Pathway to Adult Services at Alder Hey Children's Hospital was developed to improve the process of transition for young people with long-term health conditions moving between children's and adult services.

In February 2017, Edge Hill University in collaboration with the transition team at Alder Hey commenced an external evaluation of the implementation of the 10-Steps Transition Pathway at Alder Hey Children's Hospital as part of a PhD project. The aim of the evaluation was to investigate how the 10-Steps Transition Pathway was being implemented by healthcare professionals across the trust and to identify areas for improvement.

Between July 2017 and January 2019, twenty-six semi-structured face to face and telephone interviews with healthcare professionals involved in the development and/or implementation of the 10-Steps Transition Pathway at Alder Hey Children's NHS Foundation Trust, were undertaken. A qualitative review of programme documentation complemented this. Data were analysed thematically and resulted in three overarching themes: extraneous factors, organisational factors and individual service level factors that helped to support and/or hinder implementation of the 10Steps Transition Pathway.

This report highlights key features of the 10-Steps Transition Pathway that were either successfully adopted by practitioners or overlooked, and factors which facilitated and hindered implementation efforts. It concludes with ten key recommendations for practice.

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#### Background

## Transition to Adult Services

Transition has been described as a "purposeful, planned process that addresses the medical, psychosocial and educational and vocational needs of adolescents and young adults with chronic physical, neurodevelopmental and medical conditions as they move from child-centred to adult-orientated health-care systems" (Colver et al., 2019: 23). Transitioning from adolescence into adulthood can be a challenging time for all young people, however for those young people with long-term health conditions the journey can be even more problematic due to changes in the delivery of their care (RCN, 2013; Campbell et al., 2016).

Ensuring that services provide a planned and co-ordinated transition process is a key priority for healthcare organisations (NICE, 2016). Research suggests that young people who experience poor transitions between children's and adult health care services, suffer physically, emotionally, socially and educationally in the long term (DOHSC, 2006). Furthermore, poorly planned and delivered transitions are associated with discontinuity of care (Dogba et al., 2014), risk of non-adherence to treatment (DOHSC, 2006), poor clinical outcomes and increased health care costs (Moore Hepburn et al., 2015) and negative consequences relating to morbidity and mortality (DOHSC, 2006). Effective transitions on the other hand, have been evidenced to lead to improved experiences and long-term outcomes (CYPHOS, 2012).

# The 10-Steps Transition Pathway to Adult Services

Since 2014, Alder Hey Children's Hospital has embarked on a journey to improve the process of transition for young people with long-term health conditions moving between children's and adult services. This work stemmed from a Care Quality Commission (CQC) inspection undertaken in May 2014 which identified the need for improvement to transitional services at Alder Hey (CQC, 2014). The 10-Steps Transition Pathway to Adult Services (Appendix A) is central to this process of quality improvement and was developed alongside the Trust Transition Policy through trust wide consultation and engagement (Rogers, Brooks, Aizelwood & Kaehne, 2018). It is a multi-disciplinary, collaborative pathway consisting of multiple interventions aimed at both supporting and facilitating transition for young people, their parents and carers and professionals in both children's and adult healthcare services. The pathway incorporates key standards of good practice in transition services (DOHSC, 2008; NICE, 2016), with the aim to standardise transition practice across the trust, improve the process of transition for young people and their families and lead to improved long-term health outcomes.

### Evaluating the implementation of the 10-Steps Transition Pathway

Implementation of the 10-Steps Transition Pathway commenced in 2016. The transition team based at Alder Hey adopted a phased approach to implementation of the 10-Steps Transition Pathway with early implementation efforts being initially targeted to four identified specialities within the trust. In the first twelve months, the transition team worked with Clinical Business Units (CBU) transition leads and transition champions to facilitate implementation. Implementation was then scaled up with the support of the transition team and transition champions to additional specialities within the trust between 2017-2019. Implementation of the 10-Steps Transition Pathway was monitored by the trust transition steering group chaired by the Medical Director and Executive Lead for Transition (Brook & Rogers, 2016).

In February 2017, Edge Hill University in collaboration with the transition team at Alder Hey commenced an external evaluation of the implementation of the 10-Steps Transition Pathway at Alder Hey Children's Hospital as part of a PhD project. The aim of this evaluation was to:

- 1. Investigate how the 10-Steps Transition Pathway was being implemented by healthcare professionals across the trust;
- 2. To identify areas for improvement

# **Evaluation methods**

### Methodology

A single qualitative embedded case study design informed by Realist Evaluation was employed to evaluate the implementation of the 10-Steps Transition Pathway.

#### Methods of data collection

# **Review of transition pathway documentation**

Documents pertaining to the development and implementation of the 10-Steps Transition Pathway were provided by the transition team and reviewed by the researcher. Documents provided insight into the objectives and purpose of the 10Steps Transition Pathway and highlighted potential facilitators and/or barriers to implementation. This aspect of the evaluation supported the development of the semi structured interview schedule.

#### Interviews with key stakeholders

Between July 2017 and January 2019, twenty-six semi-structured face to face and telephone interviews were undertaken with healthcare professionals working for Alder Hey Children's NHS

Foundation Trust. Interviews were conducted by an independent researcher from Edge Hill University. Healthcare professionals were purposefully selected based on their involvement in either developing and/or implementing the 10Steps Transition Pathway.

#### Data analysis

Qualitative data from documentation review and semi-structured interviews were analysed thematically using Braun and Clarke's (2006) thematic analysis framework and data management software NVIVO. Data were further subjected to context, mechanism, outcome analysis, which is informed by the study's methodology, realist evaluation. This report describes the main thematic findings from the evaluation.

#### Ethical review and governance

The evaluation was granted approval from both Edge Hill University's Faculty of Health and Social Care Research Ethics Committee (FREC) and the Health Research Authority (HRA).

#### Findings

Findings from the evaluation suggest that the work of the transition team and implementation of the 10-Steps Transition Pathway had a significant impact on transition practice across services within Alder Hey. Practitioners described feeling involved in the change process and supported by the transition team to improve transition processes within services and make changes to their practice. Practitioners recognised the importance of using the 10-Steps Transition Pathway to support young people moving between services and valued the flexibility of the pathway. Practitioners described using the 10-Steps Transition Pathway flexibly alongside existing transition processes and adapting the pathway to meet the needs of their patient group. The active involvement and support of the transition team helped paediatric practitioners to form and improve important relationships with adult providers. These findings are discussed in more detail in the next section of this report.

Findings from the evaluation are structured around three main themes: extraneous factors, organisational factors and individual-service level factors that helped to support and/or hinder implementation of the 10-Steps Transition Pathway.

#### **Extraneous factors**

Extraneous factors are defined as those that are external to the organisation itself yet played an important role in influencing practitioner decision making around implementation of different interventions within the 10-Steps Transition Pathway. Practitioners highlighted three dominant

factors external to Alder Hey which impacted on implementation decisions. These are: interorganisational commonalities and differences, geographical proximity of paediatric and adult hospitals' and funding for transition. These are discussed in detail below.

#### Inter-organisational commonalities and differences

Similarities in the structure and delivery of services in paediatric and adult organisations was identified as a key enabler of implementation. In services where existing transition processes were well-integrated and relationships with adult services were established, services had a similar structure for the delivery of care. In these services, similar ways of working had been developed over the years and appeared to be motivated by the nature of young people's conditions and their treatment requirements in adulthood. In this context, inter-organisational commonalities supported practitioner decision making on implementation of the 10Steps Transition Pathway.

However, practitioners across other services highlighted important interorganisational differences which affected how they responded to the 10-Steps Transition Pathway. A lack of equivalent adult services, moving between tertiary to non-tertiary hospitals and different approaches taken to supporting patients were commonly raised by practitioners as barriers to transition. Where interorganisational structures were not in place to support transition, practitioners described feeling 'disheartened by the lack of services' and feeling transition was 'too hard' to achieve.

Several practitioners' commented on the nature of paediatric services describing these as more 'nurturing', 'protective' and 'supportive' than adult services. How often young people were able to be seen in adult services compared to paediatric services was further highlighted by practitioners as a key difference. Practitioners suggested that perceived disparities between paediatric and adult services at times generated anxiety for young people, their parents and professionals with practitioners finding it difficult to 'let go' of young people. The inter-organisational differences described by practitioners appeared to affect their decision making around implementation of the 10-Steps Transition Pathway. For some practitioners, implementing steps within the transition pathway within their own services was considered to be contra productive if their adult counterparts were not equally collaborating with implementation, and/or inter-organisational structures were absent.

#### Geographical proximity of paediatric and adult hospitals'

The geographical proximity of paediatric and adult hospitals was identified by several services as both a facilitator and barrier to implementation of joint transition reviews. Joint transition reviews were more likely to be implemented where paediatric and adult services were in close proximity to one another. For young people receiving their adult care out of area, joint transition reviews were less likely to be implemented and transfer rather than transition was more likely to occur. Practitioners suggested joint transition reviews were more feasible and easier to organise where services were in close proximity. Inter-organisational professional networks were also more established between paediatric and adult services that were closely located. Not having established links with key professional's in out-of-area adult hospitals was one of the main reason given by practitioners as to why it was more difficult to implement joint transition reviews.

### Funding

Implementation of joint transition reviews were further affected by the wider financial context of adolescent care. Practitioners across two services commented that adult services were funded to attend joint transition reviews and transition was integrated within adult professionals job roles. As a result, joint transition reviews were more likely to be implemented in services that had existing funding for transition. In contrast, practitioners in services that did not have funding were less likely to implement joint transition reviews and implementation was dependent on the 'good will' and 'motivation' of individual healthcare professional's across both services. In most services, pre-transition joint reviews were more likely to be implemented than post-transition joint reviews. Lack of capacity within teams and in particular resource implications for consultants were given as reasons why post-transition reviews were more difficult to implement.

#### **Organisational factors**

Practitioners highlighted six organisational factors which enabled and/or hindered implementation of the 10-Steps Transition Pathway. These include: well-established, existing transition processes, shared professional values, time constraints, technological challenges, inclusive/partnership approach and service-specific key professionals to co-ordinate transition. These are discussed in detail below.

#### Well-established, existing transition processes

In some services, existing transition processes were well-established and integrated into usual care. Several practitioners within these services viewed the 10-Steps Transition Pathway as being very similar to and compatible with their established transition processes. Some practitioners discussed the possibility of using the pathway flexibly alongside their own processes, whilst others expressed a preference to remain with existing transition practice. In these services practitioners reported none or fewer changes to their transition practice, however commented that the new pathway had formalised transition practice across the trust.

Alternatively, several practitioners in services that reported having no existing transition process prior to the introduction of the pathway and those whose processes where in place but not as wellestablished, described considerable changes to their transition practice as a result of the 10-Steps Transition Pathway. Changes to practice included setting up joint transition reviews, changing the way joint transition reviews were delivered to allow adult practitioners to take more of a lead, beginning transition preparation at an earlier stage and introducing planned transition appointments.

### Shared professional values

Practitioners across services shared a set of professional values about transition preparation in which it was seen to be an integral part of routine adolescent care. Practitioners reported that conversations to prepare young people for transition were happening from an early age. However, it was evident that in some services transition preparation was being done informally most of the time rather than being recorded using a transition preparation tool or transition plan. Practitioners ability to implement transition preparation tools were reported to be hindered by time constraints and technological challenges which are discussed below.

#### **Time constraints**

Difficulties in using transition preparation tools and transition documents were associated with time constraints. Practitioners across several services commonly reported that the use of transition preparation tools generated extra paperwork which required additional time resources that were not available to support implementation. Practitioners stated that priority was given to discussing the medical aspects of a young person's condition with them over transition preparation during routine clinics which impacted on their use of transition preparation tools.

# **Technological challenges**

In later interviews practitioners also cited technological issues as a common barrier to implementation of transition documents. Practitioners described difficulties associated with locating and using documents on Meditech. Although some practitioners' had received training from the IT department, they described feeling 'confused' and 'not understanding' how to use transition documents. Practitioners also communicated that they felt transition documents needed to be more focused on what young people need to know about transition.

#### Inclusive partnership approach

The inclusive partnership approach adopted by the transition team to the development, training and implementation of the 10-Steps Transition Pathway was viewed positively by practitioners. Many practitioners described how the transition team had consulted with them and drawn upon their knowledge and experiences of transition. Several practitioners described feeling 'supported', 'valued' and 'encouraged' to move transition practice forward and make changes to improve transition in their service. In particular, the perseverance and dedication of the transition lead nurse was recognised by many practitioners as key to moving implementation of the 10-Steps Transition Pathway forward. Active participation and involvement of practitioners in the change process helped to facilitate high levels of commitment to implement the pathway for some practitioners. However, other practitioners communicated that they felt the transition team required more capacity to be able to accommodate the amount of work required to make significant changes. Additionally, support for the 10-Steps Transition Pathway from senior leadership in Alder Hey was recognised as important, however, a perceived lack of support and 'buy-in' from senior managers in adult organisations' impacted on how practitioners interacted with the 10-Steps Transition Pathway.

#### Service-specific key professionals to co-ordinate transition

The 10-Steps Transition Pathway and transition training delivered to practitioners emphasised the importance of identifying a transition key worker to co-ordinate transition. However, difficulties in identifying who the key worker would be, particularly when multiple services were involved, were often reported by practitioners across services. It was also suggested by some practitioners that it was not clear in the transition pathway who should take on responsibility for this.

Two services had identified key workers who would be responsible for co-ordinating transition. In these services, transition was more defined as part of their job roles. However, they were not given any additional resources, such as time for transition.

There were also differences between these services and others which included smaller numbers and existing transition processes which made the key worker role more achievable. Some practitioners reported that they were reluctant to take on the key worker role when it was not formally part of their job role and time was not allocated for transition tasks.

# Individual-service level factors

Practitioners highlighted five individual-service level factors that were important to the implementation of the 10-Steps Transition Pathway. These are: perceptions of transition and the 10-

Steps Transition Pathway, motivation and interest in transition, use of professional autonomy and agency to benefit young people, collaborative relationships between individual practitioners across paediatric and adult services and improved knowledge and changes to practice resulting from the 10-Steps Transition Pathway. These are discussed in detail below.

#### **Perceptions of transition**

In some services, practitioners perceptions of transition, transition programmes and a perceived lack of engagement from adult services acted as a barrier to implementation of the 10-Steps Transition Pathway. Previous experiences of using different transition pathways that were viewed negatively affected how some practitioners regarded the new transition pathway. A number of practitioners described feelings of frustration due to what they perceived to be a lack of engagement from adult services in relation to transition. Feeling that adult services were not cooperating with the transition pathway impacted negatively on some practitioners decision making about implementation. Furthermore, practitioners in one service described difficulties around getting all professionals in their own service to support the 10-Steps Transition Pathway. Practitioners expressed that the 10-Steps Transition Pathway had not been received positively by senior clinical team members in their service and this directly affected how they implemented the pathway. However, it is important to note that senior clinical team members in this service were not interviewed as part of this study. Findings in relation to this are therefore based on the perceptions of practitioners.

### Motivation and interest in transition

Individual motivation and commitment of practitioners across both paediatric and adult services supported implementation of the 10-Steps Transition Pathway, and in particular, joint transition reviews. As previously discussed in this report, joint transition reviews were sometimes dependent on the motivation and good will of individual healthcare professionals from both sectors. In one service, a practitioner communicated that joint transition reviews would not happen if it were not for individual professionals from the adult sector who were committed and motivated to make changes. However, they recognised the dangers in relying on singular individuals and described how joint transition reviews in their service were not always possible as they depend on the availability of one consultant in one adult service. This was not the same for services who had well-established, existing transition processes, shared inter-organisational commonalities and funding to support transition. In these services, joint transition reviews were more embedded in routine transition practice.

#### Use of professional autonomy and agency to benefit young people

In most services, practitioners described value in using the 10-Steps Transition Pathway with some young people. Decisions to use interventions within the pathway, such as transition tools and documents, were determined by practitioners perceptions of the young person's needs rather than the process itself. Perceptions of individual needs were however informed by information provided by the young person themselves and their families as well as professionals knowledge and understanding of the young person's condition. Individualised, person centred approaches were at the heart of professional decision making with regards to implementation of the 10Steps Transition Pathway

Many practitioners commented on the relevance of transition preparation tools and transition documents to those young people who had fewer complex needs. In some instances, practitioners reasoned that not all young people would require a transition preparation tool and decisions to use the tool should be determined by the needs of the individual. In services with well-established transition processes, practitioners communicated that 'Ready, Steady, Go' was not condition-specific enough to their patient group and they continued to use their own transition preparation tools or used it alongside their own tools. Practitioners across most services expressed their agency choosing to use the pathway flexibly, prioritise and adapt tools/documents based on perceived relevance and 'benefit' to each individual. The flexible design of the 10-Steps Transition Pathway supported this.

In some instances, practitioners expressed that they were unable to 'see the benefit' of implementation and exercised their professional autonomy in not implementing certain steps within the pathway. An example of this is a practitioner who noted that they did not 'see the advantage' of using the transition exception register as they did not feel it 'would bring value to the patient's care'.

#### **Collaborative relationships**

Collaborative relationships formed between professionals across paediatric and adult services were highlighted by multiple practitioners as an important factor that supported implementation. Practitioners had developed good relationships with their adult colleagues in local hospitals that predated the introduction of the 10-Steps Transition Pathway. Relationships with adult professionals from out-of-area were however not well-established which impacted on implementation. For services that did not have funding to support transition, relationships were driven more by the individual motivations and interests of professionals in paediatric and adult sectors. For one service in particular, the introduction of the 10-Steps Transition Pathway had helped them to establish a vital relationship with a key professional in adult services. Practitioners in services who reported having good, well-established relationships with their adult counterparts further communicated how they were able to use joint transition reviews to work collaboratively with their adult colleagues. Joint transition reviews supported the sharing of information between professionals, education, contact and engagement, which in turn resulted in paediatric practitioners having an increased sense of confidence and trust in their adult colleagues. For some practitioners having trust and confidence in adult professionals provided a good message to young people and their parents supporting them to develop trust and confidence in adult services.

A few practitioners reported poor or strained relationships with adult professionals. They appeared to result from issues associated with communication. This affected the establishment of trust and confidence that was evident in services who described having strong relationships with their adult colleagues.

## Improved knowledge and changes to practice

Improved knowledge and changes to practice were key outcomes reported by practitioners across services. Practitioners frequently stated that transition training had made them more aware of transition thus improving their knowledge. A few practitioners stated that their knowledge of a young person's route into urgent care had improved as a result of the training offered. Whereas for other practitioners improved knowledge related to having a better understanding of where young people fit in to transition and what healthcare professionals should be doing to ensure that young people are fully involved. For many, the visual pathway diagram supported this by providing structure and guidance. Several practitioners communicated that transition training had enabled them to reflect on their practice to identify where the gaps were within their services and what they needed to improve on. In some services, multi-disciplinary team (MDT) meetings were being used as a platform to share learning and discuss implementation of the transition pathway. Staff in these services reported that they felt better informed about where implementation efforts were up to as a result of MDT discussions.

One of the most common changes reported by practitioners across several services was starting to identify and prepare young people for transition at an earlier age. In many services, transition training had further supported practitioners to either establish joint transition clinics or change the way in which they were delivered. In one service, practitioners had identified the need to make their transition clinics more MDT focused, whilst in another, one practitioner had requested additional

time for transition clinics. In a different service, joint transition clinics were changed in order for adult sector professionals to take more of a leading role. Further changes to practice included changing the structure of appointments with young people to ensure that young people were offered the opportunity to be seen without their parents in preparation for adulthood.

# **Key findings:**

- 1. The work of the transition team supported implementation of the 10-Steps Transition Pathway which had a significant impact on transition practice across services within Alder Hey
- 2. The active involvement and support of the transition team helped paediatric practitioners to form and improve important relationships with adult providers
- 3. Similarities in the structure and delivery of paediatric and adult services supported implementation whilst inter-organisational differences affected how practitioners responded to the 10-Steps Transition Pathway
- 4. Joint transition reviews were more likely to be implemented where paediatric and adult organisations were in close proximity to one another
- 5. Funding supported implementation of joint transition reviews in some services, however in others implementation was dependent on the 'good will' of individual healthcare professional's across both services
- 6. The 10-Steps Transition Pathway had more of an impact in services with no pre-existing or less established transition processes
- 7. Transition preparation forms an integral part of routine adolescent care, however conversations are not always recorded formally through the use of a transition preparation tool or plan
- 8. Time resources were not always in place to support implementation of transition preparation tools and documents
- 9. Technology created a barrier for practitioners when accessing and using transition documents on Meditech
- 10. Active participation and involvement of practitioners in the change process facilitated high levels of commitment to implement the pathway
- 11. Practitioners experienced difficulties in identifying key workers to co-ordinate transition
- 12. A perceived lack of engagement from adult services impacted negatively on practitioner decision making in some services

- 13. Practitioners expressed their agency choosing to use the pathway flexibly, prioritise and adapt tools/documents based on perceived relevance and 'benefit' to each individual
- 14. Collaborative relationships between paediatric and adult professionals supported implementation of joint transition reviews
- 15. Transition training improved practitioners knowledge of transition and facilitated changes to practice across services

# **Conclusion and recommendations**

This report has described how the 10-Steps Transition Pathway is being implemented by practitioners across Alder Hey Children's NHS Foundation Trust to improve the process of transition for young people. The extensive work carried out by the transition team and the support provided to practitioners has been recognised as having a significant contribution to changes made to transition practice across services within the trust. Extraneous, organisational and individual-service level factors that help to support and/or hinder implementation of the 10-Steps Transition Pathway have further been highlighted. Findings discussed in the previous section of this report indicate several clear recommendations for practice. These are stated below:

- Continue to improve networks with adult organisations, particularly those that are outside of the local area, utilising the training and implementation of the 10-Steps Transition Pathway
- Consider the earlier involvement of adult organisations in implementation of the 10-Steps Transition Pathway
- Consider undertaking joint transition reviews online for young people who are transitioning to an out-of-area adult service
- Continue to work with commissioners from adult organisations to evidence the need for additional funding to support the implementation of joint transition reviews
- Ensure that practitioners are made aware of the importance of recording conversations that take place as part of transition preparation
- Consider the additional time resources that practitioners require to effectively use transition preparation tools and documents with young people
- Assess the workability of transition documents built onto Meditech through consultations with practitioners and young people using them to identify: a). are they specific enough to what young people need to know about transition and b). do practitioners know where to find them and how to use them appropriately?
- Consider using service specific transition co-ordinators who work across both Alder Hey and adult organisations. If this is not feasible, support practitioners to identify who should fulfil the transition key worker role in each service, providing additional time for practitioners to fulfil their responsibilities within their current job roles
- Through consultation with practitioners, review current internal barriers to transition within teams who do not have well-established transition processes
- Consider making transition training mandatory for practitioners across Alder Hey and extending the offer to key practitioners in adult organisations

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## Appendix A: 10-Steps Transition Pathway to Adult Services



## 10 Steps Transition Pathway

Transition to adult services for young people with long term conditions



