

The 10 Steps Transition Pathway: Improving Transition for Children in Hospital Settings

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Abstract

Background: Health transition from children's to adult services has been recognised as an important aspect of quality and service improvement for many years. However, transition for young people remains a disruptive experience for everyone involved. Alder Hey Children's NHS Foundation Trust is one of the busiest children's hospitals in Europe and its transition arrangement had been identified as an area for improvement within a previous CQC report.

Aims and Objectives: The paper outlines a project to develop a 10 step transition pathway for a complex cohort of young people that was produced as part of a care quality improvement programme at Alder Hey.

Methods: We used a mixed method approach to capture views and opinions of members of staff at engagement events and utilised a survey instrument to collect perceptions of key professionals on the barriers and facilitators of good transition. The analysis of data was then used to develop a ten step transition pathway and protocol.

Findings: The transition improvement programme and development of the transition pathway brought about an increased understanding about the barriers and challenges of transition work. It demonstrated what is and isn't working well, where policies conflict or practice inconsistencies exist across the trust between different specialties.

Conclusions and Implications for Practice: The project showed the clear need of a key worker or lead consultant for each individual. The pathway identifies a 10 step protocol which lists key steps to be taken by those key workers to ensure a successful transition. The protocol developed was seen as a useful resource to plan transition pathways for children with complex care needs.

Keywords: Transition, young people, children, long term conditions, continuity of care, Multi-agency work

1. Background

Transition to adult services (referred to in this report as 'transition') has been recognised as an important aspect of quality and service improvement for many years, both locally and nationally. Safe and effective transition involves three important and challenging areas of health and social care provision, adolescent medicine, complex long term conditions management and the transfer of care across care settings.

Safe and effective transition requires exemplary communication, established networks, continuity and co-ordination. These challenges and how they are met provides a useful barometer regarding the functioning of teams, services and organisations. There is evidence to support better outcomes for patients who experience a well-planned, coordinated transition. However, these outcomes cannot be achieved without good relationships between children's and adult services, and cohesion between teams. Transition for young people remains a disruptive experience for everyone involved. Due to the complexity of health care provision, good quality health care during transition poses a considerable challenge to interagency co-ordination and service collaboration (Kaehne & Beyer 2014; Kaehne 2010b; Kaehne & Beyer 2013).

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There has been some research on mental health transitions for young people with learning disabilities (Kaehne 2010a; Bailey & Cooper 1997). Health transitions from children to adult health care providers however have received far less attention from researchers although some disease specific transitions have been studied (Lyne et al. 2000; Borlot et al. 2014; Robling et al. 2010; Gleeson & Turner 2012; Bruce & Evans 2008; Viner 1999; Abbott et al. 2009). Some organisational studies have also contributed to our understanding of the barriers and challenges to smooth transition for children with complex care needs (Belling et al. 2014; Kaehne 2010c; Kaehne 2011)

The Department of Health and medical research councils have long recognised the importance of research on transition for young people in general, and young people with complex health problems in particular (DH 2001; DH 2007; DH & DfCSF 2008). Although the NIHR has funded some conceptual studies on continuity of care and transition (Wallis 2007; Schalock & Verdugo 2012; While et al. 2004; Freeman et al. 2007; Parker et al. 2010; Viner 1999), with the exception of small scale qualitative studies (Kaehne 2010b; Robling et al. 2010; Blum 2003), transition from children to adult hospital care for young people with complex care needs is still a largely under-researched field. Transition studies such as Colver et al. (2013) will make a welcome difference to the evidence base when they report (Colver et al. 2013).

Alder Hey Children's NHS Foundation Trust is one of the busiest children's hospitals in Europe and provides care for more than 270,000 children, young people and their families every year. The Trust provides a range of services at the main Alder Hey Hospital site and leads research into children's medicines, infection, inflammation and oncology. The trust also provides an inpatient and community child and adolescent mental health service (CAMH's) to support young people between the ages of 5 and 14 years. Alder Hey treats everything from common illnesses to highly complex and specialist conditions from our main hospital site in Liverpool and across community sites and clinics throughout the North West.

In 2014, the hospital turned 100 years old and a new Alder Hey Children's Hospital was built adjacent to the old site over the last couple of years, and the Trust moved into the new Hospital in October 2015. Within Alder Hey Children's Hospital there are examples of excellent practice in transition. These are predominantly single specialty transitions for example a patient with Diabetes or Cystic fibrosis. However, there are also patient groups where transition is widely recognised as being more difficult, frequently poor or does not happen at all, for example child and adolescent mental health (CAMHs) patients, or those patients with a complex neuro-disability (Care Quality Commission 2014).

Poor transition is frequently rushed and unsupported with little or no handover between professionals or support for young people and families. There is poor transfer of information to support care in the adult sector. In addition for many areas characterised by poor transition there is a lack of specialist skills and knowledge in the adult sector, a lack of advocacy support for young people and little understanding of the additional needs of young people. Unsatisfactory transition results in poor co-ordination and communication at all levels. Young people may become "lost" in transition. Alternatively young people may continue to access children's services in some cases many years into adulthood.

The Care Quality Commission (CQC) inspection in May 2014 identified the need for improvement transitional services within Alder Hey. This was primarily due to a lack of evidence. The CQC noted that some young people past the age of 18 continue to visit Alder Hey, and outlined a number of reasons that contributed to this, for example there was no overarching Trust vision or strategy for transition, there was a lack of overall responsibility or leadership for transitional services, and reporting arrangements to the Trust board were unclear. There was also a lack of clarity regarding responsibilities of nurses and doctors for transition in learning disability. The paper outlines a project to develop a 10 step transition pathway for this complex cohort of young people that was produced as part of a care quality improvement programme at Alder Hey.

The key objectives of the programme were to increase staff engagement and staff understanding of transition; assess professional's education and training needs with regard to transition; identify markers for "tricky transitions"; identifying successes and barriers to transition; explore key roles in transition and co-ordination of care e.g. Lead Consultant, Keyworker and the GP. The ultimate aim of the programme was to formulate a transition policy ("The 10 step transition pathway") and identify key roles and responsibilities for professionals within it.

2. Methods

We used a mixed method approach to capture views and opinions of members of staff at engagement events and utilised a survey instrument to collect perceptions of key professionals on the barriers and facilitators of good transition. The analysis of data was then used to develop a ten step transition policy. The survey was distributed online and a series of questions were asked to staff members including: What is working well? What is not working well? What needs to change? What are the biggest barriers? What are possible solutions?

A one day workshop (expert panel discussion) was held in March 2015. The morning session of the workshop involved a number of focus groups, each of which was facilitated by a member of staff to ensure discussions remained focused. Groups each looked at one of the 10 Steps from the Transition to Adult Services pathway and developed ideas around their step, in particular, looking at difficult transitions and possible solutions to assist with these.

Similarly, the afternoon session of the workshop involved delegates working in focus groups using a “world café model” to explore four topics: three key roles in transition, the GP, the Lead Consultant and the Key worker, as well as identifying markers for “tricky transitions”. The world café model exercise was run by floating facilitators, who spent 8-10 minutes discussing their topic with one group, before moving on to a second group and building upon the first groups discussions and so on.

A series of 17 Road shows were delivered, where members of the Transition Team met with teams and services across the Trust at a date and time convenient to them, usually a regular team meeting. A series of open questions was used to explore issues and concerns regarding transition within the team and specialty as well as the wider trust. Field notes were taken and subjected to thematic analysis.

3. Results

The following section reports the survey results first and then outlines the ‘10 Step Transition Pathway’ including detailed actions which should be undertaken at each step. It then outlines the responsibilities of key roles by professionals within the transition process.

Table 1: Survey Respondents by Professional Category

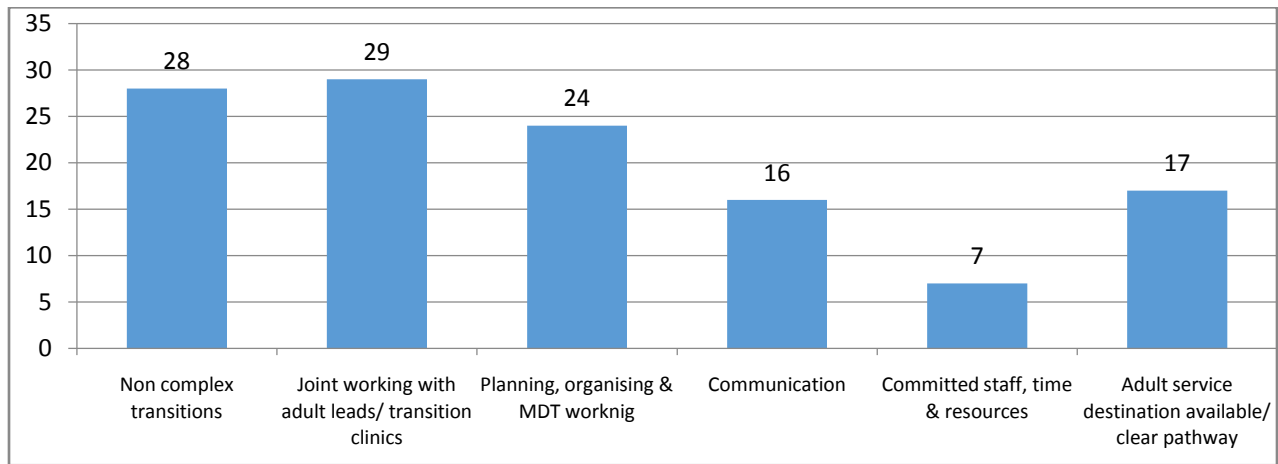
Professional Category	Number of Respondents	Percent
Allied Health	13	6.1
Doctor	109	51.4
Nurse	79	37.3
Other	11	5.2
Total	212	100

The trust-wide web based survey was completed by 212 professionals. Survey respondents’ professional demographic data is displayed in Table 1 below. The majority of respondents were from nursing and medical backgrounds. Other professional backgrounds included: Dentist, Healthcare Assistant, Service Manager, Charity Representative, Administration & Clerical and Research. There was a good mix of respondents from different CBUs (see Table1 below), with the most represented being integrated community services, medical specialties, neurosciences, musculoskeletal and specialist surgery and Surgery, cardiac, anaesthetics and critical care. CBUs that were underrepresented are Corporate, Research and Development and staff at Executive or senior management level across the trust.

3.1. Survey Results

In the first instance a range of barriers, solutions and ideas around transition were identified from responses to the web based survey and comments analysed from the roadshows. We focus on six key themes below.

Figure 1: What is working well?

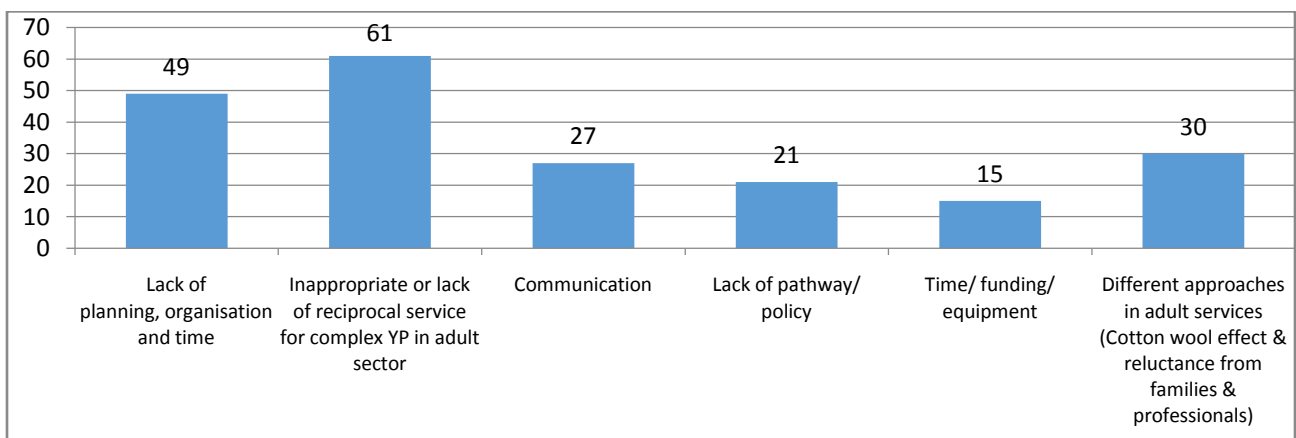


It was identified that two of the most important factors in transitions that, described by staff, are currently working well was the transitions of non-complex patient; for example when a patient is only seen by one specialty, the transition to that specialty in adult services often seems to work well and is a smooth process. Secondly when there is an identifiable lead in the adult services to refer the patient on to, when the young person’s transition is planned and organised in collaboration with children’s and adult’s services (including special transition clinics for adolescents).

Other key themes that emerged when asking staff (of varying disciplines) what works well when transitioning a patient to adult services included where there are good channels of communication- both between professionals (adult’s and children’s), and between professionals and the patient and their families. Additionally it was identified that transitions often work well when there is an obvious adult service destination for the young person.

A number of responses included comments around having a number of committed staff members who were responsible for making transitions work appropriately within their specialties, and a number of comments focused on transition clinics within their specialties being a factor that influenced transition success. An example of this was a statement made by one member of staff who stated “Staff have young people’s best interests at heart and do their best to support positive transitions”

Figure 2: What is not working well?

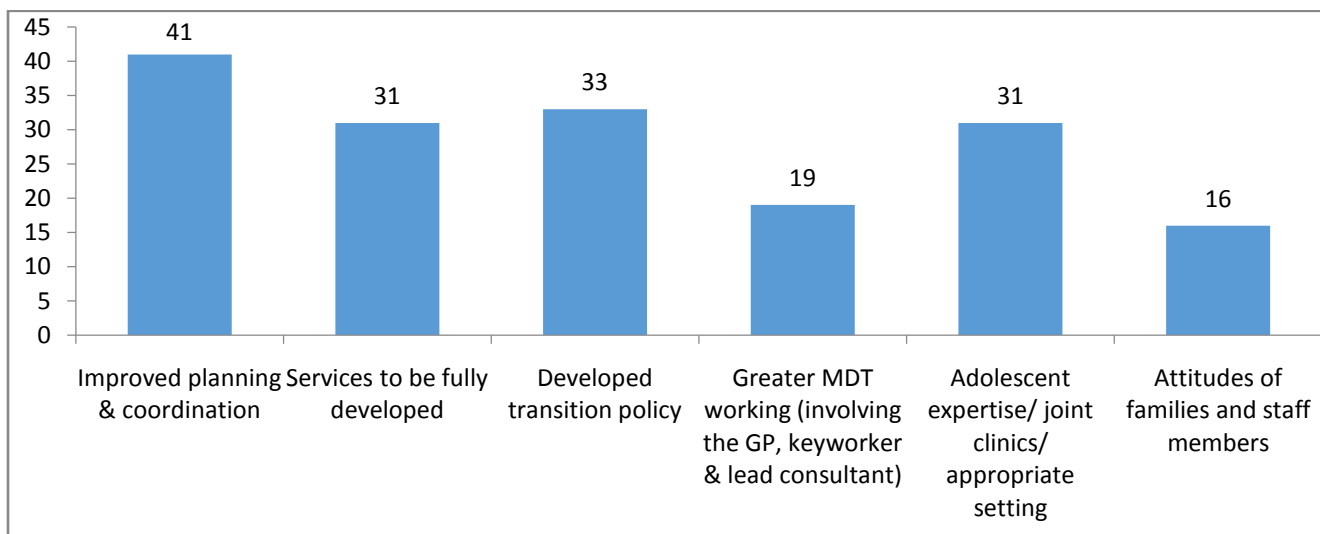


Respondent’s answering the questionnaire responded to the question “what is not working well?”two hundred twelve (n=212) responses from respondents answered this question in the questionnaire. The main theme running throughout the responses to the question asking what is not working well was around inappropriate services for adolescents or lack of like-for-like services in adult and children’s services, meaning that often professionals from children’s services are unable to refer a child on as there is no service to refer to.

A second theme that ran throughout these responses was that there is a lack of planning and organisation as well as time available to spend on supporting young people to transition to adult services. Time was seen as one of the main reasons for this lack of planning as professionals often referred to this as a reason why they were unable to plan and coordinate transition appropriately. Whilst identified as a theme which helps transition, communication, or lack of communication, between services was seen as a big issue amongst respondents, as well as staff (both in children's and adults) not having the appropriate skill set to support with transition to the best of their abilities and a lack of leadership to guide the process.

A different approach towards care in adult services compared with children's services was identified as a factor in less successful transitions. This manifest in comments around attitudes from staff and from families, which was seen as a barrier to positive transitions and it was mentioned a number of times that families don't want to move to adult services as they fear a lesser quality experience to what they receive in paediatric care- possibly an attitude picked up through discussions with paediatric staff. Additionally, there were a number of comments expressing generically negative views about transition, without giving explicit reasons as to why transition is not working well.

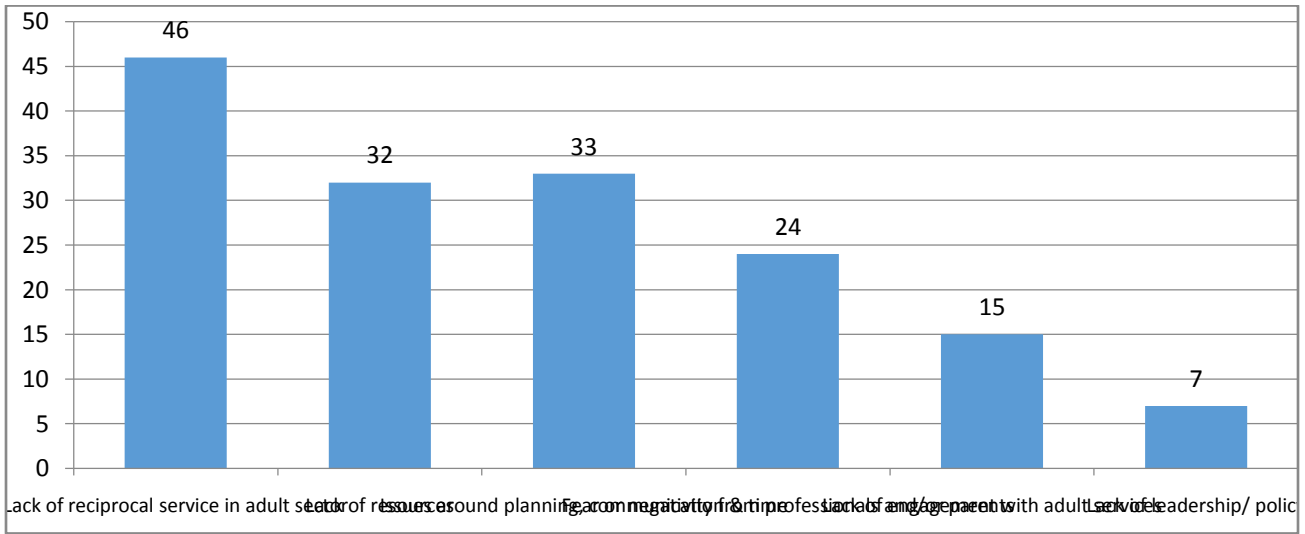
Figure 3: What needs to change?



In response to the question “what needs to change?” there were 212 responses from respondents who answered this question in the questionnaire. The most common themes around what needs to change reflect the answers to the previous question illustrating the importance of improved planning and coordination of transition as well as more fully developed services. Ideas to help with planning and communication included developing system alerts to identify young people of transition age and “health information passports” to help families communicate with professionals from different services. Similar issues were raised around developing better links and joint clinics between adult and children's services, which had previously been raised as areas that currently make transition work well.

The importance of developing a specific transition policy was discussed and the need for a leadership structure around the processes of transition within both adult and paediatric trusts. One Respondent answered stating the need for “One person in every adult Trust at whose desk the buck stops, and who is answerable if families find that things are not right” Although not identified as a standalone theme, a large number of the comments reflected issues around funding, time and resources.

Figure 4: What are the biggest barriers to transition? (In percent) (multiple selections possible)



Answers to this question around the biggest barriers to a young person’s transition were similar to the previous question, eliciting responses about what is not currently working. The main barrier identified being a lack of like-for-like services in the adult sector, meaning that some patients have nowhere to go when they reach the age of transition and therefore continue being seen and cared for at Alder Hey. This links with a second key theme, where comments were centred on the issue of lack of resources being a barrier to transition.

Emerging again were numerous comments around lack of time available for planning and coordinating transitions being a problem. Fear and/or negative views from professionals and from parents about moving a young person’s care to adult services was also abundant in responses to this question. For example one respondent stated “Parents are worrying about not being able to stay with child and adult services not prepared to accommodate parents/ carers of complex needs children”.

Table 2: The 10 steps Transition Pathway

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's services to assist with transition. To identify a lead to communicate with and coordinate all specialties to ensure transition happens. For the ten 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 program, and that a % of all 14+ year olds with a long term condition who 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 between adult and paediatric 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 was considered to be an important role, and lastly which was considered very important was a "One stop shop" clinic model for complex patients.	Positive feedback from families is a measure of a good quality service and patient journey, feedback also from professionals around confidence in transition would be a firm indicator. The % of GPs 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's 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 dataset 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 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 adults and Paediatrics with shared care plans for patients and community teams. Again a measure of feedback from patients and families was discussed.	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. 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 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 MDTS 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 specialties and services was 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.

3.2. Key roles for transition

Focus group discussions were held to discuss what is required and involved in the identified key roles. Barriers were identified and potential solutions were developed. Summaries of the discussions for each role are displayed in the table below.

3.2.1. Role of GP

The role of the GP was considered to be a lynch pin in transition, it was highlighted that the GP may perform annual health checks for patients. There should be a specific management plan to support the GP, and that the GP should be a catalyst for picking up lost patients and re-referring to consultant. The lack of a 24 hour service was considered a barrier, and that GP's were not always easily available. However it was acknowledged that by our own omission we have disempowered GP's in patient's care and involving them in the transition of their patients. It was also acknowledged that some of the complexities of these patients may make them 'scary', also GP's cannot prescribe certain drugs patients may be taking. There will be a requirement of investment in GP job plans to develop a 24hr service. It will be necessary to build relationships with specialist consultants and have a phone a friend option and supporting GP through transition of such complex patients, of which transition preparation needs to commence earlier. A clear escalation strategy for complex patients needs to be designed.

3.2.2. Role of the Keyworker

A flexible and fluid job role acting as a single point of contact, and delivering continuity of care would be necessary, with a role that acts as a patient advocate, following the patient through the transition preparation process to Transition on to adult keyworker (handover), then to follow up patients after 12 months in adult sector. The key worker should be a good communicator, with knowledge of transition and integrated working with other agencies, having the ability to empower the patient, their families and professionals.

No Barriers were identified- discussion around what is the best model of key-working was held. Two models of key worker role were identified. Model 1: A team of keyworkers who would require knowledge of personal health plans, signposting, navigating, identifying patients etc. Model 2: Investing into current teams. Someone who is already involved in the child's care becomes the key worker and has dedicated time built into the role to deliver the role of the keyworker; i.e. an identified % split of clinical and non-clinical time.

3.2.3. Role of the Lead Consultant

The lead consultant would take the lead and overall responsibility and accountability for transition of a patient, overseeing the delivery of care of the whole patient, Coordinate joint clinics, and coordinating transition with all specialties at the same time, whilst being committed to attending complex care meetings. The lead consultant will mentor the keyworker, and have the ability to provide support, empower and give a voice to YP and families.

There were some identified limitations of scope of the role, and it was identified that dedicated time would need to be required in job plans. There was a discussion about how would we identify the lead consultant- who would it be? Is it the most complex problematic area specialist, or is it the person who is most comfortable with the role, or is it who the parent and YP want it to be? It was acknowledged that at times there would be difficult decisions to be made, and there would also be safeguarding concerns and issues to manage.

The need to employ a method to identify the lead consultant, then investment into job plans to enable consultants to take on and fulfil the role. The lead consultant would be required to liaise with keyworkers to ensure the patient has fully transitioned and is engaging with adult services. The need for electronic information exchange system for sharing patient information e.g. drop box, and possible patient hand held records e.g. health passport/plan. It was identified that patients requiring a lead consultant are those under multiple specialties, patients with complex needs and those stuck in transition.

4. Discussion

The activity undertaken engaged a wide range of professionals in discussions on the subject of transition and brought about an increased understanding about the barriers and challenges of transition work. In a number of the themes regarding what is and what isn't working well, issues are repeated and conflicting, demonstrating the inconsistencies across the trust between different specialties.

Given the large number of themes that arose from these four questions on the survey and in the roadshows, it is clear that transition to adult services is not a simple task and that there are potentially a huge range of issues and barriers for different specialties across both adult and paediatric services. Throughout the development of the 10 Step Transition pathway and tool kit, it was identified that it is essential to have a clearly identified a Lead Consultant and key worker. 76 % of respondents stated they believed their patients had a lead consultant. However, it was not clearly identified from the responses if the patients are from a single specialty (or palliative care). A quarter of responses stated that their patients did not have a clearly identified consultant. A future project aims to work collaboratively with Meditec 6, to embed an area in each patient's electronic records which clearly identifies the patients Lead Consultant and key worker. Similarly respondent's views on whether their patients had key workers were mixed.

It was discussed whether patients across all CBUs are being issued with written transition plans. Responses suggest that the approach to providing patients with transition plans within specialties may be questionable. For example: Medical specialties was the CBU where most respondents reported their patients as having written transition plans; however when this is further broken down it is unclear how consistently this is done. In a number of cases, respondents from the same specialty provided completely different responses to this question. This identifies that the implementation of transition plans is not standardised across the Trust. Likewise there are huge inconsistencies between and within specialties' as to whether the patients GP is actively involved in the patients care. This finding and discussions from the road shows identifies the need for further research into defining the role and responsibilities of the GP. It was also acknowledged that utilising the GP in transitioning young people to adult services has the potential to aid the process substantially. A highly discussed theme was that of the GP being a key player in transition in a number of ways (such as following up patients to ensure transition has been successful and patients have engaged with adult services and being the only professional with the potential to offer a cradle to grave service). Similarly, to each of the other key roles, there were barriers involved with this; however a number of solutions emerged. More discussion required to determine the how the GP may fit in and compliment transition pathway and policy.

Patients under multiple specialties' were identified in the questionnaire and the roadshows as being more complex with the majority of respondents stating their patients do not have a Lead Consultant or Keyworker or a written and recorded Transition plan. This clearly demonstrates that across the trust patients who are under multiple teams or specialties are not currently experiencing fully coordinated care in relation to their transition to adult services. The study revealed that staff are less confident about who or how to access support with transition. When considering members of staff who perceive themselves as having key worker roles, the majority of staff members demonstrate understanding of transition and ability to assist in their roles of supporting young people through transition to adult services. In terms of training requirements to be taken from this- possibility for education around the role of the keyworker and the lead consultant and how these roles are critical to successful transition.

Further research could be done to explore what factors play a part in staff feeling able to support, empower and involve GPs in a young person's transition. This could potentially be an area to target when looking into developing education and training for staff involved with transition. The focus groups collected valuable ideas from delegates as to how each phase of transition might work in practice and the structures needed to support this process. Although conflicting viewpoints were aired throughout in terms of what might and might not work, a range of innovative concepts were discussed. At each stage of the 10 Steps, possible barriers to smooth transition were identified and solutions to these were suggested and developed, contributing to our understanding of the issues around transition.

The Ten Step Transition Pathway and toolkit were specifically designed to assist with the transition of patients with long term complex health conditions whilst the markers of complex long term conditions were outlined as patients who have involvement of three or more specialist services, are dependent on life sustaining technology e.g. ventilators, feeding pumps, and have three or more of either GMFM 4 or 5, severe learning disabilities, a complex long term condition or palliative care needs (life limiting or life threatening condition). The protocol developed will be a useful resource for other trusts to plan transition pathways for their children with complex care needs.

Extra support may be required for those with multiple conditions and co-morbidities, when a family has complex social circumstances, for patients who depend on carer's or respite, where parents have additional needs e.g. mental health issues, and when parents are resistant to moving to adult services e.g. if family are aware of another YP, over 18 who is still under the care of Alder Hey. It was recognised that inconsistent communication was a huge barrier, as well as manipulative behaviour from parents- wanting their child to remain under the care of Alder Hey, and previous bad experience of local services. Psychological issues of the YP or family were also identified as barriers, as well as safeguarding issues and issues around consent, patients who are out of area, not medically stable.

Other areas that may be barriers are local areas not having equitable funding, dispute between health and social care about who provides what and so many different sites to transfer to. Other areas of concern were identified one being the ASD- mainstream services might be traumatic, and lack of housing/ beds for parents when YP is in adult services. A discharge planning service was discussed as it was identified they would know what is available in different areas. Engaging and establishing third sector support in the role of transition, better sharing of information, and educating YP, parents and carers about why YP is ready for transition and how the process will work, and supporting them through this.

5. Conclusions

The project showed the clear need of a key worker or lead consultant for each individual. The pathway identifies a 10 step protocol which lists key steps to be taken by those key workers to ensure a successful transition. The protocol developed was seen as a useful resource to plan transition pathways for children with complex care needs. More research needs to be done to explore the potential impact of the 10 Step Protocol in different settings and its benefits for different patient populations, such as young people with complex conditions or terminal illness.

Ethical Approval: The paper reports the findings of a consultation of staff at the Alder Hey Children's Hospital NHS Foundation Trust. The hospital's research department was consulted whether or not full research ethical approval was required. The study was deemed a consultation that did not require full ethical approval by NHS Ethics.

Competing Interests: All authors declare that they have no competing interests, financial or other, in relation to their work.

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