

Lysosomal Storage Disorders Services

- A review of transition from paediatric to adult services in England

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1. Introduction

NHS care for patients in England with Lysosomal Storage Disorders (LSD), a group of rare inherited conditions with a varied phenotype affecting both children and adults, is provided nationally by 8 centres (5 adult and 3 paediatric). Multidisciplinary, multispecialty care and care coordination is provided with treatment options ranging from palliative/supportive care to disease modifying therapies and innovative therapeutic research interventions.

Disease modifying therapies and improved supportive care has increased the number of children surviving into adult life¹. Many of these young people still require complex medical care with the same degree of support and co-ordination in adult services as they received from their paediatric teams². As a result these young people transition to adult services when they are no longer children.

Feedback from patients and families indicates that in general transition is often poorly planned, poorly executed and poorly experienced by children and young people³. For young people with Lysosomal Storage Disorders there are the additional challenges of having a rare disease, often requiring care from multiple specialties/agencies as highlighted by the rare disease UK transition report⁴, the European Reference Network Survey⁵ and international case study publications⁶, as well as transferring their care to a different hospital often in another part of the country. Poorly planned transition can be associated with increased risk of loss of engagement and non-adherence to treatment with adverse consequences in terms of mortality and morbidity as well as social and educational outcomes³.

Following the Peer Review in Jan 2020, a key recommendation was to ensure a more consistent approach to transition across the centres in England which would be beneficial for young people and their families and a plan to review and standardise current service provision was subsequently proposed. The scope of the review included

- assessment of current transition processes
- identification of areas of good practice or potential for improvement
- creation of LSD specific principles and auditable standards,
- development of a national LSD transition pathway, clarifying the point of transfer of care to ensure high quality provision of services for young people (aged 16-25).

A national working group was established with representation invited from each specialist paediatric and adult centre in England, NHS England highly specialised commissioning team and the LSD collaborative patient associations, with a particular focus on listening to the views of patients and families. The group undertook a review of current service provision, benchmarked to existing national recommendations, and created a series of principles and auditable standards to meet the complex, specialist needs of this patient population, including development of a national pathway. The intention was for this to be a pathfinder project, working collaboratively with the regional advisors from the Burdett National Nursing Network to produce a transition pathway that will not only ensure high quality care for our patients, but may help other services treating young people with complex/specialist needs.

2. Current Guidelines

The concept of transition can be described as a gradual process of empowerment that equips young people with the skills and knowledge to manage their own healthcare⁷. It can also be defined as “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems⁸”. In practice the term “transition” describes the process of moving from paediatric to adult services, as opposed to a single “transfer” event – the point at which medical responsibility is handed from paediatrics to adult care^{6, 16}. These definitions are helpful when considering transition pathways.

Following a review of key publications recommending standards and guidance for effective transition (appendix B), two documents were then used as a framework for this project:

1. *NICE guideline NG43: Transition from children’s to adults’ services for young people using health or social care services*⁹

The existing NICE guideline was published in 2016 and describes overarching principles for good transition although it does not go on to propose auditable standards. The guideline forms the basis for the Care Quality Commission (CQC) inspection framework for transition services and clearly defines key roles within the context of broader cultural, legal and developmental changes. It places the young person at the centre of the guidance and provides recommendations for implementation for service providers.

2. *LSD collaborative model for transition*¹⁰

The LSD collaborative, comprising of patient support groups for a range of lysosomal storage disorders, carried out a project between 2010 -2014 to develop a model for transitional care for their young people. Using a combination of interviews with clinical teams, patient focus groups and quantitative patient questionnaires they were able to identify common themes and develop a best practice guideline. To support this they produced a transition passport that young people could use to track their progress through the transition process.

We engaged with the Burdett National Nursing Network and were able to access their resources and guidance throughout the project. In particular they recommended the use of the Department of Health ‘*You’re Welcome*’¹¹ criteria across our services. These quality criteria have been determined and prioritized by young people and are endorsed by the RCN, the National Youth Agency and Brook. There are eight standards each of which contain further specific essential and desirable criteria. They cover involving young people, confidentiality/consent, making young people welcome, providing high quality services, developing digital approaches, staff skills/training, linking with other services and supporting changing needs.

In addition we shared our findings with NHS England Children’s and Young Peoples policy teams for review.

We reviewed some of the commonly used transition preparation programs including *Ready Steady Go*¹², *Growing up- Gaining independence*¹³, *10 steps to transition*¹⁴ and *Together for short lives*¹⁵ Some programs may be more appropriate for individual patients and hospitals

often have an organisation wide program of choice. All of the programs encourage a gradual move towards independence and autonomy in managing health issues in the wider context as part of a family. *Ready Steady Go* is available in 10 languages and has easy read versions¹². *Together for short lives* describes five key standards to ensure that all young people are supported to achieve a good transition which encompasses the role of families, holistic care, end of life planning, joined up working and expectation management¹⁵.

We considered the principles of transition recommended by Stephien & Hendriksz (2015)¹⁶ which focused on mental capacity, communication, autonomy and self-directed care. **In addition we considered the importance of mental health and wellbeing (emotional, physical and social) and its impact on a young person's ability to cope with key life events or likelihood of engaging in high risk behaviors.**

Finally we considered professional advice and recommendations from the General Medical Council (GMC), Royal College of Nursing (RCN) and Royal College of Paediatrics and Child Health (RCPCH), reviewed published examples of good practice in other services and identified further potential resources to support training and education.

As with safeguarding, transition is everyone's responsibility and requires a team approach (Bryan 2019)¹⁷. This team should include the young person at the very centre encapsulated by principle 4 of the NHS constitution¹⁸ and it is envisaged that engagement/involvement with young people in the process will promote better outcomes. Patient support groups were represented throughout this process by the LSD patient collaborative who provided up to date input on behalf of patients and families.

1. Review of current service provision

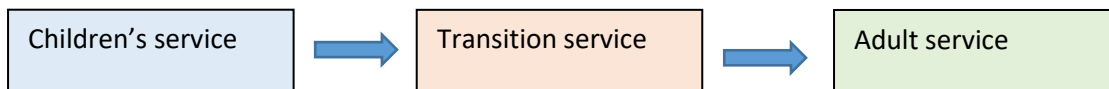
Each specialist centre in England was asked to share their hospital transition policy, transition preparation program, hospital information leaflets and other supportive tools (spreadsheets, checklists, proformas etc.). In addition they completed a questionnaire (appendix A) about the transition process in their own areas based on some of the key points identified by the LSD patient collaborative in their transition project. One centre was unable to participate in this part of the project for operational reasons but was able to contribute later in the process. The information shared was considered in relation to the key guidelines originally reviewed by the group.

Transition models

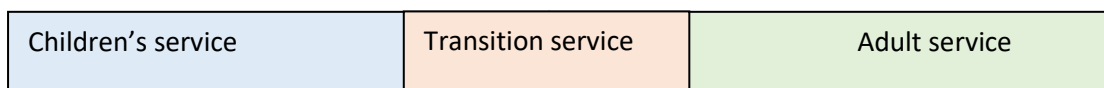
Service delivery options for 0-25yrs services

There were a variety of models in use across the centres and these are described from the paediatric centre perspective.

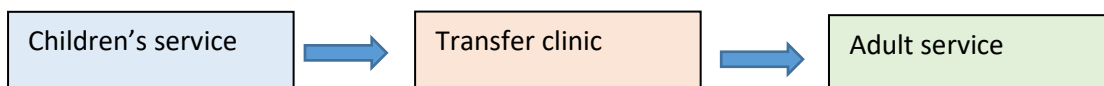
Royal Manchester Children's Hospital (RMCH) predominantly transfers its young people to Salford Royal hospital. Young people are reviewed in the joint Salford transition clinic before moving to the adult clinic when they are ready.



Birmingham Children's Hospital (BCH) hold joint transition clinics with most of the adult centres on at least an annual basis for several years prior to their eventual transfer to the adult centre of choice. These clinics may alternate between the paediatric and adult sites.



Great Ormond Street Hospital for Sick Children (GOSH) predominantly transfer patients to the National Hospital for Neurology and Neurosurgery (UCL) with whom they hold regular single transfer clinics. They can replicate this model virtually or in person for other adult centres on an ad-hoc basis as required.



Timing of transition

NICE guideline NG23: start planning from age 13/14 at the latest, developmentally appropriate.

All paediatric centres state that they start transition planning from the age of 12, with a wide range of age of involvement reported by the adult centres (12 -18)

Use of transition preparation programs

NICE guideline NG23: ensure a range of tools is available, transition plan in place

A range of preparation programs are in use, usually determined by individual paediatric hospital policy. These include *Ready Steady Go*, *Growing up*, *Gaining independence*, and *Together for Short Lives* and one centre additionally uses its own transition proforma. Adult centres generally reported participating in the programs initiated by their paediatric colleagues although one centre uses its own in house documentation and another the MPS society transition passport. *Ready Steady Go* and *Growing up Gaining independence* have easy read versions available for patients with learning difficulties and *Together for Short Lives* is available for use for patients on palliative care pathways.

Transition clinics

NICE guideline NG23: arrange joint appointments, running joint clinics

All centres report participation in transition clinics. Some centres run transition clinics with more than one adult centre. In some cases these are regular established clinics and in other cases are arranged as required to meet individual needs.

Timing of transfer to adult services

NICE guideline NG23: not based on a rigid threshold, at a time of relative stability

Age of transfer is individualised to each patient and ranges between 16 and 18. In general the intention is to transfer at 16 with the option to remain in paediatrics a few more years if there are additional complex medical needs or specialist interventions planned or if the young person is on a palliative care pathway.

Patient involvement in transition

NICE guideline NG23: involve the young person and their family/carers, support independent communication, ask how they would like to be involved, provision of accessible information to support decision making

In general the paediatric centres decide which adult centre to offer to young people usually based on demographics. One paediatric centre proactively allows its young people to choose between all adult centres. All adult centres involved have a welcome booklet or transition specific booklet that can be provided to young people and their families, although whether this is provided during transition or at the point of transfer is variable. This

literature is supported verbally during the transition clinics. Prior to the COVID-19 outbreak it was possible for young people to visit the adult centre prior to transfer either at an open day, at transition clinics or by arrangement, however restricted on site visiting and the availability of virtual technology has impacted on this option with several centres mentioning the plan to produce virtual/video guides as a supplementary option to onsite visits. Paediatric centres describe using techniques such as motivational interviewing, action planning, training and knowledge assessments during the transition preparation although this is variable across centres. Two adult centres reported running/planning focus groups and actively seeking feedback from young people using questionnaires.

Special circumstances

NICE guideline NG23: transition should be developmentally appropriate, take into account mental capacity, physical/mental health needs and learning disability

Palliative care: paediatric centres may delay transfer of care for patients on end of life pathways. Access to paediatric palliative care/respite facilities for young people up to 25 is variable and requires involvement of both specialist centre and local teams. All centres however do have access to palliative care services and specialist pain teams.

Learning difficulty: most hospitals reported access to an LD trained nurse and completion of LD specific hospital passports. Some centres have “alerts” in the electronic record system. Only one paediatric centre reported raising the issue of mental capacity assessment and the role of power of attorney/best interest meetings during the transition period. Most adult centres described the need for initial and ongoing mental capacity assessment and subsequent management in line with 2005 Mental Capacity Act, additionally reporting their hospital policy regarding “reasonable adjustment”. Some centres reported availability of easy read versions of supporting documentation.

Mental health needs: all centres described the need to ensure transfer from Child and Adolescent Mental Health services (CAMH) to adult mental health services. Some centres have access to dedicated psychology input or services such as chronic illness hubs. One centre maintains a mental health log and has additional processes in place to monitor vulnerable adults. There was no consistent approach across centres to assessing the mental health needs of young people.

Homecare

NICE guideline NG23: Children’s and adult services should work together

Homecare is provided for patients with lysosomal storage disorders with disease modifying therapies. There are currently service capacity challenges within homecare generally but specifically regarding access to paediatric trained nurses. Age of transition within homecare was identified by the LSD collaborative as having a significant impact on young people and their families. Transfer from paediatric to adult homecare nurses usually happens in conjunction with transfer to adult centres between the ages of 16-18, although individual needs and family circumstances are taken into consideration. The scope of this project did not extend to homecare and should be an area for further consideration.

Lysosomal storage disorders homecare services are provided by companies successful in applying to be part of the national framework following a formal contracting process. This agreement usually lasts for a 2-5 year period, at the end of which it is possible that individual providers may change. The next contract is due to be awarded mid-2023 and once this project has embedded in the specialist centres it would be important to review the implications for homecare with the relevant providers.

Managing multiple healthcare providers

NICE guideline NG23: work together in an integrated way, involve all relevant practitioners, and consider joint speciality working and provision of a co-ordinating role

All centres report providing a co-ordinating role with some centres offering joint clinics or one stop shop clinic models (although COVID-19 outbreak has temporarily decreased availability). Multi professional multi agency communication occurs, usually by letter, with tracker documents to collate essential information. One centre described a focus on complex clinical needs across both medical specialties and external agencies with an aim to co-ordinate transition in these different areas.

Inpatient care

Young people with LSD's between the ages of 16-25 may have complex care needs that require access to inpatient expertise not available in adult centres.

Most centres report that young people after the age of 16 are looked after in an adult inpatient setting. Admission between 16 -18 (in some places up to 19th birthday) is possible in individual cases by agreement (e.g. high risk specialist surgery, learning difficulty or complex needs).

Experience in adult services

NICE guideline NG23: ask regarding parental involvement, meet adult team before transfer, see same healthcare practitioner for 2 visits following transfer

All paediatric centres report that they arrange for young people to meet the adult team before transfer however all centres acknowledge that this does not always happen as planned. Reasons cited for this include patient non-attendance at transition clinics, capacity restrictions in transition clinics and patients diagnosed in late adolescence. There was a clear difference between level of parental involvement between the paediatric and adult centres with communication going directly to young people (with mental capacity) from the point of transfer onwards. Preparing young people and their families for this change should form part of the transition process as young people take on responsibility for their own healthcare. Adult centres report that in most cases young people can see at least one consistent member of the healthcare team for the first 2 years after transfer.

Named transition worker

NICE guideline NG23: a single practitioner should act as named person to support a young person through transition

Not every centre has a named transition worker. Some centres reported hospital and service based transition leads of both medical and nursing staff. Where not formally identified this role generally falls to the specialist nurse involved in the young person's care.

Examples of excellent practice

There are examples of excellent established practice between different centres:

Birmingham Children's Hospital /all adult centres: Genuine choice for young people results in the need for good communication with all adult centres. A system of both regular and ad hoc transition clinics is available including the option of clinics in both adult and paediatric locations.

Great Ormond Street Hospital for Sick Children (GOSH)/London adult centres: GOSH work closely with the 2 adult centres in London to identify patients in advance of the transfer clinic. Recent instigation of a telephone pre-transition clinic has better prepared patients for their transfer to adult services.

Royal Manchester Children's Hospital (RMCH)/Salford: RMCH hold a monthly transition planning meeting (taking place virtually on Teams a week prior to the transition clinic) with the adult service provider in Salford. They have developed in house documentation to support this pathway including a transition proforma and SOP and established formal transition clinics. The close working relationship between the two hospitals enables a smooth transfer of care for young people and their families.

Areas of concern

Transition for patients outside of the existing centre specific pathways is less well organised and relies heavily on individual members of staff to make this happen.

There is limited availability of multi-speciality transition clinics and transfer may occur at different times across specialities.

All centres report the challenges of finding enough time to thoroughly prepare patients during transition.

The LSD collaborative identified a real need for support and preparation for parents and families as well as young people during transition.

Assessment of mental wellbeing in young people is variable with access to psychology a limited resource. Increased awareness of suitable assessment tools is needed²¹.

All hospitals have e-health records although not all use the same system. Transfer and sharing of clinical and transition related information is variable and previously trialled patient held information (MPS society patient passport) had limited success.

Very few specialist centres reported having dedicated specific clinics for young people (aged 16 -25).

2. Proposed Principles

The working group started by determining an overall aim for a high quality, effective transition process:

AIM: To create a national pathway that will facilitate a developmentally appropriate, integrated, supportive transition process for young people and their families with Lysosomal Storage Disorders. This will ensure effective transition planning and preparation and should be adaptable to meet individual needs, with the intention of enabling children to become independent young people able to manage their own healthcare needs during their adult life to the best of their ability.

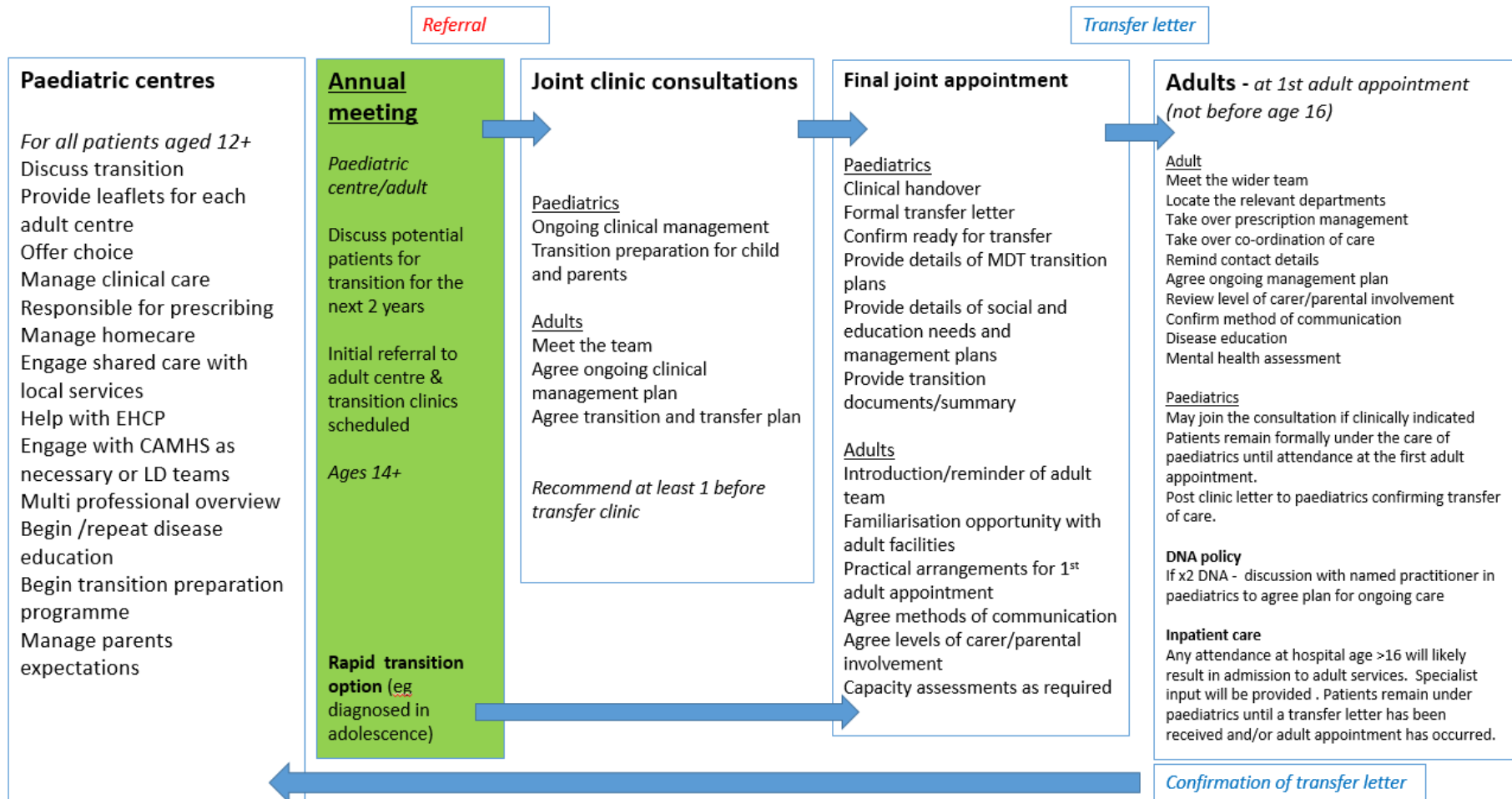
A list of 20 core principles was created based on the information gained in the review period and particularly using the feedback and previous proposals provided by the patient associations. The statements were reviewed and refined until all participants were in agreement.

Principles

1. Transition should be introduced early and positively, with introduction of the concept between the age of 11-12 years, and formal transition planning from 14-16 years
2. Adult and paediatric services should work together with an established process to identify young people likely to move to adult services within the next 2 years and agree operational points of handover of clinical responsibilities including prescription and homecare management
3. Dedicated transition clinics should be available at paediatric and adult centres to allow the young person and their family to prepare for transition using an appropriate transition preparation programme at least annually and to meet members of the adult service prior to transfer of care
4. A named practitioner should be responsible for each young person's transition in accordance with the NICE guideline NG43
5. Young people should be encouraged to become independent in managing their own healthcare needs in a developmentally appropriate way including managing their treatment, arranging/attending their appointments and empowered to agree lines of communication/contact preferences and levels of parental/carer involvement.
6. Transition planning for young people with complex care needs should include liaison with social care, welfare, education, employment and safeguarding in addition to healthcare requirements.
7. Transition preparation should include an appropriate assessment of mental health needs and support provided to the young person and their family/carers to help manage the psychological impact of this change
8. Young people with learning difficulties should be clearly identified during the transition process and have a mental capacity assessment performed when they turn 16 and a clear plan regarding future legal decision making responsibilities

9. Young people and their families/carers requiring palliative care should be involved in creating a palliative care/end of life plan/ advanced care plan (ACP) that encompasses both paediatric and adult services and that meets the "Together For Short Lives" standards
10. Support should be provided for parents to enable them to encourage the young person to become an independent adult and to manage expectations about the young person's future care
11. Information should be made available to the young person about the relevant adult services in an accessible format to enable them make informed choices about their future care. Information should be provided using mixed media (e.g. leaflet, video, web page, podcast, QR codes, apps etc.) and include the opportunity to visit the centre. This should include as a minimum information about the adult team, the location, the clinic, the appointment process and contact details for further questions
12. Young people should be encouraged to be proactive in their transition, be empowered to share their views and receive peer support through the patient associations or national youth forums. Services should be responsive and open to change
13. Transition specific documentation, with input from young people and their families, should be shared securely between adult and paediatric centres including as a minimum up to date clinical information, record of progress through the transition preparation program and a multidisciplinary/multispecialty transition timeline. Patient held information should be encouraged
14. Transfer to adult services should be at a time of relative stability for the young person between the ages of 16-18, with an agreed plan for any outstanding specialist interventions that may involve a shared care arrangement between paediatric and adult services
15. The named practitioner should be available to support the young person for at least 6 months before and after transfer and should hand this responsibility onto a named practitioner in adult services after transfer
16. Provision of specialist young person clinic should be available in the adult service to young people up to the age of 25 to provide developmentally appropriate care in line with the *You're welcome* criteria
17. Young people should meet the same adult healthcare providers at the first 2 visits post transfer to enable them to build a new therapeutic relationship with the adult team
18. If young people fail to engage with adult services despite repeated attempts to facilitate this, the named practitioner in paediatric and adult services should be notified to work with the young person to identify alternative ways to meet their health needs as described in NICE guideline NG43
19. Wherever possible appointments should be co-ordinated to avoid multiple visits
20. Staff working with young people should be suitably trained to deliver high quality compassionate personalised and developmentally appropriate care for young people. During these discussions the group agreed a standardised process for transition across the centres to help support implementation of these principles and went on to develop a series of standards as well as some proposed measures that could be reported as part of the national quality monitoring dashboard.

3. Proposed National transition pathway



4. Standards

There were 22 standards were created from the agreed principles.

Paediatric services

1	All patients start formal transition planning at 14 (excluding patients diagnosed in late adolescence)
2	All young people to be offered the choice of which adult centre they would like to go to

All services

3	Annual joint adult/paediatric service transition meeting held between centres participating in transition of young people in accordance with local guidelines
4	Every centre has a list of all patients transitioning within the next 2 years
5	All young people and their families should have met the adult service at least once prior to transfer
6	All young people up to the age of 25 should have an annual appointment focusing on transition needs
7	Every young person up to the age of 25 should have an appropriate healthcare professional as a named practitioner
8	All young people should be offered some time in each appointment to meet a member of the clinical team independently where appropriate
9	A list of all relevant healthcare and related professionals names and contact details should be available for every patient in transition
10	Each young person should be asked about their mental wellbeing*
11	All young people requiring palliative care should have discussed an end of life care plan where appropriate
12	All end of life care plans meet the together for short lives standards
13	All parents/carers should have some time in each appointment during the transition process to discuss concerns/expectations independently
14	All young people have been given information about the relevant adult services
15	All young people are offered the opportunity to be involved with their patient association
16	All centres to provide opportunity for feedback about the transition process
17	All transition preparation programs are shared with and then completed in adult services
18	All young people are transferred to adult services before age 19
19	All young people who do not attend the scheduled adult clinic appointments (DNA) should be discussed with the paediatric named practitioner and a plan agreed for their future care
20	All staff working with young people are suitably trained

**As per each centres clinical process- validated wellbeing assessment tools are available if required*

Adult services

21	All patients transferring to adult services are reviewed in a clinic suitable for young people as defined by the CQC "you're welcome criteria"
22	All young people meet at least one consistent adult healthcare provider at the first 2 visits to adult services

It was proposed that specialist centres would audit their adherence to these standards annually and would report the following data to NHS England quality dashboard:

Statement	Denominator	Comments
% of young people who do not attend a transition clinic	Number of young people between the ages of 14 -18 on the centres caseload	<i>Paediatric services</i> Further detail regarding reasons for nonattendance should be available on request
% of young people transferred to adult services after the age of 19	Number of young people transferred from paediatric to adult services in the last year	<i>Adults & Paediatrics</i> Further detail on delayed transitions should be available on request

In addition it was proposed that centres should report on their transition audit and the findings from their transition specific patient feedback, at the specialist services annual national audit day.

5. Discussion

Towards the end of the process the proposals were shared with the centre that had been unable to participate and their views were included in the final recommendations.

The principles were written primarily to encompass the views expressed by patients about what young people and their families want from a transition process. This was then extended to include current and future national and professional guidelines with the intention of maintaining areas of existing good practice and improving identified areas of concern. The standards were set to try to help staff with planning and prioritising transition related activities.

Area of concern	Comment
Transition for patients outside of the existing centre specific pathways is less well organised and relies heavily on individual members of staff to make this happen.	<p>Creation of an agreed national pathway</p> <p>Annual joint adult/paediatric meeting between centres</p> <p>Every centre to hold a list of patients transferring to adult services in the next 2 years</p> <p>Transition discussions to start early to allow plenty of time for planning with young people given the choice of centre to transfer to</p>
There is limited availability of multi-speciality transition clinics and transfer may occur at different times across specialities.	<p>Co-ordination of appointments within and across specialities is recommended although is operationally difficult to implement at the time of writing this report</p> <p>Standards to be agreed following pandemic recovery</p>
All centres report the challenges of finding enough time to thoroughly prepare patients during transition.	<p>Recommending that all young people should have an annual appointment focusing on transition to provide the time to use the preparation programs effectively.</p> <p>Transition discussions to start early to allow multiple opportunities for preparation</p> <p>The named practitioner should be responsible for ensuring this can happen for each young person</p>
The LSD collaborative identified a real need for support and preparation for parents and families as well as young people during transition.	<p>All parents/carers should have some time in each appointment to discuss concerns/expectations independently</p> <p>All young people should have the opportunity to interact with healthcare professionals independently</p> <p>Further consideration required of mentorship/support role of patient groups during transition</p>

Area of concern	Comment
Assessment of mental health and wellbeing in young people is variable with restricted access to clinical psychology.	Mental health and wellbeing assessment should be integral to clinical assessment and transition/transfer processes. Validated wellbeing scales are available for use with young people although may require adaptation for young people with learning difficulties.
All hospitals have e-health records although not all use the same system. Transfer and sharing of clinical and transition related information is variable and previously trialled patient held information (MPS society patient passport) had limited success	Key points of information sharing are detailed in the national pathway Checklist (appendix E) for minimum data set required at point of handover Recommendation that an up to date summary document is available of all those involved in the young person's care Recommendation that the transition preparation program should go with the young person for completion into adult services
The process of transition in homecare services did not form part of the scope of this review	Specialist centres are required to co-ordinate this at present with homecare but this warrants further investigation
Provision of specialist young people (ie 16-25) clinics is lacking	Specialist centres are recommend to provide specialist young person clinics in line with the <i>You're Welcome</i> criteria

6. Conclusions

The working group has developed a national transition pathway for patients with Lysosomal Storage disorders. This is supported by a clear aim, principles, auditable standards and quality outcomes.

Following an initial self-assessment process, it is proposed that the standards are audited once per year with findings reported at the NHS England annual meeting for peer review.

Standards remain to be agreed about appointment co-ordination both within and across specialities when the NHS has recovered from the operational challenges caused by the COVID-19 pandemic. The roles and responsibilities of homecare and patient support group colleagues in transition requires further consideration.

Young people and their families are at the centre of the proposals and hearing their voice in the form of post transition feedback will enable the specialist centres to refine the process in the future.

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Appendix

Appendix A

Data collection questionnaire

	Question
1	Age of 1st discussion of transition?
2	Age start of preparatory program?
3	What preparatory program do you use?
4	What age do you transfer to adult services?
5	Do you offer a transition clinic and with which other hospitals/departments?
6	Are patients offered the choice of where and /or when to transition?
7	Are there any exceptions to this pathway?
8	How do you manage transition across multiple providers?
9	What age do you ask homecare to transfer to adult nurse care?
10	What age are children no longer allowed to be admitted to paediatric wards?
11	What age do you start writing to the child not the parent?
12	What special considerations do you have for patients with learning difficulty?
13	What special considerations do you have for palliative care?
14	Any special considerations for mental health?
15	Do you have a named transition worker?
16	How do you involve young people in transitions planning?
17	Do you ensure that young people have met a representative from the adult service before they transfer?
18	Does the young person see the same healthcare practitioner for the first 2 appointments after transfer?
19	Does the young person get an opportunity to view the adult facilities?
20	Does the young person receive written information about the adult centres?
21	Is there anything about your transition policy you think works really well?
22	Is there anything about your transition policy that you think doesn't work well?

Appendix B

Together for Short Lives	
Transition Standards	
Standard 1	Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and the move to adult services. Their families should be supported to prepare for their changing role.
Standard 2	Every young person is supported to plan proactively for their future. They are involved in ongoing assessments and developing a comprehensive, holistic plan that reflects their wishes for the future.
Standard 3	Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services.
Standard 4	Children's and adult services are actively working together to ensure a smooth transition
Standard 5	Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family are equipped with realistic expectations and knowledge to ensure confidence in their care and support needs are being met in the future.

<https://www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/transition/>

Appendix C

You're Welcome standards	
	You're welcome standard
1	Involving young people in their care and in the design, delivery and review of services
2	Explaining confidentiality and consent
3	Making young people welcome
4	Providing high-quality health, wellbeing and care services (additional section for Specialist Young People's Services)
5	Developing digital approaches
6	Staff skills and training
7	Linking with other services
8	Supporting young people's changing needs

Instructions

Each standard includes 8 specific essential and additional criteria

To be compliant a service must meet all essential criteria and the required number of additional criteria

<https://www.gov.uk/government/publications/establishing-youth-friendly-health-and-care-services>

27 June 2023

Appendix D

Transfer letter checklist				
1 Demographics	NHS number	<input type="text"/>	Date of birth	<input type="text"/>
	Name	<input type="text"/>	Contact details (young person)	<input type="text"/>
	Address	<input type="text"/>	Contact details (parent/carer)	<input type="text"/>
2 Diagnostic Information	Disorder	<input type="text"/>	Biochemical diagnosis	<input type="text"/>
	Co-morbidities	<input type="text"/>	Mutation analysis	<input type="text"/>
3 Medication	Disease modifying therapy	<input type="text"/>	Start criteria	<input type="text"/>
	Dose/frequency	<input type="text"/>	Start date	<input type="text"/>
	Method of administration	<input type="text"/>	Other medication	<input type="text"/>
	History of Adverse Reactions	<input type="text"/>	Involvement in clinical trials	<input type="text"/>
4 Family history	Family tree	<input type="text"/>		
5 Presentation	Age	<input type="text"/>	Clinical features	<input type="text"/>
	Biochemical findings	<input type="text"/>	Radiological findings	<input type="text"/>
6 Clinical Information	Progress	<input type="text"/>	Recent clinical findings	<input type="text"/>
	Hospital admissions	<input type="text"/>	Causes of concern	<input type="text"/>
7 General	Education	<input type="text"/>	Risk taking behaviours	<input type="text"/>
	Family support	<input type="text"/>	Weight	<input type="text"/>
	Mental health	<input type="text"/>	Advance care plan	<input type="text" value="y/N"/>
8 Transition	Understanding of condition	<input type="text"/>	Independence with therapy	<input type="text"/>
	Preferences for family/carer involvement	<input type="text"/>		
9 Plan	Transfer to adults	<input type="text"/>	Outstanding procedures	<input type="text"/>
	Other specialities involved	<input type="text"/>	Homecare	<input type="text"/>
			Provider: