GROWING TOGETHER

Patient centred strategies for the development of LTV care

Fisher & Paykel HEALTHCARE

Resmed

BREAS

East of England Paediatric Critical Care Operational Delivery Network

Collaborative working to deliver high quality care to our children and their families

South West Paediatric Critical Care Operational Delivery Network

The Yorkshire and Humber Paediatric Critical Care Operational Delivery Network

Thames Valley and Wessex Paediatric Critical Care Operational Delivery Network

Pan Thames Paediatric LTV Programme

North Thames Paediatric Network
Connecting paediatric services

South Thames Paediatric Network
Transforming Healthcare for Children and Young People

ODN NORTHWEST SiC LTV PCC

East Midlands Paediatric Critical Care ODN

West Midlands Children's Network

Healthcare Transition Pathways for Young People using LTV:

The Manchester Model

JANICE FAUSET-JONES: LEAD NURSE LTV, NORTH-WEST ODN

Transition vs Transfer

- 'Transfer' is a ***one-off event*** whereby care of a young person is passed to another professional or service without any joint working or consultation with the service user
- 'Transition' is a planned, purposeful movement from child-centred to adult-orientated health care systems, a process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with long term and complex conditions (Blum et al,1993)
- Developmentally appropriate care is the over-arching principle, within which transition sits and is an approach that recognizes the unique needs of young people, and which views the process as outcomes and skills over time rather than age dependent

What transition aspects do YP worry about most?

- Moving to a different hospital & leaving familiar teams
- Changes to quality of care
- They feel more cared for as a child
- Parents not being able to stay
- Not being accepted
- People not listening
- Coping with self care in daily life
- Coping with grief
- The future

Challenges with transition / transfer: what have we learnt from feedback, incidents & complaints?

Parents / Carers

Allowing YP to self-advocate

Poor planning

Leaving familiar teams

Trusting in new teams / GP

Navigating services

Equipment provision

Lack of facilities for parents / carers if required

Parents thinking 'adult child' can remain in paediatrics

Understanding MCA

Funding for Continuing Healthcare

Health Care Professionals

Identifying key workers – whose job is it?

Poor communication - silo working

No transition pathways

Lack of reciprocal adult service

Lack of experience / skills in adult services

Disempowerment of GP

Understanding the law

Expensive complicated models

Transition takes time and effort

Staff feeling unclear about processes and roles

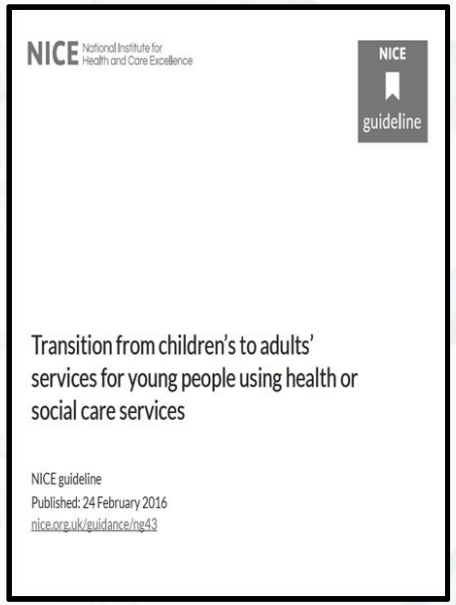
Poor engagement from YP & families

Discontinuity of care

Increase in morbidity & mortality

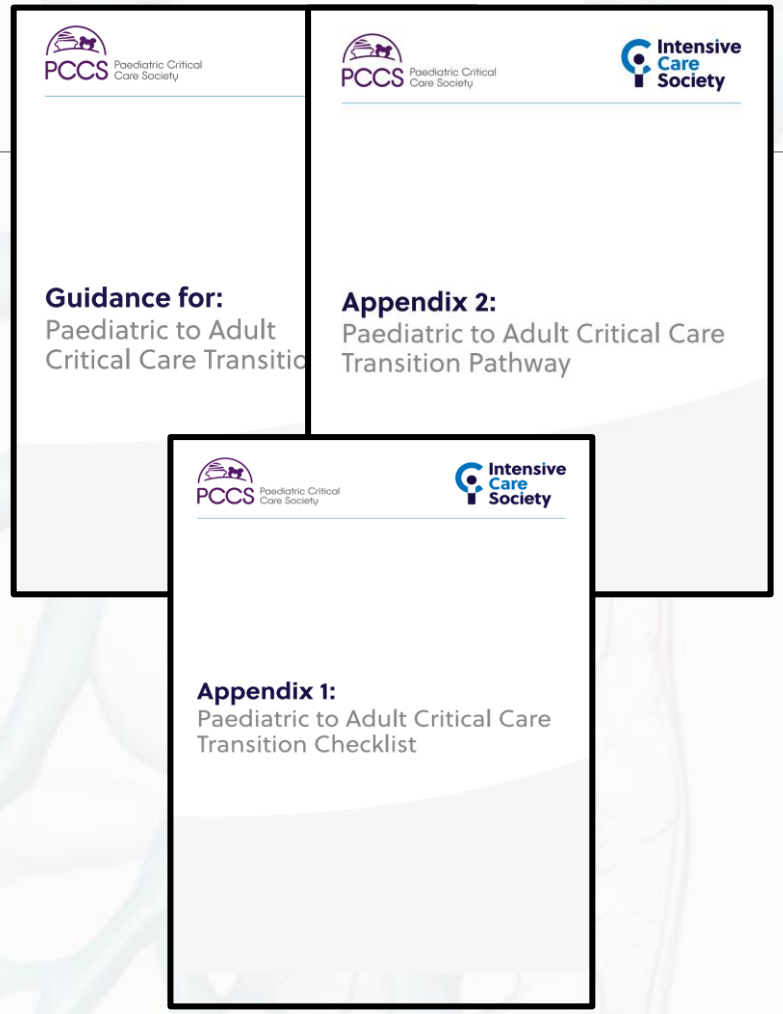
Key Documents about Adolescent Healthcare & Transition

Transition Guidance LTV



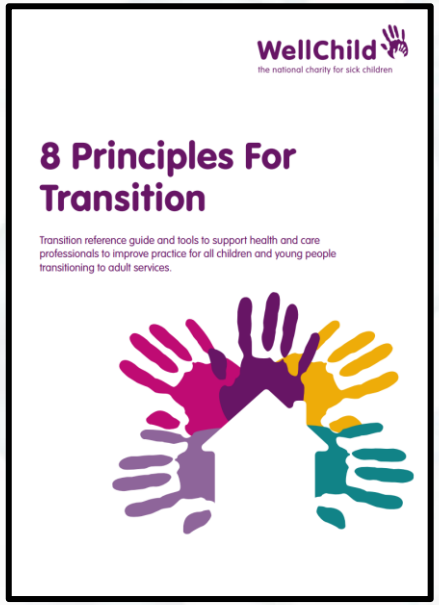
Over-arching principles Transition planning 2016

(NG43 self-assessment tool for clinical specialities)



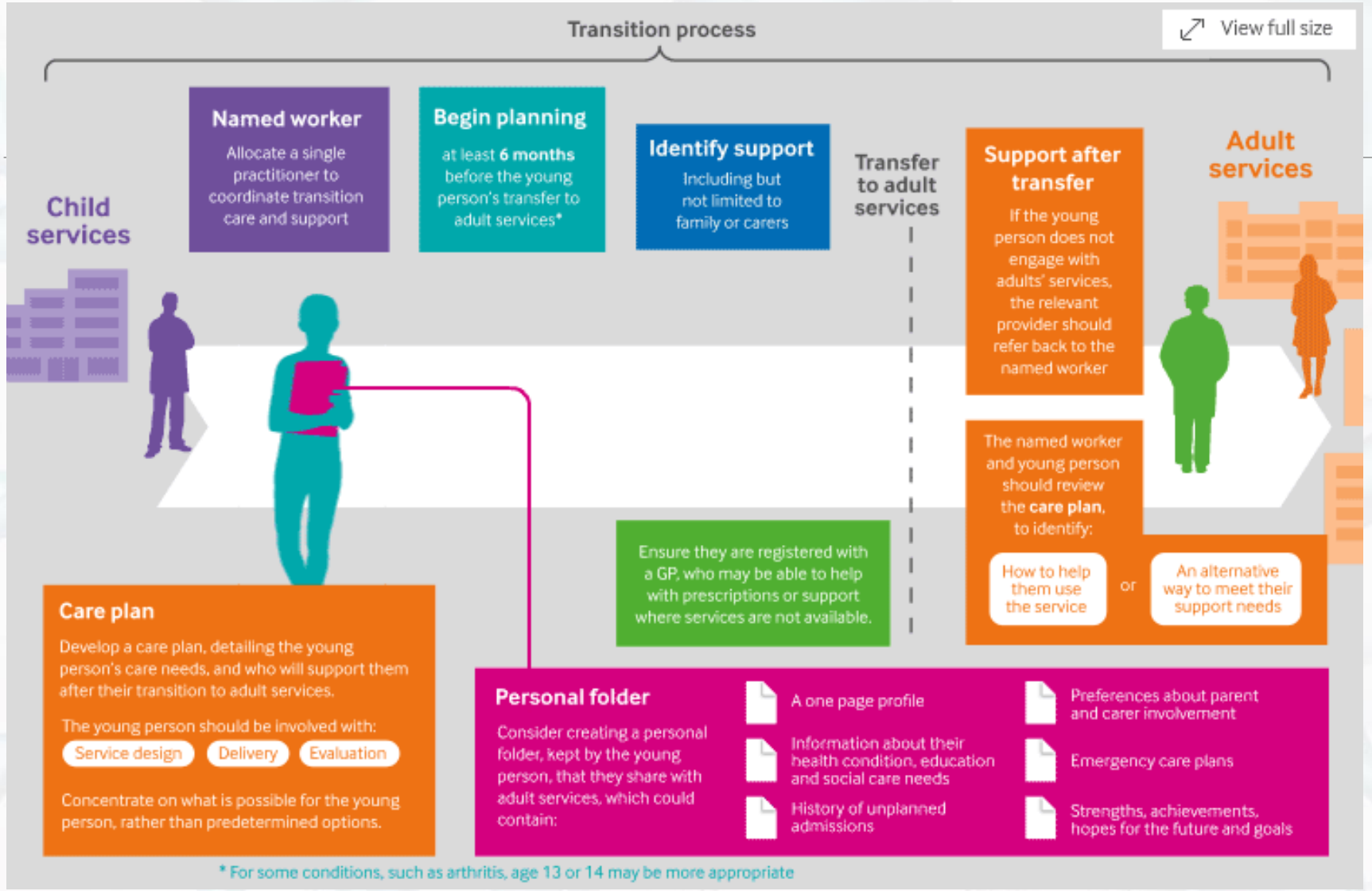
PCC Guidance 2022

NCEPOD Transition recommendations for YP with Complex Health Needs 2023 & LTV 2020



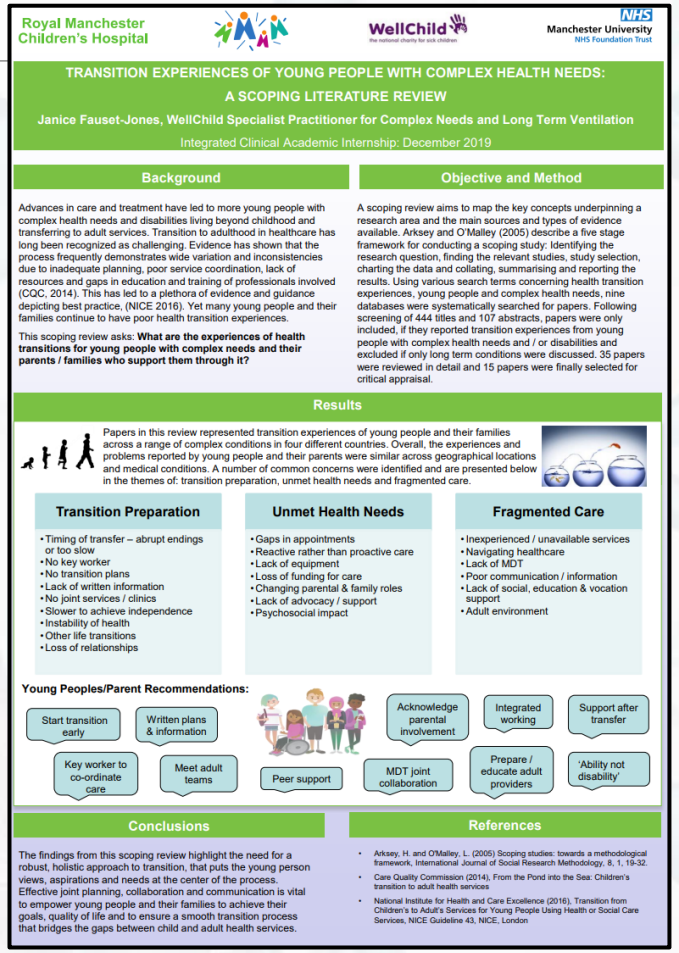
WellChild Principles for Transition 2023

NICE Guidance Summary



WellChild Transition Nurse for Complex Needs / LTV Role

- Feedback from Parents / Carers / YP post transfer re experience
- Scoping Review of Specialist Teams
- LTV – poor attendance at transition clinic, no preparation, silo working
- Research Internship – Scoping Literature Review
- Developing pathway, policy and resources
- YP support & preparation
- Engaging and responsive children's and adult LTV Teams



Royal Manchester Children's Hospital

WellChild

Manchester University NHS Foundation Trust

TRANSITION EXPERIENCES OF YOUNG PEOPLE WITH COMPLEX HEALTH NEEDS: A SCOPING LITERATURE REVIEW

Janice Fauset-Jones, WellChild Specialist Practitioner for Complex Needs and Long Term Ventilation

Integrated Clinical Academic Internship: December 2019

Background

Advances in care and treatment have led to more young people with complex health needs and disabilities living beyond childhood and transferring to adult services. Transition to adulthood in healthcare has long been recognized as challenging. Evidence has shown that the process frequently demonstrates wide variation and inconsistencies due to inadequate planning, poor service coordination, lack of resources and gaps in education and training of professionals involved (CQC, 2014). This has led to a plethora of evidence and guidance depicting best practice, (NICE 2016). Yet many young people and their families continue to have poor health transition experiences.

This scoping review asks: **What are the experiences of health transitions for young people with complex needs and their parents / families who support them through it?**

Objective and Method

A scoping review aims to map the key concepts underpinning a research area and the main sources and types of evidence available. Arksey and O'Malley (2005) describe a five stage framework for conducting a scoping study: Identifying the research question, finding the relevant studies, study selection, charting the data and collating, summarising and reporting the results. Using various search terms concerning health transition experiences, young people and complex health needs, nine databases were systematically searched for papers. Following screening of 444 titles and 107 abstracts, papers were only included, if they reported transition experiences from young people with complex health needs and / or disabilities and excluded if only long term conditions were discussed. 35 papers were reviewed in detail and 15 papers were finally selected for critical appraisal.

Results

Papers in this review represented transition experiences of young people and their families across a range of complex conditions in four different countries. Overall, the experiences and problems reported by young people and their parents were similar across geographical locations and medical conditions. A number of common concerns were identified and are presented below in the themes of: transition preparation, unmet health needs and fragmented care.

Transition Preparation

- Timing of transfer – abrupt endings or too slow
- No key worker
- No transition plans
- Lack of written information
- No joint services / clinics
- Slower to achieve independence
- Instability of health
- Other life transitions
- Loss of relationships

Unmet Health Needs

- Gaps in appointments
- Reactive rather than proactive care
- Lack of equipment
- Loss of funding for care
- Changing parental & family roles
- Lack of advocacy / support
- Psychosocial impact

Fragmented Care

- Inexperienced / unavailable services
- Navigating healthcare
- Lack of MDT
- Poor communication / information
- Lack of social, education & vocation support
- Adult environment

Young Peoples/Parent Recommendations:

Start transition early; Written plans & information; Key worker to co-ordinate care; Meet adult teams; Peer support; MDT joint collaboration; Prepare / educate adult providers; Acknowledge parental involvement; Integrated working; Support after transfer; 'Ability not disability'

Conclusions

The findings from this scoping review highlight the need for a robust, holistic approach to transition, that puts the young person views, aspirations and needs at the center of the process. Effective joint planning, collaboration and communication is vital to empower young people and their families to achieve their goals, quality of life and to ensure a smooth transition process that bridges the gaps between child and adult health services.

References

- Arksey, H. and O'Malley, L. (2005) Scoping studies: towards a methodological framework, International Journal of Social Research Methodology, 8, 1, 19-32.
- Care Quality Commission (2014), From the Pond into the Sea: Children's transition to adult health services
- National Institute for Health and Care Excellence (2016), Transition from Children's to Adult's Services for Young People Using Health or Social Care Services, NICE Guideline 43, NICE, London

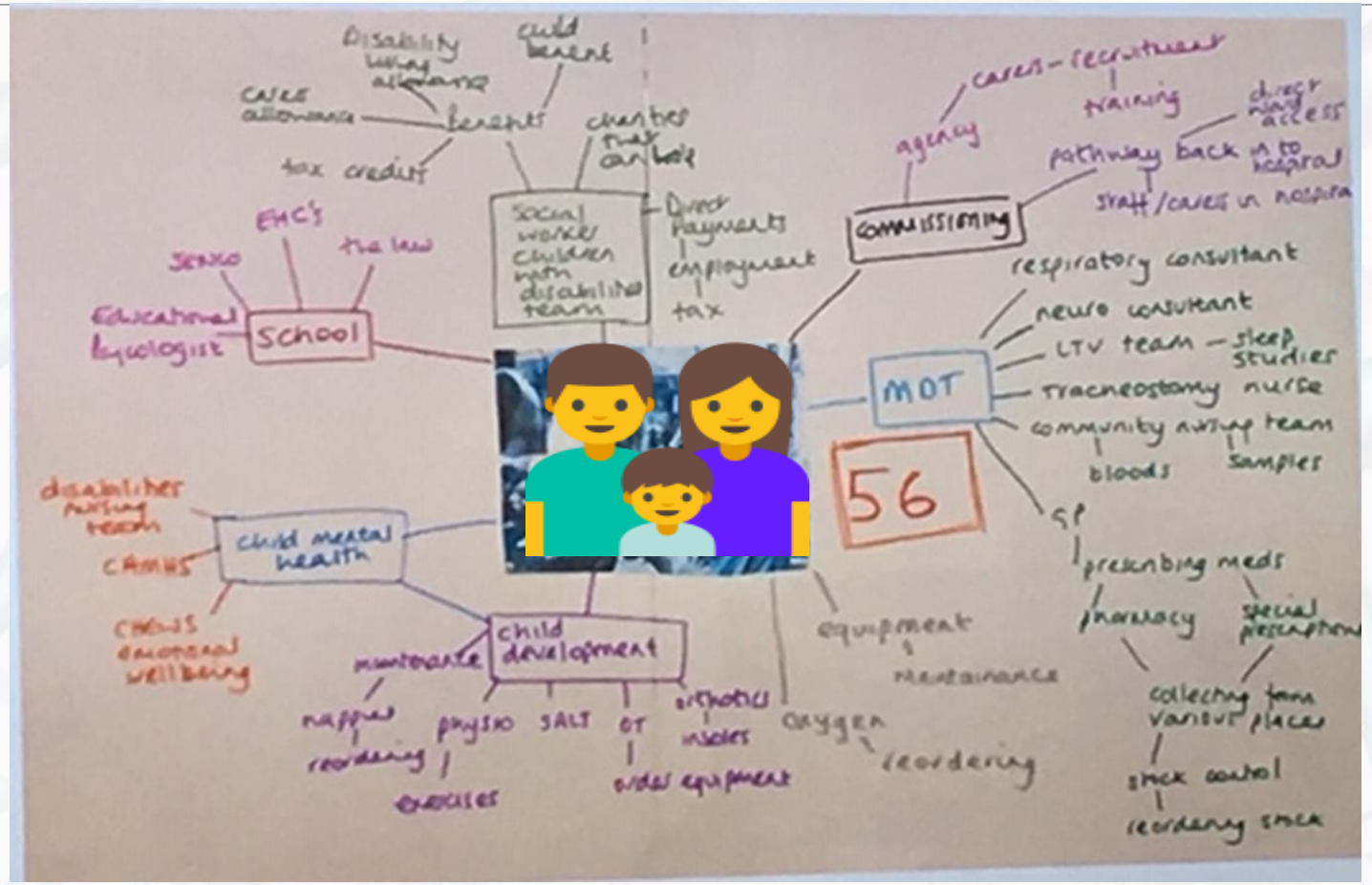
Why can transition planning and transfer be so difficult?

Royal Manchester Childrens Hospital
Tertiary paediatric specialist care all under one roof

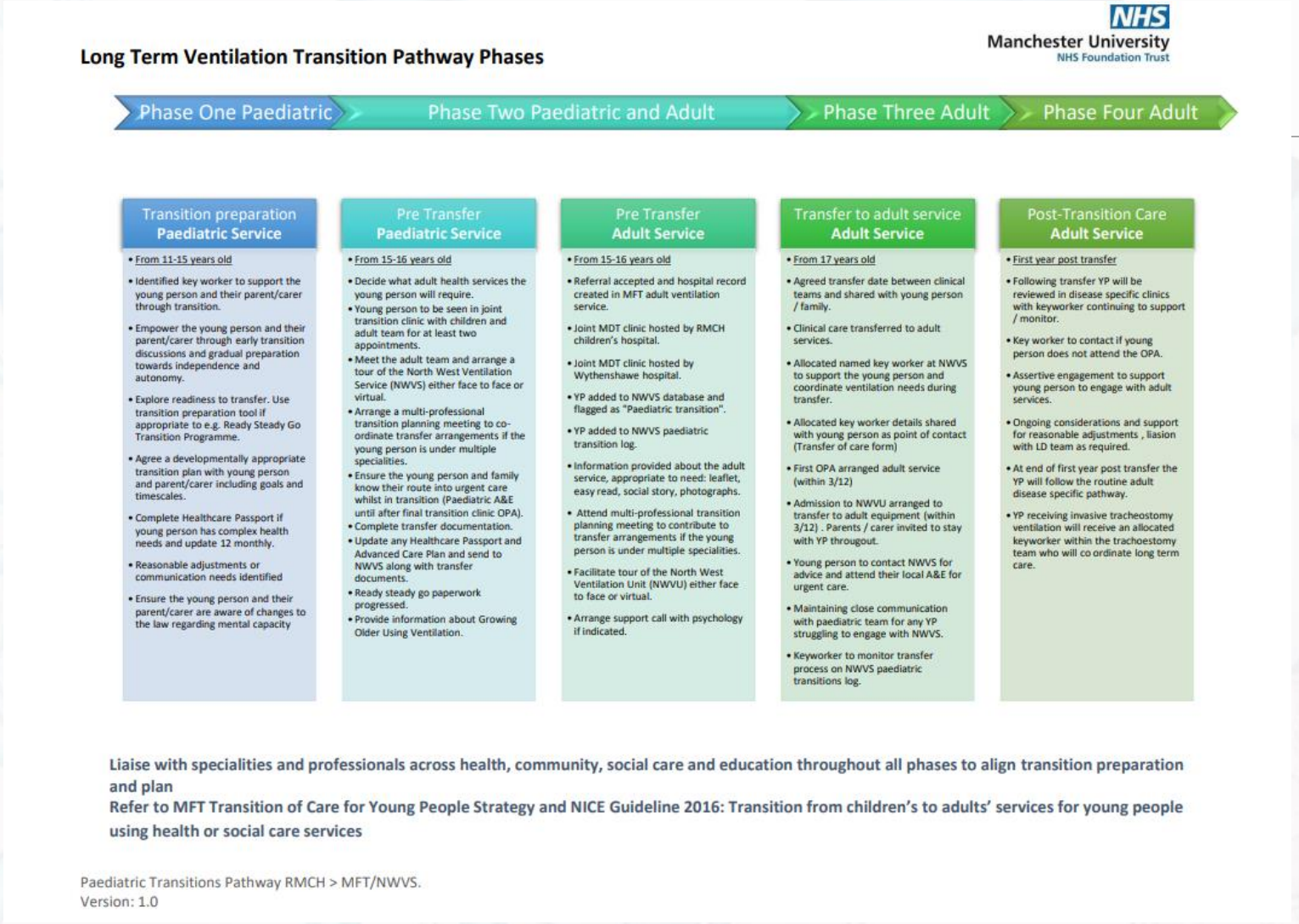
Adult care
specialist services in many hospitals across the city / GM / wider UK

Regional adult LTV service
>1500 patients on ventilation

How many professionals does it take to support some CYP with LTV?



MFT Model: LTV Pathway & Policy



NHS Manchester University NHS Foundation Trust

Long Term Ventilation Transition Pathway Phases

Phase One Paediatric → Phase Two Paediatric and Adult → Phase Three Adult → Phase Four Adult

Transition preparation Paediatric Service

- From 11-15 years old
- Identified key worker to support the young person and their parent/carer through transition.
- Empower the young person and their parent/carer through early transition discussions and gradual preparation towards independence and autonomy.
- Explore readiness to transfer. Use transition preparation tool if appropriate to e.g. Ready Steady Go Transition Programme.
- Agree a developmentally appropriate transition plan with young person and parent/carer including goals and timescales.
- Complete Healthcare Passport if young person has complex health needs and update 12 monthly.
- Reasonable adjustments or communication needs identified
- Ensure the young person and their parent/carer are aware of changes to the law regarding mental capacity

Pre Transfer Paediatric Service

- From 15-16 years old
- Decide what adult health services the young person will require.
- Young person to be seen in joint transition clinic with children and adult team for at least two appointments.
- Meet the adult team and arrange a tour of the North West Ventilation Service (NWVS) either face to face or virtual.
- Arrange a multi-professional transition planning meeting to co-ordinate transfer arrangements if the young person is under multiple specialities.
- Ensure the young person and family know their route into urgent care whilst in transition (Paediatric A&E until after final transition clinic OPA).
- Complete transfer documentation.
- Update any Healthcare Passport and Advanced Care Plan and send to NWVS along with transfer documents.
- Ready steady go paperwork progressed.
- Provide information about Growing Older Using Ventilation.

Pre Transfer Adult Service

- From 15-16 years old
- Referral accepted and hospital record created in MFT adult ventilation service.
- Joint MDT clinic hosted by RMCH children's hospital.
- Joint MDT clinic hosted by Wythenshawe hospital.
- YP added to NWVS database and flagged as "Paediatric transition".
- YP added to NWVS paediatric transition log.
- Information provided about the adult service, appropriate to need: leaflet, easy read, social story, photographs.
- Attend multi-professional transition planning meeting to contribute to transfer arrangements if the young person is under multiple specialities.
- Facilitate tour of the North West Ventilation Unit (NWVU) either face to face or virtual.
- Arrange support call with psychology if indicated.

Transfer to adult service Adult Service

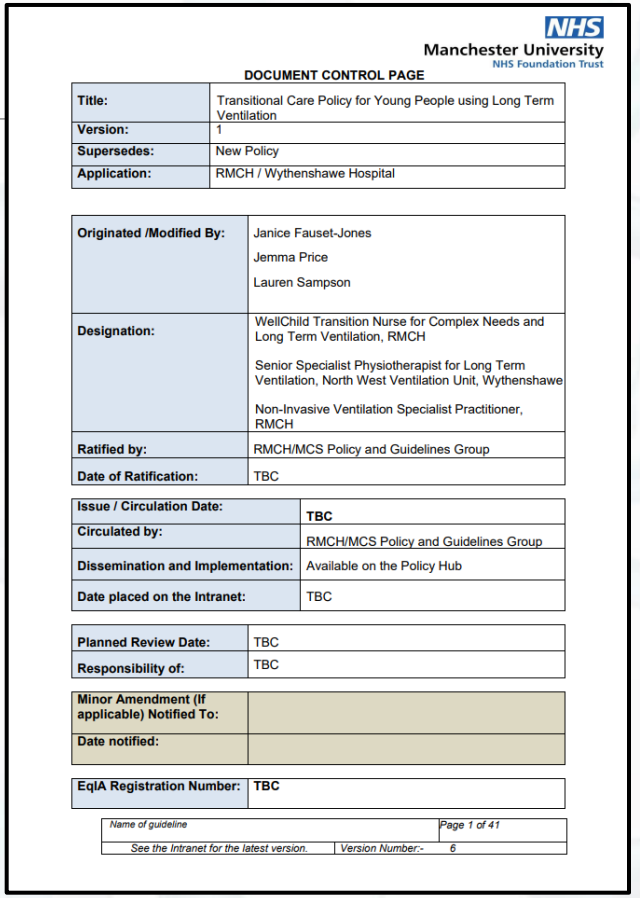
- From 17 years old
- Agreed transfer date between clinical teams and shared with young person / family.
- Clinical care transferred to adult services.
- Allocated named key worker at NWVS to support the young person and coordinate ventilation needs during transfer.
- Allocated key worker details shared with young person as point of contact (Transfer of care form)
- First OPA arranged adult service (within 3/12)
- Admission to NWVU arranged to transfer to adult equipment (within 3/12) . Parents / carer invited to stay with YP througout.
- Young person to contact NWVS for advice and attend their local A&E for urgent care.
- Maintaining close communication with paediatric team for any YP struggling to engage with NWVS.
- Keyworker to monitor transfer process on NWVS paediatric transitions log.

Post-Transition Care Adult Service

- First year post transfer
- Following transfer YP will be reviewed in disease specific clinics with keyworker continuing to support / monitor.
- Key worker to contact if young person does not attend the OPA.
- Assertive engagement to support young person to engage with adult services.
- Ongoing considerations and support for reasonable adjustments , liasion with LD team as required.
- At end of first year post transfer the YP will follow the routine adult disease specific pathway.
- YP receiving invasive tracheostomy ventilation will receive an allocated keyworker within the trachoestomy team who will co ordinate long term care.

Liaise with specialities and professionals across health, community, social care and education throughout all phases to align transition preparation and plan
Refer to MFT Transition of Care for Young People Strategy and NICE Guideline 2016: Transition from children's to adults' services for young people using health or social care services

Paediatric Transitions Pathway RMCH > MFT/NWVS.
Version: 1.0



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DOCUMENT CONTROL PAGE

Title:	Transitional Care Policy for Young People using Long Term Ventilation
Version:	1
Supersedes:	New Policy
Application:	RMCH / Wythenshawe Hospital

Originated /Modified By:	Janice Fauset-Jones Jemma Price Lauren Sampson
Designation:	WellChild Transition Nurse for Complex Needs and Long Term Ventilation, RMCH Senior Specialist Physiotherapist for Long Term Ventilation, North West Ventilation Unit, Wythenshawe Non-Invasive Ventilation Specialist Practitioner, RMCH
Ratified by:	RMCH/MCS Policy and Guidelines Group
Date of Ratification:	TBC

Issue / Circulation Date:	**TBC**
Circulated by:	RMCH/MCS Policy and Guidelines Group
Dissemination and Implementation:	Available on the Policy Hub
Date placed on the Intranet:	TBC

Planned Review Date:	TBC
Responsibility of:	TBC

Minor Amendment (If applicable) Notified To:	
Date notified:	

EqIA Registration Number:	**TBC**

Supporting Transition Pre Transfer

Communicate with the team around the YP & family – health, social care & education (EHCP meetings)

GP – Annual Health Check

Explain changes about the law / MCA

Identify & meet adult teams and know what their offer is:

joint clinics / MDT meetings / attend first adult appts

Identify Lead Consultant to co-ordinate & support transition & transfer

Use tools to support – eg transition prep tools (HIVE- EPR), healthcare passports & advanced care plans

Key worker to support YP & family before and after transfer

Ensure family know their route into urgent care –

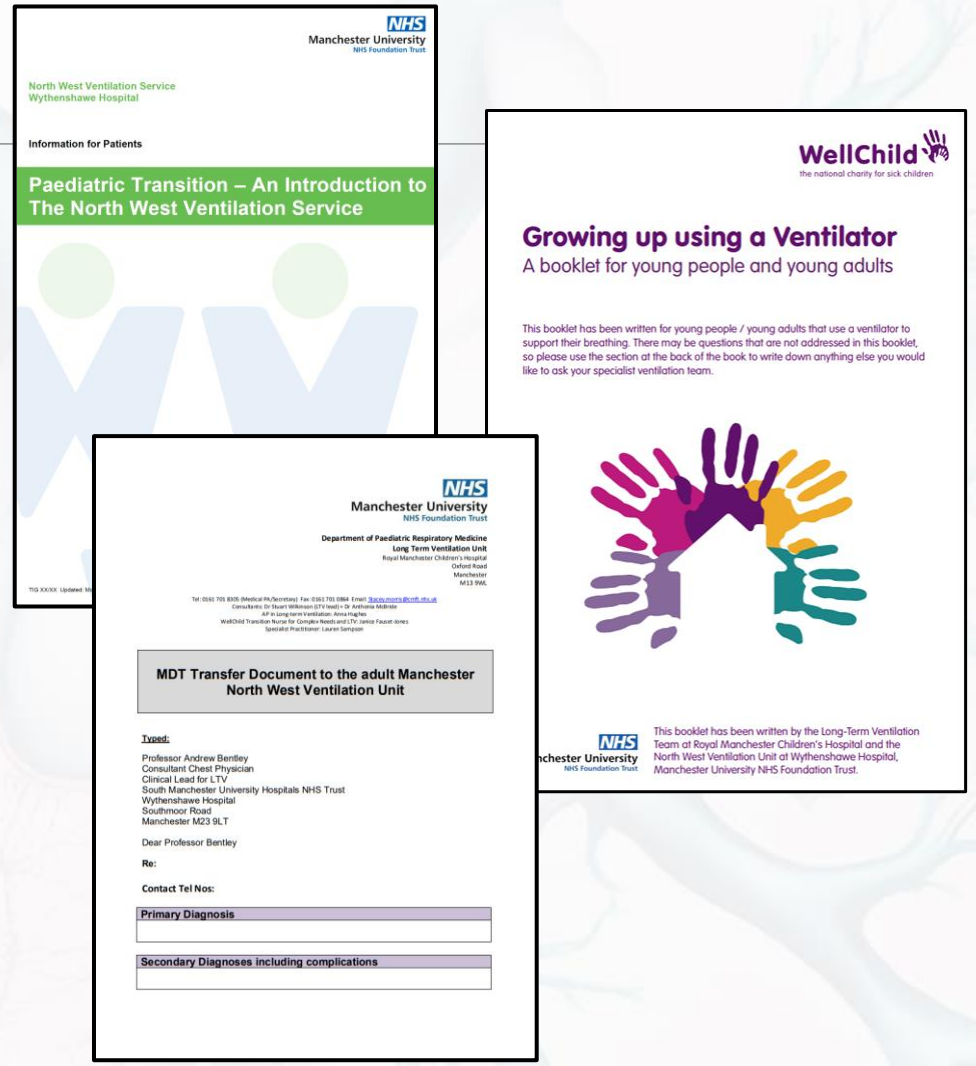
flags on A&E / NWAS

Early young person centred discussions & holistic planning – empower YP & family

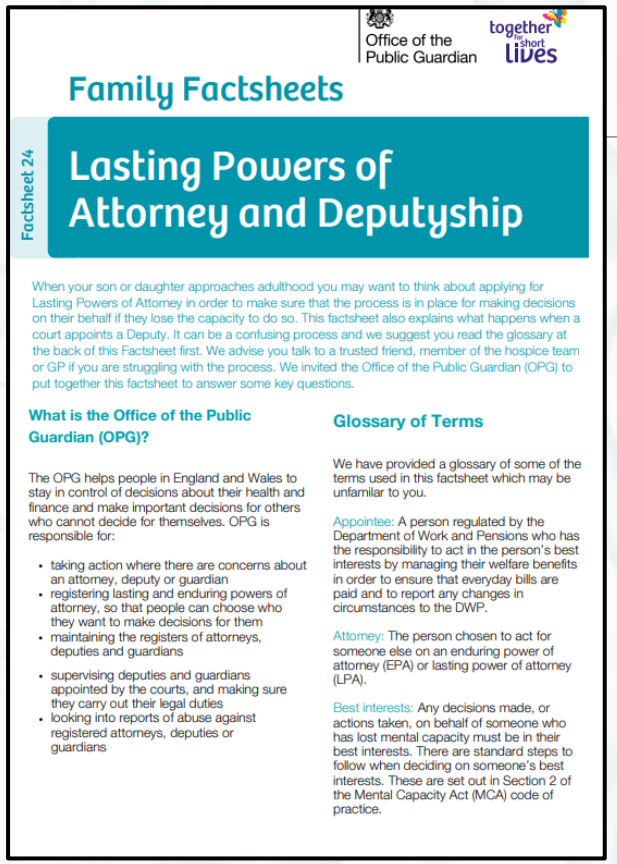
Safety net

Joint LTV Transition Clinic / MDT Meetings

- Early preparation and empowerment
- Use of Ready Steady Go transition preparation tool; built into EPR
- Referral sent prior first transition clinic appt via EPR and MDT Transfer document completed
- 8 weekly joint Paediatric and Adult clinic
  - Virtual during Covid, then a mixture of virtual and face to face in alternate children's and adult unit
  - Introduction to diverse MDT and friendly chat!
- 7 patients per clinic, age 15/16 years onwards
- Growing up Using a Ventilator & NWVU Transition Booklet provided pre clinic
- 2-3 joint clinics prior transfer of care
- Remain under care of children's hospital until last OPA
- If YP has complex health needs: MDT Transition meetings with other specialties, community, social care & education, YP & parents involved
- Each specialty to complete transition process – YP may be in children's and adult's services for different specialties at same time



Resources for YP with Complex Health Needs / LD



Office of the Public Guardian

together for short lives

Family Factsheets

Factsheet 24

Lasting Powers of Attorney and Deputyship

When your son or daughter approaches adulthood you may want to think about applying for Lasting Powers of Attorney in order to make sure that the process is in place for making decisions on their behalf if they lose the capacity to do so. This factsheet also explains what happens when a court appoints a Deputy. It can be a confusing process and we suggest you read the glossary at the back of this Factsheet first. We advise you talk to a trusted friend, member of the hospice team or GP if you are struggling with the process. We invited the Office of the Public Guardian (OPG) to put together this factsheet to answer some key questions.

What is the Office of the Public Guardian (OPG)?

The OPG helps people in England and Wales to stay in control of decisions about their health and finance and make important decisions for others who cannot decide for themselves. OPG is responsible for:

- taking action where there are concerns about an attorney, deputy or guardian
- registering lasting and enduring powers of attorney, so that people can choose who they want to make decisions for them
- maintaining the registers of attorneys, deputies and guardians
- supervising deputies and guardians appointed by the courts, and making sure they carry out their legal duties
- looking into reports of abuse against registered attorneys, deputies or guardians

Glossary of Terms

We have provided a glossary of some of the terms used in this factsheet which may be unfamilar to you.

Appointee: A person regulated by the Department of Work and Pensions who has the responsibility to act in the person's best interests by managing their welfare benefits in order to ensure that everyday bills are paid and to report any changes in circumstances to the DWP.

Attorney: The person chosen to act for someone else on an enduring power of attorney (EPA) or lasting power of attorney (LPA).

Best interests: Any decisions made, or actions taken, on behalf of someone who has lost mental capacity must be in their best interests. There are standard steps to follow when deciding on someone's best interests. These are set out in Section 2 of the Mental Capacity Act (MCA) code of practice.

https://www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/lasting-powers-of-attorney-and-deputyship/

https://www.mencap.org.uk/get-involved/campaign-mencap/treat-me-well/hospital-care-young-people-learning-disability

WellChild

the national charity for sick children

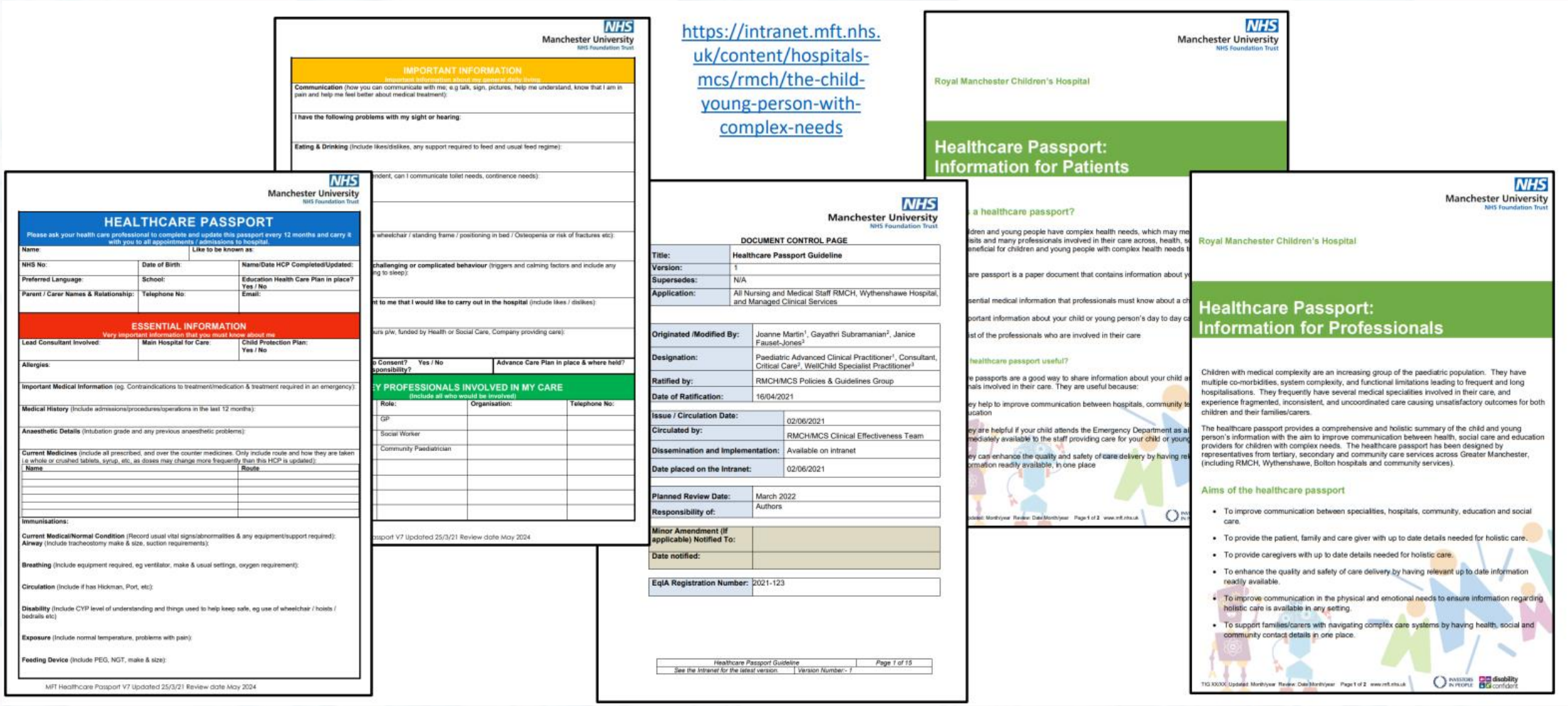
Moving from Children's Services to Adult Services

An easy read guide for young people

wellchild.org.uk

https://www.wellchild.org.uk/get-support/information-hub/easyreadtransition/

Healthcare Passport



Supporting Transition after Transfer

- Named person in adult services
- Resources: Transition booklet, Post transition information sheet & opportunity to visit adult unit
- Pathway dependent on ventilatory needs; disease specific clinics
- Elective admission within 3-4 months
- Home visits
- No discharge for first 12 months after transfer
- Psychology support prior & post transfer
- Patient Databases

Key Challenges

- Fears / Expectations
  - Childrens teams setting expectations
  - Parental / carer support in adult hospitals
- Deterioration
  - Advanced care planning / EOL (discussions may not be initiated in childrens services)
- Emergencies
  - Care fragmentation – different Trusts and IT systems
  - Escalation – disjointed care
- Complex neurodisability
  - Identifying Lead Consultant once discharged from community paediatrics ? GP
- Workforce structure
  - Identifying key worker role
  - Small part of job role – no specific person (job plans / job descriptions)
  - Limited time for service development

Long Term Plans / Aspirations

- Redo NG43 Gap Analysis since pathway in place
  - 98% of recommendations met in April 2023 compared with 30% in 2017
- Additional resources; video tours
- Start transition clinic sooner
- Young adult clinic in adult unit
- Tracheostomy pathway
- Advanced care planning
- Patient feedback on transition process since LTV pathway introduced

Thank you