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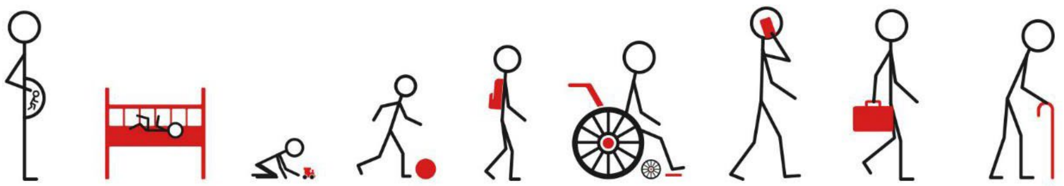
# Young People with or at risk of Inherited Cardiac Conditions (ICC)

## Protocol for transition and transfer of care between paediatric and adult ICC services in the North West of England, North Wales and The Isle of Man

**Date: February 2026**



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**APPENDICES**

# Executive Summary

This protocol has been developed to promote the planning and management of the care of young people with inherited cardiac conditions during transition and transfer of care between paediatric and adult cardiology services. This protocol has been written under the auspices of the North West of England, North Wales and the Isle of Man CHD Network and meets the current NHS England standards

# 1. Introduction

## 1.1 Purpose

1.1.1 Transition is defined in the Department of Health's 2006 publication *Transition: getting it right for young people* 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 systems."*

1.1.2 Inherited cardiac conditions describes a range of inherited heart conditions that affect the heart muscle and or the heart rhythm. This includes cardiomyopathies, arrhythmia syndromes and inherited aortopathies.

1.1.3 The aims of transition services are to ensure uninterrupted and coordinated care. To promote understanding of the patient's heart condition and its impact on adult life (higher education, employment, relationships, mental health and psychological wellbeing). To develop skills in self-care and promote independence and to support parents (DH, 2006).

1.1.4 This protocol has been developed to promote seamless transition services for young people with ICC who live in the North West of England, North Wales and the Isle of Man. This protocol is intended to:

- Promote key standards and clear pathways of care from paediatric to adult ICC heart disease services.
- Provide advice, guidance and support for the management of care during transition
- Promote the appropriate transfer of care of young people to adult services
- Build on existing relevant guidelines for routine care of young people focusing on areas where additional or different care should be offered for young people living with ICC.

1.1.5 This protocol will help practitioners achieve a seamless transfer of care by providing a framework for working with young people at each of the major phases of adolescence. It is divided into four parts and provides:

- An overview of the service provision arrangements in the region, general principles and best practice
- A description of the key standards to consider when planning and delivering transition services
- The age and timings criteria for transition and transfer of care
- A practical framework to support the delivery of transitional care
- Patient questionnaires to support discussions with young people
- Patient Information Leaflet

## 1.2 Scope

1.2.1 This protocol applies both to paediatric and Adult ICC services.

1.2.2 This protocol applies to ICC services for young people regardless of the complexity of their heart condition or where they live in the North West of England, North Wales or the Isle of Man.

1.2.3 This protocol is intended for healthcare staff involved in transition planning and delivery as well as the transfer of health care of young people with ICC.

## 1.3 Terminology

1.3.1 The term **'transition"** is used in this protocol to refer to the process of enabling a young person to become independent with their heart condition and to support their successful transfer of care to adult services. Transition has been divided into early, mid and late stages and should begin by the age of thirteen years. The term **"transition"** is not to be used in any patient facing publications following consultation with young people.

1.3.2 The term **'transfer'** or **'handover'** is used in this protocol to refer to an event within the process of transition when the care of the young person transfers from paediatric to adult health services.

1.3.3 The term "**Young Person's Specialist Nurse**" used in this protocol refers to a Specialist ICC Nurse who has the specific role of co-ordinating, managing and supporting young people through the transition process, transfer of care and until they have successfully been integrated into adult services. This service is nurse led and supports the young person throughout. They are referred to as YP Specialist Nurses to avoid using the term 'transition'.

1.3.4 The term **'young person/people'** is used in this protocol to refer to those between 13 years and 18+ years of age. It is widely recognised that it is good clinical practice to begin to discuss the need for transition early and that many young people will require support until the age of 25yrs.

1.3.5 The term "**Handover Clinic**" is used in this protocol to refer to the formal handover clinic run jointly with the paediatric and adult ICC service. This facilitates formal hand over of care to adult services for exceptional cases, those who are very complex or high risk and would be decided on a case-by-case basis by the ICC consultant

1.3.6 The term "**Young Person's Clinic**" or **"YP Clinic"** is used in this protocol to refer to the clinics run by the YP Specialist Nurses to support the young person throughout the transition process from age 13yrs to 18yrs+ regardless of how their care is transferred. This may be in the form of one-to-one clinic sessions, or they may be held as group sessions held either in the specialist centres or locally throughout the region. Every young person should be offered at least one appointment in the Young Person's clinic recognising that some patients will require several appointments during their transition journey.

1.3.7 The term **"ICC"** is used to refer to Inherited Cardiac Conditions.

1.3.8 The term "**learning disability"** is used throughout this document and in line with national policy is a formal diagnostic term for a person who has global and pervasive difficulties with social and adaptive functioning, present before the age of 18. A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty understanding new or complex information, learning new skills and coping independently. A learning difficulty, which is different to a learning disability, would encapsulate a specific difficulty in one domain, e.g. dyslexia.

1.3.9 The term "**Neurodiversity"** will be used to describe neurodivergent conditions including Autism/Autism Spectrum Condition (ASC)/autism spectrum disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

## 1.4 Current service provision arrangements

1.4.1 Young people (up to the age 18 years) growing up with ICC are cared for by the Specialist Paediatric Cardiology Teams based at Alder Hey Children's Hospital NHS Foundation Trust and Royal Manchester Children's Hospital, Manchester University NHS Foundation Trust. These two specialist centres also support 26 peripheral clinics throughout the North West of England, North Wales, and the Isle of Man.

1.4.2 Young people with ICC conditions who have required treatment by an ICC Team between the ages of 13-18yrs will be supported by a named YP Specialist Nurse throughout the process and will be invited to attend a **"Young Person's Clinic"** at either

- Alder Hey Children's NHS Foundation Trust
- Royal Manchester Children's Hospital (Manchester University NHS Foundation Trust)

1.4.3 Only young people with complex ICC phenotypes, particularly those who are very complex and high risk, will be seen in a formal handover clinic. Decisions around who needs to be seen will be made by the ICC Consultant on a case-by-case basis. These clinics will be held at either

- Alder Hey Children's NHS Foundation Trust
- Royal Manchester Children's Hospital (Manchester University NHS Foundation Trust)

1.4.4 Young people who are at risk of or affected by an ICC will have their care transferred from the paediatric ICC service to a recognised adult ICC service. Where this is located will be based on several factors including geographical location and patient preference.

## 1.5 General principles

1.5.1 Care of young people during transition and the transfer of their care between paediatric and adult ICC services should be planned and managed. Paediatric and adult ICC healthcare teams should work jointly during transfer of care.

1.5.2 Management of young people with ICC should consider their needs and preferences.

1.5.3 Communication between healthcare professionals (in paediatric and adult services) and young people and their family is essential. It should be supported by transition assessments tailored to the young person's needs.

1.5.4 General practice has a crucial role to play as this will remain consistent throughout the transition and transfer of care to adults. A new enhanced service for general practice was introduced in 2014/15 to ensure proactive care and personalised care planning for people with complex health and care needs who may be at high risk of unplanned admission to hospital. This will be under the supervision of a named, accountable GP. All documentation related to transition should be copied to the patients GP.

1.5.5 Where patients have complex needs involving several specialist teams and professionals involved. The YP Specialist Nurse will help co-ordinate be-spoke MDT meetings as appropriate to ensure good communication amongst the teams involved. This is to ensure that transitional care is coordinated and planned.

1.5.6 If emergency care is required for their heart condition during the transfer stage the paediatric ICC team would still be responsible for providing care up until the time the patient has been seen in adult services for the first time. This needs to be effectively communicated with the patient and family and documented on the patient's medical notes and transition plan. There may be individual circumstances that require emergency care to be provided by the adult service. Where this decision has been made it is imperative that this is clearly documented and shared. Once the patient has been seen in adult services all future emergency admissions would be managed within adult services. It is important that the patient and family understand how to manage urgent care during this transfer stage and beyond.

1.5.7. NICE Guidance (2016 and updated in 2023) suggests that referral to transitional services should occur in year 9 at school (between the age of 13-14yrs). The NW CHD Network has therefore adopted the NICE Guidance in writing this protocol.

1.5.8 Referrals to Transitional services at Alder Hey NHS Foundation Trust and Royal Manchester Children's Hospital, Manchester NHS Foundation Trust should be made by copying in the Specialist Nurses into relevant clinic letters from the age of 13 years. Patients seen in peripheral clinics should be referred to the appropriate transition service linked to either Alder Hey or Royal Manchester Children's Hospital.

**Young Person's Clinic at RMCH**
**Copy letters to**
**(internal referrals via HIVE)**
**Cardiac Specialist Nursing Team**
**Royal Manchester Children's Hospital**
**Oxford Road**
**Manchester**

**Young Person's Clinic at Alder Hey**
**Copy letter to**
**Cardiac Specialist Nursing Team**
**Alder Hey Children's Hospital**
**Eaton Road**
**Liverpool**
**L12 2AP**

## 1.6 Key standards for implementation

### National Institute for Health and Care Excellence (NICE)

*Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43 (2016)*

For many young people, transition will involve multiple services, including health, social care and education. NICE guidance on transition from children's to adults' services covers the period before, during and after a young person moves from children's to adults' health or social care services. It sets out how this transition should be managed and how services should work together to support a good transition. The Guidance includes 6 Quality Statements that were last updated in 2023 www.nice.org.uk/guidance/qs140

### Quality statements

| | |
|---|---|
| **Statement 1** | Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9. **[2016]** |
| **Statement 2** | Young people who will move from children's to adults' services have a coordinated transition plan. **[new 2023]** |
| **Statement 3** | Young people who will move from children's to adults' services have an annual meeting to review transition planning. **[2016]** |

**Statement 4** Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer. **[2016]**

**Statement 5** Young people who are moving from children's to adults' services meet a practitioner from each adult service they will move to before they transfer. **[2016, updated 2023]**

**Statement 6** Young people who have moved from children's to adults' services but do not attend their initial meetings or appointments are contacted by adults' services and given further opportunities to engage. **[2016, updated 2023]**

**NW CHD Network Standards (adapted from NHSE CHD Standards)**

1. The CHD Network must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. ‘Lost to follow-up’ rates must be recorded and discussed at the network multidisciplinary team meeting.

2. All services must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult ICC cardiologists. There must be access to beds and other facilities for adolescents.

3. There will not be a fixed age of transition from children’s to adult services but the process of transfer must be initiated no later than 18 years of age, taking into account individual circumstances and special needs.

4. All complex patients requiring long-term care must be seen at least once for consultation in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans must be agreed for future management in a clearly specified setting, unless the patient’s care plan indicates that they do not require long-term follow-up.

5. Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient’s wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.

6. All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.

7. Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care.

8. The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plans

9. Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.

## 2. Overview of the protocol

Wherever possible the protocol is in the format of algorithms and frameworks, supported by minimum text. The component parts of the transition and transfer of care pathway are discussed in three management stages as follows and the overall pathway is outlined in **Algorithm 1**:

## 3. Early, mid, and late-stage transition

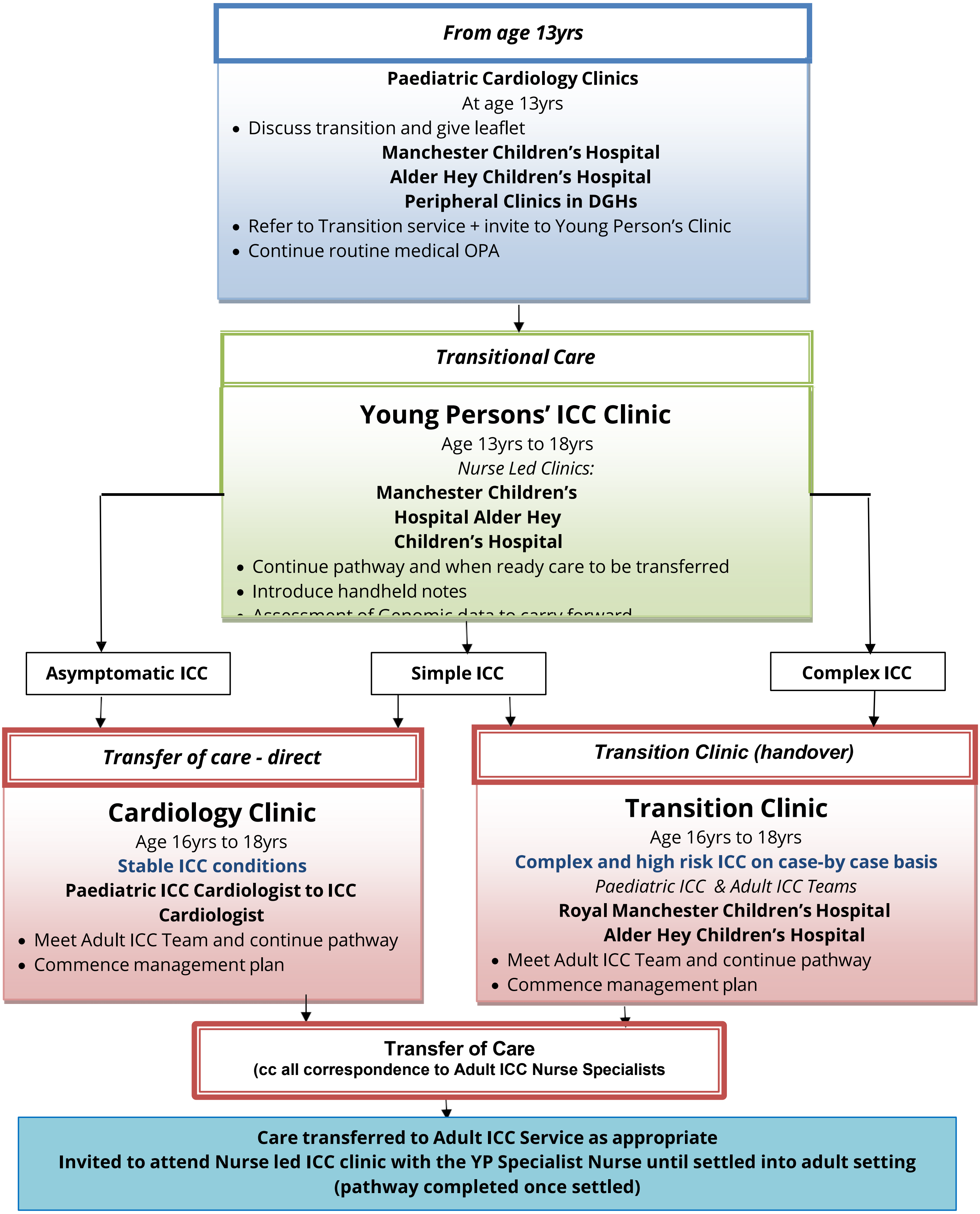
The early stage describes the period from when the decision to prepare for transition is made, usually within paediatric care. The mid phase is that of transition readiness when the young person and their parents/carers are supported to become more independent and knowledgeable. The late stage occurs when the young person not only transfers their care to adult services but is actively participating in adult care activities e.g. self-management and decision making. (Telfair etc 1l, 2004).

***Table 1***

| OVERVIEW OF THE PROTOCOL |
|---|
| **Early-Stage Transition** |
| This transition pathway identifies young people with ICC from 13 years to up to 14 years. |
| **Mid-Stage Transition** |
| This transition pathway identifies young people with ICC from 15 years to up to 16 years. |
| **Late-Stage Transition** |
| This transition pathway identifies young people with ICC from 16 years to 18 years + who will require transfer from paediatric to adult cardiology services |

## DIAGRAM 1 (OVERVIEW)

### TRANSITION AND TRANSFER OF CARE PATHWAY (AGE 13 TO 18 YEARS)



***From age 13yrs***

**Paediatric Cardiology Clinics**

At age 13yrs

- Discuss transition and give leaflet

**Manchester Children's Hospital**
**Alder Hey Children's Hospital**
**Peripheral Clinics in DGHs**

- Refer to Transition service + invite to Young Person's Clinic
- Continue routine medical OPA

***Transitional Care***

**Young Persons' ICC Clinic**

Age 13yrs to 18yrs

*Nurse Led Clinics:*

**Manchester Children's**
**Hospital Alder Hey**
**Children's Hospital**

- Continue pathway and when ready care to be transferred
- Introduce handheld notes
- Assessment of Genomic data to carry forward

**Asymptomatic ICC**

**Simple ICC**

**Complex ICC**

***Transfer of care - direct***

**Cardiology Clinic**

Age 16yrs to 18yrs

**Stable ICC conditions**

**Paediatric ICC Cardiologist to ICC Cardiologist**

- Meet Adult ICC Team and continue pathway
- Commence management plan

***Transition Clinic (handover)***

**Transition Clinic**

Age 16yrs to 18yrs

**Complex and high risk ICC on case-by case basis**

*Paediatric ICC & Adult ICC Teams*

**Royal Manchester Children's Hospital**
**Alder Hey Children's Hospital**

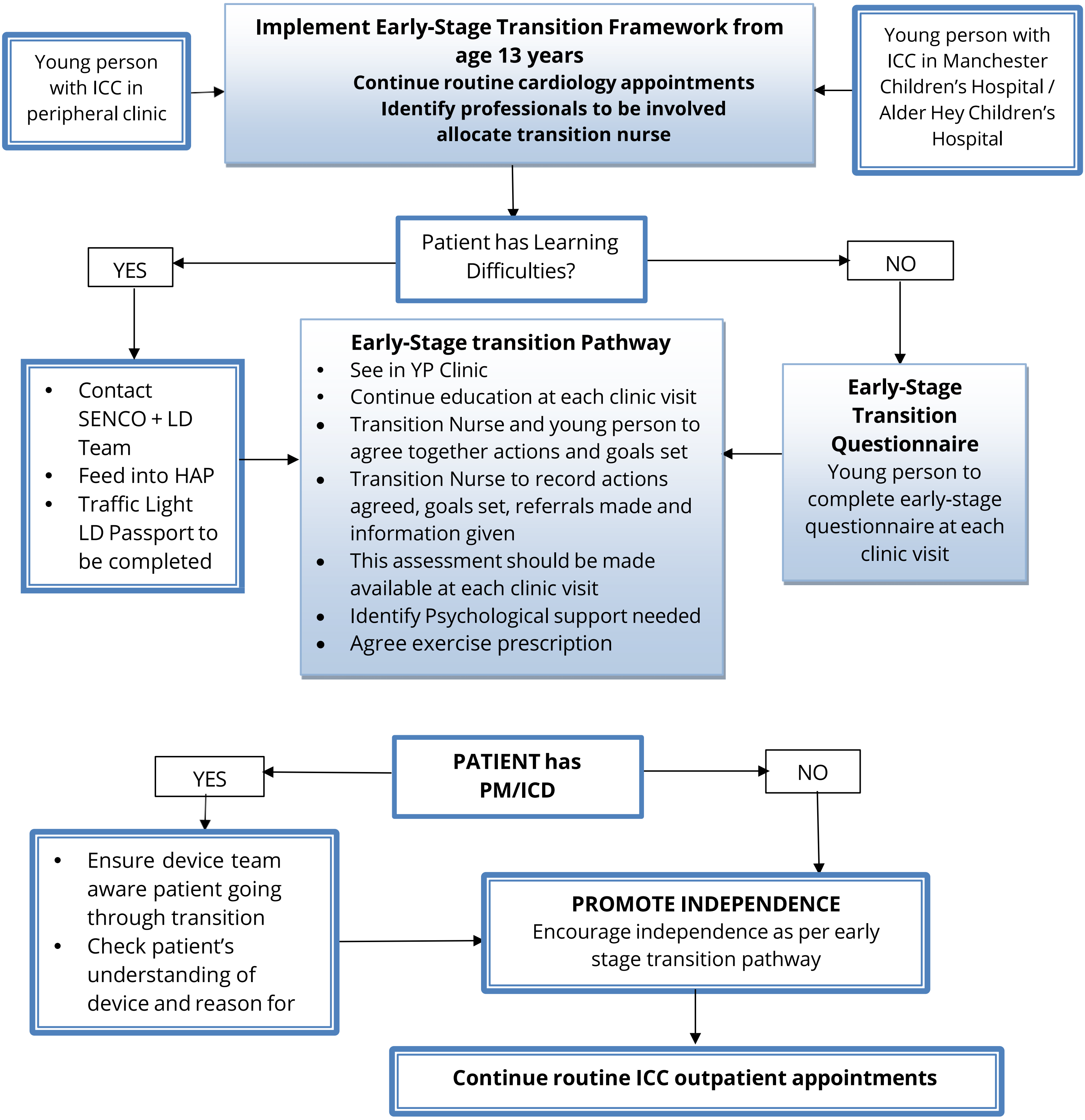
- Meet Adult ICC Team and continue pathway
- Commence management plan

**Transfer of Care**
**(cc all correspondence to Adult ICC Nurse Specialists**

**Care transferred to Adult ICC Service as appropriate**
**Invited to attend Nurse led ICC clinic with the YP Specialist Nurse until settled into adult setting**
**(pathway completed once settled)**

# EARLY-STAGE TRANSITION: 13 YEARS UP TO 14 YEARS

**Diagram 2**



Young person with ICC in peripheral clinic

**Implement Early-Stage Transition Framework from age 13 years**
**Continue routine cardiology appointments**
**Identify professionals to be involved**
**allocate transition nurse**

Young person with ICC in Manchester Children's Hospital / Alder Hey Children's Hospital

Patient has Learning Difficulties?

YES

NO

- Contact SENCO + LD Team
- Feed into HAP
- Traffic Light LD Passport to be completed

**Early-Stage transition Pathway**

- See in YP Clinic
- Continue education at each clinic visit
- Transition Nurse and young person to agree together actions and goals set
- Transition Nurse to record actions agreed, goals set, referrals made and information given
- This assessment should be made available at each clinic visit
- Identify Psychological support needed
- Agree exercise prescription

**Early-Stage Transition Questionnaire**
Young person to complete early-stage questionnaire at each clinic visit

**PATIENT has PM/ICD**

YES

NO

- Ensure device team aware patient going through transition
- Check patient's understanding of device and reason for

**PROMOTE INDEPENDENCE**
Encourage independence as per early stage transition pathway

**Continue routine ICC outpatient appointments**

## EARLY-STAGE TRANSITION: 13 YEARS UP TO 14 YEARS

## Recommended management

**Diagram 2** describes the recommended pathway for young people with ICC aged 13 years up to 14 years of age.

4.1 The paediatric cardiac nurse should start to introduce the concept of preparing to transfer care to adult health care with the young person and their family by age 13 years. They should be given a copy of the patient information leaflet which briefly describes the transition process **(NWCHDN_11.1 "Moving On")**. This should be documented in the patients' notes, with a plan to formally commence the transition process at age 13 years.

Moving On to Adult Services - Northwest, North Wales, Isle of Man Congenital Heart Network (northwestchdnetwork.nhs.uk)

4.2 The early-stage transition pathway should start by the age of 13 years. The young person should be offered an appointment in the nurse led Young Persons Clinic.

4.3 The aims of early-stage transition can be facilitated by using a planning framework which identifies the roles and responsibilities of those involved in the process (see table 2). From the start of the transition process, all organisations have a responsibility to work together to ensure that information is shared to inform each other's assessments and that coherent planning is based on a real understanding of the young person's needs.

4.4 The transition pathway provides a checklist for discussion with the young person at each of the three stages of transition. The checklists for each key area suggest some general aims and subjects for discussion, although additional areas may be identified to meet individual young people's needs.

4.5 The young person's level of understanding should be assessed by using advanced communication skills and open questioning techniques.

4.6 At early-stage transition, the young person should become aware of their own heart condition and health and care needs, lifestyle issues including how they are coping at school etc. An assessment of the young persons' level of understanding is important.

4.7 The patient questionnaire for early-stage transition can be used in the Young Person's Clinic to support this process (NWCHDN_52.2.1)

4.8 Any actions agreed, goals set, referrals made, or information (such as leaflets) given to the young person during the discussion should be recorded.

4.9 This should be completed by the YP Specialist Nurse and agreed with the young person and reviewed at least annually thereafter. This assessment should be made available for all clinic appointments throughout early transition. Once completed, the early-stage transition assessment should be filed in the young person's medical notes.

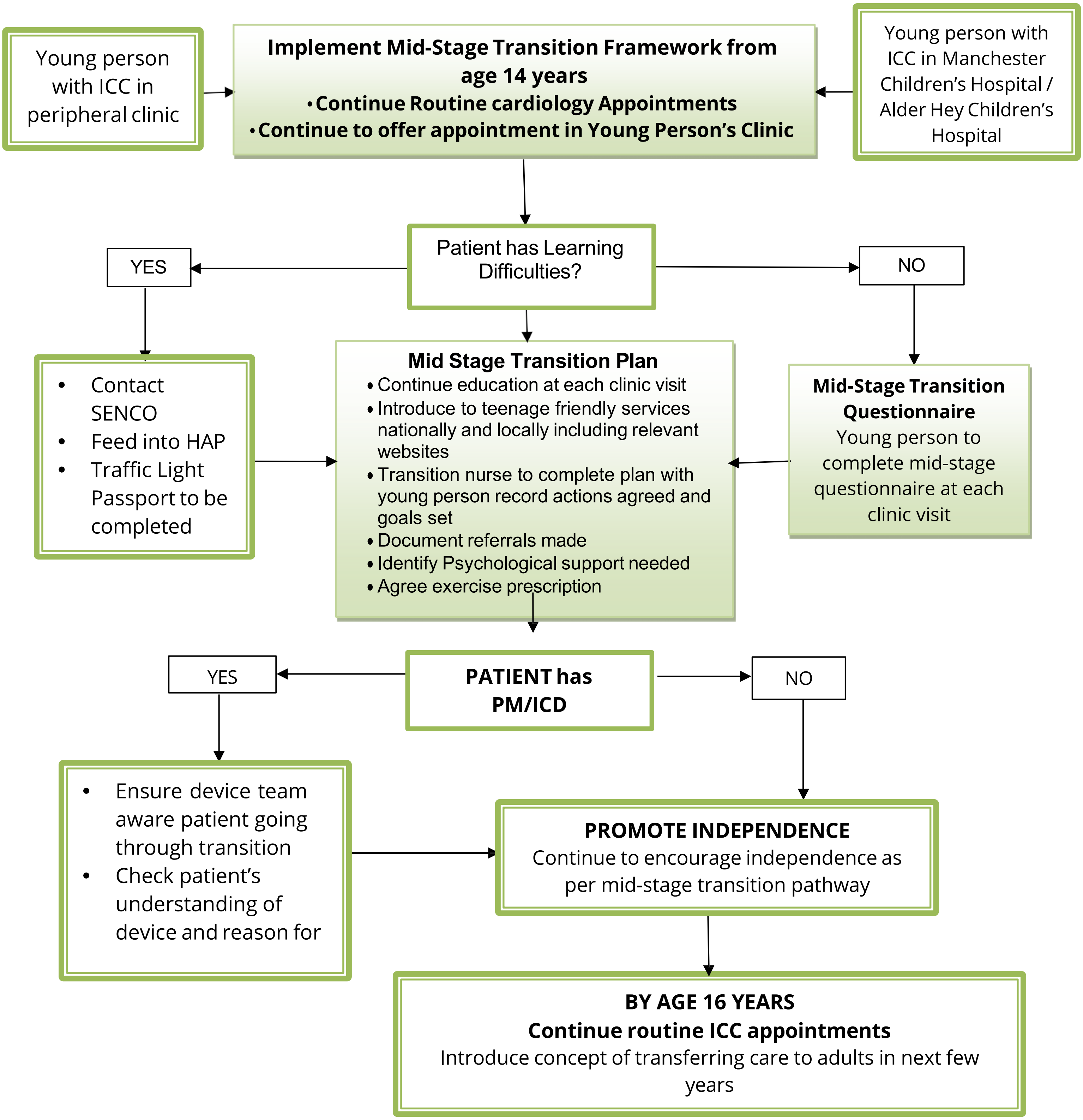
4.10 The concept of seeing a professional on their own should be gradually introduced to the young person to give the family time to adjust to this change. However, it must be emphasised that the young person can *choose* who is in the clinic appointment with them. Parents must always remain involved and should be seen with the young person at some time during the session.

## Planning Framework for early-stage transition (***Table 2***):

| **A Planning Framework for Early-Stage Transition From age 13 years** | |
|---|---|
| **What Should Happen?** | **Who Should Do It?** |
| **Outpatients** – all young people age 13 years to be referred to nurse led transition service<br>Copy transition team into correspondence | Medical staff (including Paediatric Cardiologist or SpR)<br>Clinic Nurses |
| **In-patients** - all young people age 13 years to be referred to nurse led transition service | Paediatric Cardiac Liaison Nurse (PCLN)<br>Ward based nurses |
| Give leaflet **"Moving On"** to patient and discuss with patient what is involved **(Doc: NWCHDN_11.1)** | Referrer |
| Patient invited to attend Young Persons' ICC Clinic | ICC YP Specialist Nurse |
| Begin "early-stage" transition pathway | |
| Give out early-stage transition questionnaire at each clinic visit | |
| Set up handheld (digital) notes and give to patient at first appointment | |
| Support family and young person through this early stage | |
| Contact any other relevant members of the MDT and ensure that their contact details are documented in medical notes | |
| Ensure all members of team are aware of referral including GP | |

# MID STAGE TRANSITION: AGE 14 YEARS UP TO 16 YEARS

**Diagram 3**



Young person with ICC in peripheral clinic

**Implement Mid-Stage Transition Framework from age 14 years**

- **Continue Routine cardiology Appointments**
- **Continue to offer appointment in Young Person's Clinic**

Young person with ICC in Manchester Children's Hospital / Alder Hey Children's Hospital

Patient has Learning Difficulties?

YES

- Contact SENCO
- Feed into HAP
- Traffic Light Passport to be completed

NO

**Mid-Stage Transition Questionnaire**

Young person to complete mid-stage questionnaire at each clinic visit

**Mid Stage Transition Plan**

- Continue education at each clinic visit
- Introduce to teenage friendly services nationally and locally including relevant websites
- Transition nurse to complete plan with young person record actions agreed and goals set
- Document referrals made
- Identify Psychological support needed
- Agree exercise prescription

**PATIENT has PM/ICD**

YES

- Ensure device team aware patient going through transition
- Check patient's understanding of device and reason for

NO

**PROMOTE INDEPENDENCE**

Continue to encourage independence as per mid-stage transition pathway

**BY AGE 16 YEARS**

**Continue routine ICC appointments**

Introduce concept of transferring care to adults in next few years

## MID-STAGE TRANSITION: AGE 15 YEARS UP TO 16 YEARS

## Recommended management

**Diagram 3** describes the recommended pathway for young people aged 15 years up to 16 years of age.

5.1 The middle-stage transition pathway should be started by the age of 14 years.

5.2 The aim of middle-stage transition can be facilitated by using a planning framework which identifies the roles and responsibilities of those involved in the process (Table 3).

5.3 Discussion with the young person should be recorded in their medical notes.

5.4 During mid-stage transition the young person and their family should be given information about medical, educational and psychosocial development to enable the young person to set goals for participating in their own care.

5.5 Young people should be helped to take responsibility for their own medications from as early an age as possible. This stage of the process will also prepare and equip the family for the growing independence and eventual transfer of care to adult services.

5.6 The young person's level of understanding should be assessed by using advanced communication skills and open questioning techniques.

5.7 The patient questionnaire for middle stage transition should be used in the Young Person's Clinic to support this process **(NWCHDN_52.2.2)**

5.8 Any actions agreed, goals set, referrals made, or information (such as leaflets) given to the young person during the discussion should be recorded.

5.9 This should be completed by the YP Specialist Nurse and the young person and reviewed at least annually thereafter. This information should be made available for all clinic appointments throughout middle stage transition and be recorded in the patients medical notes.

5.10 The concept of transfer to adult cardiology services should be introduced by 15 years at the latest to adequately prepare the young person and their parents for this.

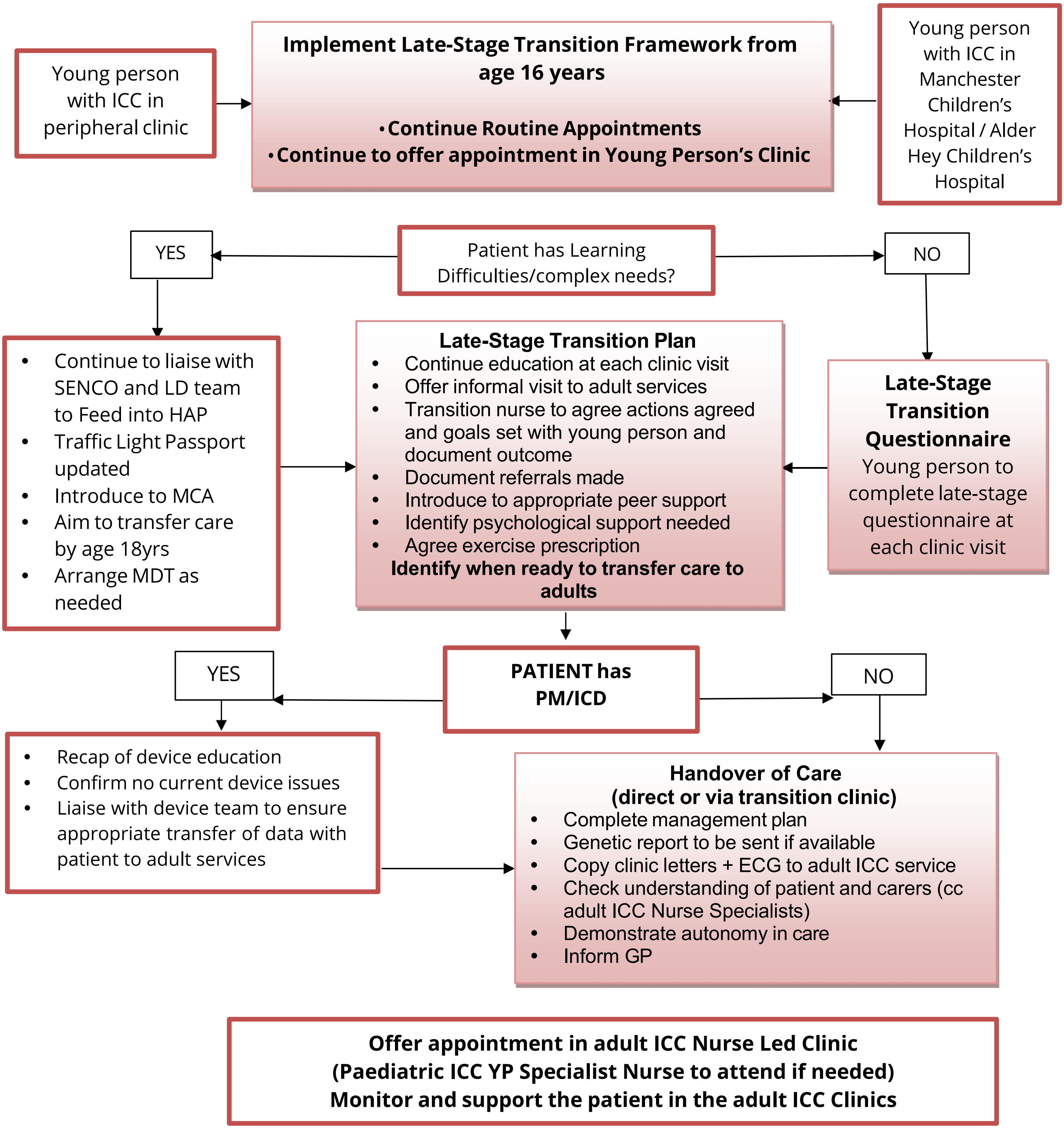
5.11 It is acknowledged that some patients who have special needs will have a statement of educational need and will already be going through a formal transition process from the age of 14 years. This will involve their educational, developmental, and social care needs, but will also address any health-related issues. It is envisaged that this pathway will sit comfortably alongside any such documentation and compliment any multiagency work that is on-going. This will ensure that their congenital heart needs are fully met.

## Planning framework for mid-stage transition *(table 3)*

| A Planning Framework for Mid-Stage Transition | |
|---|---|
| **What Should Happen?** | **Who Should Do It?** |
| Routine medical appointments to continue as normal | Medical staff |
| Offer appointments in Young Person's clinic as appropriate | YP Specialist Nurse |
| Give out mid stage transition questionnaire at the beginning of every appointment | |
| Continue with mid-stage transition pathway | |
| Introduce to teenage friendly services including | |
| Cardiac medication review – liaise with GP for review of how they are managing and issues with compliance | YP Specialist Nurse |
| If patient has learning difficulties and has an educational statement, contact SENCO at school to ensure that health issues are included in their transition process | YP Specialist Nurse/SENCO<br>Educational staff |
| Be involved in the development of Health Action Plans for those young people with learning difficulties | YP Specialist Nurse/SENCO |
| If learning difficulties - ensure patient has a traffic light passport document in case of in-patient admissions | YP Specialist Nurse |
| Ensure appropriate referrals made to MDT as appropriate and as highlighted during clinic assessments | YP Specialist Nurse |
| In the presence of cardiac devices, refresh education, ensure regular monitoring as per device team. | Provided by Cardiac Device Team<br>YP Specialist Nurse |

# LATE-STAGE TRANSITION: AGE 16 YEARS AND UP TO AGE 18 YEARS+

**Diagram 4**



Young person with ICC in peripheral clinic

**Implement Late-Stage Transition Framework from age 16 years**

- **Continue Routine Appointments**
- **Continue to offer appointment in Young Person's Clinic**

Young person with ICC in Manchester Children's Hospital / Alder Hey Children's Hospital

Patient has Learning Difficulties/complex needs?

YES

- Continue to liaise with SENCO and LD team to Feed into HAP
- Traffic Light Passport updated
- Introduce to MCA
- Aim to transfer care by age 18yrs
- Arrange MDT as needed

NO

**Late-Stage Transition Questionnaire**

Young person to complete late-stage questionnaire at each clinic visit

**Late-Stage Transition Plan**

- Continue education at each clinic visit
- Offer informal visit to adult services
- Transition nurse to agree actions agreed and goals set with young person and document outcome
- Document referrals made
- Introduce to appropriate peer support
- Identify psychological support needed
- Agree exercise prescription

**Identify when ready to transfer care to adults**

**PATIENT has PM/ICD**

YES

- Recap of device education
- Confirm no current device issues
- Liaise with device team to ensure appropriate transfer of data with patient to adult services

NO

**Handover of Care**
**(direct or via transition clinic)**

- Complete management plan
- Genetic report to be sent if available
- Copy clinic letters + ECG to adult ICC service
- Check understanding of patient and carers (cc adult ICC Nurse Specialists)
- Demonstrate autonomy in care
- Inform GP

**Offer appointment in adult ICC Nurse Led Clinic**
**(Paediatric ICC YP Specialist Nurse to attend if needed)**
**Monitor and support the patient in the adult ICC Clinics**

## LATE-STAGE TRANSITION AND TRANSFER OF CARE: AGE 16 YEARS AND UP TO AGE 18 YEARS+

### Recommended management

**Diagram 4** describes the recommended pathway for young people aged 16 years and up to 18 years+.

6.1 Late-stage transition should be started by the age of 16 years.

6.2 The aims of late-stage transition can be facilitated by using a planning framework which identifies the roles and responsibilities of those involved in the process (Table 4).

6.3 Discussion with the young person at late-stage transition should be recorded using the transition assessment/plan (see **Doc: NWCHDN_52.1**).

6.4 The young person and their family should be feeling confident about leaving paediatric services and the young person should have a considerable degree of autonomy over their own care. The young person's level of understanding should be documented.

6.5 Any actions agreed, goals set, referrals made, or information (such as leaflets) given to the young person should be recorded.

6.6 The patient questionnaire for late-stage transition can be used to support this process. **(see Doc: NWCHDN_52.2.3)**

6.7 The transition assessment/plan should be completed by the YP Specialist Nurse and the young person. Both the YP Specialist Nurse and the young person should sign the late-stage transition record. This assessment should be recorded in the patient's medical records.

6.8 This assessment will follow the patient into adult services.

## 7. Transfer of care to adult services

7.1 All young people – including those with learning disabilities or special needs – should be supported to leave paediatric services by the age of 18 years where appropriate.

7.2 A referral to the formal Handover Clinic will be required in the following situations and on a case-by-case basis:

a. Patients with a history of lack of engagement, increased risk-taking behaviours, issues around compliance with medications or any safeguarding or family/social concerns.
b. Patients with unstable ICC phenotype
c. Patient that requires intervention or change of treatment that will require more intense monitoring

d. patients with learning disabilities and complex needs
e. Patients with complex needs where there are multiple specialities involved in their care who may need a be-spoke MDT meeting to be arranged.

7.3 In the Handover Clinic a formal medical handover of care will be facilitated through an MDT approach with both Paediatric and adult ICC Cardiologists in attendance. The YP Specialist Nurse and adult ICC Nurse Specialist will also be available to support the patient and family.

7.4 A detailed clinic letter is required for all young people transferring care to adult services regardless of how their care is transferred. This should be copied to the ICC Nurse Specialists and must include as a minimum:

**Minimum information required at handover *(Table 4)***

| Information required | Details |
|---|---|
| Demographics | Include parents/carers details<br>State if has LD or special needs |
| Cardiac Diagnosis | e.g. hypertrophic cardiomyopathy |
| Genetics | formal genetic reports if available pertaining to patient |
| Co-morbidities to include developmental, neuro-psychological/cognitive and mental health issues | Include contact details of all other services involved in care |
| Summary of Surgical Procedures | Include operation notes |
| Summary of cardiac catheter procedures | Include reports |
| Relevant Investigations 12 lead ECG, ambulatory ECG/Echo/MRI/CT dates and key points | Include relevant reports (patient to receive copy of their own reports prior to transfer) |
| List of current medications and recent changes prior to transfer | |
| Check all recent pacing reports and device history has been sent to adult services | This will be sent by the pacing team |
| Current status at time of transfer | |

7.5 Share a copy of the transition letter with the patient and provide them with a copy of their genetic results if relevant and a copy of their most recent ECG.

7.6 Imaging data will be transferred where deemed appropriate to the relevant adult ICC services

7.7 A comprehensive summary of care at the point of transition will be given to the young person and a copy sent to their GP.

7.8 For young people with asymptomatic and stable ICC condition referrals should be made directly to the adult ICC service. A detailed clinic letter will be sent, and a copy of the young person's management plan will be given to the young person and a copy sent to their GP. They will be supported throughout the process by the ICC YP Specialist Nurse in the same way.

## 8. Planning framework for late-stage Transition

***Table 5***

| A Planning Framework for Late-Stage Transition | |
|---|---|
| **What Should Happen?** | **Who Should Do It?** |
| Routine medical appointments to continue as normal | Medical staff |
| Offer appointment in Young Person's Clinic as appropriate | YP Specialist Nurse |
| Give out late-stage transition questionnaire at the beginning of every appointment | |
| Continue with late-stage transition pathway | |
| Offer informal visit to adult ICC services | |
| If patient has a learning disability or neurodiversity and has an educational statement continue to work with SENCO at school to ensure that health issues are included in their transition process | YP Specialist Nurse/SENCO/ Educational staff |
| If a patient has a learning disability or neurodiversity – make sure that they understand the implications of the Mental Capacity Act once they are 16yrs of age | YP Specialist Nurse |
| Contribute to the development of Health Action Plans for those young people with learning difficulties | YP Specialist Nurse/SENCO |
| If learning difficulties - ensure patient has a traffic light passport document in case of in-patient admissions | YP Specialist Nurse |
| Ensure appropriate referrals made to MDT as appropriate and as highlighted during clinic assessments. If required coordinate an MDT meeting with all relevant teams in attendance to co-ordinate care and timings of transfer | |
| When ready ensure patient is either referred to Handover Clinic for formal handover of care or liaise with their Paediatric Cardiologist to inform them of their readiness for direct transfer of care | |
| Ensure ICC management plan completed and given to patient | YP Specialist Nurse/Adult ICC nurse specialist |
| Ensure ICC patient information leaflets are given to patient | YP Specialist Nurse<br>Adult ICC nurse specialist |
| Give copies of latest ECG and clinic letters to patient | YP Specialist Nurse<br>Consultant Paediatric ICC Cardiologist |

| | |
|---|---|
| Ensure patient understands decisions made and the plan for future care. This is to include plans for emergency care during the transfer of care. | Paediatric and Adult ICC Cardiologist and YP Specialist Nurse/ Adult ICC Nurse Specialist |
| Support and help parents/carers through this process | YP Specialist Nurse/ Adult ICC Nurse Specialist |
| Ensure referral letter sent to appropriate Adult Cardiologist as per agreed plan and copied to GP | Paediatric ICC Cardiologist/ Paediatric Cardiac Secretary |
| Ensure all relevant documentation is transferred to appropriate adult services | Paediatric Cardiac secretary |
| Ensure new appointment issued in adult service | ICC team secretary |
| YP Nurse Specialist to follow care through to adults for at least first appointment if required | YP Specialist Nurse |
| Sign off transition pathway once completed | Adult ICC Nurse Specialist |

### 7.7 Referral to Adult ICC Services

The young person should be referred to an appropriate adult ICC service or cardiologist. This referral will be based on several factors, including:

- Their geographical location
- The nature and severity of their clinical condition
- The preferences of the young person and their family

## 9. Auditing and monitoring

9.1 Activity levels in the following clinics needs to be recorded and reported to the NW CHD Network

- The Young Person's Clinic
- The formal Handover Clinic

9.2 Quality Indicators will be monitored locally via a regional patient satisfaction survey

9.3 Monitoring needs to include loss to follow up rate.

## Appendix A

### Contact Details

***(please ensure ICC Nurse Specialists are copied into correspondence)***

| Hospital | Contact | Telephone Number |
|---|---|---|
| **Liverpool Heart & Chest Hospital NHS Foundation Trust**<br>Thomas Drive<br>Liverpool<br>L14 3PE | **Adult ICC Consultant Cardiologists:**<br>**Dr Derick Todd** (Clinical Lead) invasive Electrophysiology, Channelopathies Cardiomyopathies, Implantation ICD's & Pacemakers<br>**Prof Robert Cooper** – Cardiomyopathies, MRI<br>**Dr Simon Modi** – Invasive Electrophysiology, Channelopathies, Cardiomyopathies, Implantation ICD & Pacemakers<br>**Dr Archana Rao** – Channelopathies, Cardiomyopathies, Implantation ICD & Pacemakers<br>**Dr Richard Snowdon -** Channelopathies, Cardiomyopathies, Implantation ICD & Pacemakers<br>**Prof Jay Wright -** Cardiomyopathies, Implantation ICD & Pacemakers<br>**Prof Rod Stables** – Hypertrophic cardiomyopathy<br>**Dr Jennifer Llewellyn** - Channelopathies, Cardiomyopathies, Implantation ICD & Pacemakers<br>**Dr Timothy Fairbairn** – Advanced imaging, Valve disease in Cardiomyopathies<br>**Dr Saagar Mhadia** - Cardiomyopathies, Implantation ICD & Pacemakers | Switchboard:<br>0151 600 1616<br><br>ICC Coordinator: 0151 254 3181<br>Email:<br>iccteam@lhch.nhs.uk |
|  | **Adult ICC Nurse Consultant**<br>Kathryn Abernethy<br><br>**Adult ICC Nurse specialists**<br>Angela Langton<br>Elizabeth Wilson | ICC Nurses<br>Tel: 0151 254 3456 |

| | | |
|---|---|---|
| **Liverpool Heart & Chest Hospital NHS Foundation Trust**<br>Thomas Drive<br>Liverpool<br>L14 3PE | **Aortic Team:**<br><br>**Marfan and other inherited aortopathies**<br>**Dr Afshin Khalatbari** - Consultant Cardiologist in Cardiac Imaging, Heart Valve Disease, and Inherited Aortopathies<br><br>**Aortic Surgery**<br>**Mr Jakub Marczak**- Consultant Cardiac and Aortic Surgeon | Switchboard:<br>0151 600 1616<br><br>Dr Khalatbari Secretary:<br>Office: 0151 600 1106<br><br>Mr Marczak Secretary<br>Mrs Margaret Hughes<br>Office: 01516003532 |
| **Liverpool Centre for Genomic Medicine**<br>Liverpool Women's NHS Foundation Trust<br>Crown Street<br>Liverpool<br>L8 7SS | **Clinical Geneticist**<br>Dr Katya Bennett<br><br>**Genetic counsellors**<br>Louise Dubois<br>Jessica Cadwallader<br>Sarah Maguire | Clinical PA: 0151 802 5003 / 5008<br>Email:<br>lwft.clingen@nhs.net |
| **Manchester University Hospitals NHS Foundation Trust**<br>Manchester Heart Centre, MRI, Oxford Road, Manchester,<br>M13 9WL | **ICC Cardiologists**<br>Dr Rhys Beynon<br>Prof Andrew Crean (virtual clinics)<br>Prof Aneil Malhotra<br>Dr Luigi Venetucci<br>Professor Bernard Clarke<br>Professor Bernard Keavney<br>Professor Clifford Garratt<br>Dr David Hutchings<br>Dr Charles Pearman | Switchboard:<br>0161 276 1234 |
| **Manchester University Hospitals NHS Foundation Trust**<br>University Hospital of South Manchester,<br>Southmoore Road,<br>Wythenshawe<br>M23 9LT | **ICC Cardiologists**<br>Dr Rhys Beynon<br>Professor Andrew Crean (imaging)<br>Professor Aneil Malhotra<br>Dr David Hutchings | Switchboard (Wythenshawe):<br>0161 998 7070 |
| Covering both MRI and Wythenshawe Hospitals | **ICC Nurse Specialist**<br>Sam Cummins | Email:<br>MFT.ICC@NHS.NET |

| | | |
|---|---|---|
| **Manchester Centre for Genomic Medicine**<br>**6th Floor**<br>St Mary's Hospital<br>Oxford Road<br>Manchester<br>M13 9WL<br><br>*North West Genomic Laboratory Hub (Manchester)* | **Consultant Clinical Geneticist**<br>Professor William Newman (Lead)<br>Dr Kay Metcalfe<br>Dr Claire Hopton<br><br>**Principal Genetic Counsellors**<br>Natalie Morton<br>Sarah Bennett | Switchboard (MRI):<br>0161 276 1234 |
| All Wales Medical Genomics Service | **Genetic Counsellor**<br>Bethany Fruen | Main Reception<br>03000858477<br><br>Emails:<br>north.genetics@wales.nhs.uk<br>SE.Genetics@wales.nhs.uk<br>SW.Genetics@wales.nhs.uk<br><br>Direct email for all Wales Genomics Laboratory<br>lab.genetics.cav@wales.nhs.uk |

# Appendix B

## Details of Formal Transition Clinics at Royal Manchester Children's Hospital and Alder Hey NHS Foundation Trust

**Frequency of clinics will increase as the ICC service expands**

| **Royal Manchester Children's Hospital**<br>ICC transition clinics are held for young people with complex/unstable ICC at 16 years to 18 years to support transfer of care. | |
|---|---|
| Who | Paediatric Cardiologist, Adult ICC Cardiologist, Paediatric Cardiac Nurse Specialist and Adult ICC Heart Nurse Specialist and cardiac physiologists. Cardiology Clinic staff |
| Where | Main outpatient's department within Manchester Children's Hospital NHS Foundation Trust |
| When | Formal handover (Transition) clinic once a week<br>Young People's clinics once a week |
| How | All referral letters to be copied to the Paediatric Cardiac (YP) Nurse Specialist for co-ordination of care |

| **Alder Hey Children's NHS Foundation Trust**<br>Paediatric cardiology and adult ICC handover clinics are held for young people with complex and/or unstable ICC at 16 years to 18 years to support transfer of care. | |
|---|---|
| Who | Paediatric ICC Cardiologist, Adult ICC Cardiologist, Paediatric ICC Nurse Specialist/Transition Nurse, Adult ICC Nurse Specialist and cardiac physiologist. Cardiology clinic staff |
| Where | Main outpatient department within Alder Hey Children's NHS Foundation Trust |
| When | Formal handover (Transition) clinic once a week<br>Young People's clinics 3 x a week |
| How | All referral letters to be copied to the ICC Transition Nurse Specialist for co-ordination of care |

# Appendix C

## List of Abbreviations

| | |
|---|---|
| **DH** | Department of Health |
| **CT Scan** | Computed tomography scan that uses x-rays and a computer to create detailed cross-sectional images |
| **ECG** | Electrocardiogram – a test that records the heart's electrical activity |
| **Echo** | Echocardiogram – a test that looks at the structure and function of the heart |
| **FE** | Further Education |
| **GP** | General Practitioner |
| **HAP** | Health Action Plan is a document that outlines a person's health needs, goals and steps needed to achieve them and is a key part of person centred planning for people with a learning disability |
| **ICC** | Inherited Cardiac Conditions |
| **ICD** | Implantable Cardioverter Defibrillator |
| **LD** | Learning disability |
| **LD Passport** | A learning disability hospital passport A hospital passport provides important information about a patient with a learning disability, including personal details, the type of medication they are taking, and any pre-existing health conditions. The passport also includes information about how a person communicates and their likes and dislikes. Health Guides: Hospital Passports, Summary Care Records And Flu Jabs \| Mencap |
| **MDT** | Multi-Disciplinary Team |
| **MRI** | Magnetic Resonance Imaging |
| **N/A** | Not Applicable |
| **NHS** | National Health Service |
| **NICE** | National Institute Clinical Excellence |
| **NSF** | National Service Framework |
| **PCLN** | Paediatric Cardiac Liaison Nurse |

| | |
|---|---|
| **PM** | Pacemaker |
| **SENCO** | Special Educational Needs Coordinator |
| **SpR** | Specialist Registrar |
| **YP** | Young person |

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