Document Control

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Directorate/ Network: North West, North Wales & Isle of Man Congenital Heart Disease Network

Version	Date Issued	Status	Comment/ Change/ approval
V 3.0	Sept 2015	Draft	Written previously by Angie Haynes (and Linda Griffiths) on behalf of all age Network
V 3.1	Sept 2018	Draft	Updated for Peer Review
V 3.2	Sept 2020	Draft	Sent out to Transition services for comment
V 3.3	Feb 2021	Draft	Forms/Questionnaires separated out and medical information required at handover added. Formatting and Network brand added
V3.4	March 2021	Draft	Updated contact details MFT. Included clinic at Wythenshawe. Transition clinic details updated
V3.5	29/04/2021	Draft	Meeting: clarify referral to transition nurse To remove the term "transition" following feedback from patients
V3.6	26/05/2021	Draft	Transition to start 13yrs (NICE + 10 steps) Referral from email addresses added
V3.7	08/07/2021	Draft	Amendments made as per recommendations from psychology around mental health and well-being and clarifying terminology of LD
V3.7	08/07/2021	Draft	Feedback from Transition Teams at RMCH and Alder Hey: up to date definition, inclusion of role of GP, emergency care and MDT approach for complex patients. Term "transition" removed where appropriate
V3.8	23/07/21	Draft	Definition of learning disability/difficulty clarified
V3.9	02/08/21	Final	Add cc ACHD Nurse Specialists at handover

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Approved By: NWCHD Network Ratification Task and Finish Group’s (Paediatric + ACHD) on behalf of the Network
Date: 06/09/2021

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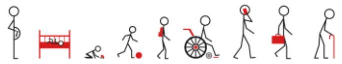

Young People with Congenital Heart Disease

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

Date: February 2021

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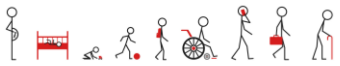

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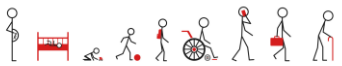


EXECUTIVE SUMMARY

Transition from child to adult cardiology services for young people with congenital heart disease can be a difficult time when they are faced with many other changes in personal, educational, social, spiritual and physical and mental health aspects of their life. Together, all these transitional phases can have an impact on adherence to therapeutic regimes and retention by supportive healthcare services. 'Standard 4: Growing up into Adulthood' (DH 2006).

This protocol has been developed to promote the planning and management of the care of young people with congenital heart disease 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 (Section I) 2016.

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 Congenital heart disease describes a range of heart conditions resulting from an abnormality of the heart structure or function that is present from birth. The majority of conditions are diagnosed in infancy or early childhood but occasionally it is not diagnosed until adulthood.

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 congenital heart disease 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 cardiology services
- Provide advice, guidance and support for the management of care during transition

- Promote the appropriate transfer of care of young people to adult cardiology services
- Build on existing relevant guidelines for routine care of young people focusing on areas where additional or different care should be offered with congenital heart disease

1.1.5 This protocol should help practitioners achieve a seamless transfer of care using a pathway framework for working with young people with congenital heart disease 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 planning framework, which is supported by assessment forms and patient questionnaires provided in a suite of additional documents.

1.2 SCOPE

1.2.1 This protocol applies both to paediatric and adult congenital cardiology services.

1.2.2 This protocol applies to cardiology 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 congenital heart disease.

1.3 TERMINOLOGY

1.3.1 The term **'transition"** is used in this protocol to refer to the whole process of supporting 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 twelve 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 Congenital Heart 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 in order to avoid using the term 'transition'.

1.3.4 The term **'young 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 congenital heart services. This facilitates formal hand over of care to adult services for all complex patients.

1.3.6 The term "**Young Person's 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 **"ACHD"** is used to refer to Adult Congenital Heart Disease services.

1.3.8 A variety of terms "**learning disability, learning difficulty**" are used colloquially and preferentially - it is useful to first clarify the language that an individual and their family prefer and use this. However, for the purposes of clarity throughout this document and in line with national policy, a learning disability 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. Generally, it is recognised as the person having an IQ score of less than 70, although this alone would not be sufficient for diagnosis. 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. It is worth noting that ADHD, autism and Asperger's do not fall into the diagnostic category of learning disability

1.4 CURRENT SERVICE PROVISION ARRANGEMENTS:

1.4.1 Young people growing up with a congenital heart problem in the North West of England, North Wales and the Isle of Man (up to the age 18 years) 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 many peripheral clinics throughout the

North West of England, North Wales and the Isle of Man so that young people can be seen nearer to home.

1.4.2 All young people with congenital heart disease 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 Young people with complex congenital heart disease will be invited to a **"Handover Clinic"**. These clinics will be held at the following hospitals:

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

1.4.4 Young people with simple and moderate congenital heart disease that is stable will have their care transferred from the Paediatric Cardiologist to an Adult Congenital Cardiologist (ACHD) based at one of the following hospitals:

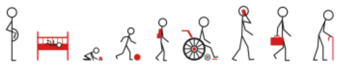
- Liverpool Heart and Chest NHS Foundation Trust (Level 1 centre)
- Manchester Heart Centre, Manchester University NHS Foundation Trust (Level 2 centre)
- Wythenshawe Hospital, Manchester University NHS Foundation Trust (Level 3)
- Blackpool Victoria Hospital, Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust (Level 3 centre)
- Wrexham Maelor Hospital, Betsi Cadwaladr University Health Board, North Wales (Level 3 centre)

1.5 GENERAL PRINCIPLES OF THE PROTOCOL

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

1.5.2 Management of young people with congenital heart disease should take into account 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 the single service that does not change as a result of reaching adulthood. 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 relevant MDT meetings as appropriate to ensure good communication amongst the teams involved. This is to ensure that good communication occurs across teams and that transitional care is coordinated and planned.

1.5.6 If emergency care is required for their congenital heart problem during the transfer stage the Paediatric CHD 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 decisions made that require that emergency care during this time is provided by the adult service. Where this decision has been made it is imperative that this is clearly documented and shared. Good communication is essential at such times between Paediatric and ACHD services. Once the patient has been seen in adult services all future emergency admissions would be managed within ACHD services where appropriate. It is important that the patient and family understand how to manage urgent care during this transfer stage and beyond.

1.5.7. CHD Standards (2016) state that referral should occur from age 12yrs. However NICE Guidance (2016) 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.

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
Rosie.fawcett@nhs.net
Clair.noctor@nhs.net
Cardiac Specialist Nursing Team
Royal Manchester Children's Hospital
Oxford Road
Manchester
M13 9WL

Young Person's Clinic at Alder Hey
Copy letter to
Amanda.haworth2@nhs.net
patricia.coyle@nhs.net
Cardiac Specialist Nursing Team
Alder Hey Children's Hospital
Eaton Road
Liverpool
L12 2AP

1.6 KEY STANDARDS FOR IMPLEMENTATION

1.6.1 NHS England published and ratified a set of service standards for transition and resource requirements for the designation of specialist services for patients with congenital heart disease: “Congenital Heart Disease Standards and Specifications (2016)”.

NHSE Transition Standards (Section I)

I1 Congenital Heart Networks 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.

I2 All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.

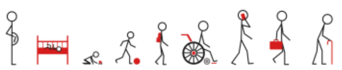
I3 There will not be a fixed age of transition from children’s to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.

I4 All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports 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.

I5 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.

I6 All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.

I7 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. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range



of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.

I8 The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan

I9 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.

OVERVIEW OF THE PROTOCOL

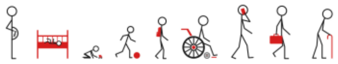
Wherever possible the protocol is in the format of algorithms and frameworks, supported by minimum text. The component parts of the transition and transfer of care pathway for young people with congenital heart disease are discussed in three management stages as follows and the overall pathway is outlined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

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).

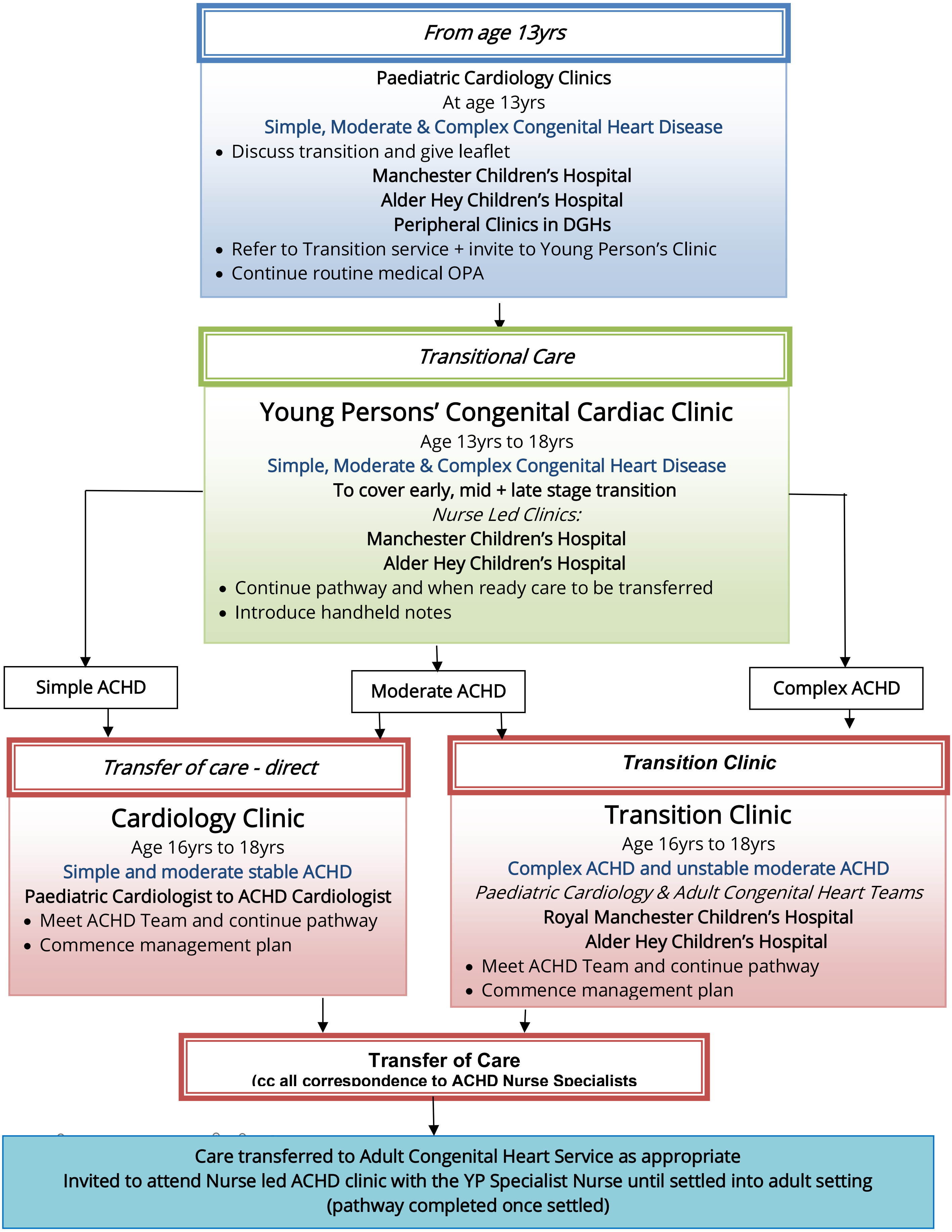
Table 1

OVERVIEW OF THE PROTOCOL
Early Stage Transition
This transition pathway identifies young people with congenital heart disease from 12 years to 14 years.
Mid Stage Transition
This transition pathway identifies young people with congenital heart disease from 14 years to 16 years.
Late Stage Transition
This transition pathway identifies young people with congenital heart disease from 16 years to 18 years who will require transfer from paediatric to adult cardiology services



ALGORITHM 1 (OVERVIEW)

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



From age 13yrs

Paediatric Cardiology Clinics
At age 13yrs
Simple, Moderate & Complex Congenital Heart Disease

- 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' Congenital Cardiac Clinic
Age 13yrs to 18yrs
Simple, Moderate & Complex Congenital Heart Disease
To cover early, mid + late stage transition
Nurse Led Clinics:
Manchester Children's Hospital
Alder Hey Children's Hospital

- Continue pathway and when ready care to be transferred
- Introduce handheld notes

Simple ACHD

Moderate ACHD

Complex ACHD

Transfer of care - direct

Cardiology Clinic
Age 16yrs to 18yrs
Simple and moderate stable ACHD
Paediatric Cardiologist to ACHD Cardiologist

- Meet ACHD Team and continue pathway
- Commence management plan

Transition Clinic

Transition Clinic
Age 16yrs to 18yrs
Complex ACHD and unstable moderate ACHD
Paediatric Cardiology & Adult Congenital Heart Teams
Royal Manchester Children's Hospital
Alder Hey Children's Hospital

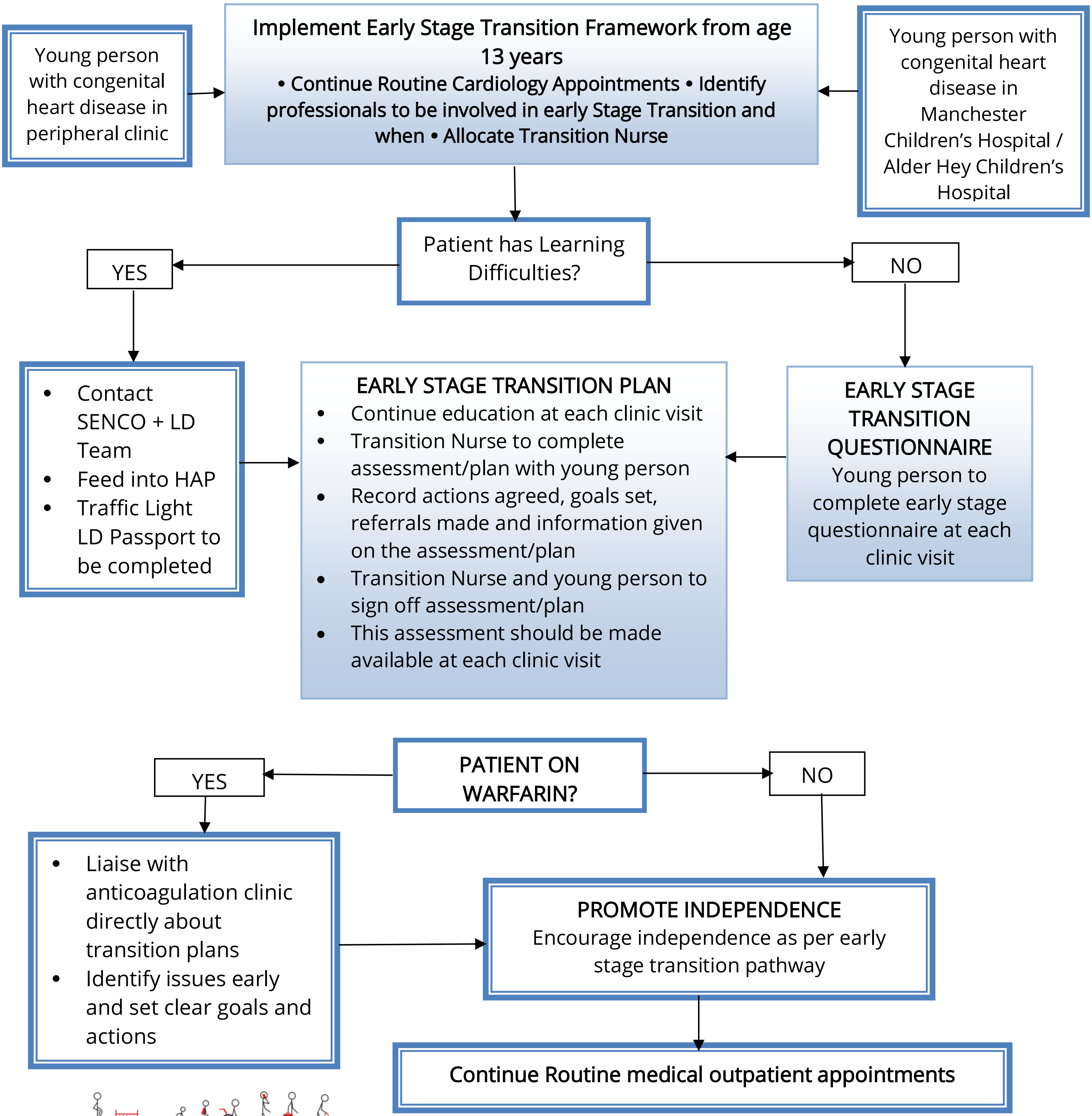
- Meet ACHD Team and continue pathway
- Commence management plan

Transfer of Care
(cc all correspondence to ACHD Nurse Specialists

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

EARLY STAGE TRANSITION: 13 YEARS AND UP TO 14 YEARS

ALGORITHM 2
SUMMARY



Young person with congenital heart disease in peripheral clinic

Implement Early Stage Transition Framework from age 13 years
• Continue Routine Cardiology Appointments • Identify professionals to be involved in early Stage Transition and when • Allocate Transition Nurse

Young person with congenital heart disease in Manchester Children's Hospital / Alder Hey Children's Hospital

Patient has Learning Difficulties?

YES

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

NO

EARLY STAGE TRANSITION QUESTIONNAIRE
Young person to complete early stage questionnaire at each clinic visit

EARLY STAGE TRANSITION PLAN
- Continue education at each clinic visit
- Transition Nurse to complete assessment/plan with young person
- Record actions agreed, goals set, referrals made and information given on the assessment/plan
- Transition Nurse and young person to sign off assessment/plan
- This assessment should be made available at each clinic visit

PATIENT ON WARFARIN?

YES

- Liaise with anticoagulation clinic directly about transition plans
- Identify issues early and set clear goals and actions

NO

PROMOTE INDEPENDENCE
Encourage independence as per early stage transition pathway

Continue Routine medical outpatient appointments

EARLY STAGE TRANSITION: 13 YEARS AND UP TO 14 YEARS

RECOMMENDED MANAGEMENT

Algorithm 2 describes the recommended pathway for young people with congenital heart disease aged 13 years to 14 years.

4. EARLY DISCUSSION OF TRANSITION TO ADULT CARE

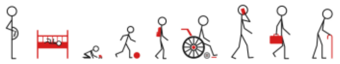
4.1 The paediatric cardiac nurse should start to introduce the concept of preparing to transfer care to adult health care with the young person by age 13 years and their family. From the age of 13 years the young person should be given the transition information leaflet which briefly describes the transition 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.

5. BEGINNING OF ACTIVE PREPARATION FOR TRANSFER TO ADULT CARE (AGE 13 YEARS AND UP TO AGE 14 YEARS): A PLANNING FRAMEWORK, PATIENT QUESTIONNAIRE AND TRANSITION ASSESMENT/PLAN

5.1 The early stage transition pathway for ALL young people should start by the age of 13 years. The young person should be offered an appointment in the nurse led Young Persons Congenital Cardiac Clinic.

5.2 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 section 6, Table 2, p.14). 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.

5.3 The transition assessment/plan provides a checklist for discussion with the young person at each of the three stages of transition: early **(Doc: NWCHDN_1.3.1)**, middle **(Doc: NWCHDN_11.3.2)** and late **(Doc: NWCHDN_11.3.3)**. 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. The young person's level of understanding should be assessed by using advanced communication skills and open questioning techniques. 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.



5.4 The patient questionnaire for early stage transition can be used in the Young Person's Clinic to support this process **(Doc: NWCHDN_11.4.1).**

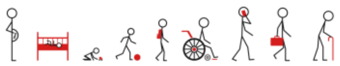
5.5 Any actions agreed, goals set, referrals made or information (such as leaflets) given to the young person during the discussion should be recorded on the transition assessment. This should be completed by the YP Specialist Nurse and the young person and reviewed at least annually thereafter. Both the YP Nurse Specialist and the young person should sign the early stage transition record. 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.

5.6 The concept of seeing a professional on their own should be gradually introduced to the young person in order to give the family time to adjust to this change. However, 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.

6. A PLANNING FRAMEWORK FOR EARLY STAGE TRANSITION (13 YEARS TO 14 YEARS)

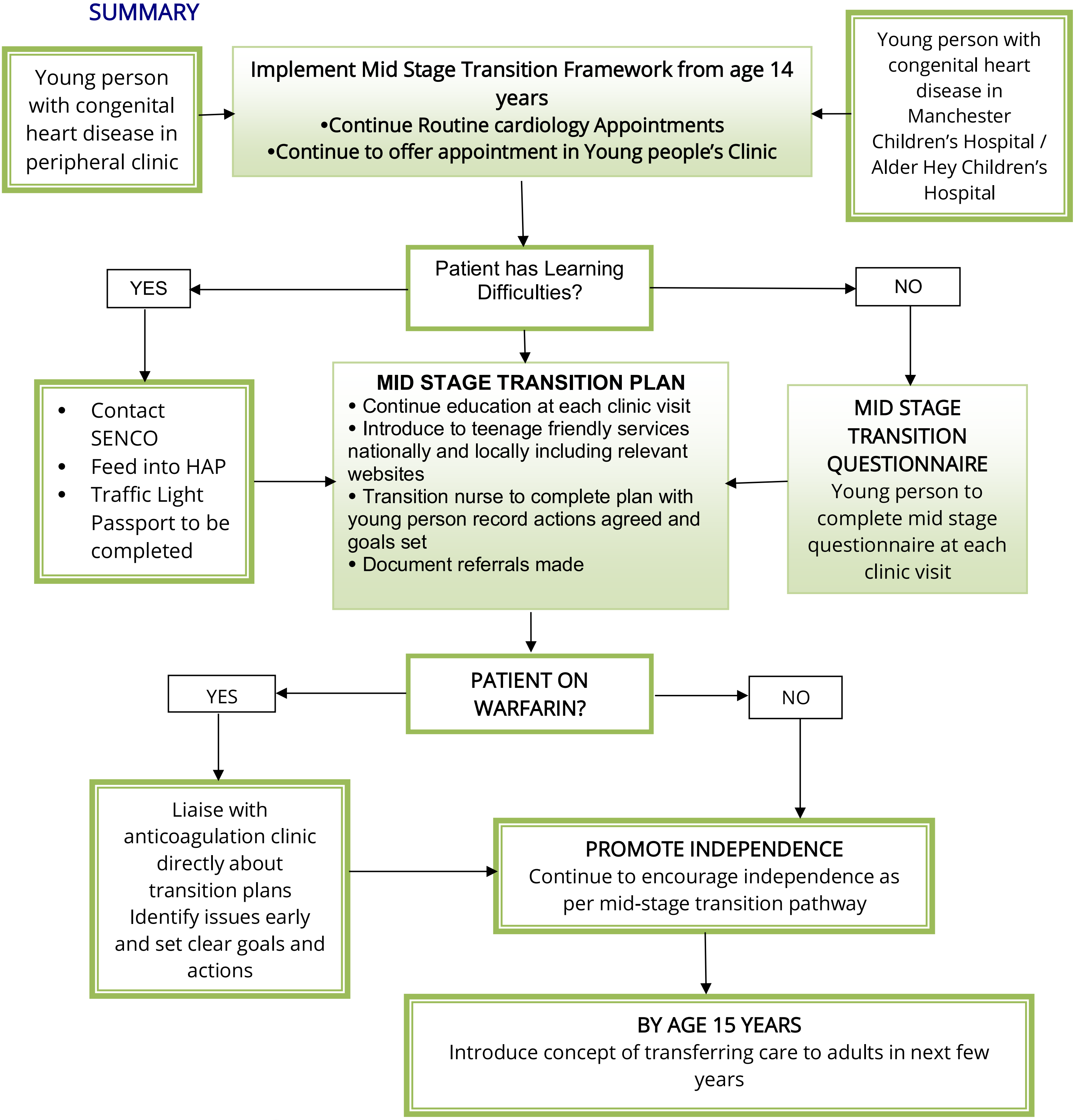
Table 2: A Planning Framework for Early Stage Transition

A Planning Framework for Early Stage Transition (to be started at age 13 years and continued up to age 14 years)	
What Should Happen?	**Who Should Do It?**
Outpatients – all young people age 13 years to be referred to nurse led transition service Complete referral form to Young person's Congenital Cardiac Clinic	Medical staff (including Paediatric Cardiologist or SpR) Clinic Nurses
In-patients - all young people age 13 years to be referred to nurse led transition service Complete referral form to Young person's Congenital Cardiac Clinic	Paediatric Cardiac Liaison Nurse (PCLN) 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' Congenital Cardiac Clinic	YP Specialist Nurse
Begin "early stage" transition pathway and continue to fill it in at each stage	
Give out early stage transition questionnaire at each clinic visit	
Set up handheld 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 on pathway	
Ensure all members of team are aware of referral including GP	



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

ALGORITHM 3
SUMMARY



Young person with congenital heart disease in peripheral clinic

Implement Mid Stage Transition Framework from age 14 years
•Continue Routine cardiology Appointments
•Continue to offer appointment in Young people's Clinic

Young person with congenital heart disease 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 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

MID STAGE TRANSITION QUESTIONNAIRE
Young person to complete mid stage questionnaire at each clinic visit

PATIENT ON WARFARIN?

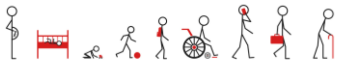
YES

Liaise with anticoagulation clinic directly about transition plans
Identify issues early and set clear goals and actions

NO

PROMOTE INDEPENDENCE
Continue to encourage independence as per mid-stage transition pathway

BY AGE 15 YEARS
Introduce concept of transferring care to adults in next few years



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

RECOMMENDED MANAGEMENT

Algorithm 3 describes the recommended pathway for young people with congenital heart disease aged 14 years and up to 16 years.

7. ONGOING PREPARATION FOR TRANSFER TO ADULT CARE: A PLANNING FRAMEWORK, PATIENT QUESTIONNAIRE AND TRANSITION ASSESMENT/PLAN

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

7.2 The aims of middle stage transition can be facilitated by using a planning framework which identifies the roles and responsibilities of those involved in the process (see section 8, Table 3, p. 17).

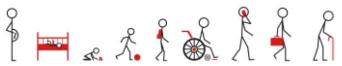
7.3 Discussion with the young person should be recorded using the middle stage transition assessment/plan (see **Doc: NWCHDN_11.3.2**). The checklist aims to give the young person and their family more information about medical, educational and psychosocial development to enable the young person to set goals for participating in their own care. Young people should be helped to take responsibility for 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. The young person's level of understanding should be assessed by using advanced communication skills and open questioning techniques. Any actions agreed, goals set, referrals made or information (such as leaflets) given to the young person during the discussion should be recorded on the assessment.

7.4 The patient questionnaire for middle stage transition can be used in the Young Person's Clinic to support this process (see **Doc: NWCHDN11.4.2**).

7.5 The transition assessment/plan should be completed by the YP Specialist Nurse and the young person and reviewed at least annually thereafter. Both the YP Specialist Nurse and the young person should sign the middle stage transition record. This proforma should be made available for all clinic appointments throughout middle stage transition. Once completed the proforma should be filed in the young person's medical notes.

7.6 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.

7.7 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

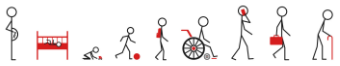


age of 14 years. This will involve their educational, developmental and social care needs, but will also address any health-related issues. It is envisaged that this pathway will sit comfortably alongside any such documentation and compliment any multiagency work that is on-going. This will ensure that their congenital heart needs are fully met.

8. A PLANNING FRAMEWORK FOR MIDDLE STAGE TRANSITION (14 YEARS TO 16 YEARS)

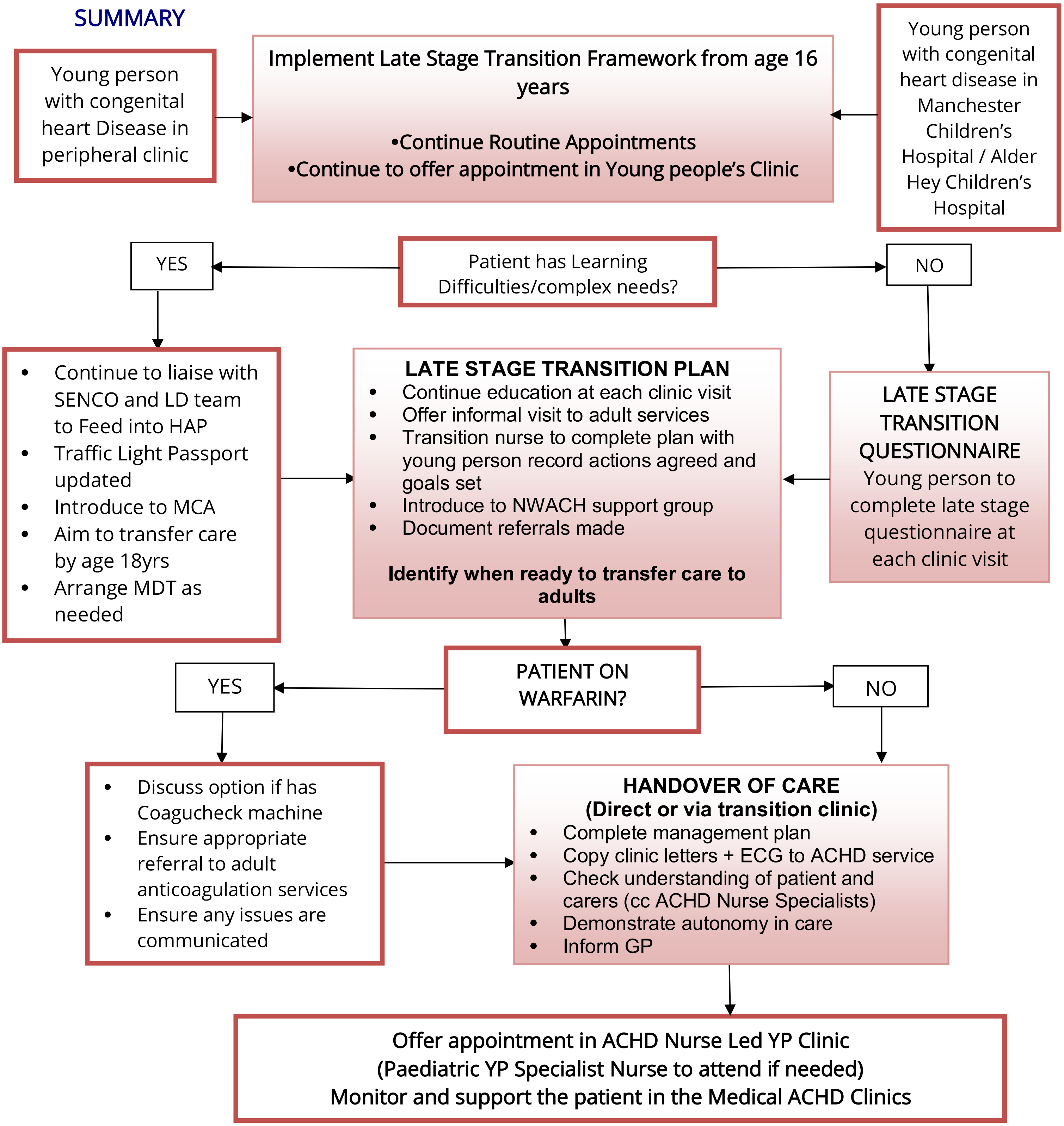
Table 3: A Panning Framework for Mid Stage Transition

A Planning Framework for Mid Stage Transition (to be started at age 14 years and continued up to age 16 years)	
What Should Happen?	Who Should Do It?
Routine medical appointments to continue as normal	Medical staff
Offer appointments in young people'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 BHF, LHM and TSF	
If on warfarin – liaise with anticoagulation service and 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 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



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

ALGORITHM 4
SUMMARY



Young person with congenital heart Disease in peripheral clinic

Young person with congenital heart disease in Manchester Children's Hospital / Alder Hey Children's Hospital

Implement Late Stage Transition Framework from age 16 years

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

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 complete plan with young person record actions agreed and goals set
- Introduce to NWACH support group
- Document referrals made

Identify when ready to transfer care to adults

PATIENT ON WARFARIN?

YES

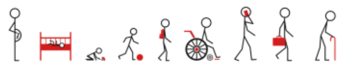
- Discuss option if has Coagucheck machine
- Ensure appropriate referral to adult anticoagulation services
- Ensure any issues are communicated

NO

HANDOVER OF CARE
(Direct or via transition clinic)

- Complete management plan
- Copy clinic letters + ECG to ACHD service
- Check understanding of patient and carers (cc ACHD Nurse Specialists)
- Demonstrate autonomy in care
- Inform GP

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



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

RECOMMENDED MANAGEMENT

Algorithm 4 describes the recommended pathway for young people with congenital heart disease aged 16 years and up to 18 years+.

9. LATE STAGE TRANSITION AND EFFECTIVE TRANSFER TO ADULT SERVICES: A PLANNING FRAMEWORK, PATIENT QUESTIONNAIRE AND TRANSITION ASSESMENT/PLAN

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

9.2 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 (see section 11, Table 4, p.18).

9.3 Discussion with the young person at late stage transition should be recorded using the transition assessment/plan (see **Doc: NWCHDN_11.3.3**). By now, 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 indicated on the assessment. Any actions agreed, goals set, referrals made or information (such as leaflets) given to the young person during the discussion should be recorded on the assessment.

9.4 The patient questionnaire for late stage transition can be used to support this process (see **Doc: NWCHDN_11.4.3**).

9.5 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 made available for all clinic appointments throughout late stage transition.

9.6 This assessment will follow the patient into adult services.

10. TRANSFER OF CARE TO ADULT SERVICES

10.1 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.

10.2 For young people with complex CHD, patients were it is anticipated that they may require surgery or intervention in the next 12 months or patients with learning disabilities and complex needs with multiple teams involved in their care a referral should be made to the formal Handover Clinic. In this clinic a formal medical handover of care will be facilitated through an MDT approach with both Paediatric and Adult Cardiologists in attendance. The YP Specialist Nurse and ACHD Nurse Specialist will also be available to support the patient and family.

10.3 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 ACHD Nurse Specialists and must include as a minimum:

Information required	Details
Demographics	Include parents/carers details State if has LD or special needs
Cardiac Diagnosis	e.g. Fallot – RVEDv abs/indexed + PR + EF +/- stenotic elements coarctation – presence of stenosis/aneurysm AR root dimensions etc
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
Specialist Investigations (MRI/CT) dates and key points	Include relevant reports
List of current medications and recent changes prior to transfer	
Current status at time of transfer	

10.4 A comprehensive management plan will be given to the young person and a copy sent to their GP.

10.4 For young people with moderate and simple ACHD a referral should be made directly to the routine ACHD Clinic. 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 YP Specialist Nurse in the same way.

11. A PLANNING FRAMEWORK FOR LATE STAGE TRANSITION AND TRANSFER OF CARE (16 YEARS TO 18 YEARS)

Table 4: A Planning Framework for Late Stage Transition

A Planning Framework for Late Stage Transition (to be started at age 16 years and continued up to age 18 years+)	
What Should Happen?	**Who Should Do It?**
Routine medical appointments to continue as normal	Medical staff
Offer appointment in young people'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 services	ACHD nurse specialist
If on warfarin – liaise with anticoagulation service for review of how they are managing and issues with compliance and identify where follow-up management will occur	YP Specialist Nurse
If patient has learning difficulties 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
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. 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 ACHD management plan completed and given to patient	YP Specialist Nurse/ACHD nurse specialist
Ensure ACHD patient information leaflets are given to patient	YP Specialist Nurse/ ACHD nurse specialist
Give copies of latest ECG and clinic letters to patient	YP Specialist Nurse/ ACHD nurse specialist
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 Congenital Cardiologist and YP Specialist Nurse/ ACHD Nurse Specialist

Support and help parents/carers through this process	YP Specialist Nurse/ ACHD Nurse Specialist
Ensure referral letter sent to appropriate Adult Cardiologist as per agreed plan and copied to GP	Paediatric Cardiologist/ Paediatric Cardiac Secretary
Ensure all relevant documentation is transferred to appropriate adult services	Paediatric Cardiac secretary
Ensure new appointment issued in adult service	ACHD team secretary
YP Nurse Specialist to follow care through to adults for at least first two appointments if required	YP Specialist Nurse
Sign off transition pathway once completed	ACHD Nurse Specialist

12. ACHD REFERRAL PATHWAY TO GUIDE WHERE TO REFER PATIENTS:

(Please refer to APPENDIX A for referral details)

Paediatric Clinics
Alder Hey
Wigan
Arrowe Park
Isle of Man
Chester

Liverpool Heart & Chest Hospital
Dr Damien Cullington (ACHD Clinical Lead)
Dr Petra Jenkins (ACHD)
Dr Vasileios Papaoiannou (ACHD)
Dr Jaspal Dua (ACHD)
Dr Reza Ashrafi (ACHD/EP)
Dr Sarah Elgamal (ACHD)

Paediatric Clinics
Royal Manchester Children's
Blackburn/Burnley
Bolton
Crewe
Wythenshawe
Stepping Hill
Macclesfield

Manchester Foundation NHS Trust
Manchester Royal Infirmary
Dr Damien Cullington (ACHD Clinical Lead)
Dr Jaspal Dua (ACHD)
Dr Petra Jenkins (ACHD + PH)
Dr Vasileios Papaoiannou (ACHD + PH)
Cardiologists with a special Interest
Professor Bernard Clarke
Dr Matt Daniels
Dr Paul Atkinson

Manchester Foundation NHS Trust
Wythenshawe Hospital
Dr Reza Ashrafi
Dr Anita MacNab

Paediatric Clinics
Barrow-In-Furness
Preston
Lancaster
Blackpool

Blackpool Victoria Hospital
Blackpool ACHD Clinic
Dr Vasileios Papaoiannou (ACHD)
(send referral to LHCH FOA of ACHD clinic at Blackpool)

Paediatric Clinics
Bangor
Wrexham
Glan Clywd
Abersywyth

→

Wrexham Maelor Hospital
Wrexham ACHD clinic
Dr Raj Thaman
Dr Petra Jenkins (LHCH)

Patients to be Referred directly to ACHD Clinics at Level 1 and Level 2

Patients with complex CHD should be referred centrally to MRI or LHCH this includes

- **Fontan**
- **Palliated CHD**
- **Cyanotic patients**
- **Pulmonary hypertension**
- **Pts where upcoming surgery is planned**
- **Pts with learning disabilities or significant comorbidities**

Inherited Cardiac Conditions and Aortopathy

Patients with inherited cardiac conditions should be referred on to the regional ICC clinics at LHCH (Drs Derick Todd and Rob Cooper) or MRI (Prof C Garrett, Dr Luigi Venutucci and Dr Matt Daniels) or the cardiologist looking after other family members

Patients with aortopathy can be referred to ICC or ACHD

Cardiac Maternity Clinics

Joint Obstetric Cardiac Clinics (JOCC)

St Mary's Hospital Manchester
Dr Sarah Vause/Dr Anna Roberts/Prof Bernard Clarke/Dr Damien Cullington/Prof Bernard Keaveney

Liverpool Women's Hospital
Dr Devender Roberts/Dr Ian Peart/Dr Vishal Sharma

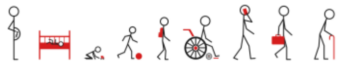
13.1 Activity levels in the following clinics needs to be recorded and available to be monitored

- The Young Person’s Clinic
- The formal Handover Clinic
- ACHD Nurse Led Transition Clinic
- ACHD Medical Clinic

14. AUDITING TRANSITION SERVICE PROVISION AND EVALUATION

13.1 Quality Indicators will be monitored locally and nationally via a national patient satisfaction survey

13.2 Key performance indicators need to be reported to the North West, North Wales and Isle of Man CHD Network. These need to include loss to follow up rate.



Appendix A

ACHD Clinics and Contact Details

(please ensure ACHD Nurse Specialist are copied into correspondence)

Hospital	Contact	Telephone Number
Liverpool Heart & Chest Hospital NHS Foundation Trust Thomas Drive Liverpool L14 3PE *(ACHD Level 1 Centre for North West of England, North Wales and Isle of Man)*	**ACHD Cardiologists:** Dr Damien Cullington (Clinical Lead) Dr Sarah Elgamal (imaging) Dr Jaspal Dua Dr Petra Jenkins Dr Reza Ashrafi (EP) Dr Vasileios Papaioannou	Switchboard: 0151 600 1616
	Anna Harrison and Fiona Andrews Specialist Nurse - Adult Congenital Heart Disease	Tel: 0151 254 3333 Mobile: 07542229889
Manchester University Foundation Trust, Manchester Heart Centre, MRI, Oxford Road, Manchester, M13 9WL *(ACHD Level 2 Centre for North West of England, North Wales and Isle of Man)*	**ACHD Cardiologists** Dr Damien Cullington (Clinical Lead), Dr Jaspal Dua Dr Petra Jenkins (PH) Dr Vasileios Papaioannou (PH and general ACHD) **Cardiologists with a special interest in ACHD** Dr Paul Atkinson, Dr Matt Daniels, Professor Bernard Clark	Switchboard: 0161 276 1234
	Laura Jole and Sophie Howard Specialist Nurses - Adult Congenital Heart Disease	0161 276 1234 Bleep: 6994 Vocera: ask for ACHD Nurse
Manchester University Foundation Trust, University Hospital of South Manchester Southmoor Road, Wythenshawe M23 9LT	**ACHD Cardiologist** Dr Reza Ashrafi **Cardiologist with a Special Interest in ACHD** Dr Anita MacNab	Switchboard: 0161 998 7070

(ACHD Level 2 Centre for North West of England, North Wales and Isle of Man)	Laura Jole and Sophie Howard Specialist Nurses - Adult Congenital Heart Disease	0161 276 1234 Bleep: 6994 Vocera: ask for ACHD Nurse
Blackpool Fylde and Wyre Hospital, Whinney Heys Road, Blackpool, FY3 8NR, *(ACHD Level 3 Centre for Lancashire and Cumbria)*	**ACHD Cardiologist** Dr Vasileios Papaoiannou *(Refer to LHCH FAO of Blackpool ACHD)*	Tel: 0151 254 3350
	Specialist Nursing Team – Adult Congenital Heart Disease via the helpline at Liverpool Heart & Chest Hospital	Tel: 0151 254 3333
Betws Cadwalader University Health Board – Wrexham Maelor Hospital, Croesnewydd Road, Wrexham, LL13 7TD *(ACHD Level 3 Centre for North Wales)*	**Consultant Cardiologist with an interest in ACHD** Dr Raj Thaman **ACHD Cardiologist** Dr Petra Jenkins (Based at LHCH)	Tel: 01978 727 801
	Nicola Coates Specialist Nurse - Adult Congenital Heart Disease	Tel: 01978 727 801

Appendix B

Comments from young people and their families on current and future transition services in the region

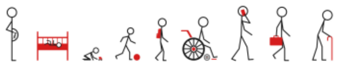
Prior to the development of this protocol a workshop was held in May 2005 with young people and their families to discuss current and future transition services. This workshop highlighted particular issues that have been considered in the development of this protocol.

This is what young people and their families said about the current transition process:

- The transition process is not always understood by young people, their parents/carers or professionals, and the referral pathways are not always clear.
- Young people and their families do not have one person they can call to assist them through the transition.
- The transition process can feel very stressful because there appears to be a lack of planning ahead.
- The expectations of young people are often not well managed, and they are not always well informed.

This is what young people and families said would improve the transition process:

- The transition plan should be more holistic and include social, employment, leisure and education opportunities.
- Young people want to feel that they are listened to as an equal partner in the transition planning.
- Young people and their parents/carers want to have access to a key worker who oversees the whole process and guides them through the transition.
- Young people want to have consistent, accessible and easy to understand information on the transition process and on their condition, medication, treatments and tests to help them make their own choices.
- The young person’s voice should always be listened to and be at the centre of the process.



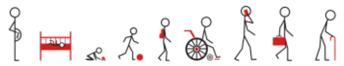
Appendix C

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

Frequency of clinics will increase as the CHD service expands

Royal Manchester Children's Hospital Paediatric cardiology and adult congenital cardiology transition clinics are held for young people with complex ACHD at 16 years to 18 years to support transfer of care.	
Who	Paediatric Cardiologist, Adult Congenital Cardiologist, Paediatric Cardiac Nurse Specialist/Transition Nurse and Adult Congenital 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 Young People's clinics once a week
How	All referral letters to be copied to the Transition Nurse Specialist for co-ordination of care

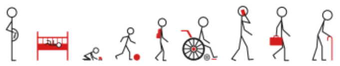
Alder Hey Children's NHS Foundation Trust Paediatric cardiology and adult congenital cardiology transition clinics are held for young people with complex ACHD at 16 years to 18 years to support transfer of care.	
Who	Paediatric Cardiologist, Adult Congenital Cardiologist, Paediatric Cardiac Nurse Specialist/Transition Nurse, Adult Congenital Heart 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 Young People's clinics 3 x a week
How	All referral letters to be copied to the Transition Nurse Specialist for co-ordination of care



Appendix D

List of Abbreviations

ACHD	Adult Congenital Heart Disease
DH	Department of Health
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
GUCH	Grown Up Congenital Heart Disease
INR	International Normalized Ratio – a blood test which measures the time it takes for blood to clot and compares it to an average
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
N/A	Not Applicable
NHS	National Health Service
NICE	National Institute Clinical Excellence
NSF	National Service Framework
PCLN	Paediatric Cardiac Liaison Nurse
PE	Physical Education
POC	Point of Care – a term used for a test which is performed for or by a patient outside of the usual laboratory setting



SENCO	Special Educational Needs Coordinator
SpR	Specialist Registrar

Appendix E

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