1. Introduction and Who Guideline applies to

Transition in this context is the method of preparing young people and their patrents/carers to move to management under the adult services within immunology

This Transition guideline sets out the processes within the immunology service for preparing young people and their parent/carers for moving from children's to adult immunology services within UHL, starting with young persons from 14 years of age at the discretion of the members of the Children's Immunology Team.

This guideline applies to all staff, medical and nursing, within both the paediatric and adult immunology team. Secretarial staff have a supportive role in distributing clinic letter.

2. Guideline Standards and Procedures

This tranistion standard adheres to the UHL policy and flowchart by establishing an individualised plan for transition and is aligned with NICE guidance on transition (see references below)

2.1 When do we start the transition process?

Not all young people in our service need to go through transition. The individual circumstances of each patient is assessed through clinical judgement and shared discussions between the young person, parents/carer, medical and nursing staff.

Transition is usually intiated from 14 years of age, but may be delayed for reasons such as an acute episode of illness or an unsettled family environment. However, it commonly begins before the young person turns 16 years of age.

2.2 Referral to the Adult Immunology Service

Once the young person has been identified as requiring transition to the adult immunology service, and has reached the age criteria, the proposed change in service provision is discussed in the Primary Immuodeficency Multidisciplinary Team meeting (PID MDT) which convenes on a monthly basis, excepting rare postponements to the following month. The young person will then be offered follow up appointments in the Paediatric Immunology transition clinic (Immtrans).

2.3 Out Patient Clinics - Transition

Immunology transition clinics are held four times each year in March, May, September and November within the Children's Out Patients' Department (COPD). Health professionals supporting the clinic include the paediatric team – Consultant Paediatrician with interest in Immunology, Children's Immunology Specialist Nurse, Adult Immunology Consultant, Adult Immunology Registrar, Adult Immunology Specialist Nurse.

The transition process is co-ordinated on an individualised basis to meet the specific needs of the young person and family to progress through the three stages of preparation: 'Think, Signal, Move'.

The young person is offered an initial appointment in a 'Transition' clinic. Appointments last for an hour comprised of 30 minutes medical review and 30 minutes nursing advice and information on taking responsibility for their own health, management and follow up. Details and douments to assist the young person and family through transition are given out at the first transition clinic appointment as a 'Patient held record.' Issues regarding consent to treatment and confidentiality are discussed and explained. Referral letters from Paediatric Consultant to the Adult Immunology

Service Consultant are expected to include relevant information about investigations, management and planned follow up.

Clinic letters should be copied to the doctor and nursing team to ensure the young people receive appropriate ongoing manamgent throughout the transition period.

At their penultimate clinic visit at Children's Out Patients (COPD), the young person will have further discussion about their final appointment and eventual transition to the adult service. The date for their clinic appointment with the adult service will be discussed, and when they can expect to receive details of it**.**

The family contact details are accessible via the UHL NHS Trust records management system which can be accessed by the Immunology secretaries.
Members of the Immunology Department have access to all the clinic letters which include demographic details about the young person and their named GP. These can be confirmed for the Adult Team at joint clinic appointments in the COPD prior to transfer and transition.

A formal referral letter is completed following the final transition appointment in the paediatric setting to facilitate the scheduling of the first adult immunology appointment.
The adult specialist (doctor and/or nurse) who saw the patient in COPD should also be present at the first adult clinic appointment to provide continuity.

2.4 Immunoglobulin Therapy

All patients with immunological problems and diagnoses including primary immune deficiency are discussed in the Immunology Multidisciplinary Team meeting. This team meeting assesses and evaluates the management and treatment of all patients with primary immune deficiencies before granting approval for immunoglobulin therapy. The responsibility for continuing immunoglobulin therapy will be transferred to the adult service following completion of the transition process. Young people with complex immune deficiencies may have care provided and co-ordinated by other NHS hospitals, in some cases the managment and delivery of immunoglobulin replacement therapy.

2.5 Intravenous Therapy

Some adolescents may receive hospital based intravenous immunoglobulin on the Children's Day Care Unit within the Children's Business Unit of UHL NHS Trust. These young people should be offered the opportunity to have an introduction to the site and location of the adult immunology service where they will continue to receive their immunoglobulin infusions. Consent will need to be obtained from the young person to continue the administration of immunoglobulin therapy and discussions about the possibility of changing to subcutaneous therapy.

2.6 Home Therapy – Subcutaneous and Intravenous Therapy

Young people already established on home therapy by the Children's Immunology Service will have their immunoglobulin prescribing taken over by the adult service. These will be overseen during the interim period between final paediatric appointment and first adult immunology assessment by the Paediatric team. Prescribing will remain the responsibility of the Children's Immunology Nurse Specialist and Consultant until their first visit to the adult immunology clinic. Timing of this must be arranged properly to ensure IV or SCIg supply is maintained and no infusions are missed. Their delivery arrangements may change if an alternative homecare provider is used by the adult service; and any new details including registration with the new provider will be discussed with the young person and family.

The adult immunology team, and especially Nurse Specialists will need to be informed of the immunoglobulin products prescribed for the young person, the dose, number of sites and ancillary equipment provided. Where the parent/carer has been trained in providing immunoglobulin

therapy at home the time will come when the young person will need to receive training in self administration or consider the need to attend for hospital based therapy.

An approach will be made to other NHS hospitals to confirm homecare and prescription provision where the young person's immunolglobulin therapy has been managed elsewhere.

2.7 Adult Immunology Clinics

The adult team should inform the Children's Immunology Nurse Specialist of the young person's first appointment with the adult service to provide a recognisable face in the department. This first appointment would be the time to confirm decisions about confidentiality and whether their parent/carer attends and remains present during consultations.

2.8 Contact with the Immunology Team

The Immunology Service is structured in a way that Nurse Specialists work together in shared office space with a shared telephone extension (0116 258 6711). The secretarial team work between both services preparing clinical letters (0116 258 6702). Access to advice and support should therefore remain unchanged with requests for information and troubleshooting readily accessible.

3. Education and Training

None – part of medical and nursing clinic reviews

4. Monitoring Compliance

What will be measured to monitor compliance	How will compliance be monitored	Monitoring Lead	Frequency	Reporting arrangements
Identification of young people for transition by Paediatric Team, discussion in PID MDT and transition clinic appointments	Provision of clinics and attendance rates	Dr Radcliffe	12 months	Review of PID MDT minutes, clinic attendances & cancellations; Feedback to PID MDT
Documentation – Clinic letters	Review ICE letter content re plans for transition and flow through transition process	Dr Radcliffe	12 months	Review in PID MDT
One page profiles	Checking of immunology drive transition document file and evidence of distribution	Dr Radcliffe/ RCawthorn	12 months	Feedback to PID MDT

5. Supporting References

NICE (2016) 'Transition from children's to adult services' Quality Standard [QS140] published December 2016

University Hospitals' of Leicester NHS Trust (2016) 'Transitional Care UHL Policy' [last approved August 21st 2020; next review 2024]

Royal College of Nursing (2013a) Adolescent transition care: guidance for nursing staff (2nd edition)', London: RCN.

Royal College of Nursing (2013b) 'Lost in transition: moving young people between child and adult health services', London: RCN.

6. Key Words

Transition; Immunology; Think, Signal, Move

CONTACT AND REVIEW DETAILS	
Guideline Lead (Name and Title) Dr. Radcliffe, Consultant Paediatrician and R.Cawthorn, Children's Immunology Specialist Nurse	**Executive Lead** **Medical Director**
None	

Appendix 1: Transition Process

1. Children with an immune deficiency attending Paediatric Immunology clinics between the ages of 14 and 16 years identified for transition to adult services will be added to the agenda and discussed in the Primary Immunology Deficiency Multidisciplinary Team (PID MDT) meeting within the UHL NHS Trust Leicester Royal Infirmary.

2. When the young person and parent/carer(s) attend their follow up appointment in the Children's Out Patients' Department (COPD) they will be informed of the need for ongoing management and treatment to be transferred to the adult immunology service by the time they reach 18 years of age.

3. The Consultant Immunologist responsible for Paediatric Immunology Services will review the management, treatment and diagnostic investigations that have been undertaken and consider the need for further investigations prior to transition to the adult service.

(The value and importance of requesting blood testing specific to immunology such as total immunoglobulin levels, pneumococcal serotypes and lymphocyte markers; whether there is any value in offering booster immunisations prior to transition; high resolution CT imagery of chest or chest x-rays will be considered.)

A review of blood test results, incidence of infections and immunoglobulin therapy will allow decisions to be made about any changes to prophylactic antibiotics and immunoglobulin infusions.

4. The investigations, diagnostic tests, management and treatment will be documented in their medical notes as a summary of treatment and planned care.

5. At their next appointment the proposed management plan will be discussed with the young person and their parent/carer; with any appropriate investigations being arranged to take place prior to transfer.

6. A referral letter will be written to the lead Consultant Immunologist in the adult service with copies to the patient's GP and the adult nurse specialists – detailing diagnoses, current management, planned investigations, ongoing treatment and proposed clinic follow up.

7. The Children's Nurse Specialist will liaise with the adult nursing service regarding the young person's hospital and clinic attendance to facilitate their attendance to meet the young person and their carer.

8. Issues relating to the transition process will be discussed in their transition clinic appointments with the young person and parent.

9. The Children's Nurse Specialist will maintain responsibility for managing the Homecare prescription or facilitating hospital based intravenous infusions until the young person has attended their first Out Patient appointment in the adult service.

10. Whenever possible, the Children's Nurse Specialist will attend their first adult service out patients' appointment with the family to provide a recognisable face during initial transition.

11. Advice, contact and support with the young person will be maintained as the Nurse Specialists' share office accommodation and telephone extensions.

12. Changes to the provision of immunoglobulin prescriptions and ordering will be sent to the hospital pharmacy with regards to hospital based infusions and the homecare provider for those receiving home therapy. (The Homecare provider and nursing team need to be made aware of their relative contacts and ordering/delivery process. – it may be necessary to

register patients with a new service provider on transition allowing for a 12 week transfer period between deliveries.)

13. The transition process and individual patient progress will be discussed in the Primary Immune Deficiency Multidisciplinary Team meeting at appropriate intervals as transition progresses noting the timing of the next appointment, proposed first adult clinic appointment and transfer date to adult services and date of completion for transition being 6-9 months after their initial adult service appointment.

14. The process will be audited using two approaches:

    - a Patient Experience feedback questionnaire to determine where the transition works well, the failings in the procedure for the individual, what could have been improved, and whether any aspects of transition were felt to be missing

    - a departmental review of the procedure followed and if any steps in the process had been missed using a criteria based checklist of the process and comments for aspects of management and treatment prior to, during and after transition that were beneficial or unnecessary

15. The transition experience and procedure will be discussed in the Primary Immune Deficiency Multidisciplinary Team meeting once the process has been completed and audit data submitted to the UHL hospital audit departmental team. The UHL Clinical Audit team will be asked to develop the audit tools to facilitate their analysis of the returning data. CASE team no longer exitis.

Appendix 2: Transition Checklist

1. Paediatric Immunology Team (Consultant and Nurse Specialist) identify adolescents and young person between the age of 14 and 16 due for transfer.
2. Decision made by Paediatric Immunology Team about appropriate transition period.
3. Adolescent/ young person discussed in the Primary Immune Deficiency Multidisciplinary Team meeting with regards to the need to transition to the adult service.
4. The need for transition to the adult service is discussed with the young person and their primary carer (parent/guardian) during their Out Patients' Clinic appointment:
5. During the appointment current management, planned changes to management and treatment, and the need for additional interventions and investigations prior to transition are discussed and arrangements made to undertake these procedures and a follow up appointment time decided upon
6. A copy of the Clinic Letter is sent to the Lead Adult Immunology Consultant, Nurse Specialist, GP and parent/guardian detailing diagnosis, current management, proposed investigations, ongoing management, and planned follow up.
7. The young person is booked into the Transition clinic in the Children's Out Patients' Department. The young person's health is reviewed, the completion of investigations requested is confirmed and all medication doses are also reviewed and amended where necessary. A follow up appointment with the Children's Service is discussed and planned for 3- 12 months time.
8. The Clinic Letter is copied to the Adult immunology Service, GP and parent/young person.
9. An Adult Immunologist and Nurse Specialist are invited to attend as part of the young person's transition appointments so that they can meet and be introduced, share important contact details and discuss concerns about transition. (Nurse Specialists may be able to meet the young person during attendance for hospital based infusions if they are recipients of immunoglobulin therapy prior to transition for young persons' receiving home immunoglobulin infusions. Future follow up is discussed with the timing of final Paediatric follow up and proposed first adult service appointments being discussed.
10. The young person attends a final Out Patients' appointment within the Children's Service offering another opportunity to review management, discuss transition and meet the adult nurse specialist. The date of the first adult appointment is reviewed.
11. A Clinic Letter detailing the clinical assessment and established transition appointment in adult services being sent to the adult immunology team, nurse specialists in adult and paediatric services, GP, young person and parent/carer.
12. The Children's Immunology Nurse Specialist will where possible attend the young person's first adult immunology service appointment.
13. Transition to the adult service is confirmed with the hospital pharmacy service for provision of intravenous immunoglobulin, the homecare company for home therapy patients and service managers responsible for co-ordinating high cost therapy budgets.
14. 6-9 months after the transition (i.e. the first adult service out patient appointment) an audit tool for feedback regarding the patient experience of transition and a departmental review audit tool are completed in clinic.
15. The completion of transition for the young person is reviewed and discussed at the next PID MDT – amendments to the procedure being discussed.