

What is the Transition Exception Register?

Alder Hey Children's NHS Foundation Trust Transition Exception Register provides a record of young people aged 14 or over, with long term conditions diagnosed in childhood; whose transition to adult services care is, or is expected to be, unavoidably delayed beyond their 18th birthday due to significant differences in healthcare provision between the children's and adult sectors.

The healthcare needs of young people Transition Exception Register are likely to be most appropriately met within the children's sector until these differences have been resolved, or specific circumstances no longer apply. In some instances, this may mean caring for a young person aged 18 or over in a paediatric inpatient unit (Alder Hey or a District General Hospital) based on risk assessment by the young person's consultant(s) at the time of admission: their case should be considered on an equitable basis as compared with a young person aged 14 – 17 years with similar needs.

Young people age 16 or over on the Transition Exception Register and requiring referral for a new condition or problem would be expected to be directed to adult services; supported if necessary, by in-reaching by children's services.

Why do we need the Transition Exception Register?

The Transition Exception Register has three purposes:

- To provide assurance for the young person and their family that their healthcare needs will continue to be met
- To provide a method of actively managing transition for patients who remain, or are expected to remain, under the care of the Trust beyond normal transition age: allowing active discussion with adult providers and commissioners to ensure that appropriate services are identified or developed
- To enable young people of 18 or over to be identified within the Trust ensuring that their additional needs are met including requirements for safeguarding, privacy and dignity.

Which patients should be included on the Transition Exception Register?

All young people aged 14 or over, with long term conditions diagnosed in childhood; whose transition to adult services care is, or is expected to be, unavoidably delayed beyond their 18th birthday should be notified to the Transition Team using the Transition Exception Register application form.

Young people are likely to be eligible for inclusion on the Transition Exception Register if one or more of the following apply:

1. There is no appropriate target service due to a relative or absolute lack of skills and experience with this type of patient in the adult sector.
 - a. Rare conditions not normally seen in adult patients
 - b. Complex neuro-disability: profound learning disabilities and multiple complex long term conditions

Young people who are expected to fall into this category should be referred to the Transition Exception Register as soon as they reach transition age (14 years and over, Section 5.1) in order to allow maximum time to develop appropriate target services in the adult sector.

2. Transition is delayed or paused due to patient instability
 - a. Life threatening illness or palliative care
3. Conditions requiring ongoing treatment at Alder Hey beyond the age when transition is normally completed
 - a. The commissioned patient pathway specifies Alder Hey as the provider of care to young people aged 18 or over e.g. young people aged 18 – 23 on active treatment for paediatric malignancies
 - b. The patient is enrolled in a clinical trial necessitating continued follow up by Alder Hey beyond the young person's 18th birthday e.g. some rheumatology patients

Young people will only be eligible for inclusion on the Transition Exception Register if there are genuine and compelling reasons why they cannot be safely transitioned to adult services. The Transition Exception Register is not an excuse for professionals not fulfilling their duty in transitioning patients in a timely fashion. The ultimate decision to include a patient on the Transition Exception Register will be made by the Medical Director who is the Trust Executive Lead for Transition

How long can patients remain on the Transition Exception Register?

Young people will automatically remain on the Transition Exception Register until transition is completed, specific circumstances no longer apply or until their 18th birthday. Young people aged 18 and over can remain on the Transition Exception Register for a period of 6 months in the first instance. Extensions may be granted in exceptional circumstances as long as the patient continues to satisfy criteria for inclusion on the Transition Exception Register and, where appropriate, professionals have engaged with the Trust, commissioners and adult providers to address the differences in healthcare provision between the children's and adult in order to facilitate transition.

How can I find out if a patient is on the Transition Exception Register?

The Trust transition team holds a record of all young people on the Transition Exception Register. Young people on the Transition Exception Register will have a Special Indicator on Meditech 6 and a Transition Exception Register letter in the Critical Patient Management Letters folder on Image Now. This letter will also be copied to the young person so that they can bring it with them when they attend the hospital.

How can I refer a patient for inclusion on the Transition Exception Register?

Contact Transition Nurse Jacqui.Rogers@alderhey.nhs.uk or
Clinical Lead for Transition Lynda.Brook@alderhey.nhs.uk