Executive Summary

Complex Needs Transition Journey

The transition from paediatric to adult services can be a frightening and confusing time for young people, their families and carers. Paediatric teams often have more flexibility and are able to take an holistic, whole person approach rather than a condition or organ specific focus. The new clinical teams often don't have in-depth knowledge of a young person's complex condition.

All professionals should strive to provide developmentally appropriate healthcare **Northumbria toolkit** up to aged 25 years. To assist with this the North East and North Cumbria (NENC) Transitions Regional Core Steering Group have developed an aspirational transition pathway known as the '**Journey to Adult Healthcare**'. The NENC 10 Stage Transition Journey builds on the work of the North West Transition Network and Alder Hey NHS FT and is based on the **10 Steps to Transition Framework**, with their support and permission. Further development work has been undertaken to consider the enhancements that may be required when a Young Person has complex or multiple needs.

The overview below provides some key information about the considerations within each of the steps of the journey

Step 1: Identify YP Needing Transition

Step 1 is all about local understanding of patient population and the identification of those individuals who may require additional support and considering the needs of the parents/carers. The elements of this step relate to:

- Considering long-term health needs for those aged 14+ and those who might need regular follow-up, those under both physical and mental health teams, those with moderate to severe learning disabilities, or complex care needs.
- Discussing transition with YP and carers, signposting to relevant information, and identification of a key worker and understanding the needs of the YP and their parent/carer
- Referring complex cases to a transition team, including transition in clinic letters, and the early involvement of primary care.
- Ensuring that transition is part of the Education Health and Care Plan and discussing consent and confidentiality regularly.

Step 2: Empower YP to Develop Self-Care Skills

Step 2 is about supporting young people to understand their conditions and needs and providing them with the tools they need to be able to manage their health and supporting them to feel confident in doing so. This includes:

- Introducing programs like Ready, Steady, Go (RSG) to help YP and carers.
- Supporting the creation of "About Me" documents, assessing the ability to complete RSG, and discussing self-management skills.
- Encouraging YP to manage prescriptions via the NHS app and review their understanding of conditions and medications.
- Involving YP in the development of new services and promoting developmentally appropriate healthcare.

Step 3: Begin Transition Plan

Step 3 is about developing personalised transition plans at an appropriate time for the YP and their family and captures key information that they will need as they move to adult healthcare services, this is mainly concerned with identifying the needs and how they will be supported once they have moved to adult services. Considerations within this step are:

- Identifying areas of anxiety and reviewing medication and transition planning with YP and carers.
- Developing a transition plan, ensuring YP knows key contacts, and documenting the stages of transition.
- Reviewing the YP's understanding of their condition and updating the Emergency Health Care Plan (EMHCP) as needed.
- Developing policies for developmentally appropriate healthcare for admitted YP.

Step 4: Review the Multi-Disciplinary Team (MDT)

Step 4 is about identifying appropriate colleagues from across the health and social care system to support with the transition process and includes:

- Identifying professionals involved and incorporation of other transition plans from other parts of the education health and social care system.
- Involving school nurses and other professionals who may already be partners in care and treatment
- Arranging MDT meetings, identification of key workers, and completing health passports.
- Encouraging uptake of Annual Health Checks and ensure communication methods are appropriate.

Step 5: Refer to Lead Adult Service/GP

Step 5 is referring the YP to the most appropriate service/setting and focusses on supporting the development of confidence and trust in alternative services, activities may include;

- Supporting YP and carers in understanding the transition to GP/Primary Care-led care.
- Identifying adult service (where there is one) to take over
- Assessing the patient’s capacity to make informed decisions.
- Completing a detailed transition summary and share with adult teams and Primary Care.
- Providing accessible information about adult services and involving youth workers (where they exist).

Step 6: Joint Review - Children’s Service Leading

Step 6 is concerned with the facilitation of a joint review, which may take place in a specific transition clinic or may be held at a regular clinic appointment but be attended by children's and adult's healthcare teams, considerations include

- Preparing YP for transition to adult services, the use of videos for introductions, and facilitating joint clinics.
- Ensuring the YP is at the center and gradually transition care to adult teams.
- Maintaining confidentiality and supporting the YP in decision-making processes.

Step 7: Plan a Route into Urgent Care

Step 7 Is about ensuring young people know what to do if they become unwell and making sure that primary care teams have been provided with sufficient information to meet their needs, key points include

- Ensuring the YP knows who to contact if acutely unwell and has an escalation plan.
- Discussing routes into urgent care, updating DNACPR if appropriate, and ensuring emergency plans are documented and shared.
- Encouraging proactive MDT involvement to prevent episodes of ill health.

Step 8: YP Confident to Move to Adult Services

Step 8 is about being assured that the YP has been given the support that they need to move to adult services and being able to assess this and to come to a collective agreement between the YP, the childrens and adults teams about the date that they will commence adult services. This includes:

- Confirming that YP and family are ready for transition and documenting plans.
- Allowing flexibility in transition timing and developing and implementing local policies for young adults not brought to appointments.

Step 9: Joint Reviews - Adult Services Leading

Step 9 relates to joint clinics that are facilitated by adult healthcare teams which enables involvement of childrens services and may include:

- Holding joint reviews between childrens and adults services with adult teams leading and ensuring shared decision-making.
- Addressing confidentiality and consent issues, and supporting joint clinics.

Step 10: YP Settled in Adult Services

Step 10 is concerned with transferring the care to adult services, usually before their 19th birthday and being assured that the YP is confidence and has been well supported through each of the steps, this is also about making sure there is opportunity for feedback and that the YP is not discharged from childrens services before partners have satisfied themselves that the YP is settled in adult services. This step includes:

- Ensuring continuity of care with the same professionals where possible, supporting the YP in managing medication, and providing feedback opportunities.
- Monitoring attendance at appointments and following up on feedback to improve transition processes.