

Early Stage T1D National Network Group

Terms of Reference



Principles of working together across the UK paediatric and adult diabetes networks

The Children and Young People's National Diabetes Network (CYPNDN) and the Association of British Clinical Diabetologists (ABCD) is a collaborative group of paediatric and adult clinicians and respective multi-disciplinary team (MDT) members coming together to share good practice to improve children, young people and adult diabetes care in early-stage type 1 diabetes through the Early Stage Type 1 Diabetes network. Its purpose is to ensure that every child, young person and adult in England and Wales, regardless of ethnicity, gender, family income or location, has access to the same high-standard care and achieves the best quality of life possible. It is expected that information and resource outputs will be shared freely across the organisations and within the spirit of collaborative working both within the network and the wider NHS system and across adults and paediatrics, including the critical transitional care period. The 11 networks of the CYPNDN namely: East Midlands, East of England, North East and North Cumbria, North West, South East Coast and London, South West, Thames Valley, Wales, Wessex and Yorkshire and Humber will work collaboratively.

Purpose

The National Diabetes Early-Stage Type 1 Diabetes (EST1D) Working Group was established in 2026 to improve care and outcomes for everyone with EST1D. We work to ensure that everyone with EST1D will have equitable access to early identification and multidisciplinary care with a focus on monitoring progression and access to therapies (both licensed and through clinical trials) ensuring better outcomes including prolonging the period before insulin therapy is required, reduction in diabetic ketoacidosis, long-term HbA1c, quality of life and mitigating the psychosocial impact of T1D

The pre-symptomatic Type 1 Diabetes Special Interest Group (adopted by BSPED) was established in 2025. Membership of this National Working Group has therefore been extended to include representation from paediatric diabetes services in Scotland and Northern Ireland. Therefore, these Terms of Reference should be read in conjunction with the BSPED Special Interest Groups Terms of Reference.

Traditionally the work of the CYP National Diabetes Network has a remit to support the care of children and young people until they transition into adult services, however the National Early-Stage Type 1 Diabetes Working Group will actively support participation from adult diabetes colleagues across the four nations and encourage their inclusion in the activities of the working groups. Similarly, the ABCD has traditionally worked to support the care of adults with diabetes, and in this venture, will work collaboratively with paediatric colleagues to support transition from paediatric to adult care.

Objectives

The National EST1D Diabetes Working Group will work collaboratively to:

- Provide strategic and clinical leadership and expertise on EST1D to the CYPNDN and ABCD
- Provide education, resources and peer support to enable MDTs to deliver comprehensive, holistic care informed by evidence and best practice
- Promote access to the latest treatments and tools e.g. rapid incorporation of new medications into practice
- Ensure CYP and adults have access to resources for self-management
- Develop cultural competency amongst HCPs
- Ensure National Guidance reflects evolving treatment options and knowledge of care
- Increase patient and family voice
- Raise awareness of EST1D testing and referral pathways within Primary Care, Community Health and Secondary Care

Participation

Members agree to:

- Work together to improve the quality of CYP and adult early-stage diabetes care and assist each other in the achievement of agreed priorities
- Work as a member of the Network (not as an individual) in the best interests of the Network
- Report back regularly to local networks
- Be action-focused
- Attend the regular meetings and other special events
- At least one paediatric service representative and one adult service representative from each regional network should be present at each meeting (selected from Medical, Nursing, Dietetics or Psychology MDT colleagues)
- One representative from each Network should be present at each meeting (from Medical, Nursing, Dietetics or Psychology and adult services)
- If a member is absent for a key decision this will be communicated to them by email. If there is no response or comment to this email within the required time, usually a week, agreement will be presumed
- Work in a style that continues to build trust and openness
- Promote effective communication between regions
- Participate in task and finish groups for agreed priorities identified by the EST1D working group, CYPNDN, ABCD and NHSE
- Support participation from NI and Scotland

Meetings

Meetings will be held 4 times per year. These will have a written agenda and minutes will be taken. Meetings will include ongoing actions and business as well as selected expert speakers (where appropriate) and opportunities to update each other. The meetings will enable sharing of good practice.

A quorum of the Chair, representation from at least half of the nations and regional networks and one Network Manager will be required for the meeting to take place.

Membership

- Membership will be made up from:
 - Network EST1D Clinical Leads
 - National Speciality Leadership in EST1D from Medicine, Nursing, Dietetics and Psychology
 - Network-Level Speciality Leadership in EST1D from Nursing, Dietetics and Psychology
 - CYPNDN and ABCD members with an interest in driving forward the standards and outcomes of EST1D care
 - Representatives in UK nations not included in the above categories
- The Chair and Vice Chair will be drawn from the membership. These roles will be rotated, and nominations will be invited from within the group and where there is more than one party interested a voting system will operate
- Length of term for the chair and vice chair lead roles will be 3 years; however, the group can agree to extend for one further term
- Representatives from other disciplines/organisations may also be invited to attend
- Patient and family voice will be included at a time deemed appropriate by the group
- Network Manager/s supporting the workstream as defined within future Network Delivery Plans
- The membership list will be held by the assigned Network Manager/s and made available on request