

## TERMS OF REFERENCE

### 1. Title

Children with Exceptional Healthcare Needs (CEN) Network- Experts by Experience (EBE) Group.

### 2. Reports to

The EBE family engagement group report to the CEN Communication and Engagement Group.

There may be a requirement for a representative from the EBE group to attend other CEN working group meetings to feedback the views of the EBE, adequate notice will be given for such requests.

### 3. Project Objective

The purpose of the CEN EBE group is to provide a key link for parents, carers and families to be represented at a national level, when designing and improving healthcare training and services for children and young people with exceptional healthcare needs ([as defined by the CEN criteria](#)) in Scotland.

The purpose of this group is to use families' experiences to drive service improvement and development **and not** a peer support group. A range of peer support groups can be accessed through third sector organisations a list of which can be found on [the CEN Website](#).

### 4. Roles and Responsibilities of Group

The main initial roles and responsibilities of the group will include;

- Help the CEN team and its Groups understand service users views on current service provision and highlight any opportunities for improvement / celebration – through providing feedback on families' own experiences
- Assist with creating new CEN Patient Care Pathways, using the EBE's own service knowledge to inform the process
- Help to produce communication materials that other families may find useful/informative e.g. leaflets, website content or videos



Chair  
Chief Executive  
Director

Keith Redpath  
Mary Morgan  
Susi Buchanan

*NHS National Services Scotland is the common name of the Common Services Agency for the Scottish Health Service*

## 5. Membership

The EBE group is open to involvement from parents, carers and families (including grandparents, siblings and guardians) who have a child or young person in the family with exceptional healthcare needs.

### Members are involved at one of the following levels:

- Information (keeping up to date with developments)
- Consultation (being asked about developments at a national or local level e.g. being asked about your experience of care, being on a steering group or consulting on documentation etc.)
- Visible (Speaking at conferences / meetings)
- Potential members are asked to register here:

## 6. Chair

Group members agreed to each take a turn at Chairing one meeting. The CEN Team will link in with each member in the planning phase. Each Chairperson will be provided with written guidance and verbal support in preparation for this role.

## 7. Frequency of Meetings

Meetings to be booked bi-monthly, avoiding school holidays, on Tuesday morning's. This arrangement will be reviewed on-going by members.

## 8. Papers

All papers and the agenda will be sent to members 5 working days in advance of the meetings. Agenda items/papers to be submitted to the Chair not less than 10 working days before each meeting, to enable Agenda Planning. Items of urgent business arising after this time will be accommodated with the agreement of the meeting. A minute of the meeting and action log will be issued to members not later than 10 working days following meeting.

## 9. Lifespan

The membership of the group will be reviewed annually with a maximum of three years input for members.

Terms of Reference Agreed: ***CEN EBE Group***

Date: ***15 March 2022***