

# Scottish Paediatric Epilepsy Network CHILDREN'S EXPERIENCE QUESTIONNAIRE RESULTS

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## Background

The Scottish Paediatric Epilepsy Network (SPEN) wanted to establish how children perceive the experience of attending outpatient epilepsy clinic appointments, what they consider to be the positive and negative aspects of clinic visits and what their ideas were for improving the clinic experience.

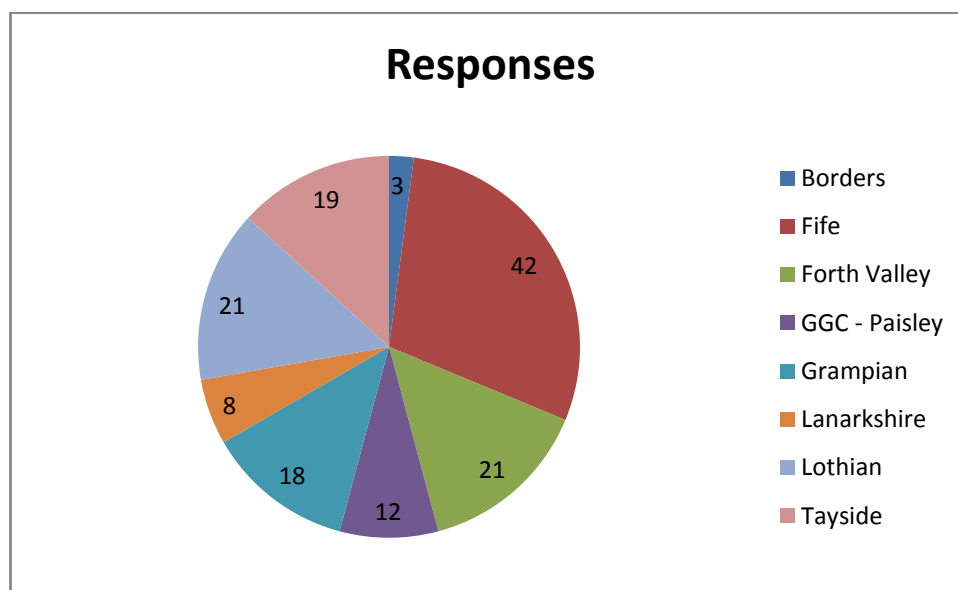
## Method

SPEN adopted a brief clinic experience questionnaire developed and piloted by the Scottish Muscle Network. The intention was that this would be completed by the children themselves, rather than by parents/carers or healthcare staff. The questionnaire was made available through all paediatric epilepsy clinics in Scotland between 5 September 2016 and 30 November 2016.

## Results

Responses were collated and analysed centrally by the SPEN network office.

Responses: 144 responses were received in total. There were variations in response to the survey due to staff sickness in some areas resulting in fewer clinics being held during the survey period. Responses by Health Board are shown in the chart below:



Demographics: The average age of respondents was 11 years (range: 2 to 19 years). The wide age range from 2 to 19 years suggests that the questionnaires were likely not always completed by the children themselves. As such, some responses may perhaps reflect parental views more than the views of the child.

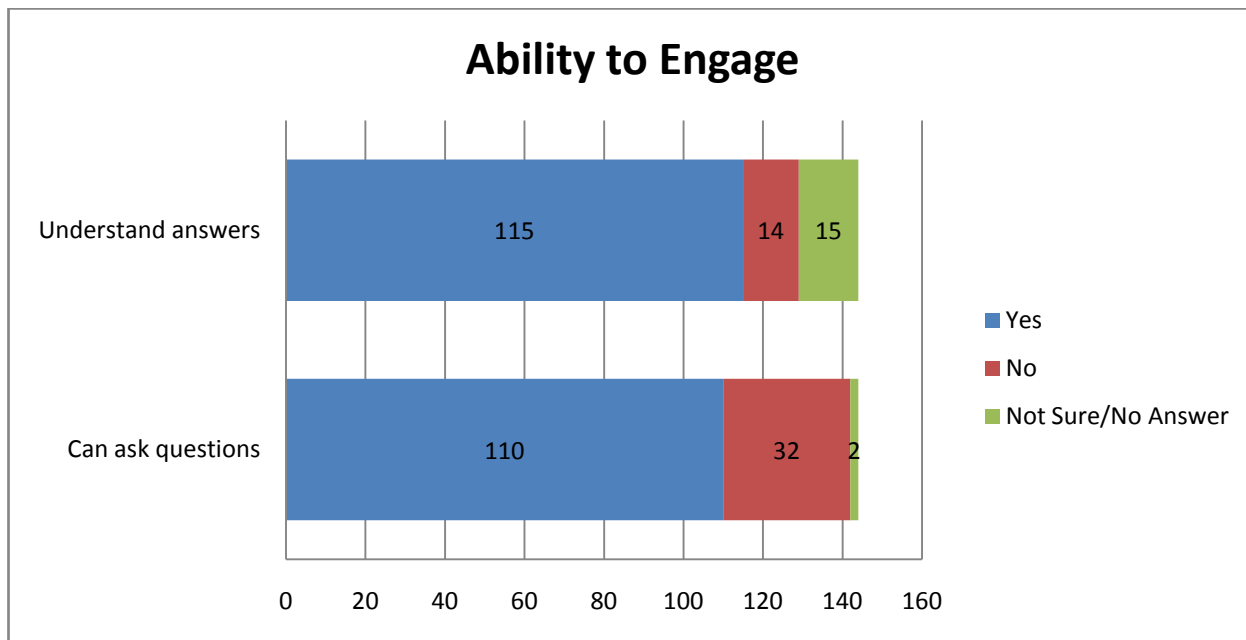
Reason for Clinic Visit: Children were asked which healthcare professional(s) they were expecting to see at clinic. Responses were as follows:

To see doctor	103
To see nurse	51
To see dietitian	3

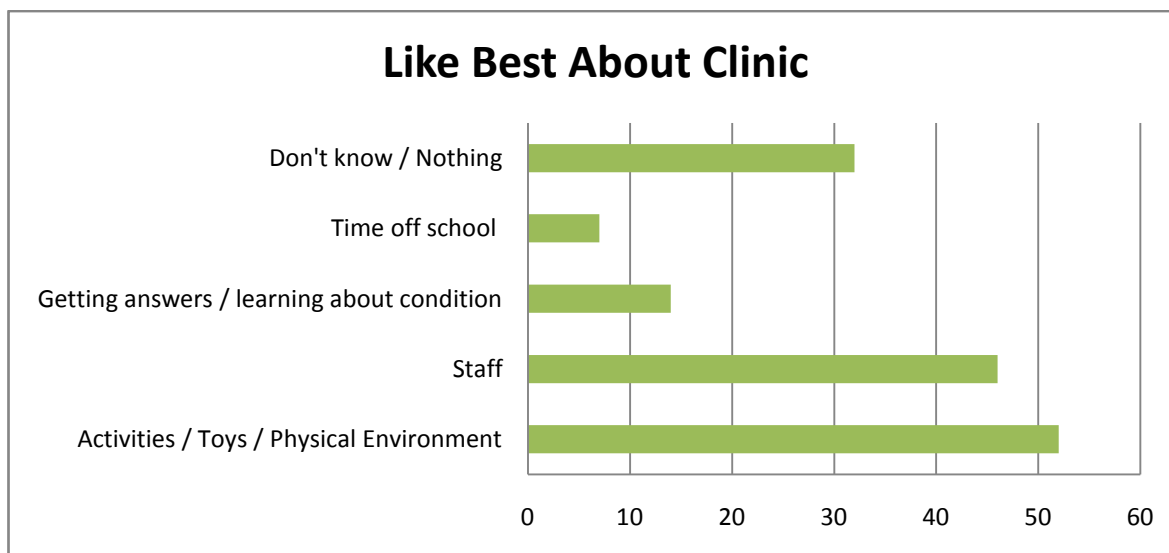
However, 3 respondents indicated that did not know or did not care who they were at clinic to see.

**Ability to Engage:** Children were asked about their ability to ask questions at clinic and whether they understood what was discussed at clinic.

The majority of responses suggest that clinics are successful at enabling the children to be actively engaged in the discussion.



**Clinic Experience:** Respondents were asked to highlight specific aspects of their clinic that they particularly like or disliked, as well as suggest potential improvements. Answers to these questions have been themed in the analysis. The most main themes emerging from the questionnaire responses are presented in the charts below:

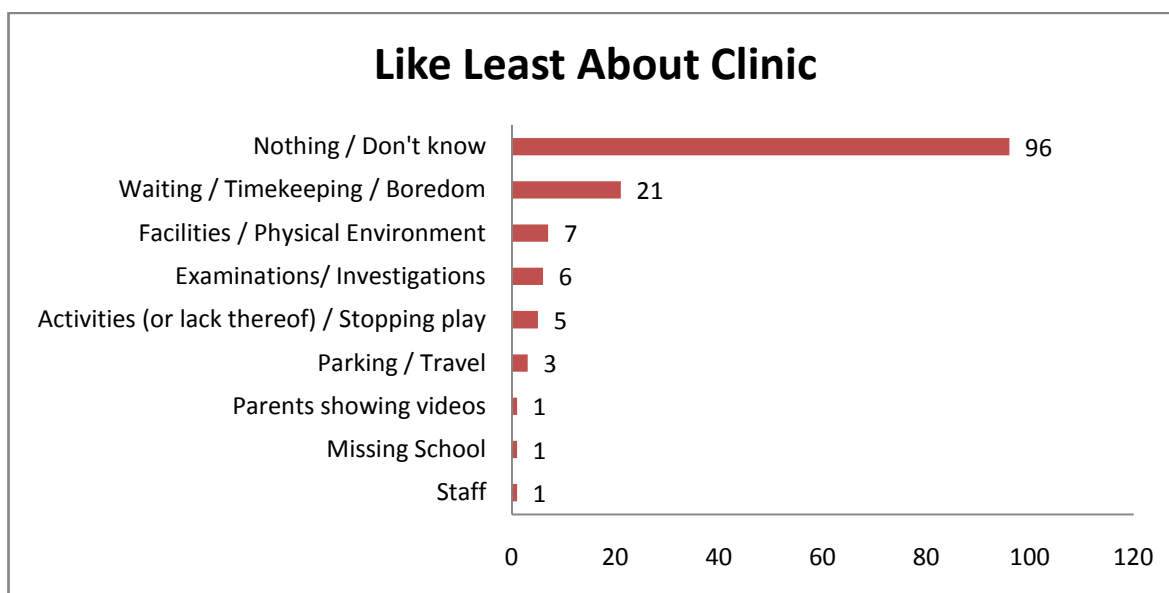


These responses suggest that clinics have been successful at creating a positive, supportive environment for children and their families, both in terms of the physical environment – waiting areas, clinic space, play facilities – as well as the approach and attitudes of staff and their perceived ability to help and support children and their families.

Below is a selection of responses to the question “What do you like best about clinic”:

- “Frances the receptionist because she makes me laugh”
- “Gets me out of school”
- “When doctors are interested in what you have to say”
- “Activities you can do in the playroom”
- “People not yelling at me”
- “Everyone is kind and explains everything”
- “EEG – goo hair”
- “Everyone is kind and there is a fun waiting room and [the nurse] knows me well and answers all my questions.”

The answers given to the question “Is there anything you do not like about clinic” also indicate that clinics are perceived very positively. The vast majority of respondents suggested that there was nothing about clinics they did not like. However, there were a number of themes that indicate room for improvement, namely issues around waiting, delays and children finding the clinic experience boring as well as examinations (taking bloods, height, weight etc). A small number of respondents also highlight difficulties with long distances to travel to clinic and parking at hospital.

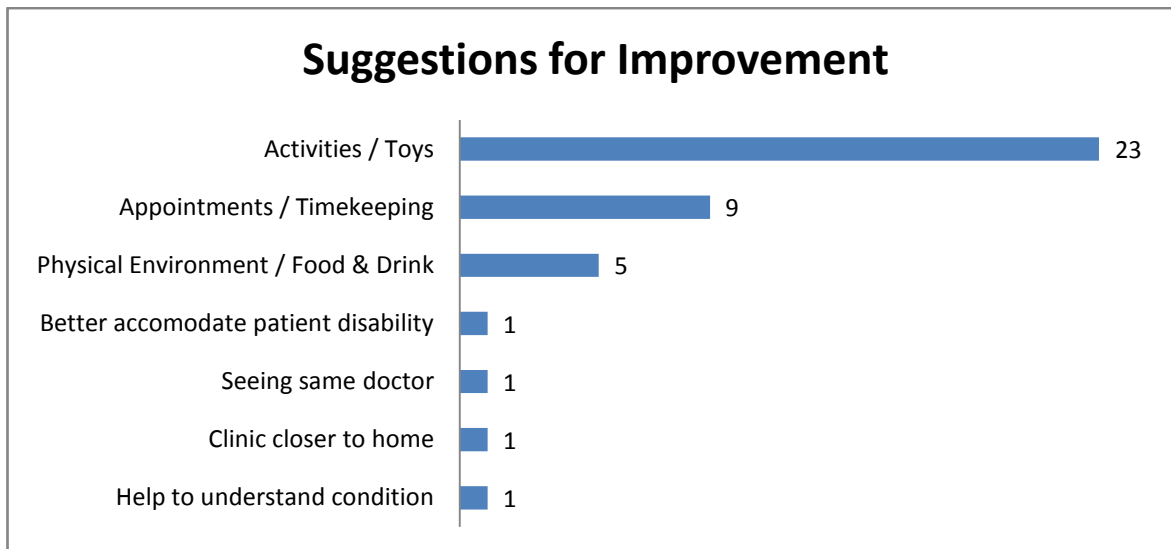


- “It is a bit boring waiting in the waiting room & there's not much to do”
- “Getting blood taken”
- “Sometimes they're a bit late in getting to you but not very often”
- “Didn't like my mum showing the videos”
- “Coming”
- “Trying to find a parking space”
- “It takes too long”

In line with the above findings, most respondents suggested that they did not have anything they wanted to change about their clinic. Those who made suggestions for change mostly made suggestions for better or different toys and activities and improved timekeeping and reduced waiting times. Comments included:

- “Some books for the big children while they are waiting e.g Roald Dahl”
- “Move the clinics closer to home so I don't have to travel & make it the same doctor I see each time”
- “Indian food”
- “More toys and an X-Box”
- “Speak to me up close as I have limited eye sight”

- “Taken on time for appointment”
- “Reduce the waiting times”
- “Giant waterslide”
- “No, I think it's all great and I wouldn't change anything”



### Conclusion

The patient experience survey findings highlight that paediatric epilepsy outpatient clinics across Scotland are well received. Feedback about the facilities provided and the staff has been overwhelmingly positive. A number of issues have been highlighted for further improvement – better, more varied activities / play facilities, less waiting / better timekeeping, travel and parking issues – but these are areas for incremental improvement and refinement, rather than requiring a radical change, and they are generic, NHS wide considerations that are not unique or specific to paediatric epilepsy or paediatric neurology services. As such, it would seem most appropriate that these issues are fed back to individual areas for action within their own local context.

## Appendix 1 - Questionnaire

1. How old are you?

2. Do you know why you are at clinic today?

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3. Who you would you like to see at clinic today? (for example a doctor or nurse)

.....

4. Do you feel able to ask questions?

YES



NO



5. Do they answer your questions in a way you understand?

YES



NO



6. What do you like best about clinic?

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7. Is there anything you do not like about clinic?

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8. Is there anything we can do to make your clinic visits better?

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**Acknowledgement:** This questionnaire was adapted with kind permission from a questionnaire developed by the Scottish Muscle Network.