

## Epilepsy12 Clinic Chat Check List Project

An engagement project to look at how your epilepsy clinic ***“helps patients and their families who need support with worries and anxieties linked to their epilepsy.”***

### SECTION 1

#### What is the Clinic Chat Check List?

The Clinic Chat Check List is a supportive self-assessment tool to identify strengths in current practice and help you in planning for the future; including ideas for no cost or low-cost changes.

- The Clinic Chat Check List is not a formal clinical assessment
- The Clinic Chat Check List is about your clinic and does not require any patient information

#### How will the Clinic Chat Check List help your clinic?

We believe that everyone involved in epilepsy clinics has a role in supporting the worries and anxieties of patients and their families and that by exploring this topic together you can make a difference and create “gold standard” care.

#### The Clinic Chat Check List project is:

- A way to identify best practice
- A way to identify gaps and future change
- A way to work with young people and support patient voice

#### The process will involve:

- A self-assessment ‘Clinic Chat Check List’. Staff members of your epilepsy clinic complete a set of ten questions about how they support worries and anxieties linked to their patient’s epilepsy.
- Once completed, you can give yourself an overall award for your epilepsy service for “helping patients and their families who need support with worries and anxieties linked to their epilepsy?”
- We suggest that you ask a group of young people to visit your clinic. They could identify changes that will cost nothing (young people are very creative!), some of the ideas might need some money! More on how you can get in touch with different groups locally later.
- After this your clinic will create an action plan to implement changes or a change that you have identified.

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## Before completing the Clinic Chat Check List we advise you to read the following information:

- We suggest that as many team members contribute to the completion of the check list, ideally this should be done together at a team meeting but if not possible through the co-ordination by one person leading to one check list
- You might wish to consider who is in your team
- We anticipate that the Clinic Chat Check List should take approx. 15-20mins to complete
- When giving answers please ensure that you include examples and give clear suggestions for future change

## What happens next?

Completed your Clinic Chat Check list and review the findings as a team. Think about what you are proud of, where there could be improvements and who could help you within the Trust, from other services or the community.

Once you have completed your Clinic Chat Check List, we encourage you to ask a group of young people to visit your clinic. This could be an existing epilepsy patient group or your hospital youth forum. You can find out more about this in section 2.

## RCPCH &Us resources

- [Epilepsy12 &Us](#)
- [Getting started with engagement](#)
- [Engagement legislation](#)

## Clinic Chat Check List

Question Number	Question	Your answer – please share your examples and any ideas about change you would like to make in the future
1	Do you provide information packs to new patients? If so, what is included?	
2	What information and advice do you provide to epilepsy patients to help them manage their condition? When is this shared? How is this shared?	
3	What support and information do you give to A&E staff to pass on to those who have had first-time seizures?	
4	How do you introduce patients and their families to their wider Epilepsy Care Team?	
5	Do patients know who to get in touch with if they have questions/concerns out of hours (evening/weekend)? Or between appointments and hospital visits?	
6	Do you have a non-medical worker (youth worker/play specialist/ advocate/ volunteer) who can go to the appointments with the patient too?	
7	What services are available to your patients that they can access for help with worries and anxieties? Please include any	

	services that patients can self-refer.	
8	How do you make time for discussions about worries and anxieties?	
9	How do you check that your patients are happy with the care you provide for support with worries and anxieties?	
10	What do you offer for patients with other access needs or disabilities e.g. language, learning, sensory, mental health need?	

**What are you most proud of within your service?**

**What are your top ideas for change?**

What award would you give to your epilepsy service for “*helping patients and their families who need support with worries and anxieties linked to their epilepsy?*”

**Bronze**

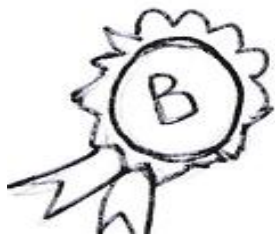
we are doing some things really well

**Silver**

we are doing most things really well

**Gold**

we are doing lots of things really well or some things AMAZINGLY!



Please tick who has been involved in the completion of this Clinic Chat Check List.

Patients/families	<input type="checkbox"/>	Receptionist	<input type="checkbox"/>
Doctor's secretary	<input type="checkbox"/>	Consultant specialist	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>	Specialist Nurse	<input type="checkbox"/>
Charity worker	<input type="checkbox"/>	Heights and Weights Nurse	<input type="checkbox"/>
Play specialist	<input type="checkbox"/>	Psychologist	<input type="checkbox"/>
Youth worker	<input type="checkbox"/>	School lead / SENCO	<input type="checkbox"/>
School nurse	<input type="checkbox"/>	GP	<input type="checkbox"/>
	<input type="checkbox"/>	Other (Please specify)	<input type="checkbox"/>

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## SECTION 2

### Epilepsy12 Clinic Chat Visit

Now that you have completed your Clinic Chat Check List, we encourage you to ask a group of young people to support you to plan for the future by meeting with your epilepsy team to discuss your assessment and ideas for the future.

#### The visit will concentrate on:

- What was going well
- Ideas for change

#### Involving a group in a visit

Organisations which are interested in promoting children and young people's voice and participation may be interested in visiting your clinic and supporting the Clinic Chat Visit.

Here are a few groups you could try:

- Hospital Youth Forum
- Youth Healthwatch Group
- Local Youth Group
- Local Youth Council or Young Inspectors Programme
- National Charity young advisors programme

#### The process will involve:

- Talking about best practice identified in your self-assessment
- Thinking about the changes you suggested in your self-assessment
- Seeking young people's perspective on what would make a difference

#### Preparation

All young people involved in the project will need to have some preparation before their visit. This could include sharing with them:

- What is epilepsy
- What epilepsy clinics do & your role in supporting children and young people
- The parameters of the visit

It is important that you work with their lead worker to arrange the visit and to support the preparation. Their lead worker will be able to advise and support the individual needs of the group members and their group dynamics, as well as supporting the risk assessment, consent form process and visit logistics.

### Clinic film

To help your visiting group we suggest that you create a 2-5min film, to be shared with the group before their visit. This could include:

- An introduction to your team – including your receptionist, play specialist etc.
- A walk around your clinic highlighting what patients would see and anything you are proud of or would like to change
- **Please note: There is no requirement for any patients to be filmed as part of your clinic film**

If you have a pre-existing film of your team and/or clinic you can share that with the group.

### Safeguarding young people

All activities which include children and young people should adhere to your organisation's child protection and safeguarding policies. Safeguarding procedures should be put in place in order to help keep young people safe. Young people should carry out visits in groups and with a member of staff that knows them well. You should ensure young people are given all the necessary information before they start their visit and that you have conducted an appropriate risk assessment. For more information you can visit: <https://nya.org.uk/skills/safeguarding-and-risk-management-hub/>

### Incentives/ Rewards:

It is important to recognise the time and energy that busy young people give to join groups like this. Acknowledging their commitment through a thank you letter, certificate of attendance, reference letter or thank you voucher as a group or individually shows that their work is valued. We encourage you to speak to the group's leader or the group themselves about what they would prefer so that it is in line with their processes and taking into account potential implications on benefits or other payments.

### RCPCH &Us resources

- [Recipes for engagement](#) (Activities)
- [Recipes for rights](#) (Activities)



## Clinic Chat Visit Questions

Question	Comment
<p><b>1.</b> What award you would give your epilepsy service for <b>“helping patients and their families who need support with worries and anxieties linked to their epilepsy?”</b> How did you decide this?</p>	
<p><b>2.</b> What are you proud of?</p> <p>What do you think makes the most difference to children, young people and families?</p>	
<p><b>3.</b> What would you like to change in the future?</p> <p>What would make the most difference to children, young people and families?</p>	
<p><b>4.</b> What are you going to focus on over the next six months?</p> <p>How are you going to make the changes?</p> <p>You should make sure that these changes are SMART (Specific, Measurable, Achievable or Attainable, Realistic, Time-bound)</p>	



## SECTION 3

# Epilepsy12 Clinic Chat Check List / Visit Review

## Project planning

Now that you have reviewed your clinic about how you help patients and their families who need support with worries and anxieties linked to their epilepsy and met with a group to support thinking for future change it's time to put plans into action.

You can decide what change/s you would like to implement.

Here are some top tips for planning:

1. Keep it simple – select the changes that will make an impact to children and young people
2. Keep it SMART (Specific, Measurable, Attainable, Relevant, and Time-Bound)
3. Ensure everyone knows – talk about it at team meetings, with partners and patients
4. Continue to review and monitor progress

## Evaluation

Evaluation is a very important part of any project. Evaluations help determine what works well and what could be improved in the future.

Here are some top tips:

1. Be honest – there may be some things that did not work out as you planned, but there might also be some unexpected achievements.
2. Ask other people such as children, young people, parents, volunteers, and other departments – what do they see as the changes or benefits?
3. Collect evidence and results from your project as you go
4. Check what you said in your original clinic chat check list– this will help you identify what you have achieved
5. Share your project with others – celebrate your journey so that others can be inspired
6. Thank your visiting group – let the visiting group know what you have achieved and how their input has supported this

## RCPCH &Us resources

- [Voice in governance](#)
- RCPCH [approach to engagement](#) (click the children and young people's engagement section)

- For other quality improvement projects, advice and resources visit [QI Central](#)
- For other engagement resources, visit [RCPCH &Us](#)

### Signposting resources for children, young people, families and workers

- [The Mix](#), a charity supporting young people/young adults online or by phoning 0808 808 4994.
- [Childline](#) for support for children and young people online or by phoning 0800 1111
- [BOLOH helpline](#) for Black, Asian and minority ethnic groups of young people
- [Papyrus Hopeline](#) for those experiencing thoughts of suicide
- [Kooth App](#) for supporting young people's mental health
- [NHS Every Mind Matters](#) lots of different resources for all ages
- [Give us a Shout](#) online or text SHOUT to 85258 for all age support
- [Student Space](#) with support for students during the Coronavirus pandemic
- [Young Minds](#) with detailed support for young people, parents and professionals
- [Wellbeing](#) support for workers
- [Blue Light Programme](#) which supports emergency workers

Should you require any further information, support in completing the Clinic Chat Check List or resources to support engagement with children, young people and families please contact [and\\_us@rcpch.ac.uk](mailto:and_us@rcpch.ac.uk)

Thank you for your commitment to developing your services and for doing this project. Thanks to all the Epilepsy12 Youth Advocates who developed the project, the check list, visit questions and helped to share the learning through the Epilepsy12 Conferences each year.



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