



EI09 SERVICE USER CONSENT POLICY

1. Policy Statement

- 1.1 Epilepsy Ireland understands that all of our services and activities are offered to service users with their consent. In the majority of situations, the issue of consent does not arise but there are a few circumstances where consent will be required. However there are situations where service user consent should be formally obtained – for example, for research studies, for print and media, for sharing of their personal information, and when working with a child or with an adult without capacity to consent. This policy identifies these aspects of consent.
- 1.2 The organisation is committed to following the HSE National Consent Policy 2014 and all contained within that policy is deemed to guide the consent policy of Epilepsy Ireland.
- 1.3 The requirement to gain consent of a service user is consistent with fundamental ethical principles, with good practice in communication and decision making and with national health and social care policy.

2. Purpose

- 2.1 The purpose of the policy is to provide clarity to staff and service users relating to issues of consent and to ensure consistency of practice in service delivery.

3. Definitions

- 3.1 'Consent' is the giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed intervention.
- 3.2 'Capacity' is the ability to understand the nature and consequences of a decision in the context of available choices at the time when the decision is to be made.

4. Legislation

- 4.1 The requirement for consent is recognised in International and European Human Rights law and under the Irish Constitution.

5. Scope

- 5.1 The need for consent extends to all interventions conducted by Epilepsy Ireland, but for the main part, this is explicit in the choice to engage with our service by the service users. All staff should be aware of the need to gain explicit consent of service users in certain circumstances.
- 5.2 This policy guides all workers in Epilepsy Ireland in ensuring they protect the rights of service users and operate consent procedures if required.

6. Responsibilities

- 6.1 The CEO has responsibility to ensure the organisation is committed to all practices which support and protect the service users rights.
- 6.2 The Director of Services has responsibility of developing the policy and ensuring workers are trained in the policy and procedures and are clear of their responsibilities.
- 6.3 All workers have the responsibility of following the consent policy and procedure in their work.

7. Further Resources

- 7.1 The HSE policy 'National Consent Policy 2014' provides a comprehensive set of guidelines regarding managing service user consent. For the main part, the HSE policy relates to residential and day-care services, services where people have reduced capacity to consent, and referring mainly to medical procedures. Our services operate outside of these factors and therefore we will refer to the HSE policy for guidance when required and this consent policy and procedure is written to relate specifically to the needs of Epilepsy Ireland.

SERVICE USER CONSENT PROCEDURES

8. What is valid and genuine consent?

- 8.1 Consent is the giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed intervention. The process of communication begins at the initial contact and continues through to the end of the service user's involvement in the engagement process, provision of social care or research study. Seeking consent is not merely getting a consent form signed; the consent form is just one means of documenting that a process of communication has occurred.

For the consent to be valid, the service user must:

- have received sufficient information in a comprehensible manner about the nature, purpose, benefits and risks of an intervention/service or research project.;
- not be acting under duress; and
- have the capacity to make the particular decision.

9. Presumption of Capacity

- 9.1 The HSE policy guides us to work on the presumption that every adult service user has the capacity to make decisions about their care, and to decide whether to agree to, or refuse, an examination, investigation or treatment. It must not be assumed that a service user lacks capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including intellectual disability, mental illness, dementia or scores on tests of cognitive function), their beliefs, their apparent inability to communicate, or the fact that they make a decision that seems unwise to ourselves.

- 9.2 Capacity should not be confused with a health and social care professional's assessment of the reasonableness of the service user's decision. The person who has capacity can make their own choices, however foolish, irrational or idiosyncratic others may consider those choices. Similarly, the fact that a service user has been found to lack capacity to make a decision on a particular occasion does not mean that they lack capacity to make any decisions at all, or that they will not be able to make similar or other decisions in the future.
- 9.3 If you are unsure whether a service user that you are working with has 'capacity' to consent or may lack 'capacity' to consent to something we are offering (e.g. research project, consent for media/print items, consent for managing seizures etc) the procedure is to contact the Director of Services for discussion and guidance, and in their absence the CEO or manager.
- 9.4 The Director of Services/CEO/manager can consult with the HSE National Consent Policy to gain guidance relating to consent, or can contact the HSE directly via the Quality Standards section that can be found on the HSE website.
- 9.5 There are no reporting requirements relating to capacity to consent issues for the organisation.

10. Areas of work where service user consent should be gained

10.1 Children under 18 – Activities and Risk

Parents/Guardians should complete the Epilepsy Ireland Standard Consent Form for children under 18 to participate in any activities and to accept responsibility relating to levels of Risk involved.

10.2 Using Images

At events, it should be noted that photographs/film are being taken and images may be used for film, print and media purposes. Adults may be invited to identify themselves if they wish not to have their images used. However, no formal written consent form is required for adults at public events.

10.3 Children under 18 – Using Images

Parents/Guardians should complete the Epilepsy Ireland Standard Consent Form for children under 18 to be included in any media/online/internal/ external print, publication or recording.

10.4 Consent for participating in Research

All research projects should include a consent form for service users which follows all national ethical research standards and procedures. Epilepsy Ireland must state clearly in any calls for research participants on behalf of another organisation or researcher, that they are NOT involved in the research directly so that those consenting are not misunderstanding that they are participating in EI research (including EI funded research).

Consent for participating in Research is detailed in the HSE National Consent Policy and should be followed when research participation is being requested.

10.5 Consent for medical information and seizure management

Service users who participate in on-going courses in Epilepsy Ireland should complete a seizure management form which identifies how they will expect a seizure to be managed by our staff and they will consent to our practices of calling an ambulance after 5 minutes.

In this circumstance, any medical information that we know about the participant relating to their epilepsy may be disclosed by us to the medical professional if required in an emergency circumstance.

In all other circumstances where no particular consent has been asked for, EI will operate our standard First Aid procedures of calling an ambulance after 5 minutes of a tonic clonic seizure.

10.6 Consent for Information Sharing

Epilepsy Ireland's practices of information sharing are outlined in our Confidentiality policy. If we are sharing a service user information with external agencies or organisations, it will be with the explicit consent of the service user (e.g. for referral or medical information purposes). However, consent to share information with external agencies is not required in certain circumstances (Disclosures of Abuse, Safeguarding Vulnerable Adults concerns, Harm to self/others etc.) Further details can be found in the Epilepsy Ireland Confidentiality Policy.

10.7 Using information for other purposes

Where contact details of a service user are shared (with the service users consent) with a third party, it is understood that the information and contact with service user is for a particular stated purpose only, and that doesn't entitle a third party to contact the service user for other purposes.

10.6 Consent for Sharing Contact details between service users

Epilepsy Ireland does not provide any service user details to another service user without consent. In the circumstance where a service user would like contact details of another, EI can contact the other service user and if both parties agree, the contact details can be exchanged.

Epilepsy Ireland is not responsible for any issues that arise between service users who we provide shared information to. Any interactions which occur are considered solely the responsibility of the service users.

However, in circumstances where a concern arises relating to Safeguarding Vulnerable Adults or Child Protection, we will follow the guidelines in these policies.

11. Appendices

Appendix One: Consent for Children – Parents Form

Appendix One – (Also contained in the child protection policy)



PARENTAL CONSENT AND RESPONSIBILITY FORM

For all events with children/teens under 18 and one-to-one working with teens aged 16/17 years.

Name, Date and Location of EVENT:	Home Address:
Name of Child/Person under 18:	Contact Phone Number of parent:
Date of Birth of Child/Person under 18:	Emergency Contact Phone Number (if different):
Parent / Guardian Name:	Email Address:

Please tick the boxes to indicate your agreed consent:

<p><u>Responsibility for the child/teenager when the Parent and Children are together at an event:</u> I understand that the child/teenager named above remains my sole responsibility for the duration of the event and that Epilepsy Ireland is not responsible for my child.</p>	<p>Yes No Not applicable</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>
<p><u>Permission to attend for the teenager when they may be at an event without a parent:</u> I understand that the teenager named above is attending the Epilepsy Ireland event named above and I have given permission for him/her to attend this event.</p>	<p>Yes No Not applicable</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>
<p><u>Permission to attend one-to-one support sessions when a teenager attends (16 – 17 years only) without a parent:</u></p>	<p>Yes No Not</p>

<p>I understand that the teenager named above will be attending one-to-one support sessions with the community resource officer in Epilepsy Ireland without my supervision and I give my consent to these meetings occurring.</p>	<p style="text-align: right;">applicable</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>
<p><u>Photosensitive Epilepsy</u> Please tick this box if you or your child has photosensitive epilepsy. We will contact you in advance of the event to discuss flash photography and ensure to avoid it when required.</p>	<p>Yes No Not applicable</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>
<p><u>Epilepsy Emergency Rescue medication and seizure management when parents and children are together at an event:</u> I understand that if epilepsy emergency rescue medication is required for my child/teenager, I will bring this with me and administer to my child/teenager. I understand that if rescue medication has not been prescribed or has not been effective, Epilepsy Ireland will call an ambulance if required. I authorise Epilepsy Ireland to seek any medical/emergency treatment required for the above child if required and I accept financial responsibility for any costs incurred.</p>	<p>Yes No Not applicable</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>
<p><u>Epilepsy Emergency Rescue medication and seizure management when teenagers may be at an event (or in a one-to-one meeting) without a parent:</u> I understand that if the child/teenager requires emergency rescue medication, this may be sent with the child/teen. This must be given directly to the Epilepsy Ireland event organiser for safe keeping, along with the administration guidelines written and signed by a doctor. The rescue medication will only be administered by trained medical professionals called by Epilepsy Ireland. Epilepsy Ireland operates a policy whereby if a tonic clonic seizure lasts longer than 5 minutes or as advised by family, an ambulance will be called. I authorise Epilepsy Ireland to seek any medical/emergency treatment required for the above child/teen if required and I accept financial responsibility for any costs incurred.</p> <p>Please tick here if you are sending Epilepsy emergency rescue medication with your child</p>	<p>Yes No Not applicable</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><input type="checkbox"/></p>
<p><u>Liability Release Form – Used for ALL sporting and other risk activities and events for children/teens</u> I understand that the participation of the child/teenager in any</p>	<p>Yes No Not applicable</p>

<p>sports/activity could include actions or tasks that may have a level of risk involved. I assume any responsibility for any risk of harm or injury which might occur and I release Epilepsy Ireland from all liability, costs and damages which might arise from participation of my child/teenager in the above event/activity. Epilepsy Ireland may provide activities and events with some elements of risk involved in the understanding that the parent/guardian will make the decision as to level of risk appropriate for their own child.</p>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<p><u>Food, dietary requirements and special needs</u> If you or your child has an allergy or a particular need relating to food provided on the day of the event, please detail it in this box and we will contact you in advance of the event. You may be requested to bring prepared snacks from home if required (e.g. ketogenic diet). If you or your child has any other special needs that you would like our help with, please detail it in this box:</p>	
<p><u>Use of Video/Photography and Sound recordings</u> I understand that Epilepsy Ireland events are sometimes filmed and photographs are taken so that images can be used in various ways to support the work of the charity and raise awareness about Epilepsy. Epilepsy Ireland will not publish the name of any child with images unless specifically agreed with the Parent/Guardian. It is Epilepsy Irelands policy not to publish or distribute images that include children without the consent of a parent or guardian. Photos can be withdrawn from the photo library at any time by contacting us directly. No payment is made for participation in photography/film/sound recordings.</p> <p>I agree that Epilepsy Ireland can take Video/Photo/Sound recordings of me/ and my child/teenager named above and that this can be used for the following purposes:</p> <p><i>Tick the boxes if you are in agreement:</i></p>	
<p><u>Print and Broadcast</u> – National and regional newspapers, broadcasting, Newsletters, Print documents such as flyers, annual reports and reports for funders</p>	<input type="checkbox"/>
<p><u>Online</u> - EI Newsletter and EI Website</p>	<input type="checkbox"/>
<p><u>Online</u> – Online media and news coverage & social media channels (EI Facebook etc.)</p>	<input type="checkbox"/>

I, _____(Name of Parent/Guardian) have given my permission and consent based on this consent form (3 pages)

Signed: _____

(Parent/Guardian)

Date: _____