



**OP.5**  
**Service User Consent Policy**  
**V2.0**

**July 2022**

Ver	Purpose/ Change Summary	Approved by Board	Effective Date	Next Revision
1.0	Original policy	21 November 2016	22 November 2016	
2.0	Full review, referencing new HSE Consent policy. Linked to other EI policies where relevant. Some simplification of wording	19 July 2022	19 July 2022	Q3/2025

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### 1. Purpose

- To provide clarity to staff and service users on the work / activities / circumstances where consent may be required from service users.
- To provide direction on how we will obtain service user consent when required.
- To ensure consistency of practice across the organisation.

### 2. Scope

- 2.1 Epilepsy Ireland understands that our services and activities are undertaken freely and without obligation by service users. In the majority of our work, the issue of consent does not arise and our policy reflects the services and activities of Epilepsy Ireland.
- 2.2 The [HSE National Consent Policy](#) provides a comprehensive set of guidelines regarding managing service user consent. The HSE policy relates mainly to residential and day-care services, services where people have reduced capacity to consent, and refers mainly to medical care and procedures.
- 2.3 Our services do not align exactly with the HSE policy; however, we will refer to it for guidance when required.

### 3. Consent and Capacity

- 3.1 The HSE National Consent Policy 2022 ([HSE National Consent Policy](#)) states that *'**consent** is the giving of permission or agreement for a treatment, investigation, receipt or use of a service or participation in research or teaching. Consent involves a process of communication about the proposed intervention in which the person has received sufficient information to enable them to understand the nature, potential risks and benefits of the proposed intervention. Seeking consent should usually occur as an on-going process rather than a one-off event'*.
- 3.2 The National Policy outlines that in relation to **capacity** *'every adult is presumed to have the decision-making capacity to decide whether to consent to, or refuse consent to an intervention unless the contrary is shown (e.g. by an assessment of decision-making capacity or by a Court declaration making a person a Ward of Court). A person's capacity should not be called into question and assessments of capacity should not be performed without good reason. Such assessments are not required in the vast majority of cases where healthcare workers seek consent for an intervention'*.

- 3.3 Where workers are unsure whether a service user has capacity to consent to any of the activities listed in Section 4, the procedure is to contact the Director of Services for discussion and guidance, and in their absence the CEO or other manager. 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.

## **4. Epilepsy Ireland Activities that may require Service User Consent**

### **4.1 Work with Children and Young People (under 18's)**

Parents/Guardians will be required to complete the Parent/Guardian Consent Form for children under 18 to participate in services and activities. Consent for use of images is included in this form. (Appendix 1 - Parent/Guardian Consent Form).

### **4.2 Use of Images**

At our events we often take photographs/film 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. No formal written consent form is required for adults at public events.

### **4.3 Seizure Management**

Epilepsy Ireland workers who are fully trained in the administration of emergency medication (Buccal Midazolam) will administer the medication to service users at Epilepsy Ireland consultations / events in line with best practice and approved procedures (Appendix 2- Seizure Management Policy).

Where required, a Seizure Management form is completed by the service users and outlines how they would like their seizure to be managed. The form includes explicit consent for administration of emergency medication (if required) and this must be completed and signed by the service user (Appendix 3 - Seizure Management Form).

In the case of under 18's, the parent/guardian must complete the Seizure Management Form.

### **4.4 Record Keeping**

Epilepsy Ireland records information relating to service users on a secure Client Management System, excel files and occasionally in paper format (e.g. Seizure Management forms etc.). This information is required to ensure continuity of service. Any information held is confidential within Epilepsy Ireland as an organisation. We report to funders on our work by compiling statistics on the numbers / types of services we provide.

Sensitive information relating to service users is managed in accordance with the relevant data protection and data management requirements (Appendix 4 – Data Protection Policy).

### **4.5 Information Sharing**

In the course of our work, you may share personal information with us so that we can offer an appropriate, supportive and relevant service. When assisting a service user to access other services, making a referral to another service or advocating on behalf of the service user, consent will be sought from the service user (parent/guardian) to share appropriate levels of information to access the relevant service.

Epilepsy Ireland's practices of information sharing are further outlined in our Confidentiality policy (Appendix 4).

#### **4.6 Sharing Contact details between service users**

We do not share information between service users without consent. If a service user wishes to contact another service user through Epilepsy Ireland, we may inform the second person that this is the case and if both parties consent, contact details may be shared with the two parties.

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.

#### **4.7 Research**

Epilepsy Ireland supports research through funding, promoting projects and calls for research participants. Epilepsy Ireland will verify that any research we support will adhere to national ethical research standards and procedures. Guidelines on consent for participating in research is detailed in the [HSE National Consent Policy](#).

### **5. Limitations of Consent**

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.)

In circumstances where a concern arises relating to Safeguarding Vulnerable Adults or Child Protection, these policies will be followed (Appendix 5 - Safeguarding Vulnerable Adults / Appendix 6 - Child Protection).

Further details on limitations can be found in the Epilepsy Ireland Confidentiality Policy.

### **6. Appendices**

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