

A guide to

Personal and Public Involvement (PPI)



Understanding Data Protection

New data protection laws came into effect on 25 May 2018. Many of the main concepts and principles are much the same as the current Data Protection Act.

This guide sets out to help you understand the data requirements when engaging Service Users and Carers for Involvement activities in Health and Social Care (HSC).

Why do I need to collect personal information for Involvement activities?

It is a statutory duty in Northern Ireland to involve and consult with Service Users and Carers in the planning, implementation and evaluation of HSC services.

To effectively involve people in a range of different ways, it will be necessary to identify and engage people who have experience of using your service. You will have to gain their consent for holding their information and outline what you are going to use the information for.

When should I record personal information?

- As part of a PPI recruitment exercise.
- After a PPI event.
- As part of a survey or ongoing opportunity for Involvement.
- When setting up a new PPI project, structure or group.

How to get consent?

You need to gain consent from people to allow you to contact them after they have left the service. This means giving them an option of how you can contact them and about what.

Consent means offering individuals genuine choice and control. If you are working with young people or adults with a learning difficulty or people living with dementia, etc, you should consider how they can give consent, for example using accessible language, appropriate communication or through a family carer, relative or advocate.

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Can I ask people to get involved via a poster or leaflet?

Yes, you can ask for people to get involved in your work using a range of different ways. The important thing is what you do when you get the information. When some-one responds to a request to get involved, you should:

- Thank the participant for getting involved;
- Tell people how you will use the information ie to communicate with them via a Service User and Carer Group;
- Inform the person how long their data will be kept on file. It is recommended that information is kept for one year after which you may contact the person to ask if they are still wishing to remain on the list; and
- Let them know that they can withdraw their information at any time and provide contact details for this. Keep information simple and easy to understand.

Can I contact a current Patient, Service User and Carer to get involved?

Yes, when a patient is currently receiving Health and Social Care services, you may approach them to get involved in a programme of work.

Can I contact a Patient, Service User or Carer who has been discharged from a Health and Social Care Service?

No, to enable you to contact a Service User or Carer who has been discharged is to gain consent at time of treatment.

How should I record personal information?

If you keep a mailing list for Service Users and Carers who are involved in your work, you need to record key information:

- Name;
- Contact details;
- How did you gain consent from the participant to be contacted and the date this was given, e.g. verbally or written; and
- Date for permission to be reviewed.

Can I ask Patients, Service Users and Carers to complete a survey regarding their experience?

Yes, if this information is anonymous you may undertake a survey. If you wish to follow this up, you will need to seek their consent at the time of completing the survey.

Can I share Patient information with others?

No, unless you have the Service User and Carers, permission you are not allowed to share the personal information with other organisations.

What would a consent statement look like? The following may be included in documentation to engage with Service User and Carer representatives:

'If you would like to get involved in (insert service area or project), please send your name and contact details to (insert contact details). We will use this information to get in touch with you about any opportunities to get involved in the next 12 months.'

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How should I store personal data?

- In a safe and secure manner e.g. an encrypted file or locked filing cabinet.
- For no longer than required.
- With the permission of the owner clearly identified.

Where can I find out further information?

Check out your organisations data protection policy. You may also find it useful to check out the Information Commissioners Office at www.ico.org.uk which provides a wide range of information in relation to data protection. Please note, this guide does not replace your organisation data protection policy.

General Data Protection Regulation (GDPR)

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|---|--|--------------------------|
| 1 | Inform people why you want their data. | <input type="checkbox"/> |
| 2 | Inform people how you will use their data. | <input type="checkbox"/> |
| 3 | Provide an option for people to consent, e.g. to share beyond stated use, invite to events or to send newsletters. | <input type="checkbox"/> |
| 4 | Store information securely. | <input type="checkbox"/> |
| 5 | Have a review date and a process for review in place, e.g. reminders, agenda items, etc. | <input type="checkbox"/> |
| 6 | Record any data or consent changes clearly. | <input type="checkbox"/> |

For more information on Involvement, Co-Production and Partnership Working please visit the Engage website.

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