Adult Safeguarding Focus Groups
Participant Information Leaflet

Who we are

We are researchers from the Institute of Public Health, a government-funded research body. The Department of Health has asked us to carry out focus groups on the subject of adult safeguarding in the health sector to help them develop a new policy on this. We are looking for participants to take part in these focus groups.

Principal Investigator: Professor Roger O’Sullivan, Institute of Public Health, 700 South Circular Road, Dublin, D08, NH90. Tel 048 9064 8494.
Project researcher: Aideen Sheehan, Institute of Public Health, 700 South Circular Road, Dublin, D08, NH90. Tel 01 478 6304.

What this leaflet is about

This leaflet explains what this focus group research involves and how it will be carried out. Please read it carefully and take time to ask questions and consider whether or not you wish to take part. Do not feel under pressure to make a quick decision.

Why this study is being done

The Department of Health is developing a new policy on adult safeguarding to help keep all adults safe from harm when they use health services, whether that’s in hospital, clinics, nursing homes, other services or at home. The aim of this policy is to introduce new laws and guidelines that will make it easier to keep people safe and take action if there’s a problem.

As part of this the Department of Health has asked the Institute of Public Health to carry out focus groups with people with intellectual disabilities, cognitive impairments, significant mental health difficulties or living in nursing homes to get their views on how best to protect people from being harmed. It is important to get the views of people from these groups because they use health services a lot and sometimes need extra support to protect them from harm.

What will the focus groups involve?

These focus groups will involves small groups of around 5-8 people who have agreed to take part meeting at an agreed location to discuss the topic of adult safeguarding. Everybody will be asked to give their views on the following topics:

- What kind of behaviours do they think can be harmful?
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- What is the best way to protect people from harm?
- If they were being harmed by someone, who would they tell?
- What would they want to happen if someone was harming them?
- What else do they think is important about keeping people safe?

IPH researchers will be at the meeting to make sure everybody gets a chance to express their views and to record what is said. Participants may be asked to vote using stickers on what they think are the most harmful type of behaviours. The focus groups will last around 1 hour 15 minutes.

We will write up a report about the views expressed at the focus groups to give to the Department of Health. The report will not contain the names of participants, or any details that could identify them to others. The report may be published on the internet or discussed at conferences. We will give participants a copy of the report if they would like one. At the end of the project, all personal data will be deleted.

Voluntary Participation
Every person we ask has a choice on whether to take part or not and will be given plenty of information about the research with chances to ask questions about it. If you agree to take part you will be asked to sign a consent form. If you change your mind later and wish to withdraw, or don’t wish to answer some questions, that is fine and you don’t have to give a reason why. If you don’t want to take part, it will not have any impact whatsoever on the services you get.

Assistance for Participants
If participants want to bring a friend or carer with them that is fine. If you want a support person to help with expressing your views that is fine also. We will ask that support person to sign a form to show they understand what the research is about, that it is confidential, and that they are there to support the participant to express the participant’s own views.

Confidentiality
- All information will remain strictly confidential at all times. Nobody’s name will be published or made known to anyone outside the research team.
- We will write a report about the different opinions and views expressed at the meetings, but people’s personal details will be removed - so no one will know who took part.
- We will use strict security to keep everybody’s personal details fully confidential and there is more information about this in the section on data protection.
- The only exception to confidentiality will be if somebody makes a disclosure that suggests somebody is at risk of harm. In that case the local HSE safeguarding team or gardai may need to be informed in order to protect that person.
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**Risks**

Talking about harm can be an upsetting topic and there is a medium risk that somebody could become upset. If somebody becomes distressed we will ask them if they want to take a break or to stop taking part in the group. They can also talk to a support worker at their organisation and we will help them do that if necessary. We will also provide details of organisations that can help them cope with being upset.

If we hear something during the focus groups that makes us think that someone is unsafe in their daily lives, then we may ask them to meet with somebody from a HSE Safeguarding Team to talk to them about the issue and to support them to decide what to do next. If we think they need urgent help to protect them from harm then we may tell the Gardaí.

There is a very low risk of personal data being lost while it is transferred or being identifiable to somebody outside the research team, but many measures are being taken to prevent this happening.

**Benefits**

There are no direct benefits to participants in taking part, but it does give you the chance to give your views to the Department of Health about what you would like to see done to keep people safe and protect them from harm when using health services. That means they can take these views into consideration when designing the new policy on adult safeguarding. It is important to hear the views of people with certain health conditions, or who live in nursing homes and who may use health services a lot, when designing new rules aimed at protecting them.

Participants in the focus groups will be given a €30 One4All gift voucher as a token of appreciation for taking part.

**Follow-up contact**

Sometime in the future we may ask to meet participants again to get their opinions about the new rules for adult safeguarding that the Department of Health will develop. If people wish to take part in this follow-up consultation they can, but there is no obligation to do so.

**Ethical Approval**

Ethical approval for this project has been received from an Ethics Committee set up by the Department of Health chaired by Professor David Smith of RCSI. Its email contact is healthadultsafeguardingpolicy@health.gov.ie.

**If you require further information**

If you want to find out more about this project you can contact us in the following ways. The Institute of Public Health address is: IPH, 700 5th Circular Road, Kilmainham, D08 NH90. Roger O’Sullivan is the IPH Principal Investigator in charge of this research. His mobile number is 086 822 1770 and email is Roger.osullivan@publichealth.ie
Aideen Sheehan is the researcher organising the focus groups. You can phone Aideen at 01 478 6304 or by email: Aideen.sheehan@publichealth.ie or safeguarding@publichealth.ie

For more information about IPH our website is www.publichealth.ie

Data Protection

This section explains what information about you (personal data) will be used in this research, how this information will be kept safe and what your rights are to make sure your data is protected and handled fairly.

Why is your personal data being processed?

People’s personal details are being recorded for the purposes of this research aimed at helping the Department of Health develop a new national policy on adult safeguarding by getting the views of people with certain health conditions about how to keep people safe.

What information about you will be used as part of this study?

Only personal details necessary for the research will be collected and processed. These include name, gender, age group, geographic location and type of disability or health condition. No medical records will be accessed. Contact details such as address, email and phone number will be recorded as necessary to pay for or arrange travel to the focus group for you, and to allow for follow-up contact about this research if you agree to it.

Who will have access to this data?

Staff members in the Institute of Public Health who are directly involved in the research, or in providing IT, data protection or financial support to the project will have access to the data or portions of the data on a task-specific basis. They will only have access to the parts of the data they need to see to do their job. Researchers working on this project are specialists in carrying out health research and have been Garda-vetted. If we hear something that makes us think you are unsafe we may pass on your information to the gardai or the HSE safeguarding office.

How will your data be kept safe?

Audio recordings and notes from the focus groups and hard copy consent forms will be stored in a locked secure room in the Institute of Public Health office in Dublin. Electronic files such as audio files transcripts of what is said at focus groups will be encrypted and stored on a secure driver with passwords known only to the research team. There will be no names on the transcripts as they will be replaced with a coded ID number to protect identities. Other details such as exact location will be removed from the final report so that
nobody knows who took part. All data will be deleted within a year of the final report being completed and earlier if it is no longer needed for this research.

**Who is in charge of your data?**

**Data Controller:** The Institute of Public Health (IPH), 700 South Circular Road, Dublin 8, D08 NH90 and the Department of Health, Miesian Plaza, Lr Baggot St, Dublin 2, DO2, XW14 are Joint Data Controllers for this project. The IPH has been commissioned to carry out this research and is responsible for collecting, storing, processing and analysing the personal data needed for this project.

**Legal Basis.** The legal basis under which the IPH will process the data is Article 6 of the General Data Protection Regulations 2018 that 1 e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. It also complies with Article 9 2h) that processing is necessary for the purposes of preventive or occupational medicine or the management of health or social care services, with suitable measures to protect and safeguard subjects’ rights.

**Length of time data stored.** Personal information will be removed (anonymised) as soon as possible after it is collected and processed. Reports and other outputs from this research will not contain personally identifying material on the participants. A timetable for deleting different elements of the data associated with this project has been drawn up and it will all be deleted within a year of completion of the research when it is no longer needed.

**What are your rights in relation to your data?**

**Withdrawal from study:** You may withdraw from the study at any time. To do so you can contact us by telephone, email, letter or in person at any of our contact points including:

Adam McCune, Data Protection Officer, Institute of Public Health, 700 South Circular Road, D08 NH90. Email: dataprotection@publichealth.ie. Tel 048 9069 0057

Aideen Sheehan. Researcher, Institute of Public Health, 700 South Circular Road D08 NH90. Email Aideen.sheehan@publichealth.ie or safeguarding@publichealth.ie. Tel 01 478 6304.

You also have the following rights:

- Right to access (see) data held about you.
- Right to restrict the use or processing of the data held about you
- Right to correct anything in the data that is inaccurate
- Right to have information about you deleted
- Right to data portability (to have your data transferred to another organisation if you wish)
- Right to object to profiling (Profiling is a type of automated decision making used to predict your behaviour. However there will be no profiling of data in this study)
The only limitation to your rights to withdraw or restrict use of your data is if the study has already been completed and the report written when you make that request.

**How do you exercise your rights?**

**Subject access request:** A person has the right to request access to all information held about them. The request will be responded to within one month. Persons may also request correction or deletion of their data or any of the rights listed above.

To do a subject access request or exercise any of these rights, you should contact the IPH Data Protection Officer.

Adam McCune, Data Protection Officer, Institute of Public Health, 700 South Circular Road, D08 NH90. Email: dataprotection@publichealth.ie. Tel 048 9069 0057

**Will we transfer your information to another country?**

The Institute of Public Health’s main office is in Dublin and that is where your data will be stored and processed. It also has a second office in Belfast in Northern Ireland which is part of Britain and subject to the same strict data protection regulations. If Brexit happens while this research is going on – i.e. if Britain leaves the European Union - and if we need to transfer any of your data to the Belfast office for this research, safeguards will be put in place to protect your information in compliance with GDPR.

**Complaints procedure and address**

Complaints about the way data is handled can be made via the following contact details.

Adam McCune, Data Protection Officer, Institute of Public Health, 700 South Circular Road, D08 NH90. Email: dataprotection@publichealth.ie. Tel 048 9069 0057

If you are unhappy with the decision of the Data Protection Officer you have the right to complain to the Data Protection Commissioner who will investigate the matter for you. The Data Protection Commissioner is the national body which works to protect people’s personal information and has legal powers to ensure that your rights are upheld.

The Data Protection Commissioner can be contacted at:

Address: Data Protection Commissioner, 21 Fitzwilliam Square South, Dublin 2, D02 RD28.
Telephone: 057 868 4800 or 0761 104 800. Email: dpcaccessofficer@dataprotection.ie

Via online form at www.dataprotection.ie. Further information on your data protection rights are also available on that website.

**Further information:** Further information on the data protection measures in place for this project and the IPH’s Data Protection Policy are available from the IPH Data Protection Officer Adam McCune at the contact details above. ENDS