Report on Adult Safeguarding Focus Groups with Health and Social Care Service Users

A report by the Institute of Public Health for the Department of Health to inform the development of a national policy on adult safeguarding in the health and social care sector in Ireland

Institute of
Public Health

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Acknowledgements

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The IPH also greatly appreciates the contribution of Department of Health officials and the Department of Health Research Ethics Committee for Adult Safeguarding Focus Groups (see Appendix 7) for their expert feedback and insights. We are also grateful to Engaging Dementia, Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) and the Trinity Centre for People with Intellectual Disabilities for their insights into conducting research with the different cohort groups.

Disclaimer: This work was commissioned by the Department of Health and carried out by the Institute of Public Health. It does not represent the opinions of the Minister for Health or the Department of Health, and any errors or omissions are the responsibility of the authors.

Prepared by Aideen Sheehan and Roger O’Sullivan, Institute of Public Health.

Foreword

As Minister for Health, I am very grateful to all the service users who took part in our focus groups for this important report on adult safeguarding in the health and social care sector. Thank you very much for sharing your time, energy, opinions and wishes with us. As my Department progresses a national health sector policy on adult safeguarding your help means that the policy, which is intended to benefit our service users, will be informed by your lived experiences and views. This policy will build on existing structures and standards and will aim to strike a balance between ensuring our service users can make their own decisions for their own lives while protecting adults at risk from harm or abuse when needed. Thank you for talking to us about what can be an uncomfortable and difficult topic. I know the policy will be all the better for it.

The safety of those at risk of harm or abuse is of fundamental importance for society. Adults at risk could be our neighbours, friends, family members or indeed ourselves, and we all want and deserve a chance to live a happy life and be protected from harm and abuse.

For good public services it is essential to listen to service users and take account of their needs and wishes. Research like this is essential to ensure that the voices of those who are affected by a policy are listened to in determining its direction. I also wish to sincerely thank the ethics committee that approved the project plan, the support organisations that assisted us to contact the focus group participants, and finally the Institute of Public Health for its excellent work on this important piece of research.

This recent time of national challenge has shown the value we place on being a community of people who take care of each other, especially those who are at risk. The Government is committed to working with the sector, informed by the voices of our service users, to ensure that we continue to evolve and improve the safeguarding of adults who may be at risk in the health and social care system.

Stephen Donnelly T.D.
Minister for Health

Glossary

ABI	Acquired brain injury (condition)
ABII	Acquired Brain Injury Ireland (organisation)
CCPC	Competition and Consumer Protection Commission
DOH	Department of Health
FVSP	Federation of Voluntary Service Providers
HIQA	Health Information and Quality Authority
HRB	Health Research Board
HSE	Health Service Executive
HSE NSO	HSE National Safeguarding Office
HSE SPT	HSE Safeguarding and Protection Teams
IPH	Institute of Public Health
ID	Intellectual Disability
IDS-TILDA	Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
IDWG	Irish Dementia Working Group
MHC	Mental Health Commission

Executive Summary

Executive Summary

Introduction

This is a report on focus groups on the theme of adult safeguarding carried out with cohorts of adults who may be at risk (also known as vulnerable adults). This commissioned research was carried out by the Institute of Public Health (IPH) on behalf of the Department of Health (DOH) to feed into DOH's policy development process on adult safeguarding in the health and social care sector. It aims to capture the views of cohorts of adults who may be at risk of harm - people with intellectual disabilities, people with cognitive impairments (dementia and acquired brain injury), people who have experienced significant mental health challenges, and residents of nursing homes - on the topic of adult safeguarding within the health service. The focus group research ran in parallel with other DOH stakeholder consultation processes including questionnaires, meetings and a stakeholder workshop which will feed into the drafting of new policy proposals and a public consultation.

12 focus groups were held involving 82 participants at locations around Ireland between November 2019 and February 2020. Participants were recruited with the assistance of advocacy groups and service providers working with the cohort groups. Participation was voluntary and by informed consent and the research received ethical approval from a Research Ethics Committee set up by the Department of Health for this project. An additional ethical approval process was also carried out with the Acquired Brain Injury Ireland Ethics Committee. Participants ranged in age from 23 to 97. The focus group discussions were semi-structured around the themes of: types of abuse, procedures for getting help and preferences for keeping people safe. They were audio recorded, transcribed and anonymised before analysis.

A summary of key findings relating to the main research topics is provided in Table 1 overleaf.

Executive Summary - Key findings

Table 1: Summary of key findings by topic

Topic 1: What kind of behaviours do you consider harmful?	• Physical abuse encompasses a wide range of behaviours including risks from other service users. Abuse in own home harder to tackle than by strangers. • Sexual abuse includes rape, inappropriate touching, sexual harassment and demanding sexual favours. • Unreasonable or insensitive pressure may occur during close routine interactions such as supported feeding and medication, particularly if there are time pressures and/or inadequate training for carers. • Isolation and a lack of meaningful activities or interactions for adults at risk seen as a form of neglect that can be very damaging to mental and physical health. • Emotional abuse seen as very damaging but more difficult to detect and tackle than physical abuse. • Financial abuse a particular risk for those reliant on others to shop/manage money. • Online abuse including financial scams, trolls and breach of privacy a source of concern for many, with some older participants avoiding the Internet for this reason. Guidelines for safe Internet use needed in some healthcare settings.

Topic 2: **If you were being harmed by someone who would you tell?**	• Wide range of potential sources of assistance, including family, friends, staff members, key workers, service manager, GP, social worker, public health nurse, advocacy service, An Garda Síochána, Ombudsman and community contacts. • Long term service users (e.g. those with intellectual disability) more aware of different options for seeking assistance than those with more recently acquired conditions (e.g. dementia, brain injury). • Those with more recently acquired conditions had less interactions with healthcare professionals and fewer known pathways to report an issue. • Very low awareness of HSE safeguarding service ("Safeguarding and Protection Teams") as a place to report harm. • Communication issues can make it difficult to get help – assistance with this vital for those who are non-verbal or have barriers to communication. • Difficulties getting help in family abuse because of fear of repercussions or of being unable to remain at home, and reluctance to go to An Garda Síochána. • Difficult to report abuse by paid carers because of fear of repercussions, fear of being labelled difficult and practical difficulties in identifying whom to report concerns to.

	- Desire for routine mechanisms such as residents' committees, service user committees and suggestion boxes to identify concerns and potential issues in ways other than making a formal complaint.
Topic 3: What would you like that person to do?	- Stopping the abuse and preventing a recurrence was the primary objective. - Assess the complaint and establish what could be done. - Proportionate response desirable especially in family abuse. Localised solutions also possible. - Appropriate sanctions or disciplinary procedures for professional carers/staff desired by some. - Zero tolerance policy/dismissal wanted by a few, particularly in relation to physical abuse. - External reporting/investigation mechanism desired by some to ensure complaints taken seriously, to identify patterns of abuse and to protect service users. - Some wanted the identity of the complainant kept confidential to prevent repercussions and to encourage third party reporting.

Topic 4: Would you like to be asked about what should happen?	• Feedback desired on outcome of a complaint. • Many participants wanted to be consulted about the outcome in relation to their care. • Particularly important to ask those living at home about their wishes to prevent unwanted outcomes. • A few felt investigation/sanctions should be a professional matter as complainants would have different views on what was appropriate. • Some third-party complainants (e.g. neighbours) didn't want to be involved in the investigation or follow-up after reporting a safeguarding concern.
Topic 5: What is the best way to keep people safe?	• Find ways to reduce imbalance of power between service users and health services. • Ensure full communication with service users who are not verbal including being alert to non-verbal signals and communication preferences such as pictures/ technology. • Independent safeguarding complaints mechanism to protect service users, some suggested HIQA. • Create feedback mechanisms that facilitate input on service improvements and allow concerns to be flagged to give a voice to service users and address power imbalances, e.g. through residents' committees, service user committees and suggestion boxes.

	• Extend and increase access to advocacy services across health sector. • Protection and confidentiality for staff and third-party whistle blowers to encourage reporting of abuse. • Protection and confidentiality for staff and third-party whistle blowers to encourage reporting of abuse. • To ensure good safeguarding and quality of care, including reduction of potential for conflict, provide appropriate training, conditions, supports and time allocations to carers. • Ensure up-to-date information on safeguarding procedures is available and promoted in accessible formats and clear language tailored to users' needs. • Safeguarding information and helpline details in multiple formats including online, hardcopy, radio/TV and wallet-sized cards. Tailor language and presentation to user needs.

Summary of key findings of potential relevance to COVID-19

Note: COVID-19-related concerns were not discussed at these focus groups which took place prior to the outbreak in Ireland. Given the impact of the pandemic on health services, IPH carried out a retrospective COVID-19 focused analysis of the findings related to safeguarding procedures. The results of this, summarised overleaf, may be helpful to consider in the context of the subsequent outbreak and ongoing/future public health measures.

Safeguarding and COVID-19 analysis	• Provide enhanced information on formal safeguarding mechanisms in multiple formats tailored to service users' abilities in light of potential reduction of opportunities to alert personal and advocacy contacts to abuse concerns. • Consult with service users, e.g. residents' committees, suggestions boxes and other means, on COVID-19-related service changes and restrictions to keep them informed and get their input on managing the challenges. • Recognise the importance of visitors and activities to mental, cognitive and physical health of nursing home residents when planning infection-control restrictions. • Facilitate digital access and communication opportunities for nursing home residents while taking account of dexterity, mobility, hearing and sight issues that make that challenging, and try to ensure opportunities for private conversation that would allow them to alert others to safeguarding concerns. • To meet safeguarding standards given the challenges of COVID-19, ensure appropriate staffing levels are maintained at nursing homes. Provide relevant training and supports to staff and home carers to manage safeguarding-related work pressures in context of COVID-19 challenges.

1

Background

Background

This is a report on focus groups on the theme of adult safeguarding carried out with cohorts of adults who may be at risk of harm. This commissioned research was carried out by the Institute of Public Health (IPH) on behalf of the Department of Health (DOH) to feed into DOH's policy development process on adult safeguarding in the health sector.

The Department of Health is developing a new overarching national policy on adult safeguarding throughout the entire health and social care sector, including public, voluntary and private services. Following approval of the policy by the Government, the Department will develop such legislation as may be required to underpin it.

Existing adult safeguarding policy is governed by a combination of standards, operational policies and procedures for the safeguarding of adults who may be at risk of harm or exploitation (DOH, 2020a). This includes:

- Joint national adult safeguarding standards were developed by the Health Information and Quality Authority (HIQA) and the Mental Health Commission (MHC) and approved by the Minister for Health in September 2019 (HIQA/MHC, 2019).
- The Health Information and Quality Authority (HIQA) is a statutory body tasked with inspecting, monitoring and reviewing health and social care services across a specified range of public, private and voluntary sector services. It inspects services for compliance and develops benchmarking standards of care.
- The Mental Health Commission is the statutory body responsible for the inspection and regulation of mental health facilities in Ireland. Safeguarding the rights of service users is a core aspect of its role.

- The HSE's safeguarding services evolved from its elder abuse service and since 2014 extend to adults with a disability and/or those over 65 who may be vulnerable to abuse. The service includes a HSE National Safeguarding Office (HSE NSO), 9 specialist HSE Safeguarding and Protection Teams (HSE SPTs), a programme of training and over 1,700 designated safeguarding officers in services.
- The HSE's safeguarding services support its policy Safeguarding Vulnerable People at Risk of Abuse – Policy and Procedures (2014), which primarily operates within the social care sector, but a draft new operational policy published in 2019 envisages its extension to all HSE and HSE-funded healthcare and social care services (HSE NSO, 2019a).

The HSE National Safeguarding Office Report 2018 (HSE NSO 2019b) shows that overall there were 11,780 safeguarding concerns reported to it in 2018, a 14% increase on 2017. 81% of these were in a social care setting, and around two thirds related to adults aged 18-64. Physical abuse was the most commonly alleged type of abuse (39%), followed by psychological abuse (28%) and financial abuse (12%), while over half of cases (53%) alleged a concern involving another service user, 14% by an immediate family member and 11% by staff.

A high-level Steering Group was set up to assist DOH in development of a new overarching national policy on adult safeguarding throughout the entire health and social care sector. DOH commissioned an independent evidence review by Mazars in partnership with an academic research team from the School of Nursing, Midwifery and Health Systems in UCD, and consulted widely with stakeholders through a variety of means, including questionnaires, meetings and a stakeholder workshop in October 2019 (DOH, 2020b). As part of this consultation process, DOH commissioned the IPH to carry out this focus group research on the topic of adult safeguarding with certain cohorts of adults who may be at risk of harm. These were:

- people with intellectual disabilities;
- people with cognitive impairments (dementia and acquired brain injury);
- people who have experienced significant mental health challenges; and
- residents of nursing homes.

The cohorts identified were selected to take part in focus groups because it was considered particularly important that their voice be heard during the development of a new adult safeguarding policy for the health sector (see more details under Methodology). UK research has shown the individuals most likely to have a safeguarding concern are those requiring physical support (42%), those with learning (intellectual) disability (13%) those requiring mental health support (12%) and those requiring support with memory and cognition (10%) (NHS Digital, 2017). Similar data was not available in Ireland at the time of planning the focus groups but it does underline the importance of ensuring these cohorts have input into safeguarding policy development.

In terms of the numbers in each cohort, there are estimated to be 23,000 people with intellectual disability in Ireland (Health Research Board, 2017). Around 120,000 people are estimated to be living with disability caused by brain injuries and around 18,800 brain injuries occur each year, including strokes and accidents (ABI Ireland, nd). There are around 55,000 people living with dementia in Ireland (HSE, nd). There are 583 nursing homes with almost 32,000 beds (HSE, 2020) and an estimated 30,000 residents (DOH, 2020c). Although estimates for the numbers experiencing significant mental health challenges vary widely depending on the definitions used, Census 2016 figures indicate there were 111,000 people with a long lasting psychological or emotional condition (CSO, 2016).

This report aims to represent the range of views and opinions of participants as expressed at these focus groups on the topic of adult safeguarding. As qualitative research, it does not aim to quantify or measure support for particular policy options, but rather seeks to note participant attitudes and priorities around safeguarding, and explore the reasons behind these.

2

Methodology

Methodology

Research Purpose

The purpose of this research was to capture the views of adults who may be at risk on the topic of adult safeguarding so that their views could be considered in the development of a new national policy on adult safeguarding in the health sector. The Department of Health is developing a new overarching policy framework, underpinned as required by legislation, for adult safeguarding throughout the entire health and social care sector including voluntary, public and private services. These focus groups are part of a wide-ranging stakeholder consultation to inform that policy.

The cohorts selected were:

- people with intellectual disabilities;
- people with cognitive impairments (including dementia and acquired brain injury);
- people with significant mental health challenges[1]; and
- people living in nursing homes.

These cohorts were selected on the basis that they might have difficulty participating through traditional consultation processes such as surveys or stakeholder meetings; be potentially at risk of harm making it important to consult them on their views; and would also have a high level of interaction with health and social care services. Previous UK research indicates that these cohorts are among those most likely to have a safeguarding concern (NHS Digital, 2017), although similar data was not available for Ireland at the time of planning the focus groups.

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1. The term “significant mental health challenges” was used to ensure a wide range of participants could be recruited if they self-identified with the term, e.g. through past or current mental illness and/or experience of mental health services.

Research Method

A qualitative approach using focus groups was chosen to get the views of adults from the target cohorts. Focus groups have been found to be a suitable way of canvassing the views of certain cohorts, whose views may not be easily reached through other consultation methods such as large stakeholder meetings or surveys which may be difficult for some to participate in. They can create a group dynamic that can spark interactive discussions between participants on a topic of mutual interest that can result in a richer exploration of the central themes than researcher-led interviews. They also provide a relatively timely and cost-effective way of getting the views of a substantial number of people. In line with the focus group methodology IPH recorded the views expressed by participants and sought clarification in some cases but did not assess or validate the accuracy of any statements shared within the focus groups. The aim of the research was to discuss the types of scenario or behaviour participants considered harmful, and how adults at risk would like to be protected from these within the health service. It was not the aim to probe into or evaluate the quality of service individuals were receiving at this time. The research aims to record the wide range of ideas and views on safeguarding expressed by adults at risk of harm in relation to the research questions, rather than to quantify participants’ support for specific policy measures.

Research Questions

The purpose of the research was to get the views of participants on the types of behaviours they consider harmful and what they consider the best way of assisting people in these situations. The following research questions were agreed with the Department of Health as being an important way to ensure a user perspective is heard and reflected in the policy being developed for adult safeguarding in the health sector:

- What kind of behaviours do you think are harmful?
- If you were being harmed by someone who would you tell?
- What would you like that person to do?
- Would you like to be asked about what should happen?
- What is the best way to keep people safe?
- Anything else important?

In order to stimulate discussion and keep it focused on types of harm, picture prompts depicting different types of abusive scenario were shown to participants to see which ones they had most concerns about and wished to discuss, though they were also encouraged to use these as a starting point to broaden the discussion to other areas of concern to them. The images were sourced from a specialist picture bank (Inspired Services) that supplies Easy Read images and from Shutterstock.

Ethics

Ethical approval for this research was received from a Research Ethics Committee specific to this project set up by the Department of Health comprising a team of external experts in the fields of ethics, disability and research, chaired by Professor David Smith of the Royal College of Surgeons in Ireland (see Appendix 7). An extensive ethics protocol was drawn up for the research, which included making emotional/crisis support available to participants via local HSE Safeguarding and Protection Teams if they felt distressed during or after the focus group. All members of the research team were garda-vetted. An additional ethical approval process was also carried out with the Acquired Brain Injury Ireland Ethics Committee.

Data Collection

Research Team

Professor Roger O'Sullivan was the principal investigator. Aideen Sheehan was the project manager and facilitator of the focus groups. Dr Annette Burns, Dr Conor Cunningham and Laura McQuade of IPH were co-facilitators.

Sampling and Selection of Participants

Purposive sampling – i.e. non-random sampling aimed at getting a broad geographic and social spread of participants with a wide range of abilities and from a variety of service types - was used to recruit participants from the four target cohorts (e.g. within the nursing home sector, participants were sought from a mix of public and private facilities). Stakeholder organisations that work directly with people in the relevant cohorts were asked to provide assistance with recruiting participants by circulating information to relevant people and in many cases facilitating the holding of the focus groups on their premises.

The stakeholder organisations were:

- The Federation of Voluntary Service Providers (intellectual disability);
- The Alzheimer Society of Ireland (dementia);
- Acquired Brain Injury Ireland (brain injury);
- HSE Mental Health Engagement Offices (mental health challenges);
- Sage Advocacy (nursing homes).

The Alzheimer Society of Ireland facilitated access to people living with dementia through the Irish Dementia Working Group, a self-advocacy group. Sage Advocacy facilitated access to nursing homes. The Federation of Voluntary Service Providers (FVSP) is an umbrella organisation for services that work with people with intellectual disability (ID) and it provided IPH with access to three of its constituent organisations from which participants were recruited. We have not named these smaller organisations or individual nursing homes to avoid any risk of participants being identified but we are very grateful for their assistance.

The IPH provided summary background information materials (see Appendix 3 and 4) and liaised with the stakeholder organisations on suitable venues and other logistical issues. The selection criteria for participants were that they:

- were aged 18 years or over
- had an intellectual disability, a cognitive impairment, had experienced significant mental health challenges, or were residents of a nursing home
- were resident in the Republic of Ireland or using services there on a regular basis.

Consent process

Participation was voluntary and information materials were provided in both standard and 'Easy Read' formats to ensure informed consent could be obtained. These were circulated in advance to the stakeholder organisations and on the IPH website. Contact details for the research team were made available which allowed participants to seek further information in advance of each focus group and a small number did so. Information briefings were held immediately prior to each focus group to explain the research and give potential participants the opportunity to ask further questions and decide if they wished to participate. After this they were asked to sign consent forms if they agreed to take part – a small number of people decided not to proceed at this stage. On the recommendation of the Department of Health Research Ethics Committee for Adult Safeguarding Focus Groups, a €30 gift voucher was provided to participants as a token of appreciation for their time. Where participants were accompanied by support persons, the latter were asked to sign a supporter's agreement clarifying they were there to assist the participant rather than to give their own views.

Logistics

12 focus groups were held between November 2019 and February 2020 with a total of 82 participants. Further details are given in the Profile of Participants section. Each focus group lasted between 60 and 90 minutes, with a further 30-60 minutes for the information briefing and consent form administration immediately beforehand – so approximately 2 hours in total. An IPH moderator and co-moderator facilitated the discussion and carried out the information and consent process. The focus groups were digitally audio-recorded on an encrypted device with additional written notes taken by the co-moderator.

Data Analysis

The audio recordings were transcribed verbatim by the research team to include references to relevant emotions expressed during the focus groups such as laughter, anger and upset. These transcripts were then anonymised and coded thematically according to the research questions and emergent themes raised by participants with codebooks developed for each topic. These codebooks were also annotated with relevant contextual observations from the facilitator and co-facilitators during the focus groups to assist with the analysis process. The key themes, concerns, suggestions and opinions were then extracted from these files to form this report. An Easy Read summary of the report has also been prepared.

Data Protection

The Institute of Public Health and the Department of Health were joint data controllers for this research and a Joint Data Controller Agreement was drawn up to outline their respective responsibilities. This was designed to ensure that to the maximum extent possible only the research team would have sight of any personal/identifying data. Stringent data protection measures were observed and outlined in a Data Management Protocol. A Data Protection Impact Assessment (DPIA) was also drawn up to identify all potential risks and mitigating measures. All material collected has been stored securely and will be deleted when the research is completed. Pseudonymisation and anonymisation of the data have been carried out to ensure no personally identifiable details are published in the report or other outputs, such as DOH or IPH media statements, conference presentations, methodological reports, summaries etc.

Research Limitations

The use of gatekeeper organisations to recruit participants was extremely valuable but it also meant they were more likely to be established service users, interested in the topic and motivated to take part. Many were recruited via advocacy services which also may have resulted in a disproportionately high-functioning and motivated cohort - though in practice people with a very wide range of abilities and views were sought and attended. There was a two to one ratio of women to men overall, possibly related to the recruitment method and the age profile of some cohorts, which left male views slightly underrepresented.

Under Health Research Regulations (DOH/HRB, 2018), participants also had to be able to give informed consent to take part, which meant that those without sufficient capacity to understand the purpose and voluntary nature of the research could not be included. However, in practice it was possible to maximise the capacity of all who were interested in taking part through the use of ‘Easy Read’ information materials and communication assistance from support workers, as well as one-on-one discussions during the consent process to clarify any questions, and ensure they could make an informed choice. A very small number of people decided not to proceed after the information process.

It took much longer to complete the information briefing and get consent forms signed with some groups than with others because of the combination of physical, visual, communication, dexterity and mobility issues among participants. This meant that out of the two-hour slot, some groups had a longer time for the actual focus group discussions (it was considered important not to overburden the participants by prolonging the overall session). A shorter consent form would have been helpful for some participants with physical or cognitive difficulties, provided all necessary ethical and data protection requirements were included.

Two focus groups with participants with significant mental health challenges were organised instead of the targeted three due to difficulties with the recruitment process – however those two focus groups involving 12 participants were particularly rich in insights.

As with all focus groups, some participants were more talkative and articulate than others, and this was more pronounced given the very disparate range of physical and communication abilities – though strenuous efforts were made to include all in the discussions. There was also a tendency at some of the focus groups for discussions to veer into a more general appraisal of the Irish health system, requiring some effort to focus it back on the topic of safeguarding. The use of pictures (see Appendix 2) helped with this though it was notable that participants sometimes had varied interpretations of the pictures. Participants were asked which of the scenarios depicted they had most concerns about and wished to discuss, which worked well for prioritising concerns, though the initial approach asking them to rank the types of abuse in order of priority by writing numbers on stickers was adjusted after the first focus group because it proved burdensome and practically difficult for some people to do.

It may have been helpful to include a short demographic questionnaire with the focus group to collect accurate information about age and residential status (e.g. whether living privately or in a residential facility) of all participants, though this would have to be balanced against the additional burden, particularly in the context of many participants' physical impairments. A limitation is also that focus groups by design are suited to topics that people are comfortable discussing in an open forum. Given the sensitivity of this topic some participants may have been more reticent about giving their views than they would have been in single-person interviews. However focus groups were still felt to be the best option because of the group dynamic factor which can encourage participants to interact and share perspectives, and for logistical reasons.

3

Profile of participants

Profile of participants

A total of 12 focus groups were held and 82 participants took part, with between four and nine in each focus group. The breakdown of attendees is shown in Table 2 below.

Table 2: Focus group participants by cohort

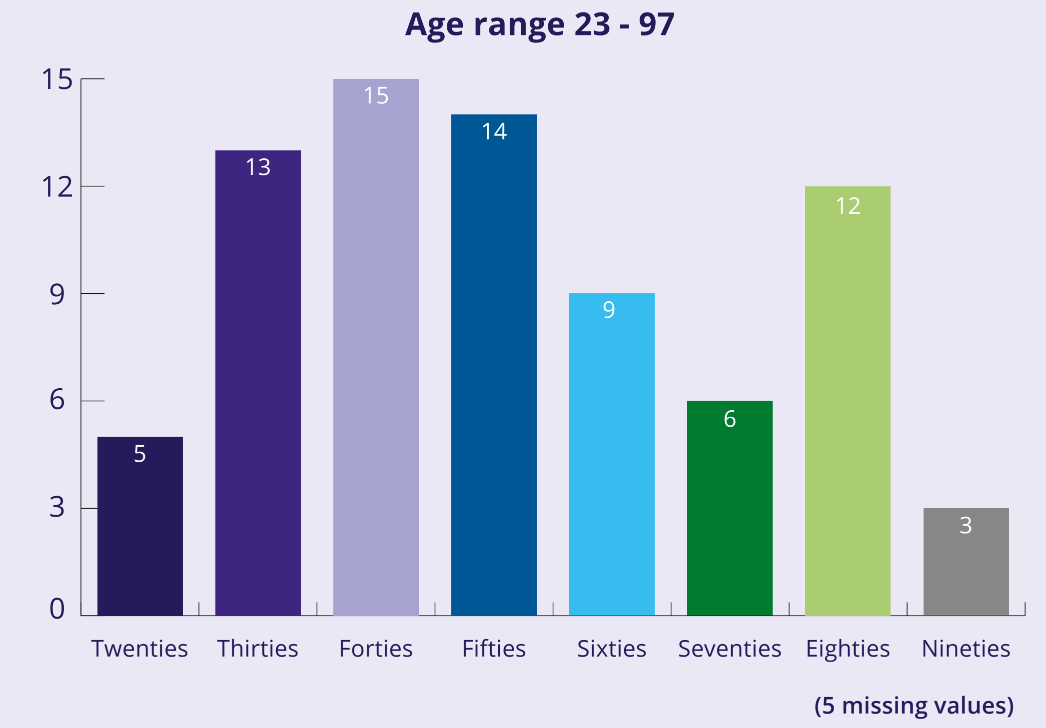
Cohort	Number of focus groups, by subgroup where applicable	Number of participants, by subgroup where applicable	Estimated number in cohort in Ireland
Intellectual Disability	4	31	23,000 (HRB, 2017).
Cognitive Impairment	3 • 2 acquired brain injury • 1 dementia	19 • 15 acquired brain injury • 4 dementia	Brain injury - 120,000 living with disability related to brain injury (ABII estimate, no date). Dementia 55,000 (HSE, no date).

Nursing Home Residents	3 • public • 1 private • 1 voluntary/ community	20 • 8 public • 6 private • 6 voluntary/ community	583 nursing homes with almost 32,000 beds (HSE, 2020). 75% of facilities and 78% of beds are private including voluntary/ community facilities. (HSE, 2020)
Significant Mental Health Challenges	2	12	111,000. Census 2016 (persons aged 15+ with long-lasting psychological/ emotional condition) (CSO, 2016).
Total	**12**	**82**	**n/a**

Age and disability profile

Participants ranged in age from 23 to 97 and there was a broad spread of ages with the highest concentration aged in their 40s and 50s as seen in Figure 1. Twelve of the participants were wheelchair users and two others used mobility aids. A number also had hearing and/or visual impairments, and one communicated primarily using assistive technology.

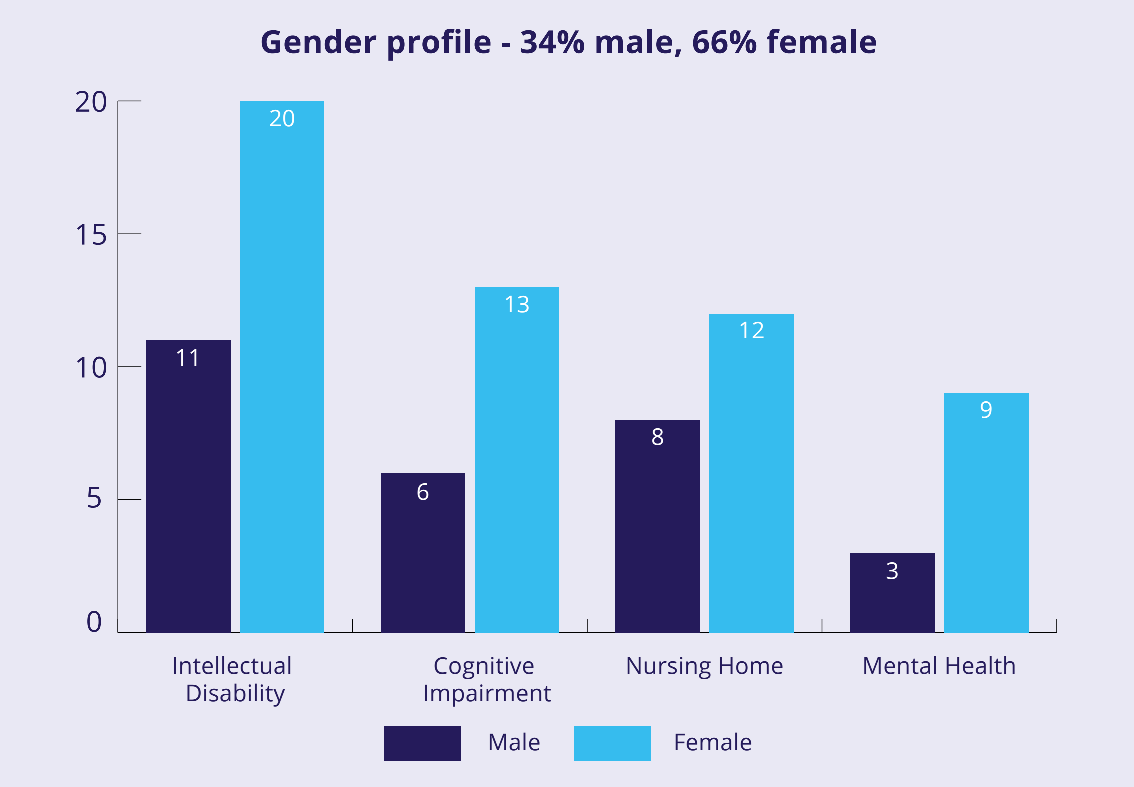
Figure 1. Age profile of focus group participants



Gender profile

In total 54 women and 28 men took part in the focus group, a ratio of two to one female. This gender imbalance partly reflects the older age profile, and the greater likelihood of women to take part in some of the community advocacy organisations from which many participants were recruited. Figure 2 shows the gender split within each of the focus group cohorts.

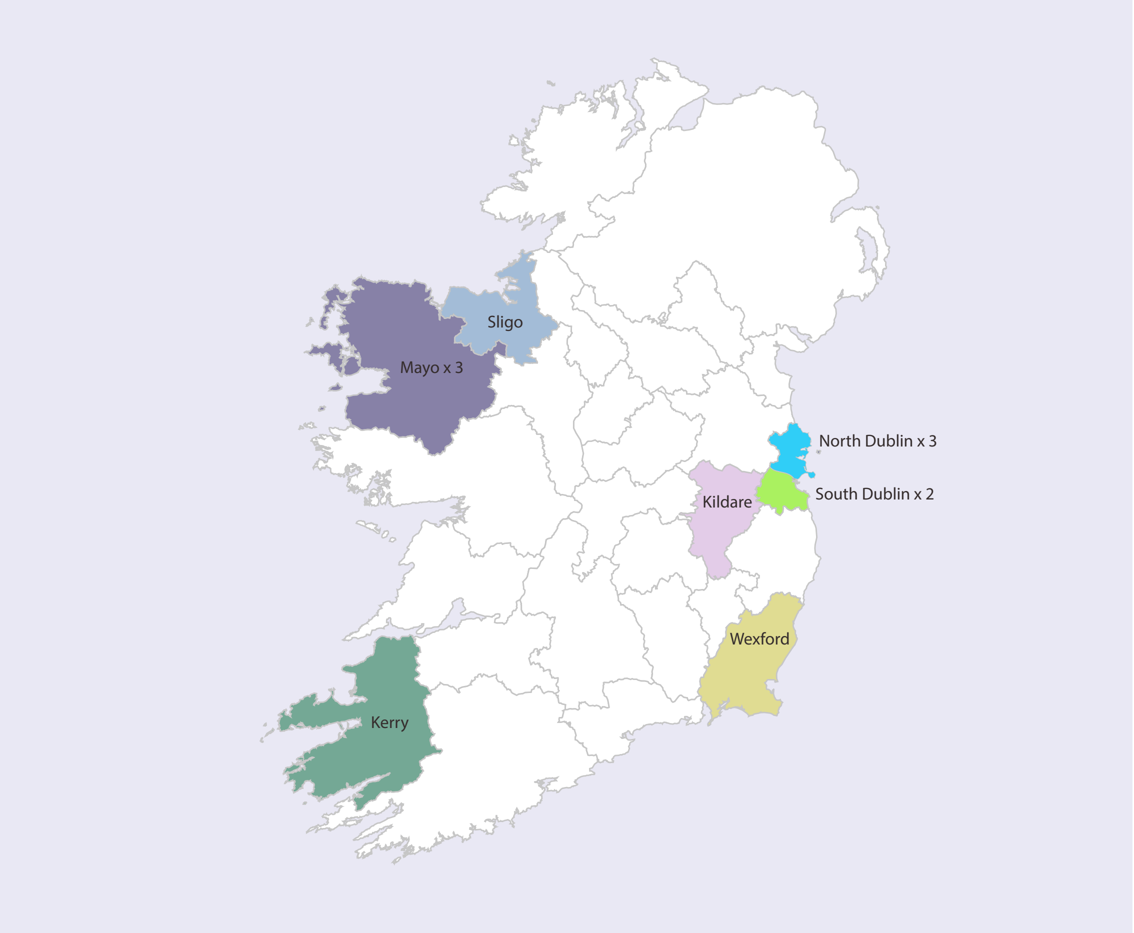
Figure 2. Gender profile of participants by cohort



Location

Five of the focus groups were held in Dublin and seven were held at other locations around Ireland as seen in Figure 3 overleaf. Some participants also travelled from other counties for the focus group, so there were participants from Kerry, Mayo, Sligo, Galway, Roscommon, Kildare, Dublin, Tipperary, Limerick, Wicklow and Wexford. The focus groups were mainly held at service centres or similar venues familiar to participants, with some taking place in hotel meeting rooms.

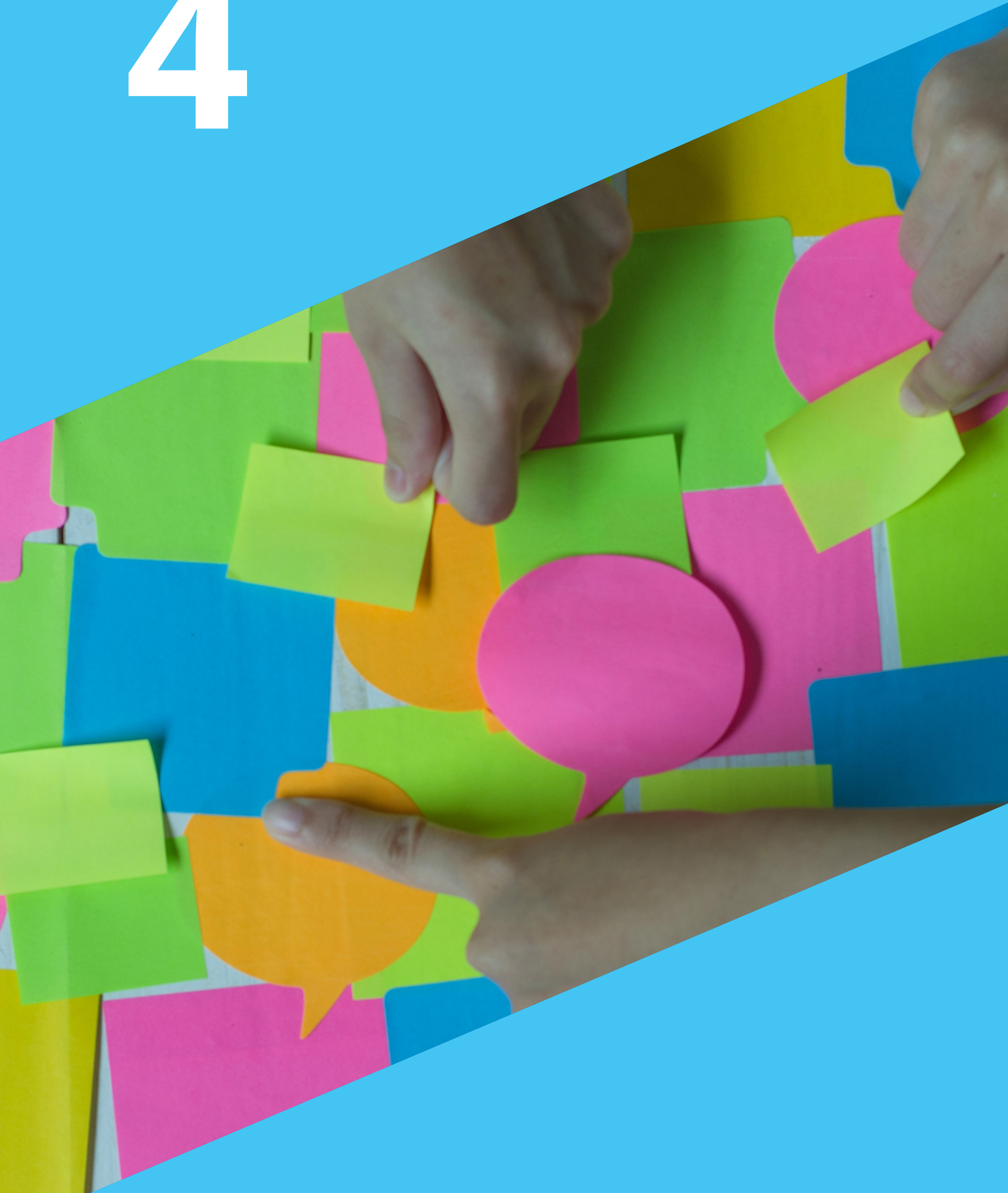
Figure 3. Locations of focus groups



The next section outlines the findings of the focus group.

4

Findings



Findings

This section explores the key findings of the focus groups in relation to the research topics, with an additional subsection, “Topic 6”, discussing findings which may be relevant to safeguarding within the context of COVID-19. Findings related to the question “Anything else important” are discussed within Topics 1-5 as applicable.

- Topic 1. What kind of behaviours do people consider harmful?
- Topic 2. Who participants would tell if they were being harmed?
- Topic 3. What they would like that person to do?
- Topic 4. Would they like to be asked about what should happen?
- Topic 5. What do they feel is the best way to keep people safe?
- Topic 6. Safeguarding in context of COVID-19*

***Note: These focus groups were all carried out between November 2019 and February 2020 prior to the outbreak of COVID-19 in Ireland. Neither COVID-19 nor the unprecedented nationwide public health restrictions subsequently introduced were foreseen or discussed at the focus groups. However, in light of the impact of the pandemic and the likelihood of ongoing public health restrictions, IPH carried out a retrospective COVID-19 analysis of the focus group findings to identify observations of participants related to safeguarding procedures which may be helpful to consider in the particular context of COVID-19 and related public health measures.**

Topic 1: What kind of behaviours do you think are harmful?

Summary of responses: Topic 1. What kind of behaviours do you think are harmful?

- Physical abuse encompasses a wide range of harms, including risks from other service users. Abuse in own home harder to tackle than by strangers.
- Sexual abuse includes rape, inappropriate touching, sexual harassment and demanding sexual favours.
- Unreasonable or insensitive pressure may occur during close routine interactions such as supported feeding and medication, particularly if there are time pressures and/or inadequate training for carers.
- Isolation and a lack of meaningful activities or interactions for adults at risk seen as a form of neglect that can be very damaging to mental and physical health.
- Emotional abuse seen as very damaging but more difficult to detect and tackle than physical abuse.
- Financial abuse a particular risk for those reliant on others to shop/ manage money.
- Online abuse including financial scams, trolls and breach of privacy a source of concern for many, with some older participants avoiding the Internet for this reason. Guidelines for safe internet use needed in some healthcare settings.

This question aimed to find out the type of behaviours participants would have most concerns about. In order to prompt discussion and keep it focused on safeguarding, a series of photographs or pictures was circulated, depicting different types of harm, specifically:

- Physical
- Sexual
- Pressurised feeding/medication
- Isolation/neglect
- Emotional/bullying
- Financial
- Online.

The aim of the pictures was to identify and focus discussions on the issues they felt most concern about (see Appendix 2). They were used as a starting point for discussion and participants were also encouraged to raise other relevant issues about behaviours they considered harmful.

Physical abuse

Physical abuse was perceived as very harmful, but (though singled out by many participants as the most worrying), it did not tend to provoke the most in-depth discussion compared to other forms of abuse. Across the focus groups it tended to be viewed as a more clear-cut form of harm with established pathways for addressing, including reporting it for example to service management or An Garda Síochána. Hitting, pulling hair, lashing out, were all cited as examples of unacceptable behaviours.

Several participants felt ‘rough handling’ by a paid carer at home or in a care setting could be a concern. Inadequate time allocations for carers were noted as a potential cause of problems.

> **“They’ve been cut back to half an hour just. They couldn’t look after patients to do it properly, I imagine…” Female.**

> **“It’s opened up the country to abuse,” Male, both nursing home cohort.**

The exchange between these two focus group participants highlighted a concern that inadequate allocation of carer time to provide appropriate care to vulnerable adults can put pressure on carers and in turn increase the potential for safeguarding issues to arise.

Physical abuse by other service users was of concern to the mental health cohort, particularly when someone might be in a highly agitated or intoxicated state in a hospital setting, with one participant noting it could be difficult to protect yourself given you couldn't lock your room or might be in a public ward.

> **"They let a guy in, I think he was doing either drugs or alcohol or something even though he wasn't supposed to be, and he did get very aggressive but I had managed to withdraw and slip away so I didn't have to have any encounter with him, but there are times where I would have had a sense of fear of physical violence." Female, mental health cohort.**

Sexual abuse

Sexual abuse tended to be seen clearly as a harm that shouldn't be tolerated by participants Most participants had strong awareness of what behaviour was inappropriate. They noted sexual abuse could include rape, inappropriate touching and sexual harassment and there was a strong awareness of the need to respect each person's "own personal space".

> **"She's telling him to back off. And he's not…. You do not, you don't put hands on a person. That person would be feeling uncomfortable…that girl would go home and tell her parents. 'Mammy or Da, I've been touched. Sexual harassment'" Male, ID cohort.**

> **"Other people don't like touching people, it's an attack, touching people, people doesn't like it. If I touch other people" Female, ID cohort.**

Some participants noted the importance of health professionals respecting people's boundaries and explaining what they were doing before doing medical examinations. One participant in the mental health cohort suggested there was a risk of those in power demanding sexual favours in return for giving prescriptions, and any such allegation should be investigated very rigorously.

Another participant in the mental health cohort noted that sometimes inappropriate touching could be more frightening than more overt physical/ sexual abuse because it affected a person emotionally but was harder to identify.

One participant noted in the context of this discussion that sometimes people felt that because you had dementia you could be patted like a child – while she was very clear she didn't classify this as abusive, she felt it showed a lack of respect for appropriate boundaries that people needed to be more aware of regardless of a person's condition.

> **"And the patting, they pat you and say 'Ah sit down, you'll be grand'. And it's like you don't know, because they don't really mean anything by it, they're not doing anything bad, but you don't really want them patting you." Female, dementia cohort.**

Pressurised feeding/medication

Pressurised feeding/medication was another type of harm which resonated strongly with participants. A picture of a person being fed food or medicine they were signalling they didn't wish to take (see Appendix 2), provoked some of the most animated discussion at the focus groups. This was particularly marked amongst those with physical disabilities who were reliant for assistance with food or medicine. Many participants noted communication difficulties could exacerbate conflict around supported feeding and medication, and that staff should be very aware of non-verbal signals, with efforts made to use sign language, pictures or other communication tools if necessary to understand people's wishes.

> **"Tell someone. Throw the spoon on the floor... Sometimes you have to" Female, ID cohort.**

> **"The non-verbal signs should be taken into account whether to keep feeding him or not or keep giving him the medicine. So heed the indications from the person." Female, ABI cohort.**

> **"he's actually...he's force feeding him. He should tell someone in a place what is happening to him." Male, ID cohort.**

Several participants noted that sometimes reluctance to take food or medicine related to physical discomfort or a food or medicine not agreeing with them, and often solutions could be found to make something more palatable or find a suitable alternative if carers made the effort to communicate effectively with the service user and observe their wishes.

Two participants described difficulties arising because a healthcare worker made a mistake or what they felt as an unjustified decision about their medication. In one case a man said a nurse decided he didn't need sleep medication, wouldn't listen to his objections and took offence when he complained to a superior, leading to ongoing coolness in his future relations with her.

> **“After that happened any other night when the nurse was on, I could see that distance, you know what I mean. And this is what prevents people from verbalising what’s going on, just the fear of repercussions, and after that I was never really treated the same by that nurse…. I feel that’s a form of abuse when someone can come in and interfere with your care” Male, mental health cohort.**

Some participants also noted that sudden refusal by a patient to accept food or medication was sometimes linked to the onset of a medical issue – for example a blocked bowel – requiring urgent treatment. This made it imperative that the wishes and opinions of service users were sought and respected by carers, as pressurising them to take something they didn’t want could have very serious consequences.

Participants with dementia noted how those with difficulties communicating could be labelled troublesome if they objected to something. One noted the importance of listening to people’s dietary preferences and restrictions (e.g. if they required gluten-free options).

> **“I think if I could go back to the Department of Health today with one message, I would say would you please train your staff. Nobody should be forcing somebody to take something that they’re already in hospital probably linked to, and they’re probably going to make it worse,” Female, dementia cohort.**

Participants with mental health challenges also noted particular issues around medication at times of crisis and the crucial importance of communicating with them about what each drug was and providing access to advocacy services to ensure their rights were upheld and that difficulties could be resolved.

Time pressure on carers, “rush, rush, rush”, was repeatedly cited as a major reason that inappropriate feeding/medication practices could occur both within residential services and in people's homes, and was seen as a crucial issue to resolve to prevent harmful practices – a topic discussed further in Topic 5.

Neglect/isolation

Neglect/isolation was a form of harm that resonated extremely strongly with participants. A picture of a wheelchair user who despite being well-dressed and clean, appeared isolated and unhappy, struck a chord with several participants who felt that people could be neglected in ways that went beyond their immediate physical needs.

> **"They are just left there, they're left sitting in the chair all on their own." Female, ID cohort.**

> **"To me she's either very lonely, it looks like she's just put out, left out in the cold and it's just kind of neglect almost, pure neglect, that's what I would be seeing there." Female, dementia cohort.**

One participant who had previously worked in nursing homes felt some staff "wouldn't bother" trying to help a resident who was quiet as it made their job easier, even if the person was suffering from a lack of engagement. Another agreed that there could be a tendency for health services to prefer people who were quiet and didn't make a fuss, but this could lead to their social needs being neglected if they were unable to assert their wishes.

> **"People have often said to me oh go on and sit there in the corner out of the way. You do feel people are telling you to get out of the way." Female, ABI cohort.**

Another felt very strongly that a person in this situation (as depicted in the image) was suffering a serious harm.

> **"The first thing that came into my mind was that this woman is deprived of her liberty, maybe if we had lived in a country where you could live in your own home, and live in the community, as we all talk about, and the importance of your own community with appropriate services," Female, dementia cohort.**

Participants expressed the need for meaningful activities especially in residential home settings and noted the dire consequences of not caring equally for people's emotional and mental health as well as their physical needs.

> **"She looks depressed actually, like she's sliding down, and if she's not careful she will lose her physical part as well. I mean she'll just be gone." Male, nursing home cohort.**

They also expressed concerns about people in the community with health conditions being left to their own devices to navigate a very difficult system and find appropriate supports and activities, which could be so difficult that some would simply give up and become disengaged. This was particularly the case where they were trying to adapt to new physical limitations, such as after a brain injury. Some noted that high costs of medication and equipment for those who could no longer work because of their condition could result in isolation as people might not be able to afford transport or necessary supports.

Others noted the need for activities or places for social interaction especially for those living with new conditions like dementia that meant they were no longer in their old social and work networks and felt more should be done to help people find and access appropriate supports.

Emotional abuse/bullying

Emotional abuse/bullying was seen as very harmful by participants. In the mental health cohort some felt it was the most harmful type because it was hardest to identify or prove.

> **“Physical stuff we can all see, and other people can witness it, but the emotional abuse isn’t always evident and people are very cunning, they don’t act it out in front of an audience, and that’s not as easy to catch, and that can be very damaging.” Female, mental health cohort.**

Shouting or screaming at someone was also seen as abusive, with one participant noting that it could be the service user themselves who could be at fault.

> **“If you’re in bad form you might roar at someone...that’s abuse as well.” Female, ID cohort.**

This showed a high level of awareness that abusive or aggressive behaviour can be peer-to-peer (or indeed peer-to-staff) and can stem from an individual’s emotional state at a particular time.

One younger participant with intellectual disability mentioned incidences of bullying during his schooldays that still hurt. He also stressed how hard it can be to tackle emotional abuse, as reporting it is made harder where the person’s confidence is undermined by the bully.

> **“I have to interject. You need to have the confidence, do you know, you need to have it or otherwise it’s just not going to work, you know.” Male, ID cohort.**

Another participant also noted the fact that bullies often targeted the most vulnerable who would find it hardest to get help.

> **“A lot of people that are bullied don’t have the strength. The bullies always pick on someone that’s weaker.” Male, ABI cohort.**

In one case an older participant mentioned the importance of not making assumptions about the cognitive abilities of people who were in a vulnerable physical condition, or of talking over them in ways that could be very hurtful.

> **"I remember I was semi-conscious, and I knew who was talking, I knew they were laughing at me and that hurt me very much. So you'd want to be very careful if there's anybody unconscious not to speak out loud. They didn't think I heard it but I did hear." Female, nursing home cohort.**

Several participants with mental health challenges said they had felt emotionally bullied by their interaction with the health services or with particular healthcare professionals, which they perceived as being due to a fundamental imbalance of power – this is discussed further in Topic 5.

Financial abuse

Financial abuse was seen as a significant concern, whether it involved being robbed, short-changed, scammed online, or someone else taking unwanted control of your finances. Participants with dementia and those in nursing homes noted the type of issues that could arise for those often reliant on others to make purchases for them, an issue they noted could affect very many older people where control over their money was taken away.

> **"They go and they get money, they get something small, and they keep the rest for themselves," Female, nursing home cohort.**

> **"I think it's something that we're all very aware of, that in particular in family situations where people, their money is taken, whether it's the home-help going into the post office to take the pension, and a tenner for herself, or go to the shop and do the shopping." Female, dementia cohort.**

Another person mentioned the need to encourage and assist people to get enduring powers of attorney and make financial plans early after diagnosis of dementia, as they felt it would make it easier to manage their affairs and prevent potential abuse as their condition progressed, as well as removing a source of anxiety. Another suggested that public information campaigns on this were needed as sometimes families were resistant or had misconceptions that it would be too costly or difficult to undertake something such as an enduring power of attorney.

A nursing home resident noted that new rules about financial terms in nursing homes (Competition and Consumer Protection Commission, 2019) would help prevent financial abuses.

> **"I remember reading about it more than anything else, that they now know they better not step over the line. So hopefully there'll be much less and none of that carry-on." Male, nursing home cohort.**

Another nursing home resident talked about small items going missing – e.g. personal supplies of soft drinks – in facilities, while another responded that they felt that though this could be an issue with so many different staff coming in and out, it wasn't very common.

Participants in the intellectual disability cohort had a very strong awareness of their entitlement to look after and hold their own money, and the fact no-one else had the right to do so without their consent. Some were also very aware of how to seek help to manage money if necessary, in a way that still preserved their own control, which suggests awareness and training has worked well to empower ID service users in safeguarding their own financial interests.

> **"Yeah, it's like if I had a thousand euro, and it was all in coins or notes, you'd be confused. And if you had to add it all up like. If I went to [support worker] and said can you count it? She might say you can count it yourself. But she might be there beside me if I done it right and she might tell me I done it right. She'd help me." Female, ID cohort.**

Online abuse

Online abuse was cited as a source of concern by most younger participants. Many (though not all) older participants said they didn't use the Internet, some because they were fearful of potential abuses and scams there and others because they were not interested. One participant noted he had been hacked the previous year and suffered a financial loss. There was general agreement by participants that more education and training was needed to help people at risk (and the population in general) use the Internet safely including how to block abusive posts and identify and report scams.

Some participants with experience of mental health challenges also suggested guidelines for safe mobile and social media use within psychiatric hospitals to protect individuals' wellbeing and the anonymity of others – particularly in relation to infringements of their privacy, for example being captured in other people's social media pictures or videos, or to protect people from their own overuse of social media etc. Suggestions for this included designated times and places where mobiles could be used. They also noted that notwithstanding the dangers of excessive use or abuse of social media, draconian restrictions or outright bans on online engagement for people within hospital settings could also be damaging given its centrality to their lives and use as a communication and support tool. The need for clear communication and discussion with people about restrictions on their online activities within the health system (e.g. in hospitals) was stressed.

> **"It's such a big part of the world, that yeah you can't just whip it away. It's like people are using them as a crutch possibly and then if you take that away, I think maybe you do need spaces for this,**

and like even for the person who wants to vlog [video log]”. Female, mental health cohort.

Recap: Topic 1 discussed the wide range of behaviours considered potentially harmful by at risk groups including physical, sexual, psychological, emotional, financial and online abuse.

Topic 2: If you were being harmed by someone who would you tell?

Summary of responses: Topic 2. If you were being harmed by someone who would you tell?

- Wide range of potential sources of assistance, including family, friends, staff members, key workers, service manager, GP, social worker, public health nurse, advocacy service, An Garda Síochána, Ombudsman and community contacts.
- Long term service users (e.g. those with intellectual disability) more aware of different options for seeking assistance than those with recently acquired conditions (e.g. dementia, brain injury).
- Those with more recently acquired conditions had less interactions with healthcare professionals and fewer known pathways to report an issue.
- Low awareness of HSE safeguarding service ("Safeguarding and Protection Teams") as a place to report harm.
- Communication issues can make it difficult to get help – assistance with this vital for those who are non-verbal or have barriers to communication.
- Difficulties getting help in family abuse because of fear of repercussions or of being unable to remain at home, and reluctance to go to An Garda Síochána.
- Difficult to report abuse by paid carers because of fear of repercussions, fear of being labelled difficult and practical difficulties in identifying whom to report concerns to.
- Desire for routine mechanisms such as residents' committees, service user committees and suggestion boxes to identify concerns and potential issues in ways other than making a formal complaint.

This section discusses who participants said they would tell if they were being harmed or had concerns about someone else being harmed. Participants across most cohorts had a high level of awareness of the need to get assistance in the event of abuse, and most spontaneously mentioned the need to tell someone. The most commonly cited were family and staff member/manager, but there was a wide range of suggestions as set out in Table 3:

Table 3: Where participants would seek assistance

Category of where person would seek help	Specific individuals within each category
Individual service (e.g. nursing home, daycare service, hospital)	Staff member Manager Key worker
Personal	Family member Friend Neighbour Fellow service user
Wider health service	GP Social Worker Public health nurse Advocacy service

Other formal sources	An Garda Síochána Ombudsman
Community	Shop assistant Security man Priest
Online	Forums such as Facebook for advice on where to get help

Awareness of HSE safeguarding services and 'safeguarding'

The HSE safeguarding service ("Safeguarding and Protection Teams") was not spontaneously mentioned by anyone as a service they would contact for assistance, though a small number of people said they had heard of it when prompted and at least one participant believed they had previously contacted it[2].

Awareness of the safeguarding service however appeared low, even amongst some nursing home residents and people with intellectual disabilities whom it would be particularly targeted at, though a few mentioned seeing information about it on a noticeboard or similar.

> **"Yes, yes. It's in mine, mine is a residential one, there's information," Female, ID cohort.**

The term 'safeguarding' itself was not well understood or recognised by many participants, with several asking what it was, particularly at

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2. A second participant also said he had contacted the HSE safeguarding service but it was unclear from the discussion if it was actually the Competition and Consumer Protection Commission (CCPC) helpline he contacted with a query over nursing home contract terms as he also mentioned new guidelines introduced in 2019 to give clarity on these (CCPC, 2019).

information meetings prior to the focus groups. There was also a tendency to conflate safeguarding with physical health and safety issues such as high-viz jackets, rules of the road, manual handling, fire drills, safety lighting and traffic lights. This suggests that in promoting a safeguarding service, great effort needs to be made to communicate to potential users in very clear language what it is for, and to differentiate its key objective of tackling and preventing abuse from safety issues dealt with by other agencies such as the Health and Safety Authority or the Road Safety Authority.

Of the 82 participants, one in the mental health cohort believed they had in fact previously contacted the HSE safeguarding service over concerns about a neighbour's wellbeing but had only come across it by asking for advice on social media on where to go for help. This suggests it does not have a high public profile, name recognition or web presence, even for those actively searching for assistance over a safeguarding issue.

> **"I was watching this [concerning issue about a person's wellbeing] for two years, I didn't know where I should contact, I didn't know if I should contact, at the end of the day it got so I was concerned, not just for his safety but for other people's safety, so you have to be more aware so people know where they can go…". Female, mental health cohort.**

Differences between cohorts

There was a particularly high level of awareness of the need to tell someone about harm amongst participants with intellectual disability who were established life-time health and social care service users. Unlike those whose condition had developed more recently (e.g. dementia), they appeared very familiar and comfortable with the idea of reaching out for help across various networks, both formal and informal, including key workers, staff and managers in services, and to escalate it to outside agencies if necessary, as shown in this discussion of a financial abuse picture.

> **Participant. "I'd go to the staff and I'd say that person has my money, I need to hold it myself.**
>
> **Researcher. And say one of the staff was saying I'll look after the money and I won't give it to you, what would you do then?**
>
> **Participant. "I'd say sorry, I'm well able to hold my money."**
>
> **Researcher. "So would you go to someone else if one person said you can't have your money?"**
>
> **Participant. "I'd go to the guards." Female, ID cohort.**

Participants with ID indicated a similar willingness to report concerns over all other types of abuse discussed. However some also noted that a person reporting abuse might have difficulty being believed, if the person complained about disputed what they said or alleged they had caused the problem.

> **"Say somebody who had job, doing that, if that person gets in trouble..., if that person get in trouble, you might get in trouble with he. Both would get in trouble," Male, ID cohort.**

Ways to overcome this suggested by participants included reporting the matter as soon as possible, and also telling a family member to get support in reporting a problem.

Those with more recently developed healthcare needs such as people with dementia or acquired brain injury were less familiar than long-term health service users with where to turn if there was an issue. This probably reflected the fact that many may not have previously had a high level of interaction with health services. This meant they had fewer routine points of connection with health services, with some noting few interactions with public health nurses who might otherwise be considered a point of assistance in the event of abuse.

> **“There’s not many nurses on the ground, public health nurses or health education. There’s not many visits. There should be some liaison between the particular nurse or some nurse that should be coming, every so often, from the GP, they should be able to discuss this”. Female, dementia cohort [discussing image of physical abuse].**

Several participants noted the difficulty of knowing where to report abuse by a carer, whether a paid carer in the home or a family member.

> **“You have to know where to go, where do you go with it. None of us know where to go. If you’ve a problem with the guards, you’ve got the garda ombudsman to go to, you know where to go”. Male.**

> **“There’s no body.” Female.**

> **“Well I couldn’t see myself ringing the police on a family member.” Female, all ABI cohort.**

Communication issues

Several participants mentioned the difficulties of communicating issues and the importance of having assistance with this.

> **“Well if you can’t find the words to express...[inaudible].... you’ve got to ask somebody but it’s very hard to ask, you feel well, I don’t know, I’m not educated and I can’t read that much you know. Words can make it difficult,” Female, nursing home cohort.**

> **"He's got to speak out, you know. It's not that easy, because I know even now there are times I can't get my words out and I can't, I suppose I'm still ok, I still can get or I'll scream. But for somebody, I mean this looks to me like an older man, an older person, it's a horrible situation to be in, they've got to try and get, if it's a family member, that's obviously even worse, but if it's not a family member someone has got to tell a family member." Female, dementia cohort [discussing image of physical abuse].**

> **"Well if they're verbal they should be complaining, but that's always very easy on the outside, everything's easy when you're on the outside. When you're actually in a situation, if you're in a situation you're probably very vulnerable." Female, ABI cohort.**

Participants in the ID cohort also noted staff should be looking out for non-verbal signs someone was upset if they had been touched inappropriately.

> **"They'd know by your face if you're upset and someone touches you," Female, ID cohort.**

Reporting abuse in the home

In discussing the scenarios depicted, participants living at home noted the particular difficulties for those reliant on carers in reporting abuse, whether within the family or in relation to a paid carer.

> **"I think if it's a family member she might be afraid to go to another person in the family. Because she might easily overwrite it and say 'oh Mammy was just in a bad mood that day'. And I definitely don't think that she'd go to the guards, because she's obviously vulnerable that somebody has to care for her. So I would say if she's a carer, I would think or I would hope she'd tell a member of the family and they would deal with it. I don't think, if she's vulnerable enough to**

> **need a carer, she wouldn't be able to know what to do to deal with it herself. I'd hope she'd have the sense to say it to somebody." Female, ABI cohort [discussing image of physical abuse]**

> **"If someone's in a position where they're a bit fragile, and you've a carer like that who absolutely does not care, all they want is a cheque on a Thursday, where does that person go? I wouldn't have a clue." Male, ABI cohort.**

Some participants were also unclear and fearful about where someone should go in the event of family abuse concerns because of the fear of repercussions and the perceived threat of ending up in a nursing home.

> **"If they are living on their own, or if it's a family member, they are afraid to say because they don't want to be put in a nursing home and they don't want to leave their home," Female, dementia cohort.**

> **"I think you go to a higher authority, but if it's a family member it gets more personal, it could get ugly," Female, ABI cohort.**

Another noted the very particular difficulties of tackling an abusive family member, in this case while sharing the care for another very ill relative who was the immediate priority.

> **"it was a really difficult situation, you still had to look after her, but you were being shouted at and thrown at all the time. So I know that's probably an extreme situation, but you know family members don't always realise what's going on firstly, or they know very well." Female, dementia cohort.**

Some participants noted that it could be difficult to get an opportunity to complain about an agency carer because people didn't get the opportunity to talk privately to a manager from the carers' service without the carer being there.

> **"That is very serious there, I mean carers in general, my experience is ridiculous because when the supervisor comes, they come with them, so what in God's name could you say about them". Female, ABI cohort.**

> **"When there is care, whether it's private or public, whoever really checks up on that person? There's a manager somewhere, all over the country there's managers, but what link is there to see if that person is actually doing their job? And that is a big, big problem in this country, is that we have nobody managing home helps or carers, you know they come in from an agency, the agency gives them their hours, they come in from the public health sector and there's actually nobody monitoring them." Female, dementia cohort.**

However some participants worried it would achieve nothing to contact a care agency head office or might even have a counter-productive response. Several participants felt they might be labelled difficult or troublesome if they complained making it harder to be believed or possibly even resulting in care being withdrawn.

> **"It's very hard though, if that's a carer sent in by the HSE, and you go and complain about them, the staff member is going to be brought in, and the carer would say, don't mind them, they've a bit of a mental problem, they're awkward." Male 1, ABI cohort.**

> **"That's what happens, he's only a f**king moan. He complains." Male 2, ABI cohort.**

Alternative ways to flag concerns rather than making a complaint were desired by some. This is discussed in Topic 5.

Concern was also raised for those without family members to flag issues or advocate for them with one participant noting a case where medical staff did not want to talk to her with regard to the care of an elderly friend of hers in a nursing home or hospital, because she was not next of kin, even though that friend had no family to assist.

Recap: In Topic 2 participants suggested a wide range of places to seek assistance in the event of harm, including family, health service and other networks. It was felt that communication barriers, fear of repercussions and uncertainty about where to go, particularly in the case of abuse by a family member or home carer, can make this difficult.

Topic 3: What would you like that person to do?

Summary of responses: Topic 3. What would you like that person to do?

- Stopping the abuse and preventing a recurrence was the primary objective.
- Assess the complaint and establish what could be done.
- Proportionate response desirable especially in family abuse. Localised solutions also possible.
- Appropriate sanctions or disciplinary procedures for professional carers/staff desired by some.
- Zero tolerance policy/dismissal wanted by a few, particularly in relation to physical abuse.
- External reporting/investigation mechanism desired by some to ensure complaints taken seriously, to identify patterns of abuse and to protect service users.
- Some wanted the identity of the complainant kept confidential to prevent repercussions and to encourage third party reporting.

This section explores what participants felt should be done if they raised a concern about harm.

Stopping the abuse

In general, stopping the abuse was the primary objective of participants. People primarily wanted the matter investigated and the offending behaviour stopped, and this applied to harmful behaviour by both staff and fellow service users.

> **"Get a warning. And if it doesn't end, then... Sometimes people say things and they don't mean it like, they don't realise, you know." Female, ABI cohort.**
>
> **Participant. "Maybe get them to see sense first."**
>
> **Researcher. "So, give them a chance to say Sorry?"**
>
> **Participant. "Yeah." Male. ID cohort.**

Some noted the importance of tailored responses, particularly in family settings.

> **"These are situations where there can be all sorts of permutations and combinations of stuff and you have to really look at each and see what's happening and what needs to be done on foot of it. So putting somebody in a room with someone, whether it's a family member or someone else, family members will know each other. If they're not family members, well there is at least another person who checks up, so there is an opportunity for, for questions and answers," Female, dementia cohort.**

Staff abuse

Some participants felt that in the case of health service staff, clear procedures such as written warnings or monitoring the behaviour of staff members might be needed where abuse was found, with tougher action needed for an ongoing issue.

> **"For a particular problem yeah, somebody should be reprimanded, the same way as for any employee there should be a warning, or they should be retrained, or sent for retraining" Male, mental health cohort.**

> **"Keep an eye on them for a while". Female, ABI cohort.**

> **"If it continues it should be looked into more." Female, ID cohort.**

If there was a pattern of behaviour by health service staff, participants felt stronger action was needed, and some felt that a zero-tolerance approach to abuse was the only way to stop it as anyone who abused someone was a risk to others.

> **"You must take them out of the system because if you leave them there they will do it again…. You have to get rid of them. One or two examples would cure it I'd say. And once or twice, the staff would learn you can't be going on like that." Male, nursing home cohort.**

> **"It should be investigated, and if there's serious physical harm, that person should not be allowed, in my opinion, to work with vulnerable…." Female, mental health cohort.**

> **"Well I'll tell you if I was a staff person, I'd sack them," Female, ID cohort.**

> **"Action, yeah. If she treats all her persons like that, she's not suitable for the job" Female, ABI cohort [discussing image of physical abuse].**

Participants tended to focus on abuse by staff and to a lesser degree abuse by fellow service users (peer-to-peer abuse). For peers they suggested warnings and the chance to apologise could apply in the first instance rather than sanctions. They also mentioned how small problems could be dealt with by local solutions to protect individuals from abuses by other service users, e.g. one noted a case where other patients were taking cigarettes from a vulnerable patient in a psychiatric hospital – and the solution found was for the nurse to give her the cigarettes one at a time to prevent them being stolen.

External Investigation

Some participants felt that there needed to be an external investigation of any allegation of harm within institutions or services, given the imbalance of power between service-providers and service users, and the strong HR and union-based protections for staff.

> **“Oh totally from outside. I think that’s important because to be honest with you there are a lot of people in nursing homes and places like these and they don’t have a voice and they’re afraid to give an opinion. You need someone, an interaction with someone from the outside who’s totally neutral in the situation.” Male, ABI cohort.**

> **“I think there needs to be somebody there who is both in a position to evaluate somebody independently, or in the same way, the patient can have more confidence, or even if it’s the staff member, can have confidence. I think the problem is to go within the local system, you have the politics, and as I said you can have someone like that and you can actually find their superior is afraid to tackle them.” Female, mental health cohort.**

One participant noted that having an independent body responsible for investigations might make it easier to identify a troublesome pattern.

> **“If you have the independent body, they may even, they may not necessarily follow through with a formal complaint, but the person who’s receiving that complaint may find that actually they’ve received a number of calls from different people in different locations that could turn out to be that person, so that’s a different way of getting the information,” Female, mental health cohort.**

Some participants in the mental health cohort suggested HIQA or the MHC might be well placed to carry investigations out.

> **"I agree that we need somebody in-house but whether you would tag that person on to the likes of the Mental Health Commission or, what's the other one called, HIQA, and I don't think hospitals like either of them, because they can come in unannounced, and they can see things as they are. I think if you were going to appoint someone, they have to be independent and they have to have a similar protection, that they're almost untouchable by the hospital" Male, mental health cohort.**

Even where concerns weren't considered serious enough to warrant a formal investigation, it was felt by some that being able to report concerns to an appropriate trained professional meant they could be logged, and action could be taken if there was a pattern of behaviour or minor issues noted.

Confidentiality

Some participants noted the importance of keeping the identity of complainants confidential and finding a solution that prevented repercussions for the care recipient.

> **"So say like it's you, I don't want you looking after my mother, we have to just take you out of that, but without saying, so you can't go back, office talk, oh yeah, I was working with that auld bitch and she complained about me, and they took me off her and, so then the next person goes in they're going to treat them the same way, cos you're after getting my friend sacked. So ok, you've been removed from Mrs Joe Bloggs, but you're not told you were removed because you grabbed her by the scruff of the neck, departmental issues that we are changing things around just to keep it fresh." Male, ABI cohort.**

CCTV

Some participants in the mental health cohort felt that the use of CCTV cameras should be considered more widely within health services to identify abuse, particularly if serious concerns about physical abuse had been raised.

> **"CCTV cameras. I think if every single hospital room and every interview room had CCTV cameras on the wall," Female, mental health cohort.**

Some felt it would be impossible to get staff and service user buy-in for CCTV use, given the sensitive data protection issues involved. However, they noted CCTV was already used in some waiting rooms, and more widespread use could make hospitals more secure from abuse and crime and could help to corroborate allegations of abuse.

> **"So safeguarding has to begin at the halldoor so to speak, at the main entrance. Like it is so easy to get into the hospital and to make your way around it," Male, mental health cohort.**

One participant felt that six-monthly reviews of staff, including getting the views of service users would help identify potential issues with abuse.

Carer issues

Some participants also expressed the need to support carers to deal with the pressures of the job to prevent problems arising.

> **"The carer has lost their patience, and thinks it's ok to vent their frustration, so the carer needs to be somehow supported, their level of stress has gone out the window, the carer is in trouble. So whether it's vicarious trauma or whatever, or just the person not suited to the job, the client definitely doesn't deserve to be treated like that,**

> **so that's a problem with that. So the service provider and the service user in that case, both of them are in trouble." Female, mental health cohort [discussing image of physical abuse].**

The issue of carers is explored further in Topic 5 as participants repeatedly highlighted the potential for abuse where people were reliant on others for assistance with routine activities, and the time constraints and challenges involved in dealing with complex health needs.

Recap: In Topic 3, participants' priority was to stop the abuse and prevent a recurrence. A proportionate response was generally supported, while some wanted appropriate sanctions as part of a policy on disciplinary procedures for abuse by staff as well as an external investigation mechanism. Some suggested a zero tolerance policy for physical abuse.

Topic 4: Would you like to be asked about what should happen?

Summary: Topic 4. Would you like to be asked about what should happen?

- Feedback desired on outcome of a complaint.
- Many participants wanted to be consulted about the desired outcome in relation to their care.
- Particularly important to ask those living at home about their wishes to prevent unwanted outcomes.
- Some felt sanctions should be a professional matter as complainants would have different views on what was appropriate.
- Some third-party complainants (e.g. neighbours) didn't want to be involved in the investigation or follow-up after reporting a safeguarding concern.

Feedback and consultation

When asked if they would like to be consulted about what would happen following a complaint, many said they would like feedback on what happened following a complaint about abuse.

> **"Even if the outcome is she was having a bad day or whatever, that's grand, at least you know, you're told. But the way they think about us at the minute, is ah sure they're always complaining, maybe they're not right, well come and tell us that, at least you'd get an answer", Male, ABI cohort.**

Such feedback could be particularly important for those living at home and reliant on carers, who expressed very strong concern that a decision about a person's care might be taken on their behalf if they reported a safeguarding issue about a family member or paid carer. One participant noted that fear they might end up being forced to go to a nursing home was a factor that would put people off reporting abuse, particularly if the person lived alone, and expressed the wish that where an abuse issue was reported, healthcare professionals would discuss the person's wishes.

> **"I think in general doctors will have the conversation as to what a person wants, I would hope, I know not all of them are person-centred," Female, dementia cohort.**

Some participants in the ID cohort said they would definitely like to be consulted about what to do while others felt it was a matter for the appropriate authorities to investigate and find a solution.

> **"They have to tell the boss,and explain what happened and then the boss can decide. Sack them or not sack them," Female. ID cohort.**

Investigation and sanctions

One nursing home participant pointed out that while feedback was desirable, there would be many different views taken as to what type of sanction was needed.

> **"I don't think so....Just for management to come back and say we've looked into that. Everybody in the room here would have a different solution." Male, nursing home cohort.**

A small number of participants expressed a view that as long as their concerns and views were listened to when reporting a concern, investigation of the matter should be a matter for the professionals and those reporting it should be kept out of it to avoid repercussions and being labelled a troublemaker. This was particularly the case for third party reporting of abuse – some participants noted that whistle blowers or those outside the situation, e.g. reporting a concern on behalf of someone else - might not wish to be involved in an investigation, and those with the necessary expertise should take over the investigation and response.

One person praised the way her concern about a third party at risk of harm was handled by the HSE Safeguarding and Protection Team.

> **"The person I contacted, they sent an email to the local health services, leaving out my name, so they took me out of the equation, saying look this came in from a concerned member of the public. They didn't involve me in it so that's very good…I didn't want the people knowing I was involved, but they still sent ahead the report to be looked at without my name." Female 1, mental health cohort.**

One participant noted that Tusla and the Child First guidelines for handling allegations concerning children provided a model for how an adult safeguarding concern might be received and investigated by a professional body.

> **"If somebody can make an educated judgement based on their experience and knowledge, or just look into it in a discrete way, but the responsibility is no longer the person who rings up, it comes to a question to investigate whether this person needs help or not. We're allowed to be involved because someone in society cared enough to make a phonecall, that the professionals took over". Female 2, mental health cohort.**

Co-operation with Tusla

Within the mental health cohort, one participant expressed a particular concern that a child protection investigation might be instigated without a parent's knowledge on foot of a disclosure they might make about their own mental health challenges – and that fear of losing their children ultimately put some families at greater risk of harm because of a reluctance to seek help.

> **"I just feel like what is the point in being honest like and saying what the problems are, if there's this thing of oh we have to report you to Tusla, you know, why do you have to report me to Tusla, you know, it's a very adversarial system…There's a whole group of people, single parents, mostly women, in this country who are suffering greatly with mental health and will not go for help because of the fear," Female 3, mental health cohort.**

Another participant in this cohort suggested that the twin aims of protecting children and parents from potential harm, including self-harm, would be met by a more actively cooperative approach between adult mental health services and Tusla to help families where the parents were coping with mental health challenges.

Recap: In Topic 4, participants desired feedback on the outcome of a complaint and some wanted to be consulted about the outcome, particularly those living at home, while others felt investigations and sanctions should be a professional matter.

Topic 5: What is the best way to keep people safe?

Summary of responses: Topic 5. What is the best way to keep people safe?

- Find ways to reduce imbalance of power between service users and health services.
- Ensure full communication with service users who are not verbal including being alert to non-verbal signals and communication preferences such as use of pictures/ technology.
- Independent safeguarding complaints mechanism to protect service users, some suggested HIQA.
- Create feedback mechanisms that facilitate input on service improvements and allow concerns to be flagged, e.g. through residents' committees, service user committees and suggestion boxes.
- Extend and increase access to advocacy services across health sector.
- Protection and confidentiality for staff whistle blowers to encourage reporting of abuse.
- To ensure good safeguarding and quality of care, including reduction of potential for conflict, provide appropriate training, conditions, supports and time allocations to carers.
- Ensure up-to-date information on safeguarding procedures is available and promoted in multiple, accessible formats and clear language tailored to users' needs.
- Safeguarding information and helpline details in multiple formats including online, hardcopy, radio/TV and wallet-sized cards. Tailor language and presentation to user needs.

This section includes responses by participants to a direct question about the best way to keep people safe when using health services as well as ideas they expressed throughout the focus group discussions. It was notable that many participants had a very clear wish for mechanisms that would prevent safeguarding issues arising by giving service users a stronger say and greater input into the way services are delivered – rather than focusing purely on tackling abuse when it arises.

Participants had numerous ideas about how to improve services to keep people safe when using health services, including greater consultation with service users, easier access to an independent complaints and investigation mechanism and more information in various formats about safeguarding rights and procedures. The importance of communication assistance in multiple formats to ensure everyone could communicate issues was also raised. A recurring theme across many groups was the importance of adequate carer time allocations, and appropriate recruitment, training and support mechanisms for carers to prevent problems arising. Participants felt that structures should be in place to ensure that problems could be reported easily, and without fear of repercussions to the care recipient because of the inherent vulnerability of a person requiring assistance with everyday activities.

Hearing the voice of health service users

The importance of listening to the preferences of service users and communicating with them in whatever form necessary was stressed as crucial across all cohorts, and particularly by those who had communication or physical/mobility difficulties requiring a high level of assistance. It was felt that getting people's views could help ward off problems by resolving issues around food or medication issues, for example and pinpointing issues.

> **“Make sure that there’s always somebody that’s verbal in case when people are not able to talk.... And pictures.” Female, ID cohort.**

> **“The non-verbal signs should be taken into account whether to keep feeding him or not or keep giving him the medicine. So heed the indications from the person.” Female, ABI cohort.**

Advocacy services

Participants in the mental health cohort suggested making advocacy services (which exist in some facilities already) more universally available, as otherwise it would only be accessed when there was a major problem. This was of particular interest to those with mental health conditions, many of whom felt ready access to an advocate, particularly in times of crisis for their care (e.g. during a breakdown or emergency admission), would be extremely beneficial in reducing negative experiences which hampered recovery, and this kind of approach would encourage a fundamental culture change.

> **“As far as I’m aware within psychiatric services there are advocates who come in ad hoc or whatever but it’s very much, in general hospital settings I would think, there would need to be a rotating, a role for that, a specific role for an advocate.” Female, mental health cohort.**

Service user forums

People with mental health challenges noted how beneficial it would be to have forums or some kind of group discussion for sharing experiences between service users and professionals. They explained in particular how traumatic involuntary admissions could be, however necessary they may be, and how beneficial it could be to share their experience of this afterwards both to aid recovery and to give healthcare providers an insight into their needs.

> **“So there is a lot of room for education, how can we approach people in a different way,” Female, mental health cohort.**

Another noted that service user committees existed in some facilities but healthcare professionals didn’t always attend.

Resident committees

Resident committees in nursing homes were also seen as a way of empowering residents– these existed in some of the facilities where focus groups took part but not every participant was aware of that, showing the need to also promote and highlight their existence to people on an ongoing basis.

Some participants in nursing homes or using day services also felt they lacked a way of highlighting issues or raising concerns about harmful practices at an early stage, or where a person didn’t want to make a formal complaint against someone, and suggested potential solutions.

> **“If you had a meeting every so often of a small committee, it would meet a similar committee of management to bring up things like that….because if they want proof you’re going to have to provide it, if you make accusations like that you better have some facts, so you have to be prepared to come out and say Nurse A, Nurse B, well she’s very difficult, if a person is in a committee it makes it a little easier,” Male, nursing home cohort.**

Suggestion boxes

Some participants in the mental health and acquired brain injury cohorts suggested placing suggestion boxes in every service and having a policy of acting on them, as a way of making it easy for users to give feedback on large and small matters, to make suggestions and criticisms and help small problems be tackled early.

> **"They could have a suggestion box in every single place, in every single ward, a suggestion box that is followed up on, in every single room or place where people are treated, a suggestion box would be the very first step... A suggestion box that is read every single week and followed up on." Female. Mental health cohort.**

> **"It's good in certain situations, because you could be under pressure, you could be bullied so much that you're kind of afraid, that way you could put it out there without..." Female, ABI cohort.**

Independent complaints investigation

Many participants felt that an independent safeguarding complaints mechanism was a crucial aspect of a system to safeguard service users, which could be an existing body such as HIQA. It was also noted that an independent complaints agency could help identify patterns of concern even if individual reports weren't followed up as formal complaints (as discussed in Topic 3).

Protection and confidentiality for whistle blowers was also seen as crucial to encourage healthcare staff to overcome fear of career repercussions by reporting abuse by other staff members – this was also seen as important in the community cases.

> **"You're kind of, to use the term, damaged goods. So even if you move somewhere else, you'd be amazed how much you're missed for promotions and things like that, so it's also about protecting your job and doing the right thing as well. Unfortunately it goes on all the time and there isn't enough protection for the people who.... you have to be very strong and brave, you have to realise it could be lifechanging." Male, mental health cohort.**

> **“My thinking would be I’m not going to go and complain, like even from my own experience working over the years, you’re ostracised,” Male, ABI cohort.**

Training and support for carers and staff

Better training, support and time allocations for staff was a recurring theme among participants. Many noted the time pressures carers were under and the lack of awareness or knowledge of how to manage the differing health and psychological needs of clients, both in residential care homes and in people’s houses.

> **“I think the biggest problem is lack of resources on the ground, and adequate training for the people who mind the people who are there, the carers.” Female, dementia cohort.**

Another nursing home resident noted how carer time allocations were sometimes completely unsuitable - when he still lived at home, a carer used to come and put him to bed at 6.30pm which was way too early so he’d have to get a neighbour to help him up again.

Some felt that carers should be screened for empathy at the recruitment stage with ongoing training and support. Some also felt that it didn’t matter how “beautiful” a facility was if there weren’t adequate numbers of trained staff, responsive to people’s needs and properly paid.

> **“It isn’t all about beauty, it’s about care. He wasn’t paying the nurses.” Female, nursing home cohort [referring to another home that had attracted media attention].**

The importance of staff knowing about and signposting service users to appropriate supports and services was also highlighted as this could prevent service users becoming isolated and depressed and more at risk of harm.

Information

Providing up-to-date information on safeguarding in multiple formats to suit the differing ways people prefer to access it (print, online, radio, posters etc) was seen as very important. It was not enough to have information in one place and assume people could get it – the information needed to be widely available and promoted through awareness campaigns and reminders. Participants also suggested specific tools such as issuing wallet-sized cards with telephone helplines and weblinks to people with ongoing health conditions. Ensuring information is up to date was seen as very important as one participant said that it was very discouraging when it was inaccurate.

> **"I feel false information is another form of harm, so if you're told your rights, and there's incorrect information or ... my direct experience is they'd give out old phone numbers," Female, mental health cohort.**

A promotional campaign to tell people how to get help was suggested by another participant.

> **"It can be done easily because last year they did domestic violence, and they did ads on the television, if you see this happening don't ignore it, this is the contact, so there is potential to make an ad, if you notice anything this, or you have concerns about that,, this is a number you could ring to contact someone." Female, mental health cohort.**

Power imbalance

As well as the importance of having their views and preferences heard, the imbalance of power between service users and healthcare staff was a dominant theme throughout these focus groups, with many participants across different cohorts identifying lack of power as a consequence and cause of vulnerability that could lead to harm.

> **“When you’ve no power... no power. And like I can’t walk. And I notice, I’ve lots of friends, I’m lucky, people are kind but it’s just luck. I really think power is so important.” Female, nursing home cohort.**

For people in the mental health cohort this was of particular concern.

> **“It’s very much about power, the power itself, the power in the structure of the health services, the patients are not empowered, if your doctor tells you this is the way it is, you’re not in a position where you can change and alter that, so therefore you’re disempowered, it’s not safe for you to argue with them because you’ll be penalised if you argue with them. And you have medication or you might be hospitalised and you’re penalised if you don’t... So there’s no safety in that structure for me.” Female, mental health cohort.**

Participants mentioned issues such as individual managers having too much power to decide who got access to what supports or employment rights, consultants “ruling the roost and calling the shots”, deciding whether people could be admitted to hospital or not, or people feeling too fearful to speak up about abusive behaviour.

> **“I came in with a very naïve attitude to ‘my service’, but oh boy, I even had one scenario where you had a doctor talking about ‘their’ hospital and, there should have been a way of going to say this treatment is absolutely disgraceful, but that person was in the position of power at the top.” Female, mental health cohort.**

Some participants felt that within a heavily unionised workforce, staff rights were prioritised over those of service users, making it hard for patients where there was an abuse of power.

> **"It's very hard for the system Ireland is in, with unions and everything, to get rid of people at the higher end, so it's hard for the people at the bottom to fight against it." Male, ABI cohort.**

Another participant also felt that HR considerations and the power of staff also hampered the willingness of managers to tackle potentially abusive practices.

> **"I remember once asking about a disgraceful situation where you had support staff speaking to patients in an absolutely disgraceful way, but I remember talking to someone else in a totally different section of the HSE, how can that be allowed to happen, and I noticed the nursing staff kept away from that particular scenario, and they turned round and said, maybe they threatened to go on strike," Female, mental health cohort.**

This lack of power was of particular concern to those reliant on care in their own home for whom complaining about something could result in the loss of crucial assistance.

> **"I think an 85-year-old, no family, and she must be so reliant, it's her only company, it's her only help. And yet this little 'b', is all you could call her, had the power to say 'we don't have to take this' and we're not going there any more." Female, ABI cohort [citing a personal example].**

Many of the solutions suggested by participants such as service user forums, residents' committees, improved access to advocacy services etc. were aimed at addressing the power imbalance and giving at risk groups a greater voice by making it easier for service users to express concerns and ideas for service improvement. This was seen by some as a way of putting service users on a more even footing with healthcare professionals that could help change the culture in which people could become unsafe or in which abuse could go unchallenged.

> “I think for me in my life, physical violence is kind of obvious, whereas there’s so much other stuff that’s not so obvious, that can be incredibly damaging, and particularly the whole system itself can be very damaging.” Female, mental health cohort.

> “I suppose with safeguarding, it’s not just about being in a safe environment, but safe is having proper people who are qualified, and being looked after by professional people rather than people in and out and not really qualified to be around that.” Female, mental health cohort.

Recap: In Topic 5 people wanted to find ways to address the imbalance of power between service users and the health services, find ways to overcome communication barriers, give people a stronger voice and input to improving services, and better information about safeguarding.

Topic 6: Safeguarding in context of COVID-19

Note: These focus groups were carried out between November 2019 and February 2020 prior to the outbreak of COVID-19 in Ireland. Neither COVID-19 nor the unprecedented nationwide public health restrictions subsequently implemented were foreseen or discussed at the focus groups. However, in light of the impact of the pandemic and the likelihood of ongoing or recurring public health measures, IPH undertook a retrospective COVID-19 related analysis of the focus group findings to identify observations of participants related to safeguarding procedures, which may be helpful to consider in the particular context of COVID-19 and related public health measures.

Summary: Topic 6. Safeguarding in context of COVID-19

Summary: Topic 6. Safeguarding in context of COVID-19

- Provide enhanced information on formal safeguarding mechanisms in multiple formats tailored to service users' abilities in light of potential reduction of opportunities to alert personal and advocacy contacts to abuse concerns.
- Consult with service users, e.g. residents' committees, suggestions boxes and other means, on COVID-19-related service changes and restrictions to keep them informed and get their input on managing the challenges.
- Recognise the importance of visitors and activities to mental, cognitive and physical health of nursing home residents when planning infection-control restrictions

- Facilitate digital access and communication opportunities for nursing home residents while taking account of dexterity, mobility, hearing and sight issues that make that challenging, and try to ensure opportunities for private conversation that would allow reporting of safeguarding concerns.
- To meet safeguarding standards given the challenges of COVID-19, ensure appropriate staffing levels are maintained at nursing homes. Provide relevant training and supports to staff and home carers to manage safeguarding-related work pressures in context of COVID-19 challenges.

Information

The provision of safeguarding information in multiple formats and the need for repeated reiteration of the mechanisms for reporting concerns become even more important in the context of COVID-19 related restrictions on people's movements and access to services which mean they have less opportunity to report abuse concerns to service managers, or to alert advocates, family or friends to issues.

The low general awareness of safeguarding services or the term safeguarding among many participants suggests extra awareness campaigns and accessible information on how to make a complaint or report a concern is very important. This is particularly the case given people may have more limited access to normal channels of support such as family, friends and disability services, and that disruption of routine regulatory inspections of facilities may occur for some time.

Communication and consultation

Many participants noted the importance of extensive efforts by staff to communicate clearly, especially with those who have communication barriers. The focus group participants highlighted how often problems could be resolved by listening to the views of service users, including those who are non-verbal, who could suggest solutions that might resolve difficulties and prevent harm arising, both in individual interactions with healthcare staff and in overall service provision. It is even more important that communication barriers are considered and addressed given the additional challenges arising from the need for PPE, social distancing and other infection control measures.

Participants also consistently expressed a wish to be consulted on the services provided through structures such as residents' committees, suggestion boxes and external policy consultations. Given the disruption to normal routines caused by COVID-19 and the likelihood of ongoing public health restrictions it is even more important that nursing home residents (and those in other residential facilities) are given clear information and the chance to offer their views and input to decisions such as visitor or activity restriction, that have a profound impact on their health and wellbeing.

Visiting

Nursing home participants repeatedly highlighted the central importance of visits for their wellbeing. Again it should be noted this point was made at focus groups prior to COVID-19-related restrictions being imposed or considered.

> **"I'd like to see advertising in the paper to say to everyone out there, if you have somebody in a home go and visit them, it's very important. Your family and friends coming in, and they only stay 2 or 3 hours, but that's half a day used up, because our day is 24 hours, you know. And there's a lot of minutes in those 24 hours. So if you have family I find I look forward to it so much." Male, nursing home cohort.**

Others explicitly linked an open visiting policy as being crucial to their positive experience of their nursing home and one noted that without that he'd “take to the road and go home”, contrasting it with his “lonesome” experience in a long-stay hospital where there were no activities and limited visits. The impact of emotional isolation and lack of meaningful activities was identified by many participants as a form of harm that could have physical repercussions and the profound need for social and personal interaction should be carefully balanced with the requirements of public health restrictions.

Across all cohorts, participants also said that in the event of abuse they would turn to family or friends for help, so particularly for those in residential settings the loss of opportunities to alert outside visitors about potentially harmful issues, could also have serious consequences where these arise. Given that restricted visiting conditions at nursing homes may be an ongoing or recurring feature of the public health response to this pandemic (or future such public health emergencies) at local or national level, it is vital that clear safeguarding reporting mechanisms are provided and communicated to residents as part of the new national adult safeguarding policy for the health sector. Similarly, at risk adults who may be experiencing abuse in other settings where health and social care services are provided, also need clear pathways to seek assistance in the context of reduced social interactions.

Loss of services

Participants in other cohorts also noted the importance of the social interaction and friendships developed in services supporting people with physical and intellectual disabilities and other conditions as vital to wellbeing, and to helping them learn to live with their conditions and access supports. They also noted the practical assistance provided by fellow service users in navigating health services as well as the meaningful exercise, creative and other activities pursued within services. The restriction or suspension of some such services during COVID-19 may have left many service users without crucial services, which may have resulted in some becoming disconnected from support networks such as healthcare and key workers to whom many said they would turn in the event of a safeguarding issue arising.

Digital literacy

Many older participants were unable, uninterested or scared of using the internet and social media and some of these may be reluctant or unable to utilise it as a substitute for face-to-face interactions during public health emergency restrictions. Within nursing homes, many residents had poor dexterity, mobility, hearing and sight issues, or a combination of these, which could add to the difficulties in communicating remotely with family, and might require tailored technological solutions and assistance to address. The fact many might need hands-on staff assistance to use technology could also result in reduced privacy which could potentially hamper opportunities to communicate safeguarding concerns to people outside the facilities who might help them.

Younger participants living in the community were more likely to use the Internet and social media, but some, particularly in the intellectual disability and brain injury cohorts, were reluctant to or had concerns about protecting themselves online (from scammers, trolls etc). This suggests efforts to improve digital literacy, broadband access and safe Internet use might help extend their capabilities and enable them to use technology in a safe manner that might reduce social isolation and provide an accessible gateway to getting assistance in the event of abuse.

Time pressure on carers

The relationship between vulnerable individuals and time pressure on carers was repeatedly highlighted during the focus groups as one that could involve stressful interactions with the potential for harm, particularly in the context of workload pressures on daily interactions such as supported feeding and dressing. The additional pressures brought by COVID-19 including the need for carers to use enhanced hygiene practices, wear PPE and socially distance where possible, could add to pressures in this regard, and could also impact on communication, particularly in the case of individuals who also have cognitive issues. Participants voiced the importance of appropriate recruitment, training and support systems for carers in people's homes and in residential care settings to prevent stressful interactions. This is likely to be even more important in the context of the extra pressures in the sector brought by COVID-19, and given restrictions to visiting which may mean less family availability to assist with personal care. Ensuring appropriate staffing levels with manageable time allocations will be vital to safeguarding vulnerable adults in the context of COVID-19.

Recap: While COVID-19 was not directly discussed at these focus groups, a retrospective analysis of the observations of participants pointed to:

- **enhanced information on safeguarding mechanisms,**
- **consultations on COVID-19 related service changes,**
- **recognition of the importance of visitors to the health of those in residential facilities,**
- **assistance with communication technology and**
- **ensuring appropriate staffing levels and supports,**

as all being important to safeguarding in the context of COVID-19.

5

Conclusion

Conclusion

As outlined in the findings, participants had a very strong awareness of different types of abuse and the need for clear pathways to report and stop harm and prevent it recurring. A number of themes stood out.

There was a strong perception of a fundamental power imbalance between service users and the health services, which combined with physical and/or mental frailty left service users vulnerable to harm and in a weak position when it came to seeking ways to stop or prevent it. Many of the solutions suggested by participants related to ways to redress this imbalance by strengthening the voice of service users within the health system through mechanisms such as residents' committees, service user forums, suggestion boxes and enhanced access to advocacy services. Participants felt that greater input and routine consultation/feedback on how specific health services are run, and on their own individual medical and care treatments would help identify problems and prevent abuse arising.

Participants also felt strenuous efforts should be made to communicate effectively with those who are non-verbal or have other barriers to communication as this would also prevent harms arising. They noted that to do this effectively it was essential to pay close attention to body language and non-verbal signals, and to have pictures or other appropriate communication tools. They also noted how patients could often provide solutions themselves to prevent potentially harmful scenarios if their preferences and opinions were closely listened to, reducing the risk of stressful interactions on routine physical interactions such as feeding and taking medicine. Allied with clearer communication was the need to promote information on how to get assistance when problems arose in multiple formats and clear language.

The pressurised conditions under which many carers work came up repeatedly and there was a strong awareness of the need to provide adequate training, time resources and supports to the sector. Participants felt there should be clear reporting mechanisms and access to help for care recipients where problems arose as some felt this was lacking at present, particularly in home care settings. Barriers to reporting abuse by a paid carer in the home included not knowing who to report to, it being one person's word against another, the fear of not being believed or being labelled troublesome or suffering repercussions.

When it came to abuse by family members, participants tended to be very unsure of what route they could take to tackle the problem, with some noting they would be reluctant to report it to An Garda Síochána for instance, and others noting limited interaction with health professionals who could assist. Participants discussed the fear of repercussions that might come from highlighting a problem both from the abuser, and the underlying fear that reporting a concern could lead to a person being put in a nursing home (see Topic 2) – making it important their wishes be consulted before action was taken.

It was notable that long term service users, such as those with intellectual disability, were more aware of different options for seeking assistance including via key workers, social workers, service managers and others in their family and community networks. Some of those with newer conditions (e.g. dementia or brain injury) had less interactions with healthcare professionals and were less sure of pathways for reporting abuse.

Awareness of the HSE safeguarding service ("Safeguarding and Protection Teams") was very low with nobody spontaneously mentioning it as the place they would report harm, although when prompted a small number of people said they had heard of it or seen information about it and one had contacted it in the past to report a concern. Some felt that an independent safeguarding complaints and investigation mechanism was needed.

The views of participants on desired actions when reporting abuse varied widely, indicating that a wide range of approaches is needed rather than a one size fits all approach. In many cases just getting the problem to stop was seen as enough – e.g. by changing a person's carer or ensuring the abusive behaviour was halted, while some wanted reprimands or disciplinary action where staff action was involved. Some felt a zero tolerance approach to abuse, particularly physical abuse, was necessary. People were very unsure of what to do in the case of family abuse because of the sensitivities involved and concerns about potential repercussions, including the possibility of having to move to a nursing home if abuse was reported. They were more likely to focus on remedies for staff abuse rather than family abuse or harmful behaviour by other service users. There was a strong desire for feedback about the outcome of a complaint and a desire to consult people about their wishes, particularly in private homes. However, some felt appropriate sanctions should be a matter for the service.

Overarching themes

In conclusion, some of the overarching themes that arose across the focus groups are outlined in Table 4 overleaf, classified according to key safeguarding principles of empowerment and partnership, protection and prevention and accountability and proportionality. Table 5 then outlines actionable suggestions from focus group participants.

Table 4: Summary of overarching themes

Empowerment and Partnership	• Overall low knowledge of the term ‘safeguarding’ and the HSE safeguarding and protection teams. • Strong awareness of different types of abuse e.g. physical, financial, emotional with some straightforward and others more complex to address. • Address underlying imbalance of power between service users and the health services to prevent safeguarding issues arising. • Meaningful involvement, feedback and input to service design and delivery desired. • Facilitate easy rapid access to advocacy-type supports to empower patients in interactions with health professionals, particularly in mental health sector. • Provide ongoing up-to-date information on safeguarding procedures and make help available in multiple formats in language tailored to the needs of people in at risk groups. • Use language that makes purpose of safeguarding service clear and differentiates it from other health and safety concerns.

Prevention and Protection	• Provide continuous training and development relevant to adult safeguarding for staff and carers working with at risk adults. • Ensure appropriate carer contact-time allocation to prevent stressful interactions between staff and service users. • Provide supports to family and paid carers to alleviate stress. • Independent service should report and investigate abuse allegations, with professionals trained to assess necessary action. HIQA suggested by some. • Provide for independent inspection of healthcare facilities by external body. • Provide opportunities for service user feedback to identify and address problems early, voice concerns and suggest improvements. • Protect third-party whistle-blowers and protect service users making complaints to prevent repercussions and encourage people to come forward.
Accountability and Proportionality	• Provide feedback about the outcome of investigations. • Overall main priority is to get harm to stop and prevent recurrence.

	• Some felt sanctions should be a matter for management or independent investigation team and should depend on scale of problem and whether a repeat or once-off issue. Clear reporting and disciplinary procedures required within services. • Zero tolerance of abuse desired by some. • A desire to avoid disproportionate responses that discourage reporting especially in family abuse scenarios and for those dependent on carers • Need to protect those reporting family abuse and carer abuse from negative repercussions

Actionable suggestions are outlined in Table 5 below.

Table 5: Actionable suggestions from focus group participants

Information	• Provide safeguarding information in multiple formats (print, online, radio, TV) and language tailored to users' needs. • Provide wallet-sized cards with information on safeguarding service helpline. • Run promotional campaigns to publicise safeguarding service and financial planning mechanisms such as enduring powers of attorney. • Facilitate rapid access to advocacy-type support to empower patients in interactions with health professionals, particularly in mental health sector.
Communication	• Ensure that non-verbal service users are communicated with in an appropriate manner.
Feedback	• Provide suggestion boxes in health facilities to facilitate feedback. • Establish residents' committees in nursing homes and residential facilities. • Establish service user committees/forums in healthcare facilities.

Carers	• Screen carers for empathy at recruitment. • Ensure adequate time allocations for carers at appropriate times. • Improve training and conditions for carers to ensure quality of care. • Provide contact number for independent person at care agency's head office to report concerns.
Independent investigation	• Independent safeguarding complaints mechanism, some suggested HIQA.

6

Appendices

Appendices

Appendix 1: Bibliography

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Appendix 2: Image prompts used to stimulate discussion about types of harm

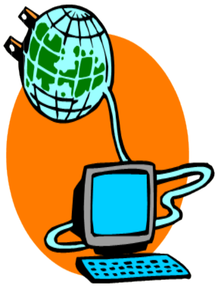

you are ugly!
Moron

Appendix 3: Participant Information Leaflet Easy Read

	Hello, my name is Aideen Sheehan. I am a researcher from the Institute of Public Health.
	The Department of Health has asked us to get people's opinions about the best way to keep people safe from harm. Professor Roger O'Sullivan from the Institute of Public Health is in charge of this research.
	We are asking you to take part in this research because your ideas are important for designing new rules for keeping people safe.
	This means we would like you to come to a group meeting with a few other people and talk about:

 	What kind of things do you think could hurt or harm you? What is the best way to protect people from getting harmed? If someone was hurting you, who would you tell? What would you want to happen if someone was harming you?
	The meeting will last about 1 hour 15 minutes and we will serve drinks and snacks at it. If you want to bring a family member or carer to the meeting to support you that is ok.

 	What you say in the group will be kept private. We will record the meeting and write a report about what everyone says. We will not put anyone's name in the report.
 	The report will be sent to the Department of Health and may be published on the internet later or talked about at a conference. We will give you a copy of the report if you would like one.
	A Department of Health Ethics Committee has said it is ok for us to do this research.
 	It is OK if you do not want to take part in the research. It is your decision and nobody will be annoyed if you don't take part.
	We will give you a €30 One4All voucher to thank you for taking part in the focus group.

	If you decide to take part in this research, I will ask you to sign a consent form.
	If you decide to take part it is OK to stop at any time and you do not have to say why. It is OK if there are some questions you do not want to answer.
	Risks: Talking about harm can be upsetting. If you become upset we will ask you if you want to take a break or stop taking part. You can also talk to someone about what made you upset.

	If you say something that makes us worry you are unsafe we will ask you to talk to another person about it. If we think you need help urgently we will talk to you about getting help. The Gardai can help us do this.
 ?	If you have any questions we can talk before the meeting begins and I will answer them for you.
☎ ✉	If you have questions later on, please contact the Institute of Public Health. Our address is 700 South Circular Road, Dublin 8, D08 NH90. Aideen's phone number is 01 478 6300. Her email is Aideen.Sheehan@publichealth.ie Professor Roger O'Sullivan's email is Roger.OSullivan@publichealth.ie

	**Here are some more details about how your information will be kept safe**. Data is another word for information like your name, address and age.
	The law to protect your data is called GDPR. We are processing your data under Article 6 1e) of the GDPR that says it is in the public interest and Article 9 2 h) that it is necessary for the management of health care services.
	We will record information about you to write a report for the Department of Health about keeping people safe.
	The information we need is your name, age, where you live and if you have a disability. We also want your opinions on keeping people safe.

	The only people who will see your information are staff from the IPH working on this research. We will keep your information locked up safely and we will store computer files so nobody else can see them.
	We will not put your name in the report we write so nobody will know what you said.
	We will only tell someone what you said is if we're worried for your safety but we will talk to you about this first.
IPH	The Department of Health and the Institute of Public Health are Joint Data Controllers for this research. That means we have to keep your information safe.
	Personal information like your name will all be deleted when the research is finished.

   	**Your rights** Taking part is voluntary and you can stop taking part at any time. You can ask to see the information we keep about you. You can ask to correct the information if it is wrong. You can ask us to stop using the information. You can ask us to delete the information

✉ ✉ ☎	**How to get your rights** You can contact our Data Protection Officer to make a complaint or to get more information. Address: Data Protection Officer, Institute of Public Health, 700 South Circular Road, Dublin D08 NH90. Email: dataprotection@publichealth.ie Tel. 048 9069 0057
30 DAYS	If you ask to see information about you we will give it to you within 30 days.
	You can also ask to have the information about you corrected or deleted

	If you are not happy with how we respond to your request you can contact the Data Protection Commissioner at: Address: Data Protection Commissioner 21 Fitzwilliam Square South, Dublin, D02 RD28. Telephone: 057 868 4800 or 0761 104 800 Email: dpcaccessofficer@dataprotection.ie
	The Data Protection Commissioner is an organisation that looks after your rights and will investigate if you make a complaint. There is more information on your data protection rights at www.dataprotection.ie

Appendix 4: Participant Information Leaflet

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 6300

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?
- 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.

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 Gardai.

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 Sth Circular Road, Kilmainham, DO8 NH90.

Roger O'Sullivan is the IPH Principal Investigator in charge of this research. His email is Roger.osullivan@publichealth.ie

Aideen Sheehan is the researcher organising the focus groups. You can phone Aideen at 01 478 6300 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

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, DO8 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 6300.

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.

Appendix 5: Participant Consent Form Easy Read

Adult Safeguarding Focus Groups

Participant Consent Form Easy Read

The Department of Health is developing new rules to help keep all adults safe from harm when they use health services. They have asked the Institute of Public Health to carry out focus groups with people who use health services a lot to find out their views on keeping people safe and write a report. The project will be finished within a year.

Adult Safeguarding Policy Focus Groups			
The researcher has talked about the research to me and all my questions have been answered.		Yes ☐	No ☐
I understand that I will join a group of people and I will talk about ways to keep people safe from harm.		Yes ☐	No ☐
I understand that I don't have to take part in this research and saying no will **not** affect the help I get.	 	Yes ☐	No ☐
I understand that I can stop taking part at any time and I don't have to say why.		Yes ☐	No☐
I understand the risks and benefits of this study.		Yes ☐	No☐

I have been given a leaflet with information about this research and a copy of this consent form.		Yes ☐	No☐
I agree that if researchers are worried I am unsafe they can talk to someone about getting help.		Yes ☐	No ☐
I agree to take part in this research.		Yes ☐	No ☐
I agree to have what I say recorded.		Yes ☐	No ☐
I agree that information about me can be used as part of this research.		Yes ☐	No ☐
I agree that personal details like my name will be kept private and not published in any report.		Yes ☐	No ☐
I agree to be contacted by researchers about this research if necessary.		Yes ☐	No ☐
I agree that you can contact me again in the future to talk about the new rules for keeping people safe.		Yes☐	No ☐

____|______________________________________|____

Participant Name (Block Capitals) | Participant Signature (or mark)| Date

--- --------------------------------------- ------

Witness Name (Block Capitals)   Witness Signature
Date

Relationship of witness to participant

____

To be completed by the Principal Investigator or nominee.

I have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

| | |

Name (Block Capitals) | Qualifications | Signature |
Date

What are your rights?

You have the following **rights** in relation to your **data** (information about you):

- Right to see the data
- Right to restrict the use of the data
- Right to correct mistakes
- Right to have information deleted
- Right to data portability
- Right to object to profiling

If you have any questions about the use of your data, or your data protection rights in relation to this project you can contact our Data Protection Officer.

Data Protection Officer
Institute of Public Health in Ireland
700 South Circular Road
Dublin 8
Ireland
D08 NH90
Telephone: +353 1 478 6300
Email: dataprotection@publichealth.ie

You can also contact the Data Protection Commissioner for Ireland directly if you wish to make a complaint about how we handle your data. They can be contacted at:

Data Protection Commission
21 Fitzwilliam Square South
Dublin 2
D02 RD28
Ireland
+353 (0)761 104 800

Email: dpcaccessofficer@dataprotection.ie

Appendix 6: Participant Consent Form

Adult Safeguarding Policy Focus Groups

Participant Consent Form

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. As part of this they have asked the Institute of Public Health to carry out focus groups to get the views of people who use health services a lot. The project is expected to take six months to a year to complete.

I understand what this research is about. The researcher has explained it and I have been given an Information Leaflet and time to ask questions about it and have them answered.	Yes ☐	No ☐
I understand that I don't have to take part in this study and that I can stop taking part at any time. I understand that I don't have to give a reason for stopping and it won't affect my future health care.	Yes ☐	No ☐
I am aware of the potential risks and benefits of this study.	Yes ☐	No☐
I have been assured that information about me will be kept fully private and confidential. The only exception to this if the researchers are worried that I am in danger or someone else is in danger and they need to tell the relevant authorities.	Yes ☐	No ☐
I have been given a copy of the Information Leaflet and this completed consent form for my records.	Yes ☐	No ☐
I consent to take part in this research study having been fully informed of the risks and benefits.	Yes ☐	No ☐

I give informed explicit consent to have my data processed as part of this research study.	Yes ☐	No ☐
I consent to be contacted by researchers as part of this research study.	Yes ☐	No ☐
I consent to be re-contacted by researchers about possible future research related to the current study.	Yes☐	No ☐

____________________________________|______________________________|____

Participant Name (Block Capitals) | Participant Signature (or mark) | Date

-- --
----- -----------

Witness Name (Block Capitals) Witness Signature
Date

Relationship of witness to participant ___________________________________
____

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

| | |

Name (Block Capitals) | Qualifications | Signature | Date

What are your rights?

You have the following **rights** in relation to your **data**:

- Right to access data held
- Right to restrict the use of the data held
- Right to correct inaccuracies
- Right to have information deleted
- Right to data portability
- Right to object to profiling

If you have any questions or concerns about the use of your data, or your data protection rights in relation to this project you can contact our Data Protection Officer.

Data Protection Officer
Institute of Public Health in Ireland
700 South Circular Road
Dublin 8
Ireland
D08 NH90
Telephone: +353 1 478 6300
Email: dataprotection@publichealth.ie

You also have the option to contact the Data Protection Commissioner for Ireland directly if you wish to make a complaint as to how we have handled and/or processed your data. They can be contacted at:
Data Protection Commission
21 Fitzwilliam Square South
Dublin 2
D02 RD28 Ireland +353 (0)761 104 800

Appendix 7: Department of Health Research Ethics Committee for Adult Safeguarding Focus Groups

Professor David Smith, Associate Professor of Healthcare Ethics/ Programme Director MSc in Healthcare Ethics and Law, RCSI

Dr Fiona Keogh, Centre for Economic and Social Research in Dementia, NUI Galway

Dr Éilish Burke, Ussher Assistant Professor in Ageing and Intellectual Disability, Trinity College Dublin

Dr Sarah Craig, Head of National health Information Systems, Health Research Board

Dr Jane McEvoy, Research Department, Saint John of God

Ms Mary Kirwan, Barrister-at-Law & Lecturer at RCSI

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