COLLABORATIVE DOCTORAL PROGRAMME IN CHRONIC DISEASE PREVENTION

Title: Guidance Document for Patient and Public Involvement within the Collaborative Doctoral Programme in Chronic Disease Prevention (CDP-CDP)

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Aim

The aim of this guidance document is to summarise our agreed approach and procedures to involve patients and the public in research throughout the Collaborative Doctoral Programme in Chronic Disease Prevention (CDP-CDP).

Purpose

The guidance is primarily intended to support the work of PhD scholars within the CDP-CDP programme but may be of interest to others seeking to adopt Patient and Public Involvement (PPI) within their work.

Background

The 2020 - 2024 CDP-CDP is funded by the Health Research Board (HRB) and delivered in collaboration with the HRB Structured Population and Health-services Research Education Programme (SPHeRE Programme).

Chronic disease prevention and management is clearly one of the most pressing current and future health challenges in Ireland. Prevention programmes are urgently needed to reduce the burden on patients and health services. In Ireland, there is a need to develop skills, leadership, and capacity in evidence-based chronic disease prevention. The CDP-CDP aims to address this need and train graduates who will be future national and international leaders in evidence-based chronic disease prevention research, research implementation, and policy development.

Why is PPI important?

PPI is defined as research that is "carried out 'with' or 'by' members of the public rather than 'to' or 'about' them" [1]. The rationale for PPI includes a moral argument where the people most affected by the research are involved in what is being done and how it is carried out [2]. Other important considerations are that PPI can increase the relevance, quality, and dissemination of the research [2]. Many research funders now require PPI, as do academic journals and ethics committees. Furthermore, evidence suggests that PPI can aid in reducing research waste, by facilitating research on questions that are most relevant to partners, including patients and clinicians [3].

How was this guidance developed?

Following participation in a series of information workshops led by the National University of Ireland, Galway (now University of Galway) PPI Ignite Network in 2021, each scholar developed a reflective summary on their plans for and experiences of PPI within their PhD research. Through group engagement and reflections, significant variations in PPI practices across Ireland became evident, in the absence, at the time, of a national guidance document. To inform and align ongoing best practice for the CDP-CDP scholars, this document was developed using a collaborative approach with reference to best practice guidelines. Overall guidance on the process was provided by the CDP-CDP PPI Lead, Dr Oonagh Meade.

Processes for consideration when integrating PPI into your PhD

Ethical considerations

Ethical approval is not required to involve those with lived experience in PPI activity, as they are not being recruited as research participants, rather as experts by experience. They are considered members of the research team. It is always good practice to clarify practices with the local organisation (i.e., university). All PPI related activities must be carried out in an ethical way with the best interests of contributors at the fore.

Starting out

PPI is an evolving area in research with many opportunities for collaboration and shared learning. Useful contacts include the PPI Ignite Network, which has seven lead university sites nationally, in addition to national and local partners. The Network aims to “provide a shared voice for PPI across Ireland, aiming to change the research culture, an important contributor to improving health outcomes for the public.” This Network is an invaluable support to all researchers when developing PPI plans within the research cycle, e.g., writing funding applications, drafting ethics applications, and developing interventions

Target Population

It is important at the outset of a research project to identify the target population, to allow for diversity in the PPI processes, ensuring those impacted by the research are involved in shaping it. The research itself may emerge from existing relationships with PPI contributors, with the research question being co-created. Also, at times research can have multiple target audiences, such as healthcare professionals, policy makers, people with lived experience and their family members and/or carers.

A selection of different approaches can be used to engage PPI.
These can include:

- Working with an existing group (e.g., from a patient support group or other organisation)
- Forming a new PPI panel
- Adapting, or merging an existing panel(s) to include new members

Considerations when working with an existing group:

- Some scholars may work with more than one PPI panel. These panels may include different partners and could be formed using variations of the above approaches
- Contact can be made with the organisation, and arrangements made through a liaison to meet the group and involve them in the research
- Consider capacity and competing demands of the PPI panel
- Clearly state the kind of contribution sought (video conferencing versus in-person, time commitment, activities etc.) to help people make informed decisions about taking part
- Find out about how the group operates. For example, how are contributors reimbursed for their time and does the schedule of meetings fit with your research needs?

Considerations when forming a new PPI panel

- Clearly state the kind of contribution sought (video conferencing versus in-person, time commitment, activities etc.) to help people make informed decisions about taking part
- CDP-CDP scholars can draft invitation materials in line with the CDP-CDP template, and consider the other principles included in this guidance document
- It is recommended to draft and agree a Terms of Reference specific to each PPI panel, highlighting roles and responsibilities, expectations, and other relevant information
- If forming a new PPI panel, scholars are encouraged to collaborate with other PhD trainees (within or outside the CDP-CDP) working in similar research areas
- After an initial expression of interest, a follow-up phone call can be arranged with prospective contributors to establish interest, motivation, and preferences for contribution to the panel (e.g., via Zoom, Microsoft Teams, email communication), and explain the next steps of the process
- As well as the role of PPI contributors, it is important to consider balance and diversity within a panel (e.g., age, gender, occupation, lived experience, etc.)
- Sources of PPI contributors may include, but is not limited to:
    - Social media
    - Organisations, e.g., community groups and patient organisations
    - PPI Ignite
    - Email lists
    - Personal and professional communications

General Data Protection Regulation (GDPR)

GDPR was introduced in May 2018 and is intended to strengthen data protection for all individuals across the European Union (EU). Considerations must be given to data processing i.e., collection, storage, recording, disclosure of, structuring, making available and deletion of data. GDPR applies to the processing of personal data by controllers and processors in the EU. At its core are seven key principles which must be observed: transparency, purpose limitation, data minimisation, accuracy, storage limitation, integrity and confidentiality, and accountability.

Generally, it is considered best practice to:

- Gain explicit written consent regarding the collection and storage of personal data from PPI contributors. This consent regarding personal data must be opt-in and obtained separately from consent to participate as a PPI contributor. Researchers should clearly outline the purpose of collection of personal data (e.g., addresses, phone numbers), how this data will be used, how long data will be kept on file, how data will be stored, how communication will be managed, and how contributors can readily withdraw consent for either storage of personal data and/or participating in PPI activities
- Only collect the minimum data that is needed for communication with contributors (e.g., name, email address, phone number)
- To protect the personal data of PPI contributors, it is good practice to use the “bcc” function on emails or documents accordingly within the Terms of Reference for the PPI group or other agreed communication practices
- Use GDPR compliant communication methods. For example, some organisations/universities will have a contract for Microsoft Teams over Zoom, some will/will not permit the use of WhatsApp as a communication tool with PPI contributors
- Consider where any recordings/files of PPI meetings are stored, e.g., university-based cloud storage (OneDrive, or Google Drive) and not personal storage platforms
- Ensure devices are password protected and encrypted
- It is good practice for scholars to have a clear data management plan for their PhDs, highlighting GDPR requirements, safeguarding data, and referring to local organisation policy or guidelines

Practicalities of engaging with PPI

Before you commence with planning and arranging your sessions it is worth checking in on your own mindset regarding PPI. This involves looking at your beliefs, attitudes, values, biases, and previous experiences. Having the right mindset and associated behaviours are key to maximising the success and outcomes of your PPI groups. Good facilitation skills are also essential, and training should be sought out if needed. It may be of benefit to have a co-facilitator for group sessions, where one person leads the session, while the other supports with timekeeping, note-taking and any other duties needed. To maximise engagement and inclusion it is important to be open to diverse ways of engaging with your group including email, telephone, and meetings.

Facilitation Skills

As a facilitator it is important to:

- Allow time to build relationships and connect with people
- Be an active listener and be aware of both verbal and non-verbal cues
- Be non-judgemental, valuing contributions whilst avoiding value statements
- Use the language of participants
- Consider diversity, inclusion, and cultural differences, respecting individual needs and wishes of participants
- Self-reflect after each meeting (e.g., What worked well? What could be improved?)

Budgeting and Reimbursement

- Prior to commencement, develop a procedure for managing reimbursement. Clarify all aspects with the finance department to ensure the process is feasible [4]
- All PPI members should be compensated for their time and other expenses incurred
- Ensure anyone in receipt of social welfare payments understands the implications receipt of payment may have on their benefits
- Transparency – members should understand and agree on the reimbursement rates prior to involvement in activities, and be informed as to when to expect payment
- Reimbursement will be in the form of an honorarium payment, paid each time a person contributes (e.g., participation in a meeting)
- Contributors will be reimbursed in line with local organisation or university policy (e.g., using gift vouchers)
- The HSE guide for costing and budgeting can be used as guidance when planning costings and budgeting [4], and NIHR guidelines can be used as guidance on reimbursement rates [5]
- Where members attend an in-person event, reimbursement for travel costs (e.g., public transport, parking, subsistence) should be considered if feasible within the budget and communicated to members in advance

- Timing – members should be reimbursed as soon as possible after the meeting. Scholars need to be aware of the time frame involved in acquiring vouchers and communicate this information to PPI members
- Members should have the option to waive the offered reimbursement or accept a reduced payment

Meeting planning

Preparation is key when it comes to planning your meetings. When planning a meeting, ask yourself the following questions:

- What venue or online platform will you use? This may vary by institution in accordance with licences and preferences
- What meeting logistics do you need to consider? For example, if face-to-face consider accessibility, parking, room set-up, timing and duration of breaks and refreshments (paying attention to specific dietary needs meeting-guidelines-final.pdf (hse.ie))[6]
- For online meetings, consider who will manage the technology? Do you (and participants) have a stable/reliable internet connection and a plan B if something goes wrong? Start meetings ahead of schedule to allow for potential connection issues. Offer participants a technical support session in advance of the meeting to troubleshoot any potential technological issues
- Who will be involved in facilitation? If working with an existing PPI group, a member of the host organisation may wish to be present
- How will you communicate with the group, and capture discussions and feedback?
- How will you manage challenging situations, such as power imbalances or if someone becomes upset, angry, or disruptive?
- How will you ensure every voice at the table is heard? It is important to be aware of literacy levels and different learning approaches as well as potential communication and cognitive challenges
- What do you want to achieve from the meeting? Providing participants with a meeting agenda with clear aims and objectives in advance can help focus discussions. As part of the agenda include “any other business (AOB)/other” to allow participants the opportunity to raise agenda items. It can be helpful to break meeting agendas into time slots too so that each agenda item is allocated enough time

- Check-in with participants if they would like to receive the meeting materials in advance of the meeting and how much time they would like to review them
- Be mindful to have realistic expectations as to how much involvement the contributors will have in various aspects of the work. Some may have experience reviewing documents, providing email feedback, or tracked changes, participating in group discussions, and be IT savvy, but others will not have these skills. It is important as a facilitator to recognise this and adjust the meetings accordingly to accommodate all

Meeting hosting

When hosting a meeting it is useful to break it down into stages:

Beginning

- Welcome all, facilitate introductions, avoiding professional titles, acronyms, and jargon
- Ice breakers can be useful, however be sure these have a clear purpose and make it clear to the group that these activities are optional
- Outline the meeting aims and objectives and desired outcome. Outline the proposed agenda with breaks
- If relevant, provide feedback on decisions made in previous meetings and how they have influenced the research

Middle

- Review the content you are covering with a specific time allocated to each task or item for review
- Consider activities that will engage the group and result in meaningful discussions

End

- Summarise discussions
- Consider how you will evaluate the session (What went well? What went not so well? How could things be approached differently next time?)
- Agree date for next meeting
- Acknowledge everyone's contribution

<u>Tracking Impact</u>

Documentation

While detailed minutes are not always necessary, notes identifying key discussion points and actions should be taken. Documenting discussion points in attendance, apologies from contributors, the duration of the meeting and any preparatory work is also best practice. It is important to stay mindful of GDPR when taking and keeping these records.

Reflexivity

Reflexivity is essential throughout the PPI process. Reflexivity involves thinking critically about the self, and the role of the self in co-constituting meaning in the research process [7]. It is important to fully record and document all PPI activities and reflect on what went well and not so well in each meeting. Making regular notes during the meetings, preparing, and circulating meeting minutes to the panel members, and completing impact logs might be helpful to ensure thorough documentation of the process and impact of PPI on the project. In some meetings, it might also be important to consider having a second person or a panel member to take notes during the meeting.

Reflective logs are personal records about a person's experiences in the context of research. Reflective logs help encourage reflexivity in practice, helping to identify and clarify processes and learnings. Gibb's Reflective Model [8] can be used as a basis for reflective practice, providing structure to the process. It has six steps:

I. Description
II. Feelings
III. Evaluation
IV. Analysis
V. Conclusion and
VI. Action Plan.

Impact log

An impact log can be completed by scholars after each meeting as a structured way to keep notes and consider impact. See example below from Foley et al. [9].

Impact log items
Date PhD scholar's name What did we do? What was discussed? What was changed? What was the impact? *(1 = small change; 2 = moderate change; 3 = large change)*

Lessons learned to date

- PPI involvement can be challenging and time-consuming. Before identifying PPI contributors, it is important to have a clear understanding of the aim of PPI, allocate some time for selection, be aware of practical constraints (e.g., budget availability, national vs regional panel), and develop a specific plan outlining targets (panel size and characteristics) and potential sources and channels
- Flexibility: It is advised to organise meetings and dates around the needs and preferences of the panel members, to enable their involvement. Involving the panel members in the decision-making about the panel's functionality at the outset can help the panel members to remain engaged
- Existing panels: As the panel has already been established, there can be less work in contacting panel members, organising meetings, and familiarising members with PPI than when establishing a new panel. However, as the panel may be advising on multiple projects there may be less of a personal connection between the researcher and the panel members, and it may not be possible to schedule a meeting exactly when required. Also, the research burden on the panel members must be considered
- Planning and preparation: It is important to carefully plan each meeting to maximise time with the panel. Sending agendas and background information to the panel members before each meeting might be helpful as many appreciate being informed or having some sense of the topics to be discussed in the meeting. This might also help to ensure that everyone remains focused on the meeting topic. In addition, it might be important to

consider conducting a training needs assessment with the PPI panel to identify whether they require any specific training before involving them in some specific research activities (e.g., qualitative data analysis).

- Relationship: Building trust and positive working relationships with the panel members can be challenging, particularly online. Ice-breaker activities at the beginning of the meetings and other informal moments can help members get to know each other better and bond - but individual needs and preferences must be taken into consideration here
- Evaluation: When planning PPI and research, consider how PPI will be evaluated
- Accountability: It is important to actively respond to the input of the panel members and make them aware of how their input had an impact on the project, so they can recognise their contribution
- Feedback: Share progress on how PPI input is shaping your research at all stages of the research process with panel members

Review:

Developed: October 2022

Next scheduled review: January 2024

Useful links:

GDPR guidance for researchers (hrb.ie)

UCD Library's Suite of Resources - Research Data Management - LibGuides at UCD Library

UCD GDPR

https://www.ucc.ie/en/gdpr/

GDPR - University of Galway

https://ppinetwork.ie/

https://ppinetwork.ie/about-us/lead-sites/

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