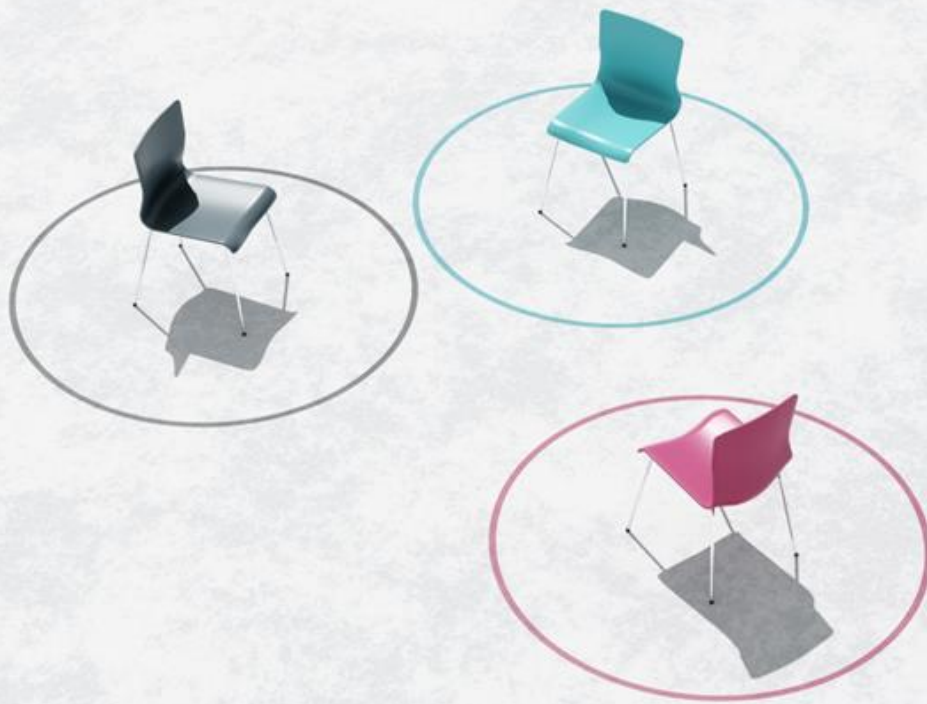


PLAYING OUR PART

Supporting Community Cancer Support Centres
in Ireland to Engage with Cancer Research



Guidance for Community Cancer Support Centres

The strides that continue to be made in the diagnosis, treatment and care of those with cancer have their roots in research. Without research, we cannot discover better detection methods, the types of medications and treatments that can slow or eradicate the spread of cancer, or the kinds of effective treatments and supports that help people during their cancer treatment and beyond.

Fundamental to most research is the willingness for people to participate in it, to fill out surveys, to take part in focus groups, to have their blood or cell samples analysed, to take part in clinical trials. While not everyone will do this, many people will participate in research, even if it will not benefit them directly. People trust that researchers are trying to improve the lives of those with cancer and are willing to take part in that.

Now, researchers are looking to engage with people affected by cancer to advise on how best to carry out their research. They are not, of course, looking for advice on the technical aspects but how best to reach and recruit participants to their studies, how to make sure the results will be relevant to patients, how to make sure that their work has impact. This process, known in Ireland as PPI (Public & Patient Involvement) or Engaged Research, is being encouraged by universities and funders, so it is timely that we provide some guidance to researchers who wish to either recruit our service users as study participants or to work with them as PPI partners. This aim of this guidance is to help Cancer Support Centres to support research participation and PPI contribution while balancing the support needs of their service users.

Community Cancer Support Centres

We are a network of Community Cancer Support Centres and Services providing information and advice about cancer to people who need it. We provide psychological or emotional support to people and many of us have survivorship programmes that will help people to live well beyond their cancer treatment and are a core stakeholder in Ireland's Model of Care for Psycho-Oncology.¹ As voluntary or charity organisations based in local communities, we run as independent entities. We are not research agencies. When people come to us, they are not seeking participation in research projects. The health and wellbeing of people living with and through cancer and their families are our priority and our focus.

At the same time, everyone with cancer, and those of us who support them, would like to see an increase in services, a greater understanding of cancer and, ultimately, improved treatments to increase and improve cancer survivorship. So, both we and those who use our service are often happy to support any process that will help that to happen, such as research. This willingness to support researchers must always, however, be balanced against the best interests of those we serve and the capacity of the service to be able to engage in something that is not part of our core work.

¹ Greally, H., Love, D., & Mullen, L. (2020). Hospital and Community-based Psychosocial Care for patients with cancer and their families: A Model of Care for Psycho-Oncology. National Cancer Control Programme: Dublin.

Why we have this Guidance

We have developed this guidance to help you to understand our role in supporting the research process, what we may be willing to do to support you but also the limitations and reasonable concerns we may have.

We appreciate that, as a researcher, you are hoping to discover new treatments, approaches or to gain other insights that will improve the lives of people with cancer. We also acknowledge that, in order to develop your skills, you must undertake studies that will build your own capacity to undertake rigorous, impactful, high-quality work. This begins at undergraduate level and will continue throughout your early career.

As Centres supporting people living with cancer, we have a responsibility to ensure that the people who use our services have the option of participating in studies or supporting researchers but that they are making an independent, informed choice about doing so.

How this Guidance was Created

We hosted a one-day workshop with Centre Managers and staff from Community Cancer Support Centres on 18th October 2023, with the aim of co-creating guidance which Centres can share with potential researchers to support research participation and PPI contribution.

The workshop was held in-person at the Cuisle Cancer Support Centre in Portlaoise and was attended by representatives from 16 organisations, from all four provinces. Eleven centres in attendance were full or applicant members of the Alliance of Community Cancer Support Centres in Ireland (69% of all members) and the remaining five centres were associate members of the Alliance. The workshop was facilitated by Mr Michael Foley from the Trinity PPI Ignite Office in Trinity College Dublin using the Health Research Charities Ireland (HRCI) and Trinity co-created Making A Start Toolkit.²



² Health Research Charities Ireland (HRCI) and Trinity College Dublin (2020) Making a Start: a toolkit for research charities to begin a PPI relationship, Dublin: HRCI

Researchers' Expectations

We understand that organisations like Cancer Support Centres may act as 'gatekeepers', with the responsibility of providing or denying access to research participants or PPI partners. This makes us an important partner in the research cycle, a stakeholder in seeking the best outcomes for people with cancer, their families and many researchers.

We are, however, always trying to ensure that people who use our services are properly supported and never put in a situation where their health or wellbeing is diminished due to the demands of an external partner or a researcher. Also, as registered charities, we must operate within what is permissible for our organisations, what will enhance or diminish the trust relationship built up with our service users, and what resources we have to be able to achieve our mission.

Seeking Participants for your Study

We appreciate that some researchers are seeking participants for their research. Researchers may require large numbers for something like a survey. They see the Centres as a way to connect with people affected by cancer.

For those seeking access to our 'database' of service users in order to circulate a survey or to advertise a study, please keep the following in mind:

- We would not supply our contacts database to anyone outside of those staff members who are authorised to access it, for privacy reasons;
- Any data on service users has not been gathered for the purposes of research and, therefore, we are unlikely to have permission from those on the database to circulate research material if it is not directly relevant to the services we deliver;
- While you may feel that your material is comprehensive and easy to understand, Centre staff may be faced with questions or negative feedback from service users who find it complex, confusing or inappropriate.

Finding participants for focus groups or interviews may prove easier to facilitate. For researchers who are seeking to find a smaller sample of people from our service users, please keep the following in mind:

- Because we will be approaching service users on your behalf, any material you provide should clearly state what your research is about and the commitment involved for the participants;
- We may not be able to accommodate any focus groups or interviews in the Centre itself;
- It is reasonable for a participant in a focus group or interview to expect that there will be, at the very least, refreshments supplied to them. This will be your responsibility.

Seeking PPI (Public and Patient Involvement) Partners

Increasingly, researchers are seeking PPI partners that will help them to develop, design, deliver or disseminate their research. This is a positive step in the area of research, placing the patient and their family at the centre of the research cycle. It is also something that funders such as the Irish Cancer Society, the Health Research Board, the Wellcome Trust and the European Union promote and encourage as a research approach.

Centres do not necessarily have expertise in research or in PPI activity and yet would expect that, in the development of PPI partnerships, that researchers would be mindful of conforming to the PPI Ignite Values and Principles Framework³ in their dealings with PPI partners.

Issues for Researchers

We understand that researchers are often constrained by time limits and budget restrictions. Also, once ethical approval has been achieved, we know that it is difficult for researchers to move outside of the terms of their application. Ideally, we would hope that researchers will consult with us **in advance of any ethics applications or funding proposals** and, on funding applications, if the involvement of the Centre is likely to be significant, we would be a co-applicant or a collaborator on the project, ensuring that the role of the centre and the expectation on participants could be discussed fully.

We are also cognisant that researchers, in order to ensure systematic rigour in their work, must follow protocols as initially stated. As small organisations, however, we cannot always prioritise the needs of researchers with the resources we have available. It is important that expectations are discussed and agreed, and that reasonable notice is given to the centres. We acknowledge that the window between a funding application opening and its closing date can be as short as one month and so, at times, there may be an urgency that is outside of the control of the researcher.

Centres' Expectations

For every group or individual we partner with, there are implications for the work of the Centre. We must consider carefully how your work will impact ours, how your behaviour will reflect on us and how your goals will make a difference for those we aim to serve.

Helping us to Make a Decision

While we appreciate that your work may have been adjudicated upon by a university or an ethics body, their assessment of the benefits vs the risks involved may be different from ours. We would like to understand your project and what you have considered to be its ethical implications so that we can make our own decisions about supporting you. We would expect you to give us a Plain English summary of your research, what will be involved and so on. We may also request to see your Research Ethics Committee application, if your project is at the stage where it has been submitted.

³ PPI Ignite Network Values and Principles Framework available to download from <https://ppinetwork.ie>

We would also favour research where the results or the process will have some benefit for the service users or the Centre itself. This may mean, for example, that the data could lead to better service provision or create a dataset that can be used to advocate for improved resourcing. Working with the Centre from the start will help researchers understand what is relevant or actionable data for a Centre. Even where there may be no direct benefit to the Centre, we would like to know how you plan to share the findings of your research with the Centre and our service users and what kind of impact you expect your research to have.

Managing Your Own Expectations

We understand that researchers and academics often carry out a lot of extra work to ensure that a research project runs to completion. We, however, are not research organisations and our staff or resources are not at your disposal. We suggest that you consider this before making a request and you reflect on whether there are time or resource implications for a Centre before making a request.

It is also important to remember that those who wish to participate in studies are only a subset of our service users. Many may not be currently able to participate or interested in doing so. This will have implications for the numbers that you can reach with a Centre. All Centres must remain sensitive to ensuring that participating in research is never a prerequisite for receiving our services so you will need to consider that the ways in which studies boost recruitment, such as a series of reminder emails, may not be appropriate for our service users.

Building a Relationship

Our Centres run on building a trusting relationship with our service users. During a time of anxiety and uncertainty, they need to know that they can rely on Centres to support them. As a researcher working with us, our service users need to trust that, if they give their time to you as participants or as PPI partners, that you will return to them during the dissemination phase of your project to let them know what happened, what was found and what are the recommendations arising from the research. If a researcher fails to do this, they make it very unlikely that a Centre or its service users will wish to work with them again or with any researchers from their institution.

Finally, consider giving Centres the opportunity to provide feedback on the research progress to help build future relationships. This may mean simply prompting people to provide feedback, having a review meeting or providing a link to an anonymous poll; whatever method that is appropriate to those whose feedback is important and allows them to provide it in an honest, constructive way.

How We Decide what Research will be Supported

Every request for support with research will be considered on its own merits. The centre will make a decision based on what facts are available to it, as well as the context within which the request is being made. The types of questions we have when deciding whether we would support a research project would be as follows:

1. Has the researcher adequately grasped the ethical implications of what they are proposing? Have they considered the impact on service users, their families and centre staff and what do they have in place to counter any negative implications?
2. Is the research likely to have any positive impact on the lives of people living with or beyond cancer or their families? Is the researcher established enough to be able to achieve that impact?
3. Will the research provide any actionable data that can be used by the Centre or the Network to improve its services? Will the researcher provide that data to the Centre?
4. Has there been PPI involvement in the research cycle? Has the research been designed with those most affected in mind?
5. Will the research put undue extra burden on the Centre staff or reflect badly on the reputation of the Centre? Recognising that all research support will lead to extra work, does the Centre have the capacity at the time proposed to be able to do that extra work?

Each Centre will endeavour to make a decision on every request for support in good faith. It may need to refuse a researcher during a busy time for the Centre or due to staff shortages. It may not consider that the potential results of the research will be worth the burden put on service users. Centres, however, may not wish to enter discussions with researchers about why they had to refuse a request for support because: a) this, in itself, is time-consuming and b) may require them to disclose operational issues that are not in the public domain.

How to Work with us to Progress your Research

Using sensitive language

Think about the language that you are using when addressing people who are experiencing cancer treatment. Consider that they may be at a particularly difficult phase or may be considering their own mortality. Please do not frame cancer as a 'battle' or that people should be 'fighting' their cancer – this is often unhelpful for people living with cancer.

Being clear

We understand that researchers have a writing style that is both detailed and indirect. We also appreciate that researchers are very comfortable using technical terms, acronyms and scientific labels to describe their work to others within their field. We may understand some of these terms, but it is best to write any material for us with us in mind. Consider how a journalist might write about your work to a general audience: what do you plan to do? When and where do you plan to do it? Why are you doing it? How do you plan to do it?

Understanding our independence

Your research may provide evidence of ways in which a service may adapt or improve. Your research may indicate ways in which treatment or supports may be more effective. While we hope to work in tandem with you on reaching your findings, we may, for other reasons, decide to not implement your recommendations.

Administration burden

We appreciate that rigorous research often produces a significant amount of paperwork in its planning and development. Certain aspects of this may not be relevant to either our service or to the people who use it in making a decision about becoming involved. While we seek transparency from any research partners, too much documentation can obscure what may be needed to make a decision about involvement.

Please give us a sense of what your research is about, what ethical considerations are important, what type and level of involvement is required from the Centre or from the people who use it and, in your opinion, what would be the benefit for the Centre or for those service users who may become involved.

Avoiding tokenism

We know that some researchers are involving people because it is a condition of their research funding and that, given the choice, they would rather not. Considering the fact that people who use our services are already dealing with significant challenges, we would ask you to consider research that does not require engaging with anyone who uses our services.

Conclusions

As Community Cancer Support Centres, our priority is to support people living with and beyond cancer who are using our services. Like researchers, our goal is to improve the lives of those impacted by cancer. We recognise that we can play a really important role in supporting researchers to recruit research participants and PPI partners. We also have a responsibility, however, to ensure that anyone using our services are properly supported and never feel under any obligation to participate in any activities. This guidance helps us to *play our part* in cancer research in Ireland and to continue to support research efforts to effectively work with Community Cancer Support Centres.

Acknowledgements

We gratefully acknowledge the generosity of management at the **Cuise Cancer Support Centre**, Portlaoise, Co. Laois, who hosted our in-person workshop.

Authors' Affiliations and Contributions

This project was developed, and funding obtained, by Dr Emer Guinan, **Discipline of Physiotherapy, Trinity College Dublin**, and the **Trinity St James's Cancer Institute**, Dublin. The report was prepared by Mr Michael Foley, **Trinity PPI Ignite Office**, Trinity College Dublin. The need for this workshop and guidance was identified by Mr John Conroy, Centre Manager, **Dóchas Offaly Cancer Support Group**, Tullamore, Co Offaly. The in-person workshop was organised by Mr John Conroy, facilitated by Mr Michael Foley, and co-facilitated by Dr Emer Guinan. All authors read and approved the final draft of this report.

Funding

This work is supported by the **Irish Cancer Society** Cancer Research Networking Award CRNA23GUI.