



Would you be interested in joining the 3CF PPI Panel?

Here at 3CF, our research and service delivery philosophy has always focused on the patients and their families that we care for, and we are proud to have been involved in many research projects over the years that have impacted the CF community locally, nationally, and internationally. Many of you have participated in these studies and your involvement has been critical, and we are very grateful to you and all of your inputs and time.

What is Public Patient Involvement (PPI)?

Public Patient Involvement (PPI) can be described as research or work carried out “with” or “by” members of the public rather than “about” or “for” them. We are looking to put together a panel of People with CF (PwCF) and/or family members of PwCF who attend our unit (can be siblings, children, parents, and partners), who will support the design and implementation of future research studies and/or clinical care services in a manner that is representative of all PwCF.

How is this different from being in a study?

If you were to join our panel, you would not be a “participant” completing surveys, or interviews, or providing samples. Instead, you would be a “contributor” whereby you would meet with the research and medical team to discuss different parts of a research study, for example: research ideas or questions, or how to write a consent form in language and terms that make sense, or looking at understanding what the results mean to the CF community, or sharing results with the CF community.

What is involved?

If you join the panel, from time-to-time you will be invited to contribute to a study or give input on a service design. In your invite you will be told as much information as possible to help you make a decision, for example what we hope to discuss and how you will be involved (time commitments, tasks to complete). If you are interested in contributing to particular project (you are not required to participate in all projects), you will then meet with the Cork CF medical team, research team, and other members of the PPI panel. At these meetings you can contribute your opinion and experiences to help us shape our research and services. If there is anywhere else you would like to contribute, please let us know, all input is appreciated.

What will I get from being part of the PPI panel?

It is really important to us that our PPI members are recognised for their work. Where possible (and of course if you agree), we will have the PPI panel group listed as an author. For example, on website materials, leaflets/pamphlets, and scientific publications. Where possible we will try reimburse you for your time. As part of UCCs policies, we are able to reimburse PPI involvement through vouchers, more information on this can be found here: <https://www.ucc.ie/en/ppi-ignite/ppiresources/budgetingforppi/>

How to apply?

You do not need to have any research or medical experience/knowledge to apply! Your experience and knowledge as a PwCF or family member is really important to us. To apply, scan the below QR code and complete the very short form. Once we have reviewed all applications, we will email you to let you know the outcome. If you or a family member are having issues with the form, please feel free to email Tamara at tamara.vagg@ucc.ie

Applications are open from February 13th – April 30th.

More Information:

You can learn more about PPI at UCCs website: <https://www.ucc.ie/en/ppi-ignite/>

Or by talking to a member of the Cork CF Team. Please feel free to email Tamara any questions you have tamara.vagg@ucc.ie If you would prefer to discuss over the phone or in person with Tamara, please let the CF Nurses know and we can set it up.

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