

# SFI FutureNeuro Research Centre Strategic Plan for Public Engagement & Public Patient Involvement 2022-2027

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# Strategy for Public Engagement & Patient Public Involvement (PPI) in FutureNeuro's Research 2022-2027

**About FutureNeuro:** FutureNeuro is a Science Foundation Ireland (SFI) funded centre of research excellence for chronic and rare neurological disease. FutureNeuro's overall vision is to empower people living with neurological conditions to access cutting-edge health diagnostics, effective treatments and digital healthcare. FutureNeuro's mission is to radically improve neurological healthcare through discovery science, novel targeted therapeutics and digital health care solutions through engaged research partnerships with our stakeholders.

## FutureNeuro's Education and Public Engagement (EPE) vision

Science Foundation Ireland aim to enhance the societal relevance of research by increasing active participation of citizens and stakeholders through public education, public engagement and by encouraging engaged research practices across all stages of research and innovation.

FutureNeuro has therefore developed a specific vision for the centre's public engagement work. The public engagement vision is to *"improve access to cutting edge neurological diagnostics, therapeutics and digital healthcare solutions for people living with neurological conditions while also positively influencing neurological literacy, health policy and health service provision for the public through impactful public engagement, engaged research and effective public communications."*

## FutureNeuro's Aim for Public Patient Involvement (PPI) in Research

FutureNeuro's research is focused on health science, on finding ways to diagnose, cure and empower patients living with neurological or brain-based conditions. Within the overall umbrella of 'Public Engagement' lies a suite of 'Engaged Research' approaches. Following discussion with senior management at the Centre and key stakeholder partners, it was decided that the most appropriate Engaged Research partnership approach for the centre to take is 'Public Patient Involvement' (PPI). This approach is described in more detail below.

**What do we mean by PPI?** FutureNeuro defines Public Patient Involvement (PPI) as the development of active partnerships between researchers, patients and stakeholders to progress research in the field of health sciences and digital health technologies which is relevant and useful to patient and public needs.

By 'patients' we mean people living with or caring for people with neurological conditions including past and current health care service users, formal carers, and informal carers such as parents and family members. By 'public' we mean people who have a specific interest in neurological health, such as patient advocates, support groups, charities for neurological conditions, clinicians, healthcare providers and policy makers.

**What do we not mean by PPI?** While FutureNeuro also actively values and supports the **engagement** of patients and public in our outreach and educational activities, as well as the **participation** of patients and public in our research studies, **'involvement'** lies on a fundamentally different part of the engagement spectrum. Our PPI collaborators are not research subjects or participants. Instead we consider them to be research or advisory team members.

See table below:

Research Type	Broad Definition	Type of typical research activity
Participation	People <b>giving their data to researchers</b> in a research study	Genetic material; Blood samples; Clinical (medical) data; Questionnaires; Interviews; Focus Groups; Surveys;
Engagement	Researchers <b>communicating about their research</b> with people	Presentations/Seminars/Conferences Stakeholder engagement Outreach programmes/activities
Involvement	Researchers <b>collaborating with patients/public</b> across the research cycle	Identifying research need/gap/questions Preparing funding /ethics applications Membership of Advisory Panels; Preparing research plans/materials/dissemination; Supporting translation into clinical devices/products/services/policy

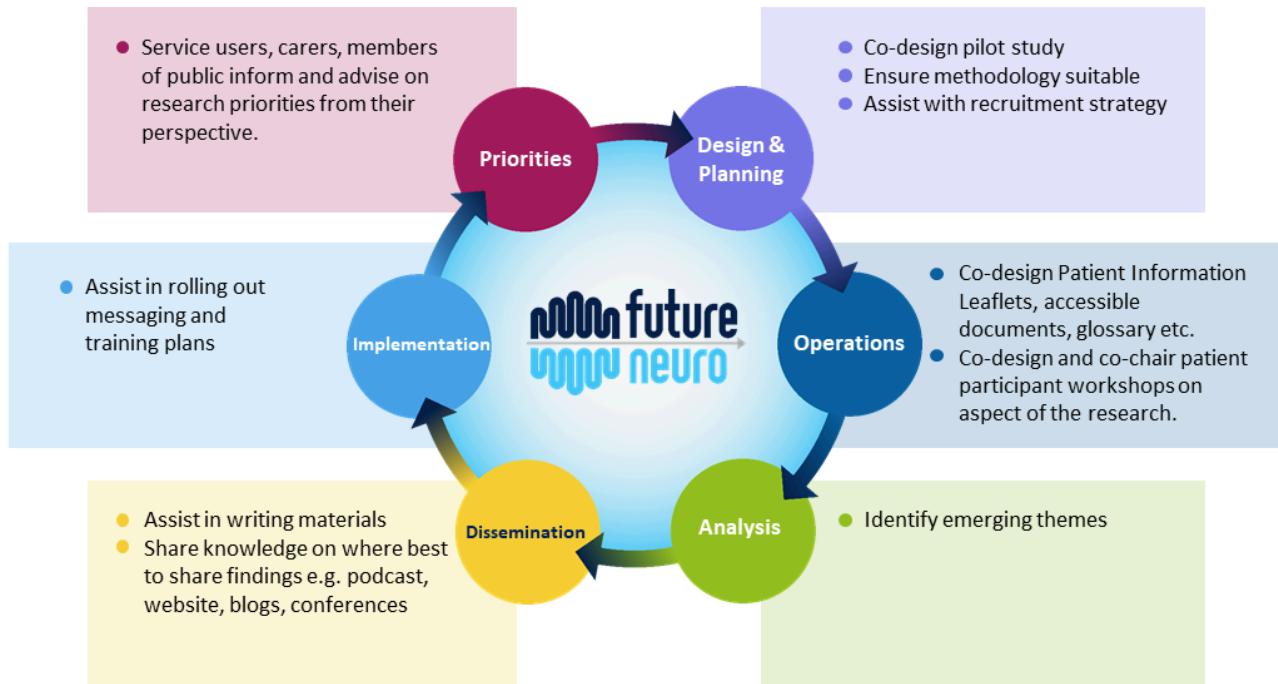
### Aim of Public Patient Involvement in research

FutureNeuro's overall aim for Public Patient Involvement (PPI) is that our researchers with scientific expertise engage in dynamic, reciprocal partnerships with people living with or caring for people with neurological conditions, their advocates and clinicians who provide their medical care. We call this collective group involved in shaping our research 'PPI Collaborators' and we have developed a FutureNeuro Patient and Public Involvement (PPI) Advisory Panel with people living with/caring for a range of neurological conditions.

### Role of the PPI Advisory Panel and PPI Collaborators

1. FutureNeuro has established a Patient and Public Involvement (PPI) Advisory Panel following best practice. One of the key roles of the Panel is to advise on FutureNeuro's research strategy in the fields of Diagnostics, Therapeutics and E-Health from the perspective of patients, carers and public stakeholders such as specialist clinicians in the field of neurology.
2. The PPI Panel also helps FutureNeuro consider public engagement plans and activities.
3. The PPI Panel supports the design and governance of FutureNeuro resources such as biobanks to ensure the research questions are valuable to patients, helps recruit members of the patient populations we want to involve in our research and supports us to communicate our research work more effectively.
4. PPI Collaborators are involved at various stages across FutureNeuro's research cycle (see figure below) including research planning, research design, interpreting data findings, dissemination of research results and advocacy on the translating research findings into practice and policy.
5. PPI Collaborators are involved in supporting the training of FutureNeuro's researchers and partners in engaged research, in public patient involvement in research and in effective public engagement.
6. PPI Collaborators are involved in reviewing FutureNeuro communications, including the website, to ensure research is communicated appropriately and sensitively to diverse patient populations.
7. Finally the PPI Advisory Panel will be involved in developing a consistent PPI evaluation tool for use by all FutureNeuro researchers to evidence the impact of PPI in FutureNeuro research, and will be involved in collaborative journal articles, conference presentation and media communications regarding this PPI impact.

## PPI in the FutureNeuro Research Cycle



### Here are examples of potential PPI activities at each research stage

**Stage 1: Priorities - identifying the research area and question(s):** Where feasible, FutureNeuro consults with the PPI panel, patient advocacy organisations and key healthcare stakeholders at the earliest research stage.

FutureNeuro seeks to identify what are the unmet research needs reported by the patient, carer and clinician populations and to prioritise research areas to consider with regards to neurological conditions.

Where this is not possible, FutureNeuro consults with patient, carer, medical and policy stakeholders to invite their opinions about our proposed areas of research with regards to its potential significance for patient neurological health and potential opportunities for PPI in the research process.



**Stage 2: Research Planning:** At the next stage of research planning, we involve patient and public collaborators in funding applications to ensure their PPI recommendations help shape the research plan.



**Stage 3: Research Conduct:** Where appropriate, we involve patient and public collaborators as peer researchers in designing research workshops, focus groups, interviews and consultations.





**Stage 4: Research Analysis:** Where feasible, we involve patient and public collaborators in considering data analysis and emerging themes to invite their perspectives as to the meaning of emerging findings.



**Stage 5: Research Dissemination:** At this stage, we ensure that the patient and carer voice informs FutureNeuro's communication of our research opportunities. This leads to more effective recruitment of patients to research relevant to their healthcare needs.

We also ensure that FutureNeuro's research findings are accessible to and inclusive of the specific communities we strive to improve health outcomes for.



**Stage 6: Research Implementation:** Where appropriate, FutureNeuro supports patient advocacy for the implementation of our research findings into medical practise, services or policy.

FutureNeuro may also invite further collaboration with PPI Collaborators to further build on research findings by planning funding applications for related research projects.

## PPI Objectives

To achieve this overall aim of incorporating PPI at every stage of FutureNeuro's research, we will achieve the following objectives in 2024-2026:

1. To grow our Public Patient Involvement (PPI) Advisory Panel to collaboratively review FutureNeuro's research strategy and research projects.
2. To have patient representatives with experience of each of the major neurological conditions inform the PPI Panel's considerations, either through direct membership or through consultation. These conditions include epilepsy, motor neurone disease or ALS, multiple sclerosis, Parkinson's disease and childhood rare neurological diseases.
3. To review and feedback on the FutureNeuro work packages in each of the three main streams – diagnostics, therapeutics and digital health.
4. To review and help shape FutureNeuro Education and Public Engagement plans.
5. To collaboratively support the planning for and delivery of 'PPI in Research' training to FutureNeuro researchers.
6. To collaboratively review FutureNeuro's website and communications to ensure accessibility and transparency.
7. To advise individual FN researchers on PPI if requests are received through the PPI panel.
8. To identify or develop a consistent PPI evaluation tool for use by all FutureNeuro researchers to evidence the impact of PPI in FutureNeuro research.

## Values underpinning PPI in FutureNeuro

It is important to FutureNeuro that our PPI Collaborators feel valued for their experience, time and commitment. Our underpinning values for PPI which have emerged through dialogue and consensus are:

- (1) Respect and inclusion of diverse non-specialist, lived expertise;
- (2) Commitment to collaborative and participatory ways of working;
- (3) A focus on the societal impact to our stakeholder audiences.

We strive to demonstrate this respect by:

- Inviting PPI Collaborators from diverse backgrounds with experience of diverse neurological conditions to join our PPI Panel or to be involved in FutureNeuro events.
- Communicating in a timely manner with regards to meeting information, documentation and PPI work requests.
- Providing a friendly, accessible, supportive online or in person space for PPI meetings.
- Communicating expectations, research terms and work tasks clearly, in easy-to-understand language.
- Listening with respect to all contributor's opinions and recommendations.
- Providing honest feedback on which recommendations are feasible to implement.
- Advising on what difference their PPI contribution is making to FutureNeuro research.
- Inviting PPI contributor involvement in journal articles, conference presentations and events where possible.
- Reimbursing vouched expenses incurred due to PPI activities.
- Reimbursing PPI Collaborators for time spent on agreed FutureNeuro PPI activities (e.g. meetings, communications, documentation review, events etc).

## Reimbursement Guidelines for PPI Activities

The reimbursement costs for PPI Collaborators, PPI administration and PPI activities will be factored into FutureNeuro's annual and multi-annual budgets.

FutureNeuro cover the cost of travel and refreshments related to attendance at any face-to-face PPI in research meetings. Travel may include public transport, road tolls, fuel costs, parking costs etc. necessary for PPI Collaborators to be involved in the research process. (Note that receipts must be kept with a log of travel related to the research project, e.g. dates, cost incurred, purpose of travel etc.)

In the case where meals or refreshments are required while attending or travelling to PPI activities, either receipts for reasonable, itemised subsistence will be reimbursed or a pre-agreed daily subsistence rate factored into the budget. Please note costs for alcoholic drinks are not eligible for subsistence reimbursement.

We also pay a small fee to compensate PPI Collaborators for their time at in person meetings, online meetings and for documentation review at the following rates:

- PPI Hourly rate €25
- PPI Half day rate €85
- PPI Full day rate €170

All reimbursement costs for time offered are honorarium payments as form of reward and recognition offered for the contribution that patient, carer and public collaborators make to research at FutureNeuro. This payment does not mean that PPI Collaborators have a contract of employment with FutureNeuro.

PPI Collaborators are not obliged to accept reimbursement for their time if they would prefer not to receive it, or they may request to be offered a lower or higher amount due to individual circumstances, which is at the researcher's discretion to discuss and pending budget availability.

Please note we can only compensate for PPI work agreed and requested by FutureNeuro, and Collaborators are required to keep a timesheet of PPI activities. Reimbursement can take the form of vouchers or bank transfer.

There are a number of other ways that FutureNeuro will strive to support our PPI Collaborators. These include:

- **Clear contact person:** The main contact person for the PPI Collaborators will be Dr Karina Halley, FutureNeuro's Ethics Lead, [karinahalley@rcsi.ie](mailto:karinahalley@rcsi.ie)
- The main contact for FutureNeuro Education & Public Engagement activities will be FutureNeuro's Education & Public Engagement Lead
- **Reimbursement contact:** The contact person for PPI reimbursement will be Karina Carey, FutureNeuro Reporting Officer [karinacarey@rcsi.ie](mailto:karinacarey@rcsi.ie)
- **Overview of FutureNeuro research:** Information sessions will be held at regular intervals for PPI Collaborators on the research being conducted by FutureNeuro to provide the opportunity to hear from each of the Principal Investigators at FutureNeuro.
- **PPI Learning and Development:** FutureNeuro will support PPI Collaborators with learning and development on aspects of PPI identified as being useful or supportive.
- **Clear documentation:** A standardized FutureNeuro form will be developed for researchers to request Public Patient Involvement in their research so the request is clear to the PPI Panel.

**Confidentiality** Due to the intellectual property requirement of FutureNeuro research, a standardized FutureNeuro confidentiality agreement will be developed so PPI Collaborators are clear what can be shared and what is confidential.



## Appendix 1: Overview

### PPI in the Broader Context of Education and Public Engagement at FutureNeuro

**EPE Vision:** Our Education and Public Engagement (EPE) vision was co-created with our Public Patient Involvement (PPI) Advisory Panel, emphasizing the stronger synergy sought between public engagement, engaged research and public communications to achieve our Public Engagement mission for FutureNeuro 2.

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*FutureNeuro improves access to cutting-edge neurological diagnostics, therapeutics and digital healthcare solutions for people living with neurological conditions while also positively influencing neurological literacy, health policy and health service provision for the public through impactful public engagement, engaged research and effective public communications.*

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**Overview of past EPE:** Since its launch in 2017, FutureNeuro's EPE programme, has centred on building public science capital, fostering an awareness of our research to the wider public, participating in national dialogue on neurological conditions and stimulating schools and public engagement in Science, Technology, Engineering and Math (STEM).

Supported by an impactful communications plan, we have performed over 360 educational outreach and community engagement activities to date. Our approach has combined both collaborative and Centre-specific initiatives – we have partnered with key national neurological advocacy organisations and, by providing education and mentoring, we have equipped FutureNeuro researchers at all levels with skills to identify and pursue their own EPE activities.

As the Centre has matured, our EPE strategy has evolved to empowering patients and communities directly impacted by our research themes to inform our research agenda through sharing their perspectives and lived expertise. In 2021, with the appointment of a specialist Public Patient Involvement (PPI) Lead, we established a PPI Advisory Panel of people living with, caring for or advocating for populations with diverse neurological conditions and collaboratively drafted a PPI strategy for our Centre.

Our underpinning values emerged through dialogue and consensus as being (1) respect and inclusion of diverse non-specialist, lived expertise, (2) commitment to collaborative and participatory ways of working, (3) a focus on the societal impact to our stakeholder audiences.

**Phase 2 EPE plans:** As we progress to FutureNeuro 2, our integrated PPI and EPE strategy is strongly informed by phase 1 PPI input and reflects our expanded research focus including new neuropsychiatric disease, digital health and well-being. To maximise our reach and impact, we will deliver the following, collaboratively-identified, key EPE priorities as summarised below.



## FutureNeuro 2 Integrated PPI & EPE Strategy

### 1. Embed engaged research for societal impact throughout FutureNeuro's culture

Our PPI Advisory panel will continue to play an integral part in designing the road-map for engaged research across FutureNeuro 2. PPI collaborators will continue to be recruited to advise on specific research projects to maximise end-user design, population reach and research impact for both platform and industry projects. Our training for all team members will be based on the National Forum for the Enhancement of Teaching and Learning NFETL accredited course 'Engaged Research for Societal Impact' enhanced by PPI content. With support of the Public Engagement Manager, our researchers will be empowered to design and deliver their own EPE activities. Our clinical network will facilitate short in-hospital rotations for early-stage researchers to meet real patients. We plan to meet and exceed our target that a minimum of 50% of researchers are equipped with the skills to instigate public engagement and deliver engaged research.

### 2. Build science capital in educational and community settings to inspire next generation researchers.

Our aim is to provide a pedagogically sound, clinician-informed education and awareness programme for primary and post-primary children, prioritising schools and community educational settings in disadvantaged areas. Activities will be developed by FutureNeuro researchers and PPI collaborators to engage children age 10-12 years on the topic of brain function. Using our #explainscience hashtag, as proposed by our PPI Panel, we will invite children and young people to engage with us on brain health and wellness through social media to coincide with key calendar dates (World Mental Health Day, World MS Day). To promote gender and diversity in STEM, our researchers will contribute to 'A Career less Ordinary', FameLab and similar campaigns. We will advertise and annually bring 6 Summer Students from across Irish third level institutes to grow our pipeline of prospective neuro

### **3. Leverage FutureNeuro's knowledge mobilization capacity to inform public and policy**

We will work with our partner national NGOs to inform public awareness, public engagement and research policy on neurological health research and services, leveraging our collective patient, research and clinical perspectives in key areas identified in consultation with our PPI panel. We will jointly plan a calendar of national public engagement campaigns (e.g. #Loveyourbrain for Brain Awareness Week with Neurological Alliance of Ireland, the National Clinical Conference with Epilepsy Ireland, Rare Disease Week, Science Week). We will grow our PPI involvement with MS Ireland, IMNDA, and Parkinson's Ireland, and commence further PPI and clinical engagement with organisations supporting neuropsychiatry disease. Working with our Host Institution, RCSI and our PPI panel, we will plan bi-annual FutureNeuro-led MyHealth public lectures, which has a broad national audience. We will leverage our connections with other SFI Centres to deliver on-line deliberative dialogues exploring topics such as the intersection of neurological health, genomics and data sharing.

### **4. Create a diverse, inclusive network of brain health champions to inform public engagement and PPI in research**

We will build a network of FutureNeuro-affiliated champions for brain health and research through building the capacity of people with lived experience of neurological conditions, their advocates and families to share their stories in ways that influence policy makers, funders and the public to understand the value and potential impact of scientific and medical research to respond to patient needs. A particular focus will be on engaging with seldom-heard populations and communities more vulnerable to neurological disability in ethically appropriate, empowering ways to develop their skills to collaborate on public engagement and engaged research.

Centrally, we will continue the very successful Epilepsy in English workshops to other neurological disease areas to engage patients and advocates with our researchers and the latest research knowledge. Following the success of our SFI-funded Discover art programme in FutureNeuro 1, we will fund a part-time artist-in-residence pilot programme to invite an artist to portray our research and the lived experience of neurological conditions through the medium of art. For example, the empowering methodology of 'photovoice' can be used with more vulnerable populations for visual expression of lived experience through photographs while retaining anonymity. The end photographic exhibitions can improve public understanding of the lived experience and impact of neurological conditions. If successful, we will seek philanthropic funding to scale up.

## Logic Model for Education and Public Engagement

PRIORITY EPE ACTIVITY	IMPACTS	SAMPLE INDICATORS
<b>Embed engaged research for societal impact throughout FutureNeuro's culture</b>	<p>PPI involvement becomes a standard FutureNeuro way of doing research, facilitating meaningful, high impact research.</p> <p>Our trainees are highly valued by funders and industry for their engaged research skills.</p>	<p>-Bi-monthly PPI Advisory panel meetings</p> <p>- Expanded patient network across neurological conditions help inform FN research.</p> <p>Peer-reviewed patient engagement publications.</p> <p>PPI-led bi-annual clinical conference.</p>
<b>Build educational and community science capital</b>	<p>Young people, patients and carers living with neurological condition help shape meaningful educational curriculum and events.</p> <p>Potential future scientists are inspired, science capital is generated through non-formal education activities</p>	<p>FutureNeuro establishes the first Irish <i>Unleash Hackathon</i> hub for teenagers</p> <p>Our trained researchers deliver <b>5 BrainBox Clubs</b> per annum</p> <p>6 Summer Students per annum.</p>
<b>Leverage FutureNeuro's knowledge mobilization capacity to inform public and policy</b>	<p>Increased public funding for brain research</p> <p>Research and patient-organisations inform public policy in relevant topics, e.g. national genomic infrastructure</p>	<p>Contribute to 5 NGO events per annum.</p> <p>Annual half-day workshop on latest neurological research and implications for policy makers</p> <p>Deliberative dialogue events</p> <p>RCSI MyHealth series to highlight neurological research</p>

<p><b>Build a network of FutureNeuro brain health and engaged research champions</b></p>	<p>Our researchers are equipped to lead public engagement activities and promote accessible research.</p> <p>Patients and carers are supported to effectively self-advocate, including seldom heard vulnerable populations</p> <p>Patient and carers perspectives are routinely included in the public discourse on neurological health</p>	<p>2 Epilepsy in English workshops and 2 other neurological disease specific w/shops</p> <p>Artist-in-residence exhibition in collaboration with PPI collaborators</p> <p>10 Patient champions trained in research and media across main neurological conditions</p>
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**Acknowledgments:** This FutureNeuro PPI Strategy has been collaboratively developed by the FutureNeuro PPI Lead in collaboration with the FutureNeuro PPI Panel and FutureNeuro staff, using the Medical Research Charities Group's 'Guide to Developing a PPI Strategy' (2018) as a template.

For any queries on this strategy, please contact FutureNeuro Public Patient Involvement Lead [LornaKerin@RCSI.ie](mailto:LornaKerin@RCSI.ie) or FutureNeuro Centre Manager [BridgetDoyle@RCSI.ie](mailto:BridgetDoyle@RCSI.ie)