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Methods & Measures

Public Patient Involvement for Global Impact: Integrating Principles and Training into an International Brain Health Program

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Introduction

The Global Brain Health Institute (GBHI) aims to address global brain health challenges through equity-based fellowship training in brain health leadership across sciences, arts, humanities, advocacy, and policy. To achieve this, Patient and Public Involvement (PPI) is essential within GBHI's training programs.

Objectives

To describe the development and implementation of PPI practice into GBHI to support up-scaling of PPI beyond the program through training of Fellows.

Methods

The PPI implementation project had three main components: (1) Establishing a PPI panel including individuals with dementia, care partners, and those at risk, to contribute to GBHI activities, integrating the activity into the existing GBHI structure using Kotter's organizational change framework; (2) Developing and implementing a PPI education program for GBHI trainees; and (3) Creating a network of GBHI fellows worldwide, to implement PPI practice in their home countries. An evaluation framework captured outputs and impact, focusing on; implementation milestones, program-specific outputs, impact of PPI training on fellows' knowledge, awareness, using the Kirkpatrick model of training evaluation.

Results

A PPI panel was established with individuals from the US and Ireland, actively contributing to GBHI's communications, advocacy, and research efforts. A PPI training program was successfully integrated into the GBHI curriculum. The training was well-received, with Fellows incorporating PPI into their project work. Additionally, a cohort of 16 GBHI Alumni (Fellows who had graduated from the GBHI fellowship programme) from various countries was formed to develop a global resource framework for PPI in dementia research.

Conclusion

The project successfully integrated PPI as a core and sustainable element of GBHI's structure, generating interest and action across its global community.

INTRODUCTION

The increasing incidence of dementia is one of the most important health concerns globally, especially in low- and middle-income countries (LMICs) with nearly two-thirds of the world's population with dementia residing in these regions.[1,2] To address global brain health challenges, the Global Brain Health Institute (GBHI) was established in 2015 as a collaboration between Trinity College Dublin (TCD) and the University of California, San Francisco (UCSF). GBHI's mission is to reduce the scale and impact of dementia and advance brain health worldwide through re-

search, advocacy, and the training and support of emerging leaders via the Atlantic Fellows for Equity in Brain Health program. This program recruits fellows globally from diverse disciplines for an intensive one-year fellowship, including a foundational brain health curriculum, equity-based leadership training, mentorship, and rotations in hospital and community settings. Fellows can also apply for pilot project funding post-fellowship, and as Alumni post graduation, they have access to ongoing support, training, and networking opportunities to build a global community.[3]

The GBHI fellowship is guided by the values of authenticity, fairness, openness, respect, courage, and empathy. It is thus crucial that the voices of those with lived experiences of dementia and other brain health challenges are central to the organization's work, informing all aspects of its mission and operations. These values align with the principles of Patient and Public Involvement (PPI), also known as Patient and Public Voice (PPV), which emphasizes partnering with individuals with lived experience in research or service design rather than treating them as participants or service users.[4,5] Despite these shared values, PPI was not initially integrated into GBHI's framework. While PPI practices are well-established in some high-income countries like the United Kingdom, Ireland, Australia, and Canada,[6-14] the concept and practice of PPI are less familiar in many LMICs, where most GBHI Fellows originate.[15,16] Additionally, the hierarchical structures in LMIC health systems can pose challenges to implementing PPI.[17]

PPI has increasingly been recognised as an essential element in dementia research, with growing awareness among funders, researchers, clinicians and the public of its potential to enhance the relevance, quality, and ethical soundness of studies. Scoping reviews, such as "Patient and Public Involvement in Dementia Research in the European Union" by Miah *et al.*,[13,18] have documented a steady increase in PPI practices – ranging from workshops, meetings and consensus conferences to consultation in protocol design and data interpretation – and have highlighted both anecdotal and formally evaluated impacts of involvement on study design, recruitment, and dissemination. (Miah *et al.*[13,18]) Moreover, evaluation of specific initiatives – for example research awareness training for older people with dementia and their care partners – has shown that such training improves participants' understanding of the research process, supports more meaningful engagement, and is generally well received.[18] Nonetheless, despite this ascendancy, challenges remain in ensuring adequate training and awareness for researchers, health workers, and clinicians so that they are equipped to facilitate PPI properly; including understanding how to support people living with dementia, adapt materials, communicate effectively, and integrate PPI findings into clinical and policy decision-making.

OBJECTIVES

To address the gap in PPI practice and training in the GBHI program, we undertook a project to; (I) to implement PPI within GBHI's organisational structure to amplify the voice of people living with or at risk of dementia and former or current care partners, reflecting reciprocity, and ensuring opportunities for bi-directional enrichment and learning; (II) to foster awareness, understanding and meaningful engagement of the GBHI community with the principles and practice of PPI; and (III) to support PPI principles and practice in international settings through the network of GBHI alumni. Here, we outline the steps taken and evaluate the project's impact within and beyond the organization.

METHODS

Coordination and Management: The study was organised to deliver a number of key objectives and overseen by a Project Management Group (PMG) (1) forming a panel of PPI contributors to advise on activities and teaching within the GBHI program, (2) implementing a PPI training program within the fellowship curriculum, and (3) establishing a PPI group of GBHI Alumni (graduated fellows) to promote PPI with global reach, integrating it into brain health beyond the Anglosphere.

Formation of a PPI panel of individuals living with dementia, with caring experience, or at risk, to contribute to GBHI's activities was an essential starting point to this project. Support was received from Alzheimer's society of Ireland (ASI) in establishing and supporting the panel, including inviting members from their own pre-existing PPI panel, the Dementia Research Advisory Team (DRAT). Some additional members were recruited from participants in ongoing research studies related to dementia. The 23-member panel was eventually called the 'Lived Experience Group - LEG' and comprised 11 women and 12 men, five of whom were people with dementia, 16 care partners and 9 living with higher risk of dementia (based on family history), and two members of the general public (18 members in Ireland, 5 in the USA). The LEG co- established Terms of Reference, Standard Operating Procedures, and a Members' Support Protocol. Monthly online meetings were facilitated by a non-PPI GBHI staff member. Panel members received Research Awareness Training twice, six months apart, following published approaches, specific to dementia PPI panels.[18] The LEG provided feedback on GBHI's communications, guided PPI-related Fellow training, and reviewed Fellow's pilot projects, and shared lived experiences with Fellows. After six months, the LEG elected a chairperson from among their membership, while operational support from the facilitator continued.

Another key objective related to training, and the project developed and incorporated PPI-related training into the Fellows' core, co-designed and led by the LEG and GBHI's learning and curriculum lead. This ensured full integration into GBHI's program structure. Between 2020/21 and 2021/22 (two fellowship cohorts), the training was phased in: optional in 2020/21 and part of the core curriculum from 2021/22. The program included workshops using GBHI's 'flipped classroom' pedagogy, introducing PPI principles and practices, alongside optional opportunities for Fellows to engage with the LEG in providing feedback on Fellows'

pilot grant proposals and observing LEG meetings (initially titled the 'pilot support program- PSP).

Finally, we established the "Global PPI Working Group," a network of GBHI Alumni Fellows from 10 countries, primarily in the Global South, to explore implementing PPI in regions where it was less familiar. This 'special interest group' included 16 Fellows from diverse disciplines, including psychiatry, neuropsychology, advocacy, and arts in health. Meeting monthly, the group collaborated to create a "Global PPI Guide," tailored to low-resource settings where PPI is novel, drawing on consensus and existing literature. Over 18 months, this guide was developed to support PPI implementation globally.

Program evaluation framework: We co-designed a comprehensive evaluation framework, combining formal and informal feedback from Fellows, the Global PPI Working Group, LEG members, and GBHI staff. Our evaluation comprised four key components (outlined in Table 1): (1) a timeline of program implementation milestones, (2) an inventory of outputs, using a monitoring checklist; (3) an evaluation of the PPI training's impact on learners' knowledge, awareness, and practice using the Kirkpatrick Model[19]; and (4) a description of how the new PPI program was incorporated into the existing GBHI structure based on a step-wise approach described by Kotter's framework for organizational change.[20] Kotter's framework is an eight-step guided implementation plan emphasizing urgency for change, the need for coalition-building and shared vision to effect change, and the importance of communication, empowerment, short-term wins, consolidation, and embedding change. To capture feedback from LEG members about stages of the implementation, we conducted an anonymized bi-annual survey to assess satisfaction with panel management and support.

The Kirkpatrick Model is a four-level framework for training evaluation, assessing (1) Reaction—participants' satisfaction and engagement, (2) Learning—knowledge or skill acquisition, (3) Behaviour—application of learning in practice, and (4) Results—overall impact on organizational goals or outcomes. We conducted bespoke online post-training surveys for the 2020/21 and 2021/22 Fellow cohorts to assess Levels 1-3 of the Model. These were in addition to the collation of evaluations of relevant classes from our standard program Quality Assurance (QA) for years 2020/21, 2021/22 and 2022/23. For Level 4, we tracked the integration of PPI in pilot applications and ongoing alumni engagement with global PPI practices. Additionally, we monitored direct PPI involvement, such as Fellows' participation in PSP and PPI-related activities during the program.

Ethical approval for evaluating the PPI program was granted by Trinity College Dublin's School of Medicine Ethics Committee (Application No: 20211007). This approval ensured that all aspects of the study adhered to established ethical standards for research involving human participants

RESULTS

Here, we outline the outputs and impacts of the three workstreams of our PPI project, organised across the four parts of our evaluation framework.

(1) TIMELINE OF PROGRAM IMPLEMENTATION MILESTONES

The implementation timeline reflected the successful establishment and implementation of the LEG within GBHI's organisational structure, with each of the milestones having been achieved. Briefly these included; creation of the LEG itself in June 2021, and the co-creation of Statement of Purpose, Terms of Reference and Distress Protocol (September 2021), and (Research Awareness Training for LEG members conducted in (September and December 2021). Other milestones related to incorporation of PPI into the fellowship program first completion of PPI Training of 2021-22 Atlantic Fellows cohort was conducted in, and delivery of the GBHI Pilot Support Program 2022 (21/22 academic year). In terms of wider visibility of LEG and PPI across the GBHI community, key milestones included the creation of the LEG webpage (March 2022), and an online session introducing GBHI Alumni to LEG and the importance of PPI was conducted October 2022.

(2) INVENTORY OF OUTPUTS OF LEG ACTIVITIES

In addition to the key milestones listed above, there were a number of additional outputs and activities arising, or drawing from, the work and expertise of the LEG. An early achievement of the LEG was the co-development of the "Words and Images to Use in Dementia and Caregiving"[21] guide, created to help GBHI faculty, staff, and fellows use appropriate language when speaking to or about individuals with lived experience of dementia. The LEG also contributed to external communications efforts, notably in developing the aforementioned PPI project and LEG webpages on the GBHI.org site, and provided additional feedback on the overall GBHI website. Wider inputs of the LEG into research and advocacy included; input into Irish Disease Modifying Therapies (DMT) position paper (February 2022), a dedicated session at the GBHI annual conference (June 2022); input into EU-Joint Program Neurodegenerative Disease Research (EU-JPNDR) funding application (STRAP Consortium) (July 2022); input into World Health Organization (WHO) Brain Health position paper (August 2022) and involvement in 'Supporting two-way learning between researchers and participants through a virtual conference' study at Alzheimer Association International Conference (AAIC) 2022 (August 2022).

Finally, the Global Resource Working Group aimed to create a toolkit that integrates diverse perspectives and provides a framework for implementing PPI across various settings. The output, titled *Global Resource Framework: A Global Perspective for Implementing PPI in Research*, includes recommendations for incorporating PPI into research, education, and training guidelines. It emphasizes the importance of ethical practices and value-driven research to fos-

Table 1. GHBI PPI program evaluation framework

Evaluation Framework Part	Evaluation method	Group providing evaluation
(1) Timeline of implementation milestones	Monitoring checklist	Project Management Group
(2) Inventory of specific outputs from the program	Monitoring checklist	Project Management Group
(3) impact of the PPI training program based on 4 level Kirkpatrick model of training evaluation	Post training PPI surveys (online anonymised) n=8 (2021/22), n=26 (2021/22)	GBHI Fellows who received the PPI training, across two cohorts, 2020/21 and 2021/22
	Standard program QA for PPI classes (online anonymised (2020/21, n=8 2021/22, n=26 2022/23) (aggregate quantitative data)	GBHI fellows from 2020/21, 2021/22 and 2022/23 cohorts.
	Semi-structured interviews n=10	GBHI Fellows, 2021/22 cohort
	Retrospective survey n=8	GBHI Fellows, 2021/22 cohort
	Engagement with Pilot Support Program (PSP)	GBHI Fellows, 2021/22 cohort
	Self-initiated PPI practice/activities	GBHI Fellows, 2021/22 cohort
	Ongoing commitment to PPI as alumni	GBHI fellows, 2020/21 cohort, project management group
	Incorporation of PPI in pilots	GBHI Fellows, 2021/22 cohort
(4) Description of how the new PPI program was incorporated into the existing GBHI structure	Monitoring checklist mapped against the 4 Kotter stages.	Project Management Group
	End of project Survey to gauge awareness of project, and perspectives on PPI (online anonymised) n=17	GBHI faculty and staff

ter long-term patient and person-centered collaboration. In addition to the guide, the framework features a case study on PPI research survey feedback related to aging, which includes an abstract, introduction, detailed methodology, analysis, results, and an in-depth discussion with an impact statement. Furthermore, this working group has transitioned into a formal special interest group dedicated to global PPI, ensuring a sustained presence within the GBHI structure.

(3) EVALUATION OF THE IMPACT OF PPI TRAINING ON LEARNERS' KNOWLEDGE, AWARENESS AND PRACTICE

GBHI PPI education and training was delivered to two cohorts of Atlantic Fellows (2020/21 and 2021/22), with LEG members actively involved in both its development and delivery. Applying the Kirkpatrick 4-level training evaluation framework,[19] we found the following (see table 2); At Level 1 (Reaction), the exposure to PPI training received positive feedback, as measured by post training QA surveys and a retrospective survey conducted post-fellowship (see Table 3). For the 2021/22 cohort, reactions, learning, and attitudinal changes were further assessed through interviews with Fellows who accepted feedback on their pilot projects from the LEG. The feedback indicated a generally positive response to PPI principles and the opportunity to collaborate with the LEG. Evaluations also demonstrated a solid understanding of PPI methodologies and an increased consideration of how these principles could be applied in their own professional contexts. At **Level 2 (Learning)**, Fellows showed a good grasp of PPI principles, with many reflecting on their potential to incorporate these approaches into future projects. At **Level 3 (Behaviour)**, behavioural changes were observed through engagement with the optional pilot support program from the LEG, as well as through Fellows' inclusion of PPI contributors in public-facing activities they led or curated, such as conference sessions and annual meetings. At **Level 4 (Results)**, the impact of the training was reflected in the inclusion of PPI in several pilot applications, despite PPI not being a required criterion for these proposals. Post-fellowship, alumni demonstrated continued commitment to PPI, notably through leadership from the GBHI PPI interest group in developing a global PPI resource framework.

(4) ORGANIZATIONAL CHANGE INCORPORATING PPI WITHIN THE INSTITUTION

As shown in Figure 1, the overall impact of the PPI initiative on the culture and organizational approaches at GBHI can be evaluated using the Kotter 8-Step Framework for Organizational Change. This model outlines an approach to creating and monitoring change through eight steps: establishing a sense of urgency, forming a guiding coalition, developing a vision and strategy, communicating the vision for change, empowering employees for broad-based action, generating short-term wins, consolidating gains and producing further change, and anchoring new approaches in the organizational culture.

Table 2. Kirkpatrick's Evaluation of Training framework applied to the GBHI Patient and public involvement (PPI) training program

Level	Activity	Evaluation findings	Comment
1. Reaction (The degree to which participants find the training favorable, engaging, and relevant to their work)	Evaluations from sessions in GBHI curriculum from 2020/21, 2021/22, and 22/23 academic year, conducted as part of regular programme QA (aggregate Quantitative feedback) Retrospective survey (Qualitative and Quantitative) (2021/22 cohort)	• **2020/21 cohort**: 100% of respondents indicated training "met expectations" (n=8). • **2021/22 cohort**: ◦ Session 1: 91% "satisfied/very satisfied" (n=21). ◦ Session 2: 94% "satisfied/very satisfied" (n=18). • **2022/23 cohort**: ◦ Session 1: 100% "satisfied/very satisfied" (n=26). ◦ Session 2: 82% "satisfied/very satisfied" (n=11). **Retrospective Survey Findings (n=8)**: • 50% indicated GBHI training was their first formal introduction to PPI, and all found it relevant to their discipline. • Respondents highlighted the effectiveness of the training, noting new skills gained and the value of lived experience in shaping approaches to treatments and research. • 100% reported a change in understanding of PPI after training, and 75% were "extremely likely" to use PPI in future work. • 50% noted PPI was not commonly practiced in their region, 25% were unsure, and 25% reported it was common. • 5/8 respondents had used PPI in their work before, with 2 using it "very often" and 3 "sometimes." • Positive experiences with PPI were common, though one respondent cited issues with funding and power dynamics as barriers to meaningful collaboration. • Suggestions for improvement included better accessibility, dedicated funds for participant reimbursement, and clearer communication and ethical guidance.	This level of consistent satisfaction with the PPI training was somewhat higher than that seen with most other curriculum elements.
2. Learning (The degree to which participants acquire the intended knowledge, skills, attitude, confidence, and commitment based on their participation in the training)	Qualitative interviews post training (2021/2022 academic year)	**Feedback from Fellows Engaged with the Pilot Support Program (n=10):** • Strong positives about PPI training: described as an "eye-opener," "breath of fresh air," and a "very human reminder of why we are here [at GBHI]."	

		• Many experienced their first formal introduction to PPI, allowing them to frame and structure previous collaborative practices. • Training empowered fellows to become PPI advocates, highlighting the importance of meaningful engagement and involving individuals with lived experience in shaping research from start to finish. • Identified benefits of PPI for research: enhancing dissemination, supporting engagement, co-creating contextually relevant research, and demystifying dementia in resource-poor settings. • Broader societal and individual impacts: reducing traditional research hierarchies, balancing power, contributing to global health equity, and reducing stigma. • Emphasized the importance of building relationships between researchers/clinicians and individuals with lived experience. • Enabled grassroots advocacy and empowered people with lived experience, reinforcing that "our voice is valid and it matters."	
3. Behaviour 4. (The degree to which participants apply what they learned during training in their brain health work)	• Participation in the (optional) pilot support program 2021/22 year • Involvement of People with lived experiences in fellow led activities	• Fellows engaged in Pilot Support Program (n=10). • Fellow- led session at an international Alzheimer conference and the GBHI annual meeting, 2022	
5. Results (The degree to which targeted outcomes occur as a result of the training)	• Degree of incorporation of PPI in pilot applications • Leadership and contribution to the PPI resource framework	• Fellows who engaged with the Pilot Support Program in the 2021/22 academic year included PPI in their pilot applications (n=4). • Fellows from the 2020/21 cohort led the development of the resource framework, and the creation of the GBHI PPI special interest group (n=3).	

Table 3. Project approach and outcomes mapped against the Kotter framework[20] for organisational change

Kotter Model Step	Activities/actions
1. Establishing sense of urgency	**Submission to Executive Committee:** The core project team, with support from several GBHI Directors, submitted a brief to the GBHI Executive Committee, highlighting the importance of addressing the absence of Patient and Public Involvement (PPI).
2. Create a guiding coalition	**Partnership Development:** Leveraged internal and external partnerships to access expertise and resources and create a core coalition with GBHI faculty and staff as well as external supporting stakeholders such as the , The Alzheimer's Society of Ireland PPI group, relevant ongoing research studies in dementia, and others.
3. Developing a vision and strategy	Project proposal developed Workstream to address the three objectives of the project: • Creation of GBHI PPI panel • Introduction of PPI training into fellowship program • Empowering Alumni to develop resources to support PPI globally
4. Communicating the vision change	Information meeting in December 2020, featuring the contributions of people living with dementia and their care partners, to introduce the GBHI community to the topic and project. Consistently sharing updates within the GBHI community via GBHI Blogs and outside GBHI through social media support from The Alzheimer's Society of Ireland and Trinity College Dublin's School of Medicine newsletter. PPI elements included in the GBHI annual meetings of 2021 and 2022 (including presentations from GBHI Fellows and staff along with conversations with people with lived experience of dementia).
5. Empowering employees for broad based action	Through the training program fellows were empowered to learn from, and work with the PPI panel. Staff in different functions were given the opportunity to engage with the project team and the PPI panel and develop complementary activities in their own areas (primary examples include the learning experience, communication, and alumni teams).
6. Generating short term wins	In the first year of the project: • Creation of training opportunities in the program • the establishment of the PPI panel (Lived Experience Group, LEG). • Engagement of the panel in core and additional activities within GBHI • Development of the *'Words and Images to Use in Dementia and Caregiving"*
7. Consolidating gains and producing more change	Embedding PPI training into the core curriculum of GBHI exemplifies a significant long-term change. The collaborative efforts of a diverse, interdisciplinary global group of alumni in developing the *Global Resource Framework* further demonstrate the potential impact of this project on changing practices worldwide.
8. Anchoring new approaches in the culture	**Incorporating PPI Training:** Integrating PPI training as a core element of the GBHI curriculum. **Sustaining PPI Initiatives:** Implementing a plan to sustain PPI and the panel beyond the project's funding lifespan, including: • Integrating support and coordination for the Lived Experience Group (LEG) into the regular operations of GBHI. • Co-developing new operational processes with group members and expanding recruitment for new panel members from a broader geographical base. • Transitioning the working group for the Global Resource Framework into a formal GBHI Special Interest Group.

This process of change has led to the integration of PPI into the culture of GBHI, which has been sustained after projects end. Evidence of this acceptance is found in a survey of staff and faculty, where 82% of respondents "completely agreed" that the introduction of PPI to GBHI was a positive and important step. The same percentage expressed a desire for PPI to continue as part of GBHI in the future, while 94% agreed that PPI aligns with GBHI's values.

DISCUSSION

PPI has been increasingly 'normalised' in the health research space in the global north (particularly UK, EU and Ireland), with wider incorporation and some element of lived experience input into design and implementation of studies becoming mandated by funding agencies, and development of best practice frameworks and guidelines.[12, 22-24] However, as noted above the concept is less well developed or understood in global contexts, and in global north settings there are concerns about its inappropriate implementation leading to tokenism.[25]

As such, education and training are key enablers to ensure, awareness of best practice in PPI in and beyond the research space. As reported by Paxino et al., while PPI has been integrated into Health professions education to a varying degree in certain jurisdictions, '' the transformative potential of genuine patient voice in preparing future health professionals remains largely unrealised''.[26]

The GBHI PPI project was thus an attempt to address this gap in the context of our wider mission; in terms of meaningful incorporation of PPI within a training programme, considering how one empowers a global network to adapt and adopt PPI, and indeed considering the impact and practicalities of embedding PPI as a core part of an organisation's ethos and practice.

Through the GBHI PPI project, we successfully achieved our original objectives and leveraged emerging opportunities to embed the voices of people with dementia, their care partners, individuals at risk, and members of the public within our organisation. This approach fostered genuine reciprocity and bi-directional learning across the Global Brain Health Institute (GBHI) network. A key achievement was the establishment and induction of lived experience group (LEG), whose lived experiences meaningfully informed the development of the PPI curriculum and directly supported Fellows' pilot projects. While forming a group with such diverse purposes presented challenges—particularly around clarifying roles and expectations, which led some early members to seek more direct involvement with Fellows rather than governance or strategic goal-setting—the LEG ultimately coalesced into a sustainable and evolving entity. Notably, the group has continued to thrive beyond the original project's funding and remains active, exemplifying the enduring impact of participatory structures when embedded meaningfully within institutional frameworks.

Another major objective of the project was to enhance awareness, understanding, and meaningful engagement with PPI principles among GBHI Fellows. Integrating opportunities to learn about and collaborate with the LEG into the GBHI fellowship curriculum has ensured ongoing exposure to PPI concepts for successive cohorts of fellows. Furthermore, faculty, staff, and alumni were introduced to PPI's value and application through workshops, blogs, and institutional communications. These activities collectively strengthened a culture of inclusion and participatory practice across GBHI. Importantly, the project also facilitated engagement with global dementia stakeholders, including the World Health Organization's Brain Health Unit, the Alzheimer's Association, and Alzheimer's Disease International, extending the program's influence and contributing to wider advocacy for patient and public involvement in dementia research.

Given GBHI's international scope, a further achievement was the conceptualisation and planned dissemination of the *GBHI Dementia Global PPI Toolkit*, aimed at researchers and policymakers worldwide. This initiative, co-developed by 15 Fellows and alumni from nine countries, capitalises on regional expertise and diverse cultural contexts to inform global best practice. Its forthcoming launch in 2026 represents a major step toward ensuring equitable access to PPI resources and training. Complementing this effort, the establishment of a GBHI Special Interest Group (SIG) will promote the continued development, dissemination, and sustainability of the toolkit, ensuring that PPI remains an integral and evolving part of the Institute's mission.

Evaluation and sustainability were integral to the project's design. Strategic reviews, combining qualitative and quantitative data, were undertaken throughout the program with oversight from the evaluation committee. Dissemination of outcomes across multiple formats ensured transparency and knowledge exchange, while cost-efficiency measures enabled the project to conclude under budget. Its rapid integration into normal operations of GBHI facilitated planning to ensure the sustainability of its principal achievements on a cost-neutral basis, demonstrating the feasibility of maintaining impactful PPI practices with limited ongoing financial investment.

Despite its successes, the GBHI PPI project faced several limitations. Some objectives, such as the development of dedicated PPI training modules for staff, were not fully realised due to time and resource constraints. Additionally, while the LEG model was effective, its composition and evolution did not fully represent the diversity of perspectives across all global regions, potentially limiting transferability of lessons learned (however it is worth noting that subsequently the overall network of PPI perspectives has widened through the work of Alumni establishing PPI in their own regions). Finally, evaluation data were drawn primarily from internal reporting and participant feedback rather than longitudinal or independently verified outcomes, which may constrain the generalisability of findings. Future initiatives could strengthen these aspects through more structured evaluation frameworks and broader inclusion of underrepresented voices.

CONCLUSION

Overall, the GBHI PPI project was successful in embedding participatory practices within a global training and research network. Since the original project the initiative was sustained through core funding and resourcing, and PPI increasingly normalised as a key part of GBHI's 'business as usual'. The LEG itself, through the leadership and input of its members evolved from a 'panel' of mainly Irish and US based members to a small advisory group of 5 members connected to a much wider global network of contributors, creating and connecting contacts between fellows and researchers and contextually relevant lived experience expertise. The integration into the training programme has also become more adaptive, agile and tailored – standard classes where fellows learn about principles and practices of PPI now sit alongside more meaningful engagement of PPI in groupwork and fellow's individual projects. In addition, this work increasingly anneals with other initiatives across our global community, such as the 'walking the talk for dementia' project.[27] We would intend to build on this momentum, potentially capturing this 'network effect' through further evaluations.

As such, although certain objectives remained incomplete, the project's overall approach offer a scalable and transferable model for incorporating PPI into institutional training and research cultures. Most importantly, it has catalysed a sustained, international community of practice

dedicated to advancing meaningful, inclusive, and impactful PPI in dementia and brain health research.

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AUTHOR CONTRIBUTIONS

EJC: contributed to project design and delivery, and the writing and revision of this article. AB: led project delivery, collated project data and created initial drafts of this article. MW, JM, SF, MF, MG, SY COR, HBM, EC, contributed to project design and delivery, and contributed and reviewed final draft. IL: oversight of design and delivery of project, an overall editorial oversight, and creation and approval of final draft.

RELATED LINKS

https://www.gbhi.org/gbhi-lived-experience-group

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