Involving Research Participants in a Pan-European Research Initiative: The EPAD Participant Panel Experience

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Abstract

Background

Patient, public and participant involvement (PPPI) is increasingly acknowledged as a key pillar of successful research activity. PPPI can influence recruitment and retention, as well as researcher experience and contribute to decision making in research studies. However, there are few established methodologies of how to set up and manage PPPI activities.

Methods

In this paper we describe the set-up, running and experiences of the EPAD participant panel. The EPAD study was established as a pan-European cohort study aiming at understanding risks for developing Alzheimer's disease and building a readiness cohort for Phase 2 clinical trials. Due to the longitudinal nature of this study, combined with the enrolment of healthy volunteers and those with mild cognitive impairments, the EPAD team highlighted PPPI involvement as crucial to the success of this project. The EPAD project employed a nested model, with local panels meeting at least twice a year established in England, France, Scotland, Spain and The Netherlands, feeding into a central panel who met once a year at the project's General Assembly. The local panels were governed by terms of reference which were adaptable to meet local needs. We discuss the recruitment opportunities employed by the centres and the set-up of the panels.

Results

Impact of the panels has been widespread, and varies from feedback on documentation, to supporting with design of media materials and representation of the project at national and international meetings.

Conclusions

The EPAD panels have contributed to the success of the project and the model established is easily transferable to other disease areas investigating healthy or at-risk populations.

Introduction

The importance of patient, public and participant involvement (PPPI) in health care research has been increasingly acknowledged over the last 25 years (1). Compared to participation or engagement, involvement empowers PPI members to take an active role in the shaping of research in partnership with researchers. PPPI opportunities are expansive and range from involvement in the commission and design of research ideas through to involvement in the active process of managing the research study as well as dissemination of findings. Review bodies such as the UK based Health Research Authority (HRA) and

funding bodies strongly encourage PPPI as part of a successful application package, and the INVOLVE network has been established in the UK to support integration of PPPI into health and social research (2, 3). While PPPI initiatives are well established in the UK, there is less experience in many other European countries, with guidelines for involvement recently produced (4, 5).

The literature on PPPI identifies four areas of significant impact; on the individual, the research, the researchers and societal benefit (6). PPI involvement has been linked to benefits in securing funding (7), modest effects on recruitment (8, 9) and an increased retention (10), as well as benefiting researchers themselves (11). Interestingly, a study in the primary care setting found researchers perceived the most positive impact of PPI when the approach included more indicators of good practice such as offering training to PPPI contributors (9). However, researchers often feel unequipped in knowing how best to involve patients and members of the public and what benefits they might reasonably expect (12).

There is, moreover, growing interest in learning from those currently taking part in biomedical research as well as from patients and the wider public, on a systematic and ongoing basis (13, 14). It has been suggested that the expertise of participants, as well as the wider public and patient community, can "contribute knowledge and ethical perspectives highly relevant to research decisions" (15) that can improve the success of the research project. Participant perspectives are thus being incorporated throughout the research process, ranging from decisions about data access (16) to the establishment of 'participant panels' in studies including the ALSPAC study (17), the UK's 100,000 Genomes project (18) and the US *AllofUs* precision medicine initiative (19). However, there has been little discussion of how such participant involvement can work. This paper presents the experience of the European Prevention of Alzheimer's Dementia (EPAD) programme with establishing and running panels of research participants across multiple European countries.

EPAD is a pan-European initiative aiming to better understand the early stages and risks of developing Alzheimer`s disease, at the same time developing a platform to run innovative interventional trials to test new compounds (20, 21). The project recruited over 2000 participants in 11 countries throughout Europe, with annual visits to the research centres to complete a range of physical and psychological assessments (with a 6 month visit in year 1 to evaluate cognitive function). Participants were seen in the longitudinal cohort study (LCS) for up to 4 years of clinic visits. Participants eligible to enrol in EPAD LCS were cognitively healthy or have mild cognitive impairment (MCI), were generally fit and well, had someone to attend as a study partner and were willing in principle to consider enrolment into a clinical trial of an investigational medicinal product (CTIMP).

One of the founding pillars of the EPAD programme was the involvement of participants as research partners. It had been acknowledged from study conception that in order for the project to maximise its chances of success, there must be input from the participants, who make a fundamental contribution to the project. This has built on learning from previous approaches to PPPI work during the project setup with research participants and patient groups (22), and the success of PPPI input within the PREVENT Dementia project, a parent cohort in the UK for EPAD (i.e. an ongoing research cohort from which EPAD

recruits) (23, 24). It was agreed participant input should be incorporated throughout the study, including but not limited to study design, understanding the research experience, input on communications and future planning. To this end, EPAD established a series of participant panels throughout the project.

In this paper we describe the approach to setting up both the country level and project wide participant panels, the impact participant involvement has had on the project and how the model developed in EPAD could be used by other research fields. The paper draws on our experience of being involved in designing, setting up and participating in the panels, including the perspective of research participant panellists across the study. It is based on reports from study staff at each centre with a currently operating panel, study documents related to the panel developed by the EPAD ethics workgroup, and feedback from panellists in each local participant panel. This paper was written in line with the GRIPP2 guidelines, with additional information available in the GRIPP2 short form checklist [see additional file 1].

How Do The Panels Work

The EPAD panel set-up drew upon the experience of the PREVENT Dementia Study (23). Key features of the EPAD participants' panels included a nested panel structure, in which multiple panels function locally and independently (Figure 1). Individual members or small teams of members of these panels then formed a single study wide panel. This central panel met once a year, alongside the General Assembly of the project. Local meetings were chaired by participants rather than staff. The central panel meeting was chaired by the EPAD Ethics group and was closed to other members of the consortium unless specifically invited by the panel members.

Central panel

The central panel meeting had two main goals – to co-ordinate activities across the local panels, and to provide for direct participant input into the development of the study. Participation in the General Assembly has also provided the opportunity for participants to learn about the progress of the study and to provide feedback, through both plenary meetings and closed meetings chaired by the EPAD ethics workgroup. Two meetings of the central panel have taken place, in 2018 and 2019, with six and ten members respectively. In addition, one participant representative attended the 2017 project General Assembly.

In addition to meetings of the central panel, participant panel members have also contributed to the planning of the future direction of the project as it approaches the end of its initial funding. Participant panel members from two EPAD countries worked with the research team in planning for the sustainability of the project and the long-term use of EPAD samples and data.

Local panels

Each country was given a mandate to establish participant involvement on either a research centre or country level in the form of a panel. Whilst the common language spoken at the central panel was English, requiring a certain level of ability to speak English, the local panels facilitated multi-lingual involvement with participants. A terms of reference document was created as a guide for research teams (Appendix One), however these terms could be adapted as appropriate to meet local requirements and based on discussions with local panel members. We describe below the set up and running of the panels with commonalities first described, followed by any unique adaptations made:

Scotland

In Scotland there was an established centralised country wide panel, with membership from four recruiting centres (NHS Lothian, Grampian, Greater Glasgow & Clyde and Tayside). The choice to form one country wide panel was advocated for by the participant members and worked well in a geographically small country.

England: OXFORD, WEST LONDON AND BRISTOL

England similarly established a panel to represent participants from multiple centres. The panel ran from Oxford, England and involved participants from three centres (Oxford, West London and Bristol).

The Netherlands: Amsterdam

The panel in the Netherlands was housed at the VuMC (Vrije Univercentreit Medical Centre). As there was only one centre in the Netherlands this panel operated both as the country and centre wide panel.

France: Toulouse

France had one panel in operation, based and run from the Toulouse centre. As one of the largest centres in the EPAD study Toulouse was able to harness the participant voice onto this panel.

Spain: Barcelona

Spain's panel was in Barcelona, the first EPAD centre to open in Spain.

Establishing the panels

The panels were in operation for a range of time, with the Scottish and Barcelona based panels established in early 2017, and the newest panels, England and Toulouse, established in 2019. All panels have met at least twice at the time of this paper.

Panels employed a variety of recruitment methods, with equal levels of success, during the initial set-up period. Three panels (Scotland, England and Toulouse) contacted all local participants via letter or email to explain that a participant panel was being established and asking for interested participants to contact the coordinating centres to receive more information. In Amsterdam the panel was first introduced during an annual meeting for participants, to which all EPAD participants were invited, and the panel opportunity was followed up during the dissemination of minutes from this meeting. In order to maximise the engagement of the participants and the output of the panel, the team in Barcelona established a list of criteria for the selection of the potential panel members such: proximity to the centre, sex, age, English language level, motivation. These were participants who had previously expressed interest in being more involved in the study and each participant was contacted by phone to assess interest in joining the panel. Most panels enrolled people on a first come first served basis, with the exception of Toulouse which enrolled based on longevity in the EPAD study. At the time of the cohort study closing a waiting list was in operation at the Scottish, English, Toulouse and Barcelona panels due to levels of demand. New recruits were informed about the participant panel using flyers in Scotland and via email in Barcelona, whilst Amsterdam elected to maintain a static panel as the participants involved have the most experience of the EPAD study and were motivated to remain in the panel. Scotland is a unique example in this group as it was initially established as an Edinburgh based panel and had since expanded on the advice of the panel members to include participants from all Scottish centres.

The initial meetings of each panel involved similar agendas set by EPAD staff, with setting the scene and explaining the purpose of the panel, establishing rules of engagement around confidentiality and terms of reference for the panel, and nominating a participant as chair of the panel. At the Barcelona and Toulouse panels, a vice-chair was also selected to support with the leadership of the panel.

Logistics of running the panel

The panels were all set up to run twice a year, with ad-hoc contact in between for matters arising that are time sensitive. The Barcelona panel met up to 4 times a year on the request of the participant panel members. Numbers of panel members ranged from 7 at Amsterdam to 12 in the Scottish panel, with the group size aimed to be large enough to capture a diversity of experience and opinions, whilst remaining small enough to allow everyone time to meaningfully contribute to the meetings. EPAD study staff were in attendance at every panel meeting, and in most centres the Chief Investigator or Principal Investigator also attends. The staff attended to organise the logistics of the meeting, provide study updates and answer specific questions from the panel, facilitate discussions if required and to minute the meetings. Panels met at locations convenient for participants, travel expenses were provided alongside refreshments, be that coffee or lunch depending on the preferred time of the meeting at each centre. Communication varied between countries depending on formats allowed under data protection laws, and included email, post and closed WhatsApp groups.

Content of panel discussions

The content of panel discussions was led by structured agendas which are developed by the panel chair and members with the support of EPAD study staff. As an example the Scottish panel had standing items discussed at every meeting including dementia moments (recent news stories about brain health and dementia), an update on the study progress to date (both internationally and for Scotland) and the proof of concept trials. Other topics discussed in the panels include sustainability and longevity of the project, communicating about EPAD, feedback on study visits (including experiences, practicalities and logistical aspects), reviewing documentation and discussing personal views on receiving desirability of receiving feedback through the EPAD study on risk factors for dementia.

Results

The EPAD participant panels have contributed in four main areas; study advocacy, review of study documentation, streamlining of study visits and input into overall EPAD study planning.

Study advocacy

Panel members have attended a variety of events in every country to speak about their involvement with EPAD and contribute to meetings based on their experiences both as participants and as panel members. These include the IMI Stakeholder Forum 2017 where a participant represented the EPAD study on a panel discussion on PPPI, National Research Scotland (NRS) annual meeting in Perth 2018 where two panellists co-authored a poster about the panel, the EUPATI (European Patients Academy) 2018 meeting where two panellists spoke about their involvement in EPAD, and co-hosting a webinar to discuss the set up and running of a participant panel to support other centres considering hosting a panel. The Scottish and English panels have both contributed to the annual EPAD conferences held in these countries where all centre staff gather to share experiences with the study. The Barcelona panel are credited by centre staff with raising the profile of Alzheimer's disease research in the Catalonia region through their outreach activities.

Review of study documentation

Review of study documentation has been an important role played by the panels, helping to ensure any information provided to participants is understandable and appropriate for use. The participants have provided valuable feedback for the on-going development and updating of the EPAD website. Suggestions from the panel led to rewording of study documents, improving readability and adapting images used in videos. Staff developing documents have commented on the impressive feedback received from the panel, noting the benefit of receiving both positive and constructive criticism to improve the documentation. Multiple panels have also been asked to discuss protocol amendments and consulted for advice on implementation, particularly when changes had the potential to have a significant

impact on study participants. By discussing with the panel the centre staff felt confident in the protocol amendment roll-out across the centre.

The Barcelona centre has developed videos with the panel focusing on the mandatory lumbar puncture procedure in the study protocol. Perhaps unsurprisingly, participant panel members in most countries discussed experience of lumbar punctures and suggested improvements for the information provided about these. Panel members worked alongside centre staff to make two videos to provide more information about the procedure. In the first, health care professionals (a physician and a nurse) provide a detailed explanation about the procedure. In the second, volunteers, who have already had the lumbar puncture procedure share their experience and explain the main steps during the lumbar puncture procedure from their perspective. Participants were able to watch these videos prior to the procedure as a communication mechanism to support with the learning about the procedure. An additional benefit reported by some participants was a reduction in pre-procedural nerves. Also, animated videos are supplied by the central EPAD team to introduce participants to both the project and provide information about the amyloid protein that is associated with Alzheimer's disease. Many centres had not worked with digital information in studies prior to EPAD and were hesitant to implement this in an older aged participant group. However based on positive feedback from panel members, staff felt able to confidently introduce this information to participants and were reassured of the importance of offering information in a multitude of formats.

In Amsterdam, the panel initially fed back that they often did not know whom they were seeing during their visit, as the complex procedures required a large number of staff to successfully deliver the study. Following this the team introduced a 'study card' to better explain the logistics of the visit and the roles of the EPAD team members involved, with the panel members collaborating on the wording and presentation of this card. This simple communication tool ensured that participants have the knowledge they want and need about their study visit, improving their overall experience at the centre.

Streamlining of visits at trial centres

At each panel meeting participants were invited to provide feedback on any study activities they had recently completed with the aim of maintaining a high level of positive study experience for the participant group. Changes made on the basis of this feedback ranged from small changes such as improved signage to clearly signpost participants to one of the Scottish centres, through to changes in communication methods. Feedback on how incidental findings could be disclosed (such as blood pressure, blood results or magnetic resonance imaging (MRI) findings of clinical significance) suggested a preference for either over the phone or face-to-face disclosures, which the centres implemented. Panels also fed back issues with the salivary cortisol sample collection, a procedure which was started at the study centre but continued at the participants home. Following feedback centres spent longer discussing the instructions in person which led to a better experience and compliance of this part of the protocol by participants. While the study as a whole did not routinely communicate the results of cerebrospinal fluid

(CSF) tests to healthy participants, in Amsterdam the participant panel advocated for disclosure of the CSF data on the explicit request of the participant. This led to the development of standard operating procedures to support with this, and to the disclosure of amyloid status to 20 participants based at the VuMC centre.

STUDY PLANNING

Participant panel members from Scotland and Amsterdam were invited to participate in a meeting to plan the future of the EPAD study following the end of the initial funding period. Prior to this meeting members of the EPAD consortium (EPAD sites, academic and industry partners) had completed a survey to outline their views on what EPAD should prioritise to continue in the next stage of the project. During the meeting these survey responses were reviewed and a guidance document produced to advise the EPAD Management team on the next steps they should take and the possible outcomes of how the study could function in the next phase. Panel members were asked to attend to give a voice to the participant experience and add their views to how EPAD should evolve.

Participant panel perspective

The Scottish and BBRC participant panels were asked by a fellow panel member to reflect on their experiences of the panel and provide feedback for use in this evaluation of the panel successes. These experiences are reported below.

Prior to joining the panel, members had few expectations of what joining might mean, and there was some doubt about how much *'influence the participants would have on the day-to-day workings of EPAD'*. People did anticipate that the meetings would be forums to '*provide (sic) feedback on our EPAD experiences'* and '*the chance to get to know other participants and to share experiences with them*'. Participants thought the panel would offer an avenue for collaboration and to spread the word about both EPAD and Alzheimer's disease. Panel members were often motivated to join the panel by their personal experiences of living with parents with dementia.

Considering the set-up of the meetings, panel members felt there was a *'nice balance'* of a structured approach that remained '*flexible as the agenda is set by the participants in conjunction with EPAD staff'.* Members appreciated the attendance of staff members who *are 'aware of the items on the agenda…and know the outcome of each discussion*'. They report the meetings as *'inclusive*', with a pleasant working atmosphere, and the Scottish group in particular note that '*the fact that [the Principal Investigator] takes the time to come to meetings is hugely empowering'*. These experiences demonstrate the importance of providing resources to PPPI groups to ensure efficient operation and maintaining an informal and flexible meeting style to encourage all participants to voice their experiences and opinions. In some centres participants advocated for more regular meetings. This led to conflicts between the ambitions of the panel and desire for increased regularity of meetings, against the limits of resources the research team

have to allocate, which is an ongoing challenge the centres are working to both acknowledge and manage. The Barcelona team had been able to support an increase in regularity of meetings, whilst other centres maintained a six-monthly schedule.

Panel members reflected staff views that their input had helped to improve the participant experience by providing *'a forum for participants to have their concerns voiced and attended to*' which has made the yearly visits to study centres *'as comfortable as possible*'. Importantly the panel members were key decisions makers in *'the decision to have a Scottish panel rather than a participant panel for each Scottish trial delivery centre'.* By combining the collective experiences from these centres it is likely the panel has been able to have a bigger impact than that of four individual panels. They felt that it is clear that the Scottish Participant Panel *has 'done a great deal to publicise the study, to disseminate the Scottish experience and to learn from what's happening in other countries'*. The panel has managed to solidify participants as stakeholders in EPAD, by *'reinforcing (sic) their importance in the scheme of things'* and demonstrating the *'humanity of EPAD'*. Participant panel members felt they had contributed to *'the transition from EPAD to EPAD2',* which relates to sustainability discussions about the long term goals of the project, in which the participant voice has been invaluable. Panel members reported attending numerous events but by meeting other panel member groups from across Europe at the EPAD General Assembly, the groups *'had found a voice'.* One panel has the slogan *'we want to be part of the solution'* and this ethos is clearly reflected in many of the EPAD participant panels.

Discussions were held in panels to develop strategies to makre sure *'everyone's voices [are] heard by the research team'*, not just those who were panel members. As part of this the Scottish group set up a satellite participant led group in Aberdeen which fed into the country wide panel.

Discussion

The EPAD participant panel model proved beneficial to the set-up, running and future of the EPAD project, providing access to participants as key stakeholders in the research. A key feature of the participant panels has been that they aim to be both participant-centred and, where possible, participant-led. Thus, the aim has been to create spaces for participant involvement and to establish the remit and scope of this involvement through ongoing dialogue between researchers and participants. The panels were established using overarching terms of reference that mandated meetings that were participant-led and held at least twice a year. Each centre has then developed and adapted the set-up in line with the needs and ideas of the local panel members. Overall, the panels have many similarities, with meetings chaired by a participant member and EPAD staff in attendance to organise and minute meetings. Some differences arise in how regularly panels meet and how panels communicate between face to face meetings. The panels have been able to achieve success in affecting how the study is run in the local centres, provide support on documentation, advocate for the study at local, national and international meetings, and provide opinion on the future directions that EPAD should take.

Strengths

We believe this nested participant panel model is adaptable for use in multi-national cohort settings. PPPI can often focus on involving people living with a particular disease, who often are not directly enrolled as participants in the research project. This works well in these areas because there is an identifiable group of people to approach as PPPI members. However when we consider the research fields of the general healthy population, or even ‘at risk’ groups, we need to be more creative. From our experience with the EPAD panels it is valuable to approach those who are enrolled as participants to get involved with P{PI activity as they are both at risk and committed to involvement in a research project.

Benefits of PPPI involvement in the EPAD study have been reported by both panel members and researchers. Participant panel members feel they had a voice as part of the research team by being involved in PPPI activities, and that being part of this was an empowering experience. Panel members reflected that they had been able to influence EPAD to make study visits as comfortable for fellow participants as possible, felt they had advocated successfully for the study in public facing forums, and had importantly introduced a reminder of the human aspect of EPAD when researchers have been making strategic decisions about the next steps for the EPAD project. By taking the step of garnering involvement from participants, rather than interested members of the public, EPAD benefited from advice given by participants with ongoing experience. This has meant other participants in the study were also able to benefit in the immediate term, as opposed to just future participants potentially benefiting from participant panel advice. Central panel feedback on the experience of taking part in the EPAD study contributed to the development of a mixed methods sub-study of participant experience across the EPAD centres. The EPAD researchers have always been committed to enabling a truly meaningful involvement of the participants and avoid a ‘tick box’ effort. As such, researchers attributed the panel with making changes to how centres run parts of the study visit, supporting centres with changes to documentation and providing confidence in using information tools, advocacy work on behalf of the study and contributing to strategic decisions at a project level. Overall the feedback provided by both panel members and researchers has been overwhelmingly positive.

Challenges

There are, however, challenges to be considered by researchers when establishing panels. Due to the time spent setting up the panel and learning from the establishment of the PREVENT Dementia panel, the EPAD panels have largely managed to avoid these pitfalls.

Challenges at the central panel level have included the time commitment of participants and resourcing of travel for non-research staff to attend meetings that are held across Europe, the need to develop glossaries of the acronyms and jargon associated with a large research study, and the challenge of explicitly incorporating a participant role into pre-defined governance structures. The first has benefited from the allocation of a specific budget for participant involvement at the outset of the project, and a glossary has been developed with input from participants. The question of formal governance involvement has been discussed in detail with the central participant panel and participants have been invited to attend meetings of the study’s governance committees. Thus far this invitation has been

declined with participants stating that involvement in the General Assembly, alongside the EPAD research community, and directly with study leads through the local panels, provides a sufficient level of input into decision-making.

Despite the lack of formal involvement in governance, the EPAD team have worked hard to ensure that the panels are not a 'tokenistic' gesture of involvement. True involvement should recognise the value of participant perspectives, ensure that mechanisms are in place to effect changes based on panel discussions, and be transparent about the limits of such action. One of the major factors that has supported EPAD to ensure the panels are not tokenistic is the minute taking in meetings with assigned action points. In this way research team members are held to account by panel members at meetings if actions have not been followed up on, ensuring that feedback led to meaningful change.

The participant-led nature of the panels also raises challenges. For example, both researchers and panel members have found occasional conflicts between the ambitions of the panel and the realities of what the research staff can deliver. During the meetings each panel encourages open and transparent dialogue, listening to all feedback and discussing what can and cannot be acted on with reasons discussed for actions that cannot be delivered. As the panels became established over time the conflicts tended to decrease, with the group learning how to best work together to achieve the best outcomes for the study.

Particular challenges related to the area of research and the scope of the study. The first was the recruitment of a group of participants across the diagnostic spectrum involved in the cohort study, which recruited both healthy volunteers and people with mild cognitive impairment. In the panel the aim was to capture a variety of voices to represent the spectrum of experiences in the EPAD study. However, the panel members at all centres were for the most part representative of healthy volunteers rather than participants with mild cognitive impairments. One of the contributors to this imbalance was that the original participant recruitment to the study was biased towards healthy volunteers and as such when the panels were established the majority of participants invited to join were cognitively healthy. As such there was a group of participants in the EPAD LCS cohort who were currently not well represented in the panel memberships. Reasons for this difficulty in engagement, reported by the staff involved in supporting the panels, include both researcher bias about burdening patient participants, participant confidence in attending an unfamiliar environment and logistics of attending for someone who may prefer to have a study partner with them. Future work in this area should consider ways to tackle inequity so as to ensure equality with regard actual involvement in PPPI work (25).

The final notable challenge specific to the EPAD context has been the pan-European context and the variety of languages spoken by participants. Although local panels operated in each country's native language, the central panel was conducted in English and thus required participants to speak English. Non-UK panels thus had to ensure that at least some participants had a level of English sufficient to enable the panel to be involved in central study discussions. While panels occasionally worked with their local centres to produce written English reports on their activity, EPAD continually developed to ensure

English ability was not a barrier to participation and that EPAD researchers led this to make involvement at all levels possible. However, the EPAD panel structure allowed for local panels to be more inclusive and less likely to be biased to a sub-set of participants likely to have a higher level of education.

LESSONS LEARNED

It is possible to set up and establish a successful network of participant panels across countries and languages to achieve meaningful involvement of participants as a stakeholders in the research process through a hybrid centralised-localised model. Ensuring there are some shared terms of reference across the local panels is important to manage the involvement process and feed into the central panel. Similarly having a degree of flexibility within these terms of reference allows the panel to adapt to the local needs and wishes of panel members, which can lead to positive responses from PPPI members. Staff members attending the panels was deemed important in all centres, with staff taking responsibility for organising the logistics of the meetings as well as taking notes and taking action on change where relevant. Communication methods varied across the panels with the importance placed both on what is preferred by panel members and possible under local governance. Successes have included the development of appropriate communication tools, representation at meetings and input into the planning of the EPAD project. There are acknowledged challenges with PPPI, such as taking time to establish what is possible to change whilst hearing feedback from panel members and ensuring people with cognitive impairment are able to access and engage with panels. As the panels became more established the community of panellists and researchers adapted to working together and meetings became ever more productive.

Conclusion

The EPAD participant panel model has proven a successful governance structure supporting participant involvement in a multi-centre, pan-European study. While its participant-led approaches can present challenges to both researchers and participants in terms of the initial clarity of role, it also ensures that the panels are reflective of and responsive to, the needs and concerns of participants themselves. We believe this is a model that can be adapted to suit similar study populations.

Abbreviations

EPAD
European Prevention of Alzheimer's Dementia
AD
Alzheimer's disease
LCS
Longitudinal cohort study
PoC
Proof of concept

CTIMP
Clinical trial of an investigational medicinal product

Declarations

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Ethics approval and consent to participate

All participants provided informed consent to join the EPAD LCS and ethical approval was obtained from ethics committees local to each study site. The establishment of participant panels formed part of the ethics submission in each country. No additional written consent was taken to join the participant panels.

Consent for publication

Not applicable

Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Competing interests

The authors declare that they have no competing interests

Authors contributions

S. Gregory & R. Milne developed the idea for the manuscript and are responsible for drafting the first, interim and final versions. R. MIlne, E.M. Bunnik and D. Gove provided information for the initial conception of the participant panels and the central panel set up. A.B. Callado, K. Fauria and I. Knezevic provided information on the Barcelona panel set up. S. Gregory, S. Saunders, S. Sparks and C.W. Ritchie provided information on the Edinburgh panel set up. I. Carrie and D. Pennetier provided information on the Toulouse panel set up. C. De Boer provided information on the Amsterdam panel set up. S. Forster provided information on the Oxford panel set up. J. Duffus and J. Rice are participant panel members

who gathered feedback from their respective panels and supported with the development of the participant panel perspective. All authors reviewed the draft manuscripts for edits and reviewed the final manuscript to approve prior to submission.

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Figures

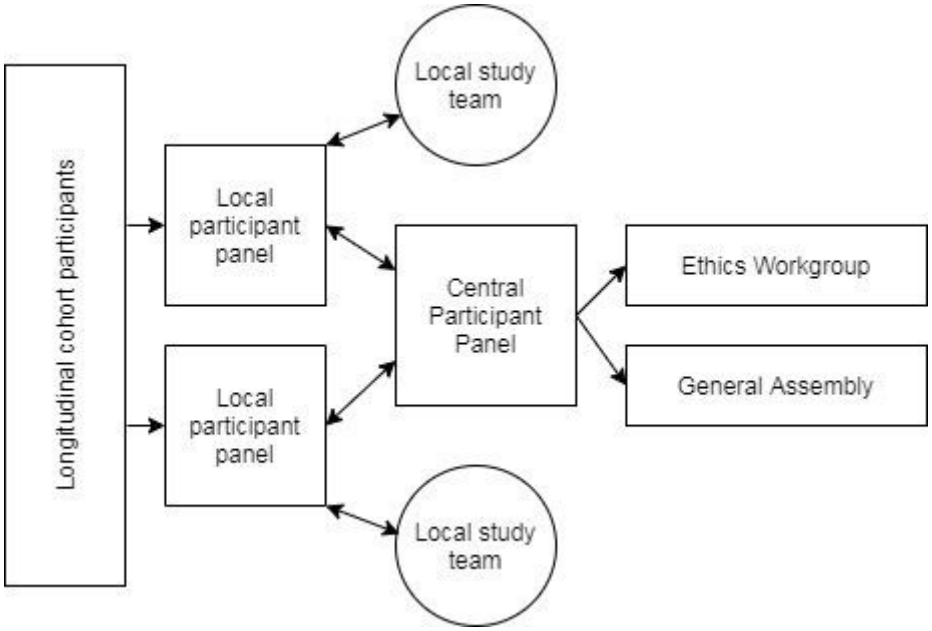

Figure 1

Overview of local and central participant panel set-up within the EPAD LCS study structure

Supplementary Files

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