



831458 – Trials@Home

Center of Excellence – Remote Decentralised Clinical Trials

WP6 – PROMS

D6.14 Recommendations and impact of lived experience in large multi-partner consortium projects

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Document History

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1. Abstract

Research and policy increasingly recognise the value of involving people with lived experience, commonly referred to as Patient and Public Involvement and Engagement (PPIE), as a core component of high-quality, ethical and impactful research. Rooted in civil rights, disability rights and patient advocacy movements, PPIE has been shown to build trust, improve relevance and quality, enhance participant engagement, and strengthen the uptake and dissemination of research outcomes. Major European institutions and funders, including the European Commission, EMA and IHI, have embedded PPIE into research frameworks and funding requirements. However, despite broad policy endorsement, challenges remain around understanding, implementation, capacity, and meaningful engagement, with risks of tokenism where guidance is limited or poorly adapted.

Addressing these gaps, a working group was formed as part of the Trials@Home project to examine PPIE in practice, drawing on the experiences of both researchers and a Patient Expert Panel (PEP) formed at the beginning of the project, to identify enablers, barriers and lessons learned, and to inform more effective, flexible and genuinely collaborative PPIE frameworks.

Trials@Home is a European public–private partnership that advanced decentralised clinical trials by moving traditional site-based activities into participants’ homes using digital technologies and telemedicine. Through a pan-European proof-of-concept trial comparing traditional, hybrid and fully remote models, the project generated evidence-based recommendations to support more patient-centred, efficient and inclusive clinical research across Europe.

This study explored how members of the Trials@Home consortium and the PEP experienced working together, and the impact of PPIE in research. Data were collected in two stages: an online survey followed by semi-structured interviews. The survey, co-designed by a subsection of the consortium and the PEP members, received 56 responses and captured a wide range of roles, countries, and levels of experience.

Survey data were analysed descriptively, and open-text responses and interviews were analysed thematically. Eight participants took part in interviews to explore experiences in more depth. Overall, views on PEP involvement were positive, with most participants seeing clear benefits from including lived experience in research. PEP input was seen as improving proof-of-concept design, relevance, and accessibility.

However, engagement varied across the consortium, and communication and coordination were sometimes unclear or overly complex. Time pressures and workload were common challenges for both researchers and PEP members. Participants suggested earlier involvement, clearer roles, better communication, and adequate support to strengthen meaningful collaboration in future projects.

This report describes the methods and results of this research and presents an infographic to support the practical implementation of meaningful engagement with people with lived experience. The research is described in more detail in a manuscript that will be submitted for publication in a scientific journal.

2. Methods

This study used a mixed methods design, combining quantitative and qualitative approaches to explore experiences and attitudes toward patient and public involvement and engagement (PPIE) among Trials@Home consortium members and Patient Expert Panel (PEP) members.

The study was conducted in two phases: an online survey (appendix 1) with both quantitative and qualitative components, followed by a small number of semi-structured one-to-one interviews (appendix 2) focused on key areas of the consortium.

A dedicated subgroup of consortium members was established to design the survey and interview guide. Participants were recruited from across the Trials@Home consortium, with the survey circulated to all members and open for four weeks; no prior PEP involvement was required.

In total, 56 individuals completed the survey, and eight were subsequently selected for interviews to reflect varying levels of PEP engagement, as well as diversity in age and gender. The survey, co-developed by the consortium and PEP members and administered via SurveyMonkey, included closed- and open-ended questions across four domains: PEP engagement, awareness, value, and impact. Quantitative data were analysed descriptively using Excel, while open-ended responses and interview transcripts were analysed thematically using an inductive, reflexive approach, with manual coding conducted independently by two researchers to strengthen analytical rigour.

3. Results

The survey and interviews included a diverse group of participants across countries, sectors, and roles, with a relatively balanced demographic spread. Many respondents had limited prior experience with projects of this scale, with over half participating in such a large collaboration for the first time. Engagement with the PEP varied widely: while four-fifths of respondents reported at least some interaction, only around half engaged frequently, and nearly one-fifth never interacted at all.

PEP involvement was concentrated within certain work packages, particularly those focused on trial operations and communication, mirroring where people reported the highest levels of contact.

Across interviews, five key themes were identified.

First, perceptions of PEP inclusion were largely positive, with most participants agreeing that the PEP role was clear, though some researchers expressed uncertainty about when and how PEP involvement was appropriate or meaningful. Many described the PEP as essential to embedding lived experience into the research, influencing study design and improving the accessibility of materials, while PEP members affirmed that research without patient insight “would not be fit for purpose.”

Second, communication and coordination were identified as uneven. Although formal structures existed, communication was perceived by more than one third of respondents as unclear or overly bureaucratic. PEP members valued respectful interactions and coordinated support, but lack of direct access to project materials and varied communication approaches created barriers. Both groups emphasised the value of informal interactions over formal training for building trust and mutual understanding.

Third, the benefits of PEP inclusion were widely endorsed. It was highlighted how PEP inputs improved the relevance, feasibility, and clarity of outputs, adding perspectives grounded in lived experience. However, challenges also emerged, including concerns about tokenism, time constraints, unclear processes for consultation, and difficulties integrating PEP contributions within fast-paced research timelines. Both researchers and PEP members noted competing workloads as a major barrier to consistent engagement. Although PEP members were invited to participate widely across the project, it was not always apparent that involvement in all activities was necessary or impactful. This raises questions about the balance between offering broad opportunities and fostering more focused, reciprocal engagement that maximises value for both researchers and PEP members.

Finally, respondents offered recommendations for strengthening future involvement. These included defining roles earlier, improving transparency about how PEP input informs decisions, ensuring adequate budgets and administrative support, and providing fair compensation for PEP expertise. Many stressed moving from consultation toward genuine co-creation, while also ensuring diversity within panels.

4. Infographic/How-To-Guide

Drawing on the findings of this study, an infographic was developed to support the practical implementation of meaningful engagement with people with lived experience. The infographic distils the key results into a structured, step-by-step guide, highlighting core principles, enablers and actions to support effective involvement across the research lifecycle. It is intended to serve as a practical implementation tool for researchers and project teams, complementing the qualitative and quantitative findings presented in this report. The infographic is provided in Appendix 1.

5. Conclusion

This study shows that Patient Expert Panels can offer substantial value to research projects and that their involvement is both welcomed and beneficial to researchers. Although challenges were identified, they were mainly logistical, relating to workload, communication, and access to information, rather than concerns about the concept or usefulness of PEPs. Continued progress will rely on involving PEPs earlier, streamlining engagement processes, providing dedicated resources, and embedding these panels as a core component of high-quality research practice.

Appendix 1 - Infographic/How-To-Guide



International
Diabetes
Federation
Europe

OPTIMISING LIVED EXPERIENCE INCLUSION IN RESEARCH

LEARNINGS FROM THE TRIALS@HOME PROJECT

WHAT IS PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT (PPIE)?

PPIE brings people with lived experience into the research process as active partners rather than passive participants. It can involve shaping research questions, advising on study design, reviewing materials for clarity or helping interpret and share findings. PPIE partners offer insights that **improve relevance, accessibility and cultural sensitivity**, ensuring the work reflects real-world priorities. Effective PPIE is built on respect, transparency, fair compensation and genuine opportunities to influence decisions. In practice, **it helps create research that is more ethical, impactful and aligned with the needs of the communities it seeks to benefit.**

WHY LIVED EXPERIENCE MATTERS IN RESEARCH?

Far from a recent trend, **PPIE is rooted in powerful civil rights and patient advocacy movements** that challenged exclusion and demanded accountability in healthcare. These movements show the risks of research carried out without considering the people it impacts.



**NOTHING
ABOUT US
WITHOUT US**

In the 1990's the Disability Rights Movement's motto, "Nothing About Us Without Us," further affirmed the **rightful place of communities in shaping decisions about their own lives**. Together, these forces established today's expectation that research should be co-created with the people it aims to serve, making it more ethical, relevant and transformative.

WHY PPIE MATTERS

- 
- ✓ **Builds trust, transparency and accountability** between researchers and the communities they work with.
 - ✓ **Ensures research is grounded in real-world priorities**, not just academic or institutional assumptions.
 - ✓ **Improves the quality, clarity and accessibility** of research design, methods and communication across disciplines.
 - ✓ **Enhances relevance, uptake and long-term impact** by aligning research questions with the lived experiences of those affected.
 - ✓ **Strengthens ethical practice and inclusivity**, helping research benefit a broader and more diverse range of people.

Co-creation reflects a commitment to **partnering equally with people who have lived experience**, motivated by ethical responsibility, the need for richer and more meaningful research, and the aim of achieving outcomes that are both inclusive and effective.

CHALLENGES TO MEANINGFUL PPIE



Because researchers approach meaningful involvement in different ways, **practices and experiences can vary widely between projects.**

Both researchers and lived-experience partners may feel **uncertain about their roles and contributions.**

Researchers may have **different expectations of what prior experience people with lived experience should have.** This may lead to a perception that people should have research experience before joining, which can unintentionally exclude valuable perspectives.

Involvement can become **tokenistic** when it lacks genuine influence, undermining trust and missing the potential for deeper, more meaningful collaboration.

Differences in roles and working styles can make it difficult for researchers and people with lived experience to fully collaborate together. Without intentional effort to bridge this gap, communication and trust can suffer.

Additionally, while **PPIE** may be implemented, it **is rarely evaluated**, limiting opportunities to understand what approaches are effective and how involvement can be improved.



A **gap** exists in the development of **guides** that are rooted in both the **experiences and best practices of researchers and people with lived experience.** Our work sought to address this by evaluating the experiences and practices of PPIE in the Trials@Home project.

TRIALS@HOME

Trials@Home was a European public-private partnership focused on transforming clinical research by **shifting trial activities from traditional sites to participants' homes or community settings** through **Decentralised Clinical Trial (DCT) models.** By combining digital tools, telemedicine and innovative data collection, the project aimed to make trials more person-centred, efficient and inclusive.

Its pan-European **proof-of-concept study**, called **RADIAL**, compared conventional, hybrid and fully remote designs, generating evidence and guidance that now inform best practices and future standards for DCTs.



Within Trials@Home, a **Patient Expert Panel (PEP)** was recruited by IDF Europe, and shared their lived experience with the consortium team. The PEP was **integrated across all project work packages.**

Researchers from the Trials@Home consortium undertook a study to gather insights from researchers and lived experience partners. This was done to create **flexible, experience-based recommendations** that support **meaningful, non-tokenistic PPIE.**

WHAT THE STUDY FOUND

→ LIVED-EXPERIENCE INPUT CAN STRENGTHEN RESEARCH QUALITY

PEP members helped make proof-of-concept materials clearer, trial procedures more feasible and decision-making more grounded in real-world experience. Their involvement helped to **reshape assumptions and provide real-world ideas for implementation.**

“It seems pointless to design a trial without patients.” – PEP Member



→ ENGAGEMENT SHOULD BE CONSISTENT, PLANNED AND SUPPORTED

Some teams collaborated with the PEP throughout the project, while others interacted rarely or not at all. This variation highlights that **PPIE cannot rely on individual interest alone**; it must be intentionally built into project structures. At the same time, striking a balance is key; over-involving PEP members without clarity or purpose risks placing unnecessary burden on them.

“I’m not so sure if that was always interesting for the PEP members.”
– Researcher



→ COMMUNICATION PROCESSES MUST BE SIMPLE, TIMELY AND TRANSPARENT

Even with defined procedures, **many researchers described engagement routes as unclear**, overly bureaucratic or too slow for project deadlines. This made it harder to share materials at the right time and limited opportunities for meaningful input.

“Do we still have time to send it to the PEP... now it’s already too late.” – Researcher



→ PRACTICAL BARRIERS, ON BOTH SIDES, MAY LIMIT MEANINGFUL INVOLVEMENT

Researchers and PEP members faced time pressures, competing priorities and limited access to information. These challenges created **risks of tokenism and limited opportunities**, especially when involvement became reactive.

“It is very difficult to plan project activities in combination with my daily work schedule.” – Researcher





RECOMMENDATIONS

Based on the results of our research

CO-DEVELOP BY DESIGN



- Build specific lived experience checkpoints into the project timeline, such as during protocol development, materials review and dissemination planning.
- Assign responsibility for each checkpoint to ensure lived experience input is actively requested and reviewed.
- Establish a clear process for documenting feedback, responding to it, and showing how it has been incorporated into project decisions or outputs.

- Involve lived experience members from the very start of the project, including during proposal development and early planning.
- Integrate lived experience members into project development and strategic decision-making, rather than limiting involvement to one-off consultations.

STRUCTURE & SUPPORT ENGAGEMENT



- Involve lived experience contributors from the project development stage and maintain regular engagement throughout the project.
- Establish communication approaches that are clear, timely and accessible, avoiding unnecessary jargon.
- Create opportunities for relationship-building that support open and informal dialogue alongside formal project processes.



MOVE BEYOND TOKENISM

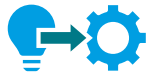
- Plan lived experience involvement as a resourced project activity, with dedicated funding, time and administrative support.
- Ensure lived experience members have timely access to relevant project materials, tools and platforms, and are clearly informed of expected time commitments so they can participate effectively and manage their involvement.

DIVERSITY & REPRESENTATION



FOSTER RELATIONSHIPS & CLEAR COMMUNICATION

- Aim to include lived experience contributors whose backgrounds and experiences reflect the diversity relevant to the research topic.
- Recognise diversity as a core element of research quality, not an optional consideration.
- Work with patient and public organisations to support inclusive and equitable representation.



HOW TO IMPLEMENT

IDEA & PROPOSAL DEVELOPMENT



Hold an early co-design meeting with lived experience members and project partners to define roles, responsibilities and expectations.

Clearly agree on decision-making pathways, including where lived experience input will inform or influence project decisions.



Document roles, expectations and decision-making arrangements in a shared, accessible file that all partners can refer back to throughout the project.



Map the types of lived experience needed for the study based on the research focus, population and context.

Allocate a specific budget line for lived experience activities, including compensation, coordination and administrative support.

Assign a dedicated liaison person responsible for coordinating engagement and acting as a consistent point of contact.

STUDY DESIGN & SETUP



Assign responsibility for each checkpoint to ensure lived experience input is actively requested and reviewed.

Establish a clear process for documenting and responding to feedback, and showing how it is incorporated into project decisions or outputs.



Build specific lived experience checkpoints into the project timeline, such as during protocol development, materials review and dissemination planning.



Schedule meetings well in advance and provide timely access to documents and platforms to allow meaningful preparation and input.



Identify gaps in representation and engage with underrepresented groups through patient or public associations.

Adapt engagement approaches, formats or materials as needed to reduce barriers to participation and support meaningful involvement.

Co-create meeting schedules and timelines with lived experience members to support regular, predictable engagement.

Develop a simple glossary of key research terms to support shared understanding.

PROJECT EXECUTION



Share project materials early enough to allow meaningful input and provide short, plain-language summaries where needed.

Create informal spaces for dialogue, such as short social check-ins before meetings, to support trust and open communication.



Build in regular check-ins to close feedback loops and confirm how input is used.



Schedule meetings well in advance and provide timely access to documents and platforms to allow meaningful preparation and input.

Apply lived experience checkpoints during materials review and delivery adjustments.



Continue targeted engagement if participation gaps emerge.

RESULTS & DISSEMINATION



Request and document lived experience input into interpretation of findings.



Share emerging findings in accessible formats and invite reflection.



Include lived experience checkpoints in dissemination planning and outputs.



Close feedback loops and communicate how contributions shaped outcomes.

Involve lived experience members in shaping future research and proposals.

Reflect on representation achieved and plan improvements for future projects.



The research leading to these results has received support from the EU/EFPIA Innovative Medicines Initiative [2] Joint Undertaking (H2020-JTI-IMI2) Trials@Home grant n° 831458.

www.trialsathome.com

www.idf-europe.org



Appendix 2 – Survey Questions

Trials@Home PEP Engagement Evaluation - Consortium Survey

- Q1. What country are you based in?
- Q2. What type of organisation do you work for ?
- Q3. What is your role in your organisation?
- Q4. Please state your gender:
- Q5. How often have you been involved in large consortia research projects such as Trials@Home? (e.g. HorizonEurope, IMI, etc.) *
- Q6. Which T@H work package/s were you involved in? (select all that apply)
- Q7. How have you engaged with the PEP since the start of the Trials@Home project? (Select all that apply)
- Q8. Approximately how often have you engaged with the PEP since the beginning of the project?
- Q9. The role of the PEP in the T@H project was clear to me
- Q10. The process by which to engage with the PEP for specific activities was clear to me
- Q11. The PEP members were generally well prepared prior to engagement
- Q12. When required, I provided the PEP with all necessary documents and material to support useful engagement prior to the engagement activity
- Q13. Prior training to improve my patient engagement skills would have improved the quality of my engagement with the PEP
- Q14. If you agree with the previous question, what skill(s)/knowledge would have improved your engagement?
- Q15. The PEP members I engaged with were committed to the project
- Q16. The PEP's perspectives and input helped shape the project
- Q17. How would you rate the impact of the PEP on the outcome(s) of the project?
- Q18. Please rate how useful engagement with the PEP was in relation to the following deliverables
- Q19. Please rate how extensive engagement with the PEP was in relation to the following deliverables
- Q20. Engaging with the PEP was a good use of my time and resources
- Q21. My workload did allow me to take full advantage of the PEP
- Q22. Had you had any experience of patient engagement, in any form, prior to the Trials@Home project? (more than one answer possible)
- Q23. Altogether, how many projects of any sort have you been involved in where there was some form of patient engagement (excluding Trials@Home)?
- Q24. Did you ever feel that the inclusion, of people with lived experience in Trials@Home was tokenistic ? (i.e. was made for the purpose of ticking a box, but was not really extensive/valued enough)
- Q25. How likely are you to include, or advocate for the inclusion of, panels of people with lived experience in future projects?*
- Q26. What were the main benefits of having a PEP in the project?
- Q27. What, if any, challenges did you encounter in your engagement with the PEP?
- Q28. Was the engagement with the PEP or any lessons learned different from what you experienced in other projects?
- Q29. Do you have any recommendations for improving the process of involvement and engagement of people with lived experience in research projects?
- Q30. Do you have any final thoughts or suggestions?

Q31. We are also conducting qualitative interviews to deepen our understanding of the PEP engagement in Trials@Home. If you agree to be contacted, please add your e-mail address below:

Appendix 3 – Interview Guide

PEP-Evaluation - Interview Guide

Language Statement – Participant

Researcher Information

Title: Exploring the impact of PEP on the perceptions of consortium members of the Trials@Home consortium

Name of Researchers: _____ Jessica Nastos and Cameron Keighron

Contact Details of Researchers: Jessica.Nastos@idf-europe.or Cameron.Keighron@idf-europe.org

Informed Consent Statement

Thank you for your interest in this study. We would like to invite you to take part in a research study being carried out by IDFE. Before you decide whether you wish to take part or not, you should read the information provided below and, if you wish, discuss it with (family, friends etc.). Take your time and ask questions – do not feel rushed and do not feel under pressure to make a quick decision. You should be clear about the risks and benefits of taking part in this study so that you can make a decision that’s right for you.

What Happens If You Decide Not To Participate?

You do not have to take part in this study. Choosing not to take part will not have any consequences.

Voluntary Participation And The Opportunity To Withdraw Consent

Participation is voluntary and you can withdraw your consent at any time, and without providing a reason. If you withdraw from the research, you have the right to have your data deleted upon request, unless it has already been used in analyses or in publications from the research project. If you wish to withdraw, or if you have questions about the research project, you can contact Jessica Nastos or Cameron Keighron whose details are provided above.

Why Is This Study Being Done?

The Trials@Home project aims to assess the feasibility of moving clinical trials from a hospital to an at home setting. To ensure a patient-centred approach, several people with lived experience of diabetes (people living with diabetes as well as parents) were invited to take part in the project through a patient engagement panel (PEP).

An evaluation of the PEP engagement, especially from the perspective of the consortium members who interacted with the PEP, will not only support the sustainability of this project after its conclusion, but also provide an evidence base for further patient involvement and engagement (PIE) in large-multi-partner consortium (LMPC) projects such as Trials@Home.

The following survey will be the knowledge base or guidelines and advocacy tools for future LMPC projects as well as a research paper.

To deepen our understanding of PIE in a research project such as Trials@Home, we are conducting more focused interviews with key members to get a well-rounded understanding of the benefits, challenges and lessons learned.

Who Is Organising And Funding This Study?

This study is being organized by the International Diabetes Federation of Europe. The Trials@Home project has been funded by the *Innovative Medicines Initiative 2* Joint Undertaking (H2020-JTI-IMI2), under the Horizon 2020 research and innovation program of the EU (grant n° 831458). Additionally, it receives support from the European Federation of Pharmaceutical Industries and Associations (EFPIA).

What Can I Expect If I Agree To Take Part?

If you agree to take part, we will contact you with an invitation to a one-on-one or group interview. The interview will take up to an hour of your time, at an agreed time, date and venue that is convenient to you. Interviews will be recorded using audio recording equipment. The researchers will use these recordings to ensure that there is an accurate record of your views. The audio recording will be used for a written transcript and deleted afterwards.

What Are The Benefits For Me Taking Part?

The aims of this research project include:

- Understanding the impact of PIE in large research consortiums
- Exploring the benefits of PIE in research consortiums
- Exploring the challenges of PIE in research consortiums
- Developing guidelines of engagement for the inclusion of lived experience in research

Your involvement in this interview will help us reach these aims and you have the opportunity to share your thoughts and experiences and contribute to the knowledge base on PIE research. This can also function as an opportunity for you to reflect on your experiences and your views on PIE.

What Are The Risks?

If at any point during the interview you become distressed or otherwise uncomfortable, you may ask for the interview to be paused, and the researcher will offer you a break. The researcher will ask you whether you would like to resume the interview/discussion after the break or to end the interview. The researcher will provide you with information about relevant support services.

Confidentiality

With your consent, the interview will be recorded using AI supported audio recording equipment and transcribed. All information collected during the course of this interview will be related solely to the research questions, will be anonymous and confidential. All information collected will be stored securely on an IDFE Sharepoint site (password and encryption protected) and kept confidential. Anonymised findings from the research interviews and

workshops will be made available at the end of the study. The findings will also be accessible through key publications or seminars. Your anonymity will be protected, and you will not be identified in any findings or publications from the research.

What Do I Need To Know About How My Data Will Be Protected?

Only researchers who are part of the Trials@Home project consortium will have access to the data. No information will be stored on OneDrive that could link your name to the findings. After the research interview is completed, the researcher will delete any information from the email server that could link you to the research.

Incidental Findings – the researcher will not collect any information relating to your personal health or well-being.

Where Can I Get Further Information?

If you would like further information about the research project, please contact

Jessica Nastos: Jessica.Nastos@idf-europe.org

Cameron Keighron: Cameron.Keighron@idf-europe.org

Consortium Section

I. Introduction to the Interview

*Explain the background to the interviews and discuss the proposed outcomes.
Explain how their data will be gathered, used and stored for the duration of the study.*

Explore any questions about the process they may have.

Ask them to sign and date the (online) consent form and reassure them they can withdraw at any point.

II. Understanding the context

- Do you have any prior experience with PIE (Patient involvement and engagement in research)? (Prompt for details)
- What were your thoughts on PIE at the start of the project?
- When did you first learn about PIE?
- Has your opinion changed during the course of the project; if yes, why? If no, why not?
- Is there anything you would change about the PIE setup at the beginning of the project?
- Were there any barriers you felt were present initially for PIE in this project?
Address them if mentioned, how were they overcome? Is there anything that worked well / enabled engagement?
- What, in your view, do you feel is the effect of including people with lived experience at every level of research? Is this important??

III. Research Project and PEP Engagement

- Can you describe the WP(s) you worked on?
- Can you describe the activities in which the PEP was engaged with you?

- How would you describe your general experience with the PEP?
- Did you interact with the PEP in-person or online?
- How would you characterise the engagement you had with the PEP?
- How did you feel about the engagement? *Expand on the answer.*
- What are your thoughts about how the PEP was integrated in the project?
Elaborate.
- *Did you understand the process of contacting the PEP? If applicable: How could it have been improved?*
- *Did you know how to include the PEP in your activities?*

IV. Value of PEP Engagement

- What, as you understand it, was the value of the PEP in the project?
- What would have contributed to improving the value of the engagement?
(Prompt for more time, more people)
- What were the main barriers to effective engagement?
- What should be done differently in the future?
- What are the things you feel are essential for PEP engagement in projects like this?
- What advice would you give researchers in a future project about involving a PEP?

Is there anything you would like to share that we haven't talked about yet?

Thank them for their time, explain next steps.

—

Same intro section as above

PEP Section

I. Introduction to the Interview

Explain the background to the interviews and discuss the proposed outcomes. Explain how the data will be gathered, used and stored for the duration of the study.

Explore any questions about the process they may have.

Ask them to sign and date the (online) consent form and reassure them they can withdraw at any point.

- Have you worked on any other similar projects or in research as someone with lived experience? Give chance to elaborate.
- What were your thoughts on taking part in Trials@Home at the start of the project?
- Have these opinions changed during the course of the research project?
- Is there anything you would change about the PIE set up at the beginning of the project?
- Were there any initial barriers you felt were present for PIE in this project? Were there any facilitators for engagement?
- Do you think that including people with lived experience at every level of a research project is important overall? And why?

II. Engagement in Work Packages

- What work packages, if any, did you work on or contribute to throughout this project?
- What additional tasks or events, outside of work packages, did you contribute to during the project?
- Overall, what was your experience in those tasks? *Probe for benefits and challenges, identify which activities they considered their participation is/was key - Why?*
- How did you find working with other consortium members?
- Was the reading material understandable on its own or did you have to do additional research to understand the content?
- Did you engage in person, online or both?
- Did you feel any differences in the interactions in person vs online?
- Did you feel welcome in various meetings? *What made you feel welcome?*
- Did you feel listened to in various meetings? *What made you feel heard?*
- Did you feel able to contribute to the project without being prompted?
- Did you ever find any part of your engagement challenging?
- How did you feel about being part of the PEP?
- Did you feel part of the Trials@Home project? Would something have made you feel stronger about being part of the project?

III. Value of PEP Engagement

- How would you characterise the value of the PEP engagement to the project?
Elaborate.
- What would make it more/less valuable?
- Do you think the PEP helped shape project outcomes?
- In your opinion, what could encourage consortium partners to include people with lived experience more in research projects like Trials@Home?
- What were the key facilitators/barriers to engagement?
- What should be kept/could be added or done differently to ensure effective and meaningful engagement?
- Did you feel the voice of T1D PEP members and T2D were heard equally?
- How do you feel about your contribution to the project?
- If you could tell members of a future PEP panel anything, what would be your advice for them? Did you feel that the communication you received about the PEP and its role was accessible and/or understandable?

Would you like to add anything else?

Thank them for their time, explain next steps.

Next Steps

Next Steps

The recording of this interview will be transcribed and, where necessary, anonymised. The audio recording will then be deleted. The transcript will then be further evaluated by researchers of the Trials@Home consortium and results will inform the scientific publication and guidelines mentioned above.