

COMMENT

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A commentary on ophthalmic patients co-designing a new tool to better understand their hospital letters

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Abstract

Patient and Public Involvement and Engagement (PPIE) is recognised by the National Institute for Health and Care Research in the UK as crucial for high-quality outcomes with numerous benefits for patients. Patient and public contributors can provide both personal knowledge and lived experiences which complement the perspectives of the team. In this commentary, we share our experiences of facilitating a project, Explain.Health, to co-design a digital platform to help patients better understand their hospital letters by explaining medical terms. We describe the stages in the formation of the PPIE group, the stages in the co-design process and the next steps for the project. We reflect on PPIE of the project, including lessons learned for future PPIE work in building new digital platforms. Important considerations for this PPIE work include: (1) ensuring each public contributor feels listened to and understands how their involvement contributes to the design of the platform, (2) providing regular and clear communication and (3) offering adequate support to public contributors (appropriate formatting of resources for visually impaired contributors, incentives, assistance to use the meeting platform) to establish an inclusive and considerate approach. These findings can inform future PPIE plans for stakeholders involved in similar projects.

Plain English summary

This commentary describes the activities and lessons learned from the work of a Patient and Public Involvement and Engagement (PPIE) group working with project team members to design a tool to help patients better understand their hospital letters by explaining the medical and complex terms in the letter. The PPIE group was made up of members of the public who were either diagnosed with an eye condition or cared for someone who did. Their aim was to support the team's work in building the platform while continuously receiving feedback from the PPIE group to make sure it fits their needs. The public contributors were involved in all stages of building the platform, with a great focus on clear communication between them and the team so they felt listened to and understood how their feedback contributed to the project. This report provides an opportunity to reflect on the PPIE work with a new digital platform and to reflect on involvement and inclusion. We hope that future co-design projects can learn from our experience and optimise PPIE.

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Keywords Ophthalmology, Public involvement, Co-design, Hospital letters

Background

Patient and Public Involvement and Engagement (PPIE) is defined by the National Institute for Health and Care Research (NIHR) as “research carried out ‘with’ or ‘by’ members of the public who are actively involved in the research projects” [1].

The NIHR have published a ‘Values and Principles’ framework of evidence-based practice for PPIE and the publication of UK Standards for Public Involvement [2], which has been designed to help address recurring challenges to enable more inclusive and collaborative working while involving public members in the project, as well as supporting best practice.

Co-design is one approach of obtaining multiple perspectives and sharing views, reflection, and learning, throughout a project [3, 4]. This approach is rooted in participatory research, enabling people to become involved in the shaping, designing, and testing of new healthcare interventions that are patient-centred [5]. Co-design seems to be the most effective method when the importance of the relational aspect of involvement is emphasised [6] and consists of close collaboration between PPIE contributors and the project team [7–9]. This happens through sharing perspectives and skills; respecting and valuing everyone’s knowledge; and reciprocating, building and sustaining relationships [4, 10]. Involving members of the public improves both the quality and relevance of the project. They provide both personal knowledge and experiences of using a service or living with a health condition, which complements that of the team [11, 12]. Our PPIE work was guided by the NIHR’s six standards for Public Involvement [2] namely: inclusive opportunities, working together, supporting and learning, governance, communications and impact.

The Explain.Health project aimed to build a digital platform for patients in ophthalmology, to explain the medical terms used in their hospital letters. The idea for this platform originated from patients’ feedback to clinicians and the Patient Advice and Liaison Service (PALS) who often received requests for clarifications on their letters. Patients’ feedback revolved around the need to be able to access a user-friendly tool in their own time should they need help understanding the medical terms in the letter.

Potential approaches to delivering this broadly fell into two groups: firstly, integrating Explain.Health directly into electronic patient records to make letters explainable at the point of creation; and secondly, creating a stand-alone tool that could process letters after receipt by the patient. The latter approach was opted to maximise the potential impact of the tool and minimise dependencies on a lengthy integration and restructuring of the hospital

software systems. By supporting letter processing via smartphone photography, scanning, or digital letter upload, the solution is accessible and adaptable. The solution delivers simple language explanations of common clinical vocabulary (including medications, conditions, and procedures) and links users to listed informational resources from trusted organisations.

At the start of our PPIE work, a rudimentary prototype of the platform was available, and the aim of the project was to co-design with a PPIE group the platform until we achieved its final version. The platform needs the user to scan or take a picture of their letter with their device and upload it on Explain.Health, which in turn will process the letter and provide an explanation of what the medical terms mean from reliable sources of information such as the National Health Services in the UK (NHS). A lay summary of the letter using artificial intelligence is also automatically generated. An example of how the letter is processed and the explanations is provided in Appendix 1. Explain.Health can be used on different devices such as smartphones, laptops and tablets.

A feedback questionnaire designed by one of our Biomedical Research Centre advisors at Moorfields Eye Hospital based on the UK Standards for Public Involvement [2] was distributed to all of our PPIE contributors at the end of the project so the team could reflect on their PPIE work. Anonymous quotes from the questionnaire are used throughout the commentary to illustrate our reflections based on their feedback.

According to the Health Research Authority, Public involvement means work is done ‘with’ or ‘by’ the public, not ‘to’, ‘for’ or ‘about’ them [13]. Since the project was to co-design the platform with the PPIE group, it did not involve any data collection from the PPIE and ethical clearance was not required.

Establishing a PPIE group

The first author and Health Psychologist (DS) was the PPIE Lead on this project and established the PPIE group who had experience or cared for a patient receiving treatment and diagnosis at Moorfields Eye Hospital NHS Foundation Trust. Patients were contacted through an advertisement emailed to all patients who signed up for the Research Opportunities at Moorfields (ROAM) mailing list. Advertising through ROAM provided a large pool of potential candidates ($n=120$). Due to the remit of the project, it was decided that the PPIE group should be as diverse as possible with respect to the eye condition they were diagnosed with, age, gender, ethnicity and computer literacy. Hence, each candidate was invited to complete a short screening survey to assess

the aforementioned criteria. A diverse group of eleven contributors were selected for the PPIE group. Ten contributors had no prior experience in PPIE work nor had previously partnered with a project team to co-design digital interventions.

Inducting PPIE contributors

Since most of our members were new to PPIE work, we provided an induction with a 'PPIE Handbook' to explain the project, the timeline, our role, their role and our contact details. To complement this, we held an online meeting to introduce the team and give each PPIE contributor the opportunity to discuss how they would like to be involved and have general discussions to promote the cohesiveness of the group. One contributor commented:

Although I did not meet others face-to-face, there was a friendly, relaxed atmosphere in the meeting, which I think encouraged patients to willingly contribute their thoughts and opinions.

Steps in the co-design process

The co-design process was conducted in three steps. Table 1 provides examples of the PPIE feedback along with the corresponding changes implemented at each step. We favoured an approach that ensured Explain. Health was designed not only 'in collaboration' with the PPIE group but co-designed with them at the centre of the decision-making process. To achieve this, the six standards set by the International Organization for Standardization (ISO) standards for a human-centre design were followed [14]: (1) the design is based upon an explicit understanding of users, tasks and environments; (2) users are involved throughout design and development; (3) the design is driven and refined by user-centred evaluation; (4) the process is iterative; (5) the design addresses the whole user experience; (6) the design team includes multidisciplinary skills and perspectives.

During the first co-design step, eight meetings were held online. The PPIE Lead (DS) chaired the meetings with support from the rest of the team including the principal investigators (NP, PT) and the programmers (TW, IM) and a medical staff (MA). The role of the chair was to facilitate the discussion and make sure that each contributor felt comfortable sharing their thoughts with the group to establish a collective shared learning principle and collaborative ethos. PPIE contributors often engaged directly with the medical staff and programmers during the meetings to discuss the feasibility of their proposed changes. When certain requests were not technically feasible, a mutual agreement was reached through discussion. While programmers were responsible for implementing the technical adjustments, the medical

staff ensured the accuracy and clarity of the medical explanations provided in the letters.

The success of this strategy is apparent in the positive comment by a contributor: *"At all times individuals were given the opportunity to engage and contribute to the project. I felt there was a wide range of feedback from patients, and the project lead was able to maximise group contributions taking account of individuals' skill sets."*

Ahead of each meeting, we shared a meeting agenda and invited members to try the platform highlighting all the changes made following their feedback. During the meeting, PowerPoint slides were used to illustrate the changes made in the format "you said, we did" to trigger co-design discussion and feedback. The PPIE Lead prepared a list of features to seek feedback from the PPIE group. The nature of the feedback evolved around existing features and how they can be improved. Contributors were prompted to provide feedback with open-ended questions from the team such as (e.g. "How easy did you find it to upload the letter? ") and closed questions (e.g. "Do you prefer layout A or layout B? "). Members of the team (TW, IM, NP, PT) and PPIE contributors individually and collectively shared thoughts about what might work in practice, challenged ideas, raised concerns and agreed on the changes to be made. The PPIE contributors were proactive in suggesting new ideas without prompting from the team. For instance, they suggested that maintaining a consistent font style, avoiding italics and bold, would make the platform clearer for visually impaired patients. They also recommended that definitions should not only explain the condition but also include information about available treatments. Based on this feedback, the medical staff collaborated with the programmers to improve the explanations of the medical terms.

The feedback process was iterative: following each meeting, the project team implemented the agreed changes to the platform based on the feedback and reconvened with the contributors to gather their feedback on the new version until the platform was completed. One contributor shared:

I enjoyed the meetings and providing feedback on testing the software separately. It was good to hear others' comments and suggestions whilst adding mine when it felt appropriate.

Regular communication with the group via update emails or a group chat was maintained between the meetings sustaining a good working relationship with the group. Written communications (such as slides and emails) were formatted to be accessible to visually impaired individuals by following the Royal Institute of Blind People guidance [15].

Table 1 Examples of changes made to the platform

	Feedback	Actions taken
Step 1: Online meetings	<p>Provide more context to the terms explained. For instance, when explaining the term ‘cataract’ the platform could quote where the sentence containing the word ‘cataract’ was found in the letter.</p> <p>Improve the readability of the text format for visually impaired people.</p> <p>Suggest links to trusted charities or hospital contacts to signpost users if they need to ask further questions.</p> <p>Categorise the terms explained by theme to navigate more easily through the results page.</p>	<p>Under each term explained, the quote from the letter was added. Eg. <i>“We are showing details on this to you because we found the phrase ‘She has visually significant cataract and would benefit from the surgery’ in your letter.”</i></p> <p>The font was increased and an accessibility tool (UserWay) was added to allow users to amend the font per their needs (eg. size, colour, thickness).</p> <p>Links to <i>NHS Care and Support</i> were added.</p>
Step 2: Online surveys	<p>Ensure that links with further information were provided for all medical terms, abbreviations and medications.</p> <p>Integrate the option to open each link on the same or different tab.</p>	<p>Terms were categorised under four themes where appropriate: “Diagnosis”, “Medication”, “Procedure” and “Other”</p> <p>Links to reputable websites (NHS) were listed on the results page.</p>
Step 3: User-testing exercise	<p>Review the AI summary as it could sometimes be too alarming. For example, it said that glaucoma could ‘cause blindness’ however this was not always mentioned by their doctors at their appointment.</p> <p>Improve uploading time as it was too long.</p> <p>Collate user feedback and have a ‘demo’ video to make users feel confident about using the platform.</p>	<p>Once the user selected “Process my letter”, a suggestion box asked if they preferred to open the results page on the same or different tab.</p> <p>Wording of the AI summary was revised to use more appropriate terms: “Glaucoma can cause blindness” was replaced with “Glaucoma can cause ‘impaired vision’.”</p> <p>Furthermore, users who wanted to ask further questions were signposted to the relevant team with links.</p> <p>Processing time was significantly reduced but might still take up to 30 s, depending on the number of pages. A notice was added to the processing window: “This might take up to 30 seconds.”</p> <p>A demo video will be created explaining how to use the platform.</p>

In the second step, co-design took place with two online surveys (pre and post co-design project) where contributors completed the System Usability Scale survey [16] to provide feedback Likert scale (strongly agree – strongly disagree) on their overall experience on the first prototype and the final version of Explain.Health. The survey enabled the team to measure the usability of the platform. Questions included for instance “I found the system unnecessarily complex” and “I would imagine that most people would learn to use this system very quickly”. The PPIE Lead emailed the link by email and offered to help them complete it if needed. PPIE had 3 weeks to complete the first survey on the prototype and another 3 weeks to complete the second survey on the final version. A written summary of the findings from surveys was prepared by DS on an Excel spreadsheet and emailed to the programmers and medical staff who collaboratively determined the steps needed for implementation.

One contributor appreciated how their input had an impact on the product design:

“All questions, comments and suggestions were taken onboard by the project. Changes made throughout the life span of this project have taken onboard contributions from all parties where these have made a positive contribution to the development and enhancement of the project objectives.”

For the third step, once the final version of the digital platform was ready, user-testing exercises were organised with seven PPIE contributors. User-testing exercises allowed the team to evaluate how users interact with the platform in a real-world situation, which increased the accessibility of the tool and a reduced risk of harm as stated in the ISO standards. Furthermore, providing feedback on a one-to-one basis such as in a user-testing setting can overcome some of the limitations of group feedback such as the restricted time for discussion and the social desirability bias where one may feel shy or uncomfortable sharing opinions different from other members of the group [17]. The exercise took place on a one-to-one basis with DS on MS Team to test and provide feedback regarding the Explain.Health platform while ‘thinking-out-loud’. The ‘thinking-out-loud’ method is often used to gather information in usability testing in product design and development, where contributors are asked to say out loud any thoughts that came to mind as they used the platform and is often used to understand the experience of a new product in a real-life environment [18, 19]. For example, during the ‘thinking-out-loud’ exercise, one patient commented: *“This is good but maybe signposting patients to someone in the NHS if they have questions or need emotional support. Imagine if I use the app and after when I understand my condition*

I’m worried or have questions? I think emotional support is important for those who needs it”. Contact details of Patient Advice and Liaison Service (PALS) at Moorfields was added on the letter explanation page.

From a usability testing context, the observer (DS), took notes of what contributors said and did, without attempting to interpret or influence their actions and words, and especially noting places where they encountered difficulty during the exercise as this would represent real-world interaction. For example, while observing the contributors’ interaction with the platform, a recurring issue was identified as a couple of contributors struggled to locate the ‘Home’ button. This prompted a redesign of the ‘Home’ icon to make it easier to find. The recordings of the user-testing exercises were transcribed with MS Teams and coded thematically using the framework analysis applying the user experience model by Van Waes [20] to identify issues around the usability and perceived usefulness of the platform. Each issue reported was then added to the Excel spreadsheet.

All PPIE contributors were reimbursed for their time for any feedback activity such as attending meetings, completing surveys, and the user-testing exercise as per the NIHR’s compensation rate [1].

Where are we now?

Explain.Health is now in its final version. The team and PPIE contributors determined that the final iteration was reached when no additional suggestions for improvement were provided by our PPIE group. PPIE contributors were an essential part of the Explain.Health project and were fully involved with every stage of the co-design process. Earlier this year, we came to the end of the first funding cycle and the team will endeavour to work on keeping expanding the use of the platform and its sustainability. PPIE contributors will be kept in regular contact with the team and receive monthly updates on our progress with newsletters.

Reflections

Our PPIE contributors agreed that being involved in the Explain.Health project was a positive experience where they felt listened to and their feedback was incorporated throughout the project following an iterative approach. Co-design took place in different formats (e.g. user-testing exercise) in line with the ISO standard so PPIE’s involvement did not simply consist of focus groups and surveys. For most of the contributors, this was their first experience collaborating with a project team based at the hospital, which gave them the opportunity to learn about how academic projects are conducted: *“It has certainly given me an opportunity to participate in such projects and strengthen my knowledge of what hospitals can do for eye patients.”* The contributors also enjoyed

being involved in different aspects of the project (e.g., meetings, surveys, user-testing exercises). While asking patients part of the ROAM mailing list to join a PPI is an expedient route, we recognise that advertising this way may constitute a bias in terms of computer literacy skills. A combination of recruitment through ROAM and outside of the group, for instance, in a clinic, would be preferable in the future. We appreciated how genuinely involved they were in the project while respecting different perspectives and views [2] as captured by the following quote from one of the contributors:

“Personally, I found this project very rewarding. I enjoyed the communication between professionals and non-professionals, along with service users. Everyone was encouraged to offer suggestions and ways forward that could not only benefit us as project participants but also future users of the end product.”

PPIE contributors participated in the co-design of the platform through three key methods: online meetings, pre- and post-surveys, and user-testing exercises. The online meetings proved to be an efficient way to collect substantial feedback within a short timeframe, while discussions among PPIE contributors often sparked additional insights. As the project team also attended these meetings, contributors were able to discuss their feedback and proposed solutions in real-time, facilitating a collaborative approach to problem-solving.

The pre- and post-surveys enabled us to quantify contributors' satisfaction with the platform. However, despite the inclusion of free-text boxes, contributors were potentially constrained in elaborating on their impressions. The user-testing exercise (thinking-out-loud) provided the most extensive and in-depth feedback, as contributors shared their thoughts spontaneously in real-time. While some contributors needed time to adjust to performing two tasks simultaneously, this approach allowed the team to observe the challenges potential users might face in real-life scenarios and made the most significant improvements to the final design.

We have chosen to host all meetings online for the advantage of flexibility of time and saving the need to travel for our visually impaired contributors. Furthermore, the online meetings have been time-efficient and cost-effective on our end. However, we also learned some of the disadvantages of this meeting format. For instance, one of PPIE contributors had limited proficiency in technology. We were very careful that none of our contributors were disadvantaged by the choice of format of online meetings. Hence, a dedicated person from our team helped the contributor to access the video conferencing platform prior to each meeting. Nevertheless, upon

reflection, the option to explain how to use the video conferencing platform with a video would have been another useful way to make sure that the PPIE group felt included and confident in participating in our online meetings. In addition, although PPIE contributors were involved throughout the project, involving them sooner from the grant application stage would have helped us to better design the meetings and the format of their contributions according to their needs.

Conclusions

In this commentary, we describe our experience of collaborating with PPIE to co-design a new digital platform for patients. We followed the NIHR 'Values and Principles' and the ISO framework of evidence-based practice for PPIE and the publication of UK Standards for Public Involvement [2] while conducting this project. We ensured that clear communication, inclusive involvement and a good working relationship were maintained between PPIE group and the team. The PPIE group's contributions played a pivotal role, continuously shaping the design of the platform, making their impact crucial for the completion of the project.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40900-025-00697-0>.

Supplementary Material 1

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Author contributions

NP and PT secured funding from Moorfields Eye Charity. DS was the PPIE Lead and prepared the manuscript. NP, PT, IM, TM, RR, and MA all had responsibilities in facilitating the PPIE meetings. All authors contributed, read, and approved the final and revised manuscript. KV is a public contributor who attended the PPIE meetings and helped to prepare the manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

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Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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