

# A co-designed patient reported experience measure for understanding the patient's and public experience of receiving X-ray results

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## ABSTRACT

**Introduction:** The National Health Service England (NHSE) General Practitioner (GP) contract mandates the implementation of electronic health records (EHR) to improve patient access to medical results. However, access to complex X-ray reports can lead to patient anxiety and misunderstanding, necessitating the requirement for clear communication. This paper reports an example of a good practice approach to research co-design and co-production with Patient and Public Involvement (PPI) experts to develop a Patient Reported Experience Measure (PREM) to explore accessing X-ray reports through EHR. **Method:** A participatory method of a modified e-Delphi (iterative process) utilising PPI focus groups followed by two rounds of reviewing online survey questions to gain consensus. The PREM used Likert scoring, data analysis of each subscale score, and distributions, including face, construct, and content validity, reliability coefficient, principal component and factor analysis, and dimension reduction.

**Results:** The phase one PPI focus groups ( $n = 28$  participants) co-produced  $n = 16$  themes related to the experience of receiving X-ray results. Key themes emphasised the need for patient-friendly language to reduce anxiety and misunderstanding of complex language and terminology. The PREM tool was refined through two rounds of iterative feedback. The phase two survey included  $n = 57$  questions, while the phase three survey pared down questions to  $n = 27$ .

**Conclusion:** It is critical to involve patients in the co-design and co-production of PREM tools to ensure they appropriately capture patient and public lived experiences. Implementing clear, patient-friendly communication within EHR X-ray reports could reduce anxiety and empower patients' decision-making. **Implications for practice:** National testing of the PREM involving a large sample of diverse participant demographics is recommended. Future PREM findings will assist in recommending and developing strategies to improve EHR communication of X-ray report wording, structure, and content.

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## Introduction

From October 2023, the National Health Service England (NHSE) GP contract<sup>1</sup> required all GPs to improve the patient experience by providing equitable access to online electronic health records (EHR). This initiative aimed to empower patients to better understand test results and aid decision-making in their treatment and management plans.<sup>2</sup> This important step will assist patients<sup>3</sup> who often, in face-to-face clinical consultations, only recall half of what was communicated,<sup>4</sup> and often fail to understand the complex information communicated by doctors.<sup>5</sup>

The potential to access EHR X-ray reports (the written interpretation of the images produced by projectional radiography) could enhance patient-centred values, experiences and reduce delays in accessing results.<sup>6</sup> However, the impenetrable language, format, and style of an X-ray report may alienate patients. Engaging in patient and public involvement (PPI) is essential to understanding the lay language and formats that might mitigate anxiety and misunderstanding and to inform inclusive and accessible EHR formats.<sup>7</sup>

Reporting projectional radiography images is often portrayed in research under themes of upskilling the workforce, service evaluation or auditing.<sup>8</sup> These themes support NHSE<sup>9</sup> funding of reporting radiographers as part of the skills mix initiative<sup>10</sup> to address the shortfall of consultant radiologists in the NHSE,<sup>11,12</sup> aligned to support earlier diagnosis,<sup>13,14</sup> which are integral to the

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NHSE Diagnostics Recovery and Renewal plan<sup>15</sup> and the We Are The NHS: People Plan.<sup>16</sup> The NHSE aims for at least 50 %<sup>15,17,18</sup> of X-ray reports to be completed by reporting radiographers to reduce delays in the patient pathway that impact treatment and management decision-making by clinicians. However, the impact on the patient's understanding of the radiology (X-ray) examination results, reassurance of normal findings, reducing patient requests for unnecessary medical treatment referrals, and relieving patient stress and anxiety is often overlooked. Understanding test results is essential for patients to return to a normal quality of life.

Many published radiology studies aim to improve the layout of X-ray reports for patients, focusing on structure, language and categorising lesion size and tissue invasion in abbreviated terms.<sup>19</sup> Research has focused on radiologists<sup>20–24</sup> (the reporter) and general practitioners (GP)<sup>25–28</sup> perspectives, or artificial Intelligence (AI)<sup>29,30</sup> to automate reporting, but the patient's views are often overlooked.

The radiology (X-ray) report traditionally communicates diagnoses and recommendations to clinicians,<sup>2</sup> rather than patients,<sup>31</sup> who may have a limited understanding of medical jargon and abbreviations, complex polysyllabic technical terms, and unfamiliar vocabulary.<sup>26</sup> There is currently no best practice guide for disseminating reports to clinicians or patients for radiographers' unlike radiologists,<sup>22,23</sup> so it would be beneficial to have guidance for both professions on inclusive language for EHR X-ray reports.

Active and inclusive collaboration with PPI groups (unlike patients as research study participants<sup>32–35</sup>) has been underrepresented in published radiography studies. While therapeutic radiography studies often focus on research design and materials,<sup>36</sup> patient values,<sup>37,38</sup> or compassion.<sup>39</sup> To date, there has not been research published involving PPI co-design and consensus building of a research tool to assess patient experiences for improving NHS radiology service delivery of X-ray reports. Patient Reported Experience Measures (PREM) are a common outcome measure tool used to gain patient feedback (variables of interest) on experiences<sup>40,41</sup> throughout their healthcare pathway to identify areas for service improvement.

To address the knowledge gap, it is crucial to explore the patient's perspective in this exchange of information between the reporter (consultant radiologist or reporting radiographer) and the patient. The focus should be on how the X-ray results are communicated (inclusive language, format, terminology), and what patients understand from the X-ray report findings. With this information, recommendations can be formulated to improve patient-facing services (EHR) and experiences. This paper aims to share a good practice example of research co-design with PPI groups for radiographers to adopt in future research planning and outcome measurement tool development.

## Method

The PPI co-design and co-production of the PREM data collection tool aimed to identify key determinants related to PPI experiences receiving X-ray report information, with the aim to facilitate and validate survey questions and subscales on the various multidimensional factors and elements involved. Using a participatory method, utilising PPI focus groups followed by two iterative rounds of online surveys (a modified e-Delphi<sup>42</sup> approach) to gain consensus and pare down topics and sub-topics to construct the final PREM tool.

## Ethics

The NHSE Health Research Authority (HRA) defines this project as service evaluation<sup>43</sup> aimed at improving quality through

co-design. The focus is on creating a PREM from the perspective of those receiving the service, without reference to a standard and involving no care interventions. The co-design is aligned with the NHSE HRA<sup>43</sup> standards and does not require NHS Research ethics committee review,<sup>43</sup> but follows good practice ethical guidance from Canterbury Christ Church University's research department and the local Research Design Service (National Institute of Health and Care Research (NIHR), UK Standards for Public Involvement<sup>44</sup> and Good Clinical Practice guidelines.<sup>45,46</sup> The NIHR states, "Ethical approval is not needed where people are involved in planning or advising on research, for example, as a member of an advisory group or in developing a questionnaire".<sup>44</sup> The Applied Research Collaboration Kent, Surrey and Sussex<sup>47,48</sup> advise "formal ethical approval is not required for PPI activities as public contributors are actively involved in decision making around research. Ethical review is not required as participants are informing the research, not providing research data".<sup>49</sup> Within this co-design activity, the PPI with people of lived experience<sup>50</sup> (authentic engagement over tokenistic involvement<sup>51</sup>) was defined as working 'with' members of the public to co-produce<sup>52</sup> the PREM as opposed to 'to, about, or for' them.<sup>53</sup> This supports principles of sharing power, including all perspectives, respecting autonomy, valuing working together, and reciprocity.<sup>52,54</sup>

## Sampling of the PPI group

Two adult PPI expert groups were recruited: one from the Expert by Experience/Service User and Carers group from Canterbury Christ Church University, the other through Medway NHS Foundation Trust 'Research Friends' initiative of the Research and Innovation department. Both groups met separately and agreed to engage in the focus groups and online surveys to co-design the PREM tool, and publication of the process.

## Phases of PREM development

The first phase of the co-design (February–March 2024) involved 1-hour focus group discussions led by prompting questions to start debates exploring the experiences and expectations of receiving information. Topics included who provided the report, the medium used (verbal, written, digital), comprehension (inclusive language, clarity, structure, medical or layperson terms, conclusive or vague, empowering decision making), and potential improvements (findings, terminology, medical jargon, explanations). Reflecting on access to images, if provided, were they understood or posed more questions, with the opportunity to add confidential or anonymous written comments in a thought pot. Sessions included anonymous audio recordings for transcript inductive thematic analysis, coded<sup>55,56</sup> by both researchers independently until reaching an agreement. No personal<sup>57</sup> or special category data,<sup>58</sup> including names, demographics, healthcare institutes, clinical staff referrers or diagnosis/health conditions, were discussed or recorded. The readability of the PREM questions was assessed using the Flesch Reading Ease score (0 = hard to 100 = easy) and the Flesch-Kincaid Grade Level test to ensure it met secondary school reading levels.

The second (April 2024) and third (May 2024) phases involved rounds of the PREM online survey using the e-Delphi method via Microsoft Forms (Microsoft Corporation; version 2024) to gain PPI consensus on the content and themes. The PREM tool was distributed with an information form to explain the next phase. The each review of the PREM included consent questions, which were required to be completed before answering the PREM questions.

Data analysis of responses for consensus

The PPI experts evaluated the prototype PREM using a 5-point Likert scale (low to high importance) of each question to allow statistical analysis with SPSS Statistics (IBM Corporation; version 29.0.0.0; 2020) to pare down the questions between e-Delphi method rounds (phases two and three). Analysis of the PPI expert ratings and distributions<sup>59</sup> used descriptive statistics (means, medians, mode, standard deviations (SD) and visually with stacked bar charts. Face validity assessed style, format and consistency (Kappa Inter-rater agreement<sup>60</sup>). Construct validity (Convergent and Divergent) assessed variation, error, influences, or relationships using Pearson Chi-square.<sup>61</sup> Content validity assessed the significance of themes using the Lawshe Content Validity Ratio,<sup>62</sup> with reliability coefficient measurement using Cronbach Alpha coefficient<sup>63</sup> consistency related to previous PREM results.

Cronbach's Alpha provides an overall reliability coefficient for a set of variables (questions) but cannot assess against underlying personal qualities. Therefore, a principal components analysis (PCA) was conducted. For dimension reduction (of variables), a Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy test<sup>64,65</sup> was applied in SPSS for the strength of the partial correlation (how the factors explain each other) between the variables for factor analysis, with Bartlett's Test of Sphericity (BTS)<sup>66</sup> using a correlation (identity) matrix to assess if the variables were unrelated. The KMO and BTS tests<sup>67</sup> evaluate all available data for substantial correlation. Variable collinearity, indicating how strongly a single variable correlates (or can be removed from the PREM next round), used SPSS Kaiser's Criterion<sup>67</sup> (Eigenvalue >1), a Scree plot Test<sup>79,81</sup> and the Varimax method to retain items with a factor loading above 0.4.<sup>68</sup>

However, the Likert scale format has limitations in that the answer options may influence responses,<sup>63</sup> necessitating sufficient variance in subscale questions, including repeat questions. Negatively worded questions were included to reduce confirmation bias and demonstrated psychometric properties similar to regular Likert items. Free-text responses were evaluated for any idiosyncratic aspects of the patient experience<sup>61</sup> that might have been missed in phase 1, using inductive thematic analysis to code for patterns and themes<sup>69</sup> by both researchers independently until agreement was reached.

Results

Phase one PPI focus groups comprised  $n = 28$  experts split into two groups from Kent and Medway regions. The demographic profile for the region is similar to the English national average for age, gender, household size, household composition, household deprivation, ethnic makeup, national identity, religion, health, disability, economic activity status, and socio-economic classifications.<sup>70,71</sup>

Phase one theme co-production

The focus groups gathered opinions on  $n = 16$  themes (Table 1) related to the experience of receiving X-ray reports, the language, terminology, format, understanding, recommendations and supplementary details on improving future clinical services. Comments from the PPI expert groups concerning positive and negative aspects of receiving information, the format, language, style and what could be improved were thematically analysed by both researchers independently for consensus of all themes (none were omitted) that formed the basis used to structure the phase two PREM survey.

**Table 1**  
Phase one themes, with the number of occurrences in the focus groups, displayed in brackets.

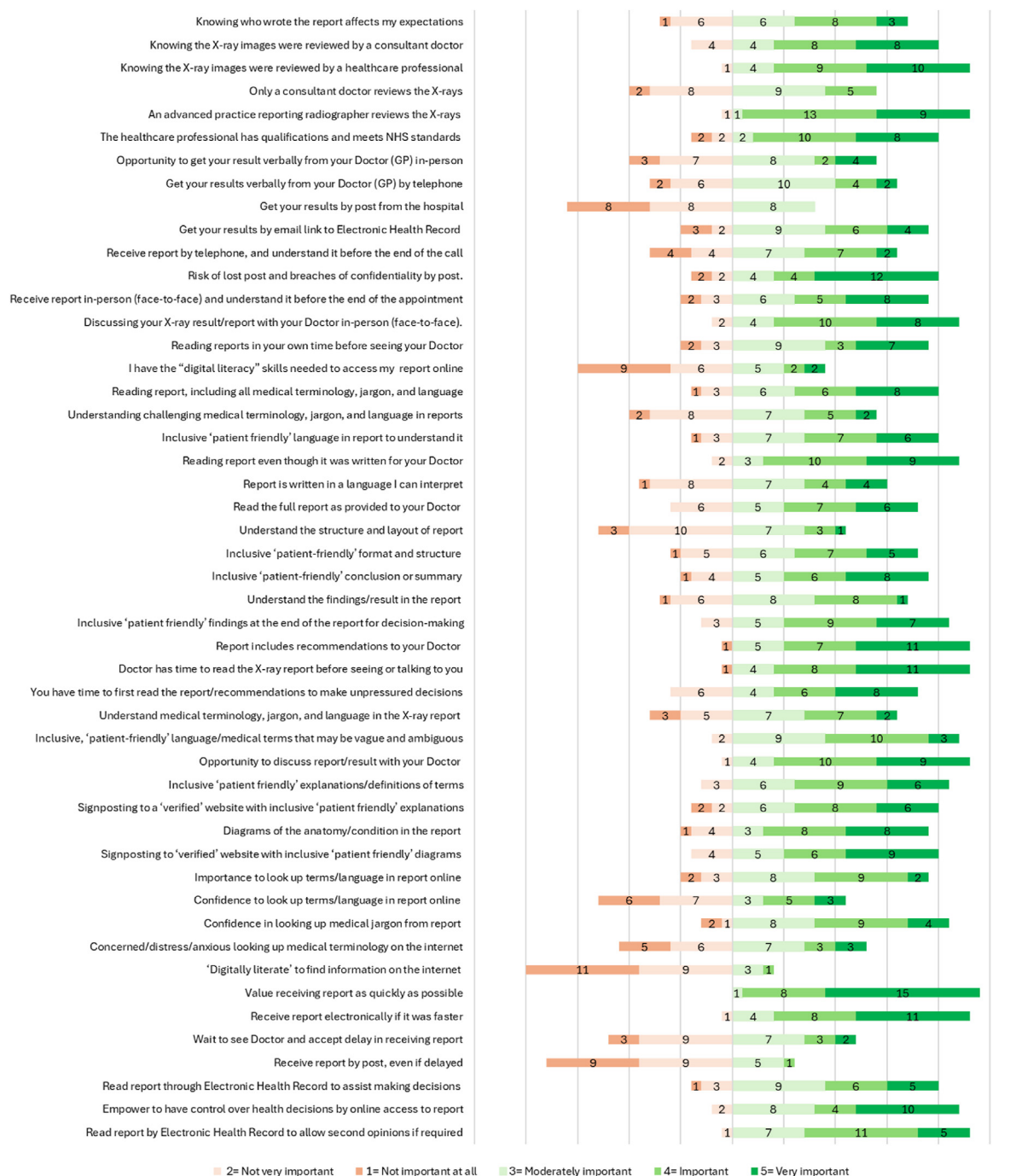
1	Interpretation of medical jargon (5)/terminology (9)/language (16) in reports
2	Information to assist decision making (15)/empowerment (8) for the patient
3	Allowing second opinions (1)
4	Cause of anxiety (2)/emotions (3)/tenterhooks (1)
5	Working (4) with not for patients/partnerships (1)
6	Patient friendly (2)/inclusive (4) language (16)
7	Role competency (1) of reporters
8	Accessibility (1) of the report electronically (8)
9	Signposting (4) to diagrams (3)/pictures (6)/images (7) of anatomy mentioned
10	Providing images (7) of X-rays
11	Signposting to verified (5) online (4) information (37)
12	Report to doctor (22)/clinician (8)
13	Supplementary (2) purpose to patient
14	Uncertainties (2)/misinformation (1) misinterpretation (1)
15	Face-to-face (10)/telephone (3)/email (1) feedback/electronic health records(1)
16	Allow time to reflect (4) before face-to-face discussions/questions (20)

Phase two PREM co-design

The phase two iteration of the co-produced PREM received feedback from  $n = 24/28$  PPI expert panel members. The PREM contained  $n = 57$  questions, covering the  $n = 16$  themes from phase 1 (Table 1), of which  $n = 49$  were Likert questions, and  $n = 8$  were free-text responses to capture any reasoning or justification of answers; these did not require individual responses in the PPI feedback but consideration of relevance within the survey layout. The phase two PREM (Fig. 1) was divided into three sections: the first addressed questions on the experience of receiving the report and which (group of) healthcare professionals wrote the report. The second section focused on the report's language, format, terminology, and recommendations. The final section questions reflected on improving the service. The Flesch Reading Ease score for the phase two PREM was 49.4; the Flesch-Kincaid Grade Level had an average reading level of 11.9.

The phase two PREM format questions were assessed for agreement between the PPI ratings of each subscale (Fig. 1) to allow the paring down. Of  $n = 57$  questions,  $n = 27$  scored median ratings of 4 or above, while the distribution demonstrated  $n = 31/57$  questions a positive skewness, with a flat (platykurtic) distribution, displaying a large similarity in scoring. Correlation analysis indicated a strong construct validity (Pearson's Chi-Square 0.72–96), although reliability was low (Cronbach's Alpha 0.3–6; Supplementary data 1). In total,  $n = 20$  PREM subscale questions were removed, including  $n = 8$  repeat questions (Fig. 2). Questions scoring below 50th and 75th percentiles ( $n = 7$ ; under three on the 'not important' ratings), paired with the Content Validity Ratio (CVR for  $n = 24$  PPI experts with a critical value of 0.417) of low subscale questions, were considered for removal. Dimension reduction using PCA to reduce the number of questions highlighted  $n = 19$  questions which scored higher on Eigenvalues (above one and confirmed on scree plots), most scored over 0.50 for KMO tests and below  $p = 0.05$  for BTS correlation testing.

The phase two ranking by the PPI experts against the importance of accessing the X-ray results online (EHR) were deemed very important, while questions on traditional methods of GP appointments or postal results were least important. PPI ranking of questions on 'patient-friendly' language, terms, and findings were ranked higher, than questions on the structure and format of the report. Additionally, PPI ranking of questions about online resource links (technical or anatomical explanations that would be NHS-



**Figure 1.** Phase 2 e-Delphi stacked bar chart displaying lower scoring e-Delphi Likert questions (orange to red). (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

verified) and accessing the full X-ray report to empower decisions and second opinions were important.

### Phase three PREM co-design

The phase three revised PREM consisted of  $n = 27$  questions ( $n = 7$  were free text responses, which did not require individual responses in the PPI feedback but consideration of relevance within the survey layout; Supplementary data 2). In total,  $n = 20$  low-scoring subscale questions were removed from the phase two PREM based on low CVR and PCA Eigenvalues. The phase three

PREM Flesch Reading Ease score was similar at 46.8; the Flesch-Kincaid Grade Level score was 12.4. The format and questions displayed a positive skewness, with a flat (platykurtic) distribution indicating similarity in scoring by the PPI experts. Construct validity (Pearson's Chi-Square) produced a moderate correlation, while reliability (Cronbach's Alpha) was 0.7 or above for 5 of the 7 sub-themes (Supplementary data 2).

The phase three PREM findings (Fig. 3; Supplementary data 2) echoed the phase two results. PPI experts ranked questions on X-ray results accessed online (EHR) as very important, while traditional methods of receiving results were the least important. The



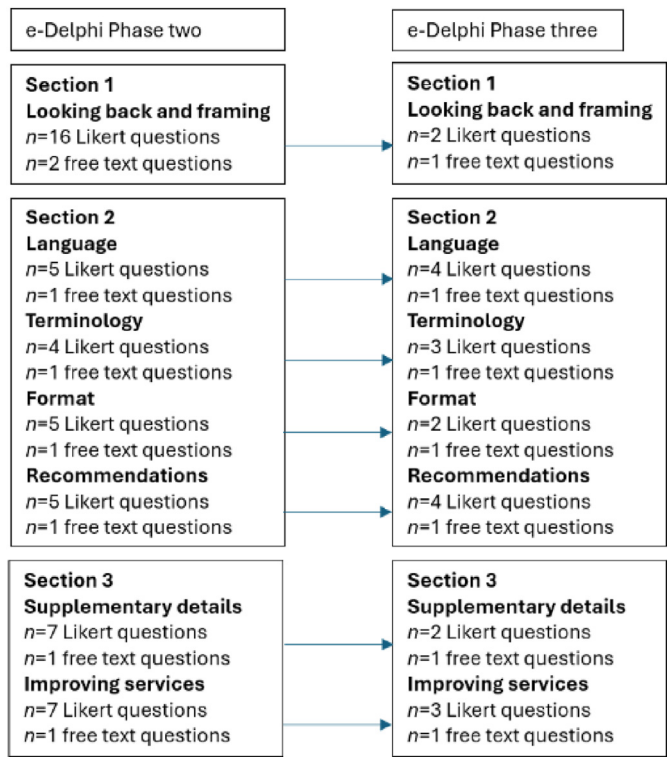


Figure 2. Paring down questions from phase two (n = 57) to phase three (n = 27).

PPI experts ranked questions on ‘patient-friendly’ language, terms, and findings as important but ranked questions on the structure and format of the report, digital literacy of accessing the EHR as least important. Additionally, the PPI experts ranked questions accessing the full X-ray report with recommendations,

empowerment for decision-making, and time to reflect upon the X-ray result information before discussing with GPs or referral to clinicians as important. The consensus from the PPI experts’ ranking indicated no further PREM revisions were necessary (Supplementary data 3).

Discussion

The phase 2 and 3 PREM data (Figs. 1 and 3) underscores the value<sup>50,52,72</sup> of engaging PPI experts early in the research process. Co-design and co-production of data collection tools to ensure the patient’s voice is considered whilst addressing real-world concerns. The e-Delphi method facilitated focus group opportunities for brainstorming invaluable insights and reasoning of key themes and refining questions that reflect patients’ lived experiences. Additionally, the iterative feedback loops of the PREM for consensus of research questions enrich the collaborative approach.

The PPI experts identified key topics from the focus groups, including the importance of clear and timely communication when receiving X-ray report information, which informed the co-production of the PREM. The phase two and three PPI expert ranking of the PREM questions allowed collective agreement of common themes and topics, highlighting the importance of patient-friendly language and terminology to address misunderstanding and anxiety from reading complex medical reports. While there was less consensus on questions on the structure and format of X-ray reports, the PPI experts ranked questions on plain English summaries to assist patients in confirming results and empower decision-making before discussing results with medical professionals as highly important.

A key theme raised by the PPI experts to include in the PREM questions was signposting patients to supplementary materials and resources to understand terminology or anatomy. A study by Oh et al.<sup>2</sup> trialled a glossary of terms to assist patients in reading Magnetic Resonance Imaging (MRI) knee reports through an EHR

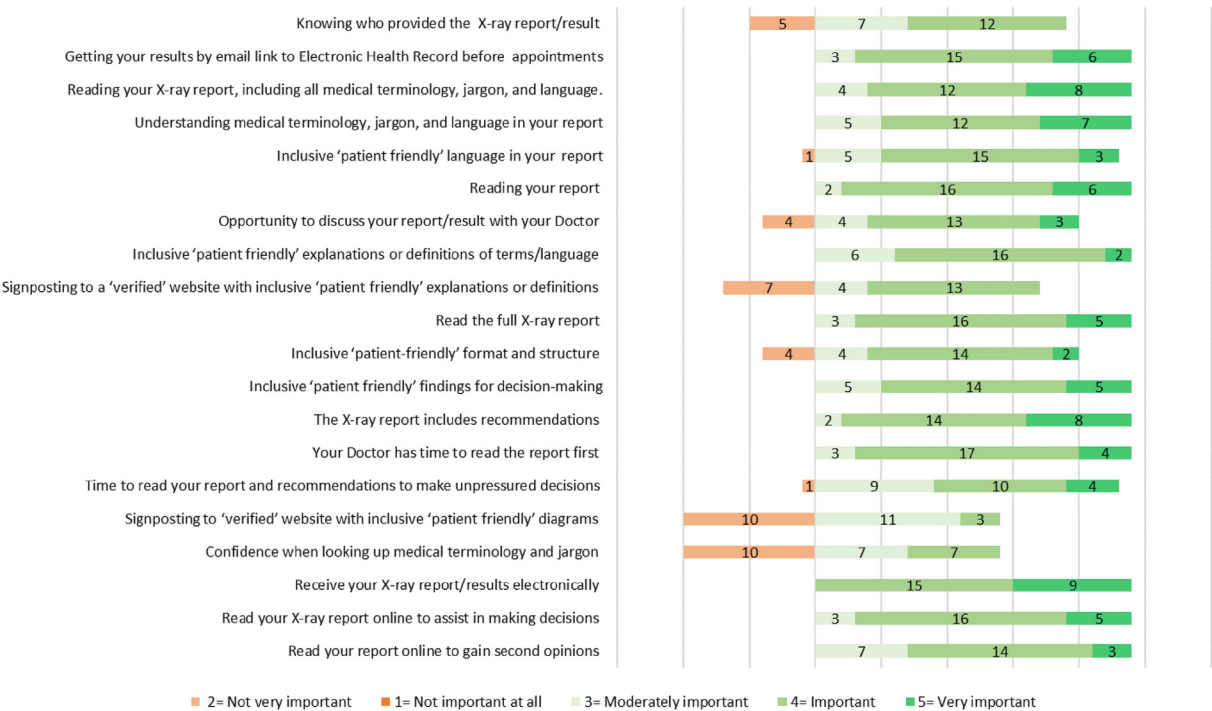


Figure 3. Phase 3 e-Delphi stacked bar chart displaying lower scoring e-Delphi Likert questions (orange to red). (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

system. However, Oh et al.<sup>2</sup> only considered EHR systems from the software coders' perspectives and overlooked the patients' lived experience. While our co-design activities did not raise computer literacy as a concern, this may vary for patients of a more diverse range of ages and educational backgrounds. Perlis et al.<sup>73</sup> explored MRI prostate reports with a small PPI group and radiology staff to improve MRI prostate reports, which echoes our findings regarding themes of laymen's terms, concise language, definitions of terms and summaries.

Kuckelman et al.<sup>74</sup> explored using artificial intelligence (large language model) to produce "layperson" summaries of radiology reports. Although AI is not perfect, technology has the potential to simplify radiology reports into plain English summaries without additional burden on reporters. The PPI experts preferred questions on patient-friendly forms of communication with the potential of digital links to NHSE approved online resources to explain language, terms, lexicons, anatomy, visual aids or diagrams. The PPI experts ranked questions on timely access to X-ray findings as important to evaluate but felt less importance in questions about digital literacy skills.

The recent Darzi report<sup>75</sup> into NHSE services articulates the voice of patients as a vehicle for change and enabling patients to empower and control their care as one of the four drivers identified for the government's upcoming 10-year health plan. The roll-out of EHR allows patients faster access to their medical data comes with some open access concerns. Lee et al.<sup>76</sup> discuss the ethical and legal implications of patient autonomy with access to radiology reports, noting sharing or granting access to personal data to friends and family or worse, social media<sup>77</sup> is fraught with risk and public scrutiny. It is difficult to control even with clear terms and conditions of EHR use by patients. Additionally, there are potential risks of children accessing radiology reports online through EHR portals, leading to privacy concerns of unintentionally sharing sensitive health data.<sup>76,78</sup>

Despite concerns over the transparency of access to EHR, the positive outcomes might lead to standardising X-ray report formats and language for improved patient understanding and reducing poor-quality reports. It may also reduce waiting times in receiving X-ray results.<sup>79</sup> Enhanced transparency of radiology reports may increase emphasis on the quality of reports<sup>80</sup> and professional accountability. Therefore, the involvement of PPI groups in service development initiatives such as EHR access to radiology (X-ray reports) and consideration of the report writing process aligns with patient-centred care<sup>81</sup> approaches to improve the patient experience and ultimately empowerment to better health outcomes.

This paper has limitations; it is not exhaustive of all possible PPI co-design and co-production approaches. The sample size of the PPI experts limits statistical variability, closeness of inter-rater agreement scores, and diversity of the patient population in England. Future large-scale repeatability and reproducibility testing for validity and reliability of the PREM are recommended to reduce homogeneous sample bias and ensure inclusive recruitment targeting underrepresented groups from diverse demographics, socioeconomic status and health conditions.

## Conclusions

Engaging PPI experts to co-design and co-produce a PREM tool has contributed uniquely and innovatively to the evidence base for PPI in radiography research. This paper aimed to foster interest and awareness of participatory research co-design to engage the lived experience of patients. Recommendations for future work will involve validity and reliability testing of the PREM to enhance the language and format of X-ray results to be inclusive of patient-facing EHR information.

## Generative AI use

During the preparation of this work the author(s) did not use any AI TOOL/SERVICE\*, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

## Ethics approval and consent to participate

Ethical approval for this study was not required as not collecting primary data, this is reporting the co-design of a survey tool. Full reporting of this is broken down within the method section.

Written informed consent was obtained for anonymised co-design information to be published in this article.

## Availability of data

Data required for this study may be made available by the author(s) upon reasonable request, although most if not all is in the supplementary data.

## Author contributions

PL/MM Conceptualisation, Methodology, Data analysis, Writing-Original/Journal Draft preparation, Reviewing and Editing.

## Conflicts of interest

The authors declare that they have no competing interests.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.radi.2025.102990>.

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