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Person centered care for primary ovarian insufficiency: developing and testing patient-facing materials co-created with patients

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Objective: We aimed to enhance person-centered care for primary ovarian insufficiency (POI) by co-creating patient-facing educational materials (PEM) with patients. We then evaluated understandability, actionability, and acceptability of the co-created PEM.

Design: Healthcare professionals spanning reproductive endocrinology, nursing, and genetic counseling partnered with patients to co-create PEM using the iterative ‘design thinking’ (human-centered design) process. Validated algorithms ($n = 8$) were employed to determine PEM readability prior to evaluation. Individuals with POI were recruited from patient organizations to complete the online evaluation of PEM. Participants completed health literacy/numeracy instruments, Patient Education Materials Assessment Tool for print materials (PEMAT-P), and provided open-ended qualitative feedback. Scores >80% in PEMAT-P domains were considered ‘high quality’.

Results: Co-creation involved three iterative rounds of development. Readability algorithms indicated PEM were ‘fairly easy to read’ for 11- to 13-year-olds (i.e., 7th grade reading level). Thirty patients completed the online evaluation (36.9 ± 6.4 years-old). All PEMAT-P domains exceeded the ‘high quality’ threshold: content (82%), word choice/style (89%), use of numbers (91%), organization (93%), layout/design (90%), use of visual aids (83%), and actionability (85%). PEMAT-P scores neither differed according to educational attainment ($p = 0.94$) nor health literacy/numeracy ($p = 0.61$). Qualitative feedback informed further PEM refinement prior to widespread dissemination and clinical use.

Conclusion: Engaging patients with POI in co-creation produced PEM that were acceptable, understandable, and actionable. Co-creation is a low-cost engagement process supporting person-centered care. The process described herein may serve as a “roadmap” guiding PEM development for other reproductive conditions.

KEYWORDS

design thinking, infertility, primary ovarian insufficiency, patient education, health related quality of life

Introduction

Idiopathic primary ovarian insufficiency (POI) is a reproductive disorder characterized by declining ovarian function and impaired fertility. Decreased serum estradiol levels manifest as menopausal symptoms, including vasomotor symptoms, disturbed mood and sleep, and altered libido and sexual function (Touraine et al., 2024). Individuals with POI have increased risk for osteoporosis, cardiovascular disease, potentially accelerated neurodegenerative aging, and increased all-cause mortality risk compared to individuals with normal timing of menopause (Stuenkel and Gompel, 2023; Kirubarajan et al., 2024). The median age of menopause onset is 49–51 years and early menopause is considered to be between 40 and 44 years (te Velde and Pearson, 2002). In contrast, people with primary ovarian insufficiency lose ovarian function and typically end menses before age 40 years (Stuenkel and Gompel, 2023). In aggregate, 3.7% of women worldwide are affected by early menopause or POI (Golezar et al., 2019). Importantly, POI is not prevalent, as it only affects approximately 1% of women younger than 40 years of age (Stuenkel and Gompel, 2023). Moreover, roughly 90% of POI cases are idiopathic and without an underlying etiology (Touraine et al., 2024). So while menopause is an expected event for women, POI is less well understood (EHRE, ASRM, CREWHIRL and IMS Guideline Group on POI et al., 2025). As such, despite the continued growth of specialized fertility clinics (The Lancet, 2024), individuals with POI often experience a lengthy process to be diagnosed (‘diagnostic odyssey’). Such experiences contribute to patient dissatisfaction with care (McDonald et al., 2022).

Notably, POI is associated with diminished health-related-quality of life (HR-QoL) stemming from negative clinical interactions during the diagnostic odyssey, isolation and stigma related to the diagnosis, and impaired ego integrity related to menopausal symptoms (McDonald et al., 2022). As such, individuals with POI have a range of unmet health, information, and psychosocial needs and are often dissatisfied with care. There is a need for more person-centered approaches to POI care to help patients better understand the condition, decrease stigma, and support alternative family planning goals (Martin et al., 2017).

Person-centered care is widely acknowledged as a means to improve a variety of health outcomes, including physical and social well-being, patient knowledge, and satisfaction with care (NEJM Catalyst, 2017). Central elements of person-centered care include collaborative decision-making, accessible care, a holistic view of well-being, consideration of family and cultural values, information-sharing, and recognizing patients and families as full partners in the design and implementation of healthcare (NEJM Catalyst, 2017). Patient and public involvement including co-creation is noted as a means to improve the person-centeredness of care (Manafó et al., 2018; Bombard et al., 2018; Leung et al., 2019; McDonald et al., 2023). Co-creation is a collaborative approach that has been used across a variety of healthcare settings and with diverse patient populations to develop person-centered approaches to care that are responsive to patient-identified needs (McDonald et al., 2023). The approach has been used across numerous countries, cultures, languages, and with patients living with conditions ranging from common to rare (McDonald et al., 2023). It can bring together diverse stakeholders, including healthcare professionals and patients, to provide insights into unmet needs, underserved or marginalized populations, and groups with low satisfaction with healthcare. Co-creation considers

patients as equal partners and empowers patients to help improve person-centered healthcare.

To address unmet patient needs and enhance person-centered POI care, we aimed to employ best co-creation practices (McDonald et al., 2023) to develop patient-facing educational materials. We then assessed the acceptability of co-created materials using the Patient Education Materials Assessment Tool for print materials (PEMAT-P) to measure understandability and actionability.

Materials and methods

This study involved two phases. The first phase drew on participatory design methodology. Healthcare professionals partnered with patients in a ‘design thinking’ process to co-create patient-facing educational materials (PEM) on POI. The second phase was a cross-sectional descriptive evaluation study that employed multiple methods. Individuals with POI used an online survey to quantitatively evaluate co-created materials and provide qualitative feedback. The study was reviewed and approved by the Mass General Brigham IRB (#2021P003242) and participants provided opt-in informed consent prior to the initiation of study procedures.

Phase 1: co-creating patient-facing educational materials on POI

The co-creation process was guided by our prior systematic scoping review of the literature that identified six best practices for co-creating patient-facing educational materials (McDonald et al., 2023) (Table 1).

TABLE 1 Overview of co-creation process according to six best practices (McDonald et al., 2023).

Co-creation best practice	Steps taken (evidence)
1. Begin with a literature review	<ul style="list-style-type: none">• Diagnosis & treatment of POI (Weyman et al., 2023)• Systematic review of HR-QoL in POI (McDonald et al., 2022)
2. Utilize a framework to inform the process	<ul style="list-style-type: none">• ‘Design Thinking’ (human-centered design)
3. Involve clinical & patient experts from the beginning	<ul style="list-style-type: none">• Patient engagement throughout the Design Thinking process
4. Engage diverse perspectives & expertise	<ul style="list-style-type: none">• Patients (people with POI)• Nursing• Medicine (reproductive endocrinology)• Genetic counseling• Researcher experienced in participatory methods & co-creation
5. Ensure patients have the final decision	<ul style="list-style-type: none">• Patients gave final approval prior to evaluation
6. Employ validated evaluation tools	<ul style="list-style-type: none">• PEMAT-P (Weiss et al., 2005; Huang et al., 2018)

POI, primary ovarian insufficiency; HR-QoL, health-related quality of life; PEMAT-P, Patient Education Materials Assessment Tool for print material.

First, we synthesized current literature on POI-related HRQoL and care/management (McDonald et al., 2022; Weyman et al., 2023). Second, we adopted ‘design thinking’ as a guiding theoretical framework (Dwyer et al., 2021a). Design thinking, sometimes called human-centered or user-centered design, is a structured, iterative process that includes: (i) empathizing (understanding end-user perspectives to define the problem); (ii) ideating (brainstorming potential solutions); (iii) developing a prototype (refined in an iterative manner with stakeholders); and (iv) testing (evaluating the co-created materials) (Figure 1). Third, we engaged two patients with POI at the outset to partner in the design thinking process. Fourth, we included diverse perspectives from patients, medicine (i.e., an endocrinologist with expertise in POI), nursing, and genetic counseling. Fifth, patients were given the final say in approving the patient-facing materials prior to evaluation. Sixth, we used a validated measure to evaluate the co-created materials. Co-creation participants included two patients and five healthcare professionals – three nurse practitioner students, a reproductive endocrinologist with expertise in POI, and a clinician/researcher experienced with community-based participatory methods who had previously partnered with patients in the co-creation process (Dwyer et al., 2021a,b). One of the patients involved in the process is a certified genetic counselor and provided input both as a patient and from a genetic counseling perspective.

To support comprehension by individuals with limited literacy, patient-facing materials are recommended to be written at the 6th–8th grade reading level. To ensure readability of the co-created materials, written materials were evaluated using eight validated algorithms to assess readability including the Flesch Reading Ease Formula, Gunning Fox Index, Flesch Kincaid Grade Level, Coleman Liau Index, Simple Measure of Gobbledygook index (SMOG), Automated Readability Index, and the Linsear Write Formula (Dwyer et al., 2021a; Badiu et al., 2017). Algorithms indicate an estimated age and grade reading level based on the number of difficult words and sentences.

Phase 2: evaluating co-created materials

We launched the online patient evaluation following final approval from the patients participating in the design thinking process. Participants were provided the patient-facing educational materials (i.e., PDF) to review and then completed an online survey (Qualtrics™). Materials were evaluated using the Patient Education Materials Assessment Tool for print materials (PEMAT-P) developed by the U. S. Department of Health & Human Services Agency for Health Research and Quality (Shoemaker et al., 2014). Individuals are asked to select agree/disagree to 17 items assessing six domain of understandability (content, style, use of numbers, organization, design and use of visual aids) and one actionability domain (i.e., the ability to identify steps to take based on the presented information). Cumulative PEMAT-P scores are expressed as a percentage (total score/possible total X 100). Psychometric evaluation demonstrates strong internal consistency, good reliability, and evidence of construct validity (Shoemaker et al., 2014).

To explore relationships between PEMAT-P scores and potentially confounding variables, we also collected sociodemographic information (age, sex, gender, education, age at diagnosis) and two validated measures of health literacy/numeracy. Subjective health literacy was evaluated using a validated single item previously shown to be comparable to lengthier validated measures (Rapid Estimate of Adult Literacy in Medicine, AUROC = 0.82) (Chew et al., 2004; Wallace et al., 2006). Objective health literacy was measured using the Newest Vital Sign (NVS) (Weiss et al., 2005). Individuals are presented with a nutrition label and asked six items requiring them to identify and interpret text and perform simple computations. Scores categorize individuals as having either adequate, possibly limited, or high likelihood of limited health literacy/numeracy. The NVS demonstrates good internal consistency (literacy: $\alpha = 0.91$, numeracy: $\alpha = 0.78$) and correlates with lengthier validated instruments (Test of Functional Health Literacy in Adults, AUROC = 0.88) (Weiss et al., 2005; Huang et al., 2018).

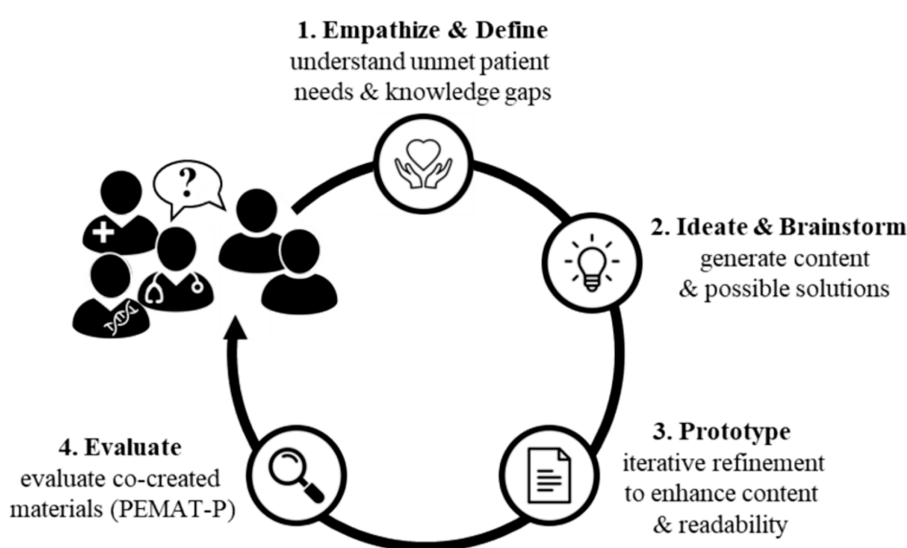


FIGURE 1

Overview of the design thinking process. Design thinking (human-centered design) comprises: (1) empathizing/defining the problem with diverse stakeholders; (2) ideating/brainstorming potential solutions; (3) developing a prototype that is refined in an iterative manner, and (4) evaluating the co-created materials. PEMAT-P: Patient Education Materials Assessment Tool for print materials. Image credits: thenounproject.com.

Participants

A convenience sample was recruited to evaluate the PEM. No formal sample size calculation was performed. English-speaking adults (18 + yrs.) who were diagnosed with POI before age 40 were included in the online evaluation survey. Patients were recruited using social media postings (i.e., Facebook) and in partnership with patient support organizations (i.e., Daisy Network, Conover Foundation, Fertility and Friends). Prior work demonstrates that online approaches and partnerships with patient organizations are effective and reliable for reaching difficult to reach patient populations (Dwyer et al., 2021b).

Analyses

Data are reported using descriptive statistics. Participant characteristics (i.e., those completing the survey vs. not) are compared using Student's *T*-test, Mann–Whitney rank sum test and Chi square as appropriate. PEMAT-P results are descriptively reported and a PEMAT-P score $\geq 80\%$ on a given parameter was deemed to represent high quality (Dwyer et al., 2021a,b). Z-scores were used to compare PEMAT-P scores (expressed as a percentage) between groups according to dichotomized educational attainment (i.e., less than college education vs. college education or greater) and health literacy/numeracy (i.e., adequate vs. possibility/high likelihood of limited health literacy) respectively. A *p*-value < 0.05 was considered statistically significant. A qualitative content analysis was performed on open-ended comments to identify categorical topics of the feedback received (Elo and Kyngäs, 2008).

Results

Co-creation process

The co-creation process (Figure 1) involved robust videoconference discussion with patients to define the aims and scope followed by an initial brainstorming session to respond to identified unmet needs and outline the structure and content of the PEM. The patients envisioned materials that could be given to newly diagnosed patients, describing them as what they wished they had known when they themselves were diagnosed with POI. Patient collaborators provided rich insights highlighting extensive unmet needs and challenges associated with the diagnosis and management of POI.

Decisions relating to patient preferences for the PEM were made by discussion to consensus. The PEM were iteratively refined by patient feedback in three rounds of revision. Patient involvement contributed to a highly collaborative process with creative problem solving. For example, the first draft of the PEM was eight pages in length. Both patients expressed satisfaction with the content of the PEM, but agreed with clinicians/researchers that the ideal handout would be one sheet of paper (i.e., recto-verso with text on the front and back). A patient presented the idea of creating a concise version with a quick response (QR) code linking to a website with more extensive content and resources. This suggestion was unanimously accepted, and further drafts of the materials focused on the abbreviated version. Evaluation of reading level revealed: Flesch Reading Ease Formula (70 = “fairly easy to read”), Gunning Fox Index (9 = “fairly easy to read”), Flesch Kincaid

Grade Level (7th grade), Coleman Liau Index (9th grade), Simple Measure of Gobbledygook index (SMOG: 7th grade), Automated Readability Index (10–11 year-olds / 5th and 6th graders), and the Linsear Write Formula (7th grade). Mean reading level across all 8 readability instruments was the 7th grade (i.e., fairly easy to read for 11–13 year-olds) thus meeting the recommended 6–8th grade reading level. The final PEM was reviewed by the content expert (reproductive endocrinologist) for accuracy, then approved by the patients for online evaluation in a final videoconference discussion.

PEM evaluation

In total, 65 patients with POI consented to take the online survey and 30/65 (46%) completed the full evaluation of the PEM. Participants completing the survey were similar to “non-completers” in terms of age, age at diagnosis, racial/ethnic identity, educational attainment and health literacy/numeracy (Table 2). Overall, participants were White, with 8/30 (27%) identifying as Black or indigenous people of color. They were also well-educated, with 6/30 (20%) having achieved less than a college degree (Table 2). The majority of participants (25/30, 83%) exhibited adequate objective health literacy and numeracy as assessed by the Newest Vital Sign.

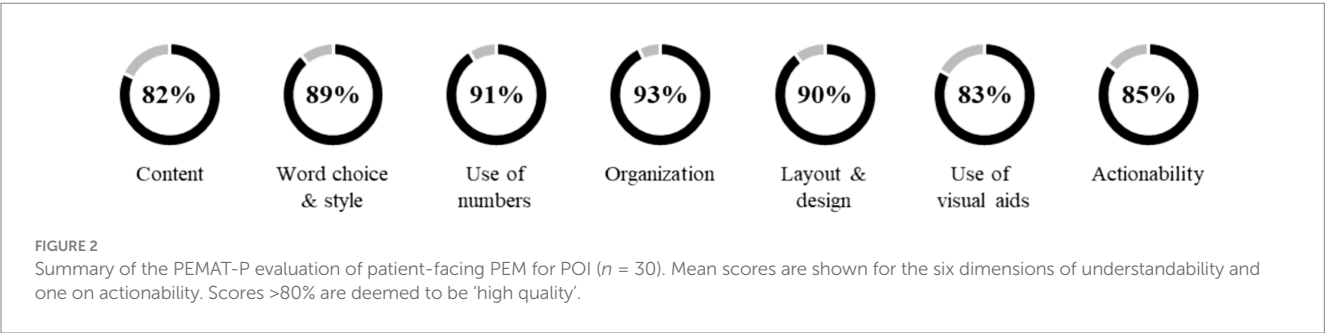
Participants approval ratings for all understandability domains and the actionability domain exceeded the 80% threshold indicating ‘high quality’ materials (Figure 2). Understandability scores ranged between 82 and 93% across the six domains while actionability received an 85% approval among participants. While all domains scored greater than 80%, four individual items had a mean score below the 80% threshold (i.e., 76–79%). Individual items focused on use and usefulness of visual aids, need for more imagery and less text, and focus of the content. The PEMAT-P findings informed further post-evaluation revision to finalize the PEM (Supplementary materials) before widespread dissemination and use with clinical patients. No significant differences were observed in PEMAT-P responses dichotomized according to educational attainment (i.e., less than college education vs. college education or greater, $p = 0.94$) or health literacy (i.e., adequate vs. possibility/high likelihood of limited health literacy, $p = 0.61$).

Qualitative feedback

Ten participants (33%) provided open-ended feedback at the completion of the evaluation. Most prevalent themes related to positive expressions of appreciation ($n = 5$) and a desire for more detailed information ($n = 5$). Specifically, respondents desired more information on causes (beyond idiopathic POI), fertility, specialists, and talking points with providers. Two comments expressed desire for more pictures/graphics. One participant was a user experience design specialist who provided specific and detailed design comments for improving the document. Three critical comments were noted. One participant felt the NVS was distracting and deterred individuals from completing the evaluation. One participant could not get the QR code to work and another participant expressed frustration that the language was “dumbed down for a 6-year-old audience” which made the material seem vague. The qualitative comments were used to make additional refinements to the PEM prior to broader dissemination and use.

TABLE 2 Participant characteristics.

Participant characteristic	Completed survey (n = 30)	All respondents (n = 65)
Age – yrs. (mean ± SD)	36.9 ± 6.4	36.6 ± 6.0
Age at diagnosis	30.0 ± 7.4	30.1 ± 7.3
Race/ethnicity		
White	27 (90%)	57 (78%)
Hispanic/Latino	4 (13%)	4 (5%)
American Indian/Alaskan Native	2 (7%)	3 (4%)
Black/African American	1 (3%)	2 (3%)
Asian/Asian American	0	1 (1%)
other/multiracial	1 (3%)	3 (4%)
Education		
Advanced/postgraduate degree	13 (43%)	27 (37%)
Bachelor’s degree	11 (37%)	20 (27%)
Some college/university	3 (10%)	11 (15%)
Associate’s/technical degree	2 (7%)	4 (5%)
High school/vocational school	1 (3%)	3 (4%)
Objective health literacy/numeracy (NVS)		
Adequate	25 (83%)	45 (69%)
Possibility of limited	4 (13%)	7 (11%)
High likelihood (>50%) of limited	1 (3%)	3 (5%)
No response	0	10 (15%)
Subjective health literacy		
Adequate	29 (97%)	54 (83%)
Low	1 (3%)	7 (11%)
No response	0	4 (6%)



Discussion

We reported on the process and evaluation of co-creating PEM for POI with patients. Employing co-creation best practices (McDonald et al., 2023), partnering with patients, and using the design thinking process produced acceptable, understandable, and actionable patient-facing PEM. Existing literature demonstrates the considerable variety in the populations and conditions who have employed the co-creation process (McDonald et al., 2023) supporting generalizability of the approach.

A robust body of literature underscores that distress is common among individuals struggling with infertility as well as those undergoing fertility treatment (McDonald et al., 2022; Greil,

1997; Van den Broeck et al., 2010). Individuals with POI face unmet health, information, and psychosocial needs that contribute to suboptimal outcomes and poor satisfaction with care (McDonald et al., 2022; Bogart et al., 2022). At a healthcare systems level, there is an urgent need to improve health outcomes, reduce costs, and enhance patient satisfaction. One way to reach these objectives is through a renewed focus on person-centered care (NEJM Catalyst, 2017). Engaging with patients and communities is important for identifying unmet needs and patient priorities to inform more person-centered approaches. Co-creation utilizing ‘best practices’ is a means to enhance person-centered care and develop solutions that are responsive to

patient-identified priorities. The example of POI presented herein shows that co-creation is a viable, innovative, and low-cost way for healthcare organizations to respond to patient priorities and enhance person-centered care, thereby contributing to improved patient satisfaction and potentially enhanced health outcomes. Co-creation has been effectively employed other patient populations with reproductive disorders (Dwyer et al., 2021a,b). The evidence-based ‘best practices’ and the co-creation example detailed in this article, can serve as a roadmap for healthcare organizations in future quality improvement projects.

A relative strength of the study is the close adherence to co-creation best practices (McDonald et al., 2023). There are several limitations to this study. In terms of co-creation, we involved two patients throughout the process. However, it is unclear if the process could have been enhanced with additional patient collaborators to enhance the diversity of perspectives, opinions, and lived experiences. We also recognize one of the participants played a dual role, providing two perspectives (patient and genetic counselor) in the challenges in communicating risk that may be different from a lay individual with POI's experience. Comprehensive care for POI includes a multidisciplinary approach, and the perspectives of specialists including psychologists or fertility counselors could further diversify and enhance the co-creation process. In terms of the evaluation, the number of participants who completed the survey was limited ($n = 30$), yet the sample size is similar to other reports evaluating PEM (McDonald et al., 2023). As such, results should be considered as pilot study findings. Additionally, the respondents were rather homogenous as most participants were White, well-educated, and had adequate health literacy/numeracy—a bias that has been noted with web-based surveys (Jang and Vorderstrasse, 2019; Patten and Perrin, 2015). The mean age of respondents who completed the evaluation survey was 36.9 ± 6.4 years, which is consistent with the PEM's focus on topics proximal to the time of diagnosis before 40 years old. PEMAT-P scores neither differed between participants dichotomized according to educational attainment nor health literacy/numeracy. However, caution is warranted in interpreting this observation as relatively few participants had low educational attainment and/or limited health literacy/numeracy. Regardless, it is plausible that the 7th grade reading level of the materials likely contributed to high understandability and acceptability ratings by the vast majority of participants. It is worthwhile to note that there are a number of tools available to assess print materials. While the PEMAT-P is considered a ‘gold standard’ evaluation tool, other approaches, such as the Baker Able Leaflet Design (BALD) method, have a stronger emphasis on layout and design and could have provided different insights than the PEMAT-P.

Notably, the recent emergence of generative artificial intelligence and large language models may hold promise for surmounting health literacy and numeracy barriers in PEM (Kirchner et al., 2023). However, patient involvement is essential to ensure that PEM responds to patient-identified needs. Following refinement based on the evaluation (i.e., PEMAT-P and qualitative comments), the final PEM revised version (Supplementary materials) will be disseminated in two channels. First, PEM will be disseminated to POI patient support organizations. In parallel, dissemination to healthcare providers and patients alike will occur via the P50 Massachusetts General Hospital – Harvard Center for Reproductive Medicine

website that was co-designed with patients.¹ The QR code on printed materials will link to the website (co-designed with patients) to provide both overview materials and opportunities to dig deeper into topics and access more detailed information (as identified in qualitative comments). Future directions could include exploring emotional responses to the co-created materials. Indeed, POI and infertility are sensitive topics and people with POI often experience significant psychosocial challenges affecting psychological wellbeing and quality of life (McDonald et al., 2022). It is plausible that people with POI may have different needs and priorities depending on the time from initial diagnosis and life stage. Accordingly examining the materials from a life-stage perspective could help inform more developmentally-tailored approaches to care. While this work followed best practices for co-creating patient-facing educational materials (McDonald et al., 2023), further work could examine how design elements of the materials align with established public health messaging and health communication practices (Zhao, 2020).

Conclusion

Engaging patients in the co-creation process produced PEM that were understandable, actionable, and highly acceptable to patients. The process described herein may serve as a “roadmap” guiding PEM development that can be easily adapted for a variety of healthcare conditions and patient populations. Moreover, co-creation is a patient engagement process that is relevant for developing interventions to address healthcare disparities.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Mass General Brigham Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their opt-in electronic informed consent to participate in this study.

Author contributions

EB: Investigation, Visualization, Writing – original draft, Writing – review & editing. IM: Investigation, Visualization, Writing – review & editing. EW: Investigation, Visualization, Writing – review & editing. DJ: Writing – review & editing. JB: Writing – review & editing. CW: Conceptualization, Validation, Writing – review & editing. AD: Conceptualization, Formal analysis, Funding acquisition, Supervision, Visualization, Writing – original draft, Writing – review & editing.

¹ www.myreproductivehealth.org

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Generative AI statement

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Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fcomm.2025.1509966/full#supplementary-material>

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