

Integrating patient voices in digital health research design: The ProPatient Decalogue

Oriol Yuguero^{a,*}, Irene Lapuente^b, Jordi Pacheco^c, Gloria Gálvez^d, Marc de San Pedro^e, Marta Aymerich^a

^a E-RLAB, eHealth Center, Universitat Oberta de Catalunya (UOC), Barcelona, Spain

^b La Mandarina de Newton, Barcelona, Spain

^c Catalonia Patient Advisory Council, Barcelona, Spain

^d Secretary for Health Care and Citizen Participation, Health Ministry, Generalitat de Catalunya, Barcelona, Spain

^e TIC Salut Social Foundation, Generalitat de Catalunya, Barcelona, Spain

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ABSTRACT

Objectives: To integrate patient perspectives into the design of digital health research through a participatory process and to develop a set of guiding principles for inclusive, ethical, and patient-centered digital research.

Methods: The Catalonia Patient Advisory Council (CCPC) coordinated a co-creation process involving 70 individuals representing ten diverse health conditions. Five sessions—four in person and one online—were conducted using design thinking and visual methodologies to facilitate inclusive dialogue. Participants identified needs and preferences related to digital health participation, which were synthesized into the ProPatient Decalogue.

Results: The participatory process revealed key factors that support meaningful patient engagement, including early involvement, trust-building, adaptive formats, and recognition of lived experience. Participants highlighted the importance of clear communication, digital accessibility, and inclusive design. The resulting ProPatient Decalogue provides ten actionable principles to guide future digital health research.

Conclusions: Patient involvement enhances the quality, relevance, and equity of digital health research. The ProPatient approach offers a replicable model for integrating patient voices and fostering participatory research.

Practice implications: Researchers and policymakers can use the ProPatient Decalogue to improve patient engagement across all phases of digital health research. Applying its principles may reduce the digital divide, strengthen user-centered innovation, and increase trust in digital health interventions

1. Introduction

The structured inclusion of citizen perspectives and expectations in health system management fosters more personalized and efficient care, enabling the system to better respond to the real needs of the population based on patient experience [1]. According to the *Framework for Citizen Participation in Health* [2], participation may occur on an individual level—when patients are involved in shared decision-making or lifestyle changes—or on a collective level, where patient experiences inform planning, management, and governance. A key example of this is the *Catalonia Patient Advisory Council (Consell Consultiu de Pacients de Catalunya, CCPC)*.

Digital health, or eHealth, is a growing field that incorporates digital

technologies to enhance access, quality, and efficiency of healthcare services. Aligned with the strategic vision of the Catalan government to create a more equitable healthcare system tailored to the population's needs, it also promotes patient involvement throughout all phases of research, increasing its overall impact [4]. Beyond being recipients of information and treatments, patients become active agents in knowledge generation and are empowered to participate in decisions about their own health.

Ethical research involves engaging relevant social actors in jointly defining strategies for the prevention, diagnosis, and treatment of health conditions. Empowering patients advances the paradigm of proactive, preventive medicine and enhances the quality and relevance of research. According to the framework of Responsible Research and Innovation

* Correspondence to: Avda. Rovira Roure 80, Lleida 25198, Spain.

E-mail address: oyuguero@uoc.edu (O. Yuguero).

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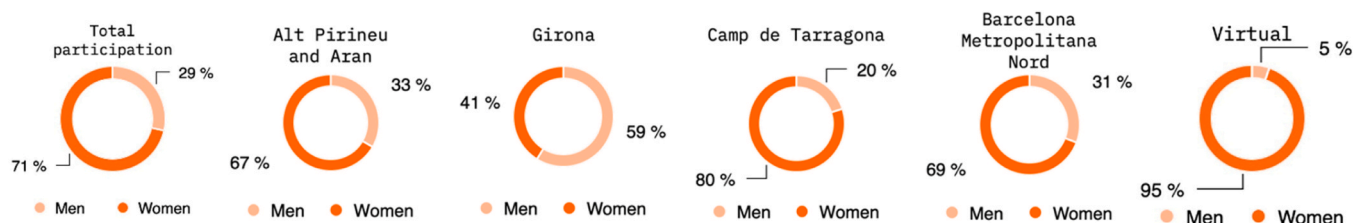


Fig. 1. Overall participants.

(RRI) [3], patients can make meaningful contributions across all research phases, from defining research questions to interpreting and communicating results. This study contributes a replicable, patient-centered methodology to identify digital health priorities, developed within a public health system and co-led by a governmental agency and academic team.

2. Methods

To co-create the *Digital Participation Decalogue ProPacient*, patients affiliated with organizations that are members of the CCPC were invited via email and an online information session. All sessions followed the same structure, with minor adjustments depending on whether they were held in person or virtually. These adjustments included the use of physical materials (templates, post-it notes), videoconferencing platforms, and online surveys.

Design thinking and visual thinking [5] methodologies were employed to empower patients and caregivers in an egalitarian, participatory environment. Constructive dialogue in a setting of collaboration and trust [6] required facilitation by professionals with sufficient subject-matter expertise and familiarity with the sociocultural context of the involved groups, as well as strong communication and group management skills.

All participants were informed of the participatory process and provided their consent to take part. Furthermore, they were aware that they could withdraw from the process at any time.

The Co-Creation process was structured into six phases: Context; Stakeholders; Logistics; Needs and preferences collection and Prioritization.

The deliberative process was structured into five participatory sessions (four in-person and one online) held in diverse territorial settings across Catalonia to ensure equity and accessibility.

The main objective of each session was to elicit participants' lived experiences, needs, and expectations regarding digital health. Sessions were designed to foster inclusion and mutual understanding among patients with diverse conditions and backgrounds.

Each session followed a common structure:

- A welcome by the Department of Health highlighting the purpose of co-creation.
- A 5W-based introductory activity to explore personal connections with health technologies (e.g., familiarity, trust, usability).
- Collective ideation: small-group discussions where participants identified challenges and generated proposals to improve digital health tools, considering specific needs related to different health conditions (e.g., mental health, physical disability, chronic disease, gender-specific and paediatric contexts).
- A final prioritization process, in which each group reached consensus on key user profiles, content, functionalities, and accessibility aspects that should inform future research and design.

This approach facilitated a participant-led agenda, ensuring that the voices of people with diverse health experiences shaped the direction of the project. The collective ideation and prioritization phases were instrumental in identifying actionable themes, informing not only

research design but also future digital health policy proposals. All stages are technically described in the supplementary file 1.

3. Results

The co-creation sessions generated a series of patient-driven recommendations organized by health condition and cross-cutting priorities. A total of 70 individuals participated, ranging in age from 16 to 85 years old, and were broadly representative of the ten health conditions identified by the CCPC. Of the participants, 50 (71 %) were women and 20 (29 %) were men. The online session enabled the participation of individuals from all ten Catalan health regions, thereby enhancing the representativeness of the process beyond the four in-person sessions. Fig. 1 presents the distribution of participants by session and health region.

More than half of the participants were engaging in a participatory process for the first time, and many expressed concern about the digital divide—an issue previously highlighted by the researchers leading the project [7]. Although the digital divide is often associated with older adults, it can affect anyone who has difficulty using technology, including individuals with limitations in reading, writing, or screen manipulation, which are common in various health conditions.

The ideas and comments shared by participants helped identify key considerations for designing a participatory process involving patients in digital health (eHealth) research. All contributions were compiled into a summary report that served as the foundation for developing the *ProPacient Decalogue*, which sets out the main guidelines to follow (Table 1). The Decalogue includes recommendations for all phases of the research process—from design through to evaluation (Fig. 2).

4. Discussion

Participants across diverse profiles emphasized the need for hybrid models, human support, and personalization in digital tools—highlighting gaps not only in access but also in usability and trust. This eHealth research model embraces a holistic view of health and care, combining clinical knowledge with lived patient experience. It is grounded in a collaborative, co-responsible relationship between professionals and patients, aiming to foster personalized care and improve prevention and disease management outcomes. Defining the research topic with precision is essential to ensure the right questions are asked—questions that truly reflect patient needs.

The process should begin by listening: through interviews with patients, expert patients, and patient organizations, researchers gain valuable insight into perspectives, expectations, and priorities. Involving participants from the outset—particularly in framing the research challenge—helps build trust and ownership, resulting in a more respectful and engaged experience. In digital health, where technology plays a central role, offering training during the early stages is vital. This promotes digital literacy, motivation, and equity in participation.

The design of co-creation processes should be inclusive and carefully structured. It must consider the complexity of patients' lives and be tailored to ensure commitment and accessibility. Partnering with patient organizations is recommended, as they play a key role in outreach and often engage individuals already reflecting on their care experiences.

Table 1
The Decalogue (aligned with the ProPatient acronym).

Principle	Explanation
Personalized and human-centered	Research must be guided by humanism, dignity, and respect. Human treatment is a priority. Models should be hybrid—technological advances must complement human support. Digital tools should explore new approaches, such as preventive and proactive health, co-led by patients and health professionals. Participation must be free and voluntary. The participatory process should be bidirectional, person-centered, and based on listening, empathy, and trust in accordance with the Patient Experience Framework, the Citizen Participation in Health Framework, and the Charter of Rights and Duties in Health. Applications must be accessible and aimed at overcoming the digital divide. Research projects must be ethical, gender-sensitive, open, and contribute to scientific literacy and self-governance.
Responsible and integrated in public digital programs	eHealth research must follow the values of the European Commission's Responsible Research and Innovation (RRI) framework and align with the mobile health app quality policy. The TIC Salut Social Foundation offers a Health App Certification Service and a Good Practice Guide for developing digital assets for citizens. This decalogue builds upon that guide.
Open and user-centered	The research and co-creation process should be rooted in citizen science, where active participation at all stages—from design to evaluation—generates new knowledge. Patients should be consulted before project drafting.
Pluridisciplinary and holistic	The process must involve the entire community of health and social professionals, as well as other sectors such as education, nutrition, public institutions, legal, technological, and communication fields.
Accessible and clear	Communication between researchers and participants must be continuous and bidirectional. Information must be complete, verified, and simplified, applying principles of optimization and open access. Equity and quality require preparing participants with understandable documentation on goals and methodologies, sent in advance, and offering training. The first session should be informative; the last should present results.
Considerate of the diversity of stakeholders	Technology reliant on reading/writing and screen use can worsen the digital divide if it excludes people with sensory, motor, cognitive, or dependency conditions. A stakeholder map must reflect these diversities and also include variables such as age, location, culture, and intersectional gender perspective. The communication strategy must ensure inclusion of priority groups. Consider whether to hold joint or separate sessions for patients and professionals. In joint sessions, avoid symbols of hierarchy like white coats.
Inclusive and adapted to participant needs	Sessions should be hybrid (in-person and online) and offer flexible scheduling, ideally no longer than two hours. In-person meetings should take place in familiar healthcare settings, be accessible, well-lit, and comfortable. Ensure privacy and

Table 1 (continued)

Principle	Explanation
Environments for sharing individual knowledge and building collective understanding	confidentiality, allow companions, and create space for socialization and well-being. Consider allergies, intolerances, and religious practices. Compensation may be needed to avoid participation bias due to financial barriers. Sessions must be held while the project is still open, so results can inform app design. Researchers must be present. Facilitators must ensure neutrality, structured dialogue, and integrity. Participants should feel free and comfortable to share. Methodologies must encourage interaction and cooperation, potentially forming learning communities. Attendance certificates should be available on request. Contributions should be recognized as knowledge assets for future digital health co-creation.
Needs-based and impact-oriented	Participant recommendations should be reflected in innovative applications and service improvements. Feedback must be provided on how contributions were used—including explanations when not adopted. Co-created digital tools should be inclusive, personalized, clear in language, intuitive to navigate, and accessible across devices. They must positively impact daily life and improve coordination between professionals and institutions. Generated knowledge should be published as manuals, protocols, guides, or recommendations.
Transformative with continuous improvement	Evaluation should include participant diversity, deliberation quality, satisfaction levels, and impact on the final project. Once implemented, the tool's real-world impact should be assessed and iteratively improved through user feedback.



Fig. 2. Development of proposals for collective discussion.

Methods and formats should be adjusted to individual needs—whether technological, physical, or social. Accessibility must be prioritized, and potential barriers (such as transport or costs) addressed. While financial compensation is not always expected, acknowledging contributions and covering necessary expenses is important.

Co-creation sessions should be welcoming and time-limited (ideally under two hours), with breaks and refreshments that respect participants' health conditions. The goal is to create a comfortable environment that encourages open dialogue, creativity, and shared learning. Researchers must approach these sessions with empathy, humility, and genuine respect for the experiences being shared.

Participant recruitment requires a diverse and strategic approach.

Patient organizations proved essential for outreach, given their established role in fostering dialogue and advocacy. Participants expressed deep motivation to improve the lives of others and contribute to a better, more inclusive healthcare system.

Crucially, participants wished to be involved throughout all stages of research—from design to analysis to dissemination. They emphasized the importance of communicating impact not only in scientific terms, but also in how it improves quality of life and care. Clear communication about roles, expectations, and levels of involvement is key to ensuring a satisfying and empowering experience.

Ultimately, this model illustrates that meaningful patient involvement—when carefully planned and respectfully implemented—enhances both the quality and the relevance of eHealth research. It supports a shift toward more ethical, inclusive, and socially impactful innovation in health.

4.1. Limitations

In this project, participation was limited to members of the CCPC. The main challenge was achieving sufficient diversity in terms of health conditions and life experiences. The perspective of healthcare professionals was only partially represented, since the research team included physicians. Another unresolved issue concerns participant compensation [8].

4.2. Conclusions

Achieving genuinely ethical and inclusive participatory research requires careful attention to several key elements, as outlined in the ProPatient Decalogue. This involves integrating diverse variables—including participants' personal and social characteristics—and valuing the documented experiences of expert patients. When participants' voices are given a central role in both setting objectives and shaping conclusions, research benefits not only in scientific quality but also in democratic legitimacy [9].

While participation is often framed as a civic contribution to the common good, the financial burden it may entail can create barriers that exclude those unable to afford it. To ensure meaningful inclusion, successful participatory research must address effective communication, adequate preparation, skilled facilitation, and the appropriate selection of physical or virtual spaces.

4.3. Practice implications

The ProPatient Decalogue offers a successful and replicable model for incorporating patient experience into the design of digital health applications. Through this research framework, we hope to make patient involvement a key component in narrowing the digital divide and empowering citizens to directly contribute to the social and digital determinants of health.

CRedit authorship contribution statement

Aymerich Marta: Writing – review & editing, Validation, Funding acquisition, Formal analysis. **De San Pedro Marc:** Writing – original draft, Visualization, Validation, Conceptualization. **Gloria Gálvez:** Writing – review & editing, Writing – original draft, Visualization, Conceptualization. **Jordi Pacheco:** Writing – review & editing, Writing – original draft, Resources, Project administration, Data curation, Conceptualization. **Yuguero Torres Oriol:** Writing – review & editing, Writing – original draft, Validation, Data curation, Conceptualization. **Irene Lapuente:** Project administration, Methodology, Investigation, Data curation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2025.109180.

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