

Co-creating principles for digital health equity: A participatory human-centred design approach for system-level transformation across Catalonia's health ecosystem

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Abstract

Background: Digital health technologies promise to democratise healthcare access yet often exacerbate existing inequalities when developed through traditional top-down approaches that prioritise technology implementation and exclude end-users from design processes. The COVID-19 pandemic accelerated digital transformation whilst simultaneously exposing how technology can both bridge and widen gaps in healthcare access. This study employed a large-scale participatory human-centred design (PHCD) methodology to co-create principles for equitable digital health transformation across Catalonia's healthcare ecosystem.

Objective: To co-create actionable design principles for equitable digital health transformation through a large-scale participatory human-centred design process involving diverse stakeholders across Catalonia's healthcare ecosystem, with the aim of establishing guidelines for information systems that support a person-centred, integrated, and longitudinal care delivery model.

Methods: We conducted a qualitative PHCD research study involving 265 participants representing diverse stakeholder groups: citizens and informal caregivers (n=106), healthcare professionals (n=83), healthcare managers and leaders (n=50), and cross-sectional experts in digital health innovation (n=26). Through two sequential rounds of participation between June 2024 and April 2025, we employed design thinking methodologies and co-creation tools in 24 sessions across the Catalan geography (north-east Spain) and 7 topic-specific expert sessions. Data collection utilised innovative visual tools including journey mapping, care model animations, future scenario storyboarding and facilitated ideation techniques. Analysis followed an inductive-deductive approach combining affinity mapping, thematic synthesis, and participant validation to transform stakeholder proposals into actionable design principles.

Results: Participants identified critical barriers to digital health equity including digital literacy gaps for both citizens and professional staff, fragmented information systems, lack of user involvement in system design, and insufficient consideration of vulnerable populations' needs. The co-creation process yielded ten fundamental principles for equitable health information systems: (1) The Person and their Care Circle at the Centre, (2) Health for Everyone, Everywhere, (3) Tools for More Compassionate Care, (4) A Better Professional Experience, (5) An Active Role of the Population, (6) Personalised and Proactive Care, (7) Systematic Use of Data for Decision-making, (8) Integrated Quality Data Working for Health, (9) An Information System that Builds Trust, (10) Collaboration as a Driver of Innovation. These principles emerged from priority challenges that span technological, organisational, and socio-cultural dimensions of digital health transformation.

Conclusions: This study demonstrates how participatory human-centred design can transform digital health development from a technology-driven to a people-driven process. Engaging diverse stakeholders as co-designers rather than mere consultants can uncover nuanced barriers and solutions that traditional approaches typically overlook as well as reveal a motivation for change that is crucial to drive such large-scale systemic transformation processes. This approach provides a comprehensive framework for developing health information systems that are not only technically robust but also genuinely responsive to people's needs, locally relevant, culturally appropriate, and accessible to all.

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Original Manuscript

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Conclusions: This study demonstrates how participatory human-centred design can transform digital health development from a technology-driven to a people-driven process. Engaging diverse stakeholders as co-designers rather than mere consultants can uncover nuanced barriers and solutions that traditional approaches typically overlook as well as reveal a motivation for change that is crucial to drive such large-scale systemic transformation processes. This approach provides a comprehensive framework for developing health information systems that are not only technically robust but also

genuinely responsive to people's needs, locally relevant, culturally appropriate, and accessible to all.

Keywords: digital health equity, human-centred design, participatory design, digital health strategy, health information systems, co-creation, healthcare system transformation, user experience

Introduction

The promise of digital health technologies to transform healthcare delivery has never been more apparent than in the wake of the COVID-19 pandemic. While the rapid adoption of telemedicine, and mobile health applications demonstrated the potential of technology to maintain healthcare access during unprecedented disruption, it simultaneously revealed a troubling paradox: the very innovations designed to improve healthcare access often exacerbated existing inequities.^{1,2} Vulnerable populations, including elderly individuals, those with limited digital literacy, people with disabilities, and communities facing language barriers, frequently found themselves excluded from these digital advances, transforming potential bridges to care into barriers.^{3,4}

This paradox stems from a fundamental flaw in how health technologies are traditionally developed. Despite decades of evidence supporting user-centred approaches, health information systems continue to be designed primarily through top-down processes that prioritise technical requirements and organisational workflows over the needs, contexts, and capabilities of end-users.⁵⁻⁷ Healthcare professionals report spending up to 50% of their time on administrative tasks related to electronic health records (EHRs), reducing time available for direct patient care,⁸ while at the same time patients struggle to navigate increasingly complex digital interfaces that assume levels of digital literacy many do not possess.⁹ These challenges are particularly pronounced for vulnerable populations whose voices are rarely heard in technology design processes.¹⁰

Participatory Human-Centred Design (PHCD) offers a radically different approach to health technology development. Rooted in the principle that those who will use a system should be central to its design, PHCD engages users as partners throughout the development process, from initial problem definition through implementation and evaluation.¹¹⁻¹³ In healthcare contexts, this means involving patients, caregivers, healthcare professionals, and community members not merely as sources of requirements but as co-creators of solutions.¹⁴ This approach is particularly crucial for addressing health equity, as it ensures that the voices of those most at risk of digital exclusion, often the same populations experiencing the greatest health disparities, are not just heard but actively shape the solutions developed.^{15,16} Growing evidence demonstrates that health information systems developed through genuine human-centred, participatory processes achieve higher adoption rates, better user satisfaction, and more equitable outcomes across diverse populations.¹⁷⁻²⁰

The concept of digital health equity extends far beyond mere access to technology. As defined by the World Health Organization (WHO), it encompasses the ability of all individuals to benefit from digital health solutions regardless of their socioeconomic status, geographic location, age, disability, or cultural background.²¹ Achieving this requires a design philosophy that places human needs, capabilities, and contexts at the centre of every decision, understanding not just what users need to accomplish with a system, but how they think, what they value, what challenges they face, and how technology fits within their lived experiences.^{22,23} Operationalising this WHO vision requires addressing what recent collaborative frameworks name digital determinants of health which include the complex, interconnected factors that determine whether the design philosophy of placing human needs at the centre can actually translate into equitable outcomes.^{24,25} Richardson et al.'s adaptation of the National Institute of Minority Health and Health Disparities Research Framework²⁶ suggests that

digital health equity operates across four different levels of influence (individual, interpersonal, community, and societal) each containing specific determinants that must be simultaneously addressed.²⁴

Like many other countries worldwide, the COVID-19 crisis accelerated the digital transformation of healthcare in Catalonia (north-east Spain), with digital consultations increasing from 2% to over 25% of all primary care visits between 2019 and 2021.^{27,28} However, this rapid digitalisation revealed significant disparities across the region's 8 million inhabitants of the region. Rural areas struggled with inadequate internet infrastructure, elderly populations faced overwhelming digital interfaces, immigrant communities encountered language barriers in digital platforms, and healthcare professionals grappled with fragmented systems that hindered rather than helped care coordination.²⁹

Recognising these challenges, the Catalan Department of Health embarked on an ambitious participatory initiative to reimagine health information systems for the future. Rather than starting with predetermined technological solutions, the Department adopted a PHCD approach that would first identify gaps in the current healthcare delivery model and envision how future care should be organised, then determine how health information technologies could support this transformation. Following this approach the idea was to reflect the growing recognition that creating truly equitable health information systems requires fundamentally rethinking not just what we build, but how we build it and who is involved in the building process.³⁰

This paper presents the results of a massive PHCD process conducted across Catalonia, aimed at designing a new health information infrastructure that places humans at the centre. Our research was guided by three interconnected objectives. First, to understand the lived experiences and challenges of diverse stakeholders navigating Catalonia's healthcare. Second, to co-create fundamental principles and guidelines that ensure health information systems are designed with and for all populations, with particular attention to those traditionally excluded from design processes. Third, to develop a replicable design approach that other healthcare systems can adapt, which centres care as a core value in transformation processes, ensuring that not only what is co-created but also how transformation is driven, gives equitable voice to all stakeholders across an ecosystem to own, shape, and drive change.

Methods

Study Design and Conceptual Framework

We conducted a qualitative participatory design research study to develop a collective vision for Catalonia's future healthcare model and actionable design principles for health information systems. Our conceptual framework integrated two complementary methodological approaches. First, human-centred design provided the foundational philosophy of placing people at the centre of the design process, understanding their needs, contexts, and capabilities before proposing solutions.^{31,32} Second, participatory design ensured that diverse stakeholders were not merely consulted but actively involved as co-creators throughout the research process.³³ This combined approach, which for the purpose of this study is called Participatory Human-Centred Design (PHCD), was selected to ensure deep understanding of user needs before solution development, aligning with evidence that premature solutioning is a primary cause of health technology failure.^{11,34}

The study design was structured around two sequential phases of participation, each addressing

distinct but interconnected research objectives. The two-phase approach enabled progressive deepening of understanding, moving from broad exploration of healthcare system experiences to focused co-creation of specific design principles for health information systems.

Throughout the study, we maintained commitment to inclusive participation, ensuring representation of voices traditionally excluded from technology design processes. This included deliberate attention to vulnerable populations and territorial diversity to capture the full spectrum of healthcare experiences across Catalonia's varied geographic and demographic landscape. As well as equitable participation that ensured existing power dynamics and hierarchies were not invisible barriers but actively bridged to bring together the voices of those tasked with leading and managing the system, with those working inside the system and those receiving care in the system.

Project Team Organisation

The study was managed through a collaborative governance structure designed to ensure scientific rigor, meaningful stakeholder engagement, and operational excellence. A project steering board comprised representatives from the Catalan Health Service (JP-J, XM, LLV, and AC). The steering board was responsible for defining project objectives, monitoring progress against milestones, ensuring alignment with regional health transformation goals, making decisions about methodological adaptations based on emerging insights, and engaging with territorial health coordinators to recruit participants.

The operational implementation was carried out by a specialised design practice in multi-stakeholder engagement, human-centred design and participatory design methodologies for enabling health and care system transformation. This team included supervisors (LP, and LH) who provided methodological guidance and oversaw the overall design process to ensure consistency and quality. A dedicated tandem project management support structure coordinated logistics including scheduling meetings across multiple territories, managing participant communications, providing technical support and coordinating the overall design methodology and facilitation team (NV). A team of four trained service-system designers who designed, facilitated and synthesised the sessions: two lead facilitators who guided overall discussion flow and ensured all voices were heard (NV, and AM), and two support facilitator who helped to document information during sessions, assisted participants with materials and provided technical support such as photography or time keeping (AF). Last, a digital health innovation expert provided knowledge and support to the facilitation team, especially in the co-creation of the specific design principles for health information systems. This multi-layered team structure, combining supervisory oversight, project management support, and specialised facilitation, proved essential for managing complex multi-stakeholder dynamics whilst ensuring comprehensive data capture across diverse participant groups and territorial contexts. Facilitators were experts in design thinking methodologies for healthcare contexts, including insight generation, translation to visual design frameworks, inclusive facilitation techniques for mixed stakeholder groups, managing power dynamics to ensure equitable participation, and cultural sensitivity for working with diverse populations.

The steering board and operational team established a coordinated governance structure with weekly alignment sessions to ensure methodological consistency, address implementation challenges, and maintain project objectives throughout the process.

Participants and Recruitment

Participants recruitment and involvement adhered to the four core criteria outlined in the Catalan Department of Health's Framework for Citizen Participation in Health: ensuring adequate methodological definition, maintaining scientific evidence and ethical standards, protecting vulnerable and minority populations, and preserving public health system sustainability.³⁵

Recruitment followed a purposive sampling strategy designed to maximise diversity and ensure representation of voices often excluded from technology design processes.³⁶ We partnered with health coordinators in each of Catalonia's health regions who identified potential participants based on explicit diversity criteria including gender and age distribution, organisation types (public, private, and non-profit sectors), health and social care service levels, and geographic representation across urban, semi-urban, and rural territories. Special attention was paid to recruiting participants from diverse populations including elderly individuals, people with disabilities, immigrant communities, and those who based on their sociodemographic characteristics, were at higher risk of poor digital literacy.

The study targeted four key stakeholder groups, each bringing essential perspectives to the co-creation process: (1) citizens and informal caregivers with diverse healthcare experiences (including expert patients and representatives of patient associations), who provide lived experience of navigating the healthcare system and represent the end-user perspective; (2) health and social care professionals across different disciplines and care settings, who offer frontline insights into system functionality and daily operational challenges; (3) health and social care managers and leaders from various organisational levels, who contribute strategic and organisational perspectives on system implementation and sustainability; and (4) cross-sectional experts in strategy, innovation and technology, who provide technical expertise and broader sectoral knowledge to inform feasible and evidence-based solutions.

Data Collection Procedures

The study spanned from June 2024 to April 2025, beginning with preparation activities conducted from June to September 2024 (Figure 1). Data collection occurred through two sequential rounds of participation and analysis from October 2024 to March 2025, followed by consolidation of results and synthesis conducted from March to April 2025. Each round addressed distinct but interconnected research objectives, building progressively from understanding current healthcare experiences to co-creating specific design principles for future health information systems.

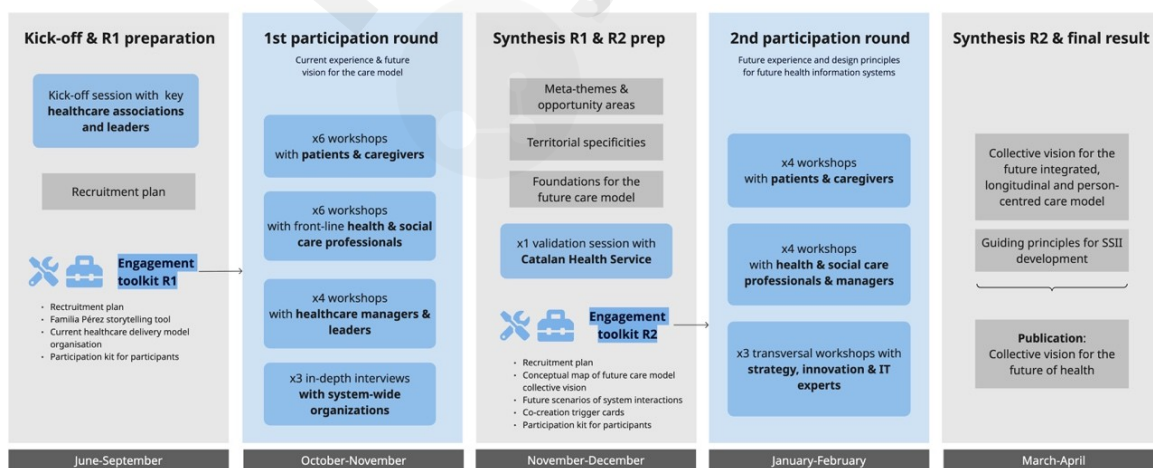


Figure 1.

Project timeline, with activities (in blue) and outputs (in grey).

Round 1, conducted from October to December 2024, focused on collective reflection about the care model. This round aimed to understand current lived experiences with the healthcare system, identify what works well and what needs improvement, and envision desired futures. The central guiding questions included: What do we understand by a person-centred, longitudinal, and integrated care model? What needs does this model address? What must change in the current system to achieve this vision? Data were collected throughout 16 co-creation sessions conducted face-to-face and strategically selected to represent Catalonia's geographic and demographic diversity. Sessions were distributed across urban territories (Badalona, Barcelona, Girona, Lleida, and Tarragona), semi-urban territories (Igualada, Manresa, Sant Cugat, Sant Feliu de Llobregat, Tortosa, and Vic), and rural territories (Amposta, Navàs, Palamós, Tremp, and Sort). Each two-hour session included between 8 and 12 participants and followed a carefully structured format designed to maximise participation and insight generation. Additionally, three online one-hour group interviews with two participants each complemented the sessions across the territory, focusing on macro-level perspectives and strategic insights into system-level challenges and opportunities. The organisations participating in these interviews were: the Agency for Quality and Assessment in Healthcare, the TICSalut and Social Foundation, and the Catalan Integrated Care Agency.

Round 2, conducted between January to March 2025, was devoted to co-creating specific design principles for health information systems. Building on insights from Round 1, this round transformed needs and barriers into actionable principles. The central question guiding this round was: What design principles should guide the future development of health information systems to ensure they serve all citizens equitably? This round started with a validation session with seven experts from the Catalan Health Service, that reviewed Round 1 learnings and bridged into defining focus for Round 2. It employed eight additional face-to-face sessions, maintaining geographic representation while focusing on development of design principles. These sessions were distributed across urban territories (Barcelona), semi-urban territories (Olot, Puigcerdà, Reus, Tàrraga, and Vilanova i la Geltrú), and rural territories (Mora d'Ebre, Solsona). Each session lasted two hours and included between 8-to-12 participants. Three topic-specific expert sessions brought together experts in specific domains identified from Round 1 learnings. Each session took two and a half hours and included six expert participants focusing on particular aspects of digital health transformation, such as strategy, innovation and technology, providing a more macro perspective on the central question.

The locations of the two rounds across the Catalan geography are depicted in Figure 2.

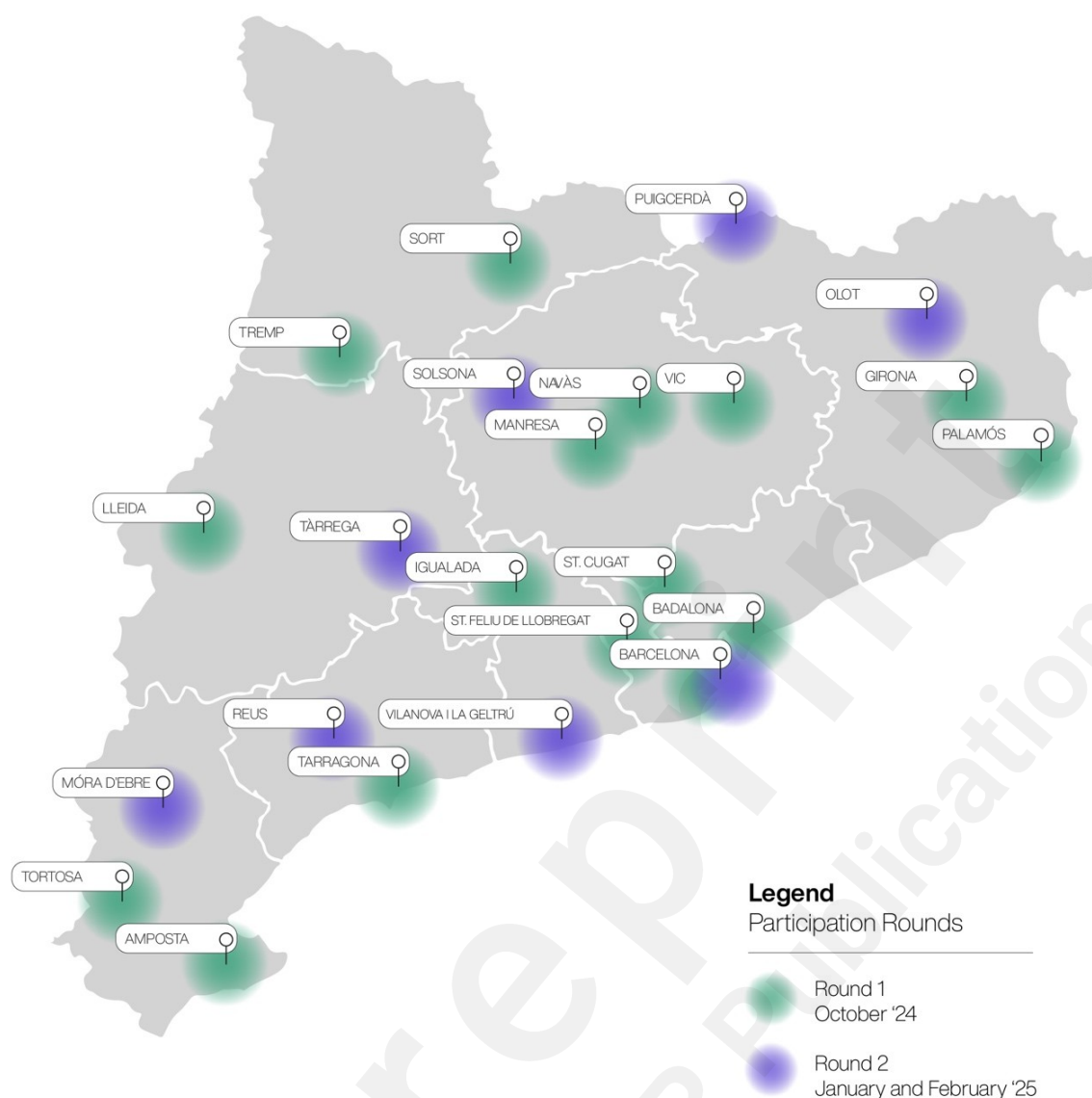


Figure 2. Territorial distribution of the face-to-face participatory sessions across the two rounds.

All sessions followed a consistent structure designed to create safe, inclusive spaces for participation. Sessions began with a 15-minute opening that established context, introduced facilitators, and introduced participation ground rules to ensure safe sharing of diverse perspectives. Core activities lasting 90-105 minutes varied by round and session type but consistently employed visual facilitation tools including journey mapping, experience sharing, ideation techniques, and collaborative prioritisation exercises. Sessions concluded with 10-15 minutes for summarising key insights, outlining next steps, and acknowledging participant contributions.

Sessions utilised innovative visual tools including journey mapping and storytelling to understand current healthcare experiences, scenario building for future visioning, and facilitated ideation techniques for developing design principles. Large-format posters, sticky notes, and collaborative boards enabled participants to contribute ideas both verbally and visually (reflecting individually, sharing collectively). Session logistics were carefully adapted to ensure inclusive participation across diverse contexts. Rural sessions addressed infrastructure challenges through flexible scheduling and accessible locations, while urban sessions accommodated participants' complex schedules while

managing larger group dynamics. All venues provided step-free access, appropriate facilities for participants with disabilities, and professional translation services when needed. Transport support was provided where needed, particularly for participants from vulnerable populations or remote areas.

At the end of each session a satisfaction questionnaire was provided to each participant to assess their participation experience and the perceived value provided by the workshop. The underpinning idea behind this feedback collection was to improve the forthcoming workshop dynamics in case any issue was identified (Supplementary Materials).

Co-creation Tools

Central to the methodology was the development and use of innovative co-creation tools designed to make participation accessible and engaging for all stakeholders. A total of four tools were developed: two storytelling visual narratives were designed for the sessions with citizens, caregivers and professionals. And two system maps for the sessions with healthcare managers and experts. The full set of tools can be found in the Supplementary Materials. The "Pérez Family" journey mapping and storytelling tool consisted of a visual narrative depicting eight healthcare interaction scenarios across the life course, from prenatal care through end-of-life support (Figure 3). This tool was designed with healthcare experts from the Catalan Health Service to ensure scenarios were realistic, relatable, and comprehensive, translating complex processes and multiple care pathways into accessible storylines to trigger exploration and discussion.

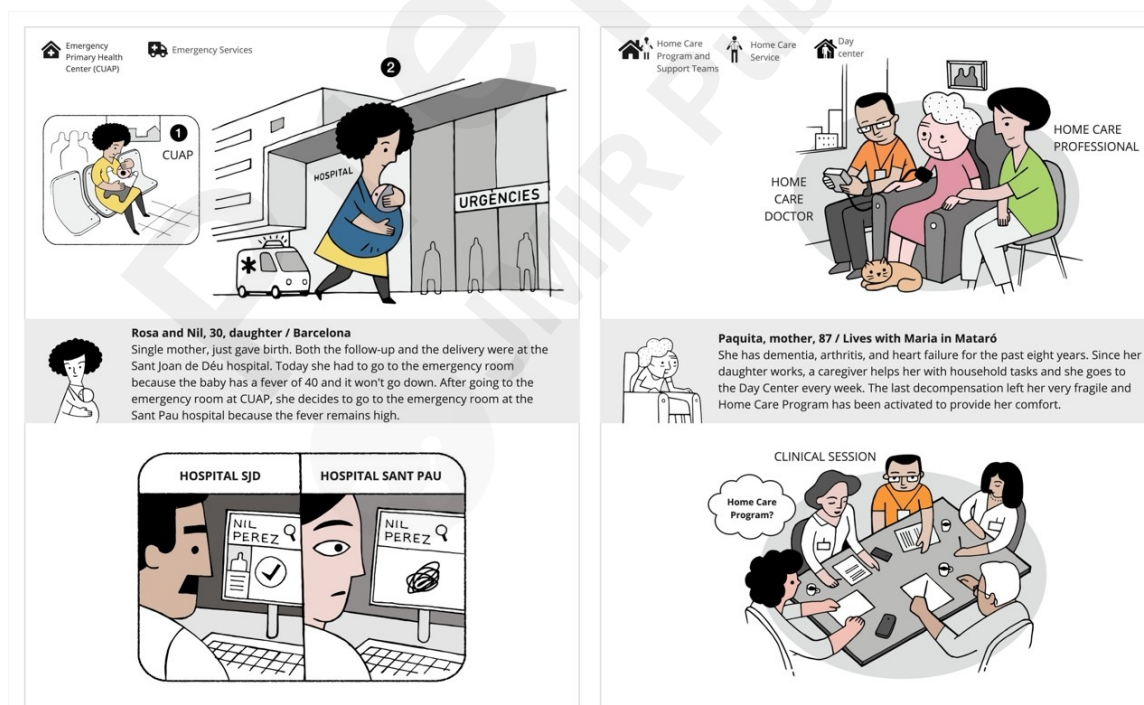


Figure 3. Sample "Pérez Family" journey (translated to English) used in face-to-face sessions with patient and caregivers—only the top scenes and descriptions—and frontline health and care professionals – full version including back end interactions.

The system maps for professional/manager sessions included behind-the-scenes system processes and pain points (Figure 4).

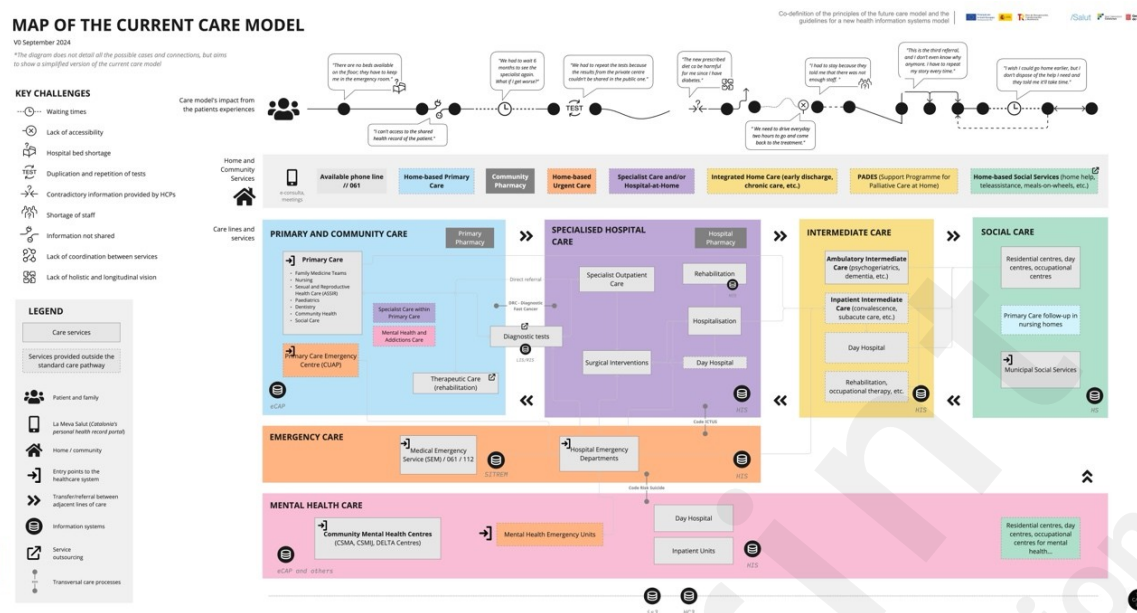


Figure 4.

Current healthcare delivery model organisation used in face-to-face sessions with healthcare leaders and managers. IS3 (*Integrador de Serveis de Salut*): Care Process Management, HC3 (*Història Clínica Compartida de Catalunya*): Shared Care Record, eCAP: Primary Care Electronic Health Record, HIS: Hospital Information System, HS (*Historial Social*): Social Care Record, SITREM (*Sistema de Tractament d'Emergències*): Emergency Treatment.

For Round 2, future scenarios were designed to portray a visual narrative of future interactions within six key themes emergent from Round 1 analysis: proximity care, empathic and quality interactions, collaborative and continuity care, personalized and proactive health prevention and promotion, active citizen participation in health, and holistic view of health. A conceptual map of the future care model vision resulting from Round 1 was another key visual used in the expert sessions.

Visual facilitation materials were carefully designed to support different communication styles and literacy levels. A facilitation toolkit was designed to enable issues to be seen at different levels of zoom or resolution: from lived experience to system overview, through technical backend and overall delivery model. Large-format posters enabled collective visioning, whilst colour-coded notes provided a simple yet effective method for categorising inputs (Figure 5). Participants were given a participation kit with materials printed individually for better readability (Supplementary Materials). All materials were tested for accessibility and refined based on feedback.



Figure 5. Participants using colour-coded notes on a large-format poster.

Data Analysis

We employed a systematic multi-stage analysis process combining inductive and deductive approaches, consistent with best practices in qualitative research.³⁷ Analysis began immediately after each session with structured team debriefs (steering board and specialised design practice) capturing key themes, surprising insights, group dynamics, emerging patterns and new questions. These immediate short downloads enabled key takeaways to be captured whilst fresh and vivid, allowing the methodology to be tuned between sessions to optimise the approach and outcomes and boost learnings and insights. Our front stage and backstage team processed detailed data in agile loops as fieldwork progressed, which avoided a build-up of data and ensured learnings were taken quickly to deepen insights. Weekly sharing sessions enabled team members not directly involved in fieldwork to follow the process, enrich insights and provide input. These immediate reflections proved invaluable for identifying areas requiring deeper exploration in subsequent sessions and fine-tuning of methods and questions to optimise the approach.

All physical materials including coloured notes, posters, and flipchart outputs were photographed and systematically transcribed into digital collaboration boards using Miro software. This digitisation process maintained original participant language and verbatims, preserved visual relationships between insights and ideas, and included contextual notes about discussion dynamics and non-verbal communications. The digital environment enabled collaborative analysis whilst maintaining a clear audit trail.

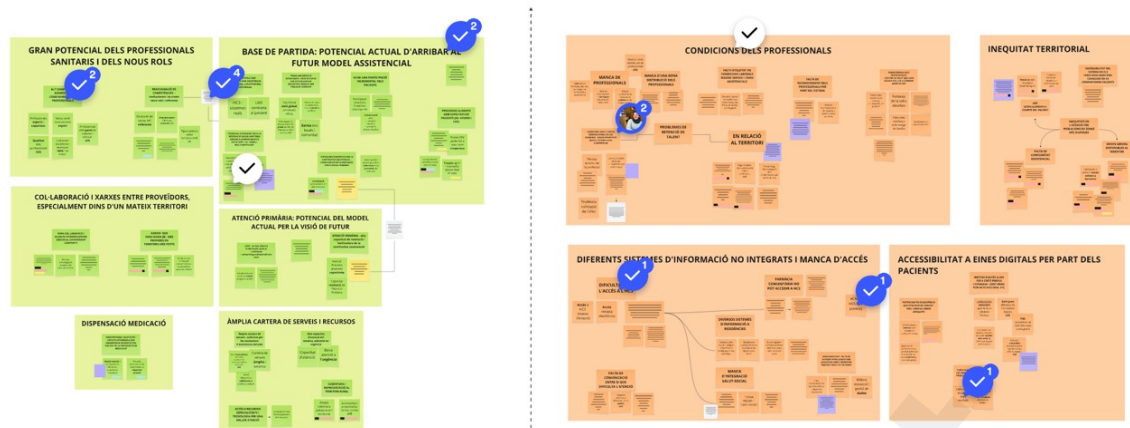


Figure 6.

Analysis of workshop outputs through axial coding.

Topic analysis proceeded through multiple stages. Initial open coding identified discrete ideas and concepts within the data. Axial coding then explored relationships between codes and began grouping them into preliminary categories. Through iterative team analysis sessions, we consolidated these categories into broader themes, ultimately identifying priority challenges and opportunities facing the healthcare system. These challenges were then mapped to potential design principles through a process of abstraction and synthesis.

To ensure analytical rigour, we implemented several quality assurance measures. Triangulation compared findings across different participant groups, territories, and data collection methods. Member checking involved sharing preliminary findings with participant representatives to ensure accurate interpretation. Peer debriefing through regular team analysis sessions challenged assumptions and refined interpretations. A detailed audit trail documented all analytical decisions and their rationales. Reflexivity was maintained through facilitator journals documenting potential biases and their mitigation. The layered team structure enabled the data to be examined simultaneously from multiple perspectives and levels of granularity, challenging interpretations, sharpening insights and conclusions, and ensuring ideas were communicated clearly to new audiences.

Territorial and Contextual Considerations

We recognised that territorial context significantly influences healthcare experiences and digital health needs. Therefore, we planned our analysis to identify and explore territorial variations in experiences and priorities rather than assuming uniform needs across geographic contexts. Our sampling strategy deliberately included representation across urban, semi-urban, and rural territories to ensure diverse contextual factors would be captured. We also considered intersectional factors in our analysis framework, recognising that age, gender, socioeconomic status, immigration status, and disability interact with geographic location to create unique barriers and opportunities that needed to be explored in our data analysis. We conducted an informed selection of the locations, in consultation with the respective health regions to ensure comprehensive coverage of key regions and strategic areas across the Catalan territory. This approach was designed to provide an accurate understanding of the realities within each context, as well as the diversity within each region.

Ethical Considerations

All participants provided written informed consent, and the study received approval from the Ethics

Committee of Hospital Universitari de Bellvitge (Reference: PR123/24). Participants were informed that their participation was voluntary and could be withdrawn at any time without consequence. Data confidentiality was maintained through anonymisation procedures, and all data was stored securely with access limited to research team members. All participants provided informed consent for the recording of verbatim statements and photographs during the sessions. When participants withheld consent for photography, this preference was respected, and no images including them were captured.

Beyond formal ethics approval, we implemented additional measures to ensure inclusive participation, including accessible session locations, provision of transport support where needed, and availability of professional translation services.

In line with the PHCD approach, we organised give-back online sessions to share the findings with participants and inform them of subsequent steps, ensuring the research delivered value to all involved.

Results

A total of 265 participants across the Catalan healthcare ecosystem participated in a two-round PHCD process that explored current healthcare delivery challenges and co-created principles for equitable digital health transformation. This process yielded comprehensive qualitative data encompassing critical system barriers, actionable design principles, and contextual insights for equitable digital health transformation. The findings reveal both systemic barriers and collaborative solutions emerging from systematic engagement with diverse stakeholders across Catalonia's healthcare territories, demonstrating how participatory approaches can translate lived experiences into evidence-based design frameworks.

Participant Characteristics and Territorial Distribution

Participant demographics and territorial distribution are presented in Table 1, reflecting robust representation across stakeholder groups and geographic contexts throughout the study period. The sample included citizens and informal caregivers (n=106), healthcare professionals (n=83), healthcare managers and leaders (n=50), and cross-sectional experts in digital health innovation (n=26). Territorial representation spanned urban centres, rural areas, and intermediate zones, ensuring diverse infrastructure and resource contexts informed the findings.

Table 1. Demographic characteristics of participants.

	Nº (%)
Patients & Caregivers	
Gender	
Male	39/106 (36.8%)
Female	67/106 (63.2%)
Age (missing=9)	
18-35	2/97 (2.1%)
36-50	16/97 (16.5%)

51-65	38/97 (39.2%)
>65	41/97 (42.3%)
Profile	
Patient	68/106 (64.2%)
Caregiver	38/106 (35.8%)
Territorial context	
Urban	20/106 (18.9%)
Semi-urban	49/106 (46.2%)
Rural	37/106 (34.9%)

Health & Social professionals. experts and leaders

Gender	
Male	57/159 (35.8%)
Female	102/159 (64.2%)
Age	
18-35	7/159 (4.4%)
36-50	100/159 (62.9%)
51-65	52/159 (32.7%)
>65	0/159 (0.0%)
Profile	
Primary care doctor	4/159 (2.5%)
Hospital & intermediate care doctor	16/159 (10.1%)
Primary care nurse	11/159 (6.9%)
Hospital & intermediate care nurse	9/159 (5.7%)
Psychology	4/159 (2.5%)
Social worker	7/159 (4.4%)
Health administration	7/159 (4.4%)
New roles (community wellbeing. physiotherapist. nutritionist)	7/159 (4.4%)
Others (emergency service. pharmacy. carehomes...)	13/159 (8.2%)
Healthcare managers and leaders	50/159 (31.4%)
Cross-sectional experts	26/159 (16.4%)
Territorial context	
Urban	91/159 (57.2%)
Semi-urban	48/159 (30.2%)
Rural	20/159 (12.6%)

Barriers to Digital Health Equity

Round 1 involved 16 co-creation sessions across diverse geographic locations, engaging participants in collective reflection about the gaps and opportunities of the current care model. Additionally, three online group interviews with strategic stakeholders provided macro-level insights into system-wide challenges and opportunities.

Participants systematically identified critical barriers that impede equitable digital health implementation, revealing interconnected challenges spanning individual, organisational, and systemic levels. The analysis of participant inputs identified the following critical challenges:

Digital literacy gaps emerged as a pervasive barrier affecting both citizens and healthcare professionals, with participants describing how inadequate training and support created parallel struggles with technology adoption across user groups. As one healthcare professional noted: *"We're expected to use these systems effectively, but many of us received minimal training and feel as lost as our patients."*

Fragmented information systems represented a second major barrier, with participants describing how disconnected platforms create inefficiencies, duplicated efforts, and compromised care coordination. This fragmentation particularly disadvantaged vulnerable populations who require coordinated care across multiple services and providers.

Lack of meaningful user involvement in system design was identified as a fundamental barrier, with participants emphasising how current development processes exclude end-user perspectives, resulting in systems that fail to address real-world workflows and needs. Healthcare professionals and patients alike described feeling like "afterthoughts" in design processes that prioritise technical specifications over usability.

Insufficient consideration of vulnerable populations' needs emerged as a systemic barrier, with participants highlighting how current systems often assume standardised user capabilities and contexts, thereby excluding those with disabilities, language barriers, limited technology access, or complex social circumstances.

Territorial infrastructure variations represented an additional barrier category, particularly affecting rural and remote areas where connectivity limitations, resource constraints, and geographic isolation compound other access challenges. Participants from mountainous regions and border areas described specific difficulties accessing healthcare resources even when geographically closer alternatives exist in neighbouring jurisdictions.

Figure 7 shows these territorial specificities.

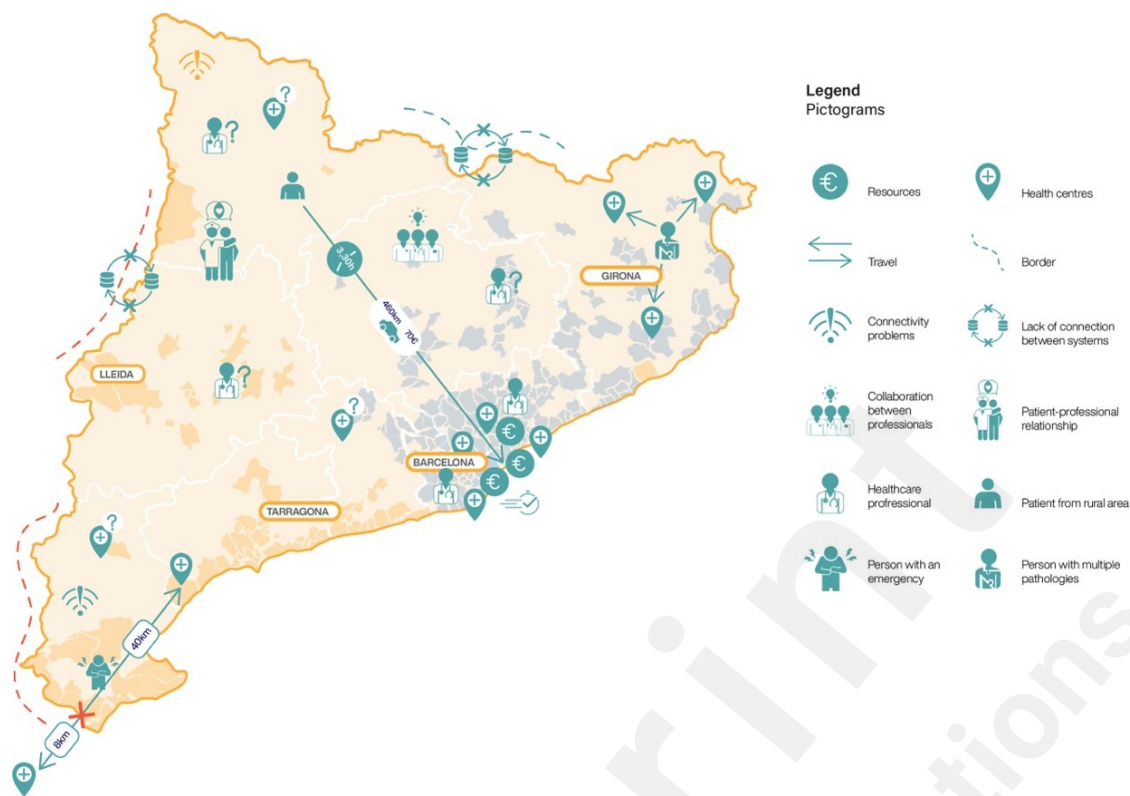


Figure 7. Catalonia map with territorial specificities and insights visualising lack of resources, connectivity issues, required patient travel and distribution of professionals.

Co-created Design Principles for Equitable Health Information Systems

Round 2 comprised one validation session with Catalan Health Service experts, eight territorial co-creation sessions focused on translating Round 1 insights into actionable design principles, and three topic-specific sessions with strategy, innovation and technology experts that concentrated on specific domains including data governance and privacy, system interoperability and integration, and user experience and accessibility design.

Building on barriers identified in Round 1 and through collaborative envisioning of future healthcare scenarios, participants co-created ten fundamental principles for equitable health information systems. These principles emerged through systematic abstraction and synthesis of stakeholder proposals, representing consensus across diverse groups while addressing the multidimensional nature of digital health equity (Table 2).

Table 2: Design principles for equitable healthcare system transformation.

Nº	Name	Description
1	The Person and their Care Circle at the Centre	The technology should enable taking into account all the interactions of people and their informal care circle as they move through the health system along

		their various life transitions in order to facilitate the user's navigation experience and enable measurement and improvement of their overall experience of care.
2	Health for Everyone, Everywhere	Information systems need to ensure accessibility and inclusion for all, removing physical, digital and cultural barriers and facilitating understanding and use of information with the aim of ensuring more equitable access for everyone to the health system and also managing their health in a digital environment.
3	Tools for More Compassionate Care	Implementing technology can help to streamline processes and furnish health professionals with more quality time to devote to direct care, maintaining and enhancing the bond between the professional, the person and their informal care circle.
4	A Better Professional Experience	The design of information systems can facilitate their use and operational efficiency, providing tools for collaboration and communication between professionals regardless of sector, tier of care or field with the aim of enhancing multidisciplinary and cross-cutting teamwork and facilitating shared decision-making.
5	An Active Role of the Population	Information systems are designed to enable the active participation of the population in the management of their health, ensuring that they have easy access to the information and tools they need to become more autonomous and able to take part in decision-making about their health.
6	Personalised and Proactive Care	Information systems help to tailor care to the needs and preferences of each individual over time by adjusting care communication, channels and formats. This empowers patient autonomy and allows professionals to identify and anticipate needs, continuously improving the experience and efficiency of the health system.

7	Systematic Use of Data for Decision-making	The use of data analytics tools and smart technologies in health makes it possible to tailor care for people to the needs of different population groups, optimising resources and decision-making to improve the quality of health services for the benefit of the community.
8	Integrated Quality Data Working for Health	Interoperability of information systems and integration of public and private health data coupled with social, educational, environmental and other aspects will ensure a holistic view of people's health.
9	An Information System that Builds Trust	Information systems need to have robust security and privacy measures in place to protect personal information and ensure ethical data management practices and use in order to build the trust of all users in the use of health technologies.
10	Collaboration as a Driver	A new way of collaborating and innovating based on co-creation with all actors involved can promote the implementation of new technologies and solutions to enhance care models and tailor them to the changing needs of the population and territories.

Territorial Context and Principle Development

Territorial analysis revealed how geographic and infrastructure contexts shaped both barrier experiences and the development of information system design principles. Rural areas emphasised connectivity and resource access issues, leading to stronger emphasis on principles addressing "Health for Everyone, Everywhere" and "Collaboration as a Driver of Innovation." Urban contexts highlighted diversity and complexity challenges, informing principles focused on cultural responsiveness and care coordination. Border regions contributed unique perspectives on administrative complexity and cross-jurisdictional care access, strengthening principles addressing system integration and user navigation support.

These territorial differences informed the development of principles that explicitly address contextual variation rather than assuming standardised solutions. The principle of "Health for Everyone, Everywhere" emerged directly from recognition that equitable digital health systems must account for diverse geographic, infrastructure, and cultural realities across Catalonia's territories.

Stakeholder Perspective Alignment and Divergence

While remarkable alignment emerged across stakeholder groups on fundamental principles,

meaningful divergences in emphasis provided valuable insights for implementation. Healthcare professionals prioritised workflow integration and administrative burden reduction more strongly than other groups, directly informing the principle of "A Better Professional Experience." Patients and caregivers emphasised ease of use and personal control over health information, strengthening principles focused on user empowerment and data governance. Healthcare managers and leaders focused on sustainability and implementation feasibility, contributing to principles addressing systematic data use and collaborative innovation. Cross-sectional experts highlighted technical interoperability and innovation potential, enriching principles related to data integration and system connectivity.

Implementation Considerations

Participants not only co-created principles but also provided detailed insights into implementation considerations. They emphasised the need for phased implementation approaches that build confidence and capability gradually. Strong change management and training programs for both citizens as well as health and social care professionals were identified as essential for successful adoption. Participants stressed the importance of maintaining human connection even as systems become more automated, ensuring that technology enhances rather than replaces human connection in healthcare.

The co-creation process itself was identified as a valuable model for ongoing stakeholder engagement throughout implementation. Participants requested continued involvement in system development and evaluation, suggesting that the participatory approach should extend beyond principle development into implementation and continuous improvement phases.

Participation Experience and Engagement

Participants demonstrated high levels of engagement throughout the co-creation process. Post-session evaluation surveys indicated strong satisfaction with the participatory experience, with participants reporting that they felt heard, respected, and valued in the process. The visual facilitation tools, particularly the "Pérez Family" journey mapping and storytelling, proved effective in enabling participants with varying communication styles and literacy levels to contribute meaningfully to discussions. As well as providing one common visual framework upon which diverse experiences, ideas and perspectives could be consolidated to create a shared mental model and enable group debate and discussion.

The diversity of profiles facilitated rich exchanges between different perspectives, with participants frequently noting the value of hearing experiences from other stakeholder groups.

Discussion

This study demonstrates how PHCD can fundamentally transform digital health development from technology-driven approaches to genuinely people-centred processes. Through engagement with 265 participants across Catalonia's healthcare ecosystem, we have shown that meaningful co-creation with diverse stakeholders reveals nuanced barriers and solutions that traditional top-down approaches typically overlook, contributing to the growing body of evidence supporting equity-centred design in health information systems. This participatory process also fosters a sense of ownership and engagement across the entire ecosystem, which will facilitate the future co-creation of the systems and their sustainable implementation.

Our participatory approach yielded ten design principles that address critical gaps in current digital health development. These principles emerge from a comprehensive understanding of real-world challenges faced by patients, caregivers, healthcare professionals, and system leaders across diverse territorial contexts. The co-creation process revealed that digital health equity requires attention to multiple interconnected dimensions: technological accessibility, organisational readiness, professional workflow integration, and citizen empowerment in data governance.

The identification of barriers such as digital literacy gaps, fragmented information systems, and insufficient consideration of vulnerable populations aligns with recent evidence from the Digital Health Care Equity Framework developed through collaborative processes in the United States²⁵. This framework similarly emphasises addressing digital determinants of health and highlights the importance of participatory design and community engagement to ensure tools are culturally and contextually relevant. Our findings extend this work by demonstrating how large-scale participatory processes can systematically translate these equity considerations into actionable design principles for health information systems.

Our study provides concrete evidence that human-centred design approaches in health information technology can lead to more equitable and effective systems. The ten principles we identified address long-standing challenges in health IT development, particularly the persistent gap between technological capabilities and real-world usability that continues to plague EHR implementations. Recent research continues to document usability problems experienced by healthcare professionals and patients, with studies showing that over one-third of medication safety events in paediatric hospitals are related to EHR usability issues.³⁸

The principle of "The Person and their Circle at the Centre" reflects growing recognition in the health informatics community that meaningful stakeholder involvement throughout the design process is essential for creating systems that genuinely support clinical workflows and patient needs.³⁹ This aligns with emerging evidence from an umbrella review of digital health intervention co-design, which identifies participatory design and community collaboration techniques as crucial mechanisms for creating digital health tools that serve diverse user needs.⁴⁰ Our study extends this evidence by demonstrating how such approaches can be scaled across an entire regional health system, but also how they can be specifically applied to define core design principles to guide the development of health information systems.

The emphasis on data control and citizen agency in the "An Information System that Builds Trust" principle resonates with recent research on patient preferences for health information exchange design⁴¹. Studies examining patient preferences for data sharing reveal complex attitudes towards health information control that cannot be simply characterised by demographic factors, supporting our finding that genuine patient engagement in system design is essential for addressing privacy and trust concerns.

Our findings contribute to the emerging understanding of equity-by-design principles for digital health interventions. Recent reviews have identified the need for actionable, evidence-based design principles that provide concrete guidance for consistent implementation of equity considerations in digital health development.⁴¹ Our study addresses this gap by providing ten principles that emerged directly from the experiences of diverse stakeholders, including those traditionally excluded from technology design processes.

The territorial diversity of our participant recruitment and the deliberate attention to vulnerable

populations in our methodology reflects growing recognition that digital health implementations require inclusive and accessible approaches to improve suitability and uptake in diverse populations. This aligns with the Digital Health Equity-Focused Implementation Research conceptual model, which emphasises that digital health tool development is a participatory process involving continuous evaluation cycles intertwined with implementations that change healthcare organisation.⁴²

The principle of "Health for Everyone, Everywhere" directly addresses concerns raised in recent literature about the digital divide in healthcare. Research has shown that digital health technologies often exacerbate existing inequalities when developed without considering diverse user needs and contexts.⁴³⁻⁴⁵ Our participatory approach demonstrates how engaging affected community members as co-creators, rather than merely consultees, can help identify and address barriers that remain invisible to traditional technology development approaches.

Our study advances the field methodologically by demonstrating how to scale participatory and human-centred design approaches across large, complex health systems whilst maintaining meaningful engagement with diverse stakeholder groups. The systematic integration of territorial considerations, the use of innovative visual facilitation tools, and the structured progression from problem identification to solution co-creation provide a replicable framework for other regions seeking to implement equity-centred digital health transformations.

The multi-stage analysis process we employed, combining immediate post-session debriefs with systematic digitisation and collaborative thematic analysis, addresses challenges identified in recent literature about inconsistent reporting of co-design methodologies in digital health research.^{40,46} Our approach demonstrates how to maintain analytical rigour whilst preserving participant voice and ensuring transparent decision-making processes throughout the analysis.

Limitations

Whilst our study provides valuable insights into participatory design for digital health equity, several limitations should be acknowledged. First, the geographic focus on Catalonia may limit generalisability to other healthcare systems with different organisational structures, regulatory frameworks, or cultural contexts. Future research should examine how these principles translate across different healthcare system contexts, particularly in low-resource settings where digital gaps may be more pronounced.

Second, our study captured stakeholder perspectives at a specific point in time during a period of rapid digital transformation in healthcare. The long-term sustainability and relevance of the identified principles will require ongoing evaluation as digital health technologies and user needs continue to evolve. Longitudinal studies examining how these principles perform in practice and how they may need to be adapted over time would provide valuable insights for the field. However, we attempted to ensure some degree of future-proofing by grounding our principles in fundamental human-centred design values that remain relevant across technological iterations, focusing on equity considerations that persist regardless of specific technologies, and validating principles through diverse stakeholder perspectives that represent enduring healthcare needs.

Third, whilst we achieved significant diversity in our participant sample across professional roles, geographic territories, and demographic characteristics, several recruitment limitations may have affected the representativeness of our findings. The voluntary nature of participation may have introduced selection bias towards individuals with stronger interest in or more positive attitudes towards digital health transformation. Additionally, participant recruitment was facilitated through

the offices of the Catalan health regions, which acted as intermediaries in the recruitment process. This intermediation added complexity to participant identification and selection, limiting our direct control over participant selection and making it more challenging to ensure the demographic variation we sought and recruit certain specific profiles. Despite implementing strategies to encourage the participation of young citizens (i.e., adjusting the timetable), we faced ongoing challenges in engaging this demographic.

Furthermore, we were unable to adequately include migrant populations and other underserved communities in our study, which may have hampered the generalisability of our results. These populations often face the most significant barriers to digital health access and may have unique perspectives on equity that were not fully captured in our research. The exclusion of these voices represents a significant limitation, as these communities are frequently most affected by digital health inequities and their insights would be crucial for developing truly inclusive principles.

Quality assurance constraints also influenced our approach. To ensure high-quality workshops, conversations, and facilitation, it was essential to limit participant numbers to a maximum of 12 per session. However, in cases involving patients and caregivers, last-minute cancellations are common. Despite having contingency plans and backup participants, in some instances we had fewer participants than planned in certain sessions, reducing the number of perspectives included in those particular locations.

Future research could explore mechanisms for engaging harder-to-reach populations who may be more sceptical of or excluded from digital health initiatives, with particular attention to developing culturally appropriate recruitment strategies for migrant communities and other underserved populations. Additionally, research examining greater ethnicity and ability diversity would strengthen the evidence base for equitable digital health design principles.

Implications for Practice and Policy

Our findings have several important implications for healthcare organisations, technology vendors, and policymakers involved in digital health development. For healthcare organisations, our study demonstrates the value of investing in meaningful participatory processes before, during, and after health information system implementations. The principles we identified provide a framework for evaluating existing systems and guiding future technology decisions with explicit attention to equity considerations.

A critical insight from our work is the importance of innovative partnership approaches when navigating system complexity to drive large-scale engagement and co-design processes. Our experience demonstrates that successful system-level transformation requires sophisticated collaboration models that bring together diverse expertise and perspectives. The partnership between public health authorities, academic institutions, and specialised design practitioners created a unique configuration that enabled navigation of complex healthcare system dynamics while maintaining methodological rigour and stakeholder trust. This collaborative approach proved essential for accessing diverse participant networks, managing territorial complexities, and ensuring that co-created principles would be both evidence-based and implementable within existing organisational structures.

The scale and complexity of our engagement process required innovative approaches to project coordination, quality assurance, and knowledge synthesis that go beyond traditional consultation methods. Our experience suggests that healthcare systems seeking to implement participatory design

approaches need to invest in building these collaborative capabilities and partnership models rather than relying on conventional procurement or consultation frameworks. This includes developing internal competencies for co-design facilitation, establishing governance structures that can accommodate diverse stakeholder perspectives, and creating mechanisms for translating participatory insights into actionable system changes.

For technology vendors, our research highlights the importance of embedding human-centred design processes throughout product development, not merely as a compliance exercise for certification requirements. The persistent usability problems documented in EHR research suggest that current vendor approaches to stakeholder engagement are insufficient.⁴⁷ Our study provides evidence that more comprehensive participatory approaches can yield insights that lead to more effective, equitable and sustainable system designs.

For policymakers, our findings support the need for regulatory frameworks that incentivise or require meaningful stakeholder engagement in health technology development. Current certification requirements for EHRs, whilst including human-centred design elements, may not go far enough in ensuring that diverse stakeholder perspectives shape system development. Our study demonstrates the feasibility and value of more comprehensive participatory approaches that could inform future policy development. Additionally, policymakers should consider how to support and incentivise the development of collaborative partnerships and co-design capabilities within healthcare systems, recognising that these represent critical infrastructure for equitable digital transformation.

Future Directions

The ten principles identified in our study provide a foundation for future research examining their implementation and effectiveness in practice. Experimental studies comparing systems developed using these principles with those developed through traditional approaches could provide evidence of their impact on user satisfaction, system adoption, and health outcomes. Additionally, research examining how these principles can be adapted for different types of digital health interventions beyond health information systems would expand their applicability.

A critical area for future research involves extending these principles to social and community care settings, recognising that health and social care integration represents a fundamental challenge in creating truly person-centred systems. Our study primarily focused on healthcare contexts, yet many of the barriers and equity challenges we identified are even more pronounced at the intersection between health, social, and community services. Future research should explore how these principles apply to integrated care models that span health and social care boundaries, examining how digital systems can support seamless coordination between healthcare providers, social services, community organisations, and informal care networks.

This expansion to social and community care contexts would require investigating several key areas: how digital platforms can facilitate care coordination between health and social care professionals working with the same individuals; how community-based organisations can be meaningfully included in digital health ecosystems; how principles of equity and accessibility translate to social care contexts where digital divides may be even more pronounced; and how to design systems that support the complex, multi-agency care arrangements that many vulnerable populations require. Such research would be particularly valuable for understanding how to implement principles like "The Person and their Care Circle at the Centre" and "Health for Everyone, Everywhere" in contexts where care provision involves multiple sectors with different governance structures, funding mechanisms, and information systems.

The growing interest in artificial intelligence and machine learning applications in healthcare presents new opportunities and challenges for participatory design approaches. Future research could explore how the principles identified in our study apply to AI-enabled health technologies, which may require additional considerations related to algorithmic transparency, bias mitigation, and human-AI interaction design. This is particularly important given that AI systems may amplify existing inequities if not designed with explicit attention to the principles we identified.⁴⁸

Another promising direction involves examining how these principles can inform the development of community health information systems that extend beyond traditional healthcare settings. This could include research on how to design digital platforms that support community health workers, patient navigators, and peer support networks, recognising that much health-related activity occurs outside of formal healthcare institutions. Such research would be particularly relevant for addressing health equity, as community-based approaches often reach populations that traditional healthcare systems struggle to engage effectively.

Finally, our study focused primarily on the development of design principles rather than their implementation. Future research examining how healthcare organisations can operationalise these principles in practice, including identifying necessary organisational capabilities, resource requirements, and implementation strategies, would provide valuable guidance for translating these insights into improved health information systems. This implementation research should pay particular attention to how organisations can build the collaborative partnerships and co-design capabilities that our study identified as essential for system-level transformation, and how these approaches can be sustained over time within existing organisational and policy contexts.

Conclusions

This study demonstrates that PHCD can serve as a powerful mechanism for advancing digital health equity when implemented with sufficient scale, methodological rigour, and genuine commitment to meaningful stakeholder engagement. The ten principles we identified provide a comprehensive framework for developing health information systems that are not only technically robust but also genuinely responsive to user needs, culturally appropriate, and accessible to all populations.

The growing recognition of digital health's potential to either bridge or widen health inequities makes our findings particularly timely and relevant. As healthcare systems worldwide continue to accelerate their digital transformations, the evidence from our study supports the critical importance of placing diverse stakeholder voices at the centre of design processes. Through engagement across Catalonia's healthcare ecosystem, we have shown that meaningful co-creation with diverse stakeholders reveals nuanced barriers and solutions that traditional top-down approaches typically overlook. Only through such approaches can we ensure that digital health technologies fulfil their promise of democratising healthcare access rather than exacerbating existing disparities.

Our research contributes to a broader movement towards care-centred design in healthcare, demonstrating that engaging people as co-creators rather than mere consultees is not only an ethical imperative but a practical necessity for achieving digital health systems that truly serve the needs of all populations. The framework and principles we have developed provide actionable guidance for healthcare organisations, technology vendors, and policymakers committed to advancing health equity through thoughtful, inclusive digital health development.

Author Contributions

JP-J conceived and designed the study, developed the methodology, acquired funding, supervised the research, and wrote the original draft of the manuscript. XM, LLV, AC, LP, LH, NV, and AM contributed to study design and methodology development. JP-J, XM, LLV, AC, LP, LH, AB, AF, NV, and AM conducted data analysis and interpretation. AF, NV, and AM managed data collection and curation. XM, LP, NV, AM, and GCS contributed to manuscript writing and revision. AC provided project administration and coordination. NV, AF and AM created visualisations and figures. All authors contributed to the interpretation of results, critically reviewed the manuscript for important intellectual content, and approved the final version for publication.

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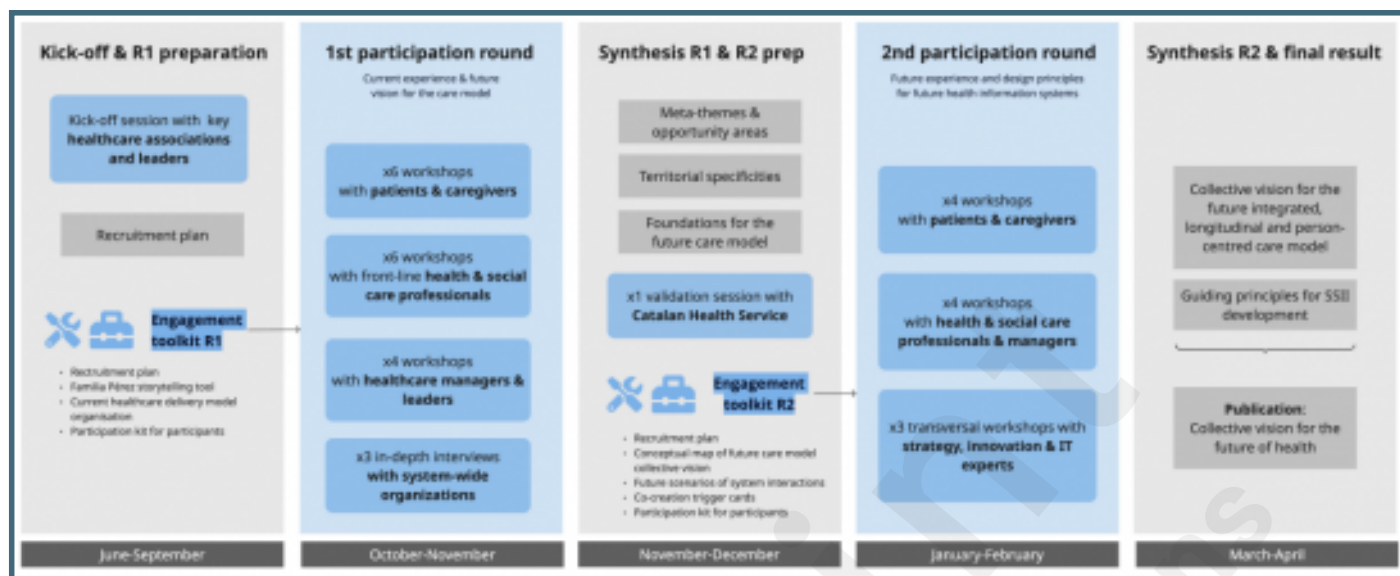
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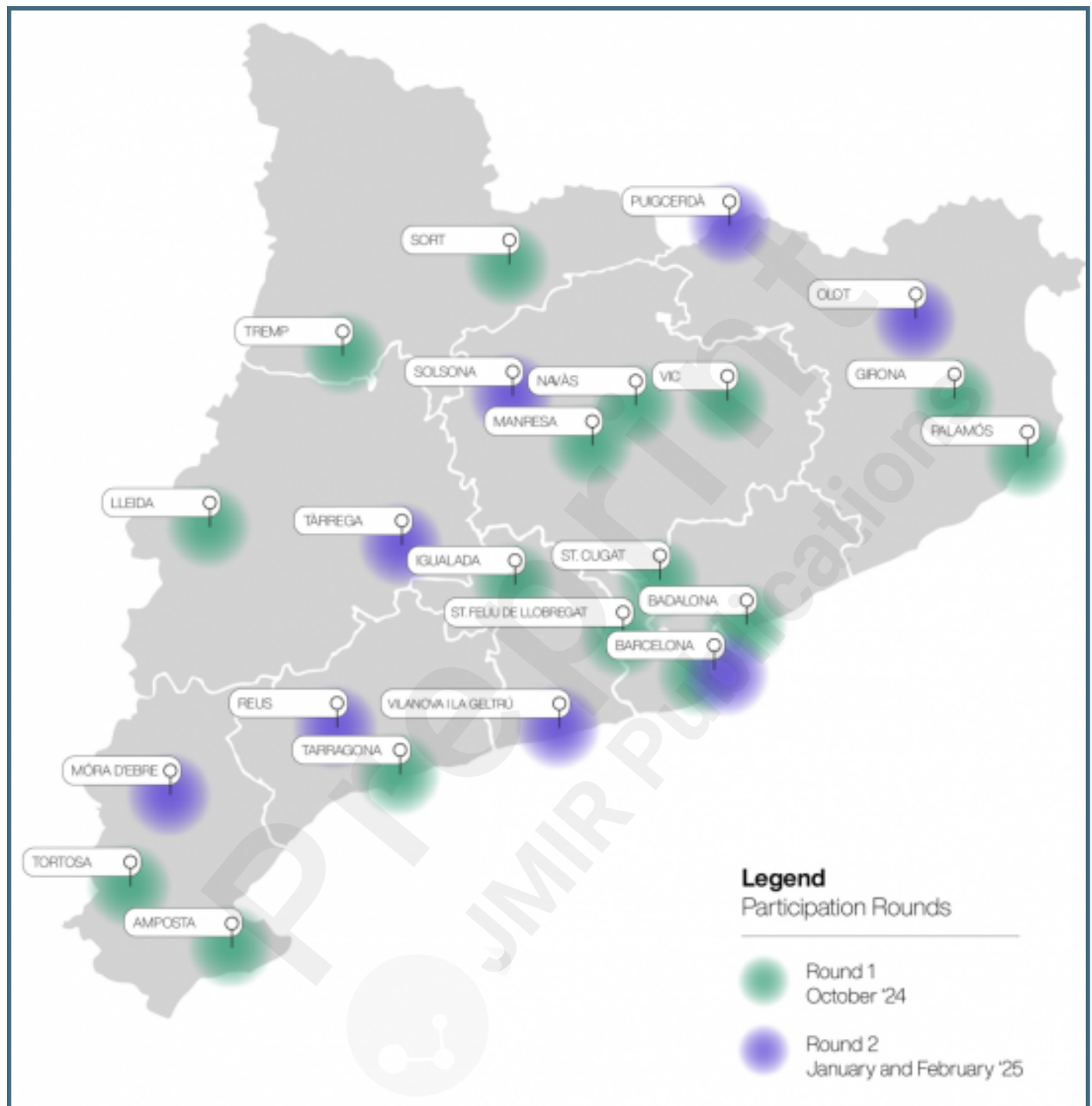
Supplementary Files

Figures

Project timeline, with activities (in blue) and outputs (in grey).



Territorial distribution of the face-to-face participatory sessions across the two rounds.



Sample “Pérez Family” journey (translated to English) used in face-to-face sessions with patient and caregivers—only the top scenes and descriptions—and frontline health and care professionals – full version including back end interactions.



MAP OF THE CURRENT CARE MODEL
19 September 2020

"The diagram shows a number of the possible views and connections, but aims to show a simplified version of the current care model"

KEY CHALLENGES

- Fragmentation
- Lack of accessibility
- Hospital bed shortage
- Optimization and repetition of tasks
- Consistency information providing info.
- Shortage of staff
- Information silos
- Lack of coordination between services
- Lack of holistic and longitudinal view

Care models impact from the patients experience

Key and Community Services

- Available phone line (24/7)
- Home based Primary Care
- Community Pharmacy
- Home based Urgent Care
- Specialist Care and/or Hospital at Home
- Integrated Home Community Discharge (events, etc.)
- MSD Support Programme for Palliative Care at Home
- Home based Social Services (non-medical, rehabilitation, mental health, etc.)

Care Sites and Services

PRIMARY AND COMMUNITY CARE

- Primary Care
 - General Practice
 - Specialist Outpatient Clinic
 - Rehabilitation
 - Hospitalization
 - Day Hospital
- Specialist Outpatient Clinic
- Rehabilitation
- Hospitalization
- Day Hospital

SPECIALIZED HOSPITAL CARE

- Specialist Outpatient Clinic
- Rehabilitation
- Hospitalization
- Day Hospital

INTERMEDIATE CARE

- Ambulatory Intermediate Care (urgent care, etc.)
- Intermediate Care (urgent care, etc.)
- Day Hospital
- Rehabilitation, occupational therapy, etc.

SOCIAL CARE

- Rehabilitation, day centres, occupational therapy
- Widely Care follow-up, nursing homes
- Non-medical Social Services

EMERGENCY CARE

- Medical Emergency Services (24/7)
- Hospital Emergency Departments

MENTAL HEALTH CARE

- Community Mental Health Centres (24/7, 111, 999, etc.)
- Mental Health Emergency Units
- Day Hospital
- Rehabilitation, day centres, occupational therapy, etc.

LEGEND

- Care services
- Services provided outside the standard care pathway
- Patient journey
- La Roche (La Roche) general health (La Roche)
- Home community
- Day centre in the health system
- Transitional between different levels of care
- Information systems
- Service monitoring
- Transitional care provided

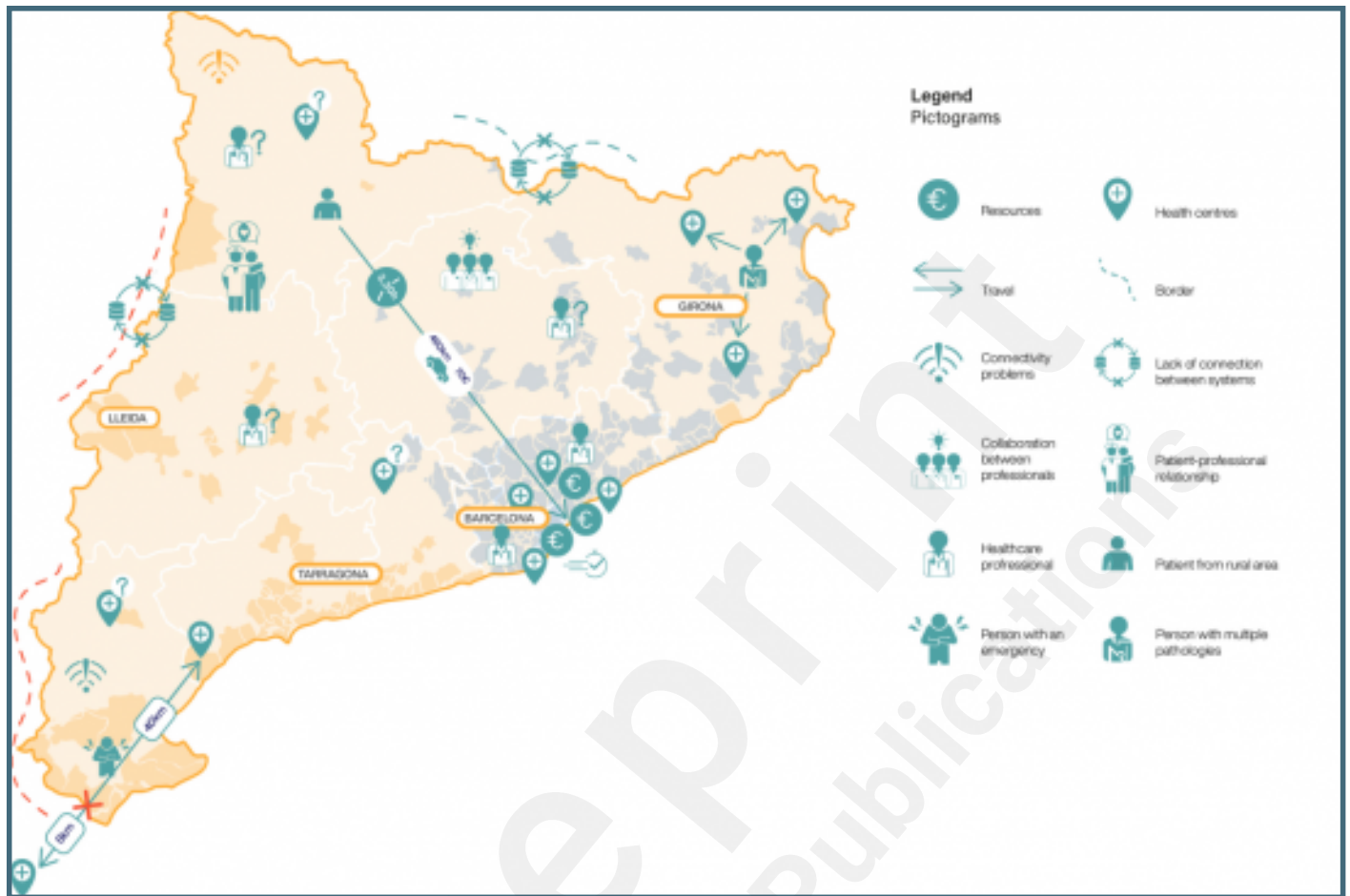
Participants using colour-coded notes on a large-format poster.



Analysis of workshop outputs through axial coding.



Catalonia map with territorial specificities and insights visualising lack of resources, connectivity issues, required patient travel and distribution of professionals.



Multimedia Appendixes

Supplementary materials.

URL: <http://asset.jmir.pub/assets/78185c716894087d666a117275f6663d.pdf>

