

Living labs and open innovation approaches to scale impact for human wellbeing

Edited by

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Published in

Frontiers in Public Health
Frontiers in Sociology



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ISSN 1664-8714
ISBN 978-2-8325-4715-1
DOI 10.3389/978-2-8325-4715-1

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Living labs and open innovation approaches to scale impact for human wellbeing

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Citation

Borda, A., Pedell, S., Konstantinidis, E., Spagnoli, F., Schuurman, D., eds. (2024).

Living labs and open innovation approaches to scale impact for human wellbeing.

Lausanne: Frontiers Media SA. doi: 10.3389/978-2-8325-4715-1

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OPEN ACCESS

EDITED AND REVIEWED BY
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RECEIVED 30 January 2024

ACCEPTED 21 February 2024

PUBLISHED 22 March 2024

CITATION

Borda A, Schuurman D, Pedell S, Spagnoli F and Konstantinidis E (2024) Editorial: Living labs and open innovation approaches to scale impact for human wellbeing.
Front. Public Health 12:1378932.
doi: 10.3389/fpubh.2024.1378932

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Editorial: Living labs and open innovation approaches to scale impact for human wellbeing

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KEYWORDS

living labs approach, quadruple helix, wellbeing, quintuple helix, innovation lifecycle, emerging technologies, ecosystems, co-design

Editorial on the Research Topic

[Living labs and open innovation approaches to scale impact for human wellbeing](#)

This Research Topic of Frontiers in Public Health focuses on different innovation aspects related to Living Labs in various thematic contexts, collectively addressing ways of scaling impact for human wellbeing. Living Labs are powerful instruments supporting healthy communities, cities and regions in their transition toward sustainable and resilient futures with the facilitation of open and inclusive innovation (1–4). As orchestrators of open innovation environments, Living Labs aim to involve all relevant stakeholders to co-create concrete, long-term solutions based on real-life problems with the goal to scale-up eventually (5, 6). The Living Lab innovation model as an emerging practice centering on open innovation has particular resonance in contexts that have wellbeing and quality of life at their heart with a focus on the role of human-centered technologies supporting this goal (7, 8). The articles in this Research Topic are best practice examples in capturing the breadth and complexity that is necessary to achieve new co-created solutions as represented by the 11 articles contributed by 72 authors.

Living lab networks, like the European Network of Living Labs (ENoLL), have a global presence and provide a collaborative approach in bringing together stakeholders to explore and design socio-technological solutions addressing real-world challenges. A critical difference to other forms of innovation or technology incubation is that the living lab approach centers the design and evaluation of these innovations directly with users (e.g., citizens, clients, patients) so they can shape the innovation to their actual life and work environments based on needs, lived experiences and expectations (9, 10).

The aim of this Research Topic is to raise the awareness and opportunities of current international research and practice in the intersection of Living Lab models and digital public health and human wellbeing across communities, cities and regions. The collection of papers in this Research Topic encompasses original research contributions, as well as selected and reworked papers from the Open Living Lab Days' 2022 top research session, ENoLL's yearly innovation conference. Together, they demonstrate a range of diverse and accessible perspectives, including stakeholder engagement in Living Labs, scaling of healthcare solutions, infrastructure in Living Labs, and Living Labs in the light of a broader societal context.

The first article in the collection authored by Fotis et al., entitled “Co-creation in a digital health living lab: A case study,” is a single use case description of stakeholder engagement to co-develop strategies in self-managed care for older adults. Specifically the community based Digital Health Living Lab (DHLL) is a partnership between the University of Brighton and the Brighton and Hove City Council supporting an open innovation process with multiple stakeholders, such as older adults, contributing to the co-development of a digital health solution led by a small business enterprise. Lessons learned provide some insights into the co-benefits of testing in a real-life environment, cost benefits of setting up a living lab within the community, and similar advantages for SMEs utilizing a DHLL to engage end users directly with their solutions.

The second article is entitled: “*Loved ones are not “visitors” in a patient’s life” - the importance of including loved ones in the patient’s hospital stay: an international Twitter study of #HospitalsTalkToLovedOnes in times of COVID-19,*” and is written by Hribersek et al.. This article differs from the ‘traditional’ Living Lab approach, presenting an interesting outlook on the role of family and friends in the life of hospital patients. This article studied 8 months of Twitter interactions using a variety of techniques, including thematic analysis, term frequency and Markov chain analysis. The study looked at 4,412 unique tweets and interactions by 7,040 Twitter users originating from 142 countries. Results indicated the important role for communication between patients, patients’ loved ones and hospitals. The study concluded that support is needed during a patient’s hospital journey, irrespective of the pandemic context caused by COVID-19. Patient empowerment and transparent communication improve the hospital experience and patient safety. Moreover, the outcomes from the study underline the need for family-centered care in the context of adult nursing clinical practice.

The third article is titled “*Innovation through the Quintuple Helix in living labs: lessons learned for a transformation from lab to ecosystem,*” from Merino-Barbancho et al.. In the digital age, prioritizing citizen-centric innovation is imperative for cultivating resilient and collaborative communities. Living Labs, and notably their use of the Quintuple Helix model, have emerged as an effective strategy for user-centered design and co-creative innovation. This study highlights the successful integration of the Quintuple Helix in the revitalization of LifeSpace, managed by the Polytechnic University of Madrid, drawing insights from the ACTIVAGE pilot. Tested at the Madrid Deployment Site with over 350 participants, the model fosters a sense of community known as MAHA. The Living Lab infrastructure combined with the Quintuple Helix model has been proven successfully by incorporating three environments: THE LAB for planning, THE CLUB for validating solutions and THE NEIGHBORHOOD for real-life implementation. This research underscores the Quintuple Helix’s role in facilitating coordinated participation from diverse stakeholders, transcending traditional boundaries in research and innovation processes.

The fourth article “*“A living lab within a lab”: approaches and challenges for scaling digital public health in resource-constrained settings*” by Mukherjee et al. address the process of establishing Living Labs and their innovation processes beyond Europe, and in

particular in low- and middle-income countries within the context of healthcare. This article investigates the challenges linked to building appropriate digital solutions for local health challenges and scaling them to other public health facilities through ongoing empirical work in India and identifies three key domains of analysis: (1) the process of establishing an enabling structure of a “living lab within a lab”; (2) leveraging the capabilities offered by free and open-source digital technologies; and (3) the driving impetus to scaling through agile and co-constructed technical support. The study findings acknowledge that processes need to be adapted to context-based and resource-constrained public health systems and that resource proximity has a further enabling role to achieve an effective “lab within a lab” model. However, any future studies should ideally examine how a model can be made more robust and sustainable.

The fifth article is titled: “*Living labs for civic technologies: a case study. Community infrastructuring for a volunteer firefighting service,*” from Viano et al.. This research delves into the increasing use of digital technologies within Living Labs, specifically examining their role in facilitating co-production processes for wellbeing-related public services. The study focuses on a case from the European project NLAB4CIT, situated in Kaisariani, Greece. Emphasizing community engagement, the report applies participatory design methods within an “infrastructuring” framework, reimagining the Living Lab model as community infrastructure and digital tools as civic technologies. It explores the initial co-design phases, offering insights into socio-technical challenges encountered. Strengths identified include an active community, a sustained collaboration space between researchers and citizens, and a civic approach to technology. Challenges outlined encompass the role of public administration, the degree of co-design and co-development of technologies, and issues such as internet accessibility. The overarching aim of this research is to furnish a valuable overview for other Living Labs involved in digital co-production.

The sixth article is entitled “*Perceived factors informing the pre-acceptability of digital health innovation by aging respiratory patients: a case study from the Republic of Ireland,*” by Byrne et al.. The goal of this study is to inform future decision-making among respiratory patients by identifying relevant themes to respiratory care and digital health experts in the Republic of Ireland. The end goal is to facilitate engagement with and appropriate use of digital health innovation (DHI). To this end, semi-structured interviews were conducted which revealed that privacy, trustworthiness, utility, equality and data literacy are key themes to take into account. A Living Lab approach can support creating effective DHI’s for respiratory care, guided by multi-stakeholder involvement and by the Quintuple Helix Hub framework. In conclusion to this study, the authors advocate for more research to bridge the gap between bottom-up end-user engagement on the one hand and top-down digital health policies on the other so that an effective and safe use of DHI is facilitated.

The seventh article is entitled “*A co-design living labs philosophy of practice for end-to-end research design to translation with people with lived-experience of mental ill-health and carer/family and kinship groups,*” by Palmer et al. (on behalf of the Co-Design Living Labs Program Members, The University of Melbourne). This

article promotes the development of a suitable infrastructure in the health sector and focuses on the lived-experience of people when translating research into practice in the area of mental ill-health. The article steps the reader through the evolution of the Co-design Living Labs program, a community-based embedded approach with 2,000 members. The authors emphasize a philosophy of practice for working with people with lived-experience called “togetherness by design.” The retrospective demonstrates how an initially researcher-driven model can share decision power to create change and have people with lived experiences move into co-researcher roles. Eight mechanisms constitute a theoretical model to frame research co-design activities and to provide space for continuous learning in the Living Lab.

The eighth article is entitled “*How to bridge the nurse innovation-diffusion gap? An in-depth case study of Create4Care*,” by [Rigtering et al.](#) (Utrecht University) and aims to scale innovative solutions for nurses. This research applies a qualitative approach studying a medical makerspace at the largest academic hospital in the Netherlands to reduce diffusion shortage. Results indicate that innovations are prevented from broadening and being developed further due to a range of personal, organizational, regulatory, and market barriers. The authors suggest that the development of innovation ecosystems can take on the role of progressing the innovation and diffusion process. Within this ecosystem perspective the main two beneficial elements are (i) support systems that can lead the development and diffusion of innovations and (ii) actors who integrate their functional specializations. The research contributes to theory and practice of making innovations available for the broader medical practice.

The ninth article has the title “*Social system design methodology for transitioning to a new social structure: holistic urban living lab approach to well-being and a sustainable city*,” authored by [Kimura et al.](#) focuses on the policy work and community interventions by the urban living lab - Center for Person-Centered Ningen, Omuta (PONI PONI) based in Omuta City, Fukuoka Prefecture in Japan. PONI PONI was established in collaboration with the public and private sectors as an “organization that is both independent and embedded” in the existing social system, crossing vertical sectors and domains to seek effective integration of two different policy areas; namely community-based comprehensive care and regional development. Central to the research is an examination of a social system design methodology used by the living lab to propose a novel way of perceiving social systems and practitioner attitudes, and supporting a process model of social system design. To test the validity and agility of the methodology, two case studies are analyzed involving long-term care prevention and employment practices related to persons with disabilities. The application of the methodology amplifies that existing social systems are prone to fundamental problems due to their cyclical structure and vertical divisions. To overcome this, the use of policy background analysis to clarify existing concepts can result in a refreshed view of social system concepts. Subsequently the support of bottom-up practices to operationalize these concepts can begin to effectively transform social systems.

The tenth article “*Grand challenges and living labs: toward achieving the sustainable development goals*,” an opinion piece by [Molnar et al.](#) brings together perspectives from a multidisciplinary multinational author team (Swinburne University of Technology,

Karlschhochschule International University and University College London) on the opportunities of the Living Lab approach for realizing substantial and sustainable change. Living Labs are seen as suitable instruments to achieve the Sustainable Development Goals (SDGs) due to their ability to support holistic solutions, encourage a continuum of learning and development and incorporate participatory design for stakeholders and ‘everyone’ to achieve transformation in the world. Specifically in regard to the complexity of sustainable innovative solutions, Living Labs are a bridge between global ambition and local necessity and its social impact process of partnership (through coordination, collaboration and co-creation). As such Living Labs can directly contribute to an innovation lifecycle of piloting, implementation, and evaluation that can be scaled more quickly and aligned with the SDG required reporting and monitoring mechanisms (e.g., place-based data collection).

The final article is titled: “*Urban living labs as innovation infrastructure for local urban intervention acceleration and student social learning: the impacts on community wellbeing in Heerlen*,” from [Blezer et al.](#). Cities increasingly use urban experiments to address societal challenges and integrate urban planning with citizen needs. This study focuses on the impacts of placemaking and Urban Living Labs (ULLs) on creating healthy environments and fostering transdisciplinary learning. The Aurora transformation process in Heerlen-North’s GMS neighborhood serves as a case study for socio-urban challenges in one of 16 Dutch neighborhoods. The research highlights two key outcomes of ULLs as crucial infrastructure for fostering innovation and community wellbeing. ULLs offer an alternative spatial planning approach for areas with severe social-urban conditions, addressing public health equity and socio-economic determinants. Additionally, ULLs serve as educational innovation infrastructure, addressing societal issues like loneliness and social exclusion. The article emphasizes its novelty, discusses findings, and outlines implications for theory, practice, policy, and research, advocating for citizen-centric, experiment-driven approaches in urban development for healthier, more resilient communities.

Reflecting on the Research Topic, the published research which comprises this collection addresses a significant gap in our understanding of the extent to which Living Lab approaches in the design and development of solutions can solve complex problems in our society and scale them within large ecosystems, particularly in sustainable ways through emerging technologies. For instance, both diverse and connected ecosystems are represented in the papers, such as public health, aged care, smart cities, rural areas, transportation and social structures, all of which are variously supported through open innovation, sustainability, and socio-technical frameworks. A key pillar of the Living Labs model, demonstrated in the collective research, is the richness of collaborative methods of participatory and experience-based co-design, co-creation, evaluation, Quintuple Helix, and social system design, among other multi-stakeholder processes across the innovation lifecycle. Critically, the Research Topic highlights that such characteristics of Living Labs are integral to real-world problem solving and validated through exemplars of positive and measurable impacts on the health of communities, societal and individual wellbeing.

Author contributions

AB: Writing – review & editing, Writing – original draft. DS: Writing – review & editing, Writing – original draft. SP: Writing – review & editing, Writing – original draft. FS: Writing – review & editing, Writing – original draft. EK: Writing – review & editing, Writing – original draft.

Funding

The author(s) declare that no financial support was received for the research, authorship, and/or publication of this article.

Acknowledgments

We would like to thank all the authors for their contributions to this Research Topic on Living Labs and their different innovation aspects.

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The author(s) declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

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OPEN ACCESS

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SPECIALTY SECTION

This article was submitted to
Digital Public Health,
a section of the journal
Frontiers in Public Health

RECEIVED 09 March 2022

ACCEPTED 13 December 2022

PUBLISHED 17 January 2023

CITATION

Fotis T, Kioskli K, Sundaralingam A,
Fasihi A and Mouratidis H (2023)
Co-creation in a digital health living
lab: A case study.
Front. Public Health 10:892930.
doi: 10.3389/fpubh.2022.892930

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Co-creation in a digital health living lab: A case study

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Co-creation in healthcare, especially in developing digital health solutions, has been widely identified as a fundamental principle for person-centered technologies that could accelerate the adaptation of innovation. A Digital Health Living Lab based on community offers a sustainable and real-life environment to ideate, develop, and evaluate digital health solutions addressing the needs of multiple stakeholders. This article presents the experience of the School of Sport and Health Sciences at the University of Brighton in establishing a Digital Health Living Lab. In addition, we share a proposed step-by-step approach to establishing such a living lab in the community, supplemented by a case study of product development.

KEYWORDS

living lab (LL), living lab approach, living lab design, digital health, innovation, co-production, co-creation

Introduction

Innovation in digital services and products is mostly dependent on enhancing knowledge on a national and international scale, targeting to foster an ecosystem of complementary evidence (1). Therefore, it has become broadly accepted that the innovation process would be leveraged by including external stakeholders from the early stages to create a competitive advantage. Meanwhile, users are also encouraged to be involved. However, the feasibility of such involvement is debated in the literature (2). The living labs are user-centric innovation tools that have become very prominent in recent years (3) to fulfill this vision.

Over the last two decades, numerous initiatives, organizations, and institutes have sprung up worldwide as “living labs.” Meanwhile, regional and national governments, as well as international bodies (i.e., European Commission) have cautiously supported the concept of “living labs” and included it in their work programs (4–6). Overall, the phenomenon of a living lab mainly refers to and supports the involvement of multiple stakeholders for the (co-) creation, application, and evaluation of innovation services or products within a real-life setting (7, 8). Currently, there are numerous living labs worldwide, but a higher concentration is observed in Europe (9).

There is no standard definition of the concept of the living lab. However, according to the European Network of Living Labs (ENoLL) (10), these are defined as “user-centered, open innovation ecosystems based on systematic user co-creation approach, integrating research and innovation processes in real life communities and settings” (10). ENoLL’s definition aligns with many definitions found in the literature. For example, the article by Leminen et al. (11) defines the living labs similarly as “physical regions or virtual realities in which stakeholders form public–private–people partnerships of firms, public agencies, universities, institutes, and users of products or services, all collaborating for creation, prototyping, validating, and testing of new technologies, services, products, and systems in real-life contexts.”

The living lab phenomenon embraces different contexts, for instance: the development of innovation activities driven by citizens aiming to improve everyday life, testing of technology-driven human-centric products from pharmaceutical companies, targeting to provide affordable and easy-to-use products to patients, or development of activities from NGOs, citizens, or other actors in developed societies (12). These differentiated actions may be initiated by various stakeholders (i.e., providers, users, and enablers), which impact the duration, focus, and outcomes of the innovation actions (11). Overall, the living labs offer a safe space for development, testing, and validation with co-creation in all stages, from conceptualization to commercialization (13). They are often characterized as testbeds for innovative solutions, systems, and products by providing a platform for collaboration (14, 15).

A living lab involves the following four main pillars:

- Co-creation: Co-design by users and producers.
- Exploration: Discovering emerging usages, behaviors, and market opportunities.
- Experimentation: Implementing live scenarios within communities of users.
- Evaluation: Assessment of concepts, products, and services according to socio-ergonomic, socio-cognitive, and socio-economic criteria.

It is worth noting that a core element of any living lab is sustainability, and there is a plethora of studies that have addressed this (16), but their perspectives differ. For example, some studies examine development and innovation activities that target to improve, in a sustainable way, the everyday life of citizens (12). At the same time, other studies explore transition labs that aim to accomplish change in sustainable development (17) or analyze the connection between living labs and sustainable innovation (13). Others investigate the role of processes, design, and practice in environmental transformation (18). Moreover, studies have also focused on sustainable development in smart city actions (19) and in entrepreneurship and urban development (20).

The existing literature gives a fruitful basis for understanding the potential and usefulness of living labs. This is due to their conceptualization and theorization (21), which further investigates the processes and methods followed (22), while also recording results from empirical studies (23–25). More specifically, Følstad (26) wrote the first review study, including 32 articles to establish theoretical foundations, methods, perspectives, and processes of a living lab. Later, Franz (27) developed an understanding of the phenomenon, which was socially centered. Schuurman et al. (5) reviewed 45 studies and concluded that practice and research in the living labs were still in the infant stages. Research in the existing literature from Leminen and Westerlund (28) established eight main research streams at the time. After reviewing 195 studies, Leminen et al. (6) aimed to understand the need around the emergence of the living labs movement. McLoughlin et al. (29) conducted a bibliometric analysis of 169 studies, while a more recent study by Westerlund et al. (30) performed topic modeling for 86 articles on the topic.

More recently, Hossain et al. (31) conducted a systematic review of 114 studies regarding living labs to gain an understanding of the main facets discussed in the developing literature. Notably, the study investigated the origin of a living lab and its key characteristics and paradigms, including contexts, stakeholder roles, main outcomes, challenges, and sustainability. It is notable that the literature in the living lab context has increased vastly since 2015, showing the urgency and advantages of the phenomenon. Scholarly studies discuss the living labs as infrastructures that could be utilized as novel tools for research opportunities to tackle needs and challenges in society (32). However, it is evident that the literature on living labs in the context of digital health and the linkage to innovation is still rather fragmented (33).

Traditional models of healthcare are experiencing significant pressure in the context of overwhelming strain on the existing systems due to the high demand for services from one side and limited funding from the other (34). As a result, an important opportunity for innovation in digital health has arisen. However, the market is currently leading in innovation in this space, but there is significant risk in bringing healthcare products and/or services that are not evidence-based to be consumed directly by the masses. “Disruption” is often proclaimed as the mark of any worthy innovation. However, this adopts a rather irresponsible view. In many cases, it is this irresponsible view that results in tensions between technologists and healthcare professionals (35).

The difficult issue of evidence-based digital health often rears its head, and it is a challenge not just for the technologists who are operating in a rather unfamiliar space but for the academics too. The bridge between academia and industry that aims to create links between the two sides is on the rise, but it is still not fully robust. Although the relationship seems simplistic, they function in parallel. Filling the gap through a

fully developed collaboration in research between the two can boost the economy and growth by preparing a much-needed workforce with the industry's required skills and products that are developed and evaluated through evidence-based academic methodologies (36). Given that digital health interventions are often sitting at the intersection of biomedical, behavioral, and computer science, not to mention the design and user experience components, technologists feel that the classical evaluation models do not do them justice. Enhancement by collaboration from different disciplines is urgently needed (37).

The benefits to be gained from the participation of end-user groups, local health and government organizations, voluntary sector organizations, technologists, and Academic Health Science Networks (AHSNs) cannot be overstated. As outlined in Greenhalgh et al. systematic review of the challenges related to adapting new technologies, there are many obstacles to sustaining technological change, many of them resulting from the complex adaptive systems that provide healthcare (38). From this review, the Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) framework was derived as a tool to explore and identify sustainable adoption and applicability of technological innovations in healthcare and social care. The living lab model provides an opportunity to explore this complexity and shed light on the wider system which is targeting to embed the change with evidence-based models. Genuine stakeholder participation can be used as a

tool for the ideation, development, and evaluation of digital health solutions toward optimizing the conditions within the system and refining the technology to match the requirements of the system. As a result, it will create a sustained and scalable technological change with rewards that are realized and provide benefits to all involved actors.

In this study, we present the setting up of a community-based Digital Health Living Lab (DHLL).

Living lab environment

The lab was the culmination of a national scheme, the Leading Places program, that had brought together the University of Brighton with Brighton and Hove City Council (39, 40). The Brighton project aimed to help develop strategies in self-managed care for older adults, for example, in the context of medication administration, self-monitoring and self-awareness, and self-management of the emotional impact of multiple comorbidities. Therefore, the team focused on a series of interventions for groups of people living in assisted sheltered accommodation to find ways to prevent or delay entry into more intensive and expensive care programs. The lab was developed as a response to address the difficult issue of evidence-based digital health supporting self-managed care and acting as a tool to be used by various stakeholders (41).



FIGURE 1
Digital health living lab.

The site chosen to establish the DHLL was a retirement housing scheme recommended by the city council as it meets the requirements in terms of residents' demographics and caring needs. Retirement housing schemes are complexes where senior citizens live independently. They are specifically designed for those over 55, providing easy access, and being efficient and ergonomic. They are maintained by the local council, which provides on-site managers responsible for the safety and day-to-day running of the complex and catering to residents' needs. The site is comprised of 108 flats split into three building blocks, seven stories each, and is linked by a ground floor corridor and communal rooms (Figure 1). Residents were invited to attend a launching event where the DHLL team presented the concept and aims of this initiative and invited them to consider participating by registering their interest and sharing their contact details, consenting to the DHLL contacting them in future, along with basic demographic data including gender and age. Regarding the resident's profile, 81% are 65 years and older, with 58 and 42% female and male subjects, respectively, and 70% with recorded disabilities.

Step-by-step approach

The literature describes different approaches and methodologies for living labs in other disciplines and sciences (i.e., environmental, green energy, and smart cities). Here, we present our experience and propose an approach directly related to setting up Digital Health Living Lab in the community (42–46).

One of the first decisions is the location that will “host” the living lab. According to our experience, this depends on the focus of the activities in relation to the main stakeholder. Considering that the citizen is always at the center of any activity, the site might be a building block: For example, the sheltered accommodation for our Empowercare project where the building block met the demographic requirements (main stakeholder citizen). If the main stakeholder is the local council, the DHLL can be a neighborhood where the diversity of civic life is more dependent on demographics (i.e., it may be related to environmental factors). It can be based on a community space (or even university dorms) where a group of citizens meet

TABLE 1 Scoping DHLL stakeholders' needs.

Citizens of the DHLL <ul style="list-style-type: none"> Wellbeing To live as independently as possible with support as needed Health and social care that is tailored to them Choices and the ability to make decisions around health and wellbeing Seen as an asset, not a burden (what can they do to help!) 	Carers/next of kin <ul style="list-style-type: none"> Their loved one is being cared for kindly and compassionately Promote independence but ensure safety and reassurance What can they do to help? 	Staff of DHLL (i.e., site managers of the building) <ul style="list-style-type: none"> Happy residents and happy staff Eager to help but need education and training Do not want additional responsibilities or workload
General health practitioners <ul style="list-style-type: none"> Improved health outcomes Reduced demand on their services Do not want additional responsibilities or workload 	Secondary care <ul style="list-style-type: none"> Improved health outcomes Reduced demand on their services Don't want additional responsibilities or workload 	Local government implementation plans <ul style="list-style-type: none"> Mandate to work on prevention and self-management, better integration of health and social care, and incorporate aspects of local digital roadmap.
Local council/municipality <ul style="list-style-type: none"> Improved health outcomes Reduced demand on services Needing to improve specific targets (falls/out-of-hours provision/ medication compliance) Mandate to work on prevention and self-management, better integration of health and social care, and incorporate aspects of local digital roadmaps Do not want additional responsibilities, workload, or financial commitments Incorporate digital health as a cornerstone of initiative Raise their profile through an effective and positive campaign 	Commissioners <ul style="list-style-type: none"> Improved health outcomes Reduced demand on services Needing to improve specific targets (falls/out-of-hours provision/medication compliance) Mandate to work on prevention and self-management, better integration of health and social care, and incorporate aspects of local digital roadmaps Incorporate digital health as a cornerstone of initiative Do not want additional responsibilities, workload, or financial commitments 	Academic institution <ul style="list-style-type: none"> Mandate to work more collaboratively with civic authorities through the “Leading Places” project Raise their profile through an effective and positive campaign Incorporate digital health as a cornerstone of initiative Research and publications Ways to incorporate project in the curriculum of health science students
Academic networks <ul style="list-style-type: none"> Mandate to work more collaboratively with NHS, academic institutions, and industry Raise their profile through an effective and positive campaign 	Digital innovators <ul style="list-style-type: none"> Learning and training through working alongside service users Innovation Raise their profile through an effective and positive campaign Commercialization 	Voluntary sector <ul style="list-style-type: none"> Keen to be involved and offer their perspective on health and social care Raise their profile through an effective and positive campaign May seek or offer funds depending on specific organization and nature of the relationship

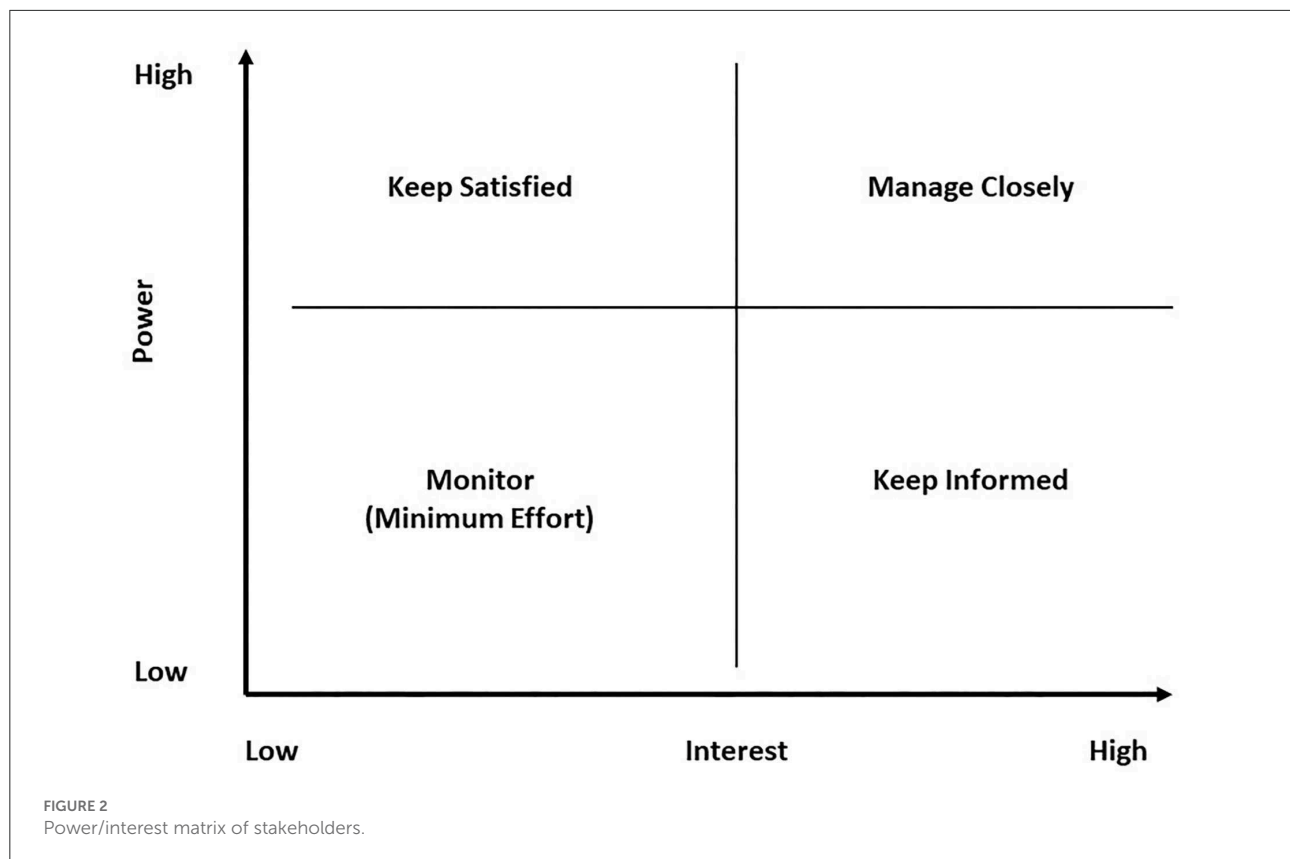


TABLE 2 Prioritization of stakeholders' needs.

		Timing (to address)	
		Now	Later
Activity	High priority	<ul style="list-style-type: none"> To live as independently as possible with support as needed in a safe manner with reassurance Choice and the power to make decisions around their own health and care needs with plans that are tailored to them Seen as an asset, not a burden (what can they do to help!) Their loved one is being cared for kindly and compassionately Do not want additional responsibilities or workload, or financial commitments 	<ul style="list-style-type: none"> Improved health outcomes and wellbeing Reduced demand on their services Raise their profile through an effective and positive campaign (commonality between multiple stakeholders raises its significance) Incorporate Digital Health as a cornerstone of initiative Incorporate project in the curriculum of health science students
	Low priority	<ul style="list-style-type: none"> Needing to improve specific targets (falls/out-of-hours provision/ medication compliance) Keen to be involved and offer their perspective on health and social care May seek or offer funds depending on specific organization and nature of the relationship 	<ul style="list-style-type: none"> Mandate to work on prevention and self-management, better integration of healthcare and social care, and incorporate aspects of local digital roadmaps more collaboratively with civic authorities through the "Leading Places" project, academic institutes, and industry Research and publications Learning and training through working alongside service users Innovation Commercialization

regularly. It can also be at a hospital ward when the main aim is disease orientated.

Once the location is determined, the next step is to create participants' profiles through interviews and understand stakeholder needs through co-production workshops. In Table 1, we present the different stakeholders and their needs from

the DHLL, followed by a further Power/interest matrix of stakeholders (Figure 2). Our approach to systematically identify the relevant stakeholders was informed by the study of Manzini (47) and followed the steps for stakeholder selection (48) as described in the AgriLink Living Lab Toolbox (49). Applying these guidelines, we started by defining stakeholders,

TABLE 3 DHLL projects.

Project	Funding body	Aim/content
EMPOWERCARE (EMPOWERing individuals & communities to manage their own CARE)	Interreg 2 seas	The project aims to create resilient communities and reduce individual frailty and loneliness by developing an approach using research-based solutions and technology to address gaps in the care of the target groups of those aged 65+ and those aged 50+ with at least one chronic condition. The DHLL is utilized as the tool providing a suitable environment to work along with citizens, carers, and healthcare professionals, co-creating, trialing and evaluating digital health solutions that would be able to be implemented across borders and healthcare systems.
AI4HealthSec (A Dynamic and Self-Organized Artificial Swarm Intelligence Solution for Security and Privacy Threats in Healthcare ICT Infrastructures)	HORIZON2020	AI4HEALTHSEC proposes a state-of-the-art solution that improves the detection and analysis of cyber-attacks and threats on Healthcare ICT infrastructures and increases the knowledge on the current cyber security and privacy risks within the digital Healthcare ecosystem and among the involved Health operators. As such, it is the first time a DHLL is being utilized as a pilot testing site for the development security framework



FIGURE 3
Activity tracker.

individuals, and organizations relevant to the living lab residents. The criterion of relevancy was based on the “position” of a citizen within the health and social care system in the UK and was defined as the type of relationship that affected directly or indirectly the residents’ lives. As such, we developed a list of stakeholders (Table 1) where the relationship might be direct (i.e., carers, neighbors, and DHLL staff) or indirect (i.e., general health practitioners, local council, and commissioners). The list was also informed by the residents themselves through 1-2-1 interviews exploring who and which

individuals and organizations they perceived as affecting their health and wellbeing.

Upon the completion of the stakeholder needs identification, we recommend prioritizing these needs reflecting the importance of the stakeholder in relation to the timeframe. In Table 2, we present an example of the prioritization of the needs of the DHLL stakeholders.

The next steps include regular project management activities, such as time framing (i.e., GANTT chart), risk analysis, and register, followed by the actual implementation of the activities (i.e., testing, evaluation, etc.).

Projects

Since the establishment of the DHLL, we have utilized it in several cross-disciplinary research projects, with two more notable recent European funded (Table 3). Within these projects, we had the chance to test and evaluate different technologies, including wearables (Figure 3) and smart glasses (Figure 4).

Case study

Sharing our experience working in the DHLL with industrial partners, here we present a case demonstrating how it can contribute to the development of a digital product, in this case, the Kraydel Konnect, throughout different stages of its maturity.

Konnect is an established, easy-to-use home communication system. The system connects the user’s TV with a communication hub using the HDMI port on the TV, and this hub connects to the internet *via* the User’s home Wi-Fi network or mobile 4G signals. The hub enables video calls by connecting with standard video-calling platforms (i.e., Vonage and Zoom) for TV-based video calling.

Konnect’s user interface is designed as a carousel system (i.e., the user cycles through options on their TV) which the user navigates through by simply responding with a “yes” or



FIGURE 4
Smart glasses.

“no” from the specially designed remote control. Kraydel has several user-related features, such as the ability to respond to questionnaires and surveys through the TV, which can be used to gather user-related insights such as wellbeing assessments. Callers can use the Konnect app on their smartphones (available for iOS and Android) to make video calls to the user’s TV. The system also offers so-called sofa-to-sofa communication. For example, any individual (relative, carer, and healthcare professional) who has a Konnect unit can make calls to the user’s TV from their own Konnect unit as long as the user allows access in advance. Users can also upload photos from their phones and upload videos through a dashboard that can be viewed on the TV.

Kraydel’s aim was to work with residents of the DHLL and through co-production workshops to share the first prototypes developed in their labs and receive end user’s input toward the further development and finalization of these early versions of their devices. As such initial prototypes (Figures 5, 6) of the Konnect units have been used by residents in the DHLL, providing valuable input and feedback for further adjustments.

The testing and development continued with further co-creation workshops, focus groups, and individual interviews (47–49) (Figure 7), ensuring the updated hardware design and

the user interface is easy and straightforward and do not provoke technophobia (Figure 8). The co-creation workshops took the shape of 1-2-1 sessions between residents and the developers’ devices, supported by user experience and design thinking professionals, exploring technical aspects (shape, materials, colors, usage, and dexterity). At the same time, the focus groups were utilized to gather qualitative feedback on usability feasibility and applicability from both the residents and additional stakeholders (in this case, DHLL staff, residents’ carers, and friends). In total, the project included two 1-2-1 sessions as described earlier and six focus groups.

The current Konnect version is also a wellbeing monitoring system that uses onboard sensors (for room temperature and physical movement in the TV room) and has Bluetooth capability with a wide range of third-party devices that are in the process of being integrated. Remote secure cloud for storage and processing of data and Application Programming Interfaces (APIs) connecting local devices to Konnect are already established for digital thermometers and pulse oximeters, and heart rate and to feed data to service provider personnel for remote assessment (Figures 9A, B).

As discussed earlier, existing literature (31) highlights the benefits of various types of living labs, like our DHLL.



FIGURE 5
Kraydel Konnect first prototype.



FIGURE 6
Kraydel Konnect remote control first prototype.

Lessons learned

In this case study, we share lessons learned from this development as well as some unique advantages linked to such a community-based DHLL:

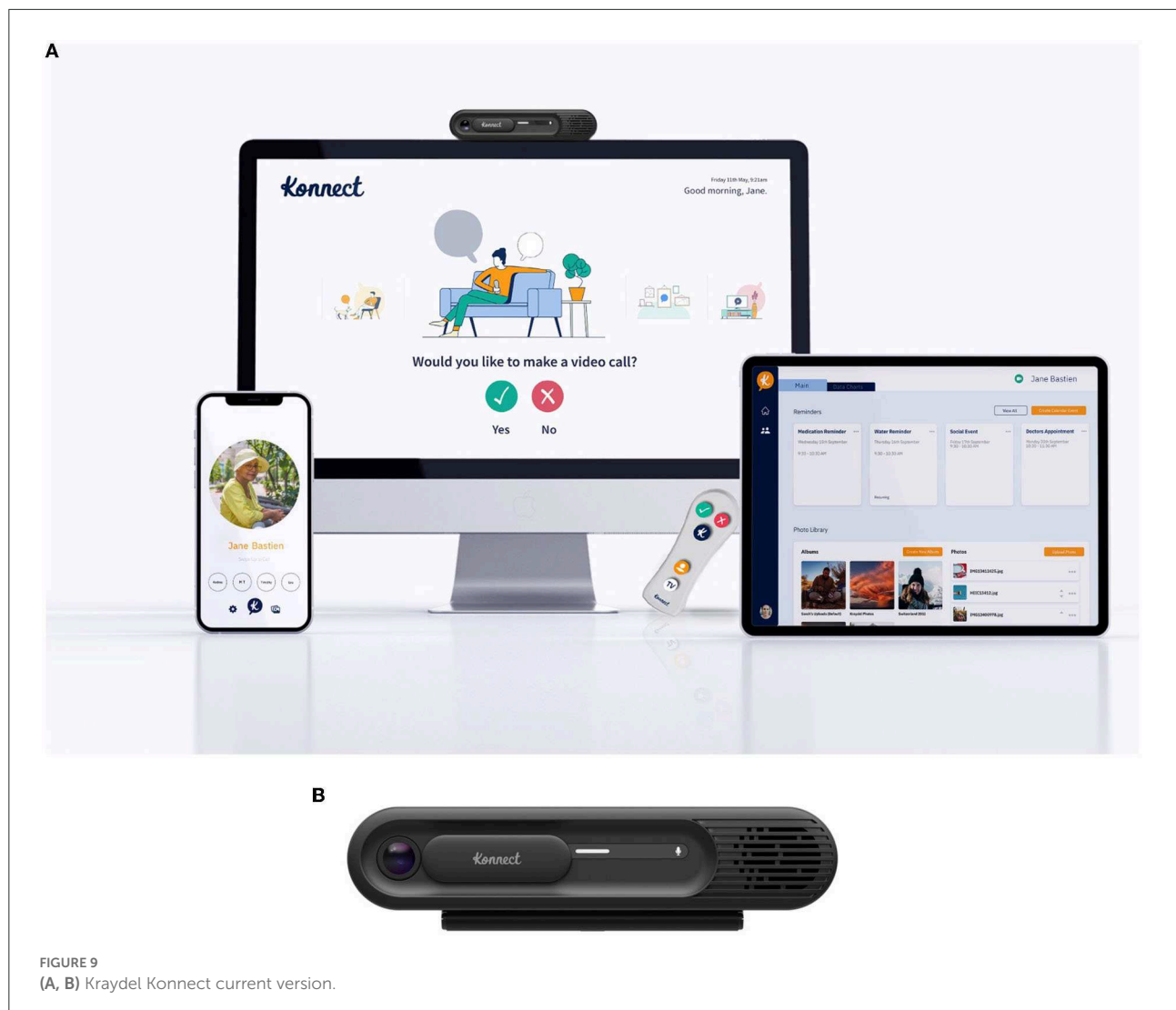
- Real-life environment. During our testing and evaluation activities, it became apparent that conducting these in participants' own homes provided a more original experience as reflected by their feedback.
- Costs. As discussed in the introduction, establishing an LL, for example, in a university environment or a municipality building, is accompanied by costs related to the actual room, facilities, maintenance, utility bills, and staff. On the contrary, our experience showed that establishing a DHLL in the community has the advantage of lower costs. It can be set up in an existing site without any additional costs for extra physical spaces and their accompanying expenses, such as utility bills and/or maintenance as these are covered by the local council. In our case, the used spaces for any of the scheduled activities are either the communal spaces or smaller rooms where we conduct interviews or focus groups.



FIGURE 7
Co-creation workshop.



FIGURE 8
Kraydel Konnect updated version.



- Sustainability. Further to the maintenance of the physical spaces of living labs, their sustainability requires the investment of personnel and time for traveling and transport, bringing participants together and keeping them engaged. In our case, an important advantage is a fact that the community-based DHLL is “self-sustained.” The group of participants engages in the labs’ activities in their own familiar spaces (homes and communal areas) without the need to travel to the university or to another site to continue networking with fellow residents even when there are no active projects. As a result, there is no need for continuous presence or visits of academic staff. In addition, the presence of on-site managers provides the advantage of fast recruitment and resuming of activities once a new project starts through the dissemination of any required material and invitations.

- A benefit for any SMEs utilizing such a DHLL is their opportunity to showcase their solutions directly to end users but also stakeholders, including commissioners and decision-makers.

Limitations

Setting and maintaining a living lab can be accompanied by many limitations, but in this case study, we have an opportunity to share our experience reflecting on a single development outside of having explored a summative project evaluation. Based on this experience, the team identified certain limitations that, if considered going forward, would expand the DHLL benefits.

One of the limitations is the demographics of the residents, where, although there is a diverse group of citizens living on this site, these might not represent the diverse community beyond the living lab. A way to mitigate this limitation would be by including more sites from areas across the council that would include hard-to-reach and/or vulnerable populations (i.e., minorities and learning disabilities).

Another limitation of this single development comes from the voluntary commitment of the residents. This results in working with residents that might already be tech-savvy and eager to contribute to such testing. This may exclude valuable input from no digitally literate citizens that hesitate to volunteer in such testing. A future solution could be to increase the number of living labs and provide incentives to potential participants.

Conclusion

In this single-case study, the DHLL proved to be an open innovation ecosystem as it brought together multiple stakeholders sourcing ideas for a small business enterprise, contributing effectively to the user-centered development of the described digital health solution. Following the approach shared in our article, we believe that establishing DHLLs in the community and engaging with the right stakeholders can be a streamlined and straightforward process with the subsequent benefits described.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Funding

The research conducted for this article was triggered by TE, KK, and HM involvement in the project A Dynamic and Self-Organized Artificial Swarm Intelligence Solution for Security and Privacy Threats in Healthcare ICT Infrastructures (AI4HEALTHSEC) under grant agreement no. 883273.

Acknowledgments

The authors are grateful for the financial support of this project which has received funding from the European Union's Horizon 2020 research and innovation programme. The authors wish to thank the Brighton & Hove City council for their valuable contribution to establishing the Digital Health Living Lab.

Conflict of interest

Author AF is employed by Kraydel Ltd. KK is employed by Trustilio B.V.

The remaining 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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OPEN ACCESS

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SPECIALTY SECTION

This article was submitted to
Digital Public Health,
a section of the journal
Frontiers in Public Health

RECEIVED 16 November 2022

ACCEPTED 06 January 2023

PUBLISHED 26 January 2023

CITATION

Hriberšek M, Eibensteiner F, Kapral L, Teufel A, Nawaz FA, Cenancovic M, Sai CS, Devkota HP, De R, Singla RK, Parvanov ED, Tsagkaris C, Atanasov AG and Schaden E (2023) "Loved ones are not 'visitors' in a patient's life"—The importance of including loved ones in the patient's hospital stay: An international Twitter study of #HospitalsTalkToLovedOnes in times of COVID-19. *Front. Public Health* 11:1100280. doi: 10.3389/fpubh.2023.1100280

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"Loved ones are not 'visitors' in a patient's life"—The importance of including loved ones in the patient's hospital stay: An international Twitter study of #HospitalsTalkToLovedOnes in times of COVID-19

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Background: Hospitals are institutions whose primary task is to treat patients. Family-centered care, which considers loved ones as equal partners in patient care, has been gaining recognition in the adult care setting. Our aim was to record experiences of and opinions on communication between hospital-based healthcare providers and patients' loved ones, related but not limited to the rigorous mitigation measures implemented during the COVID-19 pandemic.

Methods: The Twitter profile @HospitalsTalkTo and hashtag #HospitalsTalkToLovedOnes were created to interact with the Twitter public between 7 June 2021 and 7 February 2022. Conversations surrounding #HospitalsTalkToLovedOnes were extracted and subjected to natural language processing analysis using term frequency and Markov chain analysis. Qualitative thematic analysis was performed on the 10% most interacted tweets and of tweets mentioning "COVID" from a personal experience-based subset.

Results: We collected 4412 unique tweets made or interacted by 7040 Twitter users from 142 different countries. The most frequent words were patient, hospital, care, family, loved and communication. Thematic analysis revealed the importance of communication between patients, patients' loved ones and hospitals; showed that patients and their loved ones need support during a patient's hospital journey; and that pediatric care should be the gold standard for adult care. Visitation restrictions due to COVID-19 are just one barrier to communication, others are a lack of phone

signal, no space or time for asking questions, and a complex medical system. We formulate 3 recommendations to improve the inclusion of loved ones into the patient's hospital stay.

Conclusions: "Loved ones are not 'visitors' in a patient's life". Irrespective of COVID-19, patient's loved ones need to be included during the patient's hospital journey. Transparent communication and patient empowerment increase patient safety and improve the hospital experience for both the patients and their loved ones. Our findings underline the need for the concept of family-centered care to finally be implemented in adult nursing clinical practice.

KEYWORDS

family-centered care, doctor–patient relationship, hospital care, social media, visitation restrictions, patient experience, patient safety, crowdsourcing

1. Background

Hospitals are institutions whose primary task is treating patients, with specialized care given by expert healthcare teams. While the patient is the focus of the healthcare team, their loved ones (family/relatives/friends) also require attention. The inclusion of loved ones in a manner that allows collaboration between the patient, their loved ones, and the healthcare team is recognized in both the family-centered care (1) and shared decision making (2) models of healthcare provision. While originating in pediatrics (3), the value of family-centered care has also gained recognition in the adult care setting, with the Society of Critical Care Medicine releasing guidelines for family-centered care in the ICU (4) and first attempts being made toward developing a universal model of family-centered care (5). Furthermore, direct support from physicians and nurses for patients' loved ones is very important, with support strategies having been shown to reduce prolonged grief symptoms for relatives of patients dying in the intensive care unit (6).

In 2020, at the start of the global COVID-19 pandemic, hospitals implemented strict visitation restrictions intended to minimize hospital traffic and the spread of the virus. Their implementation created a situation which nullified the concept of family-centered care (7). In response, US and Europe created guidelines and toolboxes to uphold the standards of family-centered care (8) and family involvement (9) respectively. For infants and their parents and caregivers, there was also strong advocacy for a zero-separation policy in response to COVID-19 visitation restrictions (10).

The social distancing measures associated with the COVID-19 pandemic resulted in the significant shift to digital communications. Many conversations were transferred to a variety of social media channels, such as Twitter. Twitter allows users to create their own content, disseminate content from other Twitter users or other online material, and participate in discussions related to specific tweets or hashtags (#). All content can be publicly shared and read, while the use of hashtags makes the content searchable and discoverable and allows communities to be built around topics of interest, e.g., disease-specific hashtags about cancer care (11). While the first papers on the use of Twitter for health-related research were published in 2009, the publication count has increased rapidly since 2015 (12). Twitter can be used as a tool for promoting healthcare advocacy (13), gathering opinions on health topics through surveys (14), analyzing behavioral patterns within the society (15), and disseminating healthcare research through the use of hashtags (16).

It is also a very useful tool for public health research using methods such as content or network analysis (17).

Including lived experience and public opinion into research improves quality and impact of the research (18). Family-centered care is predominantly described from the healthcare and clinical significance perspective (1, 4, 5, 8, 19) while directly from the personal experience point-of-view, we found only one study from 2014 describing the inclusion of a daughter into her mother's hospital stay, however in a not so positive way (20). The main goal of this study was to explore the public's experiences of and opinions on communication between hospital-based healthcare providers and patients' loved ones, as related but not limited to the rigorous mitigation measures implemented during the COVID-19 pandemic.

2. Methods

2.1. Campaign development and outreach

This study was designed to explore the public's opinions regarding all aspects of priority to loved ones in a patient's hospital journey by leveraging Twitter as an easy tool for widespread outreach for crowdsourcing studies. We therefore conducted a campaign on Twitter to share relevant content regarding our research question and to actively engage in accruing discussions to explore the Twitter public's opinion more in-depth in a crowdsourcing style. We created the Twitter profile @HospitalsTalkTo to use as a professional front for the campaign and to share content using #HospitalsTalkToLovedOnes on the topic of involving loved ones in a patient's hospital journey. The campaign was conducted from 7 June 2021 to 7 February 2022 (end of the 3rd wave through to the middle of the 4th wave of COVID-19, northern hemisphere). Shared content included own material, relevant tweets of other Twitter users regarding our research question, relevant news, articles and other informational content and scientific papers (Supplementary Table S1). The Twitter profile was managed by MH while the other authors of this paper were asked to promote the visibility of #HospitalsTalkToLovedOnes. Occasionally, other Twitter users whose profiles indicated a connection to the healthcare setting were tagged in tweets as a means of gathering their opinion and increasing interaction and visibility within the Twitter community.

2.2. Data extraction

Using the Twitter API, tweets containing #HospitalsTalkToLovedOnes as well as the entire resulting conversation (i.e., all replies and quotes, as well as the replies and quotes to those tweets) created during the study period, were fetched. The following parameters were collected for each tweet: hyperlink, date of creation, rendered content, unique ID of the tweet, conversation ID (the unique ID of the first tweet in a thread), number of replies, number of likes, number of quotes, hashtags used, links to other websites, all media data and username of the author of the tweet.

Furthermore, the following information about the user who created the tweet and the users who responded to the tweet (replied, liked, retweeted or quote-tweeted) was collected for each tweet: username, unique user ID, joining date of the user, location as provided by the user, number of followers and number of accounts the user follows.

In addition to the set of all tweets, a subset of tweets was compiled which contained only tweets that were created by other Twitter users (excluding authors of this paper to ensure an unbiased view) in response to a tweet by @HospitalsTalkTo carrying #HospitalsTalkToLovedOnes. We used the parameter “links to other websites” to determine whether a tweet included a Twitter link or a link to another website. Differences between both datasets were tested using the Chi-squared test at an alpha of 0.05 using R software (21).

2.3. Data cleaning and analysis

Tweet processing, natural language analysis and further downstream analysis were conducted using R Software. Initially, retweets and tweets which contained only emojis, hashtags, hyperlinks and user references were removed. Then emojis, hashtags, hyperlinks, user references as well as names, academic titles, numbers, punctuation and common stop words [retrieved from the R package tidytext (22)] were removed from within each tweet. Words were manually harmonized by the authors to their infinitive (e.g., agrees/agree) or singular form (e.g., doctors/doctor) before the absolute and relative frequencies of single words and bigrams were calculated for both datasets, results were represented as word clouds.

Furthermore, from the dataset containing all tweets word bigrams were extracted and subjected to network analysis where each node represents a single word being part of at least one of the extracted bigrams and each directed edge the connection of the first and second word of these bigrams with opacity indicating absolute frequency of bigram occurrence. This results in a Markov chain display where the point of each arrow of each word depends on its previously occurring word. We conducted this Markov chain network representation of the most commonly occurring bigrams (more than three times) using the R package tidytext (22) as described in (23).

A smaller subset of tweets containing conversations in response to tweets shared by @HospitalsTalkTo only, was subjected to qualitative content analysis following Braun and Clarke (20). Thematic analysis were undertaken for tweets containing the word “COVID” and for the top 10% of the most interacted tweets (=sum of replies, likes, retweets and quote tweets). Two researchers (MH and AT) independently read the tweets and identified categories

for the parts that were relevant for involving loved ones in a patient’s hospital journey. This restrictive evaluation was carried out due to the large number of tweets. Main, overarching topics were identified to which the tweets were then allocated. A tweet could be allocated to more than one theme. Finally, the selected categories were compared again with the tweets to ensure that no important topic was overlooked.

User data was summarized using median and IQR (Interquartile range). Their locations were harmonized to the country level by the authors. Where more than one location was listed, only the first one was considered.

2.4. Ethical approval and informed consent

As Twitter is a public platform where the users agree to share their activity publicly, no informed consent or ethical approval was needed. We do not provide any account names or other personal information which might allow the possibility of individual identification.

3. Results

3.1. Tweet volume and interacting users

During the campaign, a total of 4,412 unique tweets were posted that used #HospitalsTalkToLovedOnes or were created as a response to a tweet carrying the hashtag. A total of 7,040 Twitter users created or interacted with the tweets and the Twitter profile @HospitalsTalkTo gained 1,045 followers during that time.

The interacting users had a median of 704 (IQR= 207.75–2268) followers and were following a median of 974 (IQR= 371–2495) other users. They have posted a median of 6,492 (IQR= 1,168.0–30,295.5) tweets and spent a median of 2,450 (IQR= 1,018.25–3,706.0) days on Twitter before the first tweet containing #HospitalsTalkToLovedOnes was posted. Of 7,040 users, 4,361 stated their location. Altogether, users from 142 different countries interacted with the hashtag or related tweets (Figure 1). Most users ($\geq 1\%$ of users) originated from the US, followed by the UK, Canada, India, Australia, Japan and Spain.

3.2. Source content in tweets

In the total tweet set, 41% (1,799/4,412) of tweets contained only text (own content), 37% (1,620/4,412) of tweets contained a link to a source originating from Twitter (another tweet) and 23% (993/4,412) contained an external source from the internet (scientific paper, news article, etc.). In the @HospitalsTalkTo dataset, 73% (587/806) of tweets contained only text, 25% (205/806) contained links to sources on Twitter and only 2% (14/806) contained links to external sources. All named frequencies were significantly different between the two data sets ($p < 0.01$).

3.3. Word frequency analysis

To gain more detailed insight into the content shared about #HospitalsTalkToLovedOnes, the tweets were analyzed by a language processing algorithm (see Methods: Data cleaning and analysis).

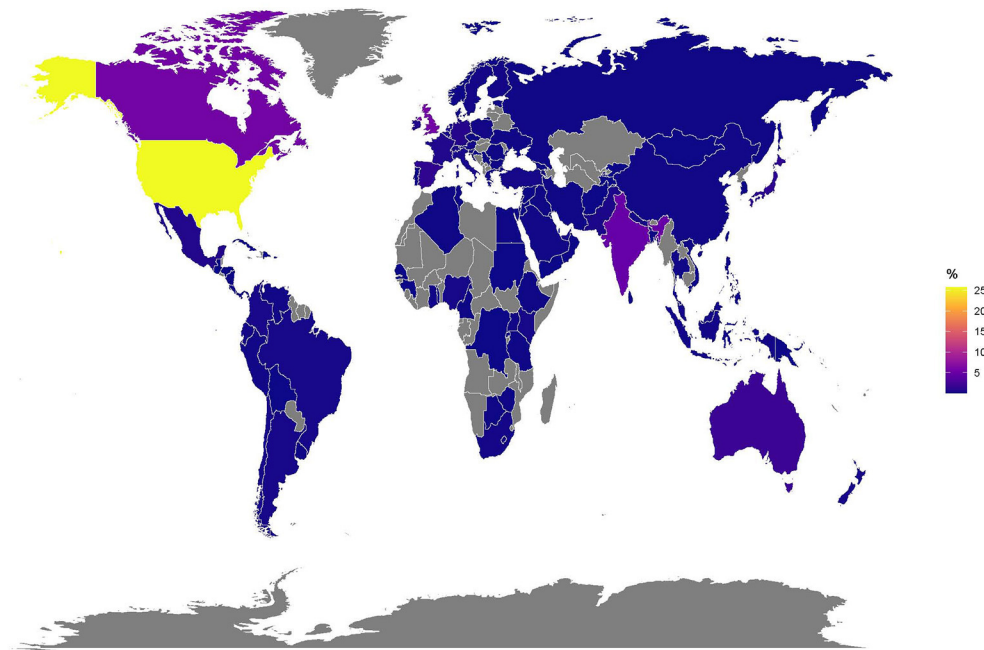


FIGURE 1
Locations of users who interacted with @HospitalsTalkTo or #HospitalsTalkToLovedOnes on a world map (N = 7040).

The whole dataset yielded 3,908 unique words from a pool of 34,536 words; the @HospitalsTalkTo dataset yielded 2,144 unique words from a pool of 9,029 words (Figure 2). Within both datasets, the most frequently used words were “patient”, “hospital”, “care”, “family”, “loved”, and “communication”, which present a good summary of #HospitalsTalkToLovedOnes (Figure 3). The @HospitalsTalkTo dataset also included the word “time” among those most frequently used, and was also very abundant in all tweets. In both datasets, other frequently occurring words were “experience”, “information”, “understand”, “visit”, “COVID-19” and words related to the reason for communication (“hear”, “support”), type of communication (“call”, “talk”), healthcare team (“doctor”, “nurse”), affected persons (“caregiver”, “child”, “mother”, “friend”), type of hospital stay (“surgery”, “ICU”), health status (“life”, “die”) and emotion (“love”, “feeling”).

The most common bigram among all tweets was “COVID-19 pandemic”, among the very common were also “COVID-19 patient” and “COVID-19 vaccination”. The most common bigrams within the @HospitalsTalkTo dataset were “shared decision”. In both datasets, there were bigrams related to the hospital system (“patient care”, “hospital staff”). Among all tweets, healthcare concepts (“family-centered care”, “digital health”, “patient safety”, “patient experience”, and “shared decision”) were frequently mentioned. The @HospitalsTalkTo dataset contained bigrams related to the type (“phone call”) and content (“break bad”, “bad news”) of communication and personas to communicate (“care team”, “life specialist”, “patient advocate”) displaying a more personal experience-based Twitter communication.

3.4. Markov chain analysis

Markov chain analysis with network representation of connections between frequently occurring words within the

whole dataset was done. In accordance with the largest word hubs, seven clusters were identified with respect to the thematic background and connectivity of these hubs. The central cluster is the hospital system with its most important players: nurses and doctors. It is surrounded by clusters relating to patients, loved ones, care, communication, health, and COVID-19 (Figure 4).

3.5. Qualitative analysis of the top tweets within the @HospitalsTalkTo dataset

Qualitative analysis of the top 10% tweets (= 81 tweets of 806) that gained between 22 and 928 interactions within the @HospitalsTalkTo dataset revealed seven prominent themes (Table 1). Seven tweets bore no relevance to healthcare (e.g., “I’m such a cliché”).

1. Communication between hospitals and loved ones is important (32/81).

Problems in obtaining information about a patient in the hospital were frequently mentioned. Barriers in communication were: “no signal in hospital rooms” and “hospital staff not having much time for giving updates”. A suggestion for improving communication was “there only being one designated loved one to communicate information to”. Digital communication tools were mentioned as being useful, e.g., an app that provides text updates on the status of surgery.

2. Needing/finding support as a loved one (24/81).

A patient’s hospital stay was reported as being very emotional and stressful for loved ones (“traumatic experience”, “pace and worry”, “excruciating”). There was a consensus that loved ones should be involved in a patient’s hospital stay as “Loved ones are not ‘visitors’

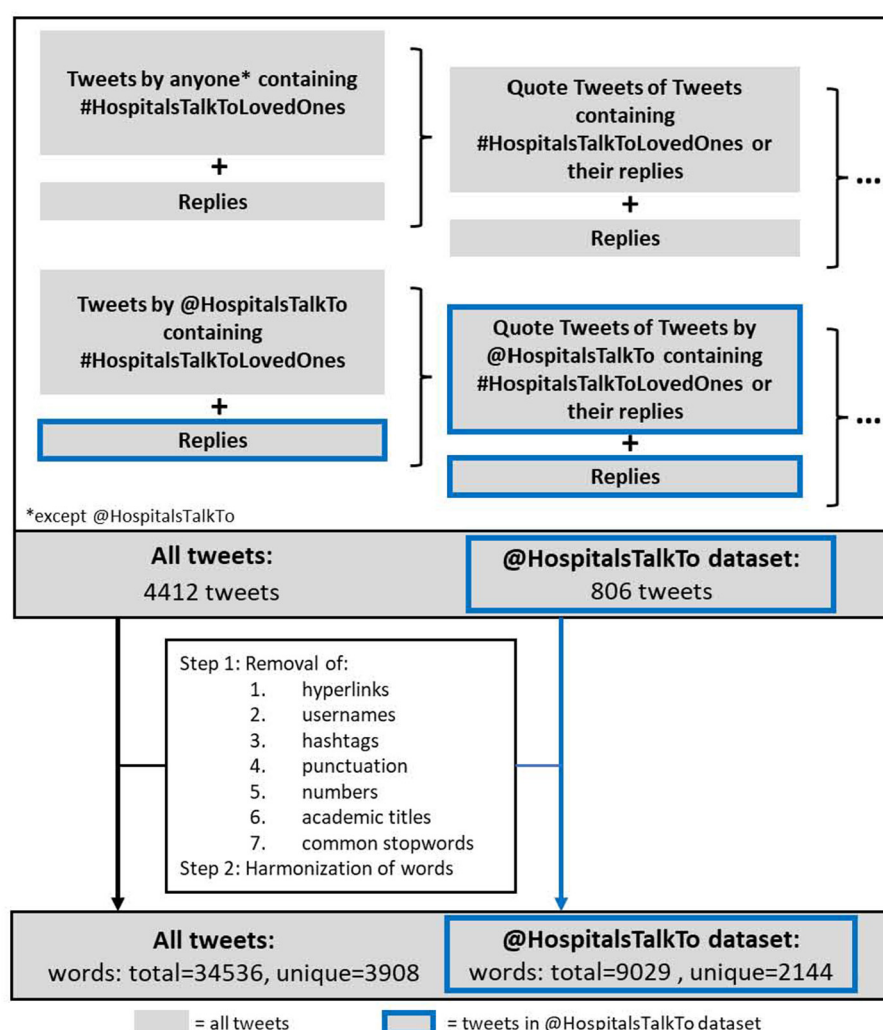


FIGURE 2

Tweet analysis flowchart. All tweets (=4412, gray) and tweets within the @HospitalsTalkTo dataset (=806, blue) were subjected to clean-up processing, resulting in 34536 words overall (3908 unique) for all tweets, and 9029 (2144 unique) within the @HospitalsTalkTo dataset.

in a patient's life". They are emotionally invested themselves and need support in their role.

3. Loved ones should have a place at the bedside (20/81).

The hardship of not being able to be at a patient's bedside when they are dying was recounted. Patients reported feeling frightened when waking up after surgery alone or wondering whether the PTSD from an ICU stay would be less severe with loved ones more present. There was an appreciation for hospital systems that allowed visitation.

4. The importance of human interaction (19/81).

The value of personal interaction was indicated as it can create the feeling of safety and value and can make a world of difference.

5. Healthcare system should support patients more (18/81).

The focus was also on patients and their need to experience more support ("we need adult life specialists") and empowering hospital healthcare professionals so they can trust and rely on the medical system and know how to navigate it in all its complexity.

6. Improving communication with patients (11/81).

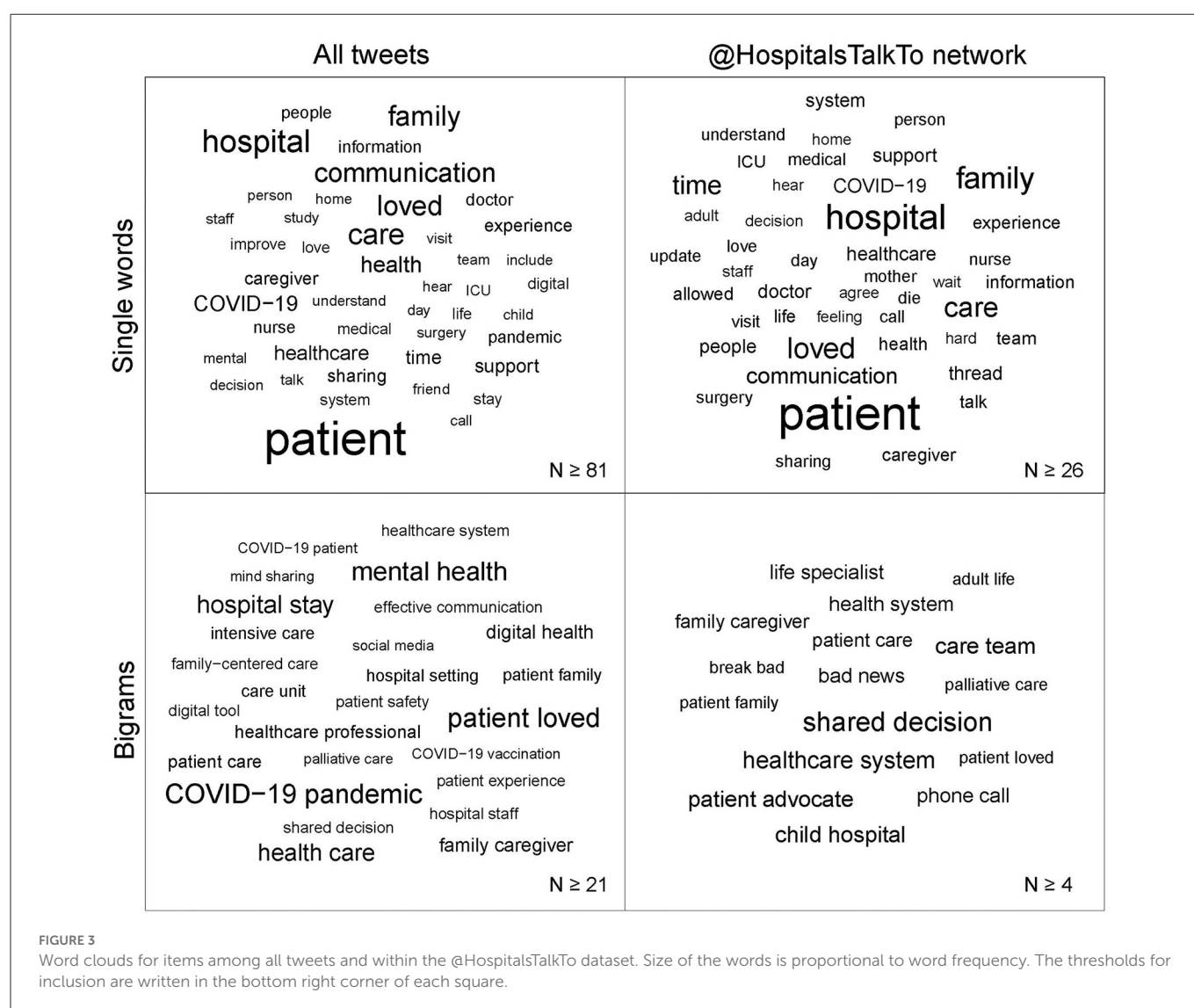
Users stated that patients shouldn't feel bad when asking questions and should gain a realistic expectation of the disease management and outcomes. Clear suggestions were offered regarding necessary communication with patients: "Knock, introduce yourself, describe what you are there to do, sit/slow down.", "Talk less...listen more".

7. Adult care should strive to be more like pediatric care (8/81).

Pediatric care was used as an example of how adult care should be, with Twitter users providing only positive examples of how pediatric care includes families (loved ones) and is sensitive to the patient's needs.

3.6. COVID-19 effects on communication

Qualitative analysis of tweets explicitly mentioning "COVID" within the @HospitalsTalkTo dataset yielded 41 (of 806) tweets,



which were allocated to three main themes (Table 2). Five tweets were not related to communication.

1. Visitation restrictions: implications for loved ones (24/41).

Twitter users described the hardship of hospital visitation restrictions. They reported not being able to see patients at all, trying to gather information through interns, or only being granted access because they themselves were doctors.

2. Visitation restrictions: implications for patients (13/41).

A Twitter user reported that her patient would “rather die than go back into hospital”. Another reported problems occurring due to her not being at the bedside to advocate and translate the patient’s needs to the healthcare team, which led to severe patient safety issues. Not being able to have visitors is increasingly hard on patients with depression and anxiety.

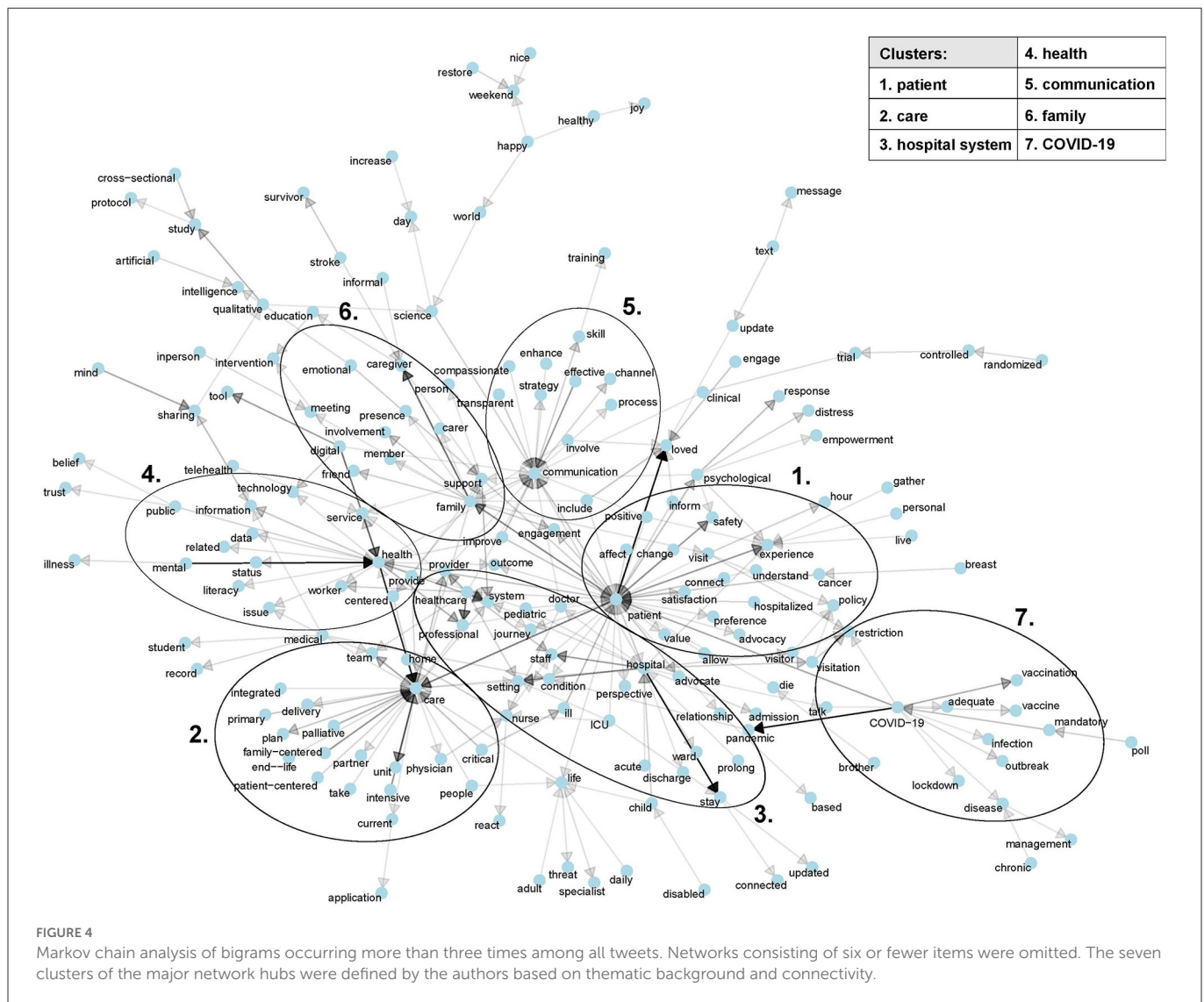
3. Visitation restrictions: implications on communication (13/41).

Some reported special measures adopted to inform patients’ loved ones, such as a nurse designated to only communicate with loved ones, and nurses getting instructions from patients about what

to communicate. However, there were also negative examples of physicians forgetting to update the loved ones, resulting in “We did not know if she was alive for 24h”. Communication was by text, video and phone call.

4. Discussion

This study underlines the importance of communication between hospital-based healthcare professionals and a patient’s loved ones in the context of, but not limited to, COVID-19-related hospital visitation restrictions. The main findings are: firstly, the need for communication between hospital-based healthcare professionals and a patient’s loved ones is global. Secondly, transparent communication and human interaction are an important part of a healthcare system and can be supported by digital communications. Thirdly, pediatric care should be the gold standard for adult care as a model of incorporating loved ones into family-centered care. Finally, hospital visitation restrictions are harmful both to patients and their loved ones, with patients feeling lonely, not having their loved ones to advocate and explain their needs to the healthcare team, or even refusing to go to hospital to seek treatment.



The experience of loved ones, as well as patients, is strongly influenced by “mepathy”, i.e., it is only after the personal experience of a hospital stay that the problems and potential areas of improvement are acknowledged. Moreover, the contribution of loved ones to patient care usually goes unrecognized (24). Testimonials based on personal experience of the importance of including loved ones have been published by impactful medical journals of different specialities:

“Through my family tragedy, it became clear to me that the environment in our ICUs often serves the convenience of the staff who work in the ICU, rather than the critically ill patients and their loved ones who are, as a family unit, the objects of our care.” Dr. Levy, Critical Care Medicine, 2007 (25)

“Those of us who have survived trauma need our healthcare providers to meet us in our Quiet Place. We need them to find their way into that dark chamber, light a candle, and fill it with the words that build a bridge for us to walk out.” Ms. Flanary, MA (wife to internet comedian Dr. Glaucomflecken), Journal of Cardiac Failure, 2021 (26)

Currently, efforts are being focused on meeting the needs of the loved ones of patients on intensive care units. Although missed opportunities are common (27), systematic support strategies for loved ones are being developed to change this situation (6). In the US, the needs of loved ones are also addressed during the time surrounding surgery (28–30). However, as our data and the literature (20) shows, most loved ones’ needs are not being met and are often overlooked, especially outside the intensive care setting.

4.1. COVID-19 effects on inclusion of loved ones into hospital stays of patients

Strict visitation restrictions during COVID-19 impacted the hospital care and were discussed on Twitter. Our data shows that alternatives to personal communication at bedside with the aim to include loved ones into patients’ hospital stays were varying. There were reports of designated nurses in charge of communicating with loved ones, of failures in communicating that a surgery went well and subsequently loved ones not knowing for 24 h if the patient was

TABLE 1 Tweets representative of the seven main topics mentioned in the top 10% of tweets within the @HospitalsTalkTo dataset.

<p>Communication between hospitals and patients' loved ones is important (32/81)</p> <ul style="list-style-type: none"> • “If you're a doctor reading this, be the bridge that connects your patients to their families [...]” <p>Barriers of communication</p> <ul style="list-style-type: none"> • “It was probably an innocent oversight, but this turned into a traumatizing problem for me during what was already the most traumatic event of my life. Please, never make anyone wait alone with no signal in a situation like this.” • “As a nurse I'm happy to talk to the family, but I'm often so busy that I have to schedule it. [...]” <p>How to improve communication</p> <ul style="list-style-type: none"> • “[...] It also helps if there's a single point person & not 4-6 family all calling at different times asking for the same info.” <p>Digital communication tools</p> <ul style="list-style-type: none"> • “When our son had surgeries (children's hospital) there was an app that provided text updates as well as a person that would go between ORs and waiting room to update. It was wonderful! [...]”
<p>Needing/finding support as a loved one (24/81)</p> <ul style="list-style-type: none"> • “Loved ones are not ‘visitors’ in a patient's life.” • “Don't be afraid to call and ask! It may take all night, but you have the right to know what's going on” • “1. Don't neglect yourself; 2. Fortify yourself emotionally; 3. Rely on others.” • “[...] It's so NOT simple to die at home: unpaid, untrained, anxiety-ridden family caregivers (who may also be the Proxy, facing push-back) get scared, overwhelmed and unable to cope.” • “No one calls to give updates. You pace and worry.” • “[...] Sitting in a waiting room most always excruciating for loved one(s). [...]”
<p>Loved ones should have a place at the bedside (20/81)</p> <ul style="list-style-type: none"> • “It's heartbreaking to sit at home because your loved one is taken to hospital by ambulance and you not allowed in. [...] We lost our precious last hours being apart. No final words of comfort.” • “I was hospitalized for open heart surgery when the pandemic first hit in 2020. Imagine, I had to take an Uber to the hospital at 4:30 a.m., by myself, as no family could enter the hospital. When I woke up in recovery, no one was there waiting to see me. [...]” • “I sometimes wonder if the PTSD from all my ICU stays would be significantly less severe if my loved ones were always allowed to be there.” • “When I was in the ICU, the hospital allowed [...] to come, sit with me and talk to me. He was in full PPE and just his presence made a world of difference to me emotionally & am sure that helped with my recovery too. Please allow loved ones.” • “Having a #Caregiver or friend at the bedside to advocate or soothe is essential to patients' health. [...]”
<p>The importance of human interaction (19/81)</p> <ul style="list-style-type: none"> • “[...] As humans our relationships sustain us, help us grow, heal, feel safe. [...]” • “[...] A personal touch is very important apart from the treatment given by doctor!” • “Communication during care is important also because it helps the grieving process. If our doubts/fears/questions are addressed we have more peace (trust) overall which in the long run is good for everyone involved.” • “[...] Cut off from loved ones, my mother was allowed to see me for just 15 mins. Seeing her though made the world of difference.”
<p>Healthcare system should support patients more (18/81)</p> <ul style="list-style-type: none"> • “I was shocked [...] by how isolated and powerless I felt as a patient. And this was despite the fact that I was a physician at the hospital where I was admitted! We need to do more to support and empower our patients.” • “[...] When you are dependent on care and you don't get the info and support you need, when the healthcare system doesn't listen to your concerns, it's a betrayal of trust. [...]” • “[...] we need adult life specialists who help us not traumatize adults with procedures and help people cope with hospitalization!” • “I think the reality is that when you or a loved one are sick the medical system is a complex, confusing, and scary place and we don't do enough to acknowledge and help with that”
<p>Communication with patients is important (11/81)</p> <ul style="list-style-type: none"> • “When patients apologize for “bothering” me, I feel awful; experience taught them I'll be annoyed or think their concerns are foolish. No. They trusted our care team to take good care of them; we need to see the job through.” • “Clear picture painted for them about what it will be like going home, how will the illness behave, what will be the anticipated hurdles & milestones. How to prepare for the twists & turns of the illness. Honest, realistic, informed picture.” • “[...] Knock, introduce yourself, describe what you are there to do, sit/slow down. Applies to all settings!” • “Talk less...listen more. This is the space where the real stuff happens.”
<p>Adult care should strive to be more like pediatric care (8/81)</p> <ul style="list-style-type: none"> • “[...] As a pediatrician I'm often struck by how I wish my adult care was more like pediatrics” • “[...] there are many ways that adults ARE just big kids! We in the grown-up world need to be better at considering the whole person, the social context, and emotional suffering.” • “I once had to get imaging at a children's hospital [...]. A child life specialist came and explained to me what was going to happen and what the contrast injection would feel like. It was amazing!”

Quotation marks represent (excerpts) of original tweets. Some tweets were corrected for grammar.

alive, and of a patient saying they would rather die than go back to the hospital. Overall, visitation restrictions were traumatic and had negative influences on all involved: patients, loved ones and hospital staff (9, 31–34) and limited to nullified the possibility of providing family-centered care (7, 9). Instead of complete visitation restrictions, visitations should be treated as a limited yet highly important

resource (7) and independent committees should be allocated to manage them (35, 36).

Family-centered care needs to adapt to include strategies regarding the inclusion of loved ones that are not physically present at bedside, either due to pandemic conditions (31, 36), seasonal influenza (37) or lack of means or opportunities on the side of

TABLE 2 Tweets representative of the three main topics which mention COVID-19 within the @HospitalsTalkTo dataset.

Visitation restrictions: implications for loved ones (24/41)
<ul style="list-style-type: none"> • “One of my patients lost her fiancé to COVID. He had been admitted to the hospital. She could only visit once a day for 15 mins. When he was admitted to ICU she could no longer visit him. He had to die alone, and she never got to tell him goodbye. She needed to see him.” • “[...] Hospital had rules for visitation of COVID patients. Nobody was allowed to. We even tried through interns there to check [...]” • “[...] luckily allowed to visit as a special exception was granted due to my being a physician. No other visitors were allowed due to COVID19 restrictions. [...]” • “I recently had surgery, COVID rules meant he wasn’t allowed to set foot inside, either to drop off or collect. This broke the handover process on “how to find out how your loved one is going” [...]”
Visitation restrictions: implications for patients (13/41)
<ul style="list-style-type: none"> • “A 80+ year old patient of mine said he’d rather die than go back into hospital after being in last year (non-COVID) during time of no visitors. He felt like he was going to go crazy not being able to see people. [...]” • “Sometimes they need to see a friendly face and someone to care. Hospitals are short staffed, and doctors have little time to spend with patients. [...]” • “[...] If a person has depression or anxiety being alone while being hospitalized makes it worse. [...]” • “My near deaf husband in SICU during COVID couldn’t communicate clearly with staff who didn’t know how to work with him. Had I been allowed to be there the staff would have benefited from my help. Instead he was traumatized & terrorized by one nurse who lost it”
Visitation restrictions: implications on communication (13/41)
Personal communication by healthcare professionals <ul style="list-style-type: none"> • “During the peaks of COVID-19 our ITU had a senior nurse each day dedicated to phoning relatives and giving them updates.” • “I always get permission before talking to family members; a lot of times COVID patients don’t want us talking. [...]” • “The surgeon forgot to call my mom to let her know the surgery went OK, and my aunt was too sedated to be able to call. We did not know if she was alive for ~24 h.”
Communication technology
<ul style="list-style-type: none"> • “[...] I relied on video call to connect to my dad regularly and make him emotionally fit.” • “[...] They had a texting service with updates and it was such an anxiety reducer for me especially in the age of COVID-19. [...]”

Quotation marks represent (excerpts) of original tweets. Some tweets were corrected for grammar.

loved ones. This was the first pandemic where digital and telehealth tools were used to support phone-call based communication. Virtual visiting was shown to reduce loved ones’ anxiety, benefit patient recovery and staff morale (32, 38). It seems only reasonable for hospitals to invest in and routinely adopt digital and telehealth tools to uphold and offer robust and inclusive family-centered care irrespective of the circumstances.

4.2. Recommendations for better including patient’s loved ones in the hospital stay

Based on the experiences and wishes gathered through our #HospitalsTalkToLovedOnes campaign, we have formulated three recommendations to establish better communication between hospitals and patients’ loved ones.

1. Establishing a reliable communication channel and allowing loved ones at the bedside.

The Twitter community provided suggestions for better including patients’ loved ones: by guaranteeing a stable phone connection in areas where patients or loved ones are waiting or staying; having only one designated loved one to manage all communication; and sending text updates. There was strong advocacy for allowing loved ones at the bedside, their absence being associated with anxiety, fear, PTSD, and mourning the missed opportunity to say goodbye. Studies from the intensive care unit from the perspective of patients, loved ones and healthcare professionals (39, 40) support an open visitation policy. We are aware of the significant pressure hospitals are under, both during COVID-19 and on an everyday basis, however, in hindsight and going forward, hospitals should prioritize and allocate staff to

managing communication with loved ones. One example given by Twitter users was having a nurse dedicated to phoning relatives and giving them updates. Special bespoke teams have been positively accepted by loved ones during COVID-19 (41). Furthermore, creating room for communication with loved ones also positively affects the healthcare team (42).

2. Embracing digital communication tools.

Irrespective of COVID-19 visitation restrictions, strategies are needed to involve loved ones who cannot be physically present in the hospital (due to work, distance, personal reasons, etc.). Even before COVID-19, in the US digital communication between hospitals and a patient’s loved ones took place around the time of surgery through the use of perioperative messengers (30, 43). Further development of digital communication tools (44, 45), virtual visiting options (32, 38) and patient portals (46–48) has huge potential to help alleviate non-communication or support current forms of communication both with patients and loved ones. However, in purely online communication, attention must be paid to the quality of communication, as the quality of diagnosis information exchange affects patient initiative and the quality of physician treatment recommendations (49).

3. Applying the principles of pediatric care to an adult care setting.

People want adult healthcare to be more like pediatric care. While pediatric care relies on family-centered care (19) and shared decision making (50), adult care requires a high degree of patient autonomy and independent skills, and provides few interdisciplinary resources and support (51). The contrast is clearly demonstrated during the transition from pediatric to adult care (52, 53). To a large degree, our results coincide with the guidelines created to apply family-centered care at the neonatal, pediatric and adult ICU (4).

Our study supports the need for family-centered care in the adult setting, not just from the perspective of loved ones' involvement (5), but also to achieve a more holistic approach which considers all the patient's needs—physical, social, and emotional. As navigating any healthcare system is complex and confusing, Twitter users raised the idea of implementing adult life specialists: these act as a support person, explain the proceedings to the patient and their loved ones, and advocate for the patient in the hospital. This idea is based on child life specialists—professionals who work with children, helping them understand and cope with illness or hospitalization and striving to alleviate their stress and anxiety (54, 55). Support strategies as described by Kentish-Barnes et al. (6) are a step in that direction, although such strategies also need to be developed outside the end-of-life, intensive care setting.

4.3. Strengths and limitations

One of the major strengths of our study is the integrative knowledge and experience transfer between individuals from all over the world. Online communities on Twitter can serve as a source of health information transfer and practice exchange (56). Social media campaigns, including on Twitter, are also likely to improve care for patients (57). However, there are some limitations associated with Twitter studies. First, a self-selection bias is unavoidable as only Twitter users can interact and contribute to the conversation. Secondly, there is no transparency as to who see the tweets and to whom the Twitter algorithm promotes the tweets in the Twitter feed. Twitter hashtag communities provide more transparency and clustering of topics, however, one needs to know the hashtag to be able to search for it. Thirdly, our study is limited in its power to express the content of tweets using single words and bigrams with respect to the holistic experiences and opinions shared. This we have counteracted by applying a qualitative thematic analysis of tweets and providing direct quotes from those tweets. Lastly, there are no established success metrics for social media studies, and a scoping review from 2021 identified only a few studies on the public health community's use of social media for policy advocacy over the last decade (58). Our study combines views of patients, loved ones and hospital based healthcare professionals, achieving international interaction. The study strongly supports active communication with and integration of loved ones into the patients' hospital stays.

4.4. Conclusion

“Loved ones are not ‘visitors’ in a patient’s life” and hospitals must include them in the patient’s hospital journey. Our data shows the public’s experiences regarding not only but also COVID-visitation restriction related loved ones’ involvement in hospital stays of patients and wish for more inclusion, transparency, communication, and importance of being at bedside, which to a high degree overlaps with the objectives of family-centered care. We conclude that while the theoretical basis is already in place, family-centered care is lacking in application. Finishing with a statement by a Twitter user, “If you’re a doctor [or any kind of hospital-based healthcare professional or decision maker] reading this, be the bridge that connects your patients to their families”.

Data availability statement

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

Ethics statement

Twitter is a public platform where the users agree to share their activity publicly, therefore no informed consent or ethical approval was needed. We do not provide any account names or other personal information which might allow the possibility of individual identification. Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent from the participants' legal guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements. Written informed consent was not obtained from the individual(s), nor the minor(s)' legal guardian/next of kin, for the publication of any potentially identifiable images or data included in this article.

Author contributions

MH, AGA, and ES conceptualized and designed the study and were responsible for the decision to submit the manuscript. MH was leading the Twitter campaign and MH drafted the manuscript. FAN, MC, CSS, HPD, RD, RKS, EDP, CT, and AGA supported the Twitter campaign. LK extracted the data from Twitter. MH and LK verified the underlying data. FE and MH analyzed the data. FE, MH, AT, and ES interpreted the data. All authors had full access to all the data in the study, had final responsibility for the decision to submit for publication, participated in the critical review of the manuscript, read, and approved the final manuscript.

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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Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2023.1100280/full#supplementary-material>

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RECEIVED 18 March 2023

ACCEPTED 18 April 2023

PUBLISHED 12 May 2023

CITATION

Viano C, Tsardanidis G, Dorato L, Ruggeri A,
Zanasi A, Zgeras G, Mylona V, Efthymiou I and
Vlachokyriakos V (2023) Living labs for civic
technologies: a case study. Community
infrastructuring for a volunteer firefighting
service.

Front. Public Health 11:1189226.

doi: 10.3389/fpubh.2023.1189226

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Living labs for civic technologies: a case study. Community infrastructuring for a volunteer firefighting service

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Digital technologies are increasingly adopted and developed in living labs, to support and enable co-production processes around wellbeing related public services. This research report presents the case of one of the local laboratories established by the European project NLAB4CIT, in the city of Kaisariani, Greece. In order to enhance community engagement, participatory design methods are applied under an “infrastructuring” notion; the living lab model is reapproached as community infrastructure; and digital tools are understood as civic technologies. The article reports on the initial co-design phases, in order to provide other living labs on digital co-production with an overview on the socio-technical challenges encountered. These challenges concern how community actors can engage in the process of co-production of public services, and how digital technologies can be introduced to this purpose. Strength factors emerge such as the existence of an already active community, the creation of an enduring space of collaboration between researchers and citizens, and a civic approach to technology that makes them accessible and tailored. Open challenges concern the role of the public administration, the extent to which technologies are actually co-designed and co-developed, and some technical issues such as internet accessibility.

KEYWORDS

civic digital technologies, service co-production, community infrastructuring, civil protection, environmental protection, participatory design, urban living labs

1. Introduction

All over Europe, various living lab (LL) initiatives are being implemented to address quality of life issues, by exploring digital solutions together with the concerned citizens. The European project NLAB4CIT¹ aims to engage with citizens in the co-production of public services through digital technologies at local level, so that services are more responsive to emerging social needs. The project is expected to set up a network of Local Laboratories on civic technologies, starting from three laboratories in the cities of Collegno (Italy), Roeselare (Belgium), and Kaisariani (Greece).

The three laboratories have in common the focus on citizens' active participation for maintaining and developing physical spaces, such as public gardens and parks (in Collegno), kindergartens (in Roeselare), and forests (in Kaisariani). These (peri)urban spaces provide communities with assets such as air quality, climate protection, and spaces for physical activities and where people can gather for social and cultural activities. They are an important resource contributing to the quality of life of urban inhabitants, and to their wellbeing. The latter is meant not only as physical and mental health, but also in terms of emotional and relational benefits coming from participation in the local community, and from access to services that are perceived respondent to one's needs. This focus on a broader meaning of wellbeing is mirrored in the overall orientation of the NLAB4CIT labs. Like LLs in general, these labs emphasize multistakeholder co-production and digital innovation. However, the latter is functional to the former: digital tools are supporting or enabling instruments toward the restructuring of governance processes. Conversely, LLs on digital health and wellbeing are in most cases focused on the user-centered co-creation and testing of digital platforms and devices for the health system [see for instance (1–5)]. This article aims at complementing this kind of product-centered approach, offering insights on methodologies that address the community and dynamics in which the digital tools are introduced.

This article presents the Kaisariani Local Lab, on volunteer services for forest protection against fires. In this case, participatory design methods are applied under an “infrastructuring” notion (see section 2.1 for references). The LL is reappraised as community infrastructure. The research questions that guide this experimentation are (a) how stakeholders can engage in this local lab environment to co-produce public services, and (b) how digital technologies can be introduced to this purpose. This article reports on the socio-technical challenges encountered during the initial phases of the experiment, which is still ongoing. Section 2 of this article sets the theoretical background for the adopted methodologies. Section 3 describes the context, and the methodology adopted in the local lab. Results are presented in Section 4, and related socio-technical challenges discussed in section 5.

2. Background

2.1. Participatory design and infrastructures

Of relevance for LL approaches to citizen engagement, are the notions of “information infrastructures” and the practice of “infrastructure-ing.” The notion of infrastructure in Participatory Design (PD) refers to the substance rather than substrate of information systems (6), to make visible what remains unnoticed and in the background (7, 8). “Infrastructure-ing” is defined by Karasti et al. as an attempt to underline the processual, ongoing quality of such participatory activities, and can be a way of advancing community interests through integrating design activities for extended periods within local communities (9, 10). Such activities, instead of focusing on the target artifact or service, are mainly concerned with its situated and contextual socio-political parameters (11).

Of particular relevance to our work, is the work of the Malmö Living Labs (12, 13). Here, infrastructuring is construed as a long-term platform for social innovation. Through embedded LLs, relationships and engagements are developed with local communities. Similarly, in past related work (14), the authors developed an approach for the emergence of community solidarity practices and methods for infrastructuring social innovation (15). The authors bring the focus on the negotiations (and agonistic processes) that took place between researchers, local communities, and other civic actors; and on participatory methods and strategies that create the conditions for civic-led co-production. The project reported in this article is an attempt to further unpack the complexities at play in these negotiations.

2.2. (Urban) living labs as community infrastructures

Living labs (LLs) are one of the most common approaches through which community infrastructures take place. LLs are broadly defined as real-life test and experimentation environments and ecosystems (16), and as physical regions or virtual realities (17) for the creation, testing, and validation of new products, services, and technologies (18). Major networks and international initiatives, such as the European Network of Living Labs (ENOLL), identify five key components: (a) active user involvement, (b) co-creation approach, (c) real-life settings, (d) multi-stakeholder participation, and (f) a multi-method approach (19, 20). For an extensive overview of the concept of LL and its origin and paradigms, we refer to a review by Hossain et al. (21). LLs overlap with other types of collaborative innovation where the public plays an important role, such as innovation labs (18, 22) and policy labs (23).

Another definition is that of Urban Living Labs (ULLs) (24, 25). This resonates with the understanding of community and information infrastructure mentioned above, due to the focus on socio-political contexts and processes. Their core components are: (a) geographical embeddedness; (b) intentional ongoing evaluation and learning, through municipalities-researchers partnerships; (c) citizens participation; and (d) alternative modes of leadership to those of the private sector and traditional urban planning (26, 27). Rather than focusing on digital technologies and their users, the attention is on change in governance and policies, on geographical situatedness (28), and on the active role of citizens (29).

¹ Network of Laboratories for Civic Technologies Co-Production: Digital Services for the Public Administrations of the Future, www.nlab4cit.eu. Funded under the Preparatory Action: Smart local administration using IoT, AI, VR and Machine Learning tools to get closer and more present to the citizen (CNECT/2020/3855995), launched in July 2020 by the European Commission Directorate-General for Communications Networks, Content and Technology.

2.3. Digital co-production

In this project, our attempts to establish a local LL, as an infrastructure for the community, aims to create the conditions for digital co-production. Scholars in policy analysis and public management (30–33) understand digital co-production as the collaboration between citizens, government and other actors, improved, supported or enabled by digital tools in the different stages of service delivery. However, it is observed that participation is often limited to the design and monitoring of the service, and to the “citizen-sourcing” (30) mode of collaboration between citizens and government, rather than contributing to the actual delivery of services (30, 34, 35). The same happens with ULLs, due to their experimental nature (34).

In order to address these limits, useful approaches come from recent works on co-production, in fields such as Human-Centered Design (HCD) and Human-Computer Interaction (HCI). The recent civic turn in such fields [e.g., (20, 36–38)] has seen a proliferation of research concerned with developing socio-technical tools and processes aiming to support dialogs and collaborations between civics and between civics and institutions. Research in this area is motivated by aspirations to advance equitable societies through fostering civic engagement, in areas such as, among others, local politics (39, 40), social innovation (12, 15, 41), and grassroots civic advocacy initiatives (14, 39, 42, 43).

3. Context and methods

3.1. The NLAB4CIT local labs and the Kaisarieni context

The three local labs of the NLAB4CIT project combine the concept of digitally enabled co-production (30–33) and of digital civic technologies (32, 41, 44). The labs are defined as local in order to focus on their geographical, social and political situatedness, as in ULLs. The innovation processes revolve around the co-production of services of public interest, rather than on market-oriented improvement of digital products. Services can either be provided by the public administrations, or by the civil society supported in different ways by the public actor. A broad understanding of “lab” is adopted, acknowledging that the modes through which civic technologies are introduced can vary a great deal. There are no pre-defined common governance models across the three labs. Civic digital technologies are expected to facilitate citizens’ participation in collective forms, rather than just digitizing services for efficiency purposes. Intentional actions are taken throughout the whole cycle of design, development, and use of the digital tools, in order to embed public values (e.g., openness, inclusion, accessibility, and technological sovereignty) in their features.

The Greek local lab has been activated in the municipality of Kaisarieni, a suburb of Athens identified as a left-wing stronghold since its historic role in the Greek resistance during World War II. This background has forged a common identity of active citizen participation and community organization, which also caused the Skopeftirio Park green area in the Hymettus Mountain to come under public ownership. In this context, the Volunteer Forest Protection Team of Kaisarieni (VFPTK) was born. VFPTK is a self-organized team of volunteer citizens (70–120 persons) to protect the Hymettus

forest against fires. After a series of interviews with the municipality civil servants about possible sectors and initiatives related to community wellbeing, in which intervention could take place, VFPTK was selected as the main pilot case scenario, due to their important contribution to the community and their technical needs.

3.2. Community engagement and co-design

Following an infrastructuring approach for participatory design (9), and related methods and strategies for participatory action research in the field of digital civic co-production (14, 15), the research teams set up a lab in Kaisarieni. The research team engaged with the VFPTK, starting with preparatory meetings to delve into: (a) their activities and the status of their existing technical infrastructure, (b) organizational models developed over the years, and (c) problems and challenges, which helped map potential interventions. These meetings were in the form of field visits in VFPTK facilities and outposts. The research team kept notes on explanations, created diagrams and took photos.

In the second phase, a series of co-design sessions was organized, in order to identify specific challenges in the everyday activities and to co-design technology-enabled solutions. VFPTK members, employees of the Municipality of Kaisarieni and research team members worked together. Co-design canvases (available as supplementary materials to this article) were used to stimulate and document the discussion. Researchers undertook facilitating roles, while the VFPTK members were the main contributors in information and ideas. The main workshop took place at the Kaisarieni Museum of National Resistance on the June 5, 2022, and lasted 3 h. There were six members of VFPTK, five municipal employees (three from IT department, one from the civil protection service, and one from the administration), and three researchers. Participants were split into two groups of seven, both representing all stakeholders. Data were collected through the co-design canvases and researchers’ notes (Figure 1).

During the first part of the co-design workshop participants mapped places of interest in the area (e.g., fire-fighting headquarters, watchtower) and problems regarding these spaces. An aerial photography of the area was used. This canvas format was selected because from preliminary meetings it was evident that challenges and potential interventions were related to specific locations (Figure 2).

In the second part, participants worked on service proposition canvases. They were required to elicit: the needs the proposed infrastructure will address, its desired functionalities, and challenges that may arise. Finally, they had to draw a detailed diagram of the desired infrastructure in an appropriate form (e.g., a flow chart and data structure or blueprint). Researchers played the role of facilitators. Four services were co-designed with a high level of detail (two by each team). All data collected through the canvases were analyzed by the research team and restructured as independent reports, containing the service details and which technologies can be used to produce them. These reports were submitted to VFPTK, which internally discussed them and concluded to start implantation of three distinct actions (see section 4.2).

In the third phase, we focused on actually co-producing the services along with the citizens. For the first service (see section



FIGURE 1
Co-design Workshop, 5.6.2022.

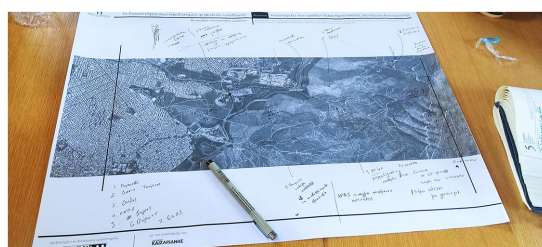


FIGURE 2
Canvas 1 filled at the Co-design Workshop of 5.6.2022.

4.2), the equipment required was immediately provided and VFPTK set up the service. For the other more complex services (see section 4.2), researchers produced detailed technical reports that were later discussed in collaborative sessions with the VFPTK to finalize the desired functionality. This is an ongoing process in which both researchers and VFPTK contribute with their respective knowledge and technical capacity. Open-source software and open design hardware are used as much as possible. The results of these actions are reported below.

4. Results

4.1. Existing infrastructure

Volunteer Forest Protection Team of Kaisariani existing infrastructure has been developed over the years by VFPTK members and is composed of “homebrew” systems. These systems use mostly unconventional or outdated practices and methods, selected more for the ability of VFPTK members to employ them than on grounds of adequacy. Nevertheless, their usage over a long period of time and constant small-scale improvements made them tailored to the needs of the team. These systems include a very high frequency (VHF) radio station, a do-it-yourself weather station and a homebrew local

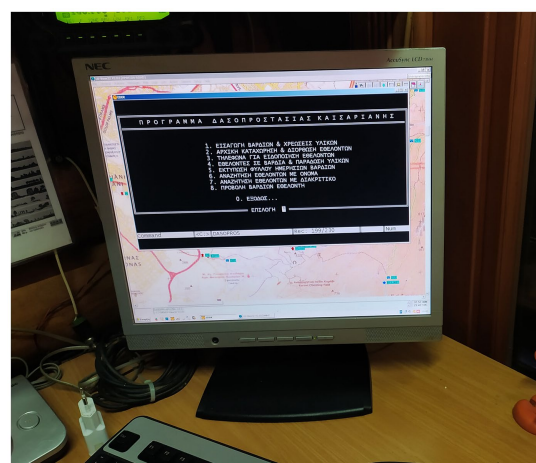


FIGURE 3
The “homebrew” database of VFPTK.

database (45) built on dBASE and running on Windows XP or older operating systems (Figure 3).

The database was built from scratch by one of the most long-standing members, without professional experience of programming. The system includes most of the functionalities needed to administer VFPTK, such as a member’s registry and shift management.

Volunteer Forest Protection Team of Kaisariani has been working as an improvised technology development lab for decades. The group benefits from the skills of amateur radio broadcasters, amateur programs, and professional technicians. The municipality supports by providing the space for their headquarters and by occasionally repairing their vehicles, but no consistent direct funding is made available. Self-funding from sympathizers is necessary. VFPTK preserves a strong do-it-yourself and maintenance culture. Technical equipment, from PCs to vehicles, are not easily replaceable: the team tries to maintain everything as much as possible, even if this compromises the usefulness, ease-of-use, and reliability.

4.2. Co-designed services

Through co-design, the participants developed three distinct services, mostly replacements of or enhancements to existing ones:

1. A device to record operational data transmitted through the VHF radio.
2. A weather station.
3. A software system for the team's management.

The first system was rapidly implemented, since the volunteers had already decided on the device they needed to record data. A commercial solution was purchased with the project funding, and added to the existing VHF radio station by VFPTK members.

The second service is a weather station to be used for gathering data about temperature, humidity, wind, and atmospheric pressure. It was designed in detail at the co-design workshop (Figure 4).

The station will be positioned in one of the watchtowers operated by VFPTK. It will use (Arduino) open hardware microcomputers and will transmit data to the headquarters *via* the internet. Arduino was selected for its simplicity, and since one of the volunteers has relevant expertise for developing and maintaining the service. Through the research project, the Municipality of Kaisariani has funded the installation of solar panels to provide energy, and has hired the mentioned volunteer with Arduino expertise, to help co-develop the weather station with VFPTK members. Serious obstacles remain, such as internet access in the remote watchtower.

The third service aims to totally replace the homebrew local database. The new system will have all the functionalities of the old one (member's registry, shift management), and will also support a vehicle registry. It will be web based and will follow a three-tier architecture. This way, VFPTK administrators will be able to use the system at their headquarters as well as in the main summer outpost. Until now, they have been using USB storage devices to move data from one local database to others, which caused several problems. A crucial aspect is the addition of a mobile phone application through which volunteers will be able to register for shifts and receive push notifications. The research team prepared a detailed technical report,

then discussed extensively with VFPTK members to get feedback. In this case, development will be undertaken mainly by the research team using open-source web technologies such as Angular and the Strapi content management system (CMS), since VFPTK does not have these advanced capabilities. A prototype of the member's registry has already been developed in Strapi. The goal is to have a beta implementation of the system in the beginning of summer 2023.

4.3. Community engagement

The volunteers engaged in the process were already part of a highly committed group, willing to provide satisfactory solutions to practical problems. Their involvement and intense interaction over a long period of time have formed a strong community, able to overcome any obstacles with limited external support. Personal skills, both professional and amateur, were put at disposal of the group. The same now happens in the co-production process. The latter was regarded by team members as a long-awaited opportunity for change, especially for younger members. But even older members overcame their reluctance, which was rooted in previous unsuccessful attempts to update systems.

Previous commitment of public institutions was limited. VFPTK complained about inadequate and irregular support from local, regional, and national public authorities. The engagement of Kaisariani Municipality has intensified during the co-production process. An example is the allocation of public funds for both material and human resources of the second co-designed service.

The constant engagement of the research team, along with the project resources available, played an important role. As regard the first service, the acquisition of a commercial technology, even though diverging from the co-design methodology, was crucial in proving to VFPTK the usefulness of the process, and thus helped gain their trust. The co-design intervention on the second services facilitated the coming together of the different stakeholders. As the co-production process continues, it will be possible to see how different stakeholders contribute to overcome remaining obstacles, such as internet access. For the third service, the research team plays a more relevant role in technology development: coding the system together with the volunteers is not possible at the moment due to the required skills, but VFPTK decided on the data structure and user flow.

5. Discussion

This section discusses the results presented above, highlighting the socio-technical challenges arisen (strengths and criticalities), and addressing the two research questions concerning (a) how actors engage in the lab, and (b) how civic digital technologies can be introduced.

The relevance of specific interventions in support of VFPTK's services, through digital tools, was recognized by the researchers for the following reasons. Firstly, the field of forest protection, already addressed for a long time by citizens concerned for Skopeftirio Park, has become more important in recent years because of the acceleration of climate change. Secondly, many needs were related to the lack or inadequacy of technical infrastructures, which affected the effective coordination of the actors. Moreover, the opportunity to combine outdated equipments with more advanced civic technologies, and the

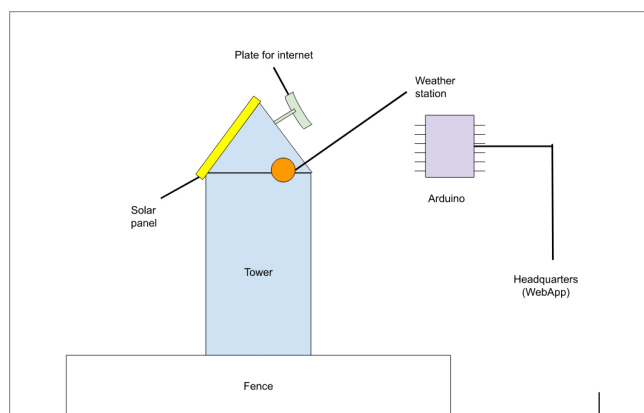


FIGURE 4
Weather station diagram created on Canvas 2 at the Co-design workshop of 5.6.2022.

availability of additional resources from European funds, encouraged the actors to participate.

The following strengths emerged. The existence of an active community was an important precondition for getting *actors engaged in the co-production process*. The rich experience of community culture should not be disregarded but cherished and incorporated in any community infrastructuring project. Moreover, a common space has emerged where researchers and citizens share knowledge and experience, working as equals. Resistance to change, which is common when such digital infrastructures are introduced, can be overcome when a circle of trust is created, and community members understand that the research team has a long-term commitment to producing positive effects with mutual interest. As regards the introduction of *digital tools*, it is worth noting that the educational part of engaging citizens with civic technologies is integrated in an extended co-design and co-development phase, where technology is discussed as tangible, accessible, and suitable to addressing the challenge of forest protection. The attitude of the volunteers (do-it-yourself and maintenance) to technical devices is also relevant. The second service is a good empirical case of selecting simple and open digital solutions on which expertise is already available, and of motivating different actors to cooperate.

Some criticalities were observed. Regarding *actors engagement*, the role of public administration in the case study deserves attention. Informal LLs such as VFPTK have been producing civic technology for years because they have been disconnected from public institutions. The research project has been an opportunity for the municipality to engage and acknowledge the needs of the community. Regarding the *digital tools*, firstly, the digital systems implemented with civic effort mostly involve unconventional practices and methods. This can strengthen the willingness of members to find accessible solutions, but these solutions could be selected more for the ability of members to employ them rather than for their adequacy. Secondly, participants must be aware of how deeply the community can actually influence the technology. In the first service, the community wanted to directly adopt a commercial technology that could “do the job,” and did not share the researchers’ academically-motivated considerations on co-design. Similarly, an open issue concerns to what extent technology experts and communities can co-develop digital tools. A deep involvement is possible when the community has relevant expertise, as with the second service. But often, the research team needs to do the bulk of the development work, as with the third service. Thirdly, any digitally-enabled co-production process must address technical limitations. In the example of the second service, there is currently no internet access in the watchtower, neither from cable internet nor from the weak mobile signal. It will be necessary to find innovative solutions along with the communities, since the telecommunication companies contacted are unwilling to cooperate. One option is to get internet access *via* a direct link from the nearby University of Athens campus.

6. Conclusion

The Kaisariani local lab adopts an infrastructuring approach and participatory methods that create the conditions for services co-production, supported by civic technologies. This article reports and discusses the sociotechnical challenges emerged during the first phases of the lab implementation. The reported observations have

some limits in that the Kaisariani lab is ongoing, and some issues are still open. The results attain in particular the initial phases of a LL on civic technologies: namely, the engagement of the actors within the local community, the analysis of the digitally-supported services, and the design of new digital tools. In this regard, these insights are relevant for LLs on digital coproduction of wellbeing-related services.

The applied methodology seems effective in establishing trust; creating a common space for pooling knowledge and resources; making digital technologies tangible, accessible, and tailored to community needs. However, contextual factors such as the volunteers’ commitment and their attitude to technologies have been core preconditions for the collaborative process. Open issues concern the long-lasting commitment of the public administration, some technical limitations, and the extent to which the community actually wants and can be active in co-designing and co-developing digital tools. The processes of bringing actors together, and of introducing technologies with a civic approach, are strictly intertwined. Cultural, social, and political preconditions had an influence on the setting up of the lab. Conversely, the co-design of open and customizable technologies activates collaborations and resources in the community.

Data availability statement

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

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

AZ and CV wrote the first draft. GT, GZ, IE, and VM implemented the Kaisariani lab and wrote sections 1, 2.1, 2.3, 3 and 4. CV, LD and AR wrote sections 1, 2.2, 5 and 6. VV wrote parts of the background work sections 2.1, 2.2 and 2.3 and made overarching changes in relation to civic technology literature and community infrastructure-ing. All authors contributed to the manuscript, critically reviewed its content, and have read and agreed to the published version of the manuscript.

Funding

The NLAB4CIT project is funded by the European Commission, Grant Agreement number LC-01688130.

Acknowledgments

The authors would like to thank all VFPTK members.

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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Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2023.1189226/full#supplementary-material>

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OPEN ACCESS

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RECEIVED 18 June 2023
ACCEPTED 05 July 2023
PUBLISHED 24 July 2023

CITATION
Molnar A, Lepenies R, Borda A and Pedell S
(2023) Grand challenges and living labs: toward
achieving the Sustainable Development Goals.
Front. Public Health 11:1242138.
doi: 10.3389/fpubh.2023.1242138

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Grand challenges and living labs: toward achieving the Sustainable Development Goals

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KEYWORDS

grand challenges, living labs, Sustainable Development Goals, global opportunities, scale, transformation

1. Introduction

In 2015, the United Nations (UN) established a set of Sustainable Development Goals (SDGs) and an Agenda for sustainable development to achieve these goals by 2030 (1). The Agenda¹ was adopted by all member states of the UN. The SDGs are a collection of 17 interlinked global goals² designed to be a “blueprint to achieve a better and more sustainable future for all”. Through its targets, the SDGs encourage the international community and all stakeholders to promote sustainable actions for people, planet and prosperity—tackling issues from multidimensional poverty, education, and the promotion of health and wellbeing, while addressing climate change, biodiversity and protecting the environment. The SDGs also encourage partnerships to maximize the value created by collaborations and the interconnectedness of the goals. The SDGs have become a global framework that is guiding action for public and private actors alike: whether national, regional or local sustainability plans in policy; sustainability reporting for corporations or campaigns for NGOs—increasingly, sustainability is framed in terms of the SDGs. In this article, we explore the role of living labs in achieving SDGs—their potential and limitations. Achieving the SDGs means also achieving a reorientation of how we think about sustainability: leaving no one behind, thinking intersectionally, and simultaneously considering the synergies and trade-offs when creating transformations toward a more just and sustainable world.

2. SDGs and living labs—A problem of scale?

The role of living labs as a contributor to the SDGs is particularly relevant through its social impact process of partnerships and innovative solution development. In a systematic review of living lab literature (2), the identification of living labs and sustainable development was noted as a growing intersection of activity, focusing on the support of holistic solutions and general support of sustainability through a continuum of learning and development that considers socio-economic, educational and environmental impacts.

1 <https://sdgs.un.org/2030agenda>

2 <https://sdgs.un.org/goals>

Living labs are spaces (either physical or virtual) through which stakeholders meet to collaborate on finding solutions to a complex issue (2). They could be used to generate ideas, develop and/or test solutions (3). Living labs are not only used by researchers but they could be also activities started by citizens, non-profit organizations or industry (4).

The SDGs have a global ambition and are the result of decades of deliberation at the international level about sustainability involving an unprecedented number of stakeholders. And while much of Agenda 2030 is directed to policy makers representing nation states and calls for top-down policy change, the SDGs explicitly call for the involvement of everyone to achieve the “transformation of our world”. At the same time, sustainability must be rooted in local, concrete actions and bottom-up activities—which often take a more experimental form. It is in this tension between global ambition and local necessity that living labs can play a vital bridging role.

Considering the complexity of SDGs’ goals, and the multitude of stakeholders needed to be involved in order to address a single goal, living labs seem to be a highly pertinent tool through which stakeholders can come together, generate ideas and work collaboratively. Living labs can also support testing solutions before being deployed on a large scale.

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The Open Living Lab Days 2018 hosted by the European Network of Living Labs (5) reinforced the potential of living labs to contribute to the SDGs in domains such as health, energy and education, among others. Sustainability and sustainable development are integrated into the activities of individual labs, such as urban living labs with a focus on the green economy, environmental health, and achieving net zero efforts, for instance (6, 7).

Larger networks similarly share a number of sustainability goals. The Australian Living Labs Innovation Network (8) incorporates organizational values encompassing a circular economy, water waste and energy, natural environment and climate change resilience. The multi-national iSCAPE living labs network have centered on advancing air pollution remediation strategies and solutions, and the UnaLab cities consortium is working toward developing sustainable urban communities through the implementation of nature-based solutions. The Living Laboratories Initiative in Canada is an example of a sectoral network focusing on new approaches to agricultural innovation addressing agri-environmental issues (9).

Massachusetts Institute of Technology Office of Sustainability has made exemplary strides in transforming the campus into a living lab responding to the challenges of a changing planet (10). However, it is noted in selected studies that such sustainability efforts by universities can be implicit (11), and the concept of

sustainability itself can be oversimplified (12). Notwithstanding, there is evidence that universities are beginning to acknowledge that the greatest SDG challenges can only be solved by systems thinking and finding solutions for a shift toward interdisciplinary collaboration to achieve this (13, 14). Achieving the SDGs, therefore, implies a change in mindsets, behaviors and policy.

3. Sustainable Development Goals and Grand Challenges

The concept of “Grand Challenges” has been adopted by policymakers and research organizations to frame and communicate their respective agendas (15). These challenges also represent more than ordinary research questions or priorities, they are outcomes at global scale which capture the public imagination (16). In general, Grand Challenges initiatives are characteristically anchored by a set of foundational principles (17) like the characteristics of the living lab approach. Engagement through multi-stakeholder involvement, experimentation through openness, implementation of solutions in the real world and transformation—the focus on having impact. These fundamental pillars are evidenced in the Grand Challenges in Global Health initiatives launched by the Bill & Melinda Gates Foundation in 2003 which continue to address solutions to health problems in the developing world across 15 identified challenges (18). Governments have engaged in grand challenges, such as Grand Challenges Canada supported by the Canadian government and based upon the Gates Foundation model to develop solutions to critical health and development challenges in disadvantaged communities. It is also a vehicle to empower innovators “who are closest to the world’s health challenges because they have the knowledge and are best positioned to develop lasting solutions”.

Sectoral areas have defined their futures through key challenges like the Grand Challenges for Social Work initiative led by the American Academy of Social Work and Social Welfare (17). Universities have similarly adopted the model as part of their strategic vision. University College London (UCL) has established a six-grand challenge agenda to develop cross-disciplinary collaborations related to solving some of the world’s most pressing problems (19). These are linked to achieving the SDGs across global health, human wellbeing, cultural understanding, sustainable cities, justice and equality, and transformative technology.

The UCL Grand Challenges reflect the six Transformation areas developed to organize SDG interventions in which each transformation is intended to engage different levels of government, industry and civil society, to facilitate targeted problem-solving (20). This new way of thinking about tackling “wicked” challenges has its roots in what can be termed “mission-oriented research and innovation” which can potentially provide a more effective and crucial link between the Grand Challenges of the SDGs and the multidisciplinary research and innovation knowledge needed to tackle them (21).

Horizon Europe has recently opted to use missions for its research and innovation program for 2021–2027 (22). These missions support Commission priorities, such as the European Green Deal, Beating Cancer, Climate Adaptation Strategy, and

Europe's Rural Areas. A key stakeholder cross-cutting approach is the incorporation of citizen engagement in events, online discussions, and social media polls, for instance, at the Conference on the Future of Europe.³

4. Limitations and opportunities

In reflecting on the positioning of living labs in a Grand Challenge context, there is much potential for living labs to demonstrate their intrinsic value in accelerating SDG progress. The SDGs in their breadth and scope require the collective intelligence that living labs have fostered—that is an understanding in practice that the resources of intelligence can be brought together and shared, from localized insights and inventions from people on the ground, to data and evidence (23). Not least, Grand Challenges are nearly impossible to accomplish without coordinated, collaborative, and co-created innovation (24). As Gilbertson et al. (13) acknowledge, stakeholder support is vital to the success of partnerships addressing complex problems.

4.1. About direct contributions to the SDGs

Living labs are recognized as progressive platforms for fostering innovation and strengthening collaborative partnerships from bottom-up (25–27). They are often networked which means solutions can be distributed and scaled more quickly from local to national to global levels (26). These networked ecosystems more readily support an innovation lifecycle of piloting, implementation and evaluation (27). However, studies on the sustainability directions of living labs have been oversimplified in comparative studies (12). When considering the situated nature of sustainability research (28), living labs are relevant study points and drivers of real-world initiatives enabling the investigation of sustainability in place (12). For instance, living lab approaches have been considered in the design and implementation of Nature-Based Solutions as a means of reducing the exposure to natural disasters, such as increased flooding in changing climates (29).

In contributing formally to the SDGs, there are two main ways in which living labs can be involved: first, by implementing or supporting measures that lead to improvement of SDG implementations (27), second, by contributing to SDG reporting and monitoring. Now, living labs mostly contribute in the first way: their actions might lead to solutions that contribute to the achievement of the underlying aims or goals of the SDGs (e.g., by providing a healthier urban climate in a specific context, or by fostering equitable partnerships in a given location), but do so in broad—and difficult to measure—terms. This can also be done indirectly, e.g., by holding policy makers or business corporations to account as part of networks in which SDG topics are discussed and/or political movements organized.

The second opportunity might be for living labs to officially contribute to the SDG reporting and monitoring mechanisms. All countries (in their voluntary national reviews at the UN level), but also many cities and communes report their progress on

SDG achievement by using SDG indicators. There are limited examples in which citizen science initiatives or living labs have formally partnered up with mandated statistical authorities to aid in these efforts (30). These have been closely aligned with directives on air quality monitoring, for example (30, 31). Given the technical nature of sustainability reporting, it is understandable that living labs often do not have the expertise to directly contribute to specific monitoring mechanisms. There are, notwithstanding, opportunities for living labs to be involved in place-based data collection and/or as part of data hubs which collectively contribute, such as through the UN Habitat urban observatories or OECD program on city region-based approaches to tackling SDGs (32).

4.2. Achievability

Critically, the timeline for achieving the SDGs is 2030. There is an urgent acknowledgment on government and political agendas of the need to further advance collective work on the SDGs (12). The Social Progress Index (33) indicates that the COVID-19 pandemic may have delayed achievement of the SDGs by several decades and may have even reversed some efforts. According to the UN SDG 2019 report (34), progress toward SDGs had already been lacking in several areas. The COVID-19 pandemic has magnified these largely unmet areas, such as racial and cultural inequities in access to healthcare and education, and a widening gap of gender-based inequities globally (35).

In 2019, the UN Development Programme (UNDP) supported the establishment of a global network of accelerator labs to tackle some of the most pressing and underachieved SDGs in the global south. The network covers 115 countries and nearly 100 labs addressing goals such as Goal 5: Gender equality, Goal 13: Climate action, Goal 15: Life on land, Goal 17: Partnerships for the goals (36).

The AI4Good Foundation (ai4good.org) is an example of an emerging technology organization supporting AI applications to help accelerate the achievement of SDGs with the use of shared datasets, such as Global Forest Watch under Goal 15: Life on Land, and Ocean Tracking Network under Goal 14: Life Below Water.

It is difficult to ascertain the extent to which living lab initiatives formally align with specific SDG indicators or are represented in the official monitoring system (UN SDG Indicators). At present, national governments have the primary responsibility for monitoring the SDG indicators in which each SDG indicator has one or more custodians (e.g., a UN agency) who are responsible for identifying the data sources that can contribute to each SDG indicator. This may entail practical limitations for living labs, due to potential resourcing requirements, for instance. A recent study (37) has explored the fact that information is still lacking regarding the current and potential contributions of citizen science collected data to the SDG indicator framework. The same study noted that both indirect and direct contributions are valuable assets toward achieving targeted SDGs, but the contribution process can be highly context-dependent in different countries.

Looking into the future, living labs have the potential to contribute to the SDGs. Using the SDGs as a framework

³ <https://futureu.europa.eu/>

allows living labs to map out the synergies and trade-offs between different dimensions of sustainability. This will avoid siloed thinking and will embrace the holistic and systemic attitudes that are at the core of the SDGs. It is this type of thinking that could break down—at the very local level, and in concrete contexts—the global ambitions for sustainability into concrete, contextually rooted actions in communities.

5. Final reflections

With the global push for achieving the SDGs in less than a decade, there remains a wide opening for living labs to significantly contribute as individual and collaborative networks both in formal and informal ways. The process of tackling SDGs highlights their complex nature.

Optimizing the process has elicited targeted and mission-oriented agendas alongside the broader Grand Challenges approach. What is shared is the transformative and global opportunity for living labs to leverage their relationships, technology, and communities, to collectively enable the most positive and sustainable impacts to the benefit of humanity and the world we share.

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All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Acknowledgments

Many thanks to Julia Beckmann who has provided feedback and help proofreading the article.

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RECEIVED 28 February 2023

ACCEPTED 11 July 2023

PUBLISHED 02 August 2023

CITATION

Merino-Barbancho B, Abril Jiménez P, Mallo I,
Lombroni I, Cea G, López Nebreda C,
Cabrera MF, Fico G and Arredondo MT (2023)
Innovation through the Quintuple Helix in living
labs: lessons learned for a transformation from
lab to ecosystem.
Front. Public Health 11:1176598.
doi: 10.3389/fpubh.2023.1176598

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Innovation through the Quintuple Helix in living labs: lessons learned for a transformation from lab to ecosystem

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Introduction: In the process of growing societies, and especially in the digital era we live in, there is a need for a strong push for innovation that puts citizens at the center of the process from the beginning to build more resilient, cooperative and flexible communities. Different collaborative design approaches have emerged in recent decades, one of the most interesting being Living Labs, which involves user-centered design and co-creative innovation that bring together different actors and roles. However, although these new methodologies are harnessing creativity, some aspects of this new, more ecosystemic and complex vision are not clearly understood: possible barriers, how to facilitate local and operational solutions, overcoming institutional blockage, integrating new roles, etc.

Methods: The incorporation of the Quintuple Helix as a driver to ensure greater coordinated participation of local actors has proven its usefulness and impact during the re-adaptation of LifeSpace (previously named Smart House Living Lab), managed by the Polytechnic University of Madrid (Spain), a transformation based on the experiences and lessons learned during the large-scale ACTIVAGE pilot funded by the European Commission, more specifically at the Madrid Deployment Site. It involved more than 350 older adult people and other stakeholders from different areas, including family members, formal and informal caregivers, hospital service managers, third-age associations, and public service providers, forming a sense of community, which was called MAHA.

Results: The living lab infrastructure evolved from a single multi-purpose environment to incorporate three harmoniously competing environments: (1) THE LAB: Headquarters for planning, demonstration, initial design phases and entry point for newcomers to the process, (2) THE CLUB: Controlled interaction environment where returning users validate solutions, focusing mainly on AHA services (MAHA CLUB), such as exergames, social interaction applications, brain training activities, etc. (3) THE NEIGHBOURHOOD: Real-life environments for free and open interaction between actors and implementation of previously validated and tested solutions.

Conclusion: The Quintuple Helix model applied in LifeSpace's new vision allows a coordinated involvement of a more diverse set of actors, beyond the end-users and especially those who are not traditionally part of research and innovation processes.

KEYWORDS

living lab, Quintuple Helix, society, innovation, ecosystem, digital transformation

1. Introduction

At the beginning of 2022, at the London School of Economics, Luis de Guindos, Vice-president of the European Central Bank, made a strong statement (1) urging everyone to work together toward three key goals for the EU post-pandemic economy: recovery, renewal, and resilience. These three goals are essential to address Europe's transition toward a green zero-carbon and digital economy in a post-pandemic scenario and increasing uncertainty of the economy and policy balance.

Building a solid economy requires many components that involve society as a whole (2). A strong innovation-driven factor is necessary, placing citizens at the center of the revolutionary process as a fundamental pillar to build more resilient, cooperative and flexible communities. In recent decades, collaborative design approaches have been launched to coordinate and co-manage innovation, facilitating the empowerment of communities, and solving, in the end, complex challenges. One of the most interesting approaches is the Living Lab (LL) approach which includes end-user-driven innovation, bringing together different actors and roles to solve a particular problem (3). Living Labs operate as facilitators in testing environments in which users and producers can co-create solutions. Their main objective is to create new products, services and infrastructures adapted to the real needs of society (4). Both public and private groups participate in these processes by iteratively involving manufacturers and end-users, from ideation to testing, experimentation, and evaluation in real settings (5). Traditionally, living labs involve producers and end-users in the whole production process of a new solution or service. Smart Cities, the Internet of Things (IoT), Artificial Intelligence (AI) and Big Data paradigms have transformed these collaborative methods and have recently gained traction in the field of living labs because they have accelerated access to innovation, transitions for greater sustainability, data, and knowledge exchange, becoming drivers for policy development and scale-up (6). Moreover, given the constant demographic change and according to the European Digital Strategy (7), rising health and social costs threaten the sustainability of current health system models. Consequently, the number of people dependent on one another to age is steadily increasing. Therefore, it is important to also synergise these existing technological solutions to create value for those involved in the care of older adults (8). Expanding living labs beyond the limits of laboratory settings, new forms of enlarged living lab governance models have emerged in a variety of daily settings, such as Urban Living Labs (ULL) and enriched the innovation process by including other issues in addition to technology, such as human behaviors, lifestyles, barriers to access or social interaction across the socio-economic and cultural spectrum (9). In this context, several models of innovation are constantly evolving. First, the Triple Helix model emerged, which consists of an articulation between three social actors, the university, the private sector and the government, to generate regional development. The innovation-based collaboration practice between these stakeholders was not enough to meet the real needs of society (10). Subsequently, the Quadruple Helix Model emerged, which acknowledges four main actors in the innovation system: science, politics, industry and society; according to this model, more and more governments are giving priority to greater public participation in innovative processes (11). This approach gave growing importance to the "user" involvement in the innovation process, becoming crucial for the inclusivity and sustainability in the

innovation process and the initiation of the living labs and innovative tools for testing, validating and developing co-created solutions in all stages of a design and commercialization chain of a product or service (12). Now, the number of models promoting new citizens' roles and local and regional problems toward more sustainable and green services is representing a new completely new phenomenon for engaging citizens in participation, experimenting, and learning in the cities (13). Some authors highlighted the unclear role of some of the stakeholders within living labs and the lack of understanding about living labs and communities and neighborhoods (14, 15). In this sense, the introduction of the Quintuple Helix in recent years defines the environment as its entity, promoting characteristics of social ecology and natural interactions between actors and their context and surroundings, making innovation ecosystems more operative (16). However, while new experiences are emerging that leverage innovation, there is no clear understanding of the potential barriers, facilitators, and impact for catalyzing development around these creative environments to make local innovation operational, overcome institutional lock-in situations, and integrate new roles, sectoral approaches, and identify strategies of co-development. Living Lab experiences to guide urban living lab co-development are still few (9). This paper aims to frame the understanding of how living labs can incorporate Quintuple Helix as a driver to ensure more extensive participation and cooperation of local stakeholders through the experiences and lessons learned from the ACTIVAGE Large Scale Pilot and Madrid Deployment Site (Madrid DS), and the subsequent digital transformation of LifeSpace Living Lab by LifeStech at the Universidad Politécnica de Madrid (17).

2. Materials and methods

2.1. The participatory experimentation environment

LifeSpace is a city-scale ecosystem that is instrumented to undertake participatory multi-method experimentation for co-creative design and validation of any type of technical and socio-ecological solutions in real-life environments with a large variety of users. This aims at emphasizing the importance of mutual learning and knowledge sharing to foster multidisciplinary and intergenerational innovation. The ecosystem has its origins in the Smart House Living Lab (now renamed LifeSpace) (Figure 1), founded in 2009 by the LifeStech Research Group of the Universidad Politécnica de Madrid. Originally, the Smart House was guided and operationalized according to socio-ecological system models (18), in which social, digital, cultural and physical ecosystems interact at individual, community and societal levels to generate new services and products. This original research infrastructure was the current building, replicating a living place (i.e., home, residence, hospital, etc.) with the facilities to support temporary experimental individuals. In addition, this living lab becomes the initial dynamic multi-stakeholders network that supports user-driven innovation and the interaction between technology and socio-economic research parties. In a continuous transformation to face new societal challenges such as population aging, sustainable development, digitalization, etc. (1), the initial infrastructure was re-engineered in detail and the methodological approach incorporated the interdisciplinary and

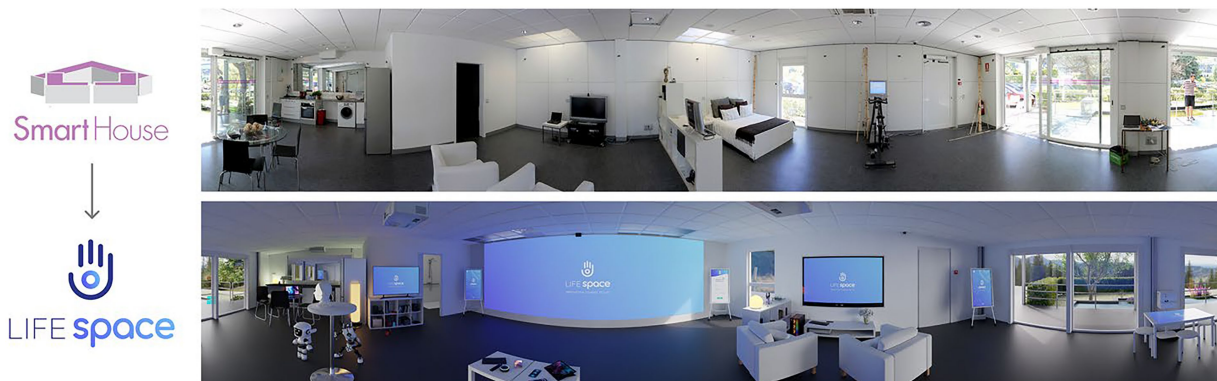


FIGURE 1
Reconfiguration of the main user area at LifeSpace Living Lab (author's elaboration).

transdisciplinary methods from the Quintuple Helix Model (19) and recent research and methods for user involvement (20). In this way, our living lab includes the traditional “4P” (private-public-people-partnership) living lab definition of the real-life environment. The Quintuple Helix allowed grasping and specialization on the sum of societal, more interaction and academic exchanges, and overall, innovating in a way that the generated solutions are more flexible and versatile, and, beyond their first purpose with its end-users, produce additional value for the society to lead current European challenges. In this way, our living lab approach turns users from observing subjects with limited explorative capabilities (the physical living lab building) into active participants of co-creators of value for a more sustainable and resilient society. In the end, the new LifeSpace incorporated the dynamism of the PERSONAS in the ecosystem and scaled up. A PERSONA is a model of the individual that serves to understand the behavior, needs and preferences during the design process (21). Introducing these user archetypes by following the guidelines set out in the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA Blueprint) (22), we better understand potential users further development, considering their needs, aspirations, attitudes, and dreams and other relevant characteristics relevant to build our socio-technical system.

The systematic analysis of the PERSONAS and the ecosystemic approach of the ecological and Quintuple Helix models allows combining a wide range of expertise (technical, but also social and natural science) and stakeholders to offer innovative and customized solutions aimed at promoting socially oriented services. In this way, LifeSpace becomes a mediator between innovation stakeholders while stimulating interaction between technical, social, economic and environmental factors.

2.2. User-centered living lab transformative methods

This section describes LifeSpace's methodological perspective during its revitalizing process: it considers the involvement of different stakeholders and their influence on their environment and vice versa. The final objective is facilitating societal changes. This allows a new opportunity to foster a transformative potential for innovation and

mutual learning cooperation, incorporating PERSONAS and Quintuple Helix as drivers in this transition from a living lab to a cooperative ecosystem. To reinforce elements facilitating the user-centered approach, the formal involvement of all the representatives of the stakeholders, including citizens (in this case, older adult users, but also families, relatives, friends, and other informal careers) in the governance of collaboration were constituted. All these elements have been provided and analysed through the activities and research framework that the Universidad Politécnica de Madrid has been entrusted with in the European H2020 ACTIVAGE project under license number 732679 and VITALISE project under license number 101007990.

2.2.1. Design procedures

Including end-users from the early stages of design is a recognized golden standard practice (23) that helps to identify their needs and ensure the follow-up of a common stakeholder vision. One of the most important driving forces to incorporate this into LifeSpace evolution was the ACTIVAGE project, one of the Large Scale Pilots (LSP) funded by the European Commission to demonstrate the usefulness of IoT on European digital market growth (24), specifically for the provision of Active and Healthy Ageing (AHA) services, and particularly the Madrid DS, one of the nine pilots along Europe, in the project.

The foundations of the Madrid DS (also named MAHA, Madrid Active and Healthy Ageing) were established based on extensive prior research projects focused on AHA and Smart cities (25–27) and consultation via interviews, information meetings and focus groups with each of the actors involved in the current AHA service provision. The systematic use of the BluePrint PERSONAS allowed the incorporation of representative users from all the selected domains, an aspect that traditionally hampers the results in the co-creation design process (28). The results of this consultation were complemented by expert knowledge of health and care services provision. Madrid DS partners acted as initial bounded space draw on the already LifeSpace established stakeholders' network (organizational, political, social and institutional) to enable the participation of new actors such as public service providers, facilities, professionals, etc., at this first stage. While hospitals, professionals, facilities and researchers were only consulted, older adult people

associations and public service providers were invited to play an active role in the project, even with their participation in the governance of the activities. The final objective of this phase was to transfer to users and service providers the final decision on how they want to participate in the rethinking of aging in terms of purpose and identity of life.

2.2.2. Implementation procedures

Addressing current societal challenges requires strong communities (29). LifeSpace responded to this by putting people at the core of innovations, not only in the design phase, facilitating the generation of new ideas and entrepreneurship, but going beyond the ideas and turning them into prototypes. Once the basis for the service innovation was established in the previous typology of the procedures, users continued to engage in co-creation activities. The user participation approach combined a set of involvement activities that were opened to each of the interested citizens. As part of an LSP, Madrid DS emphasizes a high level of participation, as an opportunity to enroll a community: not only the target group (in this case older adults), but also other actors traditionally out of the innovation process, and which the Quintuple Helix approach allows to participate actively, such as those responsible for supporting daily activities of citizens including workers in the transportation sector, social activities, proximity shops, etc. The combination of open events that generate interest in the end-user environment with a small group of users, made it easier to engage them with the continuous development cycle of digital services and allowed effective implementation of Quintuple Helix innovation. With this, LifeSpace was ready to head out of the living lab physical space and be able to incorporate neighborhoods as the element to avoid loss of identity and motivation in older adults. In these open spaces building processes, the actors of the daily participation of older adult users, confirm their effective participation enriching the social innovation toward empowerment of older participants as citizens with the ability to plan their aging process.

2.2.3. Evaluation procedures

Following the basic principles of co-creation methodologies, evaluation procedures could not be clearly distinguished from the design and implementation phases but embedded into them. At this point, the Quintuple Helix has allowed the generation of different involvement levels for evaluation that can be exchanged dynamically according to the needs of the previous phases. In the first stage of the evaluation, a reduced selection of end-users is invoked to test the results of the previous phases, which will be further analysed to extract conclusions. In the second stage, the different methods to evaluate the process are fed back into the innovation loop of design and implementation. During this, users are asked reiteratively to accompany research and interim results are regularly and automatically incorporated into design and implementation loops. Finally, in the last stage, users are also participating in the co-creation of the evaluation phase, methods and instruments to use.

3. Results

The Smart House Living Lab transformation into LifeSpace, by applying the Quintuple Helix as the main driver of its re-engineering,

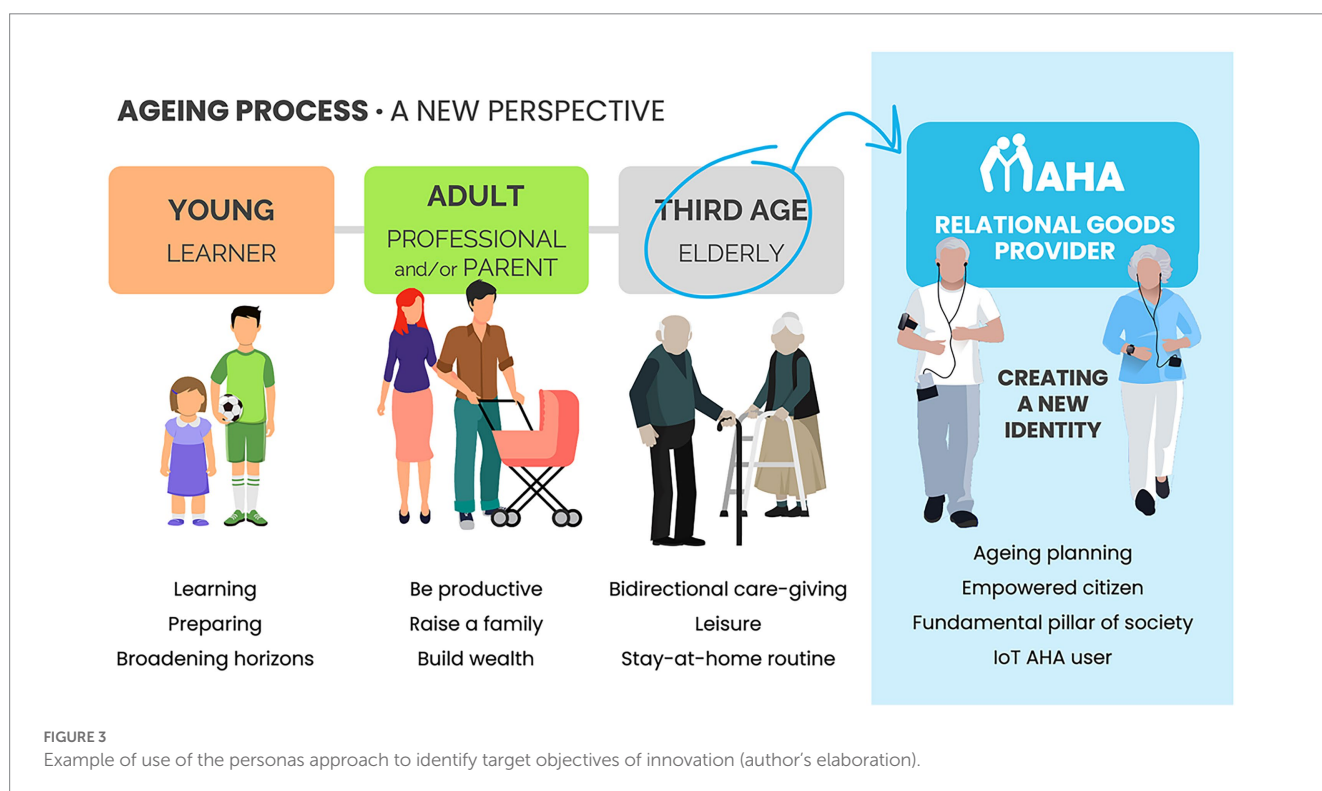
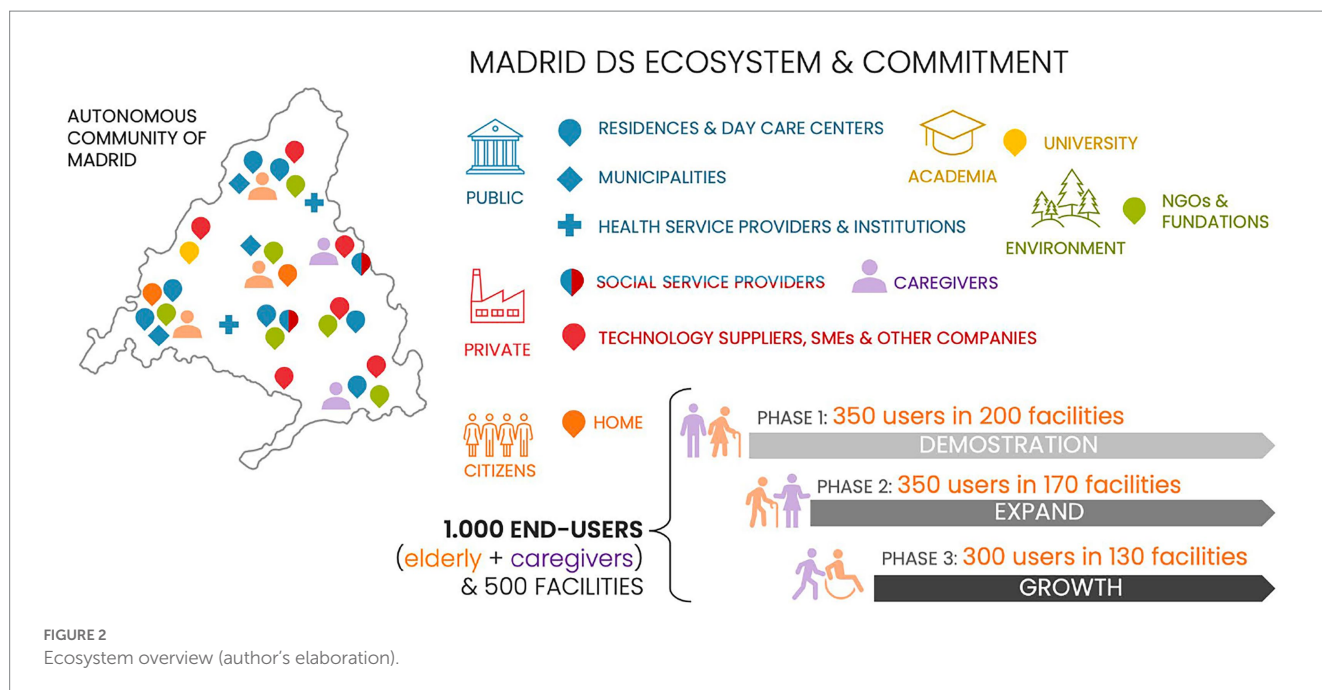
has managed to be successfully implemented in a deployment environment. This process was possible thanks to the early alignment of our socio-technical system view, the social and contextual factors influence activities and engagement with the living lab ecosystems as a whole. There exists a mutual relationship between actors, involved organizations (Figure 2), and functional and non-functional requirements that trigger the success of our living lab experimentation.

Incorporating the PERSONAS definition (Figure 3) from the early beginning of the project facilitated the engagement of users and generated a participatory process beyond a technological solution co-creation, creating personal synergies toward a common rethinking of aging in terms of purpose and identity.

Stakeholder interests were acknowledged from early on in the lab's planning. Key actors of the innovation chain around the Triple Helix (researchers, industry, and government) became a community, resulting in a consolidated and strong collaboration between researchers and public-private actors. This allowed the expectations and needs of members to be included in the plans of the living lab adaptation. The consolidated work around the Smart House Living Lab, and the solid commitment to transform this collaborative space into a more flexible environment, have enabled the exploration of new interaction methods on top of a previous well-established infrastructure, composed of a main user area for interaction and experimentation (Figure 1), a control room, which through a unidirectional mirror and strategically placed cameras, allows supervising user interaction and behavior happening in the main room in a non-intrusive way, and a virtual reality room, which allows for the rapid prototyping of new services and virtual training.

The use of this infrastructure was traditionally aimed at simulated environments for focus groups and open interviews focused on participants' narratives, as well as their body language and ways of relating to each other. The enriched incorporation of the target groups due to the use of the PERSONAS definition empowered the need to discover and examined potential barriers and pitfalls in the project approach that could hamper the engagement of the participants in the cooperation activities, such as the lack of trust in the solution, data protection doubts or privacy concerns, all very common when digital services and monitoring services are created.

The focus of Madrid DS was to provide social and care support to older adult people through innovative services including unobtrusive monitoring, suggestion systems, engagement with physical and cognitive training, and well-being habits acquisition; through this process, a set of unmet actors and scenarios were identified. The traditional approach of the living lab, which the SMART HOUSE Living Lab was previously based on, has pitfalls to address these needs; but, once collaborative networks were established in Madrid DS, researchers could efficiently test the combination of different techniques to engage different stakeholders along the Quintuple Helix, traditionally not involved in the innovation loop: services providers, technicians, formal and informal caregivers, service managers (see Figure 2). These new ways of collaboration required frequent design adaptations to different needs, decision times, workflows, and even business visions supported by the establishment of core groups for the LL process. This includes representatives of each of the groups for gaining a better understanding of the context of the specific experiment. At this point, a well-coordinated core group formed by researchers from the UPM team, services providers with an extended experience in the social and care service provision as Tercera Edad



Activa (TEA), and the continuous involvement of representatives of regional public health service, acted as catalyser for laddering of concepts around the services innovation process and to explain data protection policy, meet and understand stakeholders' needs and assign the user and other actors to the solution development that best suits them.

After the assessment of needs, was involved again in the direct interaction of solutions and services, some half-developed or in a prototype stage, others already available in the market but now

integrated into a new context of use in the MAHA ecosystem (Madrid DS). To combine different solutions during a session but avoid making interactions too monotonous, complicated, or boring for users unaccustomed to the use of many different technologies or validation processes as a whole, such as the older adults, a dynamic MAHA CLUB is designed that integrates gamification techniques. In MAHA CLUB, users visiting the LL answer a registration form that allows their identification (and their evolution monitoring during future sessions), and a cognitive and physical evaluation so that they can

receive a personalized path with activities appropriate to their condition (Figure 4 shows the screens displayed for this starting point). The activities proposed are divided into four categories: health & well-being (oriented to health management and care, especially for chronic diseases), active body (exercise, balance and movement coordination through exergames, wearables and other physical activity sensors), cognitive training (memory games, logic, mathematics, among others) and friendly environments (introduction of digitalization in activities and situations of daily life and the city, such as transportation or payment methods). Each MAHA interactive point integrates one or more AHA technological and/or digital solutions and involves a controlled interaction limited to a few minutes including a final feedback questionnaire on the user experience. One of the clear advantages of this dynamic format was its flexibility to be displayed in different locations (day care centers, town halls, temporary fairs, etc.) and closer to the homes of older adult users with difficulties of movement or means of transport. This was possible, firstly, thanks to portable equipment (Figure 5) and digitized solutions and, more importantly, to a real implementation of the LL process rethought from an ecosystemic point of view.

The evaluation phase was embedded from the beginning of the transformation process, generating longitudinal measures to capture the effects and impact of the tested concepts and design systematically, from the early stages of the collaboration process and compare these results with previous experiences. This allowed even from the design phase, to compare the current service providers' technological support with the last research on assistive technology and the legal framework to introduce these new services in the public social system obtaining a deep understanding of the key enablers to improve from a realistic point of view. This facilitated the overlaps between these three actors' innovation visions while fulfilling their expectations. As a result of this process, new ways of understanding user behavior emerged. Named MAHA CLUB, the new collaborative methods deployed in the living lab combine *in situ* implementation of the design and early implementation of continuous participation of all stakeholders as a fundamental value to supporting innovation. In the case of Madrid

DS, the MAHA CLUB methods explored the older adult users' needs about early symptoms of frailty using a holistic vision of the living routines: physical, emotional and cognitive. In this sense, the personalization of the technology is the core to the success of the solution, so more than 350 people participated in the MAHA CLUB experience design, validation and testing. This continuous loop in which the assessment was embedded into the design and implementation facilitates the early meeting of user behavioral needs to maintain a long-term engagement with the solution. The design offered a combination of low threshold activities and options to more deeply discuss and a solution created together; identifying the convenient frequencies of the sessions, balancing the time of the sessions, the adequate number of participants and roles against the maintenance of the interest and motivation is one of the more challenging aspects of the process. Besides this enriched experience, the professional management of all the tasks behind co-creation guaranteed the results of these activities were documented as a complementary source of learning, increasing knowledge, boosting innovation in other related areas and facilitating the generation of new business models around the envisioned concepts. Finally, as part of the evaluation phase, a series of Key Performance Indicators can be implemented from two perspectives: from the evaluation of the user perspective, including validated questionnaires such as the EQ-5D-3L (quality of life) (30), the UTAUT (use of technology) (31) questionnaire and the TAM (technology acceptance) (32) and from the technology perspective including heuristic evaluations. However, as the methodology is flexible enough, this KPI framework can be enlarged or modified depending on the environment in which deployment takes place, including also smart city metrics (33).

Expanding living lab experiences to real-life settings was the last stage in our living lab rethinking the iterative process. To this end, the living became a real city area, namely, THE NEIGHBORHOOD. In a less controlled way than THE CLUB setting, which replicates a semi-guided and monitored user experience from that generated in THE LAB, THE NEIGHBORHOOD allows an even more open and free interaction between actors, services and solutions. Synergies and

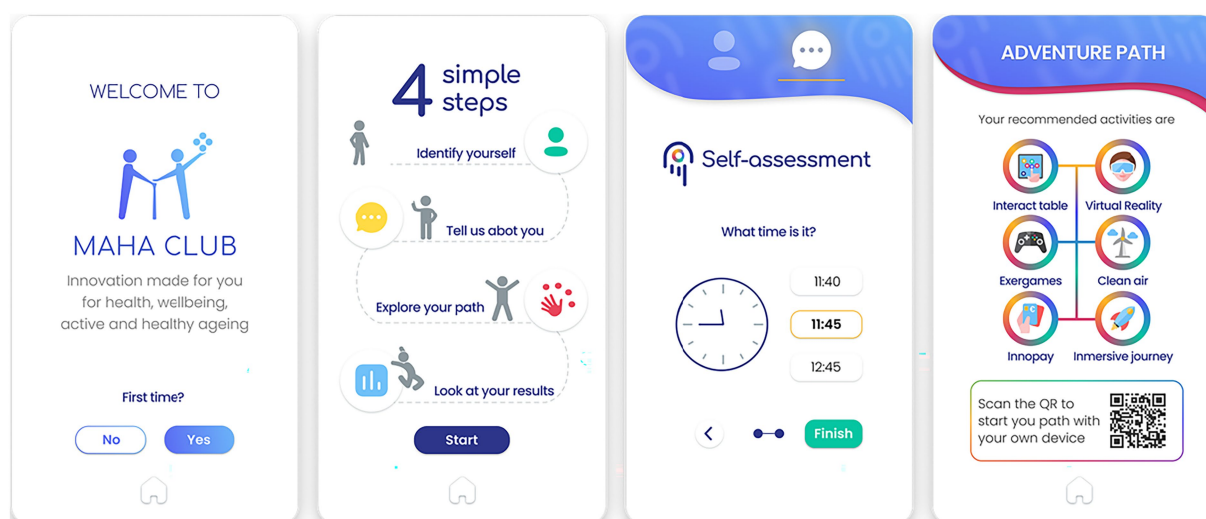


FIGURE 4

Screens from the MAHA CLUB recommendation system for a personalized user experience (author's elaboration).

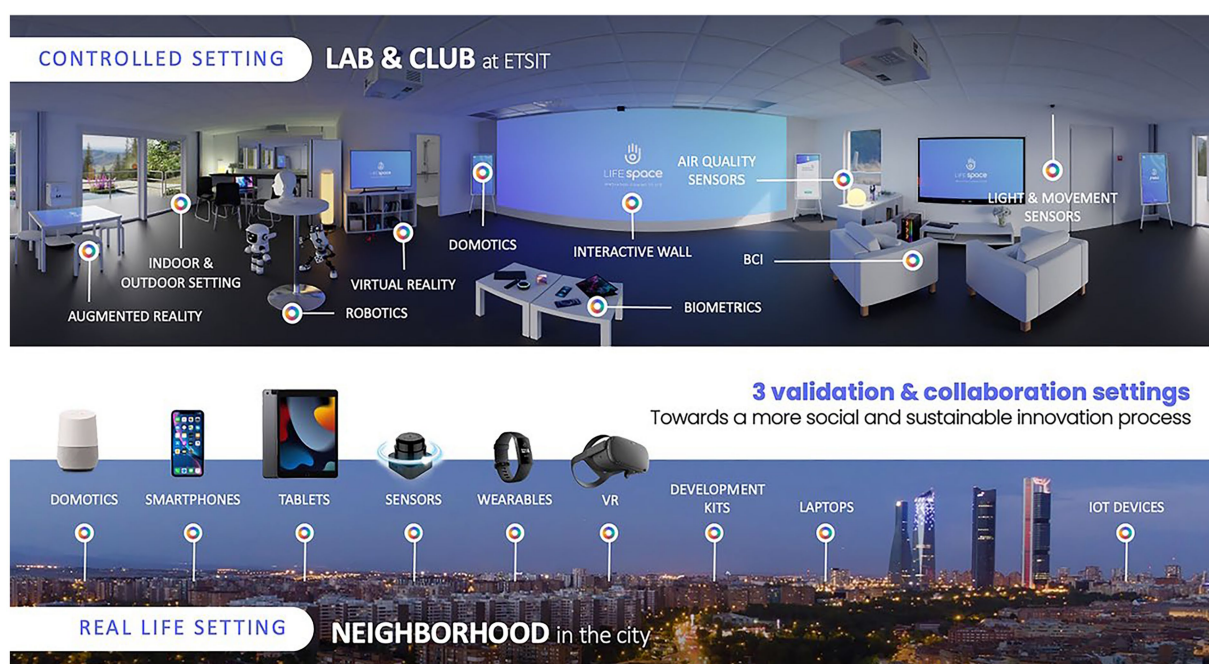


FIGURE 5
Infrastructure in controlled vs. real-life settings in LifeSpace (author's elaboration).

networks established in the early stages of the living lab re-design, as well as the numerous visible activities for attracting public attention, generated a high networking capability that allowed to mobilize and obtain local knowledge of very heterogeneous groups. To this end, THE NEIGHBORHOOD uses the streets to facilitate access to low-threshold activities such as demo totems and awareness activities, that gain insights into people's perceptions. This demonstrates that the success of LifeSpace research lies in the permanent availability of the (interconnected) stakeholders around the Quintuple Helix ecosystem. Figure 6 shows the evolution of the LifeSpace through the helix models.

As a result of the deep understanding of the specific location and population gained using these extended living lab sources, the business model identification becomes a core aspect of the co-creative sessions to identify critical success factors behind the tested solutions and how different actors' needs, factors, and interests affect the results of successful innovations.

4. Discussion and lessons learnt

The constant evolution of our society and, particularly, the new challenging situations we are facing in the last decade, with a very high impact on social relationships, health and care systems, and urban planning, has led us to try to understand the complexity of every social context from a more holistic point of view, incorporating new methods and techniques, and accompanying citizens in these changes. During this transformation, we have analysed strategies and practices through which the Smart Home Living Lab has become an innovative ecosystem embedded in the socio-spatial context of the neighborhood. This process has left us with a series of lessons learned that should be shared with the community to offer a view of how living labs, through the LifeSpace case study, have unavoidably renovated from the Triple Helix to the Quintuple Helix incorporating some new key

elements that allow this plasticity to respond to the different changing challenges that Europe is facing.

While intelligent environments, such as LifeSpace, serve to establish a symbolic location of the changes and evolution, a key event that has proven beneficial is the extension outside the physical infrastructures. In particular, it was proven useful in stimulating new challenges, allowing interaction patterns, behaviors and early discovery of needs and elements that contribute to empowering citizens and creating their own meaningful experiences (34). As human behavior is deeply influenced by the environment and its social relationships, breaking the physical walls of LifeSpace and extending the co-creation process to the neighborhood has allowed us to go one step further in the social innovation process, improving the understanding and perception of older adults as providers of relational goods and services, and the importance of these goods for the sustainability of our societies (35). In this context, the expansion of the LifeSpace into the city brings a much deeper, more detailed and dynamic insight into these phenomena of creating and understanding citizen relationships. The inclusion of older adult citizens in the governance and management bodies of the LifeSpace constructively generates engagement and commitment of all the parties, facilitating the needs and ideas transfer process.

Breaking the limits of the traditional vision of the Living Labs, conceptualized in LifeSpace brings new methods and forms of collaboration; extending the environment as part of the interaction and relationships experimentation has allowed discovery, enhancement, and empowerment of new exchange patterns between different groups of users, service providers, decision-makers and other stakeholders that traditionally do not participate actively in the co-creation process in such unstructured but fully monitored manner. Opening the creative space to citizens who normally do not participate in planning, creation or design activities is necessary not only to enrich the creative process but to raise awareness of innovation and

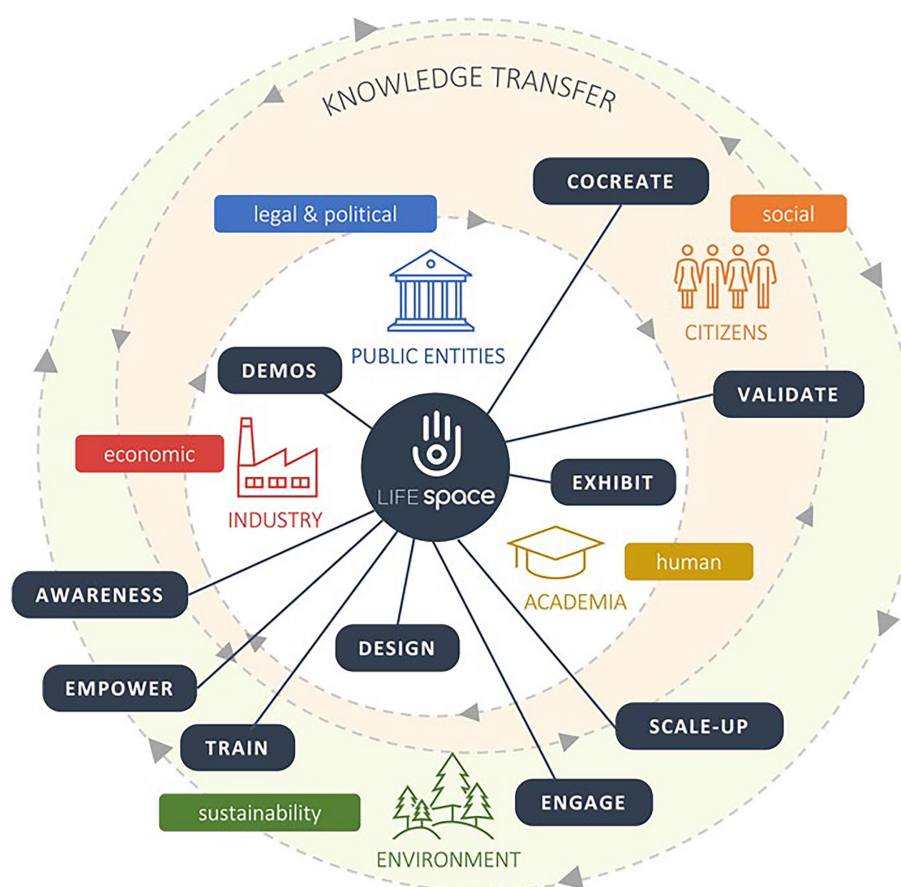


FIGURE 6
From Triple to Quintuple Helix evolution in the LifeSpace Living Lab (author's elaboration).

increase stakeholders' acceptance demands. However, it also opened new challenges in service innovation management. The incorporation of new perspectives on the analysis of the local environment influence issues based on the value co-creation process. In addition, the Quintuple Helix approach has helped to create an unlimited experimental collaborative environment, more holistic and integrative than before. LifeSpace becomes a sustainable environment that allows the seamless integration of specific needs, interests, willingness, and organizational context of all the participants at each stage of innovation, in their environment. With that, cooperation methodologies become more consistent and, consequently, apply user-driven innovation techniques more efficiently as a pillar for designing technological solutions. Using this perspective, service innovations in any type of public services view, not only assistive or medical services, could be provided as local service systems whose success depends on the ability of the involved actors to access and share common resources and information to create mutual incremental value.

The well-established LL process core group deployed within LifeSpace facilitated the mobilizing effect of local participants and stakeholders by combining co-creation (ICT solution testing) and shared decisions (how and when I, as the user, wish to use the solution) integrated into an interactive and flexible environment set-up. The early discovery of preconditions for viable medium- and long-term collaboration is necessary to set indicators to assess the key drivers, strategies, and performance at each stage of development and make results from the living lab comparable, scalable, and

reproducible. The optimal management of the LifeSpace ecosystem could be extended to a large number of dimensions regarding different types of communities. Focusing on the socio-technical dimension and system-centric perspective, this experience could pave the way for new ways of sharing and reusing knowledge regards citizens and their surrounding environment. This requires insight into the business viability of these ecosystems across the different collaborative activities and creative projects (Table 1).

5. Conclusion

The systematic analysis of the LifeSpace ecosystem, its changing interests as societies evolve, and considering the fields of health technology, digital health and innovation, reveals that sustainable development in knowledge societies can only be achieved when new insights are promoted and produced, and when innovations are further developed (19). The redesign of LifeSpace Living Lab has allowed us to accumulate a wealth of experience in understanding the ecosystem and how its members themselves can cooperate and improve to generate better solutions for all stakeholders involved whose collaboration and success require the efforts and commitment of the various actors. This paper unpacks the challenges of adopting innovation models in a changing technological context, as well as some lessons learned that can be incorporated into future methodological approaches that may emerge in other living labs. The

TABLE 1 Summary of the main lessons learnt.

1. Living labs become a key tool to boost innovation as the key driver for societal challenges and engage citizens in this process
2. Living labs cannot be only a structural driver of innovation but a mechanism to facilitate community transitions in a real-world context
3. The inclusion of representatives of each of the involved actors in the governance of the living lab generates engagement and commitment and facilitates the vision transfer process
4. Breaking the physical limits of the living lab opens co-creation to new unstructured collaboration methods that facilitate the participation of actors traditionally out of the innovation process loop
5. These new methods also create new research challenges to be incorporated systematically into the innovation process and become meaningful information
6. With Quintuple Helix living environments and communities become an actor in the innovation process that can influence the co-creation process
7. Living environment involvement facilitates the early discovery of particular needs and preferences of the other actors (i.e., hospital managers, healthcare professionals, final users, policymakers, industry), favoring holistic solutions creation and avoiding resistance to change behaviors
8. This could make scaling up to another local setting difficult. To avoid this problem, a clear understanding of facilitators and barriers is required

main lesson learned is that living labs are increasingly becoming a well-known, necessary, and facilitating means to encourage the participation of end-users, public and private entities, citizens, and the environment in the process of ideation, co-creation, development and testing to increase the maturity of a solution, whether product or service, in terms of technical reliability, usability, acceptability, satisfaction, adoption and trust before its deployment in the market.

This paper contributes to the literature focusing on Quintuple Helix collaboration as a driver to empower participants in the innovation process, thanks to the holistic visions of the global ecosystem. This has allowed for a greater impact of the proposed solutions: improved engagement and awareness of end users and other stakeholders, who can now play an active role, interact seamlessly with each other and more clearly see their contributions at the end. LifeSpace success demonstrates that Quintuple Helix is a bridging concept capable of generating insights across a case. Future work needs to emphasize the need of adopting an inclusive approach that overcomes geographic, thematic and institutional diversity to generate opportunities to explore system dynamics at different (global, regional, local) levels of challenge.

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Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

PA, BM-B, and IM: conceptualization. PA, GF, IL, and GC: methodology. MA: project administration. BM-B and MA: supervision. CL and IL: validation. PA, BM-B, and IM: writing—original draft. PA, BM-B, IM, IL, GC, and GF: writing—review and editing. MFC: revision. All authors have read and agreed to the published version of the manuscript. All authors contributed to the article and approved the submitted version.

Funding

The authors of this paper would like to thank the collaboration of the consortium partners that made up the European H2020 ACTIVAGE project (N.732679), as well as those involved in the development of the Madrid Deployment Site, particularly TEA and finally the H2020 VITALISE - Virtual health and wellbeing Living Lab Infrastructure – is funded by the Horizon 2020 Framework Programme of the European Union for Research Innovation, Grant agreement number: 101007990.

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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OPEN ACCESS

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RECEIVED 21 April 2023

ACCEPTED 17 July 2023

PUBLISHED 03 August 2023

CITATION

Rigtering C, Spaans LJ and de Jong JPJ (2023)
How to bridge the nurse innovation–diffusion
gap? An in-depth case study of Create4Care.
Front. Public Health 11:1209965.
doi: 10.3389/fpubh.2023.1209965

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How to bridge the nurse innovation–diffusion gap? An in-depth case study of Create4Care

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Introduction: Nurses frequently innovate in response to operational failures, regulations, procedures, and/or other workflow barriers that prevent them from delivering high-quality patient care. Unfortunately, most nurse innovations do not diffuse to a broader audience, depriving other nurses from taking advantage of solutions that have already been developed elsewhere. This under-diffusion is problematic from a societal and welfare point of view. The goal of this paper is to understand how diffusion shortage of nurse innovations can be reduced.

Methods: We develop a qualitative case study of a medical makerspace at the largest academic hospital in the Netherlands. This medical makerspace reported unusually high rates of nurse innovation diffusion. Our data collection includes on-site observations, archival data, secondary data, and fifteen in-depth interviews with key informants. Qualitative coding procedures and a combination of deductive and inductive reasoning are used to analyze the data.

Results: Our data show that personal, organizational, regulatory, and market barriers prevent nurses from further developing and diffusion their innovations in an anticipatory manner. That is, because nurses expect that transforming an initial solution into an innovation that can be shared with others will be too time consuming and difficult they do not proceed with the further development. The medical makerspace that we investigated adequately addresses this problem by developing an innovation ecosystem that largely takes over the innovation and diffusion process.

Discussion: We provide a concrete example of how a medical makerspace, and innovation support systems in a broader sense, can be designed to more adequately address the nurse innovation-diffusion gap. The two main elements of the practical solution that we identified are: (1) Support systems should facilitate that others may lead the development and diffusion of innovations and (2) The support system should promote that actors integrate their functional specializations within an innovation ecosystem. We make two theoretical contributions. First, we contribute to understanding barriers in the nurse innovation-diffusion process from a psychological point. Second, we identified that an ecosystem perspective is beneficial to develop innovation support systems in which diffusion occurs more often.

KEYWORDS

single case study, ecosystems, nurse, innovation diffusion, practice guidelines

1. Introduction

Promoting nurse innovation has become an important goal in healthcare systems around the globe (1–3). In the United States, for example, the National Academy of Medicine stressed the importance of promoting an innovative mindset among nurses in their Future of Nursing 2020–2030 report (4). Successful nurse innovation is often associated with improved medical service quality, improved effectiveness of treatments, higher levels of job satisfaction, improved healthcare access, and simplified processes in delivering healthcare services (1, 5). Because nurses make up the largest segment of the healthcare workforce (6) and provide up to 80% of primary healthcare (7), nurse innovation is broadly recognized as a solution to combat the rapidly increasing healthcare costs, national nursing shortages, and variations in healthcare quality (8).

The American Nurses Association defines nurse innovation as actively seeking and developing new methods, new technologies, and new tools to promote health, prevent diseases, improve the quality of care of patients, and the application of these innovations via teamwork and support channels (9). Nurses have a long history of being innovative (10) but, ironically, are not always recognized as innovators. Nurses commonly find solutions to operational failures, regulations, procedures, and/or other workflow barriers that prevent them from delivering high-quality and safe patient care. Unlike physician innovators, they seldom develop technologically advanced innovations based on systematic research and development (8, 11–13). Unfortunately, the vast majority of the useful solutions that nurses develop do not result in systematic improvements in the healthcare system. Nurses typically do not commercialize their innovations and/or do not share them with nurses working at other departments or other hospitals—that is, their innovations tend not to diffuse (3, 8, 13). While non-diffusion is a general problem within health care (11, 14), it applies to nurse innovations in particular. For example, studies show that patent applications by nurses are very rare (15, 16) and that it takes a staggering 15 years before an evidence-based nursing practice is broadly adopted (17). Non-diffusion is problematic from a societal and welfare point of view as nurse innovations generally have a high return on investment (3) and non-diffusion prevent patients from benefitting from healthcare improvements that are developed elsewhere (8, 12, 13, 18).

Various reasons for the lack of diffusion among nurse innovations have been identified. For example, scholars have pointed out that nurses commonly lack innovation abilities (1), technological abilities (19, 20), and knowledge about the innovation process (13, 21). Other scholars have identified that hospitals generally lack a culture and/or infrastructure that supports innovation (2, 8, 11, 22). Commonly proposed solutions to combat these issues are to make innovation or entrepreneurship a key element of the nursing curriculum (1, 21, 23, 24) to appoint nurse innovation leaders (13), or to set up Nursing Innovation Centers that bring together faculty and students [see (22)]. Yet, despite implementing these solutions, innovation rates remain rather low (2, 8).

Recently, scholars and practitioners have been building on the principles of open innovation (25–27) to propose that innovation support systems such as fablabs (28), living labs (29), and medical makerspaces (3, 30, 31) are a key tool to increase nurse innovation. Medical fablabs, living labs, and makerspaces offer (staffed) innovation assistance facilities with access to prototyping equipment

such as 3D printers and laser cutters (3, 28, 30). Although these facilities do enable nurse innovation, the diffusion of the innovations remains a persistent problem. For example, Svenson and Hartmann (3) conclude that medical makerspaces encourage nurse innovation and provide potential returns of up to 14 times the investment needed to establish and run the makerspaces. Yet, a very limited amount of this potential is realized, owing to the under-diffusion of the innovations (3).

The purpose of this article is to better understand why the nurse innovation–diffusion gap is so persistent and how this gap can be overcome. Although significant progress has been made in understanding the importance of innovation support systems, studies mainly describe the process of setting up an innovation support system (31), the general design features (22), or outcomes (3). A more *in-depth* understanding of why innovation support systems oftentimes fail to generate high levels of nurse innovation diffusion is still missing. The research questions for this paper are:

Research Question 1: What prevents nurses from diffusing their innovations?

Research Question 2: How can innovation support systems be designed to adequately address these diffusion barriers?

2. Methods

2.1. Qualitative approach

We conducted a qualitative case study (32) of nurse innovations developed at Create4Care, the medical makerspace of Erasmus Medical Center. A case study was used to understand the complex phenomena of nurse innovation and diffusion in its natural, organizational setting. The case study was developed over two distinct phases. During Phase 1, one of the authors spent several months at Create4Care as an embedded researcher. She had full access to all internal databases of Create4Care, observed the various professionals, and had regular talks to better understand the context and diffusion processes. This first phase was mainly for exploratory purposes and the insights that we developed provided input for our subsequent data collection (Phase 2) in which we conducted in-depth interviews and collected secondary data.

2.2. Context

Erasmus Medical Center is the largest university medical center in the Netherlands. In 2021, Erasmus Medical Center had an annual turnover of € 2.1 billion, 659,317 outpatient visits, and 30,771 patients were admitted. The organization has 16,180 employees (including subsidiaries) and 4,093 students. Its three core tasks are patient care, education, and research.

Create4Care is the medical makerspace department of Erasmus Medical Center. Create4Care directly reports to the board of directors and is run by a professional manager (0.5 FTE). The department was set up by a nurse who identified that many colleagues struggled while developing and diffusing nurse innovations. In practice, the

department is very informally organized and the nurse that set up the department co-manages the medical makerspace with the aforementioned professional manager.

The case was brought to our attention as Create4Care reported unusually high rates of nurse innovation diffusion. To confirm if Create4Care indeed provided a best practice in terms of the diffusion of nurse innovations and was a suitable setting for our study [see (32)], our embedded researcher developed a database of all finished nurse innovation projects (26 finished projects and 19 ongoing projects at the time of the data collection). She documented all diffusion efforts done, and the relevant diffusion pathways [commercial or peer-to-peer, see (33)]. In 24 out of the 26 nurse innovations, a substantial effort had been made to diffuse the innovation. Twelve of the 24 innovations had actually diffused; four were in the process of being introduced to the market by producers (commercial diffusion) while eight were directly adopted by peers working at Erasmus Medical Center and other hospitals in the Netherlands (peer-to-peer diffusion). After understanding the context and verifying the unusually high rates of nurse innovation diffusion,¹ we proceeded with Phase 2 (interviews and secondary sources).

An example of an innovation developed at Create4Care is the Infusion Lines Flower (see Figure 1). In early 2018, a nurse in the Children's Intensive Care unit noted that the spaghetti of infusion lines surrounding hospital beds could create safety hazards as lines can get mixed up after moving patients. She, furthermore, noted that the organization of infusion lines was very time-consuming. After recognizing this problem, the development of a solution started in September 2018. In 2019, the first 3D-printed prototype was ready for testing at the Children's Intensive Care unit. A version ready for mass production followed in early 2020. The invention was later that year adopted by a commercial producer and by the end of 2020 the product was introduced in the Dutch, German, and Scandinavian markets.

2.3. Sampling and reliability

The embedded researcher identified 13 key actors [see (34)] who took charge of innovation development and diffusion, based on her on-site observations and informal discussions. Each of these key actors was invited for an interview (and accepted our invitation). We also scheduled two additional interviews with the founder of Create4Care to learn more about the broader context. The interviews were conducted over a two-month interview period. Theoretical saturation (32) was achieved after approximately 12 interviews, meaning that no additional insights that are of theoretical importance were obtained in the last three interviews.

The average interview time was about 75 min with interviews typically lasting between 60 and 90 min. To ensure reliability, we collected secondary data at Erasmus Medical Center/Create4Care (for example, annual reports and strategy reports), consulted external sources (practitioner magazines and newspaper articles), and used the field notes that were collected by the embedded researcher in Phase 1

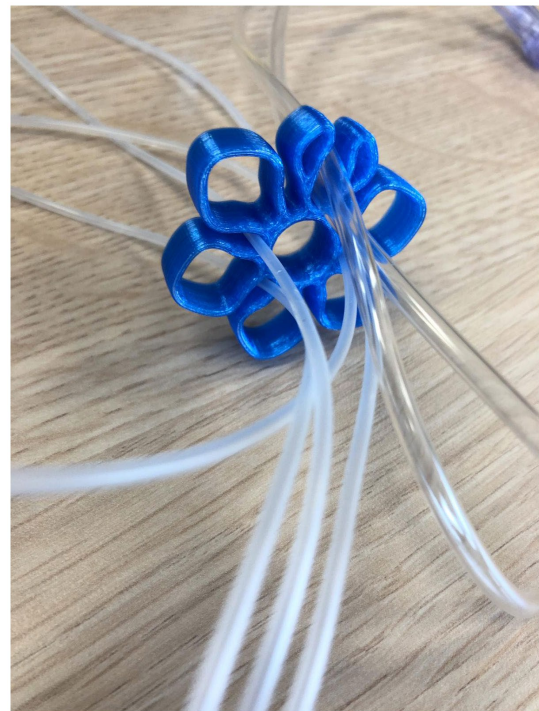


FIGURE 1
The infusion lines flower developed at Create4Care.

to triangulate the interview data. Tables 1, 2 provide an overview of the data collected during Phases 1 and 2.

2.4. Data collection instruments and units of analysis

We developed a semi-structured interview protocol designed to identify the main barriers that prevent nurse innovations from developing and spreading their solutions to a broader audience, and the procedures used within Create4Care to overcome these barriers. Additionally, we asked respondents to reflect on their role within the process and their motives to participate in Create4Care. Wherever possible, we asked the interviewees to provide concrete examples of barriers, procedures, actions, roles, and motivations. For example, to better understand the procedures within Create4Care, we first identified specific nurse innovations to which the interviewee had contributed. We asked the interviewee to provide examples of concrete actions that helped to develop and diffuse the nurse innovation(s). This approach, which prompts interviewees to provide specific examples of events, forces interviewees to use episodic memories and significantly increases the accuracy of the obtained information (35, 36). After eliciting these specific events, we asked more open follow-up questions [for example, What elements were crucial? How did you do this? Why was the approach (un)successful? Why is this procedure being used?] to gain a deeper understanding of the innovation and diffusion procedures. Most interviews were conducted in person, on location, and in a private room. Because of COVID restrictions, a limited number of interviews were held online. We recorded each interview. The interview protocol did not change throughout the event

¹ Von Hippel et al. (14) show that, across a large range of studies, diffusion rates do not exceed 25%. In comparison, more than 46% of the nurse innovations developed at Create4Care diffused to a broader audience.

TABLE 1 Overview of primary data collection.

		Phase 1				
		<i>Exploratory data collection</i>				
	Data collected by the embedded researcher	Data on the diffusion of finished nurse innovation projects, field notes, and on-site observations.				
		Phase 2				
		<i>Interviews with key informants identified by the embedded researcher in Phase 1</i>				
Respondent #	Job title	Organization/ department	Years of working experience	Educational level	Type of diffusion effort	# of interviews
1	Senior business development manager	Erasmus Medical Center/Technology Transfer Office	4	Master	Creating a suitable environment for diffusion/diffusing individual innovations	1
2	Junior business development manager	Erasmus Medical Center/Technology Transfer Office	1	Master	Diffusing individual innovations	1
3	Coordinator	Erasmus Medical Center/Create4Care	30	Ph.D.	Creating a suitable environment for diffusion/diffusing individual innovations	3
4	Manager	Erasmus Medical Center/Create4Care	7	Master	Creating a suitable environment for diffusion/diffusing individual innovations	1
5	Electronic engineer	Erasmus Medical Center/Create4Care	1	Master	Diffusing individual innovations	1
6	Instrument maker	Erasmus Medical Center/Medical Instruments Department	16	Bachelor	Diffusing individual innovations	1
7	Business advisor	Erasmus Medical Center/Medical Instruments Department	16	Bachelor	Creating a suitable environment for diffusion/diffusing individual innovations	1
8	Quality advisor/nurse	Erasmus Medical Center/Children Intensive Care	18	Bachelor	Creating a suitable environment for diffusion/diffusing individual innovations	1
9	Nurse	Erasmus Medical Center/Center for Home Ventilation and Respiratory Disorders in Children	27	Vocational training	Diffusing individual innovations	1
10	Technical coach	Rotterdam University of Applied Sciences	15	Master	Creating a suitable environment for diffusion/Diffusing individual innovations	1
11	Technical coach	Rotterdam University of Applied Sciences	24	Master	Diffusing individual innovations	1
12	Technical coach	Rotterdam University of Applied Sciences	22	Master	Diffusing individual innovations	1
13	Entrepreneur	BestCare Solutions	21	Master	Diffusing individual innovations	1

TABLE 2 Overview secondary data sources.

Type of data source	Secondary data sources	
	Coverage in years	Total number of documents
Hospital strategy plan 2019–2023	2019–2023	1
Annual report Erasmus Medical Center	2018–2020	3
Hospital online blog	2020–2021	4
		1
Newspaper articles	2020–2021	3
Create4Care page on the Website of Rotterdam University of Applied Sciences	2020–2021	1
Practitioner magazines	2016–2021	4

of the study. The interview protocol can be found in [Supplementary material A](#).

2.5. Data processing and ethics

We obtained approval for the research from the Ethical Committee of the Faculty of Law, Economics, and Governance (nr. 2020–019) of Utrecht University. All interviewees were informed of the data protection and processing procedures before the start of the interview. They verbally provided consent for using their anonymized data for research purposes. The interviews were fully transcribed for further data analysis. The interview data was stored on the secure servers of Utrecht University. We used randomly generated numbers to anonymously store the interview transcripts. The interviews are displayed in random order in [Table 1](#). In the text, we use #1 to refer to Interviewee #1 in [Table 1](#) and #2 to refer to Interviewee #2 in [Table 1](#).

2.6. Data analysis and rigor

We followed procedures recommended by Gioia et al. (37) for systematically analyzing qualitative data and achieving qualitative rigor. The approach of Gioia et al. (37) consists of three stages: open coding, axial coding, and selective coding. Open coding involves generating categories (also known as second-order codes) that are derived from interview transcripts, secondary data sources, and field notes. These are then linked to the categories to classify meaningful pieces of information. During axial coding, the categories are arranged into more abstract theoretical dimensions in a meaningful way by linking categories with each other and creating a hierarchical order. Finally, during selective coding, categories are organized around core explanatory concepts to build the theory (38).

To facilitate the coding process and knowledge sharing among the authoring team, we organized numerous discussion sessions. These discussion sessions took place directly after a set of interviews. The interview(ers) took the lead in describing the main insights that were obtained during the interview(s) to the other researchers. This ensured that all researchers were up to date with recent developments and helped in creating a shared understanding of the Create4Care case. After the interviews were completed, we continued with these discussion sessions but switched to formal coding of the qualitative

data where we made use of a combination of interview transcripts, secondary data, and field notes collected by the embedded researcher to triangulate the data. During all sessions, we relied on a combination of deductive and inductive reasoning [see (39, 40)] to situate our findings within existing work on nurse innovation and innovation diffusion. We used deduction to sort and structure the data according to the main components of the proposed framework (41). Induction was used to uncover unexpected findings and deepen the theoretical analysis of the data (37, 40, 41). [Figure 2](#) provides an overview of the outcome of the coding process. During the axial coding, we created 10 s order themes that related to three aggregate dimensions. The first aggregate dimension (Anticipatory mechanisms) describes the way innovation barriers affect the diffusion of nurse innovation. The second (Others take over a large part of the innovation and diffusion process) as well as the third aggregate dimension (Nurse innovation ecosystem) capture how the nurse innovation–diffusion gap is bridged at Create4Care.

3. Results

3.1. The nurse innovation–diffusion process: barriers that prevent diffusion

A full innovation and diffusion sequence consist of three phases (i) problem identification and prototyping to fix the problem, (ii) continued development, and (iii) diffusion (42). Continued development may include design, technological development, market research (to check for market potential and if there are similar solutions that are already available), certification, and business model development. Diffusion includes setting up production, distribution, and sales in the case of commercial production. In peer-to-peer diffusion, it is a less demanding task but still includes sharing design files with instructions in a format that other people can understand (43). During our interviewees, a large variety of barriers were mentioned that prevent nurse innovations from spreading to a broader audience. Based on previous work (1, 3, 11, 22), we grouped these reasons into personal, organizational, regulatory, and market barriers (see [Figure 2](#)). Personal barriers capture the innovation and technical skills needed to develop an innovation, as well as a nurse's belief in those innovation and technical skills (44). Organizational barriers capture hospital-specific structures that prevent the development of nurse innovations. Think of barriers such as insufficient time to develop innovations or bureaucratic procedures that stiffen further development (11). The complex certification processes that are needed for introducing medical innovations, and medical devices that require Class I or higher certification, in particular,² create regulatory barriers for nurse innovators. As documented in the literature [see (3)] and noted by one of our interviewees, “...meeting all regulatory requirements is a very time-consuming and expensive process” (#12).

While personal, organizational, and regulatory barriers have been discussed in previous nursing innovation studies (2, 8, 11, 19, 20),

² Class I medical devices are devices that have a low to moderate risk to the patient and/or user. Higher classes (Class II or III) medical devices have moderate to high risks to the patient.

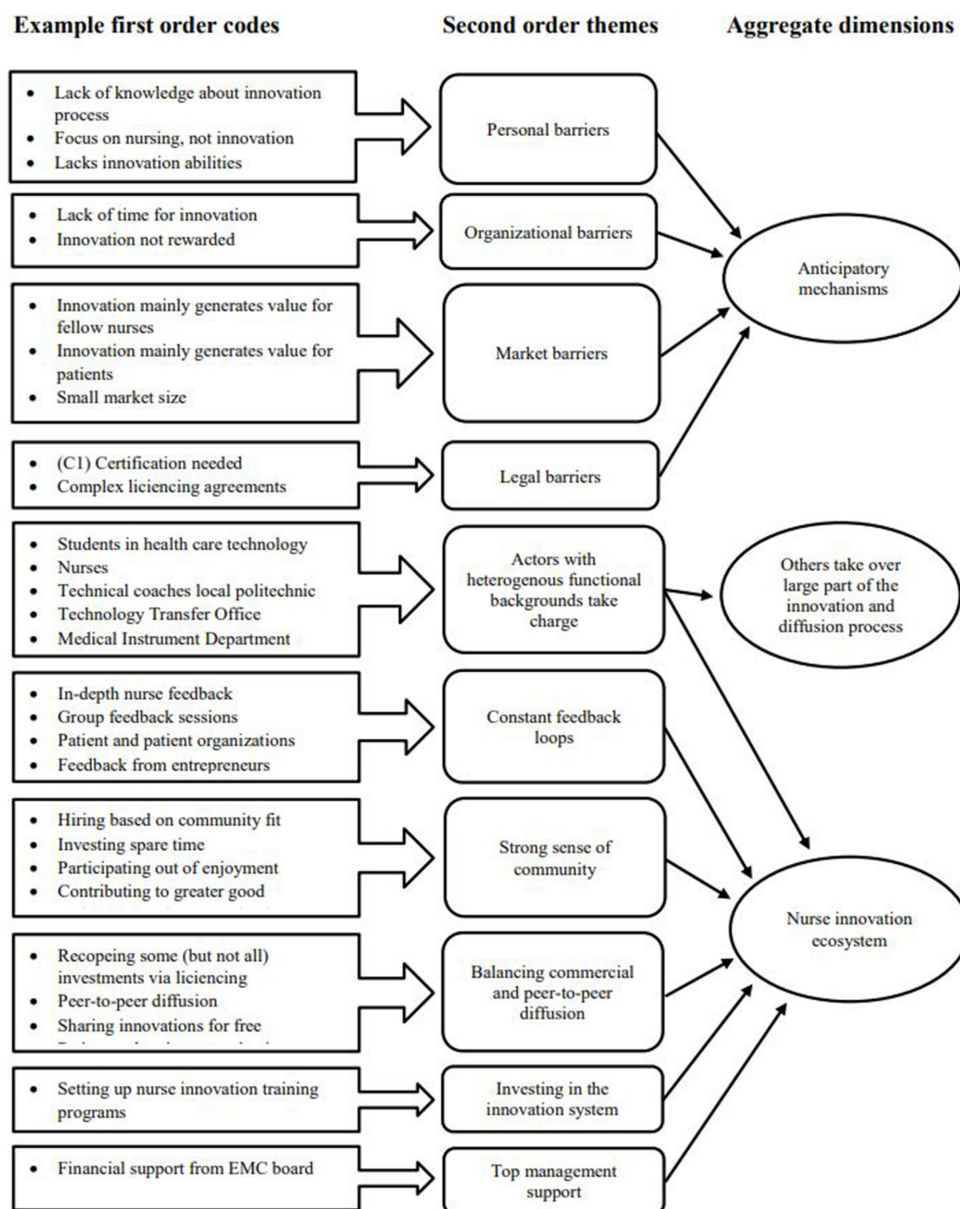


FIGURE 2
Final coding scheme.

market barriers have received little attention. Market barriers relate to the expected market size and the ability to protect nurse innovations via patents. Sufficient market size and protectability are key conditions for commercial diffusion because businesses/investors want to see the market potential and a viable business model to recoup their investments (16, 45). Unfortunately, patents are often not an option because of the low-tech nature of a lot of nurse innovations (# 1, 2). Nurse innovations mainly address unfulfilled user or patient needs and are developed in response to practical problems that nurses experience on the job instead of emerging technology. The highly practical nature of nurse innovations is well-captured by the following quote by one of the nurses (#8) “initial solutions are sometimes put together with duct tape.” It is also described in Debono et al. (12) and O’Harra et al. (8). Almost all interviewees furthermore mentioned that

a considerable percentage of the innovations that were being developed at Create4Care was not commercially viable because of “insufficient market size.” The interview extract below provides a good example. In this example, the innovation addresses a specific problem that nurses of the Children Intensive Care Unit experience. The market potential is very limited, but the innovation does offer substantial value to the nurses themselves.

“Children that receive heart surgery at the Children Intensive Care unit often have a chest drain, which are very large tubes around their heart area. These tubes run down to a vacuum pump to drain any moisture that occurs during or after surgery. The reservoir that collects the moisture needs to be placed on the floor under the patient’s bed. To check the amount of moisture, a nurse needs to read

the display on the reservoir. During the evening and night shifts, we need to do this every hour to check if there is any bleeding or alike. We could lift the reservoir, to check the display. However, because of the large tubes, the kids would immediately notice this and it can be quite painful for them. ... So, every hour one of the nurses needs to get on their knees to check the display. Not only the colleagues who are 25 years old but also our colleagues of 60 years and older who are already frequently struggling with back issues. We do not have one of these patients, but usually 2 or more simultaneously. ... The solution that was developed is a separate remote display, which is very helpful, especially for our older colleagues" (#8).

If there is insufficient market size, peer-to-peer diffusion is the only way a nurse innovation can still diffuse. Yet, peer-to-peer diffusion is particularly complex in the medical sector. Regulations do not only apply to commercial producers but “other hospitals are also not able to adopt an innovation without certification being complete” (#1). This implies that approximately the same effort and investment are needed for peer-to-peer diffusion as for the development of commercial innovations without any means to recoup these investments.

In Figure 3, we position the different barriers in the nurse innovation–diffusion process. Previous research suggests that innovation education (8, 13), technical expertise (19, 20), and innovation support systems (2, 3) would significantly lower the barriers for developing and diffusing a nurse innovation. Yet, even when nurses possess the right expertise and are provided with sufficient support, developing a viable solution may still be “a bridge to far” (# 7, 8). Intentional actions, such as deciding to develop a solution or innovation, are regulated by forethought; individuals form beliefs about what they can and cannot do, set goals, and plan courses of action that are likely to produce desired outcomes (46). Nurses thus need to assess their ability to act, need to determine their aspiration level, how they will proceed, and need to assess the likelihood success (47). These assessments are relative to the opportunity that the nurse has identified and any other goals that they might have [see (47, 48)]. In other words, innovation competes with the professional and personal goals of the nurses. Given these competing goals, the long and complex development trajectories of most nurse innovations significantly reduce the likelihood that a nurse foresees beneficial outcomes and decides to proceed. We thus posit that these barriers do not only create objective constraints, they also function as anticipatory

mechanisms. That is, because nurses anticipate that personal, organizational, and regulatory barriers reduce the likelihood of success, they do not proceed with the further development. In addition, if it is clear *a priori* that market potential might be limited, market barriers also affect the likelihood that nurses continue with the development in an anticipatory manner (this secondary effect is visualized by the dotted lines in Figure 3).

3.2. Overcoming the nurse innovation—diffusion gap: the Create4Care approach

After developing a more in-depth understanding of the nurse innovation–diffusion gap, we focus on how Create4Care manages to overcome this gap. Figure 4 provides a stylized overview of the innovation and diffusion processes used within Create4Care. We discuss the approach in more detail below.

3.2.1. Actors with heterogeneous functional backgrounds take charge of innovation and diffusion

A nurse innovation project at Create4Care can start in various ways. A nurse innovator may reach out to Create4Care when he or she has developed an initial prototype. The nurse innovator can then make use of the makerspace facilities (which include prototyping equipment such as 3D printing devices and laser cutters) to develop a more professional prototype and support from various professionals (technical, commercial, and legal support). This route is very similar to that of other medical makerspaces (3, 30, 31). In practice, however, it is seldom used. Instead, in most projects, Create4Care takes the lead in the (further) development of a prototype. Many of these projects are still initiated by nurse innovators who showcase prototypes to Create4Care but nurses, patients, and caregivers can also come to Create4Care with ideas for improvements or problems that they experience. In addition, Create4Care actively searches for ideas and solutions. One of the Quality Advisors/Nurses (#8) explains how Create4Care is involved in the quality control procedures:

“All misses or near misses related to patient safety, technical failures, etc. are reported in our quality system. Before Create4Care, we then discussed among ourselves [the nurses and Quality Advisors] how

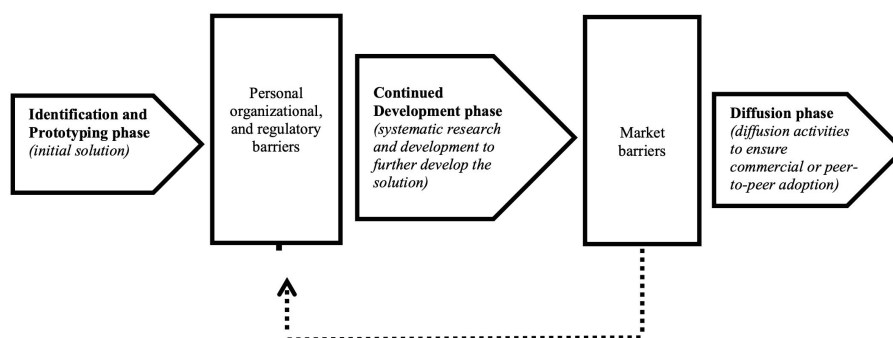


FIGURE 3
Barriers to nurse innovation diffusion.

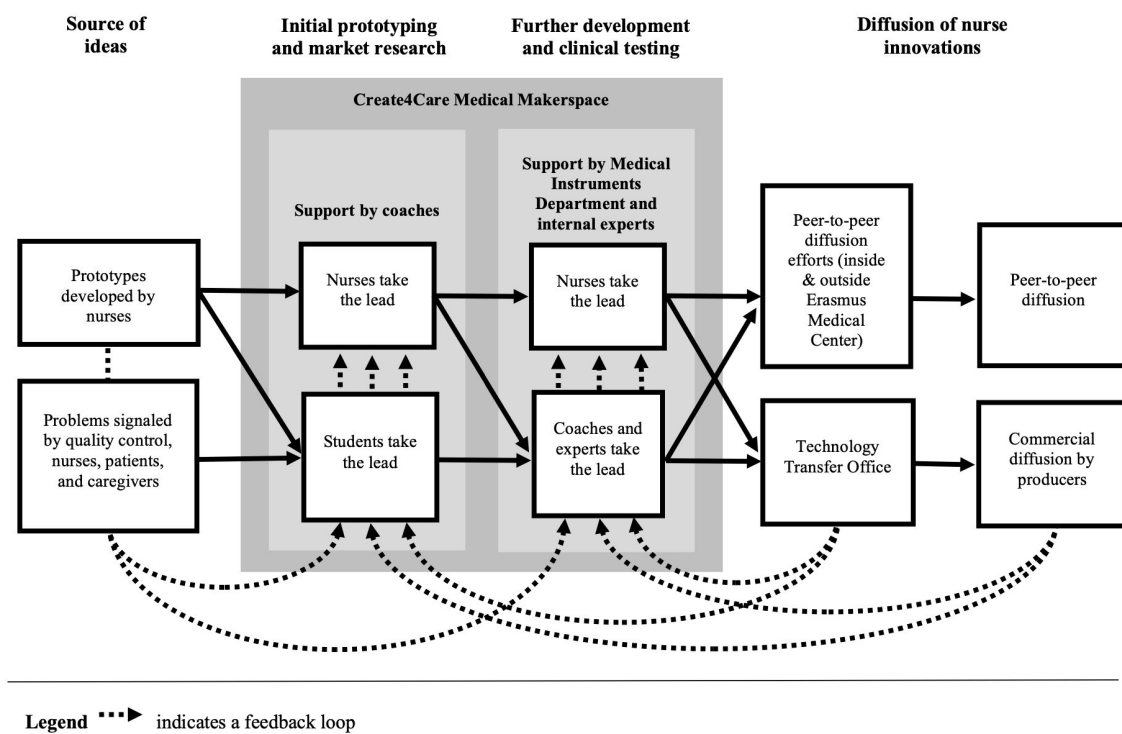


FIGURE 4
Overview of the innovation and diffusion processes within Create4Care.

we could solve these issues. Nowadays we take a more systematic approach in which we, with the help of Create4Care, first search for existing solutions that are already available on the market. If we cannot find a suitable solution, Create4Care can sometimes help to develop a solution."

The coordinator of Create4Care (#3) explains how Create4Care promotes that nurses and patients also proactively voice potential problems and/or solutions.

"My colleagues and I frequently present our innovations internally and promote Create4Care. Through these presentations, nurses learn about our work and what we can do for them. Increasingly, nurses and patients manage to find us. We carefully listen to their ideas and suggestions and select the ones that we believe we can develop a solution for."

Combining the active search with the input via the quality control procedures ensures that there is a constant inflow of new ideas and innovations.

In developing the initial prototype or further developing an existing prototype, Create4Care relies to a large extent on students from a local polytechnic (Rotterdam University of Applied Sciences). These students work on innovations as part of their healthcare technology minor and are supervised by three coaches of the polytechnic. Approximately 70 students participate on an annual basis. This not only ensures that development costs remain rather low, but students also bring new perspectives and ideas.

"We [nurses] have a fairly limited view on the type of solutions that can be implemented and oftentimes lack technical expertise. Students with a background in healthcare technologies develop totally different ideas and make use of different types of technologies and materials. This allows us to develop better solutions for our patients and colleagues" (#8).

In the later stages of the development process, the coaches may also contribute to the further development themselves and ensure a certain level of 'professionalism'. *"An innovation is never finished when the students are ready to graduate. ... They sometimes also lack the skills and expertise to make that final step. We then step in to make that final step"* (#10). Experts are then also brought along. For example, an instrument maker (#6) from the Medical Instruments Department can assist in developing a prototype that meets *"the requirements for clinical testing"* (#6) and Create4Care has a part-time electronic engineer (#5) for projects that include more complex hard- and software applications.

Relying on students and professionals for the further development of the innovations does not mean that the prospective users (nurses, patients, caregivers) of the innovation are not involved in the development processes. Each new prototype is discussed with the users for feedback and their input is integrated into each iteration. Feedback is provided informally, but there are also more formal sessions. These sessions vary from in-depth sessions with quality advisors or nurses to shorter group sessions. *"We have regular professional development sessions with large groups of nurses being present. We use some of these sessions to discuss the innovations that are being developed at Create4Care and provide feedback"* (#8). When an

innovation is targeted toward patients or caregivers, Create4Care develops the innovations in collaboration with patients/caregivers and/or patient organizations. These feedback loops are visualized at the bottom of Figure 4 as moving from the nurses, patients, and caregivers, to the students, nurses, and professionals that develop the innovations. Through their feedback, nurses and patients mainly contribute to the prototyping and clinical testing phases (see Figure 4). In addition, in the case of peer-to-peer diffusion, they are often the first adopters and serve as innovation ambassadors.

Strikingly, market and regulatory diffusion barriers are addressed already early in the development process by involving the Technology Transfer Office and Medical Instruments Department:

“Each project starts with basic market research to check if there are similar solutions available and to determine if there is market potential” (#12). “Partially this is to check if there are any liabilities or risks that we need to take into consideration” (#1) “I often have discussions very early in the development process with the students and coaches about how they can ensure that the innovation that they develop will meet certain standards. Can the innovation be designed in such a way that it meets hygiene standards, that it can be easily cleaned, and that it can be easily produced? This prevents problems and delays later in the development process” (#6).

In addition, feedback is provided by commercial parties that have already adopted some of the nurse innovations developed at Create4Care. *“I sometimes provide feedback on the innovations that are being developed. Some of these innovations are not interesting for me or my company, but I find it important to still help in developing these innovations and to provide feedback from a more commercial perspective” (#13).* In some cases, this early involvement directly enhances the likelihood of diffusion. *“As part of our marketing research, we are sometimes able to identify partners that might want to sponsor some of the development costs or we can set up a joint partnership with a commercial producer” (#1).*

Commercial diffusion is not the end goal for all innovations, but it is *“... an important way to recoup some of the upfront development costs, which can be substantial. Most commonly, we work with licenses” (#1)* Create4Care has set up several channels (including social media channels, networks, and websites) to find commercial parties that are interested in adopting the innovations. *“The advantage of not being able to patent many of the innovations is that we can more easily share innovations. We are able to attract considerable attention for our innovations via social media channels” (#2).*

To mobilize peer demand (within and outside Erasmus Medical Center) for innovations that cannot be commercially diffused, members of Create4Care present innovations during seminars and submit articles to newsletters and alike. Another way is to freely share innovations. For example, *“For the Ampule Breaker project, we distributed copies to other nurses” (#10).* Another option is to freely share innovations with the outside world. *“If there is demand at the (inter)national level but it is too small for commercialization, we just share the CAD or design files with other hospitals and tell them ‘produce it yourself.’” (#12).*

3.2.2. Critical success factors

In summary, Create4Care has two unique features compared to other medical makerspace programs (3, 30, 31). First, Create4Care does

not exclusively rely on nurses for the further development of innovations and even actively searches for problems that nurses experience on the job. Second, despite the significant development costs of some nurse innovations, peer-to-peer diffusion is actively promoted. We identified five critical success factors that support this approach: an innovation ecosystem approach, community, ecosystem co-evolution, balancing profit and non-profit, and top-management support.

3.2.2.1. Innovation ecosystem approach

Create4Care brings together a variety of internal (nurses, quality advisors, and technological and legal experts) and external (patients, parents/caregivers, patient organizations, educational institutions, and producers) actors. Each of these stakeholders provides crucial input, sometimes voluntarily (that is, without receiving direct compensation), and works together within an innovation ecosystem. We use the term ‘ecosystem’ to emphasize that innovation and innovation diffusion is enabled through complex interactions between actors and between actors and their physical environment (the makerspace facilities) in a community setting [see (49)]. Cooperation is the result of actors achieving complementary benefits by integrating their functional specializations. Think of nurses who benefit in the long run from providing the students that work on the innovations with detailed feedback or legal specialists who are willing to provide feedback in the early phases of the innovation process to prevent *“costly losses and problems later on” (#2).* The makerspace facilities facilitate informal interactions by providing a physical place where actors can meet, exchange ideas, and can work together on innovations. The coordinator (#3) and manager (#4) of Create4Care act as ecosystem leaders (50) in that they actively promote frequent interactions, institutionalize them via working procedures/best practices, and expand the ecosystem by inviting new members to contribute and benefit from the innovations developed at Create4Care.

3.2.2.2. Community

In organizations, a recognizable community emerges when the population develops an identifiable cohesion that derives from mutualistic interdependence among actors with complementary differences [see (51)]. Despite the large differences between actors in terms of their functional specialization, there is a strong cohesion and, almost without exception, interviewees indicate that advancing the nursing profession and/or helping patients is a decisive factor in why they are motivated to contribute to Create4Care. The strong motivations of the actors to contribute to a common cause result in additional effort (for example, *“I invest substantially more time than formally required” #1*) but also help to overcome arguments that might arise as a result of interdependencies and conflicting interests. The coordinator (#3) explains that safeguarding the community is a key goal. *“We just received an additional budget to hire new people. Yet, we do not hire people simply because we have the budget for it, even if they have the right expertise. New people need to fit in the community.”*

3.2.2.3. Ecosystem co-evolution

Importantly, Create4Care was *not* planned for as a result of corporate policies. Rather, it was established bottom-up by a nurse innovator (currently the coordinator of Create4Care) who worked at the Children's Intensive Care unit of Erasmus Medical Center. Nurses at the Children's Intensive Care unit commonly have to rely on workarounds to perform their day-to-day duties as *“providers of*

medical equipment do not always offer suitable solutions for kids” (#8). During the further development of one of his own inventions, the coordinator developed an extensive network within Erasmus Medical Center and strong connections to the technical and legal divisions of the hospital. After realizing that other nurse innovators struggled with the same type of problems as he faced during the development of his invention, he started helping his co-workers and mobilized his network to advance the nurse innovations of others. At first, he mainly targeted colleagues in the Children’s Intensive Care unit and started venturing out to other departments soon thereafter. Especially in the early years, Create4Care was mainly a personal project. It was financed by temporal budgets/grants, operated as an informal network, and many actors contributed voluntarily. It took more than 5 years before permanent funding was obtained and Create4Care was officially recognized as a department of Erasmus Medical Center. As Create4Care grew in terms of size and level of professionalism, the interdependencies between ecosystem actors changed. In particular, creating a more professional nurse innovation development trajectory also made the process more complex and formalized. This can easily result in a situation in which the process becomes more ‘detached’ from the nurses that contribute the ideas/prototypes and provide feedback. To prevent this and to ensure that the nurses understand why certain steps are crucial, Create4Care has developed several nurse innovation training programs in recent years. These programs mainly target innovation literacy and range from short workshops to dedicated training programs (consisting of online and in-class elements). Educating the nurses in innovation enhances mutual understanding, increases their confidence to participate in the development of innovations, and ensures that the different parts of the ecosystem co-evolve.

3.2.2.4. Balancing profit and non-profit

Because of the substantial development costs of most nurse innovations, recouping some of the investment costs via licensing agreements or other means may be tempting, and considered necessary. Yet, Create4Care recognized that a predominant focus on commercialization would be disadvantageous, and can derail diffusion. Except for the business managers (#1,2) and entrepreneur (#13), all interviewees indicated that “*enjoyment*” and/or “*contributing to a greater good*” was their main motivation for participating in Create4Care. Focusing only on nurse innovation with commercial potential and neglecting other types of innovations that bare significant use value is expected to drive out these intrinsic motivations (52, 53). Hence, within Create4Care’s culture, it is well-accepted that many innovations will never be commercialized, but can still be very meaningful when diffused freely to peers.

3.2.2.5. Top management support

Importantly, freely sharing innovations certainly helped to accomplish diffusion, but for this diffusion pathway, top management support is indispensable. Many nurse innovations mainly generate indirect benefits [more effective treatments or a less physically demanding working environment, see (1)]. These benefits are difficult to quantify in economic terms (3), and investing in the development of nurse innovations without commercial potential is difficult without (financial) support from hospital management. Interestingly, we observed that top management support at Create4Care was *not*

provided in advance. As mentioned, Create4Care emerged bottom-up as a result of the actions and efforts of a nurse innovator. He (#3) provided a proof of concept and, especially in the early years, asked for modest budgets that he knew they could not be refused (e.g., using schooling budgets to develop prototypes and produce initial test versions). As Create4Care grew, their approach became more professional, and, with the help of the manager of Create4Care (#4), the nurse innovator started formalizing and embedding Create4Care in the organizational chart. Only after obtaining a critical mass and showing numerous successful projects, permanent and larger budgets were asked for, and allocated. Top management was always supportive and considered it a low-risk investment, given the promising results that Create4Care’s contributors could demonstrate at the time. Hence, although supporting and investing in nurse innovations with limited or uncertain economic benefits is essential, top management support was not such that big budgets were allocated without convincing results. In contrast, as an evaluation of the Swedish Makerspace Program by Svensson and Hartmann (3) shows, top-down implementation of makerspace programs (with large budgets being assigned in advance) is unlikely to optimize the diffusion of nurse innovations.

4. Discussion

Our study shows that nurses face multiple barriers that keep them from innovating, from solving their personal problems, and from spreading their innovations to the benefit of all in particular. These barriers are unlikely to be fully removed via training and innovation support systems. Based on our case study, we provide a concrete example of how a medical makerspace, and innovation support systems in a broader sense, can be designed to more adequately address nurse innovation and (in particular) diffusion barriers. The two main elements of the practical solution that we identified are: (1) Support systems should facilitate that others may lead the development and diffusion of nurse innovations and (2) The support system should promote that actors with distinct expertise and skills (nursing, engineering, commercialization, legal) integrate their functional specializations within an innovation ecosystem. Below, we discuss the implications of these findings in greater detail.

4.1. Implications and contributions

Previous studies of nurse innovation have mainly focused on removing innovation barriers and tended to ignore subsequent diffusion to the benefit of other nurses. With regard to removing barriers, innovation training (1) or educational programs (8) improve opportunity recognition and may equip nurses with the necessary skills to conduct basic market research, develop their innovation, and pitch an innovation to potential investors [also see (53)]. Also, medical makerspaces provide access to the necessary equipment to develop prototypes and can connect nurse innovators to commercial businesses (3, 31). Yet, even when nurses have the right skills and are provided with technical support, innovation within the medical sector remains a lengthy and complex process and diffusion is not evident (11, 14). In addition, because most innovations are developed in

reaction to practical problems (8, 12) and do not generate significant commercial value (14, 54), only nurses who are intrinsically motivated and enjoy the innovation process are expected to further develop and diffuse their innovations (46, 47, 52, 53).

Our case study shows that both the rate and diffusion of nurse innovations can be significantly improved if others take a leading role in the development and diffusion processes. These others often bring specialized knowledge, skills, and competencies that nurse innovators may lack. This significantly lowers the barrier for nurses to engage in innovation, speeds up the innovation process, and increases the likelihood of diffusion. In other words, external contributors help to bridge the gap between early innovation prototyping, and broad diffusion via commercial or peer-to-peer pathways. Crucially, our case illustrates that the involvement of others does not have to be at the expense of nurses' involvement and that large groups of nurses can still be actively involved in the development process.

We make two contributions that are of theoretical importance. First, we contribute to understanding barriers in the nurse innovation–diffusion process from a more psychological point of view. In this view, barriers are not objective in that they can be fully removed via training/education and technical support systems. Instead, perceived barriers are both objective and subjective, and interact with one another within a complex system of personal and work-related goals (44, 46, 53). This has important implications for practice. For example, it implies that the likelihood of further developing and diffusing a nurse's innovation is not only a function of ability and creativity but of factors such as age or hierarchical level. Older individuals, for example, may value personal over professional goals while individuals who just started their nursing career may erroneously lack confidence in their innovation abilities (46). Fully taking advantage of nurses' innovation potential would necessitate that hospitals develop support systems in such a way that nurse innovators are not forced to take a leading role in the further development of the innovations.

Second, we identified that an ecosystem perspective on nurse innovation and diffusion is beneficial to develop better systems, that is, innovation systems in which diffusion occurs more often. The benefits of a more open approach to innovation (25–27) are currently gaining traction within the medical sector. An ecosystem perspective to open innovation highlights the importance of complementarity among a set of actors with diverse functional skills (49). Given the technological, legal, and market complexities of nurse innovations, it is unlikely that a single nurse possesses all the necessary skills to develop and diffuse her/himself, or has a network that can help with all relevant tasks. In an innovation ecosystem, individuals do not only maximize their own output but also that of others within a community setting. The conditions under which individuals show altruistic behavior and maximize the output of others are likely to be dependent on the goals and way the ecosystem is being managed. For example, a nurse innovation ecosystem that balances diffusion via commercial and peer-to-peer pathways and has no requirements to break-even is more likely to elicit altruistic behaviors among members of the ecosystem, compared to one with a focus on commercial revenues only. Similarly, an ecosystem that is developed bottom-up and is tailored to the needs and requirements of all members of the ecosystem would elicit higher levels of engagement and commitment among members. The critical success factors that we identified provide a starting point for further investigating and understanding the inner

workings of such nurse innovation ecosystems and why these ecosystems are successful.

4.2. Practical implications and transferability of the results

Our study provides important insights for managers and practitioners that seek to open a medical makerspace (or fablab or living lab) to facilitate nurse innovation. Most crucially, our study shows that a one-size-fits-all approach to creating a medical makerspaces is unlikely to be successful. The founders of Create4Care have built their innovation ecosystem over a long period of time; initially at a very modest level with limited budgets, and lots of voluntary contributors from their emerging network. While doing so, they incorporated best practices developed elsewhere but carefully tailored these best practices to the local innovation requirements of nurse innovations at Erasmus Medical Center. In addition, they balanced the needs of different stakeholder groups (nurses, patients, the hospital, and commercial parties) in such a way that there was not one beneficiary, but that all groups equally benefited from their contributions to the ecosystem. Only later, they gradually expanded their activities and started asking for larger budgets, permanent lab facilities, and official organizational embeddedness. These findings imply that makerspaces that are created in response to corporate policies, that is, planned in top-down fashion, are likely to be less effective than those that emerge bottom-up. To managers and other decision-makers, it is recommended not to try to create a makerspace or similar support system for nurse innovation overnight. Instead, back up those employees who truly care about innovation and diffusion processes, and facilitate an emerging ecosystem.

Other important design factors for nurse innovation makerspaces directly follow from the critical success factors discussed in section 3.2.2. First, it is important to nurture a community feeling, by developing a shared purpose first: solving nurse innovation problems with practical solutions, from which any nurse can benefit—regardless of the most appropriate diffusion pathway (commercially, peer-to-peer, or both). Second, avoid the emerging ecosystem's activities are derailed by excessive revenue targets, to be obtained from licensing or selling nurse innovations to commercial partners (which is the dominant mode of most technology transfer offices at hospitals). In our case study, this pitfall was avoided by recognizing the importance of nurses as a source of innovation, and by accepting some social responsibility for diffusing innovations even for free. Thirdly, top management support is indispensable for such a system to sustain in the longer run, if only because part of the makerspace's expenditures have to be covered by lumpsum budgets. Recall, however, that top managers at Erasmus Medical Center never felt that budget requests from Create4Care's initiators were unrealistic, because viable and generally useful innovations could be demonstrated first—the recommended gradual process of bottom-up emergence secured that all investments were considered low-risk.

4.3. Limitations and future research

Our study had limitations that translate directly into recommendations for continued research. First, although our findings

mainly emphasize the importance of “customizing” makerspaces to the needs of stakeholders, the relationships that we identified may not fully transfer to other settings or even other hospitals. Erasmus Medical Center is a research-intensive environment with a proven infrastructure for the development and diffusion of physician-led innovations. Create4Care makes use of this infrastructure (e.g., legal and technical expertise). Even though this is a representative setting for academic hospitals in the Netherlands, it is not necessarily representative of all academic hospitals and peripheral hospitals in particular. This creates the need to study the effectiveness and inner workings of nurse innovation ecosystems in a variety of settings and countries.

Second, we did not design this study to uncover individual-level decision-making processes. Instead, as is common in qualitative research, the anticipatory mechanisms that we identified surfaced as the result of our combination of deductive and inductive reasoning (39–41). Future studies should follow up on these findings and such research may want to make use of experimental designs to test the causal relationships that we propose.

Third, in terms of the selection of the interviewees, we relied on our on-site observations of the innovation and diffusion processes to select key informants. This is both a strength and a limitation. Follow-up studies may consider including a broader range of stakeholders that are involved in the nurse innovation–diffusion processes such as patients, patient organizations, commercial parties, innovation adopters, and top-level managers.

Finally, our study provides a starting point for understanding how successful nurse innovation ecosystems work, but the interrelations between the different critical success factors should be investigated in future work. These interrelations are also likely to change with the advent of artificial intelligence (AI) and tools such as ChatGPT and Bing Chat becoming available to a wide audience. Such tools empower nurses to develop different types of nurse innovations and the successful diffusion of AI-powered nurse innovations via peer-to-peer or commercial pathways likely requires different types of competencies and external relationships.

Data availability statement

The datasets presented in this article are not readily available due to the nature of the research. As is common in qualitative research and to ensure that the participants could speak freely, we informed the interviewees that the data would not be shared with company management or other third parties. The participants did not give written consent for their data to be shared publicly. Requests to access the datasets should be directed to CR, j.p.c.rigtering@uu.nl.

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Ethics statement

The studies involving human participants were reviewed and approved by Ethics Committee Faculty of Law, Economics, and Governance of Utrecht University. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

CR: conceptualization, methodology, formal analysis, investigation, writing—original draft, writing—review and editing, and visualization. LS: conceptualization, formal analysis, validation, investigation, and writing—review and editing. JJ: investigation, formal analysis, writing—review and editing, supervision, and project administration. All authors contributed to the article and approved the submitted version.

Acknowledgments

The authors would like to thank Onno Helder and Tamara de Vos for their support while collecting the data.

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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Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2023.1209965/full#supplementary-material>

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OPEN ACCESS

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RECEIVED 15 March 2023

ACCEPTED 07 June 2023

PUBLISHED 07 August 2023

CITATION

Mukherjee AS, Sahay S, Kumar R, Banta R and
Joshi N (2023) “A living lab within a lab”:
approaches and challenges for scaling digital
public health in resource-constrained settings.
Front. Public Health 11:1187069.
doi: 10.3389/fpubh.2023.1187069

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“A living lab within a lab”: approaches and challenges for scaling digital public health in resource-constrained settings

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A living lab is an emerging concept, particularly in Europe, as a vehicle to develop digital innovations through a process of co-produced design and development, which takes place, physically and socially, in real-life use contexts. However, there is limited research relating to guiding our understanding of the process by which such labs are established, and digital innovations are co-created and scaled to other settings requiring similar solutions. Furthermore, beyond Europe, the concept of a living lab has not found widespread application in low- and middle-income countries (LMICs), particularly in their public health contexts. Public health systems offer the unique scaling challenge of “all or nothing”, implying that data are required from the whole population rather than isolated pilot settings. The living lab approach promises the rich potential to strengthen public systems but comes with twin interconnected challenges. First, for building appropriate digital solutions to address local public health challenges, and second, in scaling them to other public health facilities. This article investigates these twin challenges through ongoing empirical work in India and identifies three key domains of analysis, which are as follows: the first concerns the process of establishing an enabling structure of a “living lab within a lab”; the second concerns leveraging the capabilities offered by free and open-source digital technologies; and the third concerns the driving impetus to scaling through agile and co-constructed technical support.

KEYWORDS

living lab, frugal, innovation, public health, health information systems

1. Introduction: the challenge of scale

The application of digital technologies in public health systems continues to be rapidly accelerated in current times, particularly in the context of low- and middle-income countries (LMICs). How can the value of such digital interventions be enhanced, so that they can lead to real improvements in the access and utilization of health services, particularly, among the poor and marginalized, is the broad question this article seeks to address. This question is examined within the context of the design of digital health systems, and how they can be made more relevant to supporting health challenges in locally situated contexts. Heeks (1) argues that nearly 90% of digital health applications end up as partial or complete failures, largely contributed to by “design-reality” gaps, implying that systems designed in contexts that are geographically and culturally distant from the reality of the users are unlikely to succeed. An important question then concerns how to build design approaches to strengthen the local relevance of digital health information systems.

The question of locally relevant design is analyzed through the approach of co-production of the digital systems within a “living-lab” framework. Co-production (2) represents an approach where people, from different domains, also including members from outside the organization, work together in mutually equal ways, sharing influence, skills, and experiences to design, deliver, and monitor digital health interventions. For co-production to be effective, it arguably needs to take place within a “living lab” framework, which represents a user-centered, open-innovation ecosystem, operating in the physical setting of the user environment. The physical co-location helps to integrate concurrent processes of research and the development of innovation, by creating spaces that encourage exploration, experimentation, and evaluation of innovative ideas, within the context of real-life use cases. These processes need to consider concurrently both the global performance of the product or service being co-produced and its potential adoption by users in particular situated contexts. This brings us to consider the important question of scale.

Scaling of digital systems is a multi-faceted and multi-layered concept. This is so because the public health systems offer the unique scaling challenge of “all or nothing”, implying that planning required data is required from the whole population, rather than isolated pilot settings (3). While the lay meaning of scale implies a physical expansion, in numbers or geographical areas of use (4), recent discussions have emphasized other dimensions of scale including those related to functionality, performance, and complexity. Public health information systems represent the unique scaling challenge of “all or nothing” (5), implying that health data are needed on the whole population, else it is of limited or no value. For example, an immunization manager in a province would need to know about the vaccination status of children from all the health districts in the province and not just from a few “pilot sites”, to make meaningful interventions to achieve full immunization coverage. As a result, Braa et al. (6) argue that limited-scale systems do not get supported and are not sustainable, which constrains the scaling of the systems. Sustainability and scalability are thus inextricably interrelated.

If digital innovations to address locally relevant health challenges in a district are developed based on a living lab approach, it raises the following question of scale: “how systems and learnings developing in a particular facility of this district can be taken to other similar settings, where like problems exist, but where contexts are both similar and different.” The process of building a digital innovation through a living lab approach is both resource and time-intensive (5), making it extremely challenging for resource-constrained LMIC settings to replicate systems from scratch in multiple locations. The scaling challenge then can be expressed as: “how can learnings and systems developed in one living lab be taken to the multiplicity of locations to achieve full coverage”. This requires the scaling process to find a “pragmatic balance” (7) which can respond effectively to the paradox of the systems simultaneously having to be both globally productive and locally embedded and relevant. Unraveling this paradox theoretically and methodologically is the focus of this article, which addresses the following research question:

What are the challenges and approaches to scale living lab-generated digital innovations within multiple public health facilities in an LMIC context?

Answering this research question contributes to three domains of academic research. The first concerns ICTs for Development (ICT4D), as we highlight how technology development carried out in settings of a living lab can provide a more positive alternative than top-down approaches that typically characterize technology design approaches in LMIC contexts. The second relates to the field of public health, as professionals from this field are increasingly being exposed to digital interventions, and there is an urgent need for them to develop a more intimate understanding of challenges and approaches to making digital systems work. The third concerns the broader field of IS research, through our elaboration of the concepts of frugal innovation, scaling, and co-production, which have broader relevance than just ICT4D research.

The rest of the article is structured as follows: after providing an overview of the research problem addressed in this introduction, in the next section, we discuss relevant research, with a focus on co-production within a living lab framework and the associated challenge of scale. This is followed by a description of the methods and the case study. The case analysis and discussions follow and then brief conclusions.

1.1. Public health information systems in India: the need for scale

Visions of digital health innovations as vehicles for strengthening health and development processes are now dominant, particularly in LMIC settings. For example, the UN Social Development Network has stated that “Digital technologies have the capacity to foster the levels of social and economic inclusion required to achieve SDG1, poverty eradication” (unsdn.org). In 2018, the Indian Prime Minister articulated the vision of “Digital India” as being core to national development and making India the “hotspot of digital innovation across sectors ... and leap-frog into the future while ensuring empowerment of every citizen” (8). However, achieving this level of digital innovation at scale (every citizen everywhere in the country) is a non-trivial challenge in terms of building a supporting ecosystem that is cost-effective, scalable, and enabling the necessary skills and knowledge (9).

We, however, acknowledge that all LMIC settings are not similar, and also some settings even in rich countries will suffer from challenges of health inequities and unequal access to healthcare services (10). India, although classified as an LMIC, has both similarities and also differences socially, culturally, and economically from other countries such as Brazil. In terms of economic growth, Brazil may be more advanced than India, but both suffer from health inequities, although for different reasons. India is overpopulated as compared to Brazil, which raises different challenges when considering scale. While many African countries produce wealth, they tend to be economically challenged and suffer from health inequities for very different reasons such as high disease burdens, poor health infrastructure, and the continued adverse impacts of the colonial legacies. The United States is a contradiction of sorts, although well-advanced in research, technology, and innovation, they have not effectively addressed health inequities. While the empirical focus is on India, we acknowledge that our findings cannot be considered applicable to

TABLE 1 Research workshops conducted during the project period.

Workshop	Location	Participants	Key learnings
No. 1	India	Institutions involved in building and studying patient-centric systems	A landscape view of patient-centric systems in India, and their strengths and weaknesses
No. 2	India	Healthcare workers and researchers	Initial design requirements for the proposed patient-centric system
No. 3	Norway	Researchers and healthcare institutions	What are the characteristics of Norwegian patient-centric systems and how are they implemented
No. 4	India	Researchers and healthcare institutions	Dissemination of results and receiving feedback on system improvements noted
No. 5	Norway	Healthcare and informatics researchers	Dissemination of results and discussions around future collaborative research
No. 6	India	Researchers and health department staff	Challenges to sustaining and scaling the system

all LMICs. [Table 1](#) However, there will be some learnings that may be relevant, with appropriate incorporation of context sensitivities.

It has been acknowledged that the Indian public health system needs to build effective health information systems (HISs) to support its engagement with the multiplicity of health challenges that they continue to experience (5). Given the size and diversity of India, it is of fundamental importance that these HISs can scale geographically and functionally, across disease domains, population groups, and geographical locations. India contributes to about 20% of the global burden of infectious diseases and 15% of global maternal deaths, has a 2% infant mortality rate (11), and only 62% of children are fully immunized (12). India ranks number one globally for tuberculosis, contributing 2.8 million new cases in 2015 (12), representing 27% of the global burden (13). India is the hotspot for non-communicable diseases, with 69 million people currently with diabetes (14), and more than one million smoking-related deaths annually (15). India was way behind its targets in achieving its MDGs, in contrast to their neighbors, such as Thailand, Sri Lanka, Bangladesh, and China.

While India has been engaged with digitization initiatives for more than two decades, they have not realized its promised potential, which can be attributed to weak systems of governance, inadequate human and institutional capacity, the limited culture of data use, and continued failures of integration efforts (5). The future also promises to bring more complexity as the nature and scale of diseases expand, more modern and complex technologies are being deployed, and new business models are being introduced through the engagement of non-state actors. Digital initiatives are expanding focus on the collection and use of personal data which heightens techno-institutional complexities (16). While the current focus on building pan-India digital systems through the National Health Authority undeniably creates the potential for providing information support to address health challenges at scale, they also come with the challenge of building systems that are simultaneously both locally relevant in situated settings, while also having the capability to be adapted to multiple other disease domains, population groups, and diverse geographical settings. To address this inter-connected challenge, our analytical focus is two-fold to understand: one, how can a “living lab” approach help in the development of HISs which are locally relevant and effective; and two, how can these systems built for a local context be scaled to other settings.

Empirically, our analysis is based on an ongoing and long-term engagement in building, implementing, and scaling an integrated patient-centric health information system for primary healthcare, within the public health system in two northern states of India.

Historically, health information systems in India and also other LMICs have focussed on aggregate data for geographical areas for a state or district. These systems have been characterized by multiple vertical systems for different health programs such as Leprosy, Malaria, Maternal and Child Health, and various others. In this current project, the aim was to design and build a health information system with two crucial differences from historically existing systems. The first was to move from an aggregated system to a patient-specific system, which would record and process all transactions an individual has with the health system. The second concerns integration, which would bring data from all different health services into a unified database rather than them across multiple vertical systems. This proposed system is termed as a “patient-centric integrated HIS”, and we present an analysis of the process and challenges around their development, implementation, and scaling.

1.2. Co-producing and scaling locally relevant digital innovations based on a living lab framework

This section is built around four key concepts which provide the basis for the analytical framework. The first relates to **structure**, provided by the physical and social environment of the living lab within a health facility where the system is co-produced. The second concerns the **process** of co-production, involving participatory and collaborative approaches, including users, developers, and researchers. The third concerns the **object** of the innovation, which in our case is the digital integrated patient-centric system, relevant for primary healthcare in an LMIC context. The fourth concerns the challenge of **scaling** the digital innovation developed through the living lab, to other settings.

The *living lab* is a relatively novel concept starting to emerge in the late 1990s, primarily promoted by the European Union for different member states. These labs initially focused on testing new technologies in home-like but constructed environments. As the concept has evolved, a precondition for a living lab today is situating the innovation work in real-world settings. A living lab has been described as an environment, a methodology, or a system (17, 18). It has also been described as a systemic innovation approach where users are seen as innovators rather than as guinea pigs, as often done in participatory design approaches (19). A common theme of living labs approaches is to promote human-centric approaches to co-produce and test digital innovations in open

and collaborative real-world settings. In its requirement of a real-world setting, the living lab differs from traditional participatory design methods that often take place in classroom-like settings (20). While traditional user involvement methods focus on the designer–user interaction, the living lab seeks to involve users, producers, beneficiaries, and other relevant stakeholders (21).

Feurstein et al. (19) describe different elements characterizing a living lab including (i) participation and context; (ii) services; and (iii) methodology. Participation and context relate to the engagement of relevant stakeholders, which can unfold in single-controlled or multiple emerging settings. Services offered through a living lab include those of co-production, and adoption and implementation processes of the innovation in the living lab. A living lab by definition focuses on building something new—a product or a service—rather than based on existing products and processes. Veeckman et al. (22) analyzed the links between a living lab with its outcomes. They examined two living labs, one Flemish and the other Finnish, to understand why the former sustained and the other did not. They found the difference to be in how the value developed was shared across or not. Their study raised the important question of value, what it is, and how it is relevant or not for different stakeholders.

Co-production concerns the involvement of multiple stakeholders, such as designers, users, end-beneficiaries, and researchers to build sustainable partnerships (23) aimed at creating a product or service, involving people also from outside the organization (24). Another point of departure concerns the physical setting within which co-production is carried out, which is the real-life setting where digital innovation is to be used, which in our case is the specific health facility (25). While participatory processes involve varying degrees of user involvement categorized as *for*, *with*, and *by* (26), co-production tends to involve all three elements, although with a primary focus on the third type.

Adopting a living lab approach within a public health setting is a non-trivial challenge, given the existing system development approach that tends to be closed and top-down (27), which runs contrary to the living lab approach, emphasizing the free flow of information, knowledge, ideas, and expertise (28). Open-innovation processes in public sector organizations are arguably still in nascent stages in relation to adopting innovation models based on collaboration among citizens, entrepreneurs, and civil society (28, 29). Barriers to building more inclusive innovation include top-down and hierarchical methods of development, inadequate understanding of the public sector context, institutional barriers to collaboration, including inadequate funding (28), and the adoption of technology-deterministic approaches (30).

The *object* of digital innovation, in this case, is two-fold: one, concerns the digital platform itself, and two, is the particular application developed on this platform through co-production. In the first case, the digital platform used is the District Health Information Software (DHIS2, see dhis2.org) which represents a global standard for health information systems development and has been adopted in different countries for a variety of use cases, such as health program management, disease registries, logistics management, disease surveillance, and many others (20). The second case concerns the application which is co-produced on this platform, which in our case is the patient-centric integrated health information system. Building such an application represents

a digital innovation for at least three reasons, which are as follows: first, traditionally primary care systems were aggregate-based (data for a facility or district), while this application represents a new form of the system based on patient-specific case-based data; second, the health system has traditionally been characterized by a multiplicity of verticalized systems, with overlaps and redundancies in the data being collected. An integrated system is novel, as it seeks to break down these vertical silos and create one common database, with a significant reduction of health workers' data load; and third, this system is based on DHIS2, an open-source digital platform, which is unique in public health systems which historically have relied on proprietary licensed software (5).

Digital platforms offer reusable and generic functions and services, which can be utilized by the innovation process to develop different components and link them as part of larger systems (31). Such platforms are flexible and potentially can be repurposed for performing a variety of tasks. Not being locked into proprietary licenses, the source code can be modified and extended to develop different required and new functionalities, including those not originally envisaged. These features make open-source digital platforms very relevant to develop digital innovations for public health systems in resource-constrained LMIC settings. As the informational needs of a public health system are forever evolving and changing, such as the addition of new data elements, indicators, organization units, and analytical features, a digital platform allows for extensions based on a modular design, without having to start from scratch. This provides relevant ingredients for the development of frugal innovations, implying the capability of doing “more with less” (32).

While LMICs have traditionally been seen as a source of “insights” for building innovations for Western countries and organizations (10), digital platforms provide the potential for change. However, also arguments such as digital technologies “has democratized innovation and almost anyone can now participate” (32; p. 3) may very well not hold in the context of LMICs because of multiple constraints of capacity, infrastructure, and prior experiences. How can these constraints be overcome represents a research and practical challenge, which this article engages with.

Scaling of systems represents a key challenge, which goes beyond the mere expansion of the technical artifact. The World Health Organization (33) has noted the importance of scaling to increase the impact of a technical solution on larger population groups over time. The World Bank (34) defines scaling as the process of efficiently increasing the socioeconomic impact from a small to a larger scale of coverage. Uvin (35) describes scaling as increasing the impact of grassroots organizations and their programs to move beyond being “actions on the margins” to tackling large-scale issues. Commonly understood, scaling is the process of expanding, replicating, adapting, and sustaining successful policies, programs, or projects in a geographic space and over time reaching a greater number of people. Rolland and Monteiro (7) have argued that scaling is not just physical replication but also a functional expansion, overall leading to an expansion of complexity. Puri and Sahay (36) noted that in designing and scaling a digital intervention, local needs must always be weighed against larger global needs, that encompass different communities of practice, technologies, and diverging interests and population groups. Effective scaling implies that every intervention need not

start from scratch and learnings and resources built in earlier efforts can feed into new processes.

Scaling is particularly relevant to ICT4D projects, as developmental concerns are widespread, and typically resources and time are not available to start from scratch every time. Many development projects start small and even when successful, they remain rather small, especially when compared to the scale of the challenges they seek to address. In the absence of mechanisms for scaling, successful initiatives remain little more than islands of excellence in a wider economic and institutional environment (37). As a result, understanding how the expansion of the impact of such initiatives beyond the local level can be enabled has become an important issue among practitioners, donor agencies, and researchers (38). Braa et al. (6) have argued that scaling digital health interventions is a prerequisite, not a luxury, for sustainable action research, raising the challenge of *what* and *how* to scale.

Scaling is multidimensional, spanning dimensions of quantitative, functional, political, and organizational. Quantitative scaling is where a program or an organization expands its size, by increasing its membership base or its constituency or budgets (35). Spreading interventions geographically can help reach and include marginalized groups that otherwise could remain isolated and prone to continued poor health. Functional scaling is where a community-based program or a grassroots organization expands the number and the type of its activities to its operational range. This allows the system to reach more users and access a larger set of use cases (4). Political scaling refers to the extent to which participatory organizations move the use of the digital system beyond service delivery toward empowerment and changes in the structural causes of poor health. Organizational scaling is where a health organization can improve the effectiveness, efficiency, and sustainability of its activities. It can be done through different means, such as financial, networking, resource-pooling, and strengthening of informational capabilities.

While our analysis acknowledges the potential of digital platforms to technically co-produce digital innovations within a living lab framework, it notes the need for further research to understand how this potential can be effectively materialized in practice to address these multiple dimensions of scaling remains an empirical question.

2. Methods

2.1. Study context

The study is situated under two broad phases: first, a collaborative research project that involved the establishment of a living lab and to develop the digital innovation relating to the patient-centric HIS; and second, more on a project rather than a research mode, where the innovation developed were scaled to other health settings.

2.1.1. Phase 1: setting up of the living lab and developing the digital innovation (2016–2019)

This started as a collaborative research project (called INTPART) involving the Department of Informatics, the University of Oslo (referred to as UiO), the Post Graduate Institute

Medical and Education Research, Chandigarh, India (referred to as PGIMER), and HISP India, a local NGO and technical partner for this project. This collaboration enabled a multidisciplinary team to engage in a research and development project (from 2016 to 2019) supported by the Research Council of Norway titled “Design of Patient Centric Systems for Primary Health Care in Resource Constrained Settings”. A core aim of INTPART was to establish a living lab to enable the design and development of the digital system and support its implementation in a primary healthcare clinic in the state of Punjab.

Being a designated premier center of excellence in medical and public health research and education in India, PGIMER works closely with the state and national governments both through advisory and project implementation roles. They are assigned certain primary healthcare clinics and independently manage them with their team of doctors, field nurses, and support staff. In addition to providing care facilities to patients, they are also responsible for operating the HIS and carrying out reporting to the state and national authorities. The living lab was established in one of PGIMER’s designated clinics, thus representing a “lab within a lab”. UiO is a premier institution in health information systems research and practice (see dhis2.org) and has developed the DHIS2 open-source platform used in this case. HISP India, a not-for-profit NGO, is a long-term technical partner for UiO and the state government of Punjab.

The project team based primarily at the living lab comprised 3 main groups. First, the existing medical and support team (all PGIMER staff), which is already engaged in providing health services at the health facility. Second, additional staff from PGIMER supported through INTPART, who enabled building an understanding of particular HIS informational requirements, identifying data analysis needs, and providing capacity-building support. Two senior Professors, one each from UiO and PGIMER, oversaw the research component of the project. The third group was the technical members from HISP India responsible for system design, development, and support.

2.1.2. Phase 2: scaling the systems in a project mode (2021–ongoing)

This work was done outside the framework of the research project, where the systems were taken to two different locations: (i) a medical college hospital in the state of Punjab; and (ii) to 3 primary healthcare facilities in the adjoining state of Himachal Pradesh. The adaptation and implementation of the respective systems were supported by the HISP India team.

2.2. Data collection and analysis

2.2.1. Phase 1

This involved two primary modes of engagement, including research workshops, student research, and direct primary data collection.

Research activities included: (i) research workshops; (ii) research work of PhD and masters students; and (iii) everyday engagement and observations of activities in the living lab. We

held six research workshops during the project, summarized in the table below.

2.2.2. Research work of students

One PhD student from PGIMER and two UiO Master Students did their respective empirical work for their theses under this project. The PhD student, a medical doctor, focused on understanding the design issues of a patient-centric system from a public health perspective and its impacts on the provision of primary healthcare. Both the Masters students were from an informatics background, one focused on the process of building design requirements and the other on the challenges of designing and implementing health data standards. The PhD and Masters students had systematic processes of data collection including observations, interviews with health staff, field visits, and the study of documents and registers. Their thesis learnings contributed in different ways to the building and evolution of the patient-centric system.

2.2.3. Participant observations in the living lab

This engagement served the purposes of requirements gathering and capacity strengthening of the health staff. The researchers studied the existing registers in use and understood how data were collected, recorded, and shared. We, for example, understood the interactions of health staff with patients as representing three sets of practices related to recording, tracking, and reporting data. This helped to think of the design in a modular form, representing these three sets of practices. For example, we could understand how the health ID was designed, not based on an individual but on the family, and the ID needed to also include the household location to support the health workers' outreach activities. The research team observed how the health staff interacted with the patients, the questions they asked, and the artifacts they used, all of which helped in visualizing the system. With the release of different prototypes, representing the growing understanding of the developers in how the system should look like, the health staff got increasingly involved in testing the system, providing feedback and comments, and becoming more proficient in the use of the system. This cycle represented an agile prototyping method, where design, use, and improvements were interconnected and each reinforcing the other. This helped the system design to evolve in a process that was integrated into the everyday work practices of the health staff, thus constantly adding value to practice. The researchers also gained value in gaining an intimate understanding of how a living lab worked and the workings of a patient-centric system. All the observations were documented by the researchers as notes, meeting minutes, email correspondence, test reports, capacity-building resources, and routine queries.

2.2.4. Data analysis

The analysis process involved three main modes.

2.2.5. Research mode

In the research mode, the Master student working on standards analyzed existing data nomenclature used in patient-centric systems, how these were aligned or not with national standards, and interventions to better synchronize them. The other student analyzed the process of requirements gathering and how they evolved and shared this information with the development team. The PhD student documented existing health status indicators before the intervention and compared them to the post-implementation status to identify the potential impacts of the digital system. Analysis emerging from these three theses contributed to informing this article in multiple ways, including the role of the living lab in enabling health innovations.

2.2.6. Project mode

First, we conducted a design analysis based on meetings between the researcher team and health staff to discuss different requirements. For example, by studying the 20+ primary data registers, we could identify data duplications and eliminate duplications to build a unified database capable of generating all required output reports from the health facility. The project team conducted an infrastructure analysis as an important component of setting up the living lab, which operated in particular conditions, such as limited internet access, inconsistent electric supply, extremely hot temperatures of 45°C in summer, and limited technical expertise. The system proposed needed to be web-based, collect and integrate data from remote settings, and integrate across systems. This required making cost-effective infrastructure choices, such as for backup power supply, air humidifier, and air conditioning. Establishing a robust and resilient infrastructure to support digital development and use was an important enabling condition for the living lab.

Capacity strengthening of the health staff in using the digital system, and in thinking about how it can help add value to their everyday work was another important project-related activity. During one of the workshops, the health workers told us that their primary expectation from the system is to reduce their data collection workload. They were currently spending more than 60% of their work time on data-related work, which severely compromised their time on care provision. The design of the integrated database and the identification system was driven by this need to make their work more digital and information oriented. Furthermore, the training approach adopted was "learning by doing", where health workers were encouraged to test the system, do data entry and generate reports independently, and ask for help from the technical team only when needed. In this way, slowly the health workers became more proficient in using the system and digital data, and slowly integrate it into their everyday work.

2.2.7. Theoretical mode

The analysis represented in this article exemplifies the theoretical mode of analysis, representing a "second level of abstraction" which builds upon analytical outputs flowing from the research and project modes, which was the "first level of analysis". For example, the research mode provided insights into the nature of digital innovations, how different technological

components can be combined, and not to build something new. The infrastructure and capacity analysis helped to understand what constitutes “appropriate” technology in resource-constrained settings of primary healthcare. The theoretical mode of analysis was elaborated to understand the challenges and approaches to deal with the challenge of scale.

2.3. Case study

The case study is described in two parts. The first concerns the setting up of the living lab and the development of digital innovation relating to the patient-centric health information system. The second relates to the scaling process in multiple other locations.

2.4. Establishing a living lab within a lab

The living lab was established in a primary health clinic, which was an existing study area of the PGIMER, representing a “lab within a lab”. As a practice, most Public Health departments at medical teaching colleges in India are allocated a rural and an urban primary health center as an Intensive Field Practice Area to help medical students understand primary healthcare practices. This then provided an ideal setting to establish the living lab to develop the patient-centric system.

The health facility, like any typical primary healthcare clinic in the state, was responsible for a catchment population of about 30,000, typically including urban poor and slum dwellers, many of whom were migratory and underprivileged, dependent on the public system for routine health services. The clinic attracted an everyday patient load of about 60, and preventive, promotive, and curative services were provided by a team from PGIMER comprised of two doctors, health nurses, social workers, community volunteers, and other housekeeping staff. One software developer and a data entry operator were added through the INTPART project. Services provided included outpatient consultations, dispensing drugs, and implementing various state and national health programs, such as Maternal and Child Health, Non-Communicable Diseases, and many others. The existing information system was largely manual based on primary registers (24 in number) and the use of various forms and books for collecting, recording, and reporting data. The health staff spent more than half of their everyday time on data-related work, plus 3 to 4 full days at the end of every month for making summary reports.

The living lab was established in one room of a primary care clinic to create an arena for interaction between the PGIMER researchers, the system development, and the regular health facility staff. In this lab, the researchers also had the opportunity to observe real-time the interaction of the health staff with patients. After the room was allocated and a board established of a living lab on the door, the next important step was to equip it with appropriate infrastructure to enable the system development processes. After an initial assessment of the infrastructure, where poor internet connectivity and inconsistent power supply were

identified, it was decided to go with an offline rather than online deployment of the application, supported by a high-speed server, an Uninterrupted Power Supply, and local area networking. All the desktops/laptops were connected through the local network and later, a broadband internet connection was established to enable sending automatic SMS reminders. While the local networking arrangement enabled easy local processing within the living lab, it posed challenges in scaling other health facilities in future, where web-based deployment was needed.

In terms of choices of software platforms, two free and open-source software platforms were selected, which included the DHIS2 (see dhis2.org) for data management of the outreach services provided by the nurses and the OpenMRS (see openmrs.org) for supporting the clinical patient-based work. The project plan was for the OpenMRS and DHIS2 databases to be subsequently merged to gain an overall picture of the health status of the entire 30,000 catchment population covering both outreach and clinical services.

The living lab enabled mutual learning to take place between the researchers and health staff, with the health staff understanding how the system could help them and the researcher team understanding how to reduce the data-related workload of health workers and gradually providing them with value-adding functionalities. Existing workflows were cumbersome and time-consuming, including the health worker recording data of services they provided in their field diaries, transferring that into registers, and then entering it in the computer system. The process was simplified by an automated generation of all required outputs. The researchers identified the significant need for capacity building as the health workers, who had limited experience with digital technologies, although with an intimate understanding of the data. We realized that this capacity building could not be imparted through formal training sessions, given the heavy workload of the health staff, but needed to be on the job as a part of supporting everyday work and problem-solving. A student trainee was hired to provide this on-job support.

2.5. Different digital innovations developed in the living lab

The co-production approach was adopted for system design, with the health staff guiding the researchers to understand the structure of the primary registers, their daily and monthly data-related routines, and practices used for culling the data from the registers to the reporting forms and then to the computer system. The clinic maintained 24 primary registers to record name-based information for each service provided, such as vaccination, TB, drugs, malaria, and antenatal check-ups, including both outreach and in-clinic services. For each service, health workers maintained the record of the person and service provided, and all follow-up encounters over time. Data from these registers were aggregated monthly to produce facility-based reports for state and national authorities. The system designers first understood how health workers identified patients in registers and what the identification system used. Rather than adding the same individual in multiple registers, there was the need identified to shift the focus from services to patients, including all individuals in the

catchment population. This required a major shift in the business processes, requiring multiple digital innovations, some of which are now discussed.

2.5.1. The patient identification system

To identify a patient across all registers, we understood that the unit for health service delivery was a family and not the individual. For this, the health workers used a 'household register' to list all households/families with their home addresses and the family members in each family. The household rather than the individual then needed to be used as the unit for the identification, which also needed to indicate the location of the household, to support outreach visits of health workers. Such an understanding of the identification scheme ran contrary to the common understanding that identification should be individual-based and not traceable to the individual or household. The household-based identification would be value-adding for the health workers as they could now provide services to multiple members of a household on one visit and easily know the location of the household.

While the above identification scheme worked well for the outreach services which were based on the DHIS2 platform, it was not appropriate for the clinic-based services which were supported by the electronic medical record system based on OpenMRS. This system auto-generated a unique individual identifier at the time of a new registration through a 22-digit random number. Subsequently, a challenge was encountered in the merging of the DHIS2 and OpenMRS databases because of the two different identification schemes used, one based on the family/house and the other on the individual. As a result, patient-level data could not be transferred between the two systems. This made it a tedious task for the doctor or a health worker to search for the patient in the two applications and then match the required information. To resolve this challenge, the technical team developed a workaround. At the time of registering the patient for clinic-based care, the OpenMRS application generated a unique ID that was pasted on the patient household member page in the DHIS2 by the registration clerk, which allowed the doctor to move between the two systems by clicking on the link. However, this process of linking was cumbersome and not sustainable in the long run. For addressing this, the DHIS2 was subsequently used to develop a "lite EMR" using the DHIS2 Tracker module, which allowed the elimination of the OpenMRS application.

2.5.2. Generating integrated reports

Currently, the health workers on a monthly basis prepared some 30+ facility-based reports based on source data coming from different registers. This was an extremely time-consuming and cumbersome task, taking the health workers 4–5 days a month. To automate this process, first, a unified database needed to be created including all 30,000 individuals in the catchment population; second, to include all health services data by the individuals who received them; and third, to design all required facility-based monthly reports. Taken together, this design allowed for automation where all the required monthly facility-based reports were generated by the system.

Different options were considered for building the population database. The first was to conduct a survey but this was infeasible

given the costs and efforts required. The second was the option of using the national Aadhaar number (a national biometric-based identification database), but the authorities told us that this was not permitted as its use required the prior consent of citizens, and further Aadhaar did not indicate family memberships. Three, the technical team examined the option of using the public distribution database system which was family-based but was outdated. Finally, it was decided to use an incremental approach where when a person came to the dispensary, they would be asked to provide all details of their family, which was then real-time entered into the system. Gradually, through regular use, the database slowly evolved and now covers 100% of the population. With the database in place, all reports required were automated. In this process, two value-added features were added. One, new reports, not previously available, such as the patient clinical history report, were added. Two, the system could automatically generate the primary registers since all patient transactions were included in the database. This automation reduced the major pain point of the health workers in manually dealing with the 24 registers. Three, in building the population database, redundancies in data could be identified and removed, thus reducing the data load of the health workers. It is important to note that without the active and continuous engagement of the health workers, the existing pain points could not have been identified, or the solutions to address these challenges.

2.5.3. Creating other value-adding functionalities

With the database and system fully operational, discussions were initiated on how the system could be made more "patient-centric." One suggestion from the health staff was to add the SMS functionality, which was already supported by the DHIS2, to send reminders to patients to attend their appointments. These messages were sent in the local language of Hindi to enable ease of understanding and were copied to the health worker for required follow-up. As the use of this functionality took root, a Professor of Health Promotion from PGIMER suggested adding focused health promotion messages to groups of patients, such as those suffering from diabetes and hypertension. So, focused messages were designed and sent to relevant groups of patients.

At some point in this process, we met a small research group who were specializing in IVRS (Integrated Voice Response System)-based innovations, who suggested that IVRS messaging was superior to text-based SMS, because of issues of illiteracy in the populations. Furthermore, they argued that the SMS font was often too small for older adults people to read, and also because of the large numbers of SMS being received, many of the messages were left unread. These arguments led us to technically integrate the SMS and IVRS functionalities to enable sending voice messages to groups of patients. Over time, we noted a spike in the clinic attendance rates at the health facility.

2.6. Scaling-related challenges

As the funding cycle of the INTPART project drew to a close in 2019, several scaling challenges came to the fore. First, without continued funding, the project team hired for the living lab could not be continued. Second, the PGIMER Professor who

was the driving force behind the project entered into retirement, and with this, the responsibility went to another Professor, who was not equally supportive to continue the project. Third, the two professors in the project met the state health secretary, demonstrated to him the system, and requested him to formally consider the adoption of the system for state-wide implementation. However, while the secretary was very impressed by the system and saw its value for the state, he said he did not have the authority to decide on its use, since the central government was already in the process of initiating similar systems. He said he could only consider our proposed system if it had the recommendation of the central ministry, which was not forthcoming. So, despite the technical success, the system gradually died in the health facility. However, through different circumstances, opportunities opened up to scale this system to other locations, which we describe in Phase 2.

2.7. Phase 2: scaling the system to other locations

In this section, we describe the process of scaling the application developed to four other health facilities, across two states, one in the same state of Punjab and three in the adjoining state of Himachal Pradesh. Interestingly, the opportunity for this scaling in both cases came through fortuitous circumstances. In the final dissemination workshop of the INTPART project, we had participation from Himachal Pradesh, who saw the system being demonstrated and invited us to introduce the system in their location. In Punjab, there was a professor in the medical college who was a colleague of the PGIMER Professor, who provided the impetus for the adoption of the system.

2.7.1. Medical college in Punjab

Interestingly, similar to the earlier facility, the new medical college was another form of a “lab within a lab”. The Head was looking for a digital solution wherein details of the entire catchment population could be captured and recorded, and health services rendered appropriately through systemic data analysis. After witnessing the system demo, he called the HISP India team for a visit to his college and meet with his entire hospital team. Since the original solution was an offline solution, for the presentation, the HISP India team took a complete backup of the database, and an online instance was set up. At that time, the medical college was capturing data in paper folders and catering to a catchment population of 50,000 (urban plus rural), served through their 22 health centers, including 15 in rural villages and seven in urban areas. Medical students from the medical college were responsible to provide health services across these 22 facilities spread over 40 Sq km. One health worker, deputed through the medical college, was attached to each health center.

After the team meeting, the head was ready to adopt the system and initiated a memorandum of understanding between the college and HISP India. In the meantime, a process of requirement assessment was initiated, which took as the reference the existing patient-based system, and analyzed the additions and deletions required for the medical college. A starting point wants to study

the structure and contents of the family folders by a joint team from HISP and the medical college, which yielded a detailed requirements document. This analysis identified 6 health programs that would need to be included for registering population-based services. Unlike the requirements for the original facility, in the medical college, the focus was only on outreach community services and not on clinical services. For patients coming to the facility, there was already an existing system, and it was decided not to intervene with that. This made the development far less complex, as it did not entail building integrations with the community and clinic-based data as was in the original case.

The requirement assessment document was then shared with the medical college for final approval and suggestions for change incorporated. With the final approval, HISP India started to build the system. While the original application catered to eight programs, the new systems covered a limited set of the following six programs: (i) Households; (ii) Households registration; (iii) Maternal Health; (iv) Children Under 5 years; (v) Eligible Couples; and (vi) General Individuals and Senior Citizens Screening. The first five programs were across the two systems, and the sixth was new to the medical college system. Even for the common programs, there were modifications required in the data elements, which needed to be customized. Customization could easily be done using the flexible features provided by the DHIS2. Unlike the earlier offline system, the new system was online, which was hosted on the HISP India server, enabling the development team to work continuously from remote locations. A prototype was soon created and a demo was given online, because of the travel restrictions arising from the COVID-19 pandemic.

Field implementation was severely constrained by COVID-19 as the health staff were all deployed on pandemic response responsibilities. No field training could take place as HISP India could not travel. To deal with these constraints, a local doctor was designated as the point of contact, and he was trained continuously through online means. However, delays were inherent in this situation, and only after about 8–9 months in late 2020 did the baseline data entry start at a slow pace and with dummy data. However, since the health workers were directly involved in doing the data entry work in their respective health centers, their capacity for digital work was continuously being strengthened and live data entry started in late 2021. Health workers were continuously giving feedback which was incorporated and improved versions of the revised system deployed. The health workers were motivated by seeing their requests being incorporated into the system. After baseline data were entered, including households and members, the enrolment of patients and beneficiaries was initiated in 4 health programs, and following this, follow-up data started to be captured. Custom reports and various outputs via pivot tables and dashboards were designed and made available through the system, and training was provided to the users, including a refresher training in mid-2022.

Gradually, the system was well-adopted and understood by the college staff and is now proudly owned by the medical college. In acknowledgment, the medical college has continued to extend its agreement with HISP India, which allows for continued technical support to users. Value-added outputs were gradually incorporated, such as a data status report, which allowed the college management to continuously review the progress of the use of the system and

take corrective actions where required. The medical college is now considering more significant upgrades to the application, including the implementation of an Android application and procurement of the tablets are under process. HISP India has already provided the technical resources for the use of the Android application, and this would be implemented in a live setting once the tablets are procured. As of now, the system has taken deep roots, and internal capacity developed to sustain the application over time.

2.8. Scaling to three primary healthcare facilities in the state of Himachal Pradesh

Historically, HISP India has been an important technical support partner for digital interventions in the state since 2008, building and supporting multiple health information system applications. Given the existing trust the state already had with HISP India and that a Professor from a tertiary medical college had already seen and approved the patient-centric application in the dissemination workshop, the Department of Community Medicine invited HISP India to implement the system with due adaptations in three of their primary care facilities, one Community Health Center and two Primary Health Centers. All three facilities were study areas for the medical college, providing another lab within a lab framework. The college wanted the three facilities to implement a family folder-based approach and integrate the WHO Package of Essential Non-communicable Diseases (WHO-PEN) for primary healthcare.

Like with the earlier initiatives in Punjab, the project started with HISP India conducting a thorough requirement analysis, to document relevant information flows, and identifying the challenges in making the transition from the paper to the digital system. This requirement study was done collaboratively with users from the health facility to ensure enhanced acceptance and ownership of the system by the facility. The requirement study helped establish that the proposed system was a very good fit for the facilities. However, customizations would be required, to account for the particular hilly terrain where people lived, the kinds of occupations, and the stability of their residential arrangements. While the structure of the family folder and mapping of family members could be taken as is, the state emphasized the need to have simple rather than complicated integrated programs, which would help provide effective support for decision-making.

An assessment of hardware requirements was conducted. The project had limited funds and could only provide only one system per facility. However, there were systems available from other programs, which was deployed to this initiative. This allowed for parallel work to be conducted where some staff would be responsible for registering and creating family folders and populating them with family members' details, while others could enter program-specific data. The project outcomes demanded an online system, so that data entered at the periphery could be analyzed by the state-level program managers and view the outputs and analytical dashboards that the system was capable of generating. Given the absence of internet availability in the facilities, additional budgets were solicited and obtained

for networking and server-hosting, and HISP India was made responsible for the management of the server.

Once the application was developed based on the requirements and signed off by the client, the prototype was developed and demonstrated to the medical college leaders. User credentials were then shared by the HISP team who conducted User Acceptance Testing, and feedback was received and incorporated. The beta version of the application was then released for pilot deployment, starting in one facility, and then the capacity building was conducted by the HISP India team for over 5 days. The data entered by the facility staff was monitored for 1 month and once convinced of the quality of the data, the program managers were trained on using the outputs and the analytical dashboards to support monitoring and supervision tasks. Training protocols and user manuals were developed and shared with the facility to support the future implementation and support process. User feedback was continuously received, and changes were incorporated into the application, improving and enhancing its fit with user needs.

As the system was stabilized in one facility, the hardware was procured for the remaining facilities, and the onsite training was conducted by HISP India at the other locations. This project worked very well till Oct 2022, when the nodal person for the project at the medical college was transferred to another location, which slowed progress. Project funding dried out, yet HISP India has continued to support the project because of their commitment to the cause and being located in the same state. The application continues to be used at all the facilities—sparingly in two of the facilities and very well in the other.

2.9. Analysis and discussions

The analysis and discussions are presented under three interconnected themes, all of which relate to the challenges and approaches to scaling a digital innovation developed through the living lab: (i) the enabling governance structure of a “living lab within a lab”; (ii) co-production processes leveraging on capabilities of free and open-source digital technologies; and (iii) the driving impetus to scaling through agile and co-produced technical support.

The enabling governance structure of a “living lab within a lab”: While a living lab by definition is set up within a real-use context, there is the need for a robust governance structure to ensure the lab works and delivers on its planned products and services. The living lab for the INTPART project was established within a field study area of a medical college, which had control over the working of the facility and had its staff deployed to provide routine health services. This team was then enhanced for supporting data-related processes through funding obtained for the INTPART project. However, a downside of this governance structure was that when the funding and interest from the parent lab dried out, aggravated by the retirement of the Professor driving the project, the activities in the living lab also ground to a halt. A further challenge came from the fact that the lab was set up in one primary healthcare center within a research framework and thus not well-integrated into the overall working of the official state

reporting framework. When the system was shown to the health secretary to adopt it state-wide, he expressed his reluctance citing the control of these processes from the central ministry, which was planning to introduce its systems. Without such state support, it was not possible to take the system developed in one facility to the 300-odd similar facilities that existed in the state. Changes introduced in the living lab, such as the automation of the primary registers, could not be replicated in the other facilities, without a national and state-level sanction, which was not forthcoming. This experience demonstrates how governance in a public health system is organized within a multi-level structure, which makes it important to get support at all levels. The INTPART project, working in a research mode, was too focused on the processes within the living lab and ignored the linkages with the formal state system, which was necessary for scaling the system across the state.

The first case of scaling to another medical college in Punjab was also initiated within a similar framework of a lab within a lab, with the important difference that it covered 22 health facilities and not one. This larger coverage strengthened the user base through a network-based capacity. The continuing governance framework of the medical college operationalized through an institutional agreement, allowed for systems to continue to sustain. An institutional agreement ensured that the initiative was not dependent on an individual and not restricted by project-based finite funds. Similarly, in the second state, the health facilities selected for the project were within the framework of a medical college, and approvals through an agreement could be quickly initiated. However, as in the INTPART case, the continuity of the project was hampered by the transfer of the Professor championing the initiative. But given that HISP India was committed to continuing support even without funding, the project continues, although not with the same level of intensity as would have been the case with continued governance and support from the parent lab. This experience emphasizes the importance of individual champions, and their movement can potentially adversely influence the functioning and scaling of the living lab-generated innovation.

The living lab framework allows for a technical and social environment to build and scale digital innovations. As health workers “know more than what they can tell”, the physical co-location of the users and developers allows for mutual learning to take place, which otherwise would not have been possible. For example, understanding how the identification system should be designed was only made possible by the technical team observing how the health workers carried out their everyday outreach and clinical work, by studying their primary registers and engaging in discussions to understand their pain points. Similarly, health workers could gradually learn about the possibilities offered by the digital system and raise requirements, leading to a reinforcing process of mutual learning. Effective uptake of the system in one setting can provide the impetus to scale to other settings. This was seen in the dissemination workshop in the INTPART project, where the Professor from the medical college saw a good demo of the running system and was motivated to adopt it in their college facilities.

2.9.1. Co-production processes leveraging on the capabilities of free and open-source digital technologies

While the living lab provided an enabling governance structure, co-production processes provided the approach to build digital innovation and provide it with relevant content. The free and open-source digital platform was critical to provide the basis on which the innovation was built within an agile framework. While the role of agile development has been noted as an important driver of digital health transformation (39), it has focused largely on the software development process. In contrast, we have used the idea of agility in a broader sense, covering the interconnected processes of design, development, and use, involving more than the stakeholders to also include researchers, health staff, technical team, and indirectly also the patients. Such agile processes, because of the proximity they entailed, could only be carried out within a living lab structure.

We saw many cases where the digital application co-produced, through the INTPART living lab, provided the vehicle for scaling, both across and within health facilities. Aiding this was the fact that all the facilities we were working in were within the uniform framework of the state public health system, which had largely similar reporting mandates, health structures (levels of reporting), and health programs against which reports had to be sent. As a result, a digital application built for one facility could technically be appropriate also for others. However, there would be changes required in specific details, such as the number of programs to include (7–8 in the first facility and 6 at the Punjab medical college) and to build a stronger focus on Non-Communicable Diseases as was the case in the health facilities at Himachal Pradesh. Such changes could be easily incorporated through the digital application, which is open source and was not locked into proprietary licenses which would not have allowed changes to the source code. The application could be deployed in offline or online modes, providing more flexibility on how technical support could be provided. The DHIS2 platform by design is flexible and easy to use, which allowed co-produced development processes to be rapidly deployed.

In addition to the geographical scaling needs, the digital platform also helped enable functional scaling. In the first case, the DHIS2 could be easily integrated with the IVRS, allowing for bulk messaging to larger groups of patients. The involvement of the Nutrition professor from PGIMER in the co-production team helped to provide value-added messaging, such as nutrition guides for diabetic patients. These different value-added features, easily deployed through the digital platform, not only helped to step up OPD attendance but also arguably contributed to improving care regimes for patients. Another technical challenge experienced related to integrating across the DHIS2 and OpenMRS systems is catering to outreach and clinical services, respectively. Given the challenge of incompatible identification systems, a lite system mimicking the clinical system of OpenMRS was quickly replicated on the DHIS2, and the problem was soon eliminated. This ability to flexibly repurpose the use of the application is a very useful capability for scaling in public health, where informational needs are dynamic and constantly evolving.

Another important enabling characteristic of digital platforms is the capability it provides to do more with less, a form of frugal

innovation (32). This is an extremely important consideration for resource-constrained public health contexts in LMICs. The system also allowed for value-added features to be easily incorporated into the application, which helped go beyond mere automation, the replication of manual processes into computer form, and to make visible new information, which was previously not seen, a form of information (40). For example, through the integration of the DHIS2 and OpenMRS systems, patient clinical summary reports could be developed, which was seen as being extremely important by the doctors while providing clinical care. Furthermore, the system could be made able to generate all the primary recording registers, which helped address the biggest pain point for the health workers, given nearly half of their work time was dedicated to data work. However, these enhancements could only be made through co-production processes, where the health workers could detail their needs, and the technical team was physically and socially proximate to understanding them and converting them into useful system features.

2.9.2. Driving force to scaling through agile and co-constructed technical support

The role of HISP India in providing agile technical support was crucial for the establishment of the lab (in setting up the technical environment), supporting its operations (system design, development, and support), and the scaling the application to multiple locations. Two aspects of their support process were crucial. First is related to their physical presence which allowed for agile technical support; and second, also enabled by physical presence, was the adoption of co-production principles in processes of system design and development.

Agility is crucial as the health facilities are providing healthcare, which cannot be delayed. Furthermore, they are supporting state-reporting systems that have given non-negotiable deadlines, for example, their monthly reports. So, requests coming in for technical enhancement needs to be complied with in an agile manner, both technically and institutionally, and at times, pragmatist approaches need to be adopted. For example, initially, when challenges were experienced in integrating the DHIS2 and OpenMRS data streams, an improvised solution was developed where the URL was pasted on a weblink, which the doctor could click on to view also the patient data in the other system. While this improvised solution was cumbersome, it kept the show of the care work going and bought time for the technical team to develop the clinical system on the DHIS2. New requirements coming from the health staff were rapidly incorporated into the system, leading to improvements in the system and increasing user trust in the system and technical team.

The process of co-production, representing a form of collaborative work was crucial for system development, scaling, and support. A joint participatory process to initiate the project in the requirements understanding phase was a mandatory principle adopted by HISP India. There were frequent meetings and systems demonstrations, where users would give feedback, often critical,

which was always attentively listened to and responded to. This co-production process contributed to mutual learning, where the HISP India team enhanced their understanding of the domain of use, including the everyday challenges and constraints faced by the health staff, and they in turn could learn about the digital system and its potential capabilities, which also helped them to better articulate their pain points and needs.

3. Conclusion

Our study demonstrates how digital innovation building and scaling processes are networked (41) and involves collaboration across different organization and stakeholder groups (42). In our study, in addition to networking among the technical team, health staff, and the health system, the involvement of multidisciplinary research (informatics and public health) drawn from global, national, and local expertise was also crucial, which guided how to proceed, while learning from earlier experiences. While existing research on digital innovation has focused on Western business organizations (43), our study shows how such processes need to be adapted to particular resource-constrained public health systems. LMIC settings are typically recipients of digital systems developed in contexts culturally and geographically distant; this study highlights the strong enabling role of proximity enabled through the living lab. We acknowledge that our findings may not be relevant across all LMIC contexts, given the particularity of the Indian system. However, some general principles, such as those related to the need for multi-level governance, employing the use of co-production processes, and the need for agile techno-institutional support, could be relevant, although with necessary customizations to the local context.

This study highlights that scaling is just not a matter of replicating a technical artifact uniformly in multiple settings, but concerns a social-cultural-institutional process, where many aspects have to be considered and addressed in conjunction. The role of HISP India, built around years of existing trusting relationships with the state, is a case in point, as they were fundamental to the scaling process. The study is unique in identifying the defining role of a “lab within a lab” governance structure in the functioning of a living lab, and also the accompanying challenges. Future studies need to examine how such a governance framework can be made more robust and sustainable.

Data availability statement

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found in the article/supplementary material.

Author contributions

AM, SS, and RK have contributed to the conception and design of the study. RB and NJ have contributed to the empirical case. All

authors contributed to manuscript revision, read, and approved the submitted version.

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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OPEN ACCESS

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RECEIVED 11 April 2023

ACCEPTED 22 September 2023

PUBLISHED 24 October 2023

CITATION

Byrne T, Murray N, McDonnell-Naughton M and Rowan NJ (2023) Perceived factors informing the pre-acceptability of digital health innovation by aging respiratory patients: a case study from the Republic of Ireland. *Front. Public Health* 11:1203937. doi: 10.3389/fpubh.2023.1203937

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Perceived factors informing the pre-acceptability of digital health innovation by aging respiratory patients: a case study from the Republic of Ireland

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It is appreciated that digital health is increasing in interest as an important area for efficiently standardizing and developing health services in Ireland, and worldwide. However, digital health is still considered to be in its infancy and there is a need to understand important factors that will support the development and uniform uptake of these technologies, which embrace their utility and ensure data trustworthiness. This constituted the first study to identify themes believed to be relevant by respiratory care and digital health experts in the Republic of Ireland to help inform future decision-making among respiratory patients that may potentially facilitate engagement with and appropriate use of digital health innovation (DHI). The study explored and identified expert participant perceptions, beliefs, barriers, and cues to action that would inform content and future deployment of living labs in respiratory care for remote patient monitoring of people with respiratory diseases using DHI. The objective of this case study was to generate and evaluate appropriate data sets to inform the selection and future deployment of an ICT-enabling technology that will empower patients to manage their respiratory systems in real-time in a safe effective manner through remote consultation with health service providers. The co-creation of effective DHI for respiratory care will be informed by multi-actor stakeholder participation, such as through a Quintuple Helix Hub framework combining university-industry-government-healthcare-society engagements. Studies, such as this, will help bridge the interface between top-down digital health policies and bottom-up end-user engagements to ensure safe and effective use of health technology. In addition, it will address the need to reach a consensus on appropriate key performance indicators (KPIs) for effective uptake, implementation, standardization, and regulation of DHI.

KEYWORDS

digital health, respiratory health, education, living labs, quintuple Helix hub, aging

1. Introduction

The impact of chronic disease on healthcare systems internationally is well documented (1–3). Effective and resource-efficient long-term management of multimorbidity is one of the greatest health-related challenges facing patients, health professionals, and society more broadly (3). Respiratory disease represents a diverse range of acute and chronic diseases that are a major cause of morbidity and mortality (4). This situation has been exacerbated by the COVID-19 pandemic (5). Respiratory diseases are responsible for a large proportion of the overall health burden of illness, both in Ireland and globally (6). It is estimated that respiratory disease causes one in five deaths nationally which is 38.2% higher than the EU-28% average. In 2018, a report titled “Respiratory Health of the Nation” found that respiratory disease accounted for 14.3% ($n=92,391$) of inpatient hospitalizations and 15.8% ($n=578,319$) of bed days. Comparable figures for cardiovascular disease were 8.2 and 11.3%, and for non-respiratory cancers 4.7 and 8.0% (7).

The delivery of healthcare services has witnessed an accelerated evolution in recent years. Healthcare professionals have had to exercise creativity to meet the changing needs of service users (8). For example, there is a commensurate interest in implementing strategies to support remote patient monitoring and telemedicine to help service users at home and to provide follow-up consultations. Digital health is defined by the WHO as a field of knowledge and practice associated with the development and use of digital technologies to improve health (9). There is evidence to suggest that these programs can improve the quality of care and compliance, reduce the financial burden and ultimately improve patients quality of life (10). Remote healthcare is an evolving concept that is seeing clinicians move toward remote monitoring for service users outside of the hospital setting. Malasinghe et al. (11) propose that there are many advantages to this type of healthcare. These include real-time detection of illnesses, prevention of worsening of illness/ untimely deaths, and reduced hospital admission. Noah et al. (12) reported that remote patient monitoring has many positive outcomes; however, caution must be taken by clinicians using remote patient monitoring and further research is required.

According to the report titled “Health in the 21st Century; Putting Data to Work for Stronger Health Systems” recently published by OECD (13), intelligent use of data and digital technology improves the safety and quality of care provided in healthcare. It also helps address unmet health needs and makes accessing services easier. It supports informed health system stewardship and the development of policies. Effective data collection also assists researchers to develop safer and better treatments, and enables more robust disease prevention and public health, resulting in healthier and more productive populations. The Irish government has faced challenges as to how this country will appropriately address its overwhelmed health service as attested by extensive and lengthy patient waiting lists for elective surgery and consultations. Moreover, there is also a growing concern surrounding future predictions of extreme burden due to the prolonged lifespan of the aging population. The concept of “living labs” in health care has been proposed as a framework to connect governmental, public-sector organizations, industry, higher education institutions, community-based organizations, and clinicians. The aim is to create an environment of creativity that encourages a collaborative approach in the developmental process of a product, service, or system.

Globally, the adoption of digital technologies varies significantly (8). There is evidence to suggest that the adoption of wearable technologies has significantly lagged in comparison to other established technologies such as smartphones and tablets. Cheung et al. (14) noted that when it comes to healthcare, researchers have inadequate knowledge of the adoption intentions of service users. A high proportion of the research conducted has a primary focus on the technical development of the device; therefore, there is an inadequate understanding of the diffusion process. This contrasts with the marketing research conducted for smart technologies, which is primarily focused on consumer adoption, resulting in a much quicker diffusion process. Brenner et al. (8) highlighted the significant gap in evidenced-based published literature across 10 databases on the development of key performance indicators for the development of digital health interventions where only five references were eligible. Key performance indicators play a central role in the evaluation, measurement, and improvement of healthcare quality and service performance. This also intimates a gap in knowledge concerning the service users adoption of technology within healthcare. Lycett et al. (15) suggest the use of psychological theory can enhance the effectiveness of digital interventions and ultimately result in more successful outcomes such as increased consumer adoption. The systematic review concluded with a future recommendation for researchers to further evaluate how the application of theory in the development of digital interventions impacts their overall effectiveness. It is suggested that the use of a psychological framework to gain insight and understanding into consumer adoption will lead to positive engagement with digital health technologies. More recently, future recommendations by Nadal et al. (16) identified that the gap in the current body of knowledge was in the pre-acceptance of technologies. A main thrust of research has focused on understanding people’s perspectives before and after using digital health innovations (DIH) where the initial emphasis has been placed on establishing appropriate multi-actor partnerships with relevant stakeholders including end-users, developing models for evaluation and monitoring, informed by best-published evidence, and the generation of key performance indicators (KPI’s) for measuring the effectiveness and appropriateness of DHI that is currently lacking (8). However, if the main goal is to access the effectiveness of DHI, it cannot be assumed that the service user will engage with the technology long term, or indeed at all. Dundon et al. (17) noted that digital tools for diagnosis and management of respiratory conditions are an important area for research and development; however, the long-term success in this domain will depend on identifying real needs and integrating the often-divergent interests of the various partners in healthcare systems worldwide. Thus, the overarching aim of this novel study is to gain an understanding of the pre-acceptability of respiratory patients to digital health technologies in the Republic of Ireland by interviewing key subject matter experts encompassing respiratory care and digital health.

2. Methodology

2.1. Research approach including philosophical underpinning

A reflective thematic analysis framework (18) that addresses flexibility within data analysis while maintaining the integrity of the

method was used in this study. This method for health research is supported by the literature and deemed “*an interpretive method firmly situated within a qualitative paradigm that would also have broad applicability within a range of qualitative health research designs*” (19). This study used a phenomenological approach to explore the participants’ intentions, perceived thinking, and reactions toward digital health. Subsequently, experiences were captured without any prejudice and participants were provided ample space and time to share their experiences. In line with a phenomenological approach, the phase of the study provides a detailed description of participants’ experiences from analysis through to contextualized findings (20).

2.2. Participants

Purposive sampling was used in the study to select the participants which has allowed the researcher to choose appropriate members with selected levels of expertise. Samples were not chosen randomly as not every member of the particular specialty is eligible to partake in this study. Pursuing random sampling also needs significantly more time and information, beyond the capacity of this project which led the researcher to use purposive sampling. Saturation is reached at a point where similar themes were provided as answers to the questions posed (21). However, in this particular study, not all questions that had reached saturation were void, as some were retained to expand themes and help with the discovery of new information. Saturation points were discovered as the transcription process occurred simultaneously during the interview process.

2.3. Inclusion and exclusion criteria

Participants in this study were Irish women and men. Each participant was invited to partake in the study, as they will have been identified to subject matter experts who possess particular qualities or skills relevant to the digital health technology field and /or Respiratory disease. Subject matter experts participating in this study encompassed a respiratory physician, psychologist, digital health expert, technological expert, respiratory nurse specialist, health innovation representative, and a government representative.

2.4. Ethics statement

In qualitative research, ethics is one essential part that must be considered. Ethical approval is important for all types of research to result in a benefit and to minimize the risk of harm, by protecting participants’ information by informing the participants of everything about the study and their roles as participants, and minimizing the misuse of the information given. It is equivalent to a moral contract when it comes to dealing with humans (22). Ethical applications were first sent to the Technological University of the Shannon Research Ethics Committee, and thereafter the clinical sites. The completed submissions were made on 12th Dec 2021 and were approved *via* email on January 15th 2022. The researcher carried out data collection (interviews) from March 2022 to May 2022. Ethical approval number C.A.2734.

2.5. Data collection

Semi-structured interviews were carried out with the participants. The qualitative phase was a crucial level in which the researcher gained a better understanding of behaviors and knowledge among the targeted population (23). Data collection was conducted in English, as it is the first language spoken in Ireland. Before the interviews commenced, participants were first informed through the information sheet that all the information gained from the interviews would be kept completely confidential. Besides informing participants about the study, the information sheet is a comprehensive reference for the participants to refer to; if anything ever happened to them after the interview session. It is also mentioned in that particular document about confidentiality and how the information will be stored and kept confidential using coding to respect anonymity. Participants were also informed of their rights to withdraw from the study at any stage (Protocol included in [Supplementary material](#)).

2.6. Study setting

The reasons for choosing a small number of participants for this study are as follows. Firstly, it is valuable to understand peoples experiences within their area of expertise in this topic. This helped the researcher gain valuable insight into diverse areas within the area of digital health technology and indeed technology specific to the area of respiratory diseases. It took at least one to 2 days to explore and draw a conclusion after each conversation before starting a new interview. Also, the time schedule for interviews depended on what free time the participant had, and not all who were invited could or were willing to participate in the interview. Secondly, because the locations were separated geographically, the researcher’s time to interview participants was limited, therefore the option of a virtual interview was offered. Thirdly, there were a small number of participants who had the most valuable experiences and were to deliver the expectations of the researcher purposefully. Interviews were carried out until data saturation was reached. Lastly, it is relevant that the number of interviewed participants met the research objectives and fulfilled the research aim. Data collected and analyzed at this qualitative phase I were aimed at developing an instrument for a future quantitative phase II. The data collection was performed primarily through Zoom narrative interviews, using open-ended questions. In the interview sessions, questions were asked according to the interview protocols. Participants responses also generated further questions about the study topic. Each interview was recorded, guided by an interview protocol and guide, and also by the recommendation of the regional ethics committees.

2.7. Bracketing

In, bracketing is essential for understanding the phenomenology method. In Braun and Clarke’s phenomenological research method, the application of bracketing is a process to prove the validity and to demonstrate the phenomenological approach through the research process, not only during the data collection but also during data analysis. In this particular study, bracketing began to take place as soon as the interview started. Bracketing is important for the researcher to avoid pre-judgment and assumptions.

2.8. Reflection

After utilizing bracketing, the researcher used reflection to help improve her understanding of the outcome and the meaning of the findings of this study (20). This activity involves thorough and deep thought of any factor that might contribute toward respondents' reactions about the studied topic (24). Reflection is an important activity, especially for social science research, where the relationship with scientific needs was established in exploring thoughts through culture (25). The environment and experiences are real and natural; thus, it is categorized as valuable and rich. It also involves recalling and extracting participants' details such as: who said that, how, when, where, and why. Through this research, the researcher came to learn and appreciate the art of reflection and practiced this process through the analysis of the project findings for phase 1.

2.9. Data analysis

Data was analyzed in agreement with Braun and Clarke's data analysis framework. The researcher explored the data analysis tools available and decided to adapt Braun and Clarke's framework. Braun and Clarke's framework is one of the most popular frameworks and is used widely by qualitative researchers to gain reliable results. In this study, the adaption of Braun and Clarke's phenomenological analysis method is appreciated and translated into the following steps: the interviews were conducted and the researcher practiced bracketing during the particular time to ensure original experiences and thoughts were produced by the participants. The raw data from the audio were then transcribed. Subsequently, the researcher decided to use computer-aided qualitative data analysis to help with coding and theming. Through coding, themes emerged accordingly and supported the aim of this study. Emerging themes were either similar or different from one participant to another. Transcripts were uploaded into NVivo to allow the process. NVivo also helped the researcher to see the statements made by the participants being placed under certain themes. Coding data using NVivo saves the researcher time and also helps to organize complex data. From there, themes were extracted, sub-themes were reorganized and data was organized under the identified gaps. These statements were then gathered under matrices. Finally, themes were organized again and this stage eliminated the redundancy of themes, also, all codes evolved were clustered in a bigger theme. The steps have considered the application of NVivo computer-aided data analysis software to aid the analysis process, especially in theming the transcribed data.

3. Findings

3.1. Surrounding key themes emerging from semi-structured interviews with subject matter-experts in respiratory care and digital health on beliefs and barriers to uptake of digital health technologies by patients

3.1.1. Utility and patient understanding

Participants commented on the ability of patients to appreciate and use digital technologies for personal management of their respiratory symptoms, for example, Participant 1 believed "I think

there's a little bit of work to be done first before they are given the device around getting them to understand that they can affect change or they can make something at least improve something even if they have a chronic illness that they have control over exacerbation of symptoms."

3.1.2. Digital literacy

Digital literacy was noted as a key consideration to the acceptability of technology. Digital health literacy has been identified within the literature as being a factor that influences the adoption of digital health technology but it also is a significant barrier. Slevin et al. (26) explore this theory within their study, where findings suggest that individuals with previous experience with technology, perceived these skills enhanced their digital literacy abilities, therefore empowering them to engage with digital health technology. In the same study, digital literacy was reported to be a significant adoption barrier to digital health technology.

Participant 6 in this study stated "The ability of the person to use the device is an important consideration. "I have just seen a 47-year-old lady who does not know how to send an email when I tried to give her contact details of how best to contact somebody in an emergency or if they have a question."

3.1.3. Data privacy and trustworthiness

Participants noted that despite concerns, the use of technology can have a relatively positive impact on people's lives as noted by Participant 5 "Technology has changed our lives, you know technology is a good idea for the most part."

Korpershoek et al. (27) suggest that individuals do not feel that digital health technology can be trusted. Data privacy is commonly discussed and an area that internationally raises concern. The Data Protection Acts 1988–2018 are designed to protect people's privacy. The legislation confers rights on individuals concerning the privacy of their data as well as responsibilities on those persons holding and processing such data. It is assumed that individuals may have strong opinions on their health data and how it may be used; however, to note this is only an assumption and confirmation would be beneficial. Interestingly multiple subject matter experts in this study did not feel that service users would have significant data privacy concerns.

Participant 4 believed that "I'm not sure about privacy, I do not think that's as big an issue as it may be, for some people, but not for everyone, I think it's getting across and understanding what it is in the first instance, and how your data is being used, and when it is your health data for the people who are the controllers and are the ones who are making these decisions for their clinical team, they need this information."

Participant 5 stated "I do not know if the service users in the patient cohort have huge data concerns. I do not feel like you know patients come in and say God that looks amazing but I'm worried that the Russians are looking you know I mean I just do not."

Participant 6 stated "No, I would not have said that in fact, I would consider the consultation, a lot more privacy on digital technology, because there's a lot of security and protection there for patients with the GDPR concerns some may have, so no I think there's much more privacy sitting in a room on their own."

3.1.4. Equality

Equal and fair access to the necessary amenities to engage in digital health technology is ambiguous. This is a common theme among other studies. Multiple authors such as Mathar et al. (28) and

Disler et al. (29) explore the concept that individuals claim that they have no access to technology due to their location and age, but also that they would have little to no confidence in their ability to use any device. It is somewhat unclear what individuals define as “access to.” On one hand, individuals are insinuating that they do not own a piece of technology such as a computer to access some of the available online resources, however, the lack of internet access was also highlighted. None of the studies in the literature made specific reference to the access to internet and the reasons why this was an issue. It is very unclear if the participants in the studies which vary across multiple international countries such as the United Kingdom, Australia, Denmark Norway to name a few, were from an urban or rural geographical location. One study however conducted by Sönnerrfors et al. (30) in Sweden, does however mention that data were collected in rural and urban areas however no differentiation was made in the discussion of the results. This study was unique also, as it reported that access to the internet and access to technology was a significant facilitator to the adoption of technology. The author highlights to the reader that in Sweden, approximately only 4% of the population are seldom or non-users of the internet. It is also worth noting that the Swedish government has a national vision of e-health for 2025, in which the government pledges to assist and support the population, to have increased access to the internet and digital devices. This would suggest that the successful adoption of digital health technology would require commitment and support from local government to invest in both rural and urban infrastructure and internet access. It would be safe to assume that rural Ireland would lack similar resources and most definitely requires investment.

Similarly in this study, participants believed that not every individual in Ireland has equal and fair access to digital technologies.

Participant 4 “*The IT infrastructure might be challenging particularly in rural parts of the country.*”

Participant 6 stated “*high-speed broadband so even though you are kind of maybe saying okay mine maybe that brilliant for the older population, it might be that brilliant for the younger population, because they cannot afford to engage in it.*”

Participant 7 “*Absolutely not and that goes back to you know I’m in a Council House and I am not getting the wifi because they are going to make me commit to 12 months, but the Council said, I have to move out of here in 3 months so I’m not going to sign up there.*”

3.1.5. Education

Education, or more specifically IT education, is mentioned within the literature as both a facilitator and barrier to the adoption of digital health technology. Slevin et al. (26) report from an Irish study that participants perceived that IT education should be personalized for everyone. Personalized early IT education would result in a higher uptake of engagement with digital health technology, as it would instill competence and confidence in individuals when presented with digital health technology.

Participant 6 stated, “*I mean, even in my career like I’m self-learning every single bit of it that I’ve ever done.*” Education regarding the use of technology and the intention that it is in place to support and is not intended to replace the HCP is warranted to negate any ill feeling toward technology.

Participant 1 comments “*I think, as soon as they are put on something that is remote so away from a person and they are feeling like their issues are being trivialized in some way. They need to see that it*

does not have to be an all or nothing, it can be supported by a person and use of technology.”

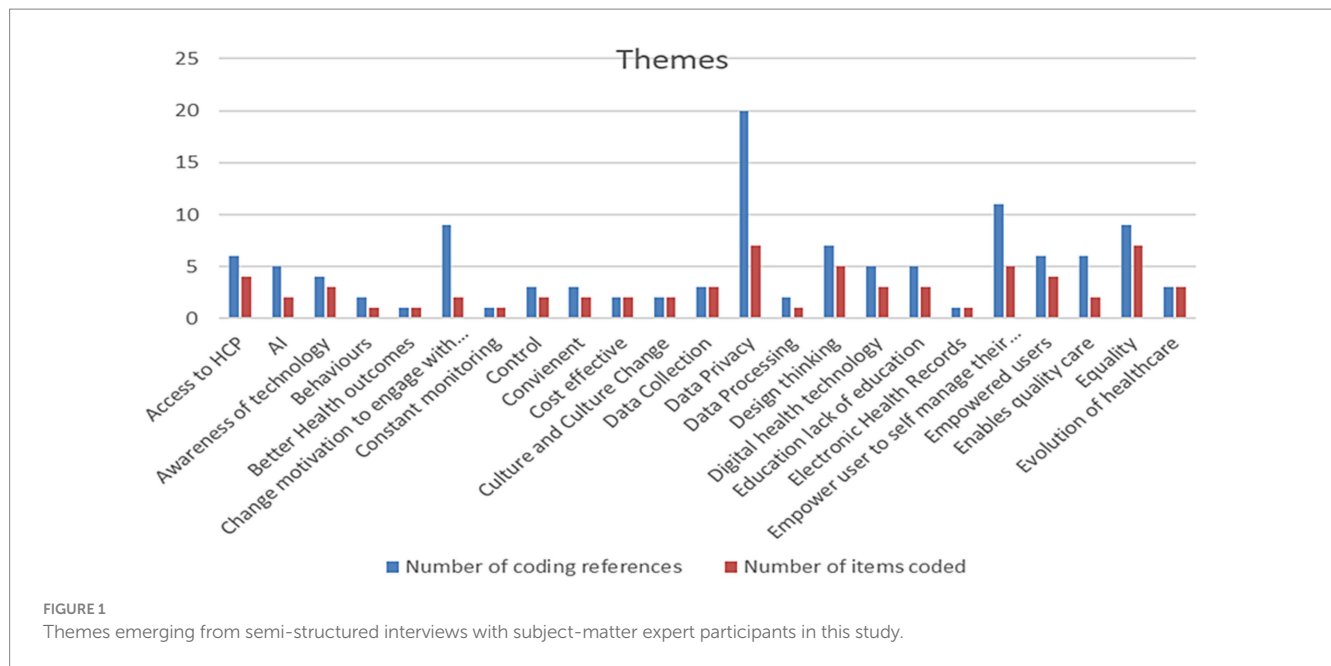
Participant 4 believed that “*a lack of protocol on the clinical side and a lack of understanding or awareness of what was happening on the service user side.*”

A summary of the themes emerging from the interviews with subject-matter expert participants in this project, on reaching data saturation, is shown in Figure 1.

The data analyzed from these semi-structured interviews highlighted many key themes among the subject matter experts on the role and potential effectiveness of DHI for remote patient use. There was a strong concern that people’s awareness of digital technologies and their perceived usefulness could be poor. There was also concern that poor awareness could hinder the acceptance of technology as people were somewhat blinkered to the advantages. The literature suggests that the increased knowledge and awareness of disease resulted in better self-management, better reported quality of life, and improved continuity of care from healthcare professionals (31). However, not all studies acknowledged this as a facilitator of the adoption to digital health technology. A qualitative study conducted in the United Kingdom by Sanders et al. (32) reflects the perception that engagement with digital health technology poses a threat to an individual’s identity, autonomy, and ability to self-care. It was believed that the use of digital health technology would result in a lifestyle that put too much focus on ill health and would encourage a high degree of dependency on the technology. Individuals were also keen to distance themselves from technology to avoid negative stereotypes of ill health and aging. The increased access to health data and focus in symptom awareness was seen as an aggravating factor for anxiety for some individuals (32) whereas counter-argument was made by Slevin et al. (33) who insinuates that engagement with digital health technology was seen to reduce an individual’s experience of anxiety. It can be concluded that an individual’s perception of usefulness is a significant element that should be considered as a facilitator, but, also a barrier to the adoption of digital health technology. The follow on quantitative phase of this study will encompass translating information from these semi-structured interviews into a questionnaire for respiratory patient participation attending both rural and urban health service clinics. The questionnaire will be developed using data from this study and will apply the Health Information Technology Acceptance Model. This framework is an amalgamation of TAM and HBM (34).

3.2. The role of living labs in supporting and enabling development and use of digital health interventions in respiratory care

Living labs are a relatively new concept within healthcare despite their existence since the early 2000s. There is no commonly accepted definition of living labs, however frequently used adjectives include, open innovation, user-centric, co-creation, test innovation, and real-life context (35). The idea of living labs facilitates the collaboration of knowledge sharing and research design which delivers a user-centered open innovation system. Broadly speaking the key concept of living labs is the idea that a safe space is created to facilitate knowledge exchange, co-ideation, and testing between diverse stakeholder groups



in real-life settings (36) The underpinning goal of living labs is to establish and accelerate networking and collaborations of key stakeholders resulting in greater and faster societal impact inclusive of service providers and service users. In Ireland, there are currently nine different living labs focusing on different aspects of digital health. While the type of disease supported varies, the main aim of the living labs is to facilitate the use of technology for remote monitoring, data collection, telehealth, and assistant apps for the older population. Respiratory living labs facilitate actively transferring the research into action. The development of a living laboratory for respiratory care management and intervention in Ireland will be informed by data generated from this study. Key candidate digital technologies to be used and developed in this digital respiratory health library include the Internet of Things (IoT) which includes personalized mobile phone apps; artificial intelligence and machine learning (algorithms) for real-time analysis and intuitive use of big data to promote ease of use and for patient risk mitigation; Edge end-to-end monitoring of data and the use of block chain to develop both business models and to address data trustworthiness; and immersive technologies to help patients and service providers understand new e-technologies. The living lab established for this respiratory patient project or DHI provides access to specialist training environments and subject-matter experts (including immersive technologies), for healthcare and industry through a university interface that also responds to community needs informed by regional policies (Figure 2).

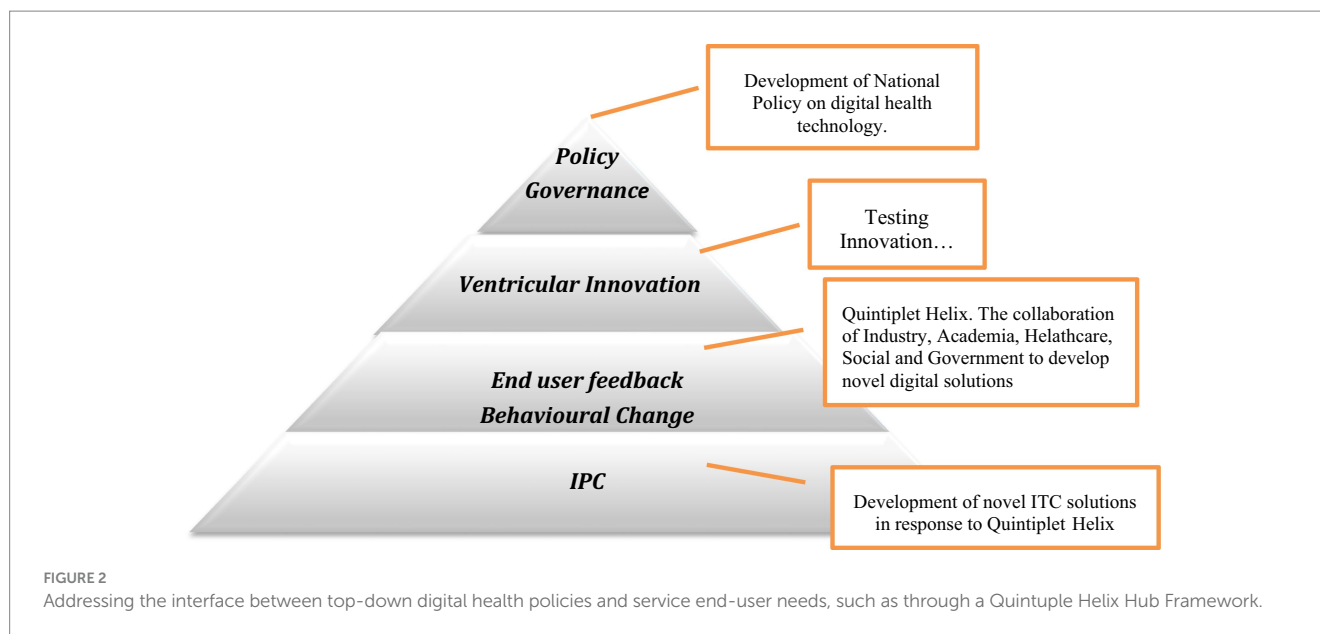
Moreover, the increasing availability and sophistication of mobile health technology continue to garner research interest (37). Liao et al. (37) noted that mobile technology has become a ubiquitous part of everyday life and is challenging the way we offer clinical and health services internationally. However, meeting the challenges posed by unprecedented access to data and the commensurate influx of wearable device data requires a multidisciplinary team of researchers, clinicians, software developers, information technologists, and statisticians. Adoption of digital health technologies in Ireland will also be accelerated by the use of open access and by knowledge transfer from adjacent domains that are more advanced in living

laboratories including additive manufacturing and smart agri-food systems (38, 39). The studies of Flott et al. (40) also corroborate the necessity for using this Quintuple Helix Hub encompassing living laboratories as a flexible patient-centered framework for evaluating the digital maturity of health services. Digital maturity is the extent to which digital technologies are used as enablers to deliver a high-quality health service. Flott et al. (40) noted that measurement systems that do exist are limited to evaluating digital programs within one service or care setting, intimating that digital maturity evaluation is not accounting for the needs of patients across their care pathways.

The use of big data and artificial intelligence is under study to stratify the delivery of healthcare. In Ireland, programs have been funded through Horizon (2020), an example being the CLARIFY project which aims to identify risk factors that impact cancer patients' quality of life after oncological treatment by using Big Data and AI. Data from more than 15,000 survivors of breast, lung, and lymphoma cancer will be reviewed. The objective is to help to stratify cancer survivors by risk to personalize their follow-up by better assessment of their needs.

3.3. Quintuple Helix hub framework for support and enabling living labs in respiratory health

The Quintuple Helix Hub framework combines academia-industry-government-healthcare and society thus providing an integrated multi-actor environment enabling digital transformation of living laboratories, such as for bespoke respiratory care and management. There is a pressing need to embrace national digital transformation strategies, particularly for healthcare; however, there is a gap at the interface between top-down strategic policies and bottom-up healthcare and end-users. This framework operates as a one-stop-shop to cross-cut different disciplines that include specialist infrastructure and equipment sharing, subject-matter expertise, demonstrator facilities, human capital building, training and mobility,



test-the tech, funding and investing (41, 42). The Quintuple Helix has its foundations in previous N-Tuple helices (namely Triple and Quadruple) that are explanatory and active models for facilitating and analyzing knowledge-based economies (43). This author reported that “the Triple Helix model of university-industry-government relations measures the extent to which innovation has become systematic instead of assuming the existence of national (or regional) systems of innovations on a priority ground.” This model also addresses the system of innovation patterns that embraces integrating (such as functions of wealth creation, knowledge production, and normative control taking place at organizational interfaces) and differentiating factors (such as exchanges on the market, scholarly communication in knowledge production, and political discourse) (43). One can determine whether innovation systems are technology-specific or sector-based by review of indicators, such as co-authorship data arising from the Science Citation Index. Leysdesdorff and Sun (44), previously showed that in Japan, “university scholars have increasingly co-authored with foreign colleagues, thus favoring internationalization above relevance when considering the triple helix model of university-industry-government.” It is appreciated that defining selection environments for delineating performing indicators for deploying effective digital health technology beyond the Triple helix of university-industry-government as it will require substantive specification and operational in terms of potentially relevant data that may require the development of additional relevant indicators. However, to effectively deploy appropriate digital technologies, consideration must be given to the additional subject domains of healthcare and society for both subject-matter appreciation, appropriateness, and socio-economic value for tax-payers; thus, inferring development of a Quintuple Helix framework for digital health in Ireland.

This present project addresses key themes for remote patient uptake of digital health innovations including informing future key performance indicators for living labs for respiratory care under a digital health living-lab framework. This challenge is not insignificant, for example, Rowan et al. (39) have noted that there are 706 digital innovation hubs in Europe under varying degrees of maturity. Yet,

Brenner et al. (8) highlighted that of the 2,192 publications reviewed and analyzed (PRISMA) between May 2021 and August 2021, only five papers have addressed approaches to inform key performance indicators for the applicability of digital health innovations. Further reading of these five mainly European publications reveals that they mainly focused on developing multi-stakeholder frameworks exploiting literature reviews and expertise meetings to classify indicators (45) and completing interviews with individual stakeholders followed by an interdisciplinary brainstorming session (46). Vedluga (47), applied the Activity Pyramid, Kane’s Model Affinity Diagrams, and Critical quality requirements tree to identify stakeholders, their needs and to determine KPIs for Lithuania’s national eHealth information system. Carrion (48), and Bradway (49), did not include methods to identify KPIs, but described DHI assessment based on principles of technical readiness and maturity, risks, benefits, and resources needed. Thus, there remains a knowledge gap in assessing both the benefits and barriers to supporting and enabling remote respiratory patient monitoring using digital technologies in a Quintuple Helix framework that also addresses appropriate KPIs for reporting on their effective implementation and management, which also embraces feedback to government on policies at the interface with end-users. This present study reports on the first qualitative phase through interviews with subject-matter experts to guide remote aging respiratory patient usage and their empowerment.

Living labs will also be supported and accelerated by digital twin (DT) activities that refer to the “virtual copy or model of any physical entity (physical twin) both of which are interconnected *via* the exchange of data in real-time. Applications of DT include real-time monitoring, designing/planning, optimization, maintenance, remote access, and so forth” (50). Operating an effective living laboratory that exploits digital technologies including digital twin applications for healthcare can increase productivity and efficiency. This Quintuple Helix Hub framework may potentially also operationally meet clinical programs and electronic medical records for the effective commensurate implementation of appropriate technologies into clinical workflow and allow feedback to measure the impact including key performance indicators on clinical outcomes (37). This hub

framework can also address the nexus to personalized home healthcare options for smart service delivery and patient-centered monitoring (51), such as respiratory care management. Alexandru and Ianculescu (51), noted that as the number of older adult patients increases with a broad spectrum of needs and specificities, the number of available or caretakers diminishes; thus, the healthcare and social system needs to evolve to meet these trends including informing appropriate and efficient decision making such as financial and human resources.

In the context of specialist training and educational programs delivered in living labs supporting eHealth, Extended Reality technologies such as Virtual reality (VR) are emerging as potential platforms to deliver learning content in a more ecologically valid manner. This is based on their delivery of 360° visuals, spatial audio, and allowing the learner to move beyond the passive mode toward an active participant in their learning experience (52). These technologies in conjunction with various wearable sensor technologies support the capture of various user physiological measures in addition to task performance and user interaction to facilitate a true “human-in-the-loop” system that supports adaptive, personalized while maintaining context-based learning (53, 54). The capture system identifies, at the individual level, key abilities of the learner (by moving beyond binary pass/fail reporting toward understanding a specific individual learning needs). This then informs how the presentation system challenges the learner; thus, optimizing the learner experience. It identifies opportunities for improved training including future provision for operator retraining. The Quadruple Helix Hub framework also supports and enables the integrated knowledge translation (IKT) approach that proposes researcher/knowledge user collaboration as a key step in achieving population impact and a way for society to direct science. IKT shifts from a paradigm where the researcher is an expert to one where researchers and knowledge users are both experts bringing complementary knowledge and skills to the team (55).

3.4. Role of DHI as an enabler to informing sustainability for respiratory health

Sustainability is referred to as a societal goal to enable co-existence. More often than not, it is a term more commonly used when referring to global warming and detrimental environmental changes that need radical change. The Irish healthcare system is a constant topic for Government debate which already is at a crisis point. Indeed, with the projected rise in the aging population, the future of Healthcare appears to be grim. The growth of the aging population in the Republic of Ireland has accelerated in comparison to other EU countries. In 2019 the estimated population of individuals greater than 65 in the Republic of Ireland was 696,300 people, which represents approx. 14% of the total population. This is estimated to reach 1.6million by 2051 (56). This level of growth is likely to increase the already lengthy waiting lists, delay elective surgeries, overburden our emergency departments, and results in poor quality care provision. The current data from January 2023 shows that 505,545 adults and 84,125 children are currently waiting time for Outpatient appointments in Ireland (57). The number of patients waiting for a Respiratory Consultant appointment is estimated to be 19,200. To put this into context, currently, One in eight of the Irish population is waiting for medical intervention. This is 12.5% of the Irish population. Healthcare is at the core of the success of sustainability in many other areas as it is the main beneficiary and contributor to development. It is suggested that

ultimately health is determined by a range of environmental, social, and economic influences, and the health of people, places, and the planet are interdependent (58). However, for healthcare to contemplate sustainability, changes need to be radical and imminent.

The introduction and inclusion of technology in the form of digital solutions into how healthcare is delivered is an exciting and welcome innovation currently being explored internationally. Digital solution goals have such diversity, therefore requiring the inclusion of stakeholders who have a particular interest in digital solutions interests (59). Collaboration is the key to success, such as through the Quadruple Helix Hub framework.

3.5. Summary

This study aimed to explore the perspectives of subject matter experts and their view of the factors that influence the pre-acceptability of digital health technology in the aging respiratory patient. The common themes identified in the literature were digital literacy, perceived usefulness, education, and access to and reliability of technology. Each theme uniquely impacts an individual's compliance with digital health technology. Participants discussed the difficulties that they experienced in gaining access to technology and also the lack of availability to the Internet. Most studies in best-published literature did not explore this theme in detail; therefore, it is unclear the reasons for this difficulty. Is it age? Is it geographical? Each of the subject matter experts raised awareness that the availability of appropriate infrastructure was a concern and that not all service users would have access to the internet or technological devices. Lack of digital literacy skills, IT education, and/or access to technology were also identified as concerns that may lead to poor engagement by service users. This topic is somewhat under-researched, and there are very limited Irish studies available for review. Data privacy was also a common theme among the participants in this study, but not a concerning one. It was suggested that service users may be very forthcoming about sharing their health data for the purposes of obtaining support and guidance from healthcare professionals and ultimately disease control. Healthcare is significantly evolving into the world of digital health technology; however, it is very unlikely that service users are evolving as rapidly to evoke change; understanding is needed of the perspectives of the service users to encourage engagement with digital health technology. It is imperative to ensure not only the success of digital health technology but also the sustainability of the Irish healthcare system so that the service users are identified as key stakeholders. Investment in digital health technology is futile if it is not accepted by the end user. Given the increasing emergence of digital innovation hubs across Ireland and Europe ($n=206$), applying an effective Quintuple Helix Hub framework that encompasses living lab activities will help define datasets and domains for improved utility and data trustworthiness.

This constituted the first study to identify themes believed to be relevant by respiratory care and digital health experts in Ireland to help inform future decision-making among a cohort of respiratory patients in the Irish midlands and Western region that may potentially facilitate engagement with an appropriate use of digital health technology. The study explored and identified expert participant perceptions, beliefs, barriers, and cues to action that would inform content and future deployment of living labs in respiratory care and related strategies for remote patient monitoring of people with respiratory diseases. The

ultimate goal of this case study was to generate and evaluate appropriate data sets to inform the selection and future deployment of an ICT-enabling technology that will empower patients to manage their respiratory systems in real-time in a safe effective manner through remote consultation with health service providers. Findings will advance Digital Health Strategies in Ireland and Europe and will have a global orientation. This study focused on respiratory patients only as it is the area of expertise of the researcher in nursing. The researcher is working full-time as an Advanced Nurse Practitioner and is undertaking this study independently. Leave has not been permitted to expand this study; therefore, this novel study focuses on the group of participants that are accessible.

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 Technical University of the Shannon Saolta Hospital Group ethics committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

TB, NR, NM, and MM-N contributed to the ideation, methods development, and review of first draft, proof editing and final review. NR and TB generated first draft of paper. TB obtained funding via

PhD project. NR, NM, and MM-N supervised PhD for data generation and paper synthesis. All authors contributed to the article and approved the submitted version.

Acknowledgments

TB acknowledges funding support from Technical University of the Shannon and Ireland's Health Service Executive (HSE) for this Doctorate study.

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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Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2023.1203937/full#supplementary-material>

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RECEIVED 17 May 2023

ACCEPTED 21 September 2023

PUBLISHED 24 October 2023

CITATION

Kimura A, Haraguchi H, Yamauchi Y and Matsuura K (2023) Social system design methodology for transitioning to a new social structure – a holistic urban living lab approach to the well-being city. *Front. Sociol.* 8:1201504. doi: 10.3389/fsoc.2023.1201504

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Social system design methodology for transitioning to a new social structure – a holistic urban living lab approach to the well-being city

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In recent years, along with the rise of new technologies such as AI, IoT, and Bigdata, there has been much discussion replacing entire cities with smart cities. These discussions have given rise to questions about what kind of society should be realized, and keywords such as well-being and sustainability are attracting attention. In this context, how concretely can we transform our current cities into new social structures? Social system design methodology is, in this paper, intend to achieve a comprehensive transition to a new social system, rather than overcoming individual social problems. In Japan, approaches to transforming society, such as elections and social activism, are not fully functional. Transitioning to a new social structure requires critiques from inside together with the presentation of concrete activities. We propose a systematized social system design methodology that aims at a principled transition; it is based on analyses of a series of practices developed in Omuta City, Fukuoka Prefecture in Japan. The methodology proposes a new way of perceiving social systems, practitioner attitude, and a practical design process. It also suggests that existing social system concepts create fundamental problems that lead to discomfort for practitioners, that clarifying existing concepts through policy background analysis can lead to a new view of social system concepts, and that bottom-up practices that realize these new concepts can begin to transform social systems. In order to confirm the versatility of this methodology, two case studies involving care prevention and the work of persons with disabilities are analyzed.

KEYWORDS

Living Labs, Sustainability Transition, well-being, smart city, participatory design, co-creation approach, design practice, systemic design

1. Introduction

The concept of Sustainable Development Goals (SDGs) aims to integrate the three aspects of society, economy and environment, and to encourage diverse stakeholders, including citizens, governments, and businesses, to transcend sectionalism and work together in a cross-sectional manner toward the meaningful society. As social issues are worsening and becoming more complex, a holistic approach to resolving the social issues is urgently required.

“Social system design” in this paper is also oriented toward the fundamental elimination of problems through a holistic transformation of the social system itself, rather than the piecewise

resolution of local problems. Many of today's social issues are caused by the discrepancy between the existing social system and the reality of our life. Post-event and reactive responses will not lead to a fundamental resolution of the issues or the realization of the future desired. What is important is an approach that perceives the current society as the cause of the problems and aims for its transformation.

2. Context

To begin this paper, we first review the weaknesses of conventional approaches in transforming social systems. The social system design discussed in this paper aims to overcome the situations that clearly show the weaknesses of conventional approaches.

In general, political activities are the most common approach to transforming any existing social system. The goal is to translate social ideals into legislation through civil debate in which representatives of citizens discuss and attempt to reach concordance. However, the representative democracy adopted by many democracies only appears to be stable because the class structure of industrial capitalism is balanced against the corresponding mass parties representing social groups, but in post-industrial capitalism, this balance is being lost (Manin, 1997). It has also been said that the unwritten norms of “mutual tolerance” and “organizational self-control,” necessary for democracy to function, are collapsing (Levitsky and Ziblatt, 2018). Thus, the dysfunctionality of representative democracy is being discussed, mainly in developed countries; the same issue has been raised in Japan (Fujii, 2021).

The main alternative to democratic elections is rooted in the diverse needs of citizens. There is a history of citizen movements led by issue groups modifying an existing social system in piecemeal fashion. This approach emphasizes the urgency of position-oriented politics driven by citizen movements; it lies outside traditional parliamentary politics. Civic movements that pursue ownership with minorities as agents emphasize the power relations of dominator / dominated and adopt confrontational actions in order to acquire political resources (Melucci et al., 1989). The assumption is that they can objectify “enemies” external to themselves. However, in the 2000s, in the face of neoliberalism, which has neutralized political antagonisms (Mouffe, 2005) and left-avoiding populism as a situation unique to Japan, it has become impossible to find an easily identifiable enemy, and civic activism is said to have transformed into something that provides a reason for living and a place for people who have difficulty adapting to society (Inaba, 2016).¹

In other words, both approaches, democratic policy formation and civic activities driven by issue groups, assume a clear-cut adversarial structure, which makes it impossible to establish valid points of contention and resolution. To escape this situation, a new approach quite different from current social structures is required.

3. Related studies and research issues

In response to the challenges noted, the search is on for a methodology that overcomes the limitations of the conventional approaches and triggers viable social system transformation; this paper is positioned within this context. Various related studies have attempted to correct the current situation, which has become increasingly pluralistic and complex, and develop architectures that are appropriate for creating rational social structures, rather than tackling the problems with simple oppositional remedies.

Regarding representation, discussions on the various forms of political participation that make democracy function effectively are calling into question the traditional electoral system (Reybrouck, 2016). Some have long advocated “citizen assemblies” that utilize mini-public forums for citizen participation and deliberation (Smith, 2009). Arguments have been made for evaluating the Irish Constitutional Assembly, which experimented with the idea, from the perspective of democratic control over policy making (Donatella della Porta, 2020). However, while these arguments for a more fully democratic system through diversification of the electoral system assume a representative system and rational debates, there is no inherent guarantee that these assumptions will be effective in achieving positive change of the social system. Indeed, they need to be validated empirically. In this respect, this is an argument that awaits further assessment and is beyond the scope of this paper, which is concerned with design methodology.

The following study of group activities for civic change is noteworthy from the viewpoint of the issues raised by this paper. It avoided a reduction to the old oppositional structure of “damage / perpetration” or “individual / government or corporation,” and instead reexamined the civic movements accompanying MINAMATA disease based on the premise that individuals are also embedded in society (Sung, 2003). Based on the interdependency of the individual and society, the perspective of objectifying the cyclically reconstituted social system itself was also emphasized in that paper.² However, the subject of this paper is a practical methodology that takes this

¹ According to Inaba, while social movements such as the Democracy Movement and Occupy Movement were revitalized worldwide in the 2000s, such movements were not so vibrant in Japan and non-protest-oriented movements attracted attention. Inaba acknowledges that social movements have become a place for minorities as described in the body of this paper; she also pointed out the need to find new political possibilities.

² “Mutuality and circularity between the individual and society” refers to the way in which our decisions and behaviors constitute the social system, and at the same time, the constituted social system also defines our decisions and behaviors. For example, let us consider the automobile traffic system. We can imagine it as a system of physical environment and rules, including traffic infrastructure such as roads, pedestrian crossings, and traffic signals, as well as traffic rules such as “stop at red lights” and “speed limit of 50km/h.” However, no matter how elaborately designed the traffic infrastructure and rules are, they alone will not make the traffic system function. It must be designed in such a way that drivers and pedestrians behave in accordance with the rules. Therefore, in order for a transportation system to work, while infrastructure and systems are being developed, people must be trained to control their bodies, for example, to “stop at red lights,” and systems are being implemented in schools and homes to educate people to behave in accordance with the rules. The fact that people are encouraged to behave according to the rules is called “Mutuality and circularity between the individual and society.” Such understandings are based on M. Foucault's theory of power [especially the discipline model (Foucault, 1975)]. This paper, however, while following this Foucauldian understanding, explores a design methodology that differs from Foucault's “archeology” and “genealogy” approaches.

cyclicity into account and approaches it in a concrete manner. Along these lines, there is research on Japanese social education theory that discusses the process by which parties to a social issue structurally perceive the issue and transform the community in a learning process called Community Development (Miyazaki, 2019). This is highly suggestive in terms of the internal change of the people involved and the formation of a collective consensus, but it remained within the framework of civil society theory, and so did not include discussions of policy or economics, and did not have the scope needed for holistic social system transformation.

Given this situation, social design³ methodologies such as Sustainability Transition (Kohler et al., 2019; Kanger et al., 2020; Markard et al., 2020; Kivimaa et al., 2021) and Urban Living Labs (Cuomo, 2022; Park and Fujii, 2022; Willems, 2022; Afacan, 2023) have attracted attention as concrete practices to ensure participation diversity in support of various parties through collaboration. The research domain of Sustainability Transition; Transition Management details a methodology in which citizens, governments, and businesses co-create a holistic agenda for social system transformation, and apply it in a way that connects it to the specific practices of the agents. However, it lacks a methodology to concretely implement the integrated transformation indicated by the agenda (Roorda et al., 2014), and has yet to fully realize a movement toward this transformation (Kohler et al., 2019). On the other hand, Urban Living Labs is a methodology in which citizens themselves take the initiative and constructively engage with urban stakeholders to solve problems through a design process directed toward sustainable urban transformation (Baccarne et al., 2014). However, a methodology to comprehensively and holistically grasp the complex intertwined elements of the entire city, called Urban Dimensions (Steen and van Bueren, 2017) has yet to be elucidated.

Two points are noteworthy in related research: the first is to take into account the circularity nature of individuals and the social systems, in which the individual is defined by society and the society is defined by the individual. The second is to ensure the diversity of participation through collaboration. However, the nature of the entities and methodologies to realize social system transformation in an integrated manner is a research issue that has yet to be adequately addressed. To contribute to social system transformation, this paper focuses on design methodologies that question the nature of subjects and practices in an integrated manner while overcoming the social conflict structures inherent in the social system through diverse collaborations based on the inner dynamics of circular dependencies of individuals and society (rather than external criticism).

What approach, then, is needed to find such a design methodology? William Gaver, a design and Human-Computer Interaction (HCI) researcher, suggests that the study of “Wicked Problems” (Buchanan, 1992) in design needs to be approached as a “generative discipline.” The engineering analytical method of HCI cannot deal with “Wicked Problems” for which there are no “right” answers, but rather multiple “good” answers. He then stated that

design studies’ unique contribution to knowledge is not to move toward generalization, standardization, and theorization based on scientific analysis, but to move toward specialization, diversification, and the generation of artifacts (designs) based on original concepts (Gaver, 2012). Given this perspective, it is a reasonable research approach to carefully describe and analyze the processes of analysis and implementation in each designer’s (practitioner’s) situation.

Therefore, in order to find a methodology for social system design based on the awareness of the aforementioned issues, this paper describes specific practices in Japan in Chapter 4, and attempts to systematize a general-purpose methodology from these practices in Chapter 5. In Chapter 6, we discuss how these methodologies can explain other practices that are oriented toward social system transformation with a similar awareness of the issues.

4. Social system design practice in Omuta city

4.1. Emerging social system design practices

OMUTA City contributed greatly to the industrial and economic development of Japan through the mining operations of the MIIKE Coal Mine (1873–1997) by the MEIJI Government and a flourishing coal-chemical complex. However, the population of the city has almost halved from 210,000 in 1959 (the peak of the coal mining era), and the current aging rate is 37.3% (as of October 1, 2022) which is one of the highest in Japan among cities with more than 100,000 people. It is also widely known as an advanced region in terms of dementia care, because the number of people with dementia is increasing in the community, creating a situation in which many people are involved. In Mouffe, 2005, Omuta City, together with its citizens, issued the “Declaration for Creating a City to Live with People with Dementia.”⁴ The concept of “a town where people can wander around with peace of mind,” which was proposed at that time, was a groundbreaking one. This concept aims to create a town in which people with dementia can live like everyone else in the community, rather than in nursing homes or in communities isolated by gates. Traditionally, the act of wandering and its positioning as a problematic behavior indicated deviation from social customs and triggered treatment and constraint. Given the emergence of similar situations in Japan, Omuta’s concept is an innovative one that aims to create a town where people with dementia, children, adults, or any other kind of person, are accepted into society.

From the perspective of this paper, this concept and the many practices in Omuta City that have accompanied it, are the seeds of a social system design practice that finds new meaning for and leads the way to a shift in social systems.

³ Manzini, an expert on social innovation, points out that modern society requires deep and significant systemic change (on the same level as the prior transition from feudal to modern society), and that what does not touch the roots of the system will not help in systemic transformation (Manzini, 2019).

⁴ In January 2005, Omuta City issued the “Declaration for Creating a City to Live with People with Dementia” in order to make it known throughout Japan that the entire city will support people with dementia and their families through cooperation among welfare, medical care, nursing agencies, the community, and government [https://www.city.omuta.lg.jp/hpKiji/pub/detail.aspx?c_id=56&id=6652&class_set_id=1&class_id=136 (Accessed March 1, 2023)].

4.2. Establishment of an organization for citizens to think and act for the entire city (2019)

It is clear that the activities traditionally proscribed by the issues of “dementia” and “older adult” make it difficult to redesign the entire social system. This is because it is impossible to take account of the social issues that arise in various parts of the community. This is due to the fact that the silo structure of local government limited the areas that could be covered by individual policies. Therefore, the OMUTA Future Co-Creation Center named Center for Person-Centered Ningen, Omuta (hereinafter referred to as “PONI PONI” using the nickname of the organization.) was established in collaboration with the public and private sectors as an “organization that is both independent and embedded” in the existing social system; it crosses vertical divisions in sectors and domains, with a core based on a new deeper concept related to dementia care (Kimura et al., 2019).⁵ PONI PONI was established as a public-private partnership. The founding members included businesses emerging within the community, those who had been involved in OMUTA’s urban development from outside the community, those who shared the concept and had strengths in policy formation outside the community, and design researchers from companies. It is a team structure that is conscious of the fact that its remit is to design social systems.

4.3. National model project of health promotion for the elderly health care (2019)

In parallel with the establishment of PONI PONI, we first focused on “care prevention” in response to the situation in OMUTA City, and developed solutions in conjunction with OMUTA City, particularly the “Health Promotion Project for the Elderly Health Care” by the Ministry of Health, Labor and Welfare. This was because we believed that it was necessary to seek the effective integration of two different policy areas: “community-based comprehensive care,” which was being promoted in the medical and long-term care fields, and “regional development,” which aimed to correct the concentration of people, money, and resources in Tokyo. The project involved understanding the policy background of each area and engaging in dialog with practitioners within and outside the region. As a result, we discovered a new transition concept: “from guaranteeing the right to exist (Article 25 of the Constitution) to guaranteeing the right to the pursuit of happiness (Article 13 of the Constitution) (Kikuchi, 2019).” This concept organically connects medical and nursing care with local development. The project report also addressed the Living Labs, which create collaboration between local players and outside companies to solve social issues, and envisions a specific approach for involving companies outside the region.

⁵ PONI PONI’s website (<https://poniponi.or.jp/>) and the ‘Questions and Dialog’ media (<https://dialogue-eureka.jp/>) jointly run by PONI PONI and the Co-Designing Institute for Polyphonic Society (Accessed March 1, 2023).

4.4. WAKU WAKU Life Salon (2019)

Subsequently, as a specific Living Lab practice project, PONI PONI implemented the “WAKU WAKU (This onomatopoeia means that “One’s heart pounded with expectation.”) Life Salon (Figure 1). This project responded to both the needs of local residents and the government to solve problems in OMUTA City and the need of companies to develop new services. In addition, the project embodied Omuta’s new transition concept which is detailed in the aforementioned “Health Promotion Project for Elderly Health Care. Specifically, participants aged 65 or older living in OMUTA City who voluntarily expressed interest in the “WAKU WAKU Life Salon” gathered for a total of five sessions to reflect on their lives to date and their daily lives, and to think about how they could become excited about the remainder of their lives.

For companies, this project was positioned as the search for concepts that would contribute to the development of IoT-based early disease detection services, and to organize UX/UI requirements. The knowledge acquired could be used to launch new commercial entities. At the same time, for residents, the project provided an opportunity for the older adult with limited places to go in the community to regain their motivation. For the government, it was an opportunity to find new measures to deal with matters that could not be approached through the existing long-term care insurance system. The project was designed and managed as a value-added activity in which the three parties involved in the Living Lab overcame their respective challenges.

In this way, we have newly discovered the potential of “dialog that stimulates motivation” in the realization of a new concept through “dialogs” between the older adult and the staff of the WAKU WAKU Life Salon.

4.5. Questioning the views of humanity (2020)

After the “WAKU WAKU Life Salon,” a dialog was held with leading practitioners and experts from within the region and beyond to identify a new view of human nature that could comprehensively support corporate service implementation, local practice, and policy development. It became clear that the humanistic view of the “modern subject,”⁶ which is the premise for all institutions and businesses in the modern society and which citizens widely believe should be realized, is no longer compatible with reality and is creating social tension. The dialog also suggested that the identity of the foundational human itself

⁶ The modern subject is a human being who organizes his or her inner self to conform to various social institutions, and whose voluntary behavior contributes to the maintenance and strengthening of those institutions. It is also a view of human beings that regards such a way of being as “normal.” Michel Foucault critically examined this view of human beings relative to the unique context of Western modernity in which it was established. Foucault sees “what is called ‘human being’ in the 19th and 20th centuries” as a combination of the “legal individual” as an ideological subject of rights and the “disciplinary individual” as a useful body obedient to normative power, and criticizes its ideological nature as “that illusion and reality called ‘human’ being.” (Foucault, 2003, p. 60).



FIGURE 1
Scene (left) and flyer (right) of WAKU WAKU Life Salon.



FIGURE 2
Official booklet (left) and booklet for citizens (center, right).

is shared with others and the environment. Furthermore, the phase of identity shifting from role (self-identity) to existence (ego-identity), not through discipline, but through release, and through “dialog,” would stimulate motivation from existence (ego-identity). In other words, a new view of the human being, which is necessary for social system design, was found.

4.6. Co-creation of Omuta city health and welfare comprehensive plan (2021)

In order to redesign the entire social system, PONI PONI and Omuta City collaborated to develop the Omuta City Health and Welfare Comprehensive Plan (Figure 2), which is a comprehensive plan for daily life, with the aim of targeting activities in a broader policy area than just long-term care prevention. This plan was developed based on suggestions from projects in the area of long-term care prevention described above, as well as from various projects in other areas. Comprehensive plans of local governments in Japan are generally prepared by combining the plans of various departments as

separate chapters into a single plan, but this does not lead to an integrated reappraisal of the community and daily life. Therefore, in this project, we attempted to create a single structure for the nine welfare-related administrative plans, and then integrated them holistically into a single comprehensive plan.

In addition, in order to replace Japan's typical approach to administrative plans, which merely creates a list of “measures that can be implemented at the present time” based on existing administrative resources and past achievements, PONI PONI and Omuta City decided to include “measures that should be addressed even though no means of implementation have been found at the present time” to create the free space expected to trigger novel co-creation activities.

4.7. Entrustment of community comprehensive support centers (2021)

In order to challenge the design of social systems in a more practical manner, we were entrusted with two Community

Comprehensive Support Centers, which are community-based, public interest entities. These centers are institutions stipulated in the Long-Term Care Insurance Law and established by local governments for the purpose of comprehensively supporting the improvement of the healthcare and welfare of the older adult by providing comprehensive consultations with the older adult in the community, protecting their rights, creating a community support system, and providing necessary assistance for long-term care. In addition, in response to the recent revision of the long-term care insurance system, OMUTA City has also established a system to actively engage in “community development. Specifically, the center is the first place to receive so-called “in-between problems (system errors)” that occur in the community, and can be said to be the center of a regional network to solve “in-between problems” and promote long-term care. Therefore, it has a great advantage as a center of practice for designing social systems in that it can detect social system deficiencies, draw out collaboration through its network, and work beyond its own domain.

4.8. Sign comprehensive cooperation agreement with OMUTA city (2022)

Furthermore, PONI PONI signed a “Collaboration Agreement for the Realization of a Community Coexistence Society” with the city of OMUTA. Its subject is the promotion of the comprehensive plan formulated in 2021. This allows PONI PONI to officially support policy formation in a wide range of areas in conjunction with government departments and to collaborate with stakeholders within and outside the community to realize the vision of the policy. This will help turn around the situation that tends to occur in Japan, where “public matters are left to the government.” The partnership between OMUTA City and PONI PONI, a community-based social system design organization, has officially paved the way for the integrated implementation of policies that have been stove-piped since PONI PONI’s founding by a private intermediary organization. From a different perspective, PONI PONI’s assumption of the planning promotion secretariat has made it possible to promote administrative planning through a collective impact approach.

4.9. National model project on housing (2022)

In addition to the Welfare department collaboration, we started collaborating with the housing department of OMUTA City, on the “Model Project on Housing through Cooperation between Welfare and Housing Departments in Local Governments” by the Ministry of Land, Infrastructure, Transport and Tourism. Housing policy is said to be a highly integrated area that is linked to not only welfare but also urban planning and immigration. Naturally, this was one of the themes of the Comprehensive Plan for Health and Welfare, but by focusing on housing, it was possible to gain a detailed understanding of the policy background and conduct a survey of the actual situation in the region. In the process, we further

discovered the concept of “substantiating social inclusion”⁷ (Miyamoto, 2017), which expands on Omuta’s new transition concept.

4.10. Hosting of the NINGEN societal festival (2022)

In 2022, we held the NINGEN Societal Festival (Figure 3) as an opportunity to share and connect with more citizens and other stakeholders within and outside of the region, based on the questions (principles) that emerged and tackled in the various projects (care prevention, housing, education, employment, etc.) that we have worked on with local citizens, local governments, and companies over the past 3 years. The NINGEN Societal Festival was held as an opportunity to share and connect with a larger number of citizens and other stakeholders in the community and beyond.

NINGEN is the Japanese word for Human. The kanji for NINGEN is composed of the kanji for “human” and “aida”/“ma,” which in Buddhist terminology means “between people,” and is used to represent “a place where people live. In the various projects that we have undertaken in Omuta, uncertainty about the meaning of NINGEN has emerged again and again. We have faced up to the questions raised and promoted projects for the future of the community and society. We believe that the concept of NINGEN, which is different from the Western view of human beings, is a universal question that require resolution if we are to tackle social issues common to Japan as well as other countries around the world, where aging and urbanization are also rampant. We then planned the NINGEN Societal Festival, which rethinks the concept of NINGEN.

Fifteen experts and practitioners in various fields engaged in generating advanced and unique questions gathered in Omuta; it provided an opportunity for a large number of participants from within and outside the region, to gather, hold dialogs, and experience technology (Figure 3). This led to efforts to demonstrate new technologies, ways of living, and ways of thinking to children and young people, and to foster a culture in which each citizen feels able to play a leading role for transition to new social systems and to be able to change society.

4.11. Project to connect with the community using VR technology (2022)

The aforementioned festival was the starting point for a variety of collaborations, one of which is a project to connect with the community using virtual reality (VR). Together with senior citizens and young people living in Omuta, a 360-degree camera

⁷ Miyamoto cites the criticism of Young (1999), author of “Bulimic Society,” that “repeatedly promoting social inclusion while society remains exclusionary will ultimately promote exclusion. He then points out that while it is good to include all excluded people as members of society, it is a logical contradiction to include people in an exclusionary or self-help society, and that social inclusion cannot be practically realized unless society itself changes.



FIGURE 3
Scene of NINGEN societal festival dialog (left) and technology experience (right).

is used to take pictures of favorite and nostalgic places in Omuta, which are then shown via VR systems to residents of nursing care facilities. When they view the memorable places, they will find themselves curious to “go a little deeper” or “touch the things in front of them,” and their bodies and minds will naturally start to move, creating an experience that is unique to VR. For the photographer as well, going out to shoot while imagining the people who will be viewing the images provides an opportunity to reconnect with the “community” and “people” in a different way than in the past.

These series of experiences are connected to the trial of how to implement the questions (philosophy) found in Omuta as technology in society. In fact, a collaborative project has been launched with a company that wants to explore the possibility of “technology to bring out the potential of people,” rather than simply introducing new technology for the sake of management and efficiency.

4.12. Model project on long-term care prevention (2023)

With the start of the Model Project on Long-Term Care Prevention by the government in 2023, the practice of structurally rethinking and redesigning existing social systems based on the new principles of “moving from guaranteeing the right to exist (Article 25 of the Constitution) to guaranteeing the right to pursue happiness (Article 13)” and “substantiating social inclusion” is finally being promoted. By making use of hands-on entities such as community comprehensive support centers, which are involved with local citizens on a daily basis, and their local networks, and through collaboration with local merchants who have not been involved in long-term care prevention, and technology providers who can transform the way of long-term care prevention with new technologies, we will be able to accelerate the transformation of local social systems into entities that are not confined to long-term care prevention.

5. Social system design methodology

In this chapter, we attempt to systematize our proposal as a general-purpose methodology, using the social system design practice in OMUTA City as a starting point.

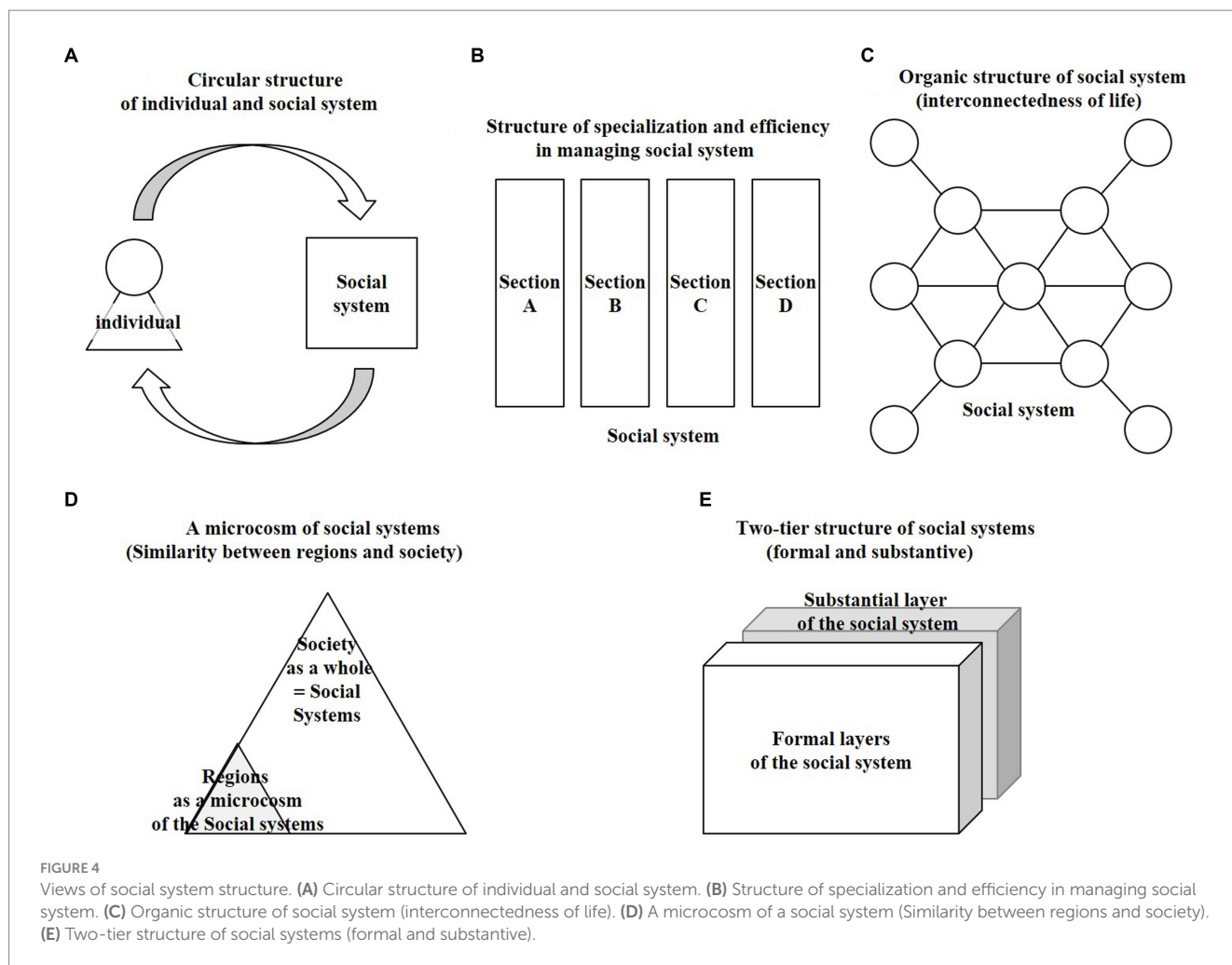
5.1. Grasping the views of social systems

Formal social systems such as laws and norms do not unilaterally influence people, but function as substantive social system only when people within the system behave in conformity with them (internalization of the system related to footnote No.2), see [Figure 4A](#). Design practitioners are strongly urged to first grasp social systems from the perspective that social systems are cyclically structured.

This makes it necessary to grasp the point that each area of the existing social system has become vertically divided due to specialization to increase efficiency ([Figure 4B](#)). On the other hand, people exist as an integrated entity, and each element of daily life is inseparably linked in a network (interrelationship) like an organism ([Figure 4C](#)). The discrepancy between the two is often exposed by social issues.

In order to specifically design a social system as a design object, it is necessary to limit the object and make it tangible. Therefore, one option is to target a specific “region” with fixed scope as a microcosm of the social system ([Figure 4D](#)).

It is also useful to use “policy” as a pathway to understand and work on the basic framework of the social systems in that region. However, it is important to discern the two-layered structure (formal and substantive) of the social systems. For example, the formal policies can be changed through official procedures, but this alone will not reach the concrete change of social systems. The approach at the “substantive” level, which is the actual implementation of the plan’s principles, requires building relationships and working with government officials and local stakeholders to collaborate in a substantive manner. In most cases, either a formal or substantive approach is taken, but in order to approach both sides (formal and



substantive) of a mutually embedded structure for social system transformation, it is essential to obtain formal ostensible standing as well as to implement concrete practices at the substantive level (Figure 4E).

5.2. Position of the social system design practitioners

As mentioned in the previous section, the principles of a social system must support both the environment and people's internal aspects like thoughts and behaviors, as both constitute the system in circulatory manner. Therefore, any entity that seeks to design a social system must internalize while escaping from the circulatory structure and implement a new concept in the existing system. The result being that those activities reconfigure the entire system. As described before, this is the target of an "organization that is both independent and embedded." Herein lies the basic position and approach of the social system design practitioner.

This is true whether the practitioner is an individual or an organization. In both cases, it is first necessary to free oneself from the functional roles defined by the existing social system. This means creating a situation in which one feels uncomfortable in one's surroundings as an undefined and contradictory entity. As people will try to pigeonhole the practitioner into an existing role, if the

practitioner's behavior demonstrates compliance, they will become subsumed by the existing system. It is necessary to continue to avoid this while retaining a certain influence on the existing social system. Influence must be both formal and substantive. The formalism acts to create an environment conducive to broad-based movement, while substance contributes to individual, concrete conceptual practices.

As regards concrete practices, the scope of involvement should be unconstrained as much as possible in order to avoid stove-piping (specialization), which is one of the weaknesses of existing social systems. Rather, it is necessary to reconfigure (rearrange) each element of the social system so that new principles can be realized through interaction across a wide range of areas. This also coincides with the breadth of collaboration partners. Social system design practitioners are expected to have a common language and interest in a wide range of areas and sectors, and to take the lead in design.

Financial independence is also important. Receiving compensation for "being of value in the existing social system" can mean being captured by the existing system. In addition, when obtaining funding from a subcontractor's standpoint, the direction of the design may be strongly constrained by existing philosophies and ideas. In light of these considerations, it is important that funding be indirect, that fair relationships be established as much as possible when making contracts, and that the independent organization should not become too dependent on funds from any one specific entity.

5.3. Process model of social system design

This section outlines the process as obtained through practice (Figure 5). It proceeds in an iterated and expanding manner.

Figure 6 shows the relationship between this process and the practices described in the previous section.

5.3.1. Process 1: practitioner's discomfort

First, it is necessary to create a position in which the “practitioner (individual or team) can be embedded while remaining independent” from the interrelated social system. In this case, the driver for design is the practitioner's own sense of “discomfort” with the existing social system, as well as the individual's sense of ownership based on personal experience. Discomfort here means that a person has a sense of being uncomfortable, having his/her freedom inhibited, or having inappropriate involvement with existing social institutions and services. However, it is difficult to cover the wide range of areas involved in designing a social system from just the direct experience of the individuals themselves. Therefore, when working as a team, it is necessary to ensure the diversity of experiences of the members and to take the experiences and positions of others as one's own. The position of being able to constantly perceive flaws in existing social systems is also a foundation of good design practice.

5.3.2. Process 2: analysis of background (concept of existing social systems)

The social system in front of us exists as if it were self-evident and invisible. However, in many cases, it was implemented at some point. As a clue to this, it is necessary to grasp how the policies were formed, find the structures and principles that created the problems beyond

the immediately obvious events, and objectify them. It is important to note that policy intentions can easily change from positive to negative depending on changes in reality. Policy intentions cannot be judged on their content alone. It is necessary to understand the current situation in relation to reality.

5.3.3. Process 3: reflecting on the concept

In order to develop a new social concept to change an existing social system, it is necessary to ask questions about the concept and deepen the dialog. To do so, we need to actively collaborate with experts and practitioners who are challenging society with advanced questions. It is important to open a forum for dialog and questioning, as this will enhance the public nature of our practice and help us find collaborators who are uncomfortable with the existing social system. Furthermore, it is essential to create a circuit that connects these questions to implementation approaches. It is necessary to reflect on the questions in the efforts of design practitioners themselves, as well as to have mechanisms to create new players in the field.

5.3.4. Process 4: practice-based approaches

It is necessary to create practices based on the new principles found, embed them in the existing system, connect them to the existing network, and make them fully functional. Implementing and linking these practices can concretely infuse the existing social system with the new concept and thus give the system a different structure. In other words, this practice means hacking the cycles of individuals and social systems in existing social systems from the inside. It is also important to ensure a network that can permeate the existing social system and expand its functions in a continuous, interrelated, and

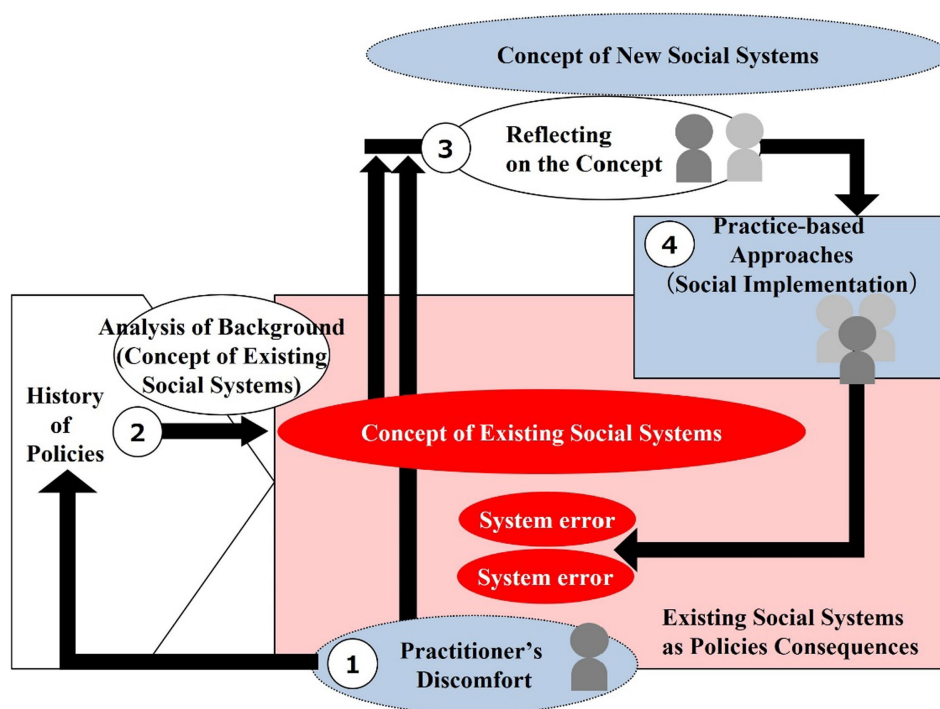


FIGURE 5
Process of social system design.

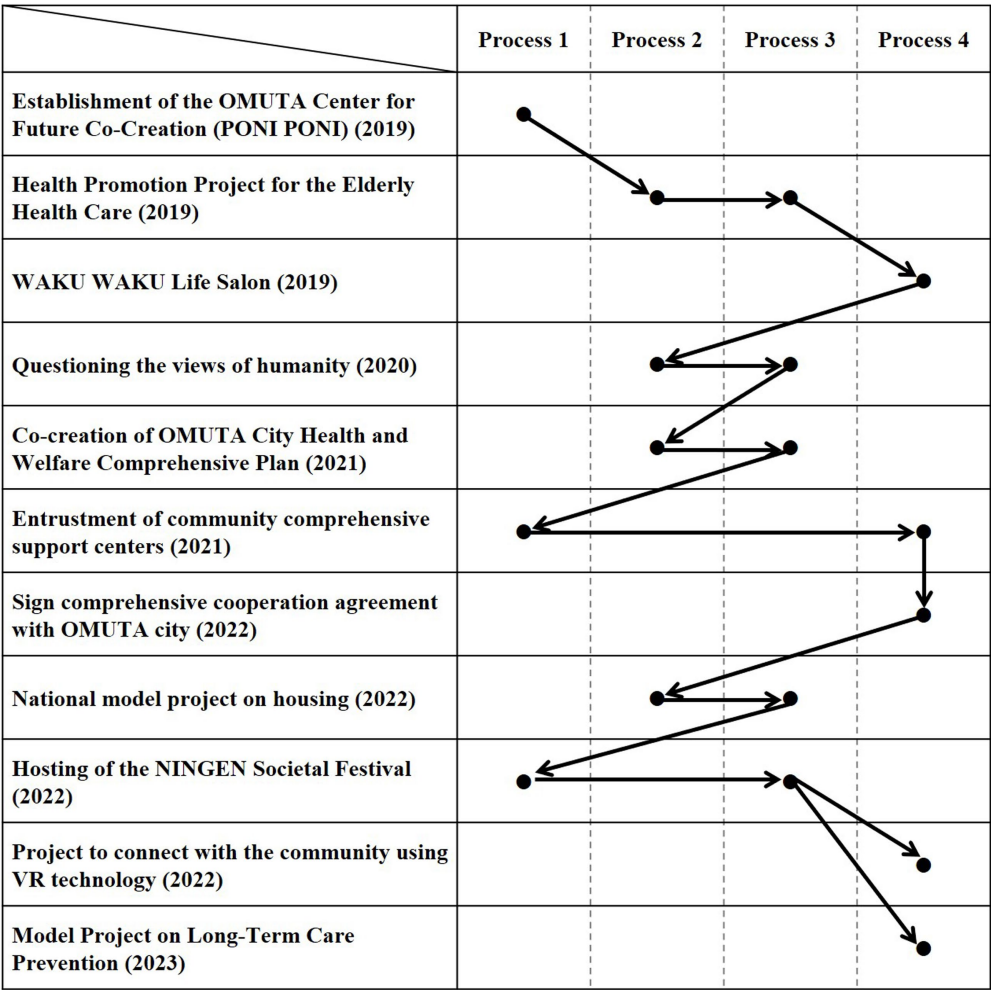


FIGURE 6
Relationship between process and practices.

chain-like manner. It is necessary to pursue not only partial prototyping, but also practices that serve as a pump to spread the concept throughout, so to speak.

6. Validation of methodology through case analysis

6.1. Target cases

This chapter examines whether the methodology described above is an explanatory model for other practices. The cases to be analyzed are those that attempt to overcome the challenges of the social system design methodology described in Chapter 3, and, once again, are those that satisfy the following two requirements.

Requirement 1: practices that consider the cyclicalities of individuals and social systems.

These are not practices in a free domain that are independent of social systems, but are practices that are intrinsic to current social systems. Moreover, like hacking a computer system with a new program, they are nurtured and modified from within, affecting both

individuals and social systems in order to attenuate the discrepancy between existing social systems and daily life.

Requirement 2: practice in collaboration with existing stakeholders.

This is the practice of not only designing systems and services from the top-down in order to transform the social system, but also finding ways to make them function as an entity in the actual living environment (community) through trial and error in collaboration with existing stakeholders.

This chapter analyzes two practices in Japan that attempt to meet these requirements from the perspective of social system design methodology. In order to gain a deeper understanding of each practice, we analyzed the logical structure of the practices by reading academic articles written by the practitioners and research reports related to their practices, and then conducted direct interviews with the practitioners to confirm the logic and supplement the information. Case 1 is described in Section 6.2 and its process is illustrated in Figure 7. In the figure, the main points of the case study are described in a way that corresponds to the process from 1 to 4. Similarly, Case 2 is represented in Section 6.3 and Figure 8.

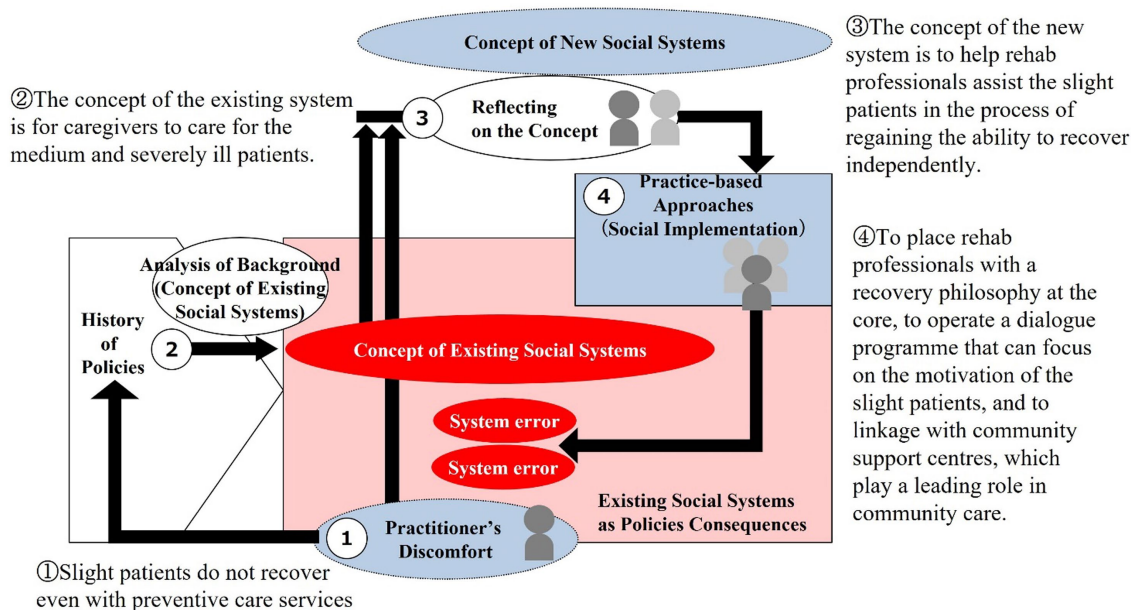


FIGURE 7
Social system design process for Case 1.

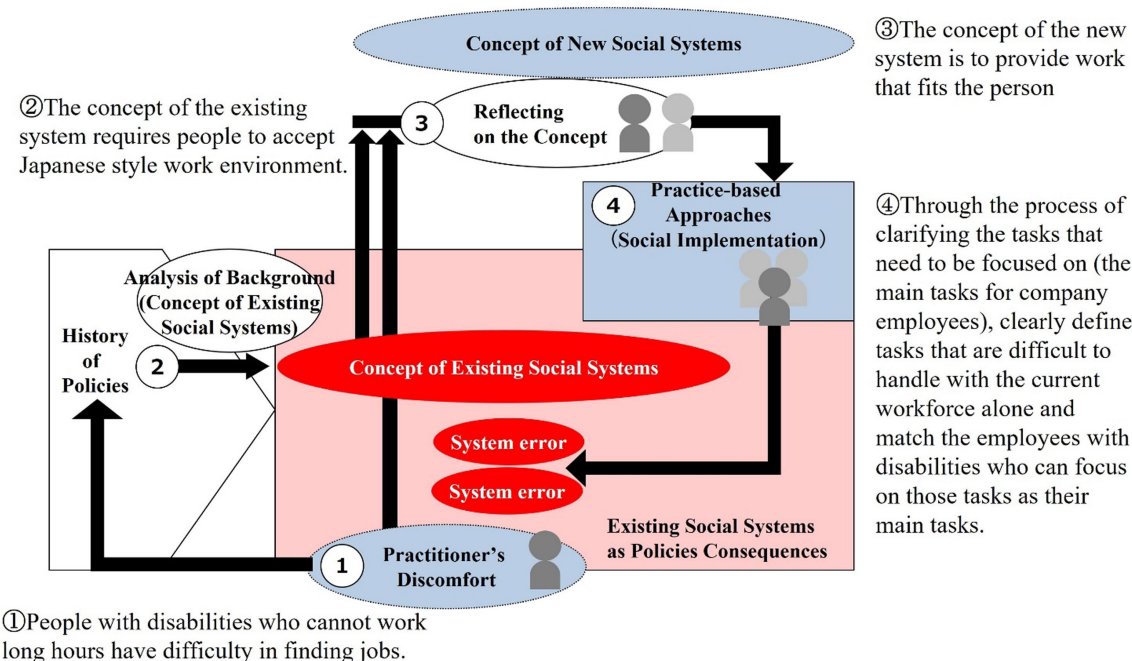


FIGURE 8
Social system design process for Case 2.

The process model for practice describes building in sequential order from Process 1, finding a new concept in process 3, and then working on the practice in process 4. However, social systems cannot be transformed simply by practices based on new concepts. A social system can be considered to have been transformed when

bottom-up practices embody the concept of the system. Therefore, in the case study analysis, after analyzing process 4 practices, we decided to describe the concept of the social system that can be regarded as embodied by these practices in the framework of process 3.

6.2. Case 1: practices related to long-term care prevention

The long-term care insurance system has played a central role in Japan's system of replacing long-term care. The long-term care insurance system is based on the principle of "support for self-reliance" (Ministry of Health, Labour and Welfare [MHLW], 1997). With the aim of increasing the effectiveness of the system, the Long-Term Care Insurance Law was revised in 2005 to amend the preventive benefits and establish community support programs, with the aim of preventing the need for more intensive long-term care. After revisions in 2008 and 2011, the 2014 revision launched the Comprehensive Project for Long-Term Care Prevention and Daily Life Support, along with the enhancement of community support services.

6.2.1. Process 1: practitioner's discomfort

However, as of the end of March 2020, the number of light patients (those requiring support 1 and 2 and those requiring long-term care 1) will exceed 3.2 million, 3.2 times the number as of the end of March 2001, and the increase in the number of persons requiring light patient care is significant (Ministry of Health, Labour and Welfare [MHLW], 2021). On the other hand, the various services provided by the comprehensive project for long-term care prevention and daily life support are not being fully utilized (Ministry of Health, Labour and Welfare [MHLW], 2022b). This can be considered to mean that the system surrounding long-term care prevention is not functioning effectively, that system-errors have occurred. This means that the system is following principles different from those set forth in the law.

In response to this situation, Hattori and others redefine "independence" in "support for independence" by clarifying "reduction or prevention of deterioration of the state of long-term care required, etc." in Article 2 of the Long-Term Care Insurance Law as "recovery to a state where long-term care is no longer required (recovery to a state where it is no longer necessary to use the system)" (International Longevity Center Japan Longevity Society Development Center, 2019), and to realize this, the short-term intensive preventive services implemented in the comprehensive project for long-term care prevention and daily life support are positioned as a key measure to shift the philosophy. Efforts are being made to put them into practice so that they can provide effective support.

6.2.2. Process 2: analysis of background (concept of existing social systems)

Under the long-term care insurance system, the maximum amount of benefits from the long-term care insurance system (maximum amount of benefits) is determined for each level of care required, and a change in the level of care required due to improvement means a decrease in income for the service provider. This means that there is a disincentive to improve the level of care required. Incentives for service providers to support independence have long been the subject of discussion at the Subcommittee on Long-Term Care Benefit Expenses of the Social Security Council, but at present, evaluation of "maintenance and improvement of the level of care required" has been implemented only for some services (Ministry of Health, Labour and Welfare [MHLW], 2017). Furthermore, there is no limit to the period of time that services can be used, except for short-term intensive preventive services, making it easier to sustain their use.

On the other hand, the comprehensive project for care prevention and daily life support has not been implemented uniformly throughout the country, which had been the norm until then, but is designed as a system that can be implemented according to the actual conditions of each municipality. This has resulted in a large difference between municipalities that are willing to implement the program and those that are not, and the fact that the approach to implementing the program differs from that of the past has also become a hurdle, which has prevented the program from spreading as a whole.

In other words, contrary to the philosophy set forth in the Long-Term Care Insurance Law, the long-term care insurance system has become a mechanism that does not provide effective incentives for "recovery to a state where long-term care is no longer required. In addition, the comprehensive project for long-term care prevention and daily life support challenged the willingness and policy understanding of the municipalities that were the implementing entities. As a result, it can be said that the operation of the system was driven by the principle of promoting "continuous use of the system," rather than "recovery to a state where long-term care is no longer required.

6.2.3. Process 4: practice-based approaches

In contrast, the practice of Hattori and others positions and utilizes the short-term intensive preventive services implemented in the comprehensive project as a core measure of long-term care prevention and daily life support.

First, they recommend that municipalities establish a process whereby basically all persons eligible for the project⁸ or those requiring support 1 and 2 who use the long-term care insurance system for the first time, with some exceptions, first use the short-term intensive preventive services. This creates a new preliminary step in the operational process of the existing long-term care insurance system, creating an area where a new philosophy can be easily realized locally, while still having links to the latter process and existing stakeholders.

Second, they have developed and implemented a dialog program that focuses on the motivation of the light patient. This is a support program centered on dialogs that draw out the motivation of light patients, in which they envision the life they would like to regain after improvement, and think together about goals and initiatives in their daily lives outside of the days when services are provided (used). Service use is basically limited to 3 months, or 6 months under special circumstances.

In the program, self-management is the foundation, and the philosophy of "recovery to a state where nursing care is unnecessary" is implemented in the form of "support for doing" (The Dia Foundation for Research on Ageing Societies, 2018). In order to achieve this, rehabilitation professionals (occupational therapists, physical therapists, etc.) accompany the light patients after full assessment of their abilities. Although rehabilitation professionals have recovery (rehabilitate) rather than nursing care (care) as their core expertise, they have not had a central role in long-term care

⁸ Officially, "persons eligible for long-term care prevention and lifestyle support service projects. This refers to those who use only the services provided by the Long-Term Care Prevention and Lifestyle Support Services Project and who fall under the category of those who have completed the basic checklist.

prevention measures in the long-term care insurance law. Therefore, it can be seen that they have gained a position where they can move with a degree of freedom toward the realization of their philosophy, while being embedded in the existing system for short-term intensive preventive services.

In addition, the short-term intensive preventive care services are basically provided by the community comprehensive support centers operated by the municipalities. Since the role of these centers is to provide guidance (comprehensive and continuous care management) to the in-home care support offices that will collaborate with them in providing care management for care prevention in the community, they will serve as a driver to expand the new philosophy.

On top of this, Hattori and others. Propose that short-term intensive preventive services, community rehabilitation activity support projects, community care meetings, and lifestyle support coordinators, measures that are related to long-term care prevention but have been difficult to link, organically, be linked and operated in an integrated manner (Mitsubishi UFJ Research and Consulting, 2019). This encourages synchronized advances in multiple measures for long-term care prevention and helps municipal officials understand the system.

6.2.4. Process 3: reflecting on the concept

The practice of Hattori and others is to redefine the philosophy of “support for self-reliance,” which has been the legal phrase of long-term care insurance since the establishment of the system, as “recovery to a state where long-term care is no longer needed,” and to make it a concrete goal of short-term intensive preventive services. The idea is to make the philosophy permeate the existing system and to reconfigure the entire system together with the philosophy by making it fully functional.

New professionals (occupational therapists, physical therapists, etc.), whose core expertise is in recovery (rehabilitation), will play a central role in implementing the services with limitations on the period of use, setting “recovery to a state where nursing care is no longer required” as a specific goal (outcome). Since the municipality designates the providers, there is no excessive competition among providers, and the system can be operated as a system that offers stable profits. Moreover, involving the community comprehensive support centers that will spread the philosophy, and by operating in combination with related systems, it becomes possible to change the entire system while hacking the existing system.

Furthermore, by creating one successful case study in each prefecture, Hattori and others hope to encourage municipalities, which tend to take a wait-and-see approach, to stimulate a sense of crisis in the municipalities by creating a situation where neighboring municipalities are working on good mechanisms, and to spread the care prevention system based on the new philosophy throughout the country.

The efforts of Hattori and others should truly be a good example of social system design, where the project hacks into and changes existing social systems.

6.3. Case 2: practices related to employment of people with disabilities

The Convention on the Rights of Persons with Disabilities, adopted by the United Nations in 2006 and ratified by Japan in 2014,

calls for the “prohibition of discrimination on the basis of disability” and “reasonable accommodation” in various policy areas such as education and employment. The Convention on the Rights of Persons with Disabilities advocates the principle of “inclusive.” Article 3 of the Convention stipulates “full and effective participation and inclusion in society” as one of its general principles. Regarding labor and employment, Article 27 stipulates the right of persons with disabilities to work in an “open, inclusive and accessible” labor market and working environment. Japan’s system of employment of persons with disabilities, which includes a system that legally obliges companies to employ persons with disabilities (e.g., an employment ratio system for persons with disabilities), has been developed in conjunction with the ratification of the Convention. At the same time, the systems of support for transition to employment and continuous employment support as welfare services for persons with disabilities have also been revised.

The employment rate system for persons with disabilities is a system that requires a certain percentage of workers employed by a company to be persons with disabilities.⁹ There, 1.0 person is counted for 30 h or more per week (2 persons for severe physical or intellectual disabilities), and 0.5 persons (1 person for severe physical or intellectual disabilities) are counted for short-time workers who work 20 to 30 h per week. As a special exception to this system, if a company’s employer establishes a subsidiary that makes special arrangements for persons with disabilities and meets certain requirements (Ministry of Health, Labour and Welfare [MHLW], 1960), the “special subsidiary” system allows workers employed by the subsidiary to be counted in the actual employment rate as if they were employed by the parent company or the entire corporate group.

On the other hand, as welfare services, persons with disabilities who wish to work at general companies can receive support for employment at labor transition support facilities. There are also two types of welfare employment for persons with disabilities who find it difficult to work at general companies: Type A continuous employment support pays wages (above the minimum wage) for labor, while Type B provides a wage (national average: about 16,000 JPN).

6.3.1. Process 1: practitioner’s discomfort

The total number of persons with physical, intellectual, and mental disabilities is approximately 9.65 mil., of which approximately 3.77 mil. are homebound persons between the ages of 18 and 65 (Ministry of Health, Labour and Welfare [MHLW], 2022c). As of 2022, there were approximately 614 thou. Persons with disabilities employed in the private sector (Ministry of Health, Labour and Welfare [MHLW], 2022a). The breakdown is as follows; The total number of special-purpose subsidiaries is 579, and the number of persons with disabilities employed is approximately 44 thou. The number of persons with disabilities employed by public organizations, etc. (national, prefectural, municipal, board of education, and independent administrative institutions) is 83 thou. On the other

⁹ Companies that have not achieved the legally mandated employment rate must pay the government a payment corresponding to the shortfall, while companies that have employed more people with disabilities than the statutory employment rate will receive an adjustment payment from the government corresponding to the excess.

hand, the number of users of welfare employment was 375 thou. (Ministry of Health, Labour and Welfare [MHLW], 2009). Looking at this from the perspective of the employment of persons with disabilities, less than half (48.3%) of the companies meet the current legal employment rate (2.3%) (Ministry of Health, Labour and Welfare [MHLW], 2022a).¹⁰ In addition, the rate of transition to general employment at labor transition support facilities remained at 54.7% (in FY2019) and in the case of welfare-type employment, the transition rate to general employment was 25.1% for Type A and 13.2% for Type B (Ministry of Health, Labour and Welfare [MHLW], 2022c).

Although the number of persons with disabilities employed in the private sector continues to increase, this number is not as large as the actual number of persons with disabilities, and the system surrounding the employment of persons with disabilities is not fully functioning.¹¹ In 2022, the UN Committee on the Rights of Persons with Disabilities, in its recommendations to Japan, calls for a stronger transition from “protected workshops and employment-related welfare services” to “open labor markets in the private and public sectors” and “equal remuneration for work of equal value in an inclusive working environment.”¹² The reality is that people with disabilities who have difficulty working more than the 20 h required by the legal employment rate are not expected to work in companies in the first place.

These situations indicate that the principles of the Convention on the Rights of Persons with Disabilities are not functioning as the principles of the system for employment of persons with disabilities in Japan. In response, Kondo and others. Are focusing on employment opportunities of less than 20 h, by creating and putting into practice the “ultra-short-time employment model” as a system implementation of the principles.

6.3.2. Process 2: analysis of background (concept of existing social systems)

Kondo points out that traditional Japanese employment practices are behind the problems in the employment of people with disabilities in Japan. According to Kondo, Japanese employment practices are based on the premise of “permanent employment,” in which new graduates are hired and employed full-time by a single company for an indefinite period of time, with a seniority-based wage system that provides security of livelihood with long-term prospects. This practice, known as “membership employment” (Hamaguchi, 2011), is also the premise of Japan’s social security system, whereby people are

connected to the unemployment insurance safety net in addition to their wage security through membership in a company.¹³

However, according to Kondo, the “need to work long hours” and the “lack of job definition at the time of hiring”¹⁴ in this uniquely Japanese employment practice are the factors that exclude people with disabilities. Kondo points out that Japanese employment practices require all employees to “orient and clarify unclear duties in accordance with the changing mission of the company” and, as the basis for this, to have “the ability to communicate with others at a high level” (Kondo, 2016). Thus, it can be said that the conventional Japanese employment system operates based on a philosophy that uniformly emphasizes human resources who can fulfill any duties in a flexible manner.

Regarding this current situation, Kondo evaluates the significance of the employment rate system for persons with disabilities as “an effort to increase the number of people certified as having a disability in the form of holding a disability certificate in a form of employment similar to regular employment” However, he points out that “strong institutional backup to encourage the employment of people with disabilities” in line with Japanese employment practices “has, on the contrary, created a situation where it has become a barrier that makes it difficult for them to enter the regular workplace” (Kondo, 2016). In this regard, Kondo is also critical of special-purpose subsidiaries and businesses that utilize legal employment quotas for people with disabilities, because while they may achieve the employment rate of people with disabilities in terms of numbers, they may actually promote a situation in which people with disabilities and able-bodied people are separated in the actual workplace.

6.3.3. Process 4: practice-based approaches

In order to solve this problem, it is necessary to critically rethink Japanese-style employment practices (the philosophy of the current system) and create a situation in which people with disabilities can work alongside able-bodied people in regular workplaces. To this end, companies that employ people with disabilities must improve their working environments to be more inclusive, rather than unilaterally conforming to the current system of employment. Kondo and others call this the “ultra-short-time employment model” (Kondo, 2020)¹⁵

10 The actual employment rate in the private sector is 2.25%.

11 In this regard, it has long been pointed out that the challenge in employment for people with mental disabilities is not “getting a job” but “getting a job and continuing to work” because the number of people with mental disabilities employed is small in comparison, although statistically the number of people with mental disabilities employed is very high (Kurachi, 2014).

12 Committee on the Rights of Persons with Disabilities (2022). Concluding observations on the initial report of Japan. The original text of the quoted passage is below. The committee also made a total of four other recommendations regarding employment, including the implementation of reasonable accommodation.

58. The Committee recommends that, in line with target 8.5 of the Sustainable Development Goals, the State party:

(a) Enhance efforts to speed up the transition of persons with disabilities from sheltered workshops and employment-related welfare services to the open labour market in the private and public sectors, with equal remuneration for work of equal value, in an inclusive work environment;

13 These forms of employment created high efficiency during the postwar high-growth period through long working hours and transfers, and were suitable for a time when only able-bodied adult males were assumed to be in the labor force (Hamaguchi, 2011).

14 If a job definition is exchanged, it becomes easier to “undergo appropriate modification and adjustment outside of the essential job duties=receive reasonable accommodation.” But the fact that it is common for this not to be defined, Kondo says, suggests that there is a background where reasonable accommodation is easily denied (Kondo, 2016).

15 The characteristics of this model can be summarized as follows: (1) job descriptions are clearly defined before hiring, (2) employees work in specific defined jobs for very short hours, (3) employees are not required to do anything other than what is essentially necessary to perform their jobs, (4) employees work together in the same workplace, (5) there are regional systems to create very short-time employment, and (6) the total employment rate is independently calculated. In introducing the ultra-short-time employment model, the following steps are taken: (1) sharing the same philosophy, (2) defining the job, (3) hiring, (4) employment, and (5) retention [Kobe City (Disability Support Division, Welfare Bureau), 2021, Very Short-Time Employment Case Studies, <https://www.city.kobe.lg.jp/documents/46683/jireisyuu.pdf> (Accessed March. 1, 2023)].

and are working on the corresponding practices. It consists of “a way of working that allows people to have a role in the regular workplace, even if it is only for a few minutes or hours a week, a support system in the community to realize such a way of working,” and “technology to create an internal work and employment environment.

When introducing the ultra-short-time employment program, Kondo and others ask companies to forget about employment of people with disabilities for a moment and focus on the work of a specific staff member working at the company. Then, while reaffirming the values and ideal forms that they want the staff to realize, they break down the work into (1) the essential tasks that the staff should perform, (2) peripheral tasks that the staff should perform, and (3) tasks that do not necessarily have to be performed by the staff but are required to be performed in the workplace. (3) Tasks that do not necessarily need to be carried out by the staff member in question, but which must be handled in the workplace. After clarifying the (3) operations broken down here as jobs, the next goal is to recruit, hire, and retain people who can handle these specific operations (jobs). At this stage of recruitment, the employment support system for people with disabilities, including welfare-type employment, is actively utilized.

Here, Kondo and others, do not consider the Japanese-style employment practice of undefined duties as causing problems only for persons with disabilities, but rather see it as a problem that companies generally face, and take a new approach by reorganizing the division and assignment of work in the workplace. What is important is that the specific tasks in (3) are not tasks that have been specifically carved out for people with disabilities, nor are they tasks that anyone can do, but are clearly defined as tasks that are necessary for the workplace but difficult for the workplace staff to handle alone. That work is defined as work that is necessary for the workplace but that cannot be handled by the workplace staff alone. In addition, the emphasis in the very-short-time employment system is on “not asking the person who performs the job to do anything other than what is necessary for the job.” By establishing each job as a job in both definition and practice, the workplace is reorganized into a workplace that consists solely of each individual’s original job, and everyone stands on the same level. By creating such a fair structure in the workplace, the ultra-short-time employment model is expected to substantiate the inclusive philosophy of “working together.” Such an ultra-short-time employment model has produced many cases in which users of Type B continuous employment support, a type of welfare-type employment for people with disabilities who find it difficult to work in general companies¹⁶ (Kondo, 2020), have been employed. This fact sharply forces us to reexamine the meaning of “being able to work in a general company.

6.3.4. Process 3: reflecting on the concept

Japanese-style employment practices today are thought to be a factor that alienates not only the disabled but also women, the older adult, and other diverse work styles, as well as being a factor in health problems such as overwork and depression caused by excessive concentration of duties on those who are skilled in progress

management and communication skills. This was thought to be appropriate when healthy adult males could be assumed to constitute the labor force, but today, when a diverse workforce including disabled persons, women, and the older adult exists, it is also pointed out that this has led to a decline in the vitality of society (Hamaguchi, 2011).

The ultra-short-time employment model has been implemented in local shopping areas in Kobe City and in small and medium-sized enterprises (SMEs) with less than 50 employees in Kawasaki City. Kondo says that the model has been realized in these regions. According to Kondo, since the ultra-short-time employment model is job-type employment¹⁷ that does not presuppose continued employment, it is necessary to have a function that supports the mobility of workers who can work for another company by drawing on their career even after their employment ends because the tasks no longer exist. Coordination and networking for this function are currently required by the existing social employment system in the region. In this regard, Kondo also says that the ultra-short-time employment model “is not a conventional model in which a single company employs one person with disabilities for a long period of time and continues to guarantee his/her livelihood, but a model that is closer to the idea of ‘employment in the community’” (Kondo, 2020).

Here, the existing social work system will be actively reimagined in the region as necessary for the regional implementation of the ultra-short-time employment model, helping to open the employment of people with disabilities from “protected welfare services” to an “open labor market. In this respect, the ultra-short-time employment model does not conclude the story of the workplace, but is considered to substantiate the idea of inclusiveness by hacking the existing system in the regional phase.¹⁸

7. Discussion

Case 1 expresses the fact that top-down philosophical concepts alone are not enough to achieve social system transformation. It is difficult to rewrite the concept of a system given the cyclical nature of individuals and social systems simply by renewing administrative systems. Therefore, the Social System Design Methodology recommends working on the ground and hacking the existing social system with practices based on the new system concept. Hattori worked through a series of practices, such as placing rehabilitation professionals with the philosophy of recovery at the core of their

¹⁶ Many people with mental disabilities are working in the ultra-short-time employment model, and many of them are users of Type B continuous employment support (Kondo, 2020).

¹⁷ According to Hamaguchi, “all countries except Japan are job-based societies,” but he points out that all countries except the U.S. have restrictions on dismissal, and the common belief in Japan that job-based employment means free dismissal is a misunderstanding (Hamaguchi, 2011, p. 110). How job-type employment should be in Japan is a separate issue to be considered.

¹⁸ While implementing the ultra-short-time employment model, Kondo and others have also continued to lobby the government to include employment of less than 20h in the statutory employment rate. In 2022, the Law for Employment Promotion of Persons with Disabilities is expected to be amended to allow employers to calculate the employment rate for persons with mental disabilities, persons with severe physical disabilities, and persons with severe intellectual disabilities who work more than 10h but less than 20h as a special case.

practice, operating a dialog program that can focus on motivating the minorities, and letting the community comprehensive support centers play a leading role in the care of the community. These multi-layered, intertwined and complex practices in the field have created a situation in which a substantially new social system's concept has emerged. As a result, there are signs of an expanding social system in which the light patients are becoming motivated and thus recovering.

Case study 2 shows that even initiatives that appear to be improving toward a new concept will not eliminate barriers to genuine employment for people with disabilities unless the essential concept is transformed. Kondo finds that the concept of the existing system is influenced by unique Japanese employment practices, among which the need for long working hours and the lack of job definition at the time of recruitment are the main disincentives for people with disabilities to work. It is then oriented toward a substantially new concept of the employment system by overlaying practices such as the process of finding work from the standpoint of realization of the company's mission, making rules for disabled people to work at the company site without anxiety, and building model cases that can be used for the existing legal employment rate. This has created a new system that enables many people to work with their own strength in their community.

Through the analysis of these case studies, it has been shown that the social system design methodology can be applied to cases where social systems are being transformed in concrete ways.

8. Contributions and limitations

The contributions of this paper are the development of a social system design methodology based on the analysis of a series of practices developed in Omuta, Japan, and the confirmation of the generality of the proposed methodology through two case studies examining care prevention and employment issues for people with disabilities.

This methodology provides insights into perspectives that have not been described in previous academic theories. The challenge with transition management has been that the agenda is considered by multiple stakeholders, but the specific practices that follow do not proceed. In response, the Social System Design Methodology proposes a methodology not only for developing agendas and policies that express concepts, but also for people to hack the system in the field of practice to make the concepts permeate the system.

Also, the challenge for the Urban Living Lab was that it had not established a methodology for setting issues in the complex and intertwined urban dimension, although it was equipped with methods to promote the engaged participation of citizens. In response, the Social System Design Methodology proposes an approach to problem-setting that is oriented toward system transformation at the urban level through an analysis of the policy context starting from Practitioner's (citizens') discomfort and a dialog that clarifies the concept of a new social system.

The Social System Design Methodology showed policy makers and practitioners in the field that it is difficult to transform to a new concept if policy makers and practitioners in the field work independently of each other. It then proposes how policy makers and frontline practitioners should co-create activities to transform social systems. Specifically, concept-oriented practices cannot emerge in the

field simply by being included in administrative plans and agendas as language and text. On the other hand, concept-oriented practices in the field alone will not spread the concept to society, influenced by the structure of the existing system. In order to overcome these problems, it is suggested that the project be initiated with the designer's (policy maker's or practitioner's) discomfort as the starting point, and that the analysis of policy background and dialog of questions be conducted in the early stages of the project, and that a team that shares discomfort be launched in the process.

Based on these implications, this study's contributions include overcoming the situation where traditional living lab projects have tended to be partial solutions to specific social problems. The practices of Omuta Living Lab follow this methodology, so the co-creation projects that are launched here consist of practices on the ground in the community, linked to the concept of a new social system. As a result, projects are being created that propose models for future housing, learning, mobility and care prevention, while also staying close to the issues at hand for citizens, and this is where municipal plans and new business development of companies are linked to these activities. In addition, attracted by the concepts challenged by these practical models, researchers and practitioners from diverse fields are visiting Omuta to engage in dialogs or projects.

In other words, Omuta Living Lab's practice is not a living lab that tackles just the problems at hand, nor is it a living lab that explores just new futures (like speculative design (Anthony and Fiona, 2013) or future center (Dvir et al., 2006)), but a living lab that creates the future by identifying the root causes connected with the problems at hand and transforming the problem structure (social system). It could be called a living lab that creates innovation in meaning (Verganti, 2009) for the future.

On the other hand, it is a limitation of this study that this legal theory is built on Japanese practices and cases. Citizenship and the relationship between citizens and society in Japan are contextualized differently than in other countries, and the meaning of the concepts of subjectivity and autonomy are different. Whether social system design methodology is applicable to countries in East Asia with similar human perspectives as Japan, and whether it is applicable to countries in the world different from them, is a subject for further study and discussion.

9. Conclusion

This paper provides a theoretical overview of the difficulties posed by social system transformation and a design logic to overcome these difficulties. It also presents concrete time-series examples to elucidate the practice of the approach, from which a general-purpose social system design methodology was derived. The applicability of the methodology was also tested by analyzing two good examples of social system transformation based on a process model of social system design.

In order to develop this methodology into something more versatile and useful, it is necessary to further elaborate its contents and clarify the leadership required of practitioner's (designer's) and the nature of actual environments. Furthermore, this methodology should never be seen as complete. It is important that the methodology offer "continuous change" in order to respond to major shifts in new values such as the SDGs, based on the fact that modern social systems have

characteristics that tend to move away from an integrated way of being and living.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

All authors were involved in the establishment of the Center for Person-Centered Ningen, Omuta (PONI PONI). All authors involved in the practice of social problem solving projects and the description of their practices.

Acknowledgments

The authors are grateful to Shinji Hattori and Takeo Kondo for the interviews of their practices that contributed hugely to grasping the

details of actual situations and to improve the quality of this manuscript. This paper is a reworked version of the following conference paper presented at the Open Living Lab Days 2022: “The city as a Lab, but now for real!” Re-working open innovation environments for inclusive, green and digital transition through emerging technologies.

Conflict of interest

AK and KM were employed by Co-Designing Institute for Polyphonic Society.

The remaining 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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RECEIVED 16 April 2023

ACCEPTED 31 October 2023

PUBLISHED 30 November 2023

CITATION

Palmer VJ, Bibb J, Lewis M, Densley K, Kritharidis R, Dettmann E, Sheehan P, Daniell A, Harding B, Schipp T, Dost N and McDonald G (2023) A co-design living labs philosophy of practice for end-to-end research design to translation with people with lived-experience of mental ill-health and carer/family and kinship groups.

Front. Public Health 11:1206620.
doi: 10.3389/fpubh.2023.1206620

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A co-design living labs philosophy of practice for end-to-end research design to translation with people with lived-experience of mental ill-health and carer/family and kinship groups

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There is increased recognition that people with lived-experience of mental ill-health ought to be centred in research design, implementation and translation, and quality improvement and program evaluation of services. There is also an increased focus on ways to ensure that co-design processes can be led by people with lived-experience of mental ill-health. Despite this, there remains limited explanation of the physical, social, human, and economic infrastructure needed to create and sustain such models in research and service settings. This is particularly pertinent for all health service sectors (across mental and physical health and social services) but more so across tertiary education settings where research generation occurs for implementation and translation activities with policy and services. The Co-Design Living Labs program was established in 2017 as an example of a community-based embedded approach to bring people living with trauma and mental ill-health and carers/family and kinship group members together with university-based researchers to drive end-to-end research design to translation in mental healthcare and research sectors. The program's current membership is near to 2000 people. This study traces the evolution of the program in the context of the living labs tradition of open innovation. It overviews the philosophy of practice for working with people with lived-experience and carer/family and kinship group members—togetherness by design. Togetherness by design centres on an ethical relation of *being-for* that moves beyond unethical and transactional approaches of *being-aside* and *being-with*, as articulated by sociologist Zygmunt Bauman. The retrospective outlines how an initial researcher-driven model can evolve and transform to become one where people with lived-experience of mental ill-health and carer/family kinship group members hold clear decision-making roles, share in power to enact change, and move into co-researcher roles within research teams. Eight mechanisms are presented in the context of an explanatory theoretical model of change for co-design and coproduction, which

are used to frame research co-design activities and provide space for continuous learning and evolution of the Co-Design Living Labs program.

KEYWORDS

experience co-design, co-design, living labs, lived-experience, mental health, research design, implementation, mental health research translation

1 Introduction

Embedding lived-experience (or what is also termed within the published literature as service users, experts-by-experience, and within government reports/policies as consumers and/or carers perspectives) within research, service design/re-design and systems re-design, and healthcare improvement has evolved into a wider trend of participation called the Participatory Zeitgeist, or “the spirit of our times” (1). This Zeitgeist has been driven by a confluence of social, cultural, political, and economic forces that permeates all sectors and indeed much of our public and personal lives (2). This spirit of our times has led to a dramatic increase in ‘co’ practices and recognition from social, academic, and political circles of the importance of experiential knowledge as evidence-based approaches. However, the extent to which this experiential knowledge is afforded equivalent weighting within the established hierarchy of evidence applied in research, policy, and service design and practice is limited (3–5).

Additionally, the growth in “co” practices has led to an increase in what has been termed co-biquity (6). This has been defined as “an apparent appetite for participatory research practice and increased emphasis on partnership working, in combination with the related emergence of a plethora, of ‘co’ words” (6). Although part of the co-biquity challenge is that many of the participatory methods and practices outlined as co-design or coproduction and other collaborative terms are rarely evaluated against core criterion such as who has been involved, how have people been engaged in collaborative processes of designing together, and what was designed or made for change or implemented as a result. Similarly, it is rare to see an evaluation of the extent to which co-design processes, methods, and outcomes have addressed structural and interpersonal inequalities in power and decision-making (7). Where evaluation material is available, it is largely qualitative interview reports of people’s experiences participating in co-design projects for service improvement (8).

Over a decade ago, authors in co-design fields began to raise concerns over the dilution and conflation of meanings and practices from collaborative traditions and the misappropriation of the terms co-design and coproduction (9). Such broad usage of coproduction and co-design terminology across a range of research disciplines (for example, urban planning, public management, environmental studies, design fields broadly, and education) and within healthcare quality improvement and in service design/re-design, has seen participatory approaches adopted in expansive ways. The pendulum has swung further in the co-design field when looking at healthcare quality improvement practices and what might be termed ‘mainstream’ service design/re-design processes. Where co-design once was defined as “the creativity of designers and people not trained in design working together in the design development process” (10), it has now

come to focus on a central role for people with lived-experience (9, 11).

Historically, published literature has been replete with reference to the concept of “user/s” to define the goal for design to centre user’s needs and perspectives (12). This phenomenon of user participation is not all that new; participatory design definitions and practices have been premised on this also (11). Lucero and Vaajakallio (13) reported that “researchers have started to see ‘everyday people’ not only as the recipients of the artefacts of the design process, but as active participants in the design and production process itself, capable of adapting products to better meet their own needs”. In short, as Steen has argued previously, co-design thus reflects “an instance of moral [e]nquiry...” and a return to pragmatist ethics where the “return to ordinary life-experiences of inherently social, embodied, and historically situated beings” (9) is key.

In the current context of co-design, however, lived-experience-centred models mean more than a workshop with users about the appropriateness or usability of a product or technology, more than the ordinary and situated life experience, and more than user engagement. Quality and service improvement fields quite rightly are about bringing “service providers, service users and other relevant stakeholders [together to] use design tools and methods to work collaboratively to ensure service provision is informed by their shared experiences” (14). In mental healthcare (both in relation to research and to the delivery of care), significant power disparities exist, and indeed human rights abuses have occurred. Thus, active participation through methods that centre experience is essential to ensure that the goals of social justice are met. In this respect, experience-based processes of co-design are core to working with existing inequities and human rights abuses and exploring experiential injustices. The current emphasis on mental health reform, at least in Australia, also means that it is critical to consider how people with lived-experience may increasingly lead or co-lead co-design processes (15). That means there is a need to attend to co-analysis and interpretation of the results of co-design so that epistemic injustices (how knowledge is formed, shared, implemented, and evaluated) are not repeated inadvertently (5). In the shorter term, where co-design is espoused, there is a need for actively attending to how power was re-balanced and where designers were positioned within co-design processes. We need to shed light not only on what happened in co-design but also on what was implemented, where it might have led to change, and what the impacts of this might have been.

While mainstream service design/re-design, quality improvement, and systems transformation efforts have grappled with the implementation of co-design for some time now, there has been less examination of how to configure academic, university, and other research settings to embed lived-experience-centred models for research implementation and translation efforts (4, 12). Given the

hierarchical nature of academic contexts and the diversity of mental health research disciplines, this is challenging, and there is a need to evaluate how lived-experience is being somewhat uncomfortably positioned as an indicator of political and social recognition of inclusion (16, 17). Centring lived-experience is particularly important in spaces where people have experienced systemic injustices and possibly significant harm and have not had the full protection of human rights and recognition of their voices. In these circumstances, people may not have been included in decisions about service design, development, or what programs are offered and how care is delivered. Inclusion alone, however, is not an indicator of political and social recognition. Increasingly, literature is emerging on co-designed interventions or co-design for research projects, and it can be an expectation by funders to illustrate co-design (or consumer and community participation as government agencies word it) in research grants (18). This gives cause to consider the kind of research architecture that is needed to embed lived-experience within end-to-end research design to translation using co-design. It also means we must pay close attention to how lived-experience is understood and included in co-design efforts.

Contemporarily, lived-experience refers to both working collectively with people who have direct experiences of the topic, issues, or problem in focus for co-design and the interaction of experiential knowledge within co-design, ensuring epistemic justice (valuing of experiential knowledge) is achieved (5). It includes attention to the framings for co-design, being clear about what social justice issues are being addressed, and how co-design is explicitly addressing power imbalances (19). In more recent developments in mental health research, suicide prevention, and within First Nations methodologies and Aboriginal and Torres Strait Islander social and emotional wellbeing programs, lived-experience has become key to addressing harms that have been experienced with the removal of rights and human rights abuses. Defining the parameters of lived-experience within co-design has become important, and ensuring lived-experience reflects “direct, first-hand substantive experience of mental distress, illness, diagnosis and/or mental health services. [Or] as associated with Lived Experience of poverty, trauma and other forms of prejudice and discrimination (e.g., racism and ableism)” (20) (p. 3) is fundamental. Publications on the importance of inclusion and lived-experience leadership expand upon substantive experience to suggest that diverse qualities are held and enacted by people with lived-experience, which generate change within and across mental health and social sectors (such as championing justice, centring lived-experience, and building relationships with peers and allies) (17). In the context of Aboriginal and Torres Strait Islander communities, lived-experience is expanded to “recognise the effects of ongoing negative historical impacts of colonisation or specific events on the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples. It encompasses the cultural, spiritual, physical, emotional, and mental wellbeing of the individual, family, or community” (21). Attention to lived-experience has become key to ensuring social justice and issues of inequity, and structural inequalities are in focus within co-design.

In the Co-Design Living Labs program and its philosophy of practice, lived-experience is described and applied as “community-led lived-experience.” This means that people engage as members of the program (referred to in our current day-to-day activities and

engagements as co-designers) with their direct, personal experiences of mental ill-health and service systems or support expertise as carer/family and kinship groups. Importantly, there may also be nuances and elements of lived-experience located from identities in community stories, events, and happenings that are critical to the framing and shaping of experience. Therefore, conveners of co-design aim to always work closely with how the communities we are collaborating with shape and define lived-experience from the perspectives and positionalities of people within co-design. Community-led lived-experience thus acknowledges a need to recognise framings that may encompass cultural, social, and political differences to direct experience. This includes attention to the appropriateness of methods that are adopted within co-design.

This study outlines the establishment and evolution of the Co-Design Living Labs program and its philosophy of practice within The University of Melbourne between 2017 to present. It documents the establishment and transitions of the program from researcher-led to increasingly co-designer-led over this period. By philosophy of practice, we refer to the values upheld in our study, the roles and responsibilities of our ways of working together for change in implementation and translational research, and the component parts required for the operationalisation of the program. We call this philosophy of practice “togetherness by design.” The philosophy of practice couples theoretical work from sociologist Zygmunt Bauman’s articulation of three forms of togetherness: being-alone, being-with, and being-for (22). Co-design is understood as the “co” equating with togetherness and therefore the practices being about “designing together.” However, in keeping with co-design traditions, designing together means thinking about both what is made and how that making attends to social justice. It includes an evaluation of supported and shared decision-making processes that were applied and how power imbalances were addressed as they play out in the living labs’ tradition of open innovation and collective empowerment (23).

2 Materials and method

The Co-Design Living Labs program was founded within the Primary Care Mental Health research group in 2017. The program is now expanding as part of a national network in the ALIVE National Centre for Mental Health Research Translation funded by the Australian National Health and Medical Research Council 2021–2026 (GNT2002047) as part of a Special Initiative in Mental Health. The ALIVE National Centre’s mission is transforming mental health and wellbeing through primary care and community action. Its vision is for vibrant communities that support mental health and wellbeing to enable people to thrive. There are currently 17 university partners engaged in the Centre’s work, with membership growing across three networks supporting research program implementation and translation. The Centre grows lived-experience research capabilities within a tailored arm of a Next Generation Researcher network called the Lived-Experience Research Collective. An Implementation and Translation network is focused on growing capabilities and a national infrastructure to support adaptive co-design, demonstration projects, and promising models. The Co-Design Living Labs network will connect co-design programs across universities to expand end-to-end research design to translation. This builds on the aim of the

Co-Design Living Labs program to create a purposeful space for people with lived-experience of mental ill-health and carers/family and kinship group members to co-create research and translation activities. Since its establishment in 2017, the program has grown from a membership of 600+ people to current membership of nearly 2000 people across Victoria and other states and territories of Australia. In this retrospective, we mark the transitions from an initially researcher-driven operational model set up by the lead author, who has lived-experience of mental ill-health (24), to one where co-designers now identify priorities for research and where their perspectives are shaping the research questions and approaches that are developed. It is important to acknowledge that the personal experiences of the lead author in navigating the re-definition of self that comes with lived-experience was a key motivator for program establishment. This included a view that there was a need to improve community-led mental health research and for better engagement processes in university-based research (25). These foundational values mean that lived-experience has shaped the co-design practices and processes undertaken since inception. More recent transitions in the program now include that co-designers have moved to co-researcher roles (which we will explain later) and an Aboriginal and Torres Strait Islander co-design research lead has been appointed in 2021. This study does not outline the transition to the inclusion of Aboriginal and Torres Strait Islander-led work; this will be detailed in a separate article illustrating the role of Indigenous Knowledge Systems whereby co-design may be articulated with different cultural practices (26). The future goal is that co-designers in the current program will adopt the living labs as a social enterprise utilising cooperative, democratic structures to maintain a commitment to the important issues of justice, power, and shared decision-making. This would support co-designers to drive the research agendas and co-convene the activities of the program with direct fiscal benefit flowing to them.

2.1 Recruitment to the co-design living labs program

The Co-Design Living Labs program membership base was grown by inviting former research participants (people with lived-experience) from completed mental health research studies to join. Two longitudinal studies were completed in the primary care mental health research program in 2016 and 2017: (a) a world-first stepped wedge cluster randomised trial (9) of an adapted mental health experience co-design approach for service improvement and psychosocial recovery outcomes, with 287 people living with conditions described in the literature as severe mental illness (herein referred to as mental ill-health)—the CORE Study (2012–2017) and (b) the diamond study (17) exploring over 700+ people's experiences of living with depression and health services use (2003–2016). Completion of these flagship studies provided a turning point and an opportunity to shift away from what may be characterised as transactional research processes and agendas to relationally oriented practices.

2.1.1 The adoption of a living labs approach

The living labs concept was identified as an open innovation pathway for mental health research to build on cooperative traditions

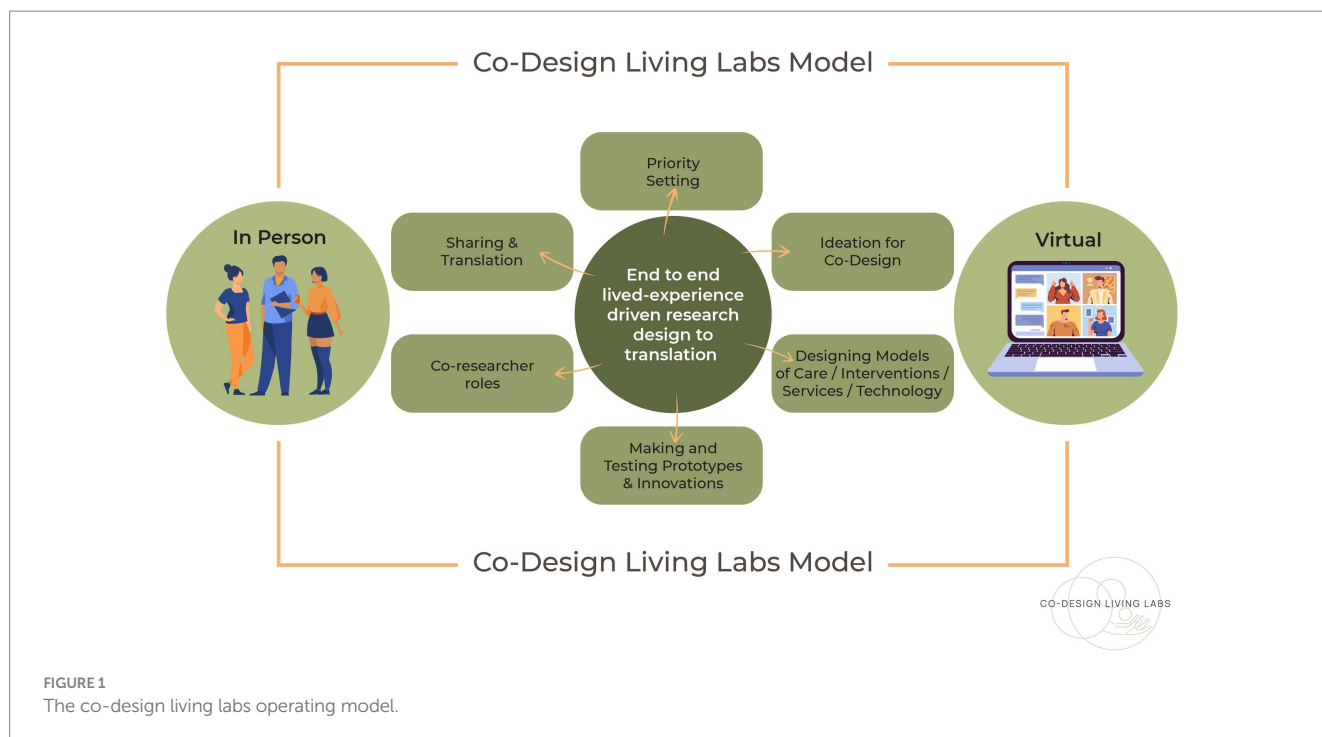
and relational practices. It was adopted with a view to a future cooperative structured social enterprise being established from the program, as mentioned in the above section. Additionally, we sought to disrupt the idea that research practices located within a medical setting are only about scientific lab-based research, which has historically been characterised as having limited engagement of the public. Living labs in these environments have also tended to foster a test bed model where users are the objects of study rather than co-creators (12). Here, the term living lab was adopted to signal life, living, being alive and dynamic, and the importance of working with people in medical and health research activities every day with lived-experience. Bringing co-design and living labs together enabled the program to foreground social justice, power, and shared decision-making in activities.

In the literature, four key traits of living labs have been described: (1) a purpose to innovate products and services; (2) co-creation with users; (3) completion of activities in real-life settings; and (4) fostering public–private partnerships (27). These traits are essential where the focus is on innovation and co-creation, and they enable our program and future network-based activities to effectively operate an *anywhere, everywhere living laboratory* focused on real-life settings. This fits with the European Network of Living Labs (ENoLL) definition of living labs as “user-centred open innovation ecosystems based on a systematic user co-creation approach, integrating research and innovation processes in real-life communities and settings” (28). Our approach, however, expands the living labs’ tradition from a grounding in social innovation, partnerships, and open approaches to operationalisation of these factors within a lived-experience context. Therefore, we intentionally brought together the practices of Co-Design with Living Labs for the naming and setup of the program (19, 29).

In this relational form of engagement, the goal was to ensure lived-experience became embedded within the priority setting of research grant proposals and the establishment of research questions. This included the ideation on component parts of these grants or other innovations, the co-creation of new models of care (also termed interventions in the health sciences literature) and healthcare technologies and processes, and the making and shaping of prototypes (using paper to technology-facilitated approaches, and with co-research and dissemination and communication). These aforementioned goals form the foundations of the Co-Design Living Labs operating model, which is presented in Figure 1.

In the next section, we provide an overview of the evolution of the Co-Design Living Labs philosophy of practice called ‘togetherness by design.’ This philosophy of practice connects the ontology of our study (our ways of being together) with the epistemology of our study (how knowing shapes experiential knowledge and coproduced knowledge) and the doing (the practices for how we work together). Ideally, these ways of being, knowing, and doing shape ways of seeing through the implementation of the ideal relation of being-for (explained next). In Table 1, the component parts of the Co-Design Living Labs program, within which the philosophy of practice is operationalised, are detailed.

We describe the evolution of the program with reference to selected examples of co-design activities undertaken during 2017–2022; the full overview of co-design conducted between 2017 and 2022 is presented in Figure 2 also.



3 Results—development of a philosophy of practice “Togetherness-by-Design”

3.1 Ontology—ways of being

As noted earlier, the implementation of our philosophy of practice hinges on a specific commitment to ways of working and being together that draws on three forms of togetherness. These forms of togetherness were originally outlined by Zygmunt Bauman and drew heavily on the work of philosopher Emmanuel Levinas (22). Bauman described the forms as being-aside, being-with, and being-for. These are types of relations exist in our everyday worlds and can be practiced (and not practiced) between people. The three forms of togetherness provide the program with a guide to how we work collaboratively with co-designers and partners of our program.

To understand what is meant by the being-aside relation, it is helpful to think of a physical space that is shared between two parties or entities (beings). In this space, these entities may indeed be co-present, but there is no recognition by any of the entities that the ‘other’ is there, has any importance, or is even “person-like”. This relation can be seen, for example, when people get on and off public transport. There is shared space but no recognition of each other; we move aside and move on. Being-aside offers a way to understand inhumane engagements characterised by people occupying physical spaces aside from each other but not seeing or acknowledging the person, the identity, or experience (30). There is no sense of need for this recognition nor associated connection in being-aside relations. It leaves people feeling deeply isolated and disconnected from each other; unseen, unheard, and unknown. For this reason, being-aside is an important relation to be aware of in ways of working in co-design—it might even be said to be the antithesis of co-designing together.

In contrast, being-with relations advance beyond the reality of occupying space together towards some recognition that there are others around us. Unfortunately, in being-with relations, this recognition is based largely on interests. Being-with, according to Bauman and his use of Levinas’ notion of the Other, is an encounter of ‘no more than the topic at hand permits’, and once exchanges have been made, nothing more evolves or continues; no more of the self is given to the encounter than the transaction that underpins it. At a community level, being-with is played out at the shopping centre with short hellos, exchanges of money for products, and a departure from the setting without further thought given to the encounter or those within it.

The ideal form of togetherness, according to Bauman (22), is being-for, where people and beings are honoured as contributors to relationships regardless of the status they bring. In being-for, actions are always oriented towards a dialogical connection—that is, my story is connected with your story, but it is not my story to share, it is always incomplete, and I can never close this off. This is a relation we share in and should be seen as beyond individual one-to-one notions of engagement and expanded to communal worldviews. In Levinas’ conception of the Other, it is a totality that can never be entirely and fully known, but it is a relational connection that persists beyond time and space. For Bauman (drawing on Levinas), one must *be for* the Other before one can *be with* the Other (31). This means seeing the face of the Other and coming to share responsibility with each other.

As a philosophy of practice, togetherness by design enables the Co-Design Living Labs program activities to move from the transactional space of being-with to enact being-for as the relational goal from which we work together with co-designers and communities beyond the university. This contrasts with the way communities have traditionally been invited to participate in research, which has largely been more reminiscent of Bauman’s concept of being-with. Sadly, in

TABLE 1 The component parts of the co-design living labs program and future network.

The component parts of the co-design living labs program and future network	How the component parts are implemented and operationalised
Membership	Invitations are sent via completed mental health research projects. We ask for information such as name, age, gender, contact details, lived-experience context, preferred modes of contact. When people join the program and network we refer to them as co-designers rather than members to develop relational ways of working. Co-designers are from different backgrounds and across the life course.
Registry/database	A registry/database is maintained by a trained data manager using Redcap. The database is used to track who is invited to co-design and who attended co-design annually. It is used to share invitations to co-design or priority setting or other co-design activities. In our registry we have more details that enable us to match co-designers with topics and we can identify when people may not have engaged for a while.
Onboarding/orientation	New co-designers receive a link to the co-created Living Handbook. This is 'A handbook by and for working with co-designers'. The examples of co-design within the handbook are also updated to stay current. People are sent an introductory pack and encouraged to introduce themselves as new members in a co-design session.
A Living Co-Designer's Handbook	The living handbook is called such because it is added to by new co-design co-leads and people as new information is needed. This includes the history and overview of the Co-Design Living Labs program and now national network. The handbook includes preparatory and post co-design self care tips from other co-designers. There are preparatory questions that have been established for people to complete ahead of attending co-design which ask for information about gender, preferred communication modes, and receiving information. An Aboriginal and Torres Strait Islander version of preparatory questions is also included and our working together agreements (also called Principles of Participation) are included in long written form.
Continuous engagement/relational engagement	Co-designers receive support from our Co-Design Living Labs coordinator and network research lead to attend sessions through taxi vouchers when attending in-person or zoom support/instructions for online co-design. Supportive phone calls can be made for further explanation of what to expect in co-design. If we have not heard from people for a while we phone to invite to co-design and to re-establish connection. Regular updates are shared by co-leads of the program and network every second month. An annual newsletter is sent to all members electronically and in hard copy. An Open House drop-in was established more recently in 2023 to facilitate connections across membership and co-lead groups.
Convening co-design virtual and in-person	We operationalise our philosophy of practice 'Togetherness by Design' through using our working together agreements, ensuring boundaries are set and members feel safe enough. Only selected convenors and consistent core team group convene (rather than people coming in and out of convening who are unfamiliar). People with shared lived-experience are the ideal convenors but where this is not possible we co-partner in the approaches. Co-design convenors used narrative methods, participatory approaches and are informed by different design approaches and design thinking techniques. A majority of co-design is conducted virtually enabling wider participation across the nation. We use a digital whiteboard to facilitate online co-design.
Co-learning and knowledge transfer strategies	All outputs from co-design are shared back to co-designers for further feedback. If a project is completed, co-designers receive an update on this and a link to the new Co-Design Living Labs network pages online for sharing stories to encourage co-learning and knowledge transfer across settings.
Respect for time contributions	Co-designers are always reimbursed following our paid participation policies within the ALIVE National Centre for Mental Health Research Translation. We will always reimburse for co-design meetings (called sessions) and co-researchers are appointed as paid casual researchers, or as research fellows and associates within the university system.
Co-leadership model	The national network is led by co-designers who form co-lead groups across the 17 university partner nodes. Capacity building is provided through co-lead roles and mentorship is supported by existing co-design research staff within the team. Capacity is being developed further through a specific Co-Design Trainee Award program to foster leadership from within co-designers.
Evaluation/Expanding our explanatory theoretical model of change for co-design and co-production	Continuous feedback after each session on co-design facilitation and processes. We use our established explanatory theoretical model of change for co-design and co-production to evaluate co-design process and outcome. The eight mechanisms of change identified within the theoretical model help guide the processes used within co-design (as articulated in the working together agreements) and the whole theoretical model of change is applied for evaluation.

some instances, being-aside has also characterised research endeavours where there has been active exclusion, avoidance, and lack of engagement with some communities. Togetherness-by-Design, with its orientation to being-for, also enables us to share unconditional responsibilities for and with each other.

To create the conditions for change and a commitment to being-for, eight mechanisms of change are employed to set relations and evaluate Togetherness-by-Design. These mechanisms are presented in Figure 3 and have been adapted from an existing explanatory theoretical model of change for co-design and

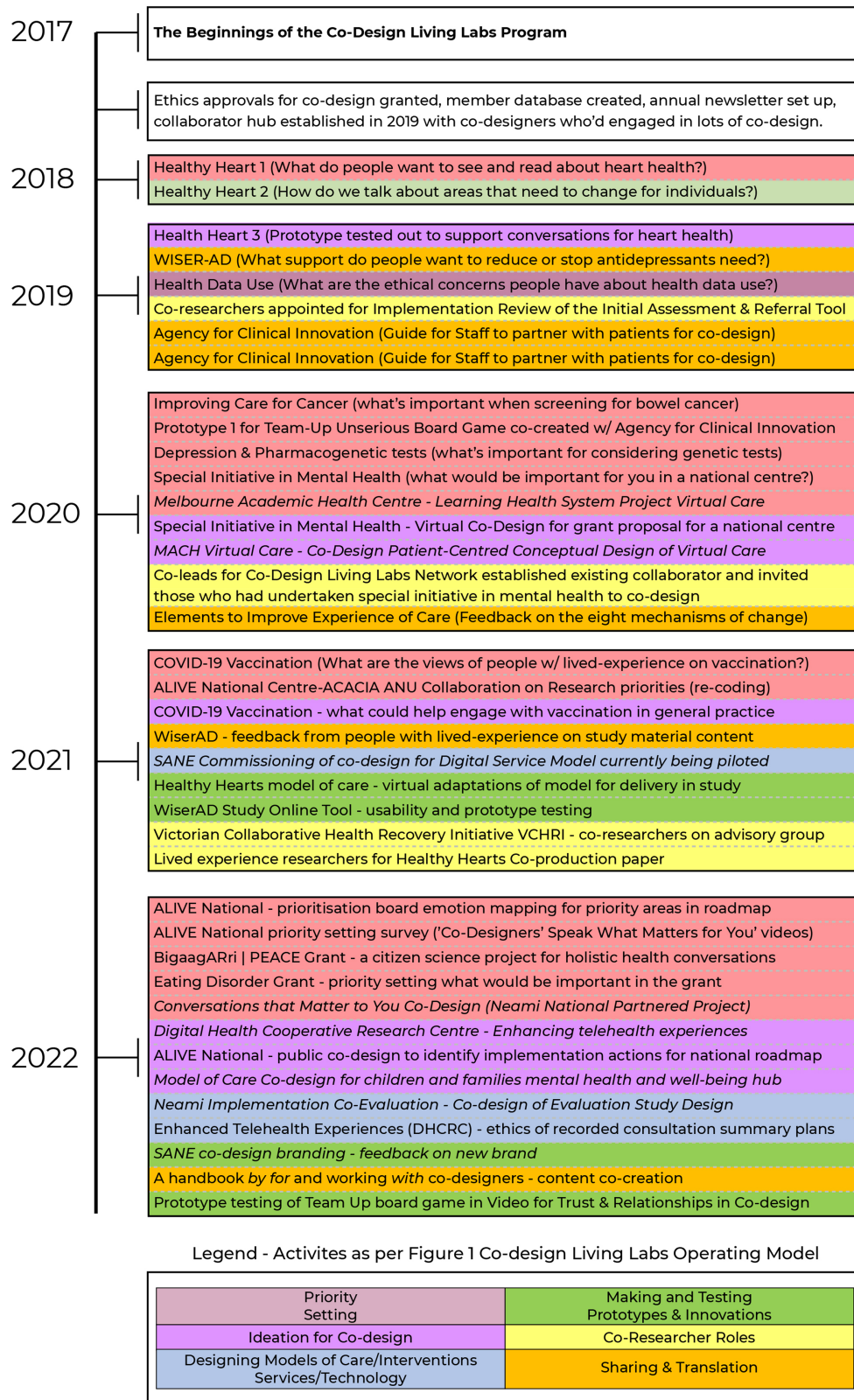
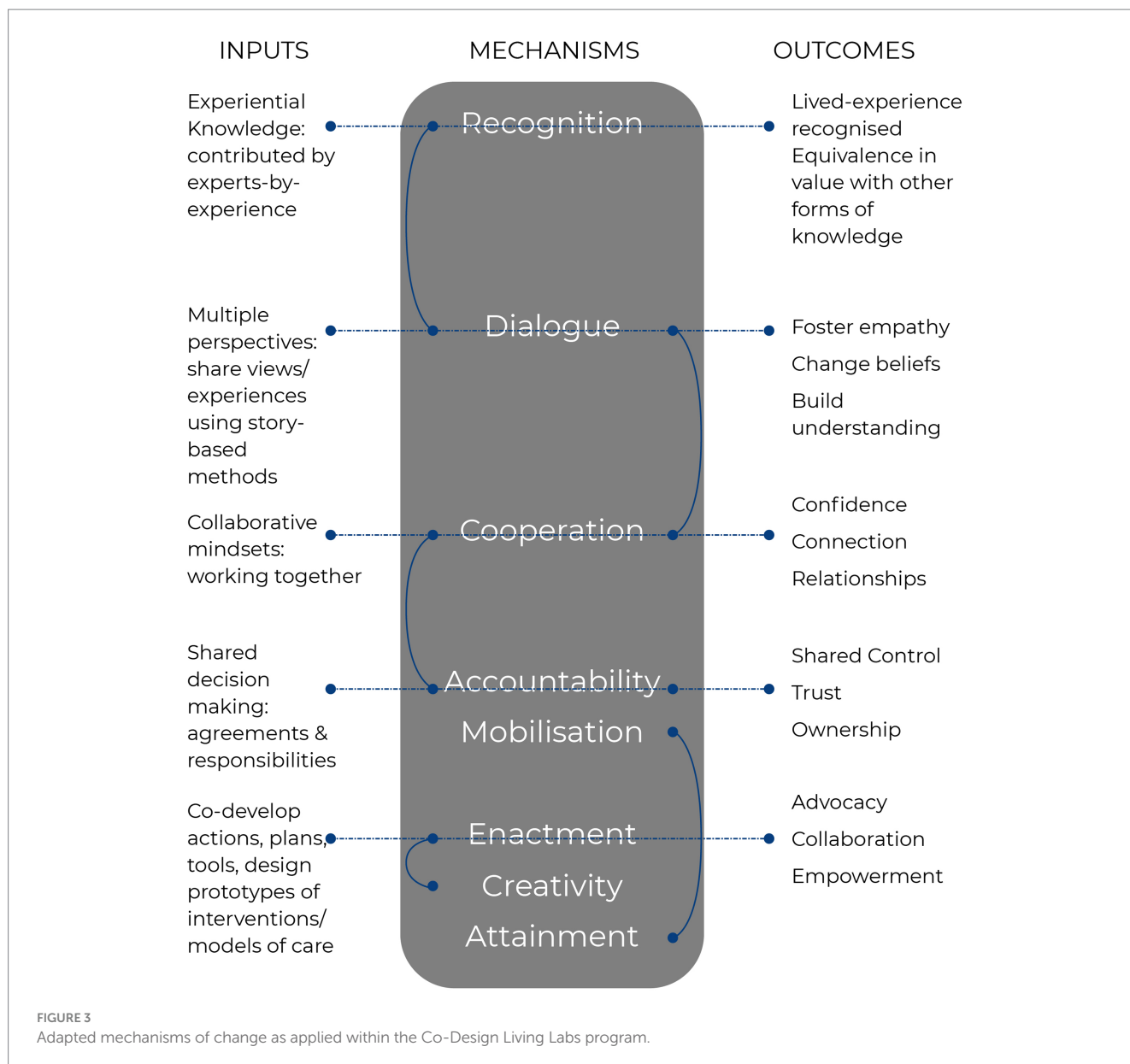


FIGURE 2

The evolution of end to end research design to translation activities in the co-design living labs program (2017–2022).

coproduction in healthcare improvement (1). The mechanisms have informed our working together agreements that we articulate in each co-design session for creating safety and shared understanding

for co-design. Coupled with the theoretical model, these mechanisms can also be used to evaluate co-design processes and outcomes.



The Co-Design Living Labs philosophy of practice thus expands university–community relationships beyond transactional one-off research engagements where they are based on no more than the topic at hand permits (25). Evaluative evidence from 11 of the co-designers, who contributed to the development of the conceptual design for a digital service model for people with complex mental health needs (32), suggested that the practice of ‘Togetherness-by-Design’ does foster connections and dialogical relations consistent with the goals of being-for. The co-designers comprised both existing members within the program and people external to the program who were invited from partnered organisations also. The co-designers, when they were asked about the sessions, said: ‘people felt that the group members did not talk over each other, people did not have to compete to feel heard, everybody had a chance to talk, the group was accommodating of a diversity of experiences, the ways of working were open, respectful, and the activities using pictorial descriptions to talk about experiences

and ideals were valued’. Co-designers who provided this feedback also added that, for them, ‘feelings of empowerment were fostered by their voices being heard, the engagement was enjoyable and met their hopes for coming to co-design’. The hopes people said that they had for engaging in the co-design included ‘the importance of being a part of solutions, creating positive change, creating better services and sharing experiences, and that a new set of ideas that others may not have thought of may emerge’. Importantly, the feedback included aspects of discomfort and challenges that co-designers had observed. Some co-designers sensed anger within the group, but the comments on this indicated that they remained comfortable expressing their discomfort around this without needing to close-off the anger or other person’s experiences. This illustrates the operationalisation of being-for as part of our togetherness as, despite conflict, the group managed to still see each other in all the forms of human expression and be in that together.

3.2 Epistemology—how knowing shapes experiential knowledge and coproduced knowledge

Togetherness-by-Design is further enacted by applying being-for to ways of knowing. Here, lived-experience is seen as a form of knowing that is essential to what is coproduced. The Co-Design Living Labs program has grown from following experience-based co-design in the early establishment phases to employing Togetherness-by-Design in its practices and processes. Originally established by Bate and Robert for service and quality improvement (33, 34), experience-based co-design (EBCD) commonly refers to two stages in a service or quality improvement process. Stage one is information gathering and stage two is co-design; these two stages are interconnected and integral to each other, so they should not be seen in isolation. What is important to highlight here is that the methods used to understand and elicit experience within experience-based co-design are deeply centred around narrative, participatory methods, and learning theory. Narrative is key as it centres on how socio-cultural contexts matter in identities and as a method; it values identity as central to the experience. Experience-based co-design enabled the program to enact being-for as a relation instead of falling to other methods where being-with might be the norm. An example of this might be in research activities where we ask for no more than the topic at hand permits. For example, structured surveys might be a case in point where often, when views have been exchanged in a question-and-answer format and submitted, the interaction is complete. The engagement is momentary and passes; nothing more occurs beyond this transaction, and often further interaction and engagement are discouraged in the style of survey administration. With experience-based co-design and its emphasis on narrative, we have fostered dialogical approaches to connect with peoples' stories, identities, and values.

As indicated above, the Co-Design Living Labs program has therefore been shaped by narrative, learning theory, participatory, creative arts, and visual methods to elicit and shape experiential knowledge for co-design. This has ensured that experiential knowledge is key to what is made and shaped. The central focus on coproduced knowledge reflects the enactment of being-for as our relational way of working. The program also importantly builds on the living labs tradition of open innovation, collaboration, and partnerships across community, industry, and government to achieve this ideal (35, 36).

In the Co-Design Living Labs program, experiences, therefore, foreground and shape all activities, and our goal is for an epistemology that elevates experiential knowledge so that it is afforded what Fricker termed "epistemic justice" (37). In this respect, we are interested in how justice in the context of knowledge can be both discriminatory (how experience is valued, heard, and acted on, for example) and distributive (how goods are distributed, for example, through information sharing or education) (37). Justice also operates within the knowledge production processes of research and the institutional settings where it is carried out. Therefore, embedding co-designers within the leadership of the program and the now national network has been important as a strategy for the distribution of justice.

Our study indicates that experience is a fundamental first premise, and this is noted within the eight mechanisms of change (as presented in Figure 3) as essential for shifting to novel interventions and models of care that can facilitate lasting change. This means the experience

drives not only what is improved in healthcare or other settings but also extends to what is researched, the research questions, and the research process from the study design to the translation processes; experience is embedded within the fabric of the program of study. This is shown in the Figure 1 model of operation. Although, critical measures of success must be about more than togetherness. They must necessarily move towards evaluating if the implementation of co-designed research projects and models of care is effective. The questions must be asked as to whether co-design results in structural and systemic shifts in power, addressing social injustices and ultimately creating better healthcare experiences and outcomes.

The Co-Design Living Labs program mirrors many elements of the arrival of the era of coproduced knowledge (38). This era of coproduced knowledge is seen as a push towards the valuing of experiential knowledge equally to that which is generated through medical and scientific positivist-focused research. Expertise based on experience has often been neglected due to the associations of subjectivity, the view that individual perspectives may be potentially biased and too subjective, and the complexity of experiential knowledge (39). Sociologist Borkman (40) referred to "experiential knowledge" in the 1970s as "the truth based on personal experience with a phenomenon." Experiential knowledge is described as holistic and emerge from the multi-faceted and ongoing experiences of living with a particular condition or experience (41). Our philosophy of practice acknowledges that different forms of togetherness bring multiple ways of knowing; what is key is to share in the understanding of these for future change. This means honouring community-led lived-experience and ensuring this knowledge is at the heart of co-design practices.

Our enactment of being-for to coproduce knowledge and new systems for implementation research was most recently demonstrated in the vision for the ALIVE National Centre for Mental Health Research Translation, for which a short case story can be read here.¹ Following the funding scheme being announced for the ALIVE National Centre, we sought to establish what the research priorities for our co-designers might be to ensure the grant proposal reflected the priorities of people with lived-experience of mental ill-health and carer/family kinship groups. To do this, three open-ended questions were circulated to co-designers by email as follows:

1. What would be important to you in a national research centre dedicated to mental health research?
2. What are the main areas you think researchers should be looking at in mental health? What are the vital signs that we should be doing better in within mental health?
3. How would you like to be involved in a national centre, for example, would you participate in training activities for research, workshops about mental health research, meetings to network and grow expertise, or would you want to be trained to be a researcher?

The email request was circulated for 2 weeks, and priorities were read by the lead for the Centre proposal (Palmer) and two researchers

1 <https://alivenetwork.com.au/our-networks/co-design-living-labs-network/case-study/case-study-2/>

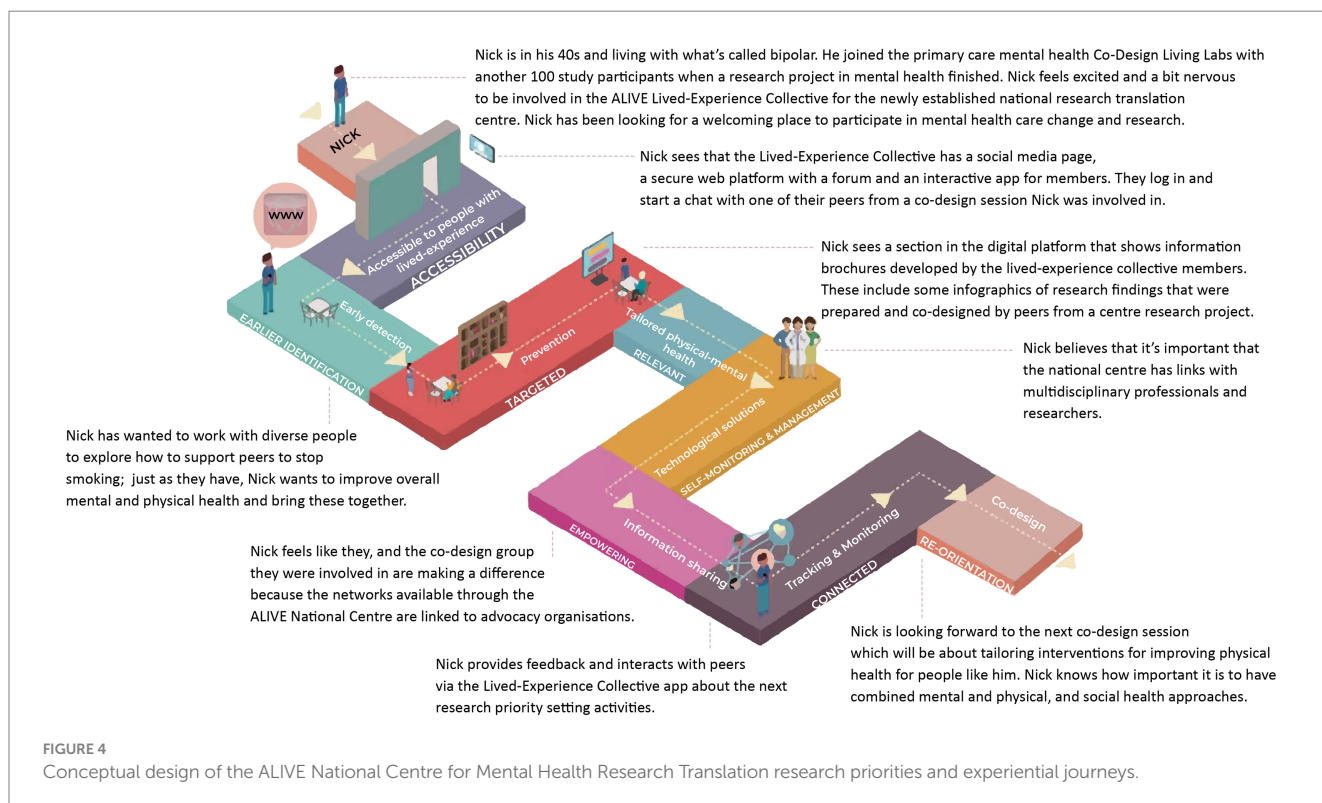
within the Primary Care Mental Health Research program. Responses were organised into thematic statements to formulate the research programs and their objectives. The overall experiential journey that someone with lived-experience of mental ill-health might have in the ALIVE National Centre was co-designed with 27 co-designers in three further ideation sessions. Of this group, eight co-designers were then named as co-leads within the grant proposal. Figure 4 presents how the thematic statements and priorities for research were translated into an ideal journey of a co-designer called Nick for the Centre's proposal.

The pathway Nick takes shows the research priorities as the foundational blocks of the path and the experiential elements that were ideated on within co-design meetings along the top of the path. These experiential elements for the ALIVE National Centre included accessibility of services, early detection, prevention, tailored physical and mental health responses, technological solutions, for information sharing, tracking, and monitoring, and co-design. The research priorities (foundational blocks) were articulated similarly for the goals of delivering at-scale mental healthcare. The goals included accessibility, earlier intervention, prevention, targeted, relevant, self-monitoring and self-management, empowering, connected, and reorientation. Importantly, this is an assemblage of a range of people's priorities and views constructed for grant purposes, and we note that experiences rarely ever mirror a neat linear path. The desired journeys articulated by people with lived-experience through the ALIVE National Centre are shared in the text as an example. This ideation and shaping of a Centre vision reflect coproduced knowledge in action whereby people with lived-experience have set out priorities and the experiential journey within the Centre, and this has subsequently been implemented within the Centre's establishment and operationalisation.

3.3 Practice—ways of doing and undoing co-design

Ways of being and knowing that privilege being-for are critical to how we practice co-design in the program. We recognise that some existing tools and techniques for co-design need to be evaluated for whether they support these ideal relations (42). Currently, the processes and techniques within the Co-Design Living Labs program draw on participatory design practices, narrative approaches, participatory action research, visual methods, and creative arts-based methods (43). However, this still means that design methods need to be continuously re-evaluated and appropriate cultural framings applied. There must be a critical evaluation and expansion of the kind of co-design techniques and processes used. It is important to also implement ways of undoing co-design. For example, we critically evaluate whether personas are essential to the co-design processes given that there are risks of these being unintentionally stigmatising with stereotypical representations. To ensure cultural security and intersectionality is respected within co-design, all methods require rigorous evaluation and consideration of appropriateness for identities and existing knowledge systems—being-for the other precedes working together.

Implementation of Togetherness-by-Design has seen the program shift its language use from Co-Design Living Labs program members to 'co-designers', as explained in the introduction. This is an important signification of collaborative relationships, where power can ultimately be shared rather than represented as a member–researcher relationship, signalling a transactional value system. Researchers within the program have had to unlearn and shift beyond the terminology of research subjects or participants and see people as they are, as individuals who bring their life stories and experiences to support research design and



translation activities. This has been an important step in moving from researcher-initiated processes to increasingly co-designer-led approaches. In valuing experiential knowledge and contributions, we therefore seek to recognise this in authorship practices and, in the longer term, in moving to a community-owned (social enterprise) model. The recognition of contributions and co-creation currently varies from the co-created pieces generated. Many co-designers prefer the use of first names only in some outputs to retain privacy or protect safety where they may be survivors of abuse, intimate partner and/or family violence. Some co-designers have become co-researchers within research teams and others also contribute actively to paper writing, editing and crafting work. Others are named on research grants as co-investigators and not solely as advisory group or committee members or as associate investigators which can be a dominant research practice. Co-designers are always reimbursed for their time contributions to co-design sessions—illustrating the importance of resourcing within the architecture and the component parts of the program (shown in Table 1). The role of the facilitators (or conveners) is to support engagement in co-development, to provide explicit frameworks, to share decisions and facilitate power-sharing arrangements, and to co-design and then use this to synthesise and develop either a set of design principles or a tangible artefact or model of care as required. At a deeper level, operating in a being-for relation also means changing our relational ways of connecting inwardly and outwardly for change to be sustained.

Co-design sessions have largely used whiteboards (digital whiteboards when virtual—a lot of co-design has been online since the COVID-19 pandemic onset in 2020). Experience and journey maps have been co-created and explored through facilitated group discussion, and final outputs were created by using emotion mapping within processes. The activities used within co-design sessions are usually selected to be matched with the co-design objectives and the experiences of people in the room; it is important to reiterate that our ways of doing are constantly in motion and changing. These reflect the evolutionary trajectory of the program over time. In current practices, many linear maps have been replaced with circular models reflecting how people with lived-experience engage in story-telling and sharing their experiences. Table 2 presents some greater detail of the adapted methods that were used within co-design sessions of the new digital service model for SANE Australia that the ALIVE National Centre for Mental Health Research Translation conducted with an explanation of why these methods were used. These methods are overviewed in multiple articles but Milton and Rogers' research methods in product design succinctly describes them (43). The table illustrates how these were adapted within our co-design approach.

The commitment to co-creation and genuine/equal collaboration within the Co-Design Living Labs program extends to the data analysis stages of research and co-designed outputs, as well representing our being-for commitment to epistemic justice. To facilitate this, conceptual designs are shared with co-designers and expanded upon before delivery to partners. This is in keeping with fostering shared decision-making throughout co-design processes so that people are making choices about how input is configured and shared; this, in turn, embeds lived-experience at the heart of the conceptual designs and outputs. The Co-Design Living Labs program has ongoing ethics approval from the university human research ethics committee, which enables co-design to

be responsive and iterative. This provides us with the capacity to run a continuous model of co-design to service the Australian mental health sector in the future and to embed lived-experience within research and improvement, re-design, and change efforts in implementation and translational research. Since we commenced in 2017, we have evolved working together agreements from our eight mechanisms of action (as noted in a previous section, and referred to as well as principles of participation), which are shared at the commencement of each co-design session (8). The eight mechanisms are part of an explanatory theoretical model of change that enables our program to enact continuous learning and evaluation of activities as well. Figure 3 details these adapted mechanisms within the program.

3.4 Ways of seeing—continuous learning and expansion of the program

The theoretical explanatory model of change enables documentation of experiential knowledge as a central driver in changing mental healthcare systems and to appreciate the concept of recognition as critical to change (44). It is important to also note that while the eight mechanisms appear neatly listed, they are not hierarchical and always remain interconnected—the intent is not for a usual program logic pathway that follows a, if this, then that, will result. In this respect, recognition and dialogue are critical to the shared understanding of narrative and storying, and the acknowledgement of polyphony (many voices) within co-design. Cooperation is then enacted through the sense of solidarity for communal causes, working together, and developing a shared agenda for making change. Accountability enables the shared agenda for change to grow through motivation as a group and agreeing to mobilise to make change happen. In this model, the co-development of actions must be accompanied by enactment of these actions with creative implementation to attain change. Actions without implementation lead only to more co-designed ideas without lasting change.

4 Discussion

The establishment of a Co-Design Living Labs program and the evolution of its philosophy of practice have been described in this paper. Using examples of co-design that have been undertaken, we have outlined the philosophy of practice for the program, Togetherness-by-Design. The key purpose of the Co-Design Living Labs program is to ensure that lived-experience is at the heart of mental health research, service design, delivery, improvement and evaluation, and research translation. Having recently celebrated its fifth year of operation, this article has shared the retrospective story of the evolution of the program. It has illustrated how Togetherness-by-Design is enacted across the model of operation by a commitment to being-for as an ideal relational ethic that shapes the ways of being, knowing, and doing in our work. The program architecture has resulted in component parts of the program that are fundamental to the realisation of our vision. These component parts have included a research-managed registry/database since inception, which has

TABLE 2 Ways of practice – examples of design activities used in the co-design of a conceptual model of care for a digital service model for people with complex mental health needs.

Aim	Co-design method/s	Purpose/application
<p>Understand current experiences in the service system and future ideal. To surface negative feelings and experiences early for setting out foundations to work together. To create a sense of a future space to work toward.</p> <p>Understand a technology (program, app, website) or general use of digital health in people's everyday life.</p>	<p><i>Photo Artefacts –</i></p> <p>Here, people are asked to provide ahead or bring to the start of a session, an image or to take a photo in their local community that they feel could help to describe the current mental health system. People are also asked to include a photo of the future ideal system.</p> <p><i>A Day in the Life –</i></p> <p>Mapping exercise used within co-design session to identify where, when and how (if at all) technology or digital health broadly may be used in day to day life. Outlines a clock and provides time for anchoring when usage occurs and for what reason people are using the technology.</p>	<p>This activity is set out ahead of a co-design session. It is ideal because it does not take people long and they can bring an existing image from home or take one for the co-design. Helps to generate an understanding of service system views from individuals and across the group. Helps to surface negative views and possible experiences within a system to inform what not to re-design or current sticking points. Asking for an ideal photo with current system scaffolds activity with a sense of future change. Helps for introducing self and others as focus is on image and not the person too.</p> <p>Orientation toward the kind of technologies used and within the day to day of people's lives, indicates the areas where there is good and not so good fit. Helps to create a picture of enablers and challenges for the new service model or technology and what kind of ways people might engage with this – and what kind of needs people might have to be supported to use technology or digital health further.</p>
<p>Eliciting the desired experiential goals/values of models of care or new service models or an intervention and new product.</p>	<p><i>Emotion Maps—</i></p> <p>Use a journey board/map to capture experiences and the touch points through service journeys. The positive and negative experiences are shared through the journey map and this enables people to share strong and not so strong feelings about these experiences. The process can result in identification of consensus within groups on the negative experiences which indicates the areas for change.</p>	<p>To elicit the service journey touch points (the places people come in touch with different parts of the service system/organisation or topic, which shape experience positively or negatively) – illuminates values and experiences of people and leads to the identification of the experiential goals of people with lived-experience for conceptual designs.</p>
<p>Identifying and co-designing the services that people would like to access in a model of care or new service.</p>	<p><i>Menu of Services—</i></p> <p>Placing ideas of services into a menu format and using the entrée, main, and dessert to organise service features from entry to the service through to follow up. This is a beneficial approach because it creates themes of nourishment, working together collectively, and all being around the table to share in service identification.</p>	<p>Identification of service elements that people are seeking and concepts of importance. The type of groups, the accompanying services, planning support and features all enable the development of the foundations of conceptual design. The concept designs usually draw additional material together from other activities undertaken within co-design—for example, they bring together emotion map desired experiential values and goals and service concepts to be visually represented together.</p>
<p>Identification of choices between core service concepts to inform the service design and development.</p> <p>Expanded model of care for implementation</p>	<p><i>Card sorting—</i></p> <p>Prioritising services that can be included or features of services. Working together to think about the component parts of the core service concepts and what choices may need to be made.</p> <p><i>Film review—</i></p> <p>Short film roll approach showing the journey exploration through different representations of people's goals, desires and experiences shared. A digital story is also co-created here to share the journey together.</p>	<p>Formulating further the preliminary design concepts and principles of the service model and understanding what is most important to users. Enables shortlisting if needed and consensus based conversations.</p> <p>Sharing the service concepts and component parts with different groups who will be responsible for implementation to ensure that the experiential goals are shared and to identify divergent points of view. Digital story for further co-design and a focus on what strategies might be needed to support implementation into practice, system and services. Digital stories help to remind people of the co-design journey that has been undertaken and the core touchpoints that were identified including providing evidence that experiences are shaping the new model or technology, and voices being incorporated alongside providing potential for celebration.</p>

facilitated continuous replenishment of the membership base and coordination of activities in a structured approach. Having a coordinator to invite and support people to come to co-design, whether in person or virtual, has been a critical ingredient for

togetherness. This is possibly because co-designers feel connected with and in a relationship with the research team. In addition, the registry/database has enabled focused engagement efforts as it is possible to see who might not have engaged and connect with people

via telephone to hear more about what people would like to be engaged in.

As a successfully funded research program, there has been continued opportunity to grow the community base of co-designers, as reflected in the recent establishment of the Alex McLeod Co-Design Training Award in 2022. This award supports two co-designers per year (until 2022–2026) to hold paid part-time roles to learn about program operations and to grow co-design capabilities for future leadership. Our growth of a registry/database living labs approach ensures that much diversity can be reflected within end-to-end co-design. In the future, we will become a program that has membership across the life course and expands with an Aboriginal and Torres Strait Islander-led component of study. Saying this, it is important to acknowledge that the Aboriginal-led program may have cultural practices and approaches that connect with, but are different from the current approaches. Additionally, there are always gaps and limitations within research structures and impositions on the conduct of activities that are funded. For example, research projects where co-designers have been recruited to date may have had specific eligibility criteria, which means that certain groups have been excluded due to the language requirements of those studies; thus, we must ask how to improve these situations. Ensuring that there is space for togetherness in these circumstances may require more attention as we move into the future. The program may not reach people who do not want to engage within what might be perceived as traditional research structures or who seek to represent their experiences in different ways to what is on offer. This is where co-partnership and relationships beyond the Co-Design Living Labs are key. As the Co-Design Living Labs network expands nationally, the membership base will necessarily need to reflect greater diversity for different local contexts. Currently, where gaps exist in the program, when we undertake co-design, we ensure that we co-partner with organisations to embed community-led approaches.

The Co-Design Living Labs engagements (or sessions) are typically short-term and entirely opt-in. We are conscious that there is potential to create high demand on people with lived-experience and carer/family and kinship group members around requests for co-design, and there are always risks of programs such as this being seen as service models—things that exist to serve other organisational needs. There will be a need to turn attention outward to explore how being-for is maintained as the ideal relation in these instances of collaboration. Given that government relationships are largely transitory and often replicate being-with as the primary relation, the opportunities for transformation from co-design will be limited. The registry/database provides the potential for the research team to manage invitations and for targeted in-reach to co-designers with specific expertise. The program also shows how it is possible to ensure community-led lived-experience is at the forefront of mental health research and that it can be embedded within traditional academic structures and work towards power-sharing despite known hierarchical systems. Saying this, however, it must be acknowledged that human resource systems are not well-designed in university contexts to support reimbursement of co-design activities and funding to ensure that participation is paid appropriately can be a challenge. When co-designers move into co-researcher roles, the pathways for engaging in research and career development are also poorly designed. The establishment of the Co-Design Living Labs program reflects how universities ought to aspire to engage not only

with but with the relation of *being-for* communities. Being guided by Bauman's (22) three forms of togetherness, the philosophy of practice Togetherness-by-Design supports a reorientation of research hierarchies in the process of working together and disrupts power-laden practices of *who* decides what is researchable and *how* this is undertaken. As the model expands and disrupts its own traditional structures with Aboriginal and Torres Strait Islander community-led research in focus in the ALIVE National Centre for Mental Health Research Translation, being-for will be a critically important foundation to re-distribute power for community-led approaches (23). Ways of doing may simply need to become ways of undoing in some circumstances.

As all funding agencies increasingly implement the prerequisite for co-design with people with lived-experience of mental ill-health and carers/family/kinship group members within grant proposals and research (18), and as health researchers increasingly dabble in co-designed interventions and digital health technologies, it is critical that the processes and methods used for co-design are better articulated, understood, and evaluated. One example of improving the information shared was recently provided by Knowles et al. (45) in a description of Public Patient Involvement (PPI) within a United Kingdom (UK) Learning Health System (LHS) project. In that article, the co-design questions, method, and proposed outcome were detailed within an overarching table to show rationales and intended outcomes; we have emulated this within our study in Table 2 to follow good practice. This is a positive first-step practice for health researchers who undertake co-design to include as part of the processes of describing interventions, model of care, or technology development. However, we must also be conscious of the need to couple this with detailed overviews of ways of working that articulate clear philosophies of practice so that the relational focus of co-design is not eroded, overlooked, and subsumed. Additionally, evaluative frameworks for the impacts and outcomes of co-design are required—this includes paying greater attention to whether structural and systemic injustices are remedied from co-designed research and how impact and outcomes might be measured. It also means acknowledging where change within established co-design programs of work might be needed in keeping with the dynamic, changing, and shifting nature of co-design more broadly. One theoretical model of change designed for evaluation has been presented within this article as useful to setting conditions for co-design, understanding processes, and evaluating for impact at individual, social, community, and organisational levels (1).

5 Conclusion

As the Co-Design Living Labs program moves from a local program model to part of a national network with the ALIVE National Centre for Mental Health Research Translation, fostering capabilities within local university nodes will be important. The key characteristics of the approach, the dedication to relationship formation, and the commitment to Togetherness-by-Design as the philosophy of practice must remain front and centre. Feedback from co-designers has suggested that Togetherness-by-Design has supported the goals, values, and processes of co-design processes and outcomes. This indicates that Togetherness-by-Design helps to realise the mechanisms of change (recognition, dialogue, cooperation, accountability, mobilisation,

enactment, creativity, and attainment) in co-design. This means shared values that facilitate relational ways of being, knowing, and doing and a full appreciation of the distinctions between non-relational and transactional ways of working (being-aside and being-with) with relational ways of togetherness (being-for) are even more important. The Co-Design Living Labs program represents one example of an adaptive and embedded approach for people with lived-experience of mental ill-health to drive mental health research design to translation, which can be delivered at scale. These approaches need to be embedded in architecture across research, government policy and practice, and service settings. As scaling commences, the emphasis on co-leadership from co-designers and the transition to a living labs cooperative social enterprise model will become key.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by The University of Melbourne Human Research Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

VP conceptualised the establishment of the Co-Design Living Labs program using participatory design expertise and knowledge from the world first trial of adapted co-design for mental health settings they led and developed the philosophy of practice with input from co-designers over the life of the program. JB co-convenes co-design activities and leads research activities within the program and supports co-lead group meetings. ML has co-convened healthy hearts project related co-design sessions with VP and works regularly with ED who is a lived-experience co-researcher from the program. KD established the registry/database for the program using redcap and provides statistical updates on membership, participation and withdrawals. RK coordinates invitations to join the program and sessions within the program and supports KD for analyses. ED, PS, AD, BH, TS, ND, and GM are co-leads within the program (with an unnamed carer co-lead) who meet once a month to guide progression and activities of the national network and foster leadership within the program. All authors contributed to the article and approved the submitted version.

Funding

The author team thanks Professor Jane Gunn for sharing the invitations (with ethics approval) to the diamond study participants (2003–2016) which was funded by the National Health and Medical

Research Council (GNT299869, GNT454463, GNT566511, and GNT1002908) and the Victorian Centre for Excellence in Depression and Related Disorders, an initiative between Beyond Blue and the State Government of Victoria; the Target-D study (2014–2018) was funded by a grant from the National Health and Medical Research Council (NHMRC) (GNT1059863) and Link-Me (2017–2021) was funded by the Commonwealth Government Department of Health. The CORE study (2012–2017) was funded by the Victorian Government Mental Illness Research Fund and Psychiatric Illness and Intellectual Disability Trust Fund led by Professor Victoria Palmer.

Acknowledgments

The Co-Design Living Labs program research team is honoured to work with the near to 2000 people in the community who have lived-experience of mental distress, illness, mental ill-health, trauma, and accessing services for mental health support. Some of our members also identify as carers/family and kinship group members, and many express having experiences of both. The ongoing commitment to the program is what makes it succeed, and we are indebted to co-designers. The contributions of our co-design co-lead groups cannot be undervalued. For this study, the co-authors are the first round of co-design leads named on the ALIVE National Centre for Mental Health Research Translation proposal, one of whom chose to remain anonymous. The others have been named co-authors on this study to reflect their contributions to what has evolved. The team expresses thanks to Dr. Caroline Tjung for the visual preparation of the Co-Design Living Labs program operational model and to Ms. Amy Coe for research support and thematic analysis of co-designer contributions to the ALIVE National Centre vision and the co-creation of Nick's journey with Professor Victoria Palmer. Our thanks also go to the research leads of mental health studies who have enabled us to invite people from completed studies from within the Primary Care Mental Health Research Program (formerly the Integrated Mental Health Research Program) located in the Department of General Practice, Melbourne Medical School, The University of Melbourne. Special thanks to carer co-lead Bev Harding for approving the naming of the Co-Design Trainee Award in memory of Bev's son Alex McLeod. Alex lived with mental ill-health and left the world far too young the year the ALIVE National Centre for Mental Health Research Translation was funded.

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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OPEN ACCESS

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RECEIVED 18 June 2023
ACCEPTED 27 November 2023
PUBLISHED 05 January 2024

CITATION
Blezer S, Abujidi N and Sap H (2024) Urban living
labs as innovation infrastructure for local urban
intervention acceleration and student social
learning: the impacts on community wellbeing
in Heerlen. *Front. Public Health* 11:1242151.
doi: 10.3389/fpubh.2023.1242151

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Urban living labs as innovation infrastructure for local urban intervention acceleration and student social learning: the impacts on community wellbeing in Heerlen

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Cities are championing urban experiments in order to address societal challenges and increased urban complexity. In fact, and following fellow researchers, urban experiments are used as a method in a broader trend in public policy to align urban planning with citizen needs by viewing cities as platforms for societal transformation that require, and should draw on, active involvement of residents. In this study, we demonstrate the impacts of placemaking and Urban Living Labs not only for healthy environments but also in facilitating transdisciplinary learning. Therefore, we elaborate on the Aurora transformation process in the neighborhood GMS in Heerlen-North as being one of the 16 Dutch neighborhoods that need extra attention to its socio-urban challenges due to the historical context and consequent local development. Hence, providing two main results for ULLs as infrastructure for innovation for community wellbeing. First, as an alternative spatial planning approach for urban contexts with extreme social-urban conditions that draw on the multitude of local values to generate and accelerate urban transformations going beyond the traditional impacts of urban transformations including public health equity, health outcomes, and addressing social-economic determinants of community wellbeing. Second, as an infrastructure for education innovation encompassing and operationalising social learning theory. Subsequently, it addresses societal issues in these neighborhoods, such as loneliness, social exclusion, or democratic decision-making more appropriately and enhances student, and urban stakeholder, learning through transdisciplinary collaboration among those involved and by connecting education, research methods and questions, and real-life socio-urban challenges. We conclude the article by emphasizing its novelty, providing a discussion, and enumerating implications for theory, practice, policy, and research.

KEYWORDS

urban living labs, social learning, placemaking, urban intervention, co-creation, community wellbeing, urban innovation

1 Introduction

Contemporary cities are going through an intense transformation phase driven by increasing urban complexity and grand societal challenges. Hence, there is a growing trend in public policy to align urban developments to citizens' needs by viewing cities as platforms for societal transformation toward addressing issues such as inclusion, equity, and human development opportunities [see, e.g., (1, 2)].

To overcome the issues related to complex societal challenges and rigid, sectoral planning, cities are engaging with innovative solutions and championing urban experiments in order to deliver on these challenges [see, e.g., (3, 4)]. Diverse approaches to work with such urban complexity go beyond the conservative, incremental practices of planning that are normally regulative and normative. To fill this gap in theory and practice, more experimental bottom-up and engaging approaches surfaced such as co-creation or participatory planning, i.e., placemaking, for which Urban Living Labs (ULLs) are used as a method for the active involvement of residents and other relevant stakeholders in healthy human development [see, e.g., (5–7)].

In this study, we will focus on the articulation of the innovation and added value of both placemaking and the ULL set-up to demonstrate the impacts of such approaches not only for vital, healthy, and inclusive environments but also in facilitating a transdisciplinary learning environment for students, researchers, and other urban stakeholders with a focus on social learning theory.

2 Context

The neighborhood GMS in Heerlen-Noord is acknowledged by the National Government as one of the 16 priority neighborhoods in the Netherlands for its severe and urgent urban challenges, such as energy poverty, low literacy, and cultural diversity (8). These urban challenges are chronic and have been deeply rooted in their local historical context, i.e., the coal mines closure in the 1960–1970s and consequent socio-urban challenges such as unemployment, low income rates, aging population, and drug-related nuisance leading to a strong negative image (stigma) on the area. In fact, these socio-urban concerns have significant implications for public health equity and community wellbeing. For example, the difference between the life expectancy of higher and lower socio-economic status inhabitants in the Netherlands is 6 years, and the difference in *healthy* years of life between them is even 15 years (9, 10), not to mention this difference increased due to COVID-19 (11).

Within this context, there are diverse concentrations and clusters of multiple urban challenges. One of them is the Aurora apartment building, a social housing unit of over 200 dwellings housing a community from over 60 nationalities. The housing block has been renovated recently and painted with the largest artistic mural in Europe. This development aligns with national targets for housing associations to upgrade their housing stock energy efficiency wise as well as the present development perspective of the municipality to enhance the quality of the urban environment by emphasizing culture and arts, while in parallel enhancing its local identity in link to its distinctive local qualities and historical context.

To come short, it is important to, amidst the challenges faced by neighborhoods like GMS, understand and examine the interplay between, on the one hand, urban development approaches and strategies and, on the other hand, public health equity and community wellbeing to improve both the quality of the built environment and the social-health fabric of these neighborhoods. Consequently, we asked ourselves the following research question:

“How can Urban Living Labs as an (urban) innovation and learning infrastructure contribute to vital, healthy and inclusive neighborhoods by physical and socio-spatial interventions in neighborhoods like GMS in Heerlen-North?”

For illustration purposes, Figures 1–3 show the location and its context.

3 Placemaking and urban living labs

According to Marrades et al. (12), placemaking in urban planning emerged as a response to the inefficiency of other planning approaches and as a reconceptualisation of how city sites are constituted and urban transformation takes place. As such, it offers an approach to bridge the gap between exchange value (economic profits) and user value (daily life activities). Placemaking also gives the chance to respond to urgent short-term needs of the local community and provide a direction to the long-term structural transformation. From a spatial planning perspective, placemaking articulates urban sites as “places” prioritizing and responding to demands from communities and focusing first and foremost on people (12). Additionally, it may be defined as an incremental way to improve the quality of a place over a long period of time with context-specific experimental interventions and activities (13). Consequently, it is seen as a process of creating “quality places” that people want to live, work, play, and learn in (13) and that creates an attachment or connection between the community and the place they live in, also referred to as their sense of place (14).

Fincher et al. (15) stress the importance of local lived experiences and everyday encounters in placemaking for professional urban planners in order to overcome the gap between exchange and user value. ULLs provide the potential to overcome this gap as they are not only concerned with the place under study but exist in relation to its historical, institutional, spatial, and temporal dimensions while seeking transformation (12). In this way, ULLs can be understood as city sites that provide a learning arena within which the co-creation of innovation can be pursued between local stakeholders and community actors (16). Rather than achieving a pre-determined objective *per se*, the focus is on learning (17) as a means through which experiments, i.e., urban interventions, become successful because urban experimentation is “*fluid, open-ended, contingent and political*” [(18), p. 260] and centers people in the urban planning process and fosters the relation between those people and their places. As such, ULLs are transdisciplinary in nature and advance “place understanding” through a process of collaboration and interactive learning among urban stakeholders. This distinguishes them from neoliberal methods of planning as they are capable of meaningfully remake public space into places that are co-designed and reimagined by a community and local stakeholders while existing in relation to its context using placemaking as a concept and philosophy to urban and spatial planning. In the Dutch context, this may seem especially relevant in neighborhoods like GMS in Heerlen due to their “vulnerability” and cultural and migration diversity because of its temporary, zoning and exclusion policy approach that creates a monoculture causing loss of potential to urban vitality [see, e.g., (19, 20)].



FIGURE 1
Aurora apartment building before painting and renovation (Source: Boa Mistura).



FIGURE 2
Aurora apartment building after painting and renovation (Source: Boa Mistura).

4 Placemaking, urban living labs, and the healthy city

Recently, Horstman and Knibbe (9) have shown that the healthy city concept is about public space, social exclusion, urban vitality, and social interactions in the city. They do state that:

“The living environment of people with low incomes often contains more health threats than the public space of high income groups” [p. (21); own translation].

These authors, for example, refer to criminality, (noise) nuisance, dilapidation, less greenery, air pollution, or fewer social



FIGURE 3

Aurora apartment building and GMS neighborhood incl. the Maankwartier station area (Source: Boa Mistura).

encounter opportunities to support their claim. Hence, three perspectives on the built environment and the healthy city arise:

1. Public space for social interactions in the built environment. Here, the concept of “public familiarity” (21) is important as it emphasizes that social interactions increase feelings of safety and familiarity consequently leading to less social isolation in cities (22).
2. Public space for connectedness to one’s neighborhood. This perspective links with the theories of placemaking, sense of place and thoughts of Jane Jacobs about city diversity, urban vitality, and its implications on human wellbeing, such as feelings of safety, ownership and community. Indeed, placemaking is a successful social movement (9) though one should note its criticisms that places may be viewed as an economic product too much [see, e.g., (23, 24)].
3. Social mixing in the built environment. Here, it is proposed that mixing certain socio-economic inhabitant groups automatically leads to more physical quality of the living environment, more social cohesion and increased social capital. However, research has shown the opposite of homogenous neighborhoods (25) and that social mixing assumptions pay too little attention to the historical context of places and the aspirations of community members (26).

Placemaking, as a conceptual shift in urban planning, not only reshapes the physical environment but also reimagines the social fabric of these neighborhoods. Additionally, ULLs advance place understanding and placemaking through a process of collaboration and interactive learning among local stakeholders. Also, research in the public health domain has repeatedly shown the importance of, for example, social interactions and community engagement to address health disparities rooted in the (re-)production of the

built environment. Hence, examining how ULLs can function as innovation infrastructure by providing a social learning arena is essential in the pursuit of community wellbeing impacts in neighborhoods.

5 Urban living labs and social learning

Sustainability challenges are visible on a global level, while sustainability transitions happen on a local level due to the fact that innovations and interactions between stakeholders are situated and understood by those involved on a local scale (27). In the urban context, sustainability transitions are about changes in markets, policy, culture, technologies, and infrastructure as well as in human behaviors and practices [see, e.g., (28)]. In the urban context, sustainability challenges are about achieving the SDGs that require widespread diffusion of technological innovations and new infrastructures [see, e.g., (29)]. Against this background on the need for innovation actions on a local scale, while having sustainability challenges on a higher scale, it is important (if not a necessity) to develop the needed and appropriate knowledge, practices, and expertise to achieve the required innovation actions to govern those changes and achievements.

ULLs arose for their potentials for collective learning and exchange of ideas about the built environment and its ecosystem (30). Yet, their understanding on how to facilitate local sustainability transitions remains limited (31). Meanwhile, the potentials of Universities of Applied Sciences have been recognized internationally and in ULL innovation literature to prepare students and stakeholders through the use of ULLs to address issues in society transdisciplinary and in line with the SDGs in context [see, e.g., (32, 33)]. In fact, sustainability transitions

require new forms of education and pedagogical tools that enable students and professionals to deal with rapid changes, increasing complexity, criticizing knowledge and uncertainty (34), also in urban innovation transformations. To that end, higher education institutes play a crucial role because they are locally rooted and globally connected (35) being able to educate location-aware global citizens (36, 37). The social learning theory therefore gained renewed interest in education literature as learning takes place via accumulated knowledge, and (inter)personal and vocational professionalization (38) in an environment where collaboration, critical thinking, and co-creation are centered (37).

The social learning theory encompasses four elements arguing that engagement with social issues is fundamental to how learning takes place and how people become who they are (38). Drawing on these four elements enhances student learning impacts as it intertwines personal and professional development with locally relevant societal issues. It also provides possibilities for transversal (students from different years in one discipline) and multi-level (vocational, bachelor, and master) collaboration and learning in addition to multidisciplinary perspectives. The elements are as follows:

1. *Learning as belonging*: Students are part of the ULL community; they learn within and with the local stakeholders and community actors. Therewith, engagement in and understanding of actual societal challenges can lead to the development of relevant knowledge, competencies, and skills.
2. *Learning as becoming*: Students collaborate with the ULL community to develop their own work identity relative to other disciplines. Therefore, professionals develop a broader understanding and knowledge base of the complexity and interconnectedness of actual urban questions.
3. *Learning as experience*: Students learn by working on real-life societal issues in a local context. The context, and its undergoing changes, makes learning and working meaningful for students. This will help to bridge the gap between abstract concepts and context-specific questions and needs. Hence, the city environment becomes the campus.
4. *Learning as doing*: Students learn to take initiative and responsibility regarding societal issues and the ULL community to gain knowledge and skills and reflect on their own as well as other disciplines. Being active in the development, implementation, and monitoring of certain interventions on the local scale bridges the gap between diverse scales that students work on. From neighborhood to building or product scale, resulting in more interrelated hands-on knowledge development.

6 Results: Aurora apartment building design co-creation process

The Aurora apartment building area has gone through a process of transformation since the coal mine closure that left a strong stigma on the building and the inhabitants, being a residence and area for mainly underprivileged communities and a place for drugs and prostitution. Many efforts and projects have been implemented in the past 10 years to transform the place and bring

better life quality and imago by the housing association Wonen Limburg. Within this context of ongoing transformation, it was an important step to work on the development of the courtyard of the Aurora apartment building to enhance the sense of community and the creation of a social place that is safe, climate-adaptive, and healthy for the tenants.

The Aurora apartment building courtyard is a parking lot for the tenants of the social housing association. However, the parking lot is only rented out for two-thirds of its capacity and the residents experience the courtyard as a site for illegal activities (ranging from illegal parking to drug usage), and as a non-inviting stressing environment (i.e. not climate resilient and physically closed). Hereto, Wonen Limburg and the research center Smart Urban Redesign (SURD) developed a co-creation process to identify residential needs and wishes for the Aurora apartment building courtyard to transform it into a climate-resilient, circular, and community place that supports the residents in their daily life activities; a place where sense of community and collective identity can flourish. Consequently, to improve community wellbeing, urban vitality and social cohesion as impacts.

In this process, both learning together and making together as part of co-creation (17) are outlined in the Aurora Days and Aurora Challenge, respectively. Both worked toward the Spektakeldag festival on 4 June 2022 in which the housing association opened the largest mural of Europe festively (postponed earlier due to COVID19 measurements). In Figure 4, the co-creation process is illustrated.

The Aurora Days included an informal pizza session, photo group discussions, and Walk and Talk sessions. These were held on March 15th, March 29th, and April 12th in 2022. These served (1) to get to know the inhabitants and for them to get familiar with the SURD students and staff, (2) to gain insights into eight different locations around the area that concerns, both positive and negative, the community and that were emphasized by the community members in conversations during the pizza session, and (3) to enhance place understanding of the direct context around Aurora with urban experiences from the community members, respectively. In the photo group discussions and Walk and Talk sessions, activities revolved around target groups, i.e., children, older adults, mothers, singles, and migrants. Therefore, in-between result posters were hung up at all four the entrances of Aurora apartment building to allow for adjustments, additions, and refinements by residents themselves. The Aurora Days were coordinated by a Built Environment and an Occupational Therapy intern duo at SURD and were supported and facilitated by researchers, teachers, fellow students, citizens, and Wonen Limburg.

The Aurora Challenge was a multidisciplinary, transversal, and multi-level design challenge held in the Aurora apartment building. The Aurora Challenge took place in the week of 25 April 2022 to 29 April 2022. Four international and interdisciplinary student groups worked for 1 week non-stop on the design challenge to translate the collected insights from the Aurora Days into an urban design intervention. The students ranged from first-year BSc students to second-year MSc students and came from the Netherlands, Iran, and Germany and the spatial planning, civil engineering, building technology, transportation, occupational therapy, and nursing disciplines. The Aurora Challenge led to a winning design,

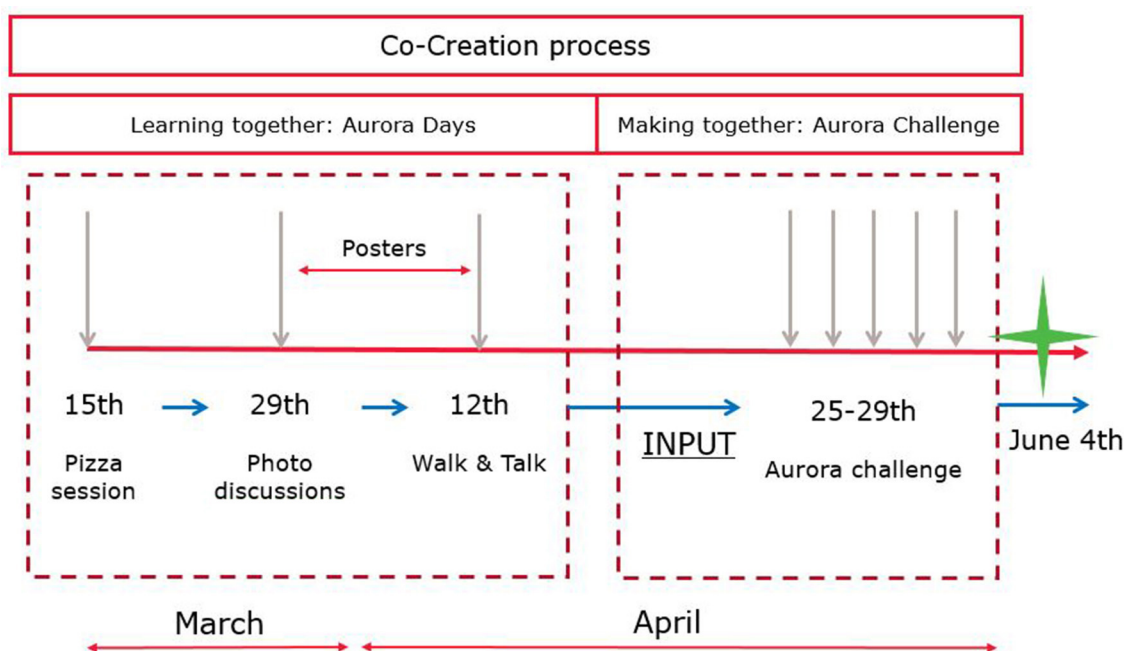


FIGURE 4
Aurora apartment building intervention co-creation process (Source: SURD).

voted for by the residents, Wonen Limburg, and local stakeholders that was showcased at the Spektakeldag festival on June 4th in 2022.

7 Results: Aurora apartment building active experimentation and intervention implementation

Since the Aurora Challenge, the involved stakeholders have been working toward the implementation of the winning design scenario. The implementation was done in two phases. First, an active experimentation of the winning design elements on, and after, the Spektakeldag festival. Second, and based on the monitoring impacts after the Spektakeldag festival, the actual intervention implementation in the Aurora courtyard.

The active experimentation phase included the making and testing of circular street furniture, trash bins and planters from the winning design that were made after the Aurora Challenge in collaboration with the local trash and recycling company (RD4) and the local vocational education institution (VISTA college). This circular furniture introduced the inhabitants of Aurora to a particular sustainability challenge, i.e. circular economy, in an appropriate way. The method for introducing citizens to sustainability challenges is especially important in “vulnerable and culturally diverse” neighborhoods as shown earlier by Abujidi et al. (19) in the city of Kerkrade-West, the Netherlands. The circular furniture was showcased and tested at the Spektakeldag festival (see Figure 5).

Since then, the impacts and use of the circular products have been monitored by a MSc. Architecture intern at SURD who lives in the Aurora apartment building. The intern has mapped the

frequency, duration, and type of activity that took place around the circular furniture as well as if citizens used the circular furniture in “unexpected ways.” To illustrate, it was observed that some children were climbing on the circular furniture that was otherwise assumed not being outside at all. Consequently, it resulted in new forms of appropriation, physical movement and sports, and social activities and interactions between children and their parents.

The intervention implementation phase started with the social housing association and a local landscaping company with jobs for people at a distance from the labor market. They captured the essence of the winning design and the experiences and insights from the impact monitoring process to develop the new Aurora apartment building courtyard. As of April 2023, the Aurora courtyard completed its physical transformation of the parking lot. The new Aurora courtyard now includes sitting places, circular furniture, edible greenery (e.g., mint leaves), a chess board, a ping pong playing field, and nature-based relaxing areas (see Figures 6–8 for the old and new situation; Figures 7, 8 taken in spring period 2023).

8 Results: social learning for students and stakeholders in practice

As explained earlier, the social learning theory encompasses four elements arguing that engagement with social issues is fundamental to how learning takes place and how people become who they are (38). It should be noted that in practice the four elements are intertwined and reinforce each other. Though, in this section, the four elements are exemplified with a couple of examples from our experiences.



FIGURE 5
The Spektakeldag active experimentation June 2022 (Source: SURD).



FIGURE 6
The Aurora apartment building courtyard in March 2022 (Source: SURD).

1. *Learning as belonging*: students are part of the ULL community; they learn within and with the local stakeholders and community actors. As the Aurora apartment building process has been ongoing for almost 2 years now, it is observed that students, professional stakeholders, and citizens are taking ownership

of the ULL, the Aurora courtyard, and local challenges. For example, third-year students who engaged themselves in the Aurora Challenge are actively asking partners like the housing association for internship positions or the SURD for graduation research positions in the current 4th year of their study.



FIGURE 7
The intervention implementation result April 2023 (Source: SURD).

Similarly, citizens who co-hosted our photo group discussions during the Aurora Days are now actively supporting teachers in student assignment presentations to elaborate upon the historical context of the area. Finally, and from a community-perspective, the intern who lives in the Aurora apartment building is an actual part of the community and therefore a continuous presence both from the University of Applied Science—formal and personal—informal perspective.

2. *Learning as becoming*: Students collaborate with the ULL community to develop their own work identity relative to other disciplines. Here, a specific example of a spatial planning student is mentioned worthy to explain. The student participated in the Aurora Challenge while being on internship at a private project developer. While working on the Aurora Challenge and currently doing her graduation research at SURD, she developed herself as an architectural activist against hostile architectural practices by the municipality that forbid certain activities for citizens in public spaces. Her experiences in the ULL community made her aware of what she stands for and wants to stand for as a professional in the built environment discipline relative to other disciplines like health or nature; not as a private developer focusing on financial profit, but as a local activist ambitioning community wellbeing for citizens in their own living environment.
3. *Learning as experience*: Students learn by working on real-life societal issues in a local context. The context, and its undergoing changes, makes learning and working meaningful for students. In essence, the actual change achieved exemplifies this element. Students reported that they experience the ULL community and its focus and activities as extremely motivating and valuable due to the fact that they see the concrete change and improvement from their efforts for the local community and their wellbeing. In contrast to traditional classroom teaching, the student learning curve is enhanced by working across various disciplines, transversal educational institutes as well as actors covering the quadruple helix model and multiple development phases. The process also allows students to change roles with other students. When students are engaged long enough in the process, they gain experience that allows them to be coach and guide other newly involved students in group assignments. As such, the interplay between student and coach roles is an important professionalization experience. Similar impacts are observed among other stakeholders.
4. *Learning as doing*: Students learn to take initiative and responsibility regarding the societal issues and the ULL community to gain knowledge and skills and reflect on their own as well as other disciplines. Here, we refer to the intern duo who were responsible for the photo group discussions, posters, and Walk and Talk sessions and another occupational therapy student intern. First, the duo explained that they learned tremendously by organizing and hosting the mentioned activities in the “learning together” phase. By actually doing and working with the ULL community, planning the activities and necessities, they improved their skills and reflected upon the role of educational institutes in local urban transformation processes. Second, the occupational therapy student elaborated to one of the involved spatial planning teachers that the circular furniture was made from waste streams yet was not user-friendly from an occupational therapy perspective due to being limited in design by waste stream dimensions. This stimulated both the



FIGURE 8
The intervention implementation impacts April 2023 (Source: SURD).



FIGURE 9
Social Learning in practice (Source: SURD).

discussion on the role of occupational therapists in the built environment improvement and the discussion on the ergonomic aspects of the circular economy transition between student and researcher-teacher (Figure 9).

9 Conclusion: ULLs as infrastructure for urban innovation

To begin with, we want to highlight the novelty of our study in two ways.

First, the future is global. Global challenges and transitions are manifested in many different ways on a local level. To master these challenges and transitions, it is acknowledged that technological innovation alone is not sufficient, but rather requires social and regulatory innovation and infrastructures as well [see, e.g., (28)]. While we move toward the knowledge society and try to address these challenges and transitions, it is observed that local and transdisciplinary knowledge generation then is not motivated by cognitive knowledge or theories but rather by real-world needs for change and reform, like the Aurora courtyard and the health of its residents. In fact, this transdisciplinary learning comes both from the conceptual development and co-design of an urban intervention on study, i.e., an experiment, as well as the implementation, realization, and observation of a transformative experiment as aspired by the local community in practice. As West et al. (39) recently put it: “*the modus operandi of knowledge societies can then be understood as continuous experimentation*” (p. 136). Consequently, the ULL has proven to function as a social learning infrastructure that connects societal issues, research questions and methods, and education across various levels to enhance transdisciplinary learning among students, and also, local stakeholders about societal challenges. Subsequently, creating meaningful experiences and personal and professional growth among involved persons and parties, like residents, professionals and students. Therefore, the ULL is capable of operationalising and fulfilling the social learning theory potentials, i.e., transdisciplinary learning and action-oriented capacities and competencies like critical thinking (40), which seems so necessary and promising for today’s sustainability transitions and challenges on local and global scales.

Second, the ULL functions as an alternative spatial planning and urban innovation approach to governing local neighborhood development in and for collective learning about a context of extreme urban and social conditions. ULLs do so due to their potential and ability to bridge a multitude of perspectives and disciplines as well as go beyond particular and traditional development phases only by the creation of a flexible process that is open for continuous evaluation, alteration, and improvement. It has proven to function as a kind of platform that is able to respond to short-term urgent needs, while at the same time, providing design scenarios and imaginative references for long-term development prospects. As such, it functions as an instrument to outline and accelerate placemaking processes and urban interventions that go beyond the design phases of urban development and explicitly experiment in practice by drawing upon local urban complexities for value creation, i.e. community wellbeing as aspired by the local community. The co-creation

process and the urban intervention have positively impacted the community wellbeing. Residents, students, professionals, researchers, and others have been actively engaged in the transformation process leading to a stronger sense of community, sense of place, and local identity. Currently, we observe and notice increased levels of trust between stakeholders and ownership toward local issues and challenges. Thus, we argue that the explicit combination of placemaking and ULLs puts the potentials of placemaking, merely grown as a conceptual approach, into practice and *beyond* project-based operations. Hence, driving the pursuit of public health equity and community wellbeing impacts in neighborhoods.

10 Discussion

We elaborate upon two main points for our discussion.

First, we argued that placemaking, as a conceptual shift in urban planning, not only reshapes the physical environment but also reimagines the social-health fabric of these neighborhoods. We have seen, and by drawing on research in the public health domain, that by the creation of social interactions and community engagement, it is possible to address health disparities rooted in the (re)-production of the built environment. Our study in fact supports this claim, and indeed existing research provides indicators to assess the success of placemaking and the quality of public space [see, e.g., (41)]. However, while the process was designed by co-creation theory from Puerari et al. (17), we notice that literature in itself from Placemaking, ULLs and the Healthy City often refers to outcome indicators to focus on rather than process indicators that are important to create those wished-for outcomes. Therefore, we question whether the impacts of placemaking practices and ULLs from a public health domain perspective can rather be assessed and evaluated by outcomes or process indicators, especially when drawing upon the local community and unique local values as a main driver of the activities and knowledge generation, instead of political or policy motivations.

Second, while social learning theory guided the learning activities, one should note that the four elements remain rather vague and seen from an individual perspective. That is not to say it is ineffective as our results show the opposite, yet, the question arises: What challenges and enabling factors hinder or stimulate transdisciplinary learning in ULLs and both from an individual learning perspective as well as cross-sectoral collaboration constellation perspective? Consequently, it prompts the question of what role education and learning, and knowledge institutes like SURD, play in the knowledge society as well as its responsibility toward the transferability of practices and learning toward other contexts. Scholl, de Kraker and Dijk (42) hereto propose a meta-level approach to ULL learning and highlighting the de-contextualization and re-contextualization of learned lessons. However, in practice and from social learning theory and our experiences so far, it remains unclear on an operational level how to organize and facilitate this meta-learning.

Furthermore, we emphasize in an enumerative manner the implications for theory, policy, practice, and further research.

10.1 Implication for theory

Our experiences show three implications for theory:

1. The importance of local sustainability transitions and localized solutions. While global sustainability challenges negotiations and frameworks, like the SDGs, are crucial in overcoming them [see, e.g., (27, 29)], our experiences suggest that real-world transitions happen indeed on a local scale. Theories should therefore be tailored to address context-specific challenges and needs, rather than only emphasizing the importance of local contexts. As a consequence, it is needed to verify and enhance theories to bridge the gap between practice and existing theories and models on ULLs that are abstract and cannot be directly implemented in local contexts. As an example, the Harmonization Cube methodology (43) or the three-layer model (44) should be understood, tested, and adjusted more intensively in practice to help stakeholders on a local scale.
2. The integration of social learning theory elements in community wellbeing affairs and ULLs by bridging the gap in monitoring the impacts of ULLs beyond the context and extending it to diverse stakeholders engaged in the processes of ULLs. Currently, we notice that transdisciplinary knowledge production and learning are presented and viewed as an additional layer to ULLs rather than an integral part of it. Hence, we argue that social learning should be an integral part of addressing societal issues and challenges among all stakeholders involved. Thus, it is not only the students who learn, but all stakeholders that must be willing to learn in order to enhance impact creation. In specific, we argue to integrate social learning (38) in education and urban planning to emphasize the need for transdisciplinary learning and collaboration to effectively address societal challenges. Examples include the urban experiment, research-based education, or challenge-based learning (4).
3. The reconceptualisation of Urban Planning in practice by combining placemaking and ULLs. It is the exact integration of ULLs as an alternative urban planning methodology that is not strongly (if at all) presented in spatial planning theory. Planning theory contains this dichotomy of theories on the one hand and practice on the other, arguably top-down vs. bottom-up and/or technical vs. communicative planning theory (45). While placemaking conceptually grew as an alternative urban planning approach [see (12)], it is the combination with ULLs that puts its potentials into practice beyond project-based operations. The prioritization of, for example, community needs and wellbeing, social cohesion, or sense of place next to economic profits and planning philosophies can put urban planning at the center of improved quality of life as exemplified by Horstman and Knibbe (9) via advancing “place understanding” through a process of collaboration and interactive transdisciplinary learning among urban stakeholders.

10.2 Implication for policy

Our experiences show two implications for policy:

1. The need for political support for placemaking and ULLs. Policymakers should consider supporting, facilitating, and

incentivising placemaking initiatives and ULL infrastructures on a local scale. Both offer the potential to bridge the gap between the quality of the built environment and community wellbeing, or the gap between exchange and user value (12), to align local actions with agreed global goals, like the SDGs. Indeed, Savini and Bertolini (46) show that this is crucial for the development pathway of ULLs in order to enhance impacts and Blezer and Abujidi (30) hinted toward similar support in that grant providers are challenged to rethink and redefine selection criteria for subsidy approvals on various political layers to enhance the transformative change capacity of ULLs.

2. The need for education reforms. Policymakers should consider reforms in higher education policies to align higher education with societal needs and sustainability goals. Social learning theory presents four elements that are important therefore, however are not sufficient by themselves. Other related concepts, like experiential learning theory, transdisciplinary learning, challenge-based learning, or real-world problem solving (4) are other perspectives. In fact, a recent publication [(47), p. 6] argues that “a university living lab governance framework is needed to generate a culture of collaboration across research, teaching, operations, and enterprise and accelerate impact, without stifling emergence and innovation.” While the authors provide recommendations like flexible coordination or relationship building between silos within the university that we acknowledge as well based on our experiences, we also add to this that there is a need to redefine the role of knowledge institutes in today’s society, particularly from policymaker perspective. For example, the funding system of education (and research) in the Netherlands is currently based on quantitative measures. However, we do argue that qualitative measurements that are aligned with societal challenges and needs are required in order to guarantee quality education and research to address societal challenges and educate location-aware global citizens.

10.3 Implication for practice

Our experiences show four concrete implications for practice:

1. *Community engagement*: Practitioners in urban planning should prioritize community engagement and co-creation processes. Placemaking and ULLs demonstrate that involving local residents, students, professionals in the design, decision-making, and implementation of urban interventions can lead to more holistic and sustainable outcomes.
2. *Transdisciplinary collaboration*: Practitioners should foster transdisciplinary collaboration among students, researchers, professionals, and community members as this enables a more comprehensive place understanding of complex urban and societal challenges with responsive solutions.
3. *Experiential learning*: Educational institutions and practitioners should promote the inclusion of Social Learning dimensions. This includes students, teachers, and researchers to actively participate in addressing local experienced societal issues within their contexts and domains. As such, it helps to bridge

the gap between scientific and theoretical knowledge with practical application.

4. *Tailored solutions*: Urban planning practitioners should tailor solutions to the specific needs and characteristics of the place that they will intervene in. Recognizing the uniqueness of places and their communities and involving them in the decision-making process can lead to more aspired and effective interventions.

10.4 Notes on further research

Our experiences call for further research along the following lines:

1. First, and process-wise, more experiences and insights are needed into the diverse roles that stakeholders can or must play based on the activity and phase in the ULL. In particular, when engaging multiple disciplines and education. For example, Vinke-de Kruijf et al. (48) provide a robust review of research roles in transdisciplinary projects. However, we observe and experience fluid roles during the process of urban interventions in ULLs that should be better understood to enhance effectiveness.
2. Second, and process-wise, we call for more intense, structured, and comprehensive monitoring and evaluation activities in ULLs. Our experiences made clear that impacts go beyond what individuals and stakeholders imagined and expected. We argue it is important to understand the full impacts of ULLs to better understand their innovation potentials. Consequently, we not only call ULL practitioners to focus on development activities but also more on impact monitoring and evaluation activities; both formally and informally as well as on the short term and the long term. Examples may be learning aspects or the maturity level of ULLs for impact creation.
3. Third, and content-wise, we call for more research in the urban planning and health domains to their interconnectedness, especially toward institutional causalities of public health equity in various geographical areas. While our experiences show and emphasize the importance of ULLs to the quality of the built environment in relation to health impacts (and other domains) on the local scale, it focuses on addressing observed societal issues; not the causalities of the societal issues in the first place. So, we argue that understanding the institutional arrangement through which health as a discipline on the one hand and urban planning as a discipline on the other influence each other mutually. It is crucial to understand these legal institutional causalities if ULLs as innovation infrastructures indeed want to scale up impacts for community wellbeing beyond the local scale and beyond the solution-focussed perspective.

Data availability statement

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

Ethics statement

Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

SB contributed to the theoretical and practical conception and design of the study, wrote the first draft of the manuscript, contributed to manuscript revision, read, and approved the submitted version. NA and HS contributed to the theoretical and practical conception and design of the study, contributed to manuscript revision, read, additions, and approved the submitted version. All authors contributed to the article and approved the submitted version.

Funding

This research is based on diverse research projects and funds; the ELSA Lab Poverty and Debt funded by the Dutch Ministry of Internal Affairs and Kingdom Relations, and the City Deal Kennis Maken programme funded by the Dutch Ministry of Science, Education, and Culture as well as Agenda Stad.

Acknowledgments

The authors would like to acknowledge that this article is based on the work of several years in Heerlen and with the team of Smart Urban Redesign Research Center. We would like to thank Marlou Driessen, Nouran Ahmed-Serag, Ingrid Severens, Jeroen Pelzer, and Anne van Dun and all the students who participated in the activities. Additionally, this paper is based on two previous versions presented at the Open Living Lab Days 2022 Conference Proceedings (section on top contributions) and the Repurposing Places for Social and Environmental Resilience 2023 Conference Proceedings (section on Educational Projects).

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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