Including the voice of the patient in healthcare: new models for health and design

Incluindo a voz do paciente no cuidado em saúde: novos modelos para saúde e design

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communication design, information design, co-design, lived experience, health, design

This paper examines how design methods – specifically information design and participatory design – can strengthen the voice of the patient within healthcare systems, particularly for equity-seeking populations. Drawing on the Cascade of Care Framework used in healthcare as a conceptual model, the paper explores opportunities for designers to intervene across stages of awareness, engagement, retention, treatment, and outcomes. Three case studies from the Design Health Research Innovation Lab at the University of Alberta illustrate how co-design, narrative methods, and information design tools can enhance health system engagement, reduce stigma, and improve health literacy. These cases include: Addictions Don't Discriminate, a public exhibition co-created with people who experience addiction; Supporting Healthy Partnerships with People Who Use Drugs, a toolkit and learning intervention supporting equitable collaboration; and a digital and print opioid education toolkit developed with communities and clinicians. The paper, originally presented as a keynote, discusses the idea that design can make patient involvement more meaningful, sustainable, and impactful, particularly when lived experience is treated as expertise and when information is made clear, accessible, and actionable. The paper concludes by identifying future directions for design research in health, emphasizing the need for equity, digital accessibility, and long-term co-design partnerships.

design comunicacional, design da informação, cocriação, experiência vivida, saúde, design

Este artigo examina como métodos de design – especificamente o design da informação e o design participativo – podem fortalecer a voz do paciente nos sistemas de saúde, especialmente no contexto de populações em situação de vulnerabilidade e que buscam equidade. Tendo como modelo conceitual o Cascade of Care Framework *utilizado na área da saúde, o texto explora oportunidades de intervenção do design ao longo das etapas de conscientização, engajamento, permanência no cuidado, tratamento e desfechos. Três estudos de caso do* Design Health Research Innovation Lab*, da University of Alberta, ilustram como práticas de cocriação, métodos narrativos e ferramentas de design da informação podem ampliar o engajamento com os sistemas de saúde, reduzir estigmas e promover o letramento em saúde. Os casos apresentados incluem:* Addictions Don't Discriminate*, uma exposição pública cocriada com pessoas que vivenciam a dependência química;* Supporting Healthy Partnerships with People Who Use Drugs*, um kit de ferramentas e uma intervenção formativa voltados ao apoio à colaboração equitativa; e um kit educativo sobre opioides, em formatos digital e impresso, desenvolvido em parceria com comunidades e profissionais de saúde. Originalmente apresentado como palestra em congresso, o artigo discute como o design pode tornar a participação dos pacientes*

mais significativa, sustentável e impactante, especialmente quando a experiência vivida é reconhecida como forma de conhecimento especializado e quando a informação é apresentada de maneira clara, acessível e acionável. Por fim, o artigo aponta direções futuras para a pesquisa em design e saúde, enfatizando a importância da equidade, da acessibilidade digital e de parcerias de cocriação de longo prazo.

1 Introduction

Design has increasingly been recognized as a critical partner in addressing complex healthcare challenges. In fact human centred design, is essential for reorienting care around people's needs, rather than fitting them within an existing systems Melles et al. (2021). Within health systems, the need for new forms of communication, engagement, and collaboration has become urgent, particularly for equity-seeking populations who have historically been excluded from decision-making processes. As an information designer and design researcher, my work seeks to translate complex clinical, policy, and social knowledge into understandable, inclusive, and actionable formats. This orientation – as a translator, facilitator, and collaborator – guides the research and case studies described in this paper.

Design work in health is not neutral; it is tied to histories of colonialism, inequity, and the uneven distribution of harm and resources. The communities I collaborate with have taught me that health systems transformation must begin with patient voice, lived experience, and community expertise.

To understand how design can support this goal, this paper uses the Cascade of Care – a sequential public health model describing the stages individuals pass through in accessing and benefiting from health services (Socías et al., 2016). I examine how information design and participatory design, used together, can expand the cascade by improving communication, supporting agency, and enabling patients and communities to shape systems rather than merely navigate them.

The paper provides a conceptual background, describing the Cascade of Care and two relevant design frameworks; applying them to three case studies; and concluding with implications for health system design and research. While these case studies have been presented and published individually, they have not previously been examined through the lens of the Cascade of Care framework.

2 Background: patient voice and health system transformation

2.1 From passive subjects to active partners in healthcare

Patients have been positioned as passive recipients of care rather than engaged contributors to healthcare design or policy (Bate & Robert, 2007). Over the past two decades, many health systems have attempted to shift

toward patient-centered or person-centered models. While this shift is promising, it remains unevenly implemented. Engagement often takes the form of consultation rather than collaboration, and patients are rarely positioned as co-designers with equal influence (Ocloo & Matthews, 2016). Meaningful engagement must address barriers such as stigma, power imbalances, trauma, and digital inequities. It must also respect lived experience as expertise. This is particularly crucial for populations whose insights reveal gaps in care that data alone cannot illuminate. As such, design holds promise for enabling new forms of participation.

2.2 Lived experience as expertise

Research in harm reduction, mental health, and community-based health services increasingly affirms that people with lived experience possess forms of situated knowledge essential to effective design and operation of services (Pauly et al., 2020). Lived experience offers insight into service gaps, system failures, and the real conditions under which health decisions are made.

Yet lived experience is often undervalued or tokenized. Despite widespread commitments to patient and community engagement, lived experience continues to be undervalued or tokenized in many health and design initiatives, with participants often included to satisfy institutional or funding requirements rather than to meaningfully shape decisions and researchers often retain ownership of research questions and how to answer them (Greenhalgh et al., 2019). Equity requires intentionally shifting participation models to ensure that patient partners – especially those from historically excluded groups – can contribute safely, meaningfully, and with appropriate compensation and influence. Participatory and co-design approaches provide a structured means of enabling this shift by foregrounding power-sharing, valuing lived experience as expertise, and embedding collaboration across all stages of problem framing, design, and implementation, one not just reserved for professional designers (Donetto et al., 2015).

3 Conceptual framework: the cascade of care

3.1 Overview

The Cascade of Care describes sequential stages that individuals move through when accessing services. It begins with awareness and identification, in which individuals often identify their own health need. This is followed by engagement and linkage to care in which patients are referred to appropriate health and social services. Retention in care reflects sustained, ongoing participation in services over time, emphasizing continuity and stability of care relationships. Adherence to treatment is the stage at which patients are able to follow recommended medical interventions and ideally the

Cascade of Care ends when patients sustained engagement and treatment options result in successful health outcomes.

3.2 The cascade for patient engagement

In addition to care access, there is an emerging Cascade of Engagement, describing how individuals become active partners in co-design, governance, and advocacy. Engagement can begin with awareness of opportunities and grows through trust, relationship-building, skill development, and sustained participation. The Cascade of Engagement provides opportunities for patients to engage in health care over a continuum, or spectrum meaning that there are many opportunities for engagement in their health. Initiatives in Canada such as the *Strategy for Patient Oriented Research* and the province of Ontario, *Canada's Patient Engagement Framework* conceptualize engagement with escalating roles and collaborative depth across governance, research, and care processes.

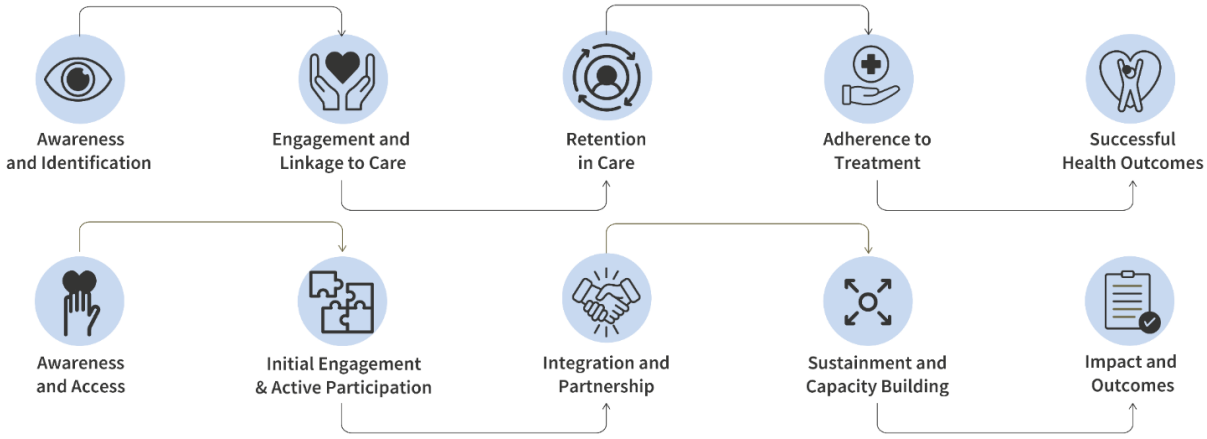

Figure 1 The Stages in the Cascade of Care and the Cascade for Patient Engagement.

4 Design lenses: information design and participatory design

4.1 Information design

Design methods can expand both cascades, strengthening communication and enabling patient involvement in several ways. Information design is an evidence-based process of making complex messages clear, usable, and accessible (Black et al., 2020). It emphasizes several stages including scoping the problem, analyzing user understanding, developing prototypes, iterative testing, and implementation and monitoring. Applied to the Cascade of Care, information design ensures that at each stage, patients receive communication that is understandable for the audience and actionable.

4.2 Participatory design

Participatory design is grounded in equity, collaboration, and shared ownership. Brandt, Binder, and Sanders (2012) describe it as bringing together different actors with varying backgrounds, interests and competencies. In health settings, participatory design creates tools and environments where patients, families, providers, and community members co-create solutions.

Some of the key principles include shifting power toward participants; using creative tools (e.g., storytelling, persona building, journey mapping); establishing shared governance structures (e.g., ways-of-working documents); fostering safety, trust, and inclusion; and enabling sustained participation. Together, information design and participatory design expand the Cascade of Care by improving clarity and enabling partnership.

4.3 Applying the design lenses to the cascade

The role of design is critical in each stage of the cascade. In the first phase, *awareness and access*, designers develop outreach materials that are clear, culturally grounded, and distributed through channels trusted by communities. Designers can also help to clarify roles and expectations within a team environment

In the second stage, *initial engagement and active participation*, design methods such as co-design workshops, storytelling activities, and early trust-building enable patients to include their input at the beginning as a project is scoped. This early involvement allows for the patients to see their involvement in the process. Design tools such as journey maps and visual storytelling can help to visualize where patient involvement is critical.

In the third *integration and partnership* stage, shared documents such as team agreements or working together documents help to confirm that participants can be co-leads in decision making. Tools such as collaborative digital spaces, and inclusive decision-making structures enable stable partnerships online and in person.

In the fourth stage, *sustainment and capacity building*, designers can provide clear documentation, feedback loops, and toolkits that might report on project phases. Reporting keeps team members accountable and can continue to provide trust in the group for future phases of the project.

At the final *impact and outcomes* stage, designers can enable solutions that are relevant, contextual, and evidence-based.

5 Case studies

5.1 Case study 1: *Addictions Don't Discriminate* exhibition

Addictions Don't Discriminate was a multi-phase, community-based research project created with local government and partners across health and social

sectors. It aimed to increase empathy, improve communication, and enhance access to information related to addictions and mental health research while working to reduce the stigma surrounding substance use disorders.

Six online co-design workshops were held during the COVID-19 pandemic with six people who had lived experience of substance use; in addition to researchers, stakeholders, and community members.

Workshop participants collaborated with illustrators to create visual narratives – maps, stories, and using symbolic imagery that used methods rooted in the idea of graphic medicine. Graphic medicine, a visual approach that uses comics or graphic novels to tell a story sequentially, has been shown to make complex health information more accessible and engaging by using visuals as a way to reframe medicine and health (Dobbins, 2018).

The final project resulted in a series of temporary, moveable interactive museum quality panels (21 double sided panels) that were exhibited first at the Stanley A. Milner Library.[1] The panels consisted of three main areas: an introduction to the concept of addition and the storytellers, the six different stories of lived experience and the overlapping themes, and finally an area that includes resources and activities about addiction that mobilize and encourage community action and allow the participants to reflect on their own relationship with substances. The exhibit presents real-life narratives of individuals impacted by addiction to draw attention to the prevalence of substance use disorders. Visitors of the exhibit participate in an immersive experience, walking through personal stories to understand addiction from multiple perspectives. The experience is also available by visiting the project website, a hosting toolkit, and evaluations for participants and hosts to complete. QR codes throughout the panels enabled participants to access additional information and show related video and audio content.

1 https://edmontonjournal.com/news/local-news/addictions-dont-discriminate-exhibit-on-display-at-stanley-a-milner-library

Figure 2 Photos of Addictions Don't Discriminate exhibition panels, photography by Cooper and O'Hara.

5.2 Case study 2: *Supporting Healthy Partnerships with People Who Use Drugs* (PWUD): a toolkit

A community-partnered realist review examined how, why, and under what conditions people who use drugs experience benefits or harms when engaged in health system projects. Findings emphasized the need for equity, safety, fair compensation, supportive environments, and anti-stigma strategies (Salvalaggio et al, 2022). The review found that healthy partnership can be transformative for PWUD, but it depends on social and structural support, clear role definition, cultural safety, and an anti-oppressive space that fosters personal development. Several recommendations were generated to guide partnership best practices, including fair compensation, clear role descriptions, psychological and cultural support, continuous learning, and meaningful input into key decisions.

We co-designed the Toolkit with PWUD and non-PWUD partners, developing visually clear vignettes on five key themes: compensation, trust and safety, physical environment, people and perceptions, and systems and processes. A workshop with healthcare providers, researchers, and PWUD then gave us feedback on content and usability.

The Toolkit is rooted in collaboration: PWUD co-researchers, academic investigators, and clinical teams have all been integrated into its design. Partnerships with local public health organizations such as AAWEAR, CRISM Prairie Node, and professional organizations ensure that the Toolkit reflects diverse voices and can be directly embedded in practice.

PWUD and non-PWUD members of the review team developed a PWUD-centered knowledge mobilization strategy for the review findings and recommendations, identifying the development of a best practice Toolkit as a key resource to maximize review impact. We obtained Foundation for Advancing Family Medicine funding to initiate the co-design of the Toolkit, intended for use by front line teams, health system planners, and adjacent academics to optimize the partnership environment for PWUD partners. To date, the project core team has co-created a series of visually oriented, plain language vignettes exploring five interrelated themes of 1) compensation, 2) trust and safety, 3) physical environment, 4) people and perceptions, and 5) systems and processes. We subsequently held a workshop with 20 Edmonton-area healthcare professionals, researchers, and PWUD with lived experience of PWUD partnership within the health system; this group provided specific feedback on the Toolkit's content and useability.

A game was developed that used illustrations to indicate personas and scenarios that participants could identity with. Instructional materials were created to clarify the game structure and strategy as well as pre and post workshop evaluation. A mixed group of clinicians, researchers, and community members then tested and refined the Toolkit in a series of co-design sessions.

Through the use of a set of facilitator instructions and a workshop participant workbook, the Toolkit provides actionable guidance to health teams seeking to collaborate ethically and effectively with people who use drugs. It clarifies roles, supports equitable engagement, and provides practical recommendations for building trust and reducing power imbalances.

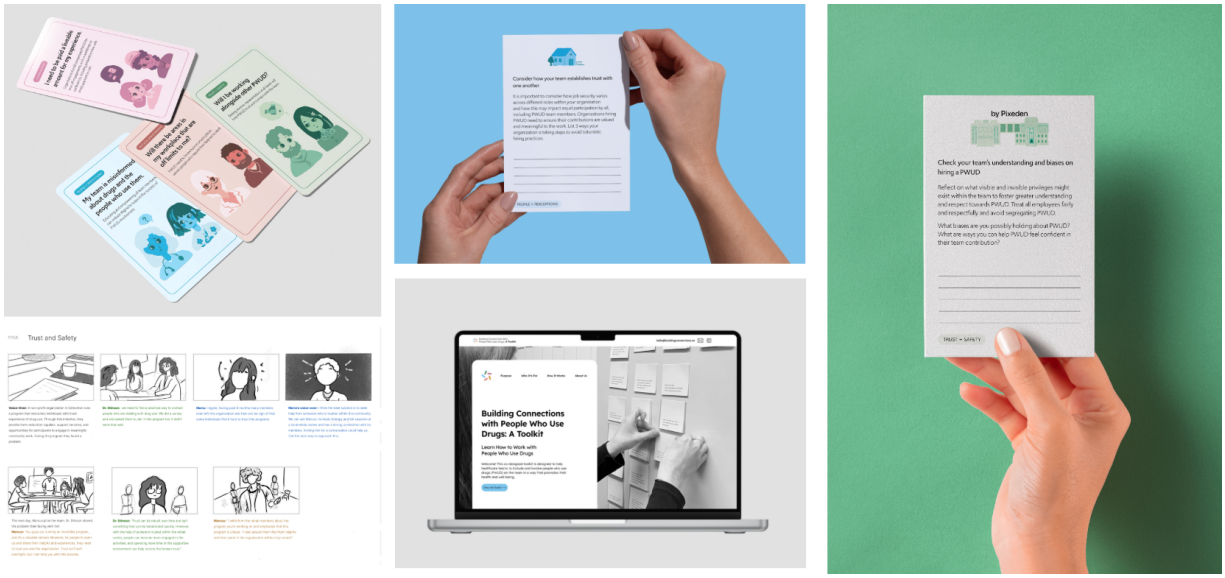

Figure 3 Photos of the Toolkit cards, storyboards, and interactive tools.

5.3 Case study 3: opioid education toolkit

Between 2016 and 2018, over 11,000 Canadians and 136,000 Americans died from accidental opioid overdose. By 2023, Alberta alone saw more than 2,000 deaths – a threefold increase since 2016. In response, Canada expanded access to naloxone kits, a medication that can reverse opioid overdoses. But access alone is not enough. Studies show that while naloxone is often present at the scene, it's frequently misused or not used at all. Part of the problem is inconsistent and unclear instructions – designs that don't meet the needs of people in crisis. Awareness and access must include not just distributing naloxone, but ensuring the information is clear, accessible, and usable for everyone – from trained healthcare workers to bystanders with no medical background. There are gaps in how overdose response instructions are delivered. There is a lack of standardized guidelines for content or format.

- Instructions often ignore graphic and legibility principles – things like hierarchy, typography, or use of color.
- There are language inconsistencies in tone and terminology.
- Few resources are translated into other languages.
- And most are written by health providers so they fail to consider the needs of lay responders to indicate that there was an urgency
- Lack of "feedback" loops

By examining existing overdose response records, we identified areas where visual communication could be enhanced to improve understanding and engagement in overdose response, specifically by community overdose responders. building on these insights, we aim to design a comprehensive guidance document tailored specifically for distribution within community

take-home naloxone programs. We employed an iterative search and screening process to generate publicly accessible 54 provincial and territorial harm reduction policy documents that were current to the end of 2015. Documents were content-analyzed using a deductive coding framework comprising 17 indicators that assessed the quality of effective communication design principles relative to how well they described key population and program aspects harm reduction.

Beyond creating a one-time resource, we focused on building long-term capacity. The toolkit was designed to be modular, customizable, and open-access – so communities can adapt it to their own needs. We also developed the Naloxone Instruction Evaluation Tool, or NIE, which helps assess the effectiveness of instructional materials. Both the toolkit and evaluation tool are available on the Design Research for Opioid Education website,[2] with printable and mobile-friendly formats. This ensures the resources can travel – whether through posters, wallet cards, or mobile apps – reaching diverse audiences across Alberta and beyond. By equipping communities with adaptable, sustainable tools, we're enabling them to carry forward stigma-reduction and overdose-response education long after the project ends.

2 https://www.droe.ca/

- Digital and printable formats allow materials to be customized and reused.
- Hosting through DROE ensures ongoing accessibility and tracking of usage.
- Evaluation tools (NIE) enable communities to assess and adapt resources.
- Iterative prototyping and feedback cycles refined the toolkit for usability across diverse audiences.

This capacity-building approach equips not just healthcare professionals, but also families, peers, and community workers, with the confidence and resources to act in emergencies and reduce stigma.

Through this process, we identified four key design themes, including the importance of clarity, cultural sensitivity, empathy, and reducing stigma. These guided the final Opioid Education Toolkit, which provides healthcare professionals, PWUD, and community members with accessible, accurate, and user-friendly overdose response resources. The toolkit lowers barriers to action in moments of crisis, giving confidence to bystanders and reducing fatal outcomes. Importantly, this work also highlights the power of participatory design: by engaging stakeholders throughout, we didn't just create a resource – we created a process for ongoing improvement and local adaptation. The impact is both immediate, in saving lives, and long-term, in shifting how overdose response information is designed, shared, and sustained. Survey and workshop participants emphasized that clear, stigma-free, and visually accessible resources would:

- Increase bystander confidence in responding to overdoses.
- Reduce misuse or hesitation when using naloxone.
- Normalize compassionate, stigma-free language in overdose response.
- Provide customizable tools for diverse contexts (healthcare, shelters, public spaces, workplaces).

The toolkit and NIE are now publicly available on DROE, supporting national dissemination. Conference presentations, community partnerships, and open-access hosting extend their reach. While further evaluation and scale-up are needed, this project offers a replicable model for co-designing effective, equitable, and stigma-reducing health communication tools in the opioid crisis. These tools help ensure anyone – even without medical training – can recognize an overdose quickly and confidently.

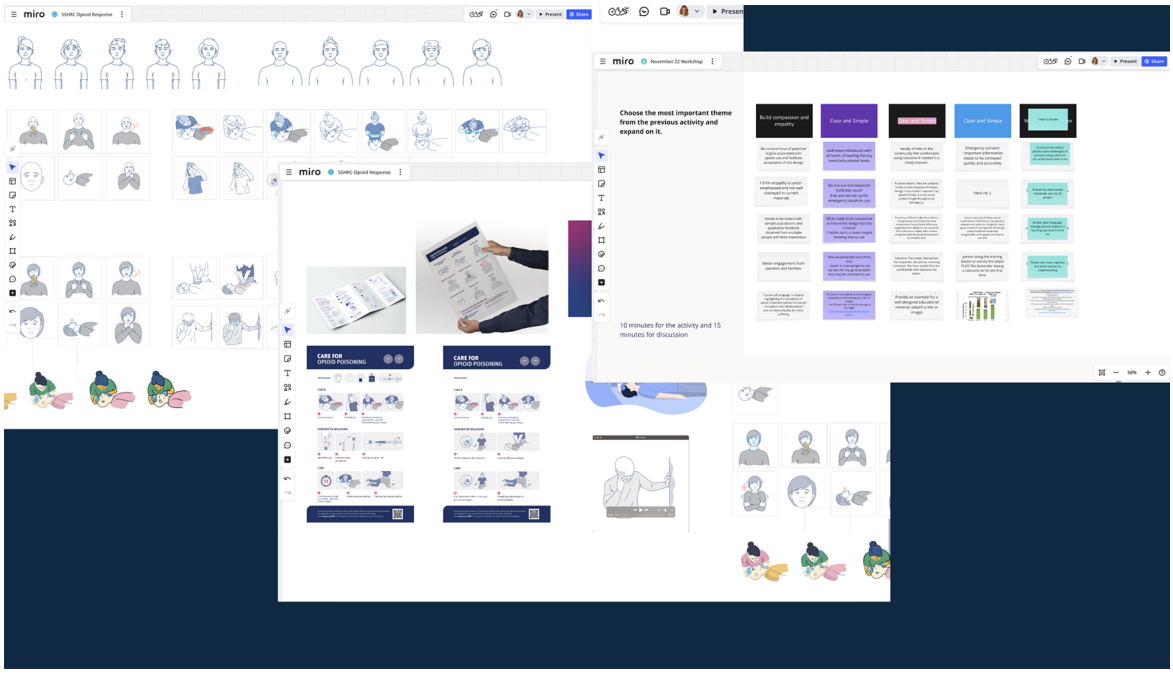

Figure 4 A MIRO board of a co-design workshop, held online in 2024.

6 Discussion and next steps

Across all case studies, design is shown to act as a bridge between communities and health systems improvement. Information design can clarity, reduce stigma, and supported navigation within g a system. Participatory design can provide structure for inclusion, safety, and shared ownership within a team environment. In fact, as described by Bason, Design offers a way of connecting people, systems, and services, enabling collaboration across disciplinary and organizational boundaries in healthcare (2014).

Together, these frameworks allowed for impact that is accessible and contextually grounded; collaborative processes where lived experience guides decision-making from the initial scope of the project to the final outcomes and creates sustained partnerships between communities and institutions; systems that acknowledge and address inequities.

Future work could expand co-design approaches to enable groups to develop frameworks for long-term partnership sustainability; evaluate

impacts of design interventions on health outcomes; and advance culturally grounded and Indigenous-led design collaborations.

7 Conclusion

Design provides powerful methods for strengthening patient voice, particularly in contexts marked by stigma, inequity, and exclusion. By integrating information design and participatory design within the Cascade of Care framework, health systems can create more accessible communication, more inclusive engagement processes, and more service environments. The case studies demonstrate that when lived experience is treated as expertise and collaboration is built on equity and care, meaningful systems transformation within the health space is possible.

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