The Planetree Global PFPC Guide to Person-Centered Co-Design

ABOUT THIS GUIDE

In the healthcare sector, the term “co-design" has been interpreted, defined, and applied in a variety of ways, sometimes leading to confusion and inconsistency in understanding and implementation. While many healthcare organizations have made great strides in efforts to integrate patient and family voices into every aspect of healthcare design and delivery, more work remains to be done. Recognizing this, Planetree’s Global Patient and Family Partnership Council (Global PFPC) has developed this guide, offering a plan of action for engaging patients, family partners, and others in the co-design process.

Person-centered care is rooted in quality, compassion, and partnership. Person-centered co-design reflects these same values. The term “co-design” is made up of two parts: “co,” a prefix derived from Latin, meaning “together, with, or jointly” and “design,” referring to “the creation of a plan.” In healthcare, person-centered co-design refers to a collaborative process via which products, services, systems, and policies are created and implemented with and alongside all the stakeholders who will experience them, rather than for them. This guide provides a comprehensive, step-by-step plan to collaborating with stakeholders in person-centered co-design, from engaging, planning and exploring to developing, executing and evaluating impact.

WHAT IS PERSON-CENTERED CO-DESIGN?

Planetree defines co-design as a participatory approach in which solutions are designed with the people who will experience them. All are treated as equal collaborators from the very beginning of the design process. Person-centered co-design brings together the lived experience and expertise of patients and families with the professional and technical expertise of healthcare staff and clinicians to foster mutual learning and create better solutions through thoughtful and intentional design. It involves patients, families, caregivers, and staff working collaboratively to explore the care journey, both the process and the emotional aspects, gathering insights from these experiences and using them to inform improvements. The knowledge that patients and families hold about their own experiences is unique, deeply personal, and invaluable. Co-design aims to access and harness this knowledge to enhance the care experience for all stakeholders.

Embedding person-centered co-design in a healthcare organization's practice and processes sets a high standard of care by emphasizing partnership and shared leadership. Co-design makes it possible for healthcare professionals to work alongside patients, families, and caregivers as equal contributors, ensuring their perspectives are respected and embedded in every stage of design and decision-making. When done right, person-centered co-design transforms patients and families from passive participants into active, engaged partners. Rather than simply being consulted, they help shape and decide the design and implementation of services, products, and policies, playing a central role in driving innovation and improvement.

At its core, person-centered co-design is about amplifying and integrating the voices of those with lived experience. Importantly, it is not a one-off fix, but an ongoing process. The most effective outcomes come from regularly seeking input, reflecting on progress, and adjusting practices as circumstances, technology, methodologies, and patient, family, and caregiver preferences and needs evolve over time.

WHY IS PERSON-CENTERED CO-DESIGN IMPORTANT?

Patient and family voices can be powerful drivers of system transformation, uncovering barriers, identifying solutions, and informing lasting change.

When patients and families are involved in person-centered co-design at the very beginning of an initiative and given a seat at the table, solutions reflect their lived experience. This leads to to solutions that are more relevant, improving stakeholder experience, increasing satisfaction, and improving health outcomes. The process of co-design actively incorporates the perspectives of diverse populations, helping to create healthcare solutions that are accessible and equitable for all, including those often overlooked. The collaborative nature of co-design fosters trust and relationships among patients, families, caregivers, providers, and the healthcare system. In essence, co-design is about moving from designing for to designing with patients and families, leading to more effective, equitable, and person-centered healthcare.

Engaging people with lived experience is increasingly recognized as crucial for developing effective and relevant solutions. Their input can help shape policies, programs, products, and services that better meet the needs of the communities they represent. Incorporating these perspectives enables advancement beyond assumptions and generalizations, resulting in more targeted and impactful approaches.

CO-DESIGN IN ACTION

When redesigning an emergency department, patient and family partner involvement led to improvements in examination room seating availability for family members, visible sharing of anticipated wait times, availability of free phone chargers, and a paging system that allowed family members the opportunity to step away from the waiting room to use the washroom, get food, and attend to other needs. These changes helped to reduce anxiety levels and enabled readier access to information, thereby improving patient, family, and emergency department staff experience and safety.

KEY PRINCIPLES OF PERSON-CENTERED CO-DESIGN

The implementation of person-centered co-design follows several key principles to ensure true collaboration, joint decision-making, and genuine valuing of perspectives and contributions from all stakeholders. The process is nonprescriptive and nonlinear and may be adjusted as the context evolves.

The key principles are as follows:

ENGAGE

- Establish “buy-in” from leadership, clinicians, and non-clinical staff, for instance by engaging senior leaders as champions for co-design
- Include at least two patient and family partners on all improvement projects from inception to ensure their lived experiences are incorporated from the start.
- Onboard patient and family partners to mitigate any power imbalances.
- Clearly demonstrate that patient, family, and caregiver lived experience is valued as much as professional and technical expertise by compensating patient and family partners and by considering patient and family partner needs when scheduling or determining the modality of meetings.
- Exercise co-leadership of the co-design project with a patient/family partner lead and an organizational lead to prioritize collaboration.
- Ensure the co-design space promotes equity by being safe, accessible, and confidential, where all are appreciated, supported, and welcomed.
- Empower individuals to contribute their expertise and experience, giving them a genuine voice in shaping healthcare.

PLAN

- Convene a working group of all stakeholders to jointly define the problem and the scope of the project.
- Respect and appreciate diverse perspectives, especially of those with lived experience.
- Ground solutions in real-world needs and preferences.

EXPLORE

- Be curious, ask questions, defer judgment, and explore with others to gain powerful insights and ideas.
- Be comfortable with uncertainty.
- Slow down to listen, connect, and learn.

DEVELOP

- Turn ideas into detailed and specific improvements.
- Strategize implementation of the identified improvements.
- Define goals and/or metrics for the success of the project.

KEY PRINCIPLES OF PERSON-CENTERED CO-DESIGN

The key principles are as follows:

EXECUTE

- Test proposed ideas.
- Determine what improvements to make, how to make them, and when to make them.

EVALUATE, MEASURE, SEEK FEEDBACK

- Seek feedback from stakeholders on a continual basis.
- Assess whether implemented ideas are achieving their intended results as defined by all stakeholders.
- Verify that the process and outputs (e.g., a policy, process, or product) create value for those they are intended to benefit.
- Adjust and make changes based on feedback.
- Debrief project experience with all stakeholders to ensure that work has been completed collaboratively and in partnership, with all stakeholders having had an equal voice.
- Continually identify areas of opportunity for improvement to strengthen impact.

CONCLUSION

This guide was created to encourage all stakeholders to broaden their perspectives and to be intentional about their improvement processes. It is intended as a resource for person-centered co-design. By providing a comprehensive, step-by-step person-centered co-design plan from engaging, planning, and exploring to developing, executing, and evaluating, this guide highlights the critical need for collaboration and partnership across the healthcare sector.

The Planetree Global PFPC intends this document to inspire stakeholders and decision-makers to adopt a mindful approach in their person-centered co-design work to amplify the voices of patients, families, and caregivers. This is a living document that will evolve over time and hence, the Planetree Global PFPC welcomes continuous feedback. This guide will be continually revised to reflect evolving best practices, ensuring its continued relevance.

ABOUT THE PLANETREE GLOBAL PATIENT & FAMILY PARTNERSHIP COUNCIL

The Planetree Global Patient and Family Partnership Council (Global PFPC) is comprised of dedicated patients and family caregivers from around the world, each with their own unique lived experience. They are committed to advancing Person-Centered Care (PCC) and to humanizing healthcare.

GLOSSARY OF TERMS

Care Partner
The individual, typically a family member or friend, the patient designates to provide for their care and support (emotional, legal, physical, medical, etc.).

Caregiver
Friend, family, healthcare staff, and others involved in providing care to a patient. When referring to a caregiver, it is important to differentiate between a professional and a “family” caregiver.

Co-Design
A participatory approach to designing solutions with the people who will experience them. All are treated as equal collaborators from the very beginning of the design process.

Experience-Based Co-Design (EBCD)
A participatory approach to designing care solutions with the people who will experience and receive it. EBCD is a joint venture that involves patients, families, caregivers and organizations working in partnership throughout the co-design process.

Family
Whomever the patient designates to be their “family.” This can be biological relatives, friends, neighbors, or others.

Lived Experience
First-hand knowledge and understanding gained from personal involvement in a particular situation or circumstance, rather than through second-hand accounts or research. It emphasizes the unique perspective and insights individuals derive from their own direct personal encounters.

Patient
An individual seeking/in need of and/or receiving medical care.

Patient and Family Engagement
Involves the actual participation and meaningful interaction among a patient and family, their care team, and the healthcare system. It is demonstrated by doing with, as opposed to doing to or for, the patient and family.

Patient Experience
The sum of all interactions, shaped by an organization's culture, that impact patient and family perceptions across the continuum of care (adapted from the Beryl Instititute).

Patient and Family Partnership Council (PFPC) and Patient and Family Advisory Council (PFAC)
A group of patient and family caregivers with lived experience dedicated to advancing Person-Centered Care (PCC) through collaboration and co-design in health systems and organizations.

Person-Centered Care (PCC)
Compassionate, collaborative care that improves outcomes by focusing on what matters to everyone involved in a healthcare experience, including those seeking, providing, and supporting care.

Stakeholder
Any individual, group, or organization that has an interest in or is affected by the outcome, success, or decision that results from a project, business, or initiative.

REFERENCES

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RELEASE NOTES

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