

Co-Design with Patients for Improving Patient Safety: Strategies, Barriers and pitfalls

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Abstract

What happens when “frontline” workers are patients and family members performing health-related tasks? As more and more complex healthcare tasks are performed by patients and family members, and more emphasis is placed on patient- and family-centered care, strategies are needed to engage patients and family members in co-design “work systems” and patient-professional collaborative work. Human factors professionals are well-equipped to apply participatory ergonomics to patient and collaborative tasks. However, there are a number of barriers and pitfalls in engaging patients in design. Moving from tokenism to meaningful engagement in research requires patience, constant reflection, and a commitment to codesign. Our panel will explore the continuum of engagement and strategies to move from tokenism to partnership to cocreation in patient safety research, ranging from ambulatory medication safety to diagnosis in the emergency department. Strategies and barriers are presented as a starting point to discuss how to achieve effective work system designs.

Keywords

Patient safety, Patient co-design, Macroergonomics, Patient engagement

Summary

Tasks performed by patient and families are not typically considered even though their roles in healthcare are increasingly recognized. Patient work and collaborative work with professionals is reflected by macro-ergonomics models such as Systems Engineering Initiative for Patient Safety (Holden et al, 2013). Healthcare is even framed as co-production of services between patients and professionals, versus one-way delivery by professionals to patients as passive recipients (Batalden et al, 2016). What happens when “frontline” workers are patients and family members performing health related tasks, as reflected by the interests to understand tasks performed by patients (Holden & Valdez, 2021)? How should patients and family members be involved to design tools and tasks? How should they be trained? As more and more complex healthcare tasks are performed by patients and family members, and more emphasis is placed on patient- and family-centered care, strategies are needed to engage patients and family member to co-design “work systems”, patient work, and patient-professional collaborative work. Human factors professionals are well-equipped to apply participatory ergonomics to patient and collaborative tasks. However, there are a number of barriers and pitfalls in engaging patients in design.

As an example, one concern is tokenism, “the practice of making only a perfunctory or symbolic effort to do a particular thing”. In patient safety in general and patient safety research in particular, engaging patients as partners in our work runs along a continuum. Moving from tokenism to meaningful engagement in research requires patience, constant reflection, and a commitment to codesign. This may be achieved in different ways at different time points within the research activities. Our panel will explore, with examples, the continuum of engagement and strategies to move from tokenism to partnership to cocreation in patient safety research, ranging from ambulatory medication safety to diagnosis in the emergency department. Strategies and barriers are presented as a starting point to discuss and share how to achieve effective work system designs that support safety improvement.

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Overview of the panel

The panel consists of researchers as well as a patient. The researchers have attempted co-design strategies in a number of healthcare settings. One team was redesigning primary care work systems to support and encourage active involvement in medication safety by older adults and their caregivers. Another team was designing for improving communication and shared decision making in diagnosis. A third team was designing tools to support medication management at home. A fourth team was designing implementation strategies. By sharing examples, the panelists will describe strategies and barriers of engaging patients and family members as co-designers in patient safety related projects. The panelists will be challenged by addressing issues in project conceptualization and implementation logistics of including patients in design processes. After introduction of prerogative and benefits of patient co-design, several project examples will be presented. The panel presentations will serve as a starting point for discussion with audience.

Panelists and Position Statements

Co-Design for Safety-II and Ambulatory Medication Safety

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Noah Hendrix is the project manager for the PROMIS Lab and is a doctoral student in public administration and public policy. **Yan Xiao** is a professor in the College of Nursing and Health Innovation at University of Texas at Arlington. The PROMIS Lab is supported by grant number R18HS027277 and a COVID supplement from AHRQ. Other key members of the PROMIS Lab include Kathryn Daniel, Yuan Zhou, Jennifer Roye, Kay-Yut Chen, Kimberly Fulda, Anna Espinoza, Kathleen Sutcliffe, Ayse Gurses, Richard Young, and Somer Blair. The PROMIS Lab is a consortium of three universities and a safety-net healthcare system with a multi-disciplinary team bringing expertise from the fields of human factors, family medicine, gerontology, nursing, pharmacy, business, industrial engineering, safety science, visual design, and patient advocacy. The focus of the PROMIS lab is to support the work of patients and families, as well as the collaborative work between professionals and patients/families, in medication use.

Engaging patients and their family members is critical for ambulatory medication safety. Through a systematic review, our team identified that patients' medication self-management activities at home are key contributors to adverse drug events in community settings, which contrasts the major research focus on primary care prescriber actions (Young et al., 2022). Interventions targeting errors and non-compliance in complex

primary care settings are unlikely to be effective (Young, Roberts & Holden, 2017). For these reasons, we adopted a Safety-II lens in our efforts to enhance patients' resilience at home and patient-provider communication and creative problem-solving in the clinic. We developed interventions through a co-design process.

Our team partnered with community-dwelling older adults and their caregivers in different stages, starting with problem definition and conceptual redesign, to specific design of tools and processes. In the first stage, semi-structured interviews and focus groups were conducted by recruiting patients in primary care and residents in a senior living facility. Older adults expressed great trust in their providers and communicated that they understand their role in safety supersedes taking pills as prescribed (Jallow et al., 2023). Older adults held varying attitudes regarding the power dynamics in their care; some deferred decision-making to providers and just followed instructions while others sought to inform themselves and engage in shared decision-making. We also conducted time-motion studies and observed visits to capture the patient journey. We narrowed our design space to innovative point-of-care education videos, a visit preparation guide, and a reward system for positive patient behaviors to help patients learn about managing their medications at home and communicate with providers during appointments. In the second stage, we conducted iterative design workshops with rapid prototyping in a simulation facility with older adults by walking through primary care encounter scenarios. In the third stage, to broaden patient participation, we conducted surveys in partner clinics to measure patient interest in potential topics for the educational videos. Our goal in the co-design process was to develop interventions that met patients at their level of health literacy and empower them to learn and communicate information that is most valuable to themselves and their provider. To support health equity, we are developing the interventions in English and Spanish and will translate the videos to other languages in the coming months. At the time of submission, we have started to implement the interventions at partner sites and began data collection for a clinical trial to evaluate their efficacy. We anticipate the next stage will be debriefing by older adults after participating in simulated primary care encounters with the new videos, visit preparation guide, and redesigned primary care workflows.

Eliciting in-depth and representative responses for qualitative interviews proved to be a barrier in moving beyond tokenism with both patients and providers. Participants understandably struggled to speak on open-ended questions, especially those focused on system redesign. We believed that those answers were critical parts of genuine co-design, as opposed to treating end users as research N's. We found that the critical incident technique enabled effective communication by allowing participants to draw on their personal experiences. There were also some logistical issues: it is easiest for patients to participate while at the clinic for appointments, but

that makes lengthy or group activities difficult. We solved that by bringing patients on campus, but that's a greater commitment for them and complicates logistics. These options required tradeoffs. Lastly, strong clinic partnerships proved incredibly helpful in all aspects of co-design.

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Optimizing the Communication of Diagnosis by Co-Designing Solutions with Patients and Families

*Kristen Miller & Carole Hemmelgarn
MedStar Health and Georgetown University*

Kristen E. Miller, DrPH, MSPH, MSL, CPPS, is the senior scientific director of the MedStar Health National Center for Human Factors in Healthcare, an associate professor of emergency medicine at Georgetown University School of Medicine, affiliate faculty at Georgetown Innovation Center for Biomedical Informatics, and adjunct faculty at Catholic University Department of Biomedical Engineering. In her role as scientific director, she leads and manages the Center's scientific research which applies novel approaches to improving patient safety and quality and includes projects that apply systems thinking and human factors engineering to clinical research to support the delivery of high-quality care. Dr. Miller is a clinically oriented human factors researcher focusing on medical decision making, informatics, and the assessment of medical interventions with an emphasis on health information technology, usability, human error and patient safety. Her work incorporates both industrial engineering and cognitive psychology components and takes into account the entire system, from cultural components to characteristics of individual patients.

Carole Hemmelgarn, MS, MS, has worked in healthcare for 30 years. Her personal interest in the field of Patient Safety has lead Carole to get a Master of Science Degree in the field of Patient Safety Leadership from the University of Illinois Chicago. Carole is an adjunct professor at the University of Illinois Chicago and Georgetown University teaching in their master's programs for Patient Safety. She holds a second Master's Degree in Health Care Ethics from Creighton University. Carole is involved in patient safety work across the country. She sits on the Patient and Family Advisory Council for Quality and Safety at MedStar Health, Board of Quality, Safety and Experience at Children's Hospital Colorado, Pediatric Sepsis Outcomes Collaborative at Children's Hospital Colorado, Clinical Excellence Council for Colorado Hospital Association, Board of Directors for the Collaborative for Accountability and Improvement and MedStar Institute for Quality and Safety Advisory Board. Her passion resides in the area of Communication and Resolution Programs, health care communication, storytelling in health

care and the aftermath endured by providers, patients and families when medical harm transpires.

Patient involvement in healthcare decisions is increasingly recognized as important for matching care plans with patient preferences, improving patient safety, and quality of care (McDonald, Bryce & Graber, 2013; Stacey et al, 2017). Research demonstrates the benefits of patient involvement on processes and outcomes of care (Bary & Edgman-Levitan, 2012) but few studies have addressed patient-targeted interventions during diagnosis to reduce error (McDonald et al, 2013; Singh et al, 2012). While there have been modest improvements in reducing diagnostic error, much of this research has focused on the epidemiology of the problem and clinician-focused mitigation strategies, largely ignoring the critical role of the patient in detecting and preventing errors in their own healthcare. Our research consistently demonstrates that patients have unique insights on the quality, safety, and experiences of healthcare, including diagnostic safety (Smith et al, 2020; Giardina et al, 2021; Smith et al, 2021). Patients not only identify diagnostic errors, but also diagnostic safety pre-cursor events akin to near misses and unsafe conditions that precipitate diagnostic errors (Stacey, et al, 2017; Bary & Edgman-Levitan, 2012; McDonald et al, 2013; Singh et al, 2012; Smith, et al, 2020). Despite recent advancements, reducing diagnostic errors requires a broader focus on improving diagnosis, one that considers diagnosis from a patient-centered perspective, as suggested by the NASEM report (Balogh, Miller, & Ball, 2015). Patients need to be recognized as vital partners in the diagnostic process both at the point of care and, perhaps more importantly, in driving fundamental research questions to address system level change and in co-designing sustainable and scalable solutions. The NASEM definition of diagnostic error is two-fold: the failure to establish an accurate and timely explanation of the patient's health problems or failure to communicate that explanation to the patient. Dr. Miller and Ms. Hemmelgarn are co-leading a team of patients, advocates, clinicians, and researchers to codesign solutions aimed at improving diagnosis at the point of care – ensuring that patients receive the information they need to not only fully understand their diagnosis but respond appropriately.

Engaging Family Caregivers to Co-Design Technology Interventions for Medication Safety in the Home

*Nicole Werner, PhD
Indiana University Bloomington*

Nicole Werner, PhD, is an Associate Professor and Dean's Eminent Scholar in the Department of Health and Wellness Design at the Indiana University School of Public Health-Bloomington. Trained in Human Factors and Applied Cognitive Psychology, she is a systems thinker and human-centered design evangelist committed to transforming the

health journey for people living with chronic conditions and their family caregivers through human-centered system design. Funded by the National Institutes of Health and the Agency for Healthcare Research and Quality, her research has produced innovative but realistic health technology and care process interventions to promote health and improve the quality and safety of healthcare within and across healthcare settings, with a particular focus on older and vulnerable populations and their care partners.

The United States relies on over fifty million family caregivers to provide unpaid care to adults and children with health or functional needs, and the need is increasing. Despite this reliance, caregivers are persistently and pervasively under-supported and under-resourced in their caregiving role. Thus, it is not surprising that caregivers often experience high levels of stress, burden, burnout, depression, and morbidity, which influences the care of the person they care for. To design interventions that better meet the unique needs of caregivers delivering healthcare at home, we are using participatory design to co-design solutions *with* caregivers. Participatory design engages end-user representatives as active members of the design team to design the intervention (*Routledge International Handbook of Participatory Design*, 2013). Empowering people living with chronic conditions and their family caregivers in participatory co-design increases the chances to produce technology interventions that will be usable, useful, relevant, acceptable, and adaptable to their actual needs and current routines (Evenson et al., 2008; Mackrill et al., 2017). Further, participatory design promotes strengths-based (vs. deficit-based) treatment of people living with chronic conditions and their caregivers.

Dr. Werner will describe two studies that used participatory co-design to engage care partners as designers of a solution to support medication safety through caregiver assisted medication management—Helping the Helpers and MedS@HOME. Helping the Helpers is focused on employing a three-stage human-centered design process, including co-design, to design and evaluate a technology intervention to support family caregivers of people living with Alzheimer's disease and related dementias (ADRD) who are managing medications for the person living with ADRD (Werner, Campbell, et al., 2022). MedS@HOME is focused on co-designing and the efficacy testing a mobile application for families of children with medical complexity. The MedS@HOME project adapted an existing mobile app intervention, @HOME, was initially designed to manage and coordinate enteral care (Cheng et al., 2020; Werner, Fleischman, et al., 2022), to improve medication safety by improving medication management across the network of caregivers required to care for children with medical complexity in the home and community.

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Walking a tightrope: The Pearl of Success and Pitfall of Tokenism in Patient-Engaged Research

*Kelly Smith, PhD
University of Toronto*

Kelly Smith, PhD, is the Michael Garron Chair in Patient Oriented Research at the Michael Garron Hospital and Associate Professor and Program Director of Health Services Research – Outcomes and Evaluation at the Institute of Health Policy, Management, & Evaluation at the University of Toronto. Dr. Smith leads a rich portfolio of research on coproducing practical solutions to challenges of healthcare delivery with a focus on patient safety and quality improvement in partnership with patients, family members, and caregivers. Dr. Smith is a leading investigator in patient-oriented research, forging partnerships with patients to codesign research and innovations to improve the quality and safety of healthcare delivery. Kelly has led large scale implementation and evaluation projects for clinics, hospitals, health centers, and health systems across the U.S. that aim to better integrate evidence into practice and is currently a leading investigator on strategies to engage patients in diagnostic safety improvement.

Contemporary research and innovation are grounded in advancing the principles of patient-centered care, with a hallmark of purposively engaging patients and family in the full path of research activities from problem identification through solution evaluation and knowledge translation (Carman et al, 2013; Domecq et al, 2014). Engagement of patients and family along this research continuum, however, takes time, advanced skills, funding, humility, and commitment to the values of patient-centeredness and meaningful engagement (Carman et al, 2013; Domecq et al, 2014). Failure in this commitment can lead to tokenism (Domecq et al, 2014). Tokenism has been defined as “the practice of making only a perfunctory or symbolic effort” to engage with patients. Tokenism in patient safety research may be easy to justify given financial or other constraints – resulting in the voice of one or two patients supplanting engagement of diverse voices and limiting trust in and the relevance of the research outputs. Thinking of research as a continuum and engagement as a matrix allows researchers to plan activities for engagement a priori, promote coproduction (Batalden et al, 2016), and mitigate risks of tokenism. Several frameworks and models have been developed to support researchers in their pursuit of meaningful engagement (Chudyk et al, 2022) and tools to evaluate the impact

of patient engagement in research activities (Vat et al, 2019) have recently emerged, providing a way to empirically assess our engagement efforts although few engaged patients in their design limiting their use (Clavel et al, 2021). Dr. Smith will share examples from her research co-leading diagnostic safety improvement science in partnership with patients from priority setting (Zwaan et al, 2023) to solution design, development, and knowledge translation (Smith et al, 2022).

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