

OCAD University Open Research Repository

Faculty of Design

2014

A communications canvas to improve and individualize patient engagement in healthcare systems redesign

Denmark, Deaunne and Olson, Danielle

Suggested citation:

Denmark, Deaunne and Olson, Danielle (2014) A communications canvas to improve and individualize patient engagement in healthcare systems redesign. In: Proceedings of RSD3, Third Symposium of Relating Systems Thinking to Design, 15-17 Oct 2014, Oslo, Norway. Available at http://openresearch.ocadu.ca/id/eprint/2073/

Open Research is a publicly accessible, curated repository for the preservation and dissemination of scholarly and creative output of the OCAD University community. Material in Open Research is open access and made available via the consent of the author and/or rights holder on a non-exclusive basis.

The OCAD University Library is committed to accessibility as outlined in the <u>Ontario Human Rights Code</u> and the <u>Accessibility for Ontarians with Disabilities Act (AODA)</u> and is working to improve accessibility of the Open Research Repository collection. If you require an accessible version of a repository item contact us at <u>repository@ocadu.ca</u>.

A communications canvas to improve and individualize patient engagement in healthcare systems redesign

DeAunne Denmark, M.D., Ph.D. and Danielle Olson, M.F.A.

Abstract

Information transfer is considered a core wicked problem and key driver of healthcare system dysfunction. Collaborative redesign efforts that facilitate efficient, transparent, and bilateral communication are paramount to dissolving barriers and effecting positive, sustainable transformation within the complex health system environment. It is now clear that prioritizing individual patient needs and values (patient-centered care), and enhancing patient involvement (patient engagement), at every stage of delivery and decision-making are critical leverage points for radical reform. Information flow that is initiated, directed, and managed by patients and caregivers aligns health decisions with those primarily affected, while substantially reducing delivery costs, eliminating waste, and increasing treatment efficacy. Such a shift is a profound and necessary departure from the historically passive role of the patient to a highly-informed partner, even leader, in disease management and health promotion. Considering the diversity among actors in any given health system, and trust as the cornerstone of effective care, focus on constructive communication and relationships is a potent strategy for designing infrastructure that supports and encourages this shift. To this end, we developed a patient-centered design tool (canvas) to help organizations improve and tailor patient engagement. Particular attention is paid to smaller practices where limited resources may prohibit the overarching changes required for substantive improvements, including those involving information technology.

Keywords: healthcare design, patient-centered care, patient engagement, health information, design tool

Introduction

Current healthcare systems are plagued by extensive barriers to efficient and accurate information transfer. Multiple issues surround the plethora of health-related data, e.g., personal data do not follow patients over time, are not standardized and integrated within or across organizations or used to guide treatment, and remain inadequate for high-quality clinical care or to understand and improve care processes (Nelson, Fisher & Weinstein, 2011). No level or participant is spared in such intricate and complex systems; patients, caregivers, providers, payers, and all ancillary service purveyors are both contributors and casualties of rapidly increasing volume, time constraints, and complexity that continue to exacerbate existing limitations (Wu et al., 2011). According to a recent independent survey of more than 400 U.S. care providers, reliance on inefficient and outdated modes of information transfer may cost the healthcare industry \$11 billion (\$1.7 million per hospital) annually in wasted time (Ponemon, 2014). Accordingly, health information exchange is considered a core wicked problem and key area for system-wide renovation.

Dissolving these barriers and effecting the substantive changes that meet the Triple Aim of improved quality and patient experience at lower costs (Berwick, Nolan & Whittington, 2008) requires distinct cultural shifts that translate into shifts in delivery. Historically, the patient role has been one of a passive, less-informed recipient of health goods and services who unquestionably follows the instructions, regimens, and treatment plans of their all-knowing providers. While the last few decades have seen a large movement of patients and caregivers to become more active, informed, and influential in all aspects of the healthcare they seek, terms like "adherence" and "compliance" still dominate and restrain progress in the majority of health systems.

Fundamental to this shift is refocusing delivery on the original intention of medicine – service. Success in service industries is predominated by satisfaction and outcomes, with competitive advantages for those who invest in developing relationships that extend beyond transactions. For health systems, this means not only creating positive, useful, and efficient interactions, but also attention to what happens when patients are away from healthcare facilities, and appreciating the critical nature of building trust. As in all relationships, trust necessitates quality communication, which is itself much more than information transfer (Chase, 2012). The concepts of patient-centered care and patient engagement (see below) have emerged as guiding principles for such changes, and while acknowledged and appreciated in theory, remain mostly unrealized in practice.

To address these needs, we developed a design tool (canvas) to help health organizations undertake fundamental shifts in culture and delivery. Influenced by highly successful change and innovation methods in business, social enterprise, and service design, the canvas aids systemic understanding, focus on service, and reimagination of the patient role as active in disease management and health promotion. A clean visual format guides users through inquiry, research, reflection and iteration, promoting value articulation and emergence of feasible solutions to the most pertinent issues. Requiring little to no additional resources, the canvas is ideally suited for small-scale practices that are often highly subject to local values and constraints, although its simple and flexible structure also allow upscaling or supplementation with team- and process-oriented support.

Resistance to new technology adoption is frequently cited as one of most prominent hindrances to progress in health systems reform. The true hindrance, however, more often lies in technologyinduced disruptions to relationships, the crux of effective care. By prioritizing and reframing health relationships to direct care delivery with, rather than to, patients (Oldenburg, 2014), and emphasizing the human and individualized aspects of communication, information transfer can be considerably improved. Most importantly, the canvas aligns care values among diverse parties, instilling and preserving the essential quality of trust. Incorporating a growth mindset (Dweck, 2006) and attention to 'bright-spots' (Heath & Heath, 2010) of real-world successes that can be leveraged and replicated, the canvas can facilitate a skillful and confident process of all scopes of systems changes, including those driven by technology.

Designing for patient-centered care

While it may seem counterintuitive that healthcare not revolve around patients, it is no secret that current systems function mostly according to the priorities and motivations of any number of other

players. Now such behavior is openly recognized as deeply dysfunctional, often outright harmful, and the movement for decision-making and delivery infrastructure to be governed first by the selfdescribed needs and desires of patients has become primary to health system reform. Termed "patient-centered care," the concept has been defined by field experts in various ways, including:

- "The experience (to the extend the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care." - Don Berwick, Institute for Health Improvement
- "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." - Institute of
- "Inclusive of cultural traditions, personal values, preferences, and lifestyles, understanding and accommodating family situations, integration of health-seeker and ecosystem into an extended care team, coordination and continuity of care." - Peter Jones, Design for Care
- "A vision for what health care should be: a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care." - Carman et al., (2013)

The Patient-Centered Medical Home (PCMH) model of primary care and Accountable Care Organizations (ACOs) are two direct and high profile outgrowths of this concept, and continue to be strongly influential in guiding the important systemic changes needed to prioritize patients.

While designing for patient-centered care is becoming common parlance in the domain of physical space healthcare renovation, the use of these principles to reconfigure delivery systems is still mostly nascent. Interfacing with patients is central to the daily interactions and core functions of health organizations, yet most have little, if any, accurate understanding of the real patient experience in illness or health system utilization (Bechtel & Ness, 2010). Thus, even minimal exposure or training in user-centered design and innovation principles, e.g., empathic interviewing, can be deeply transformative for all types of health organizations. The importance of informing healthcare redesign by the perspective of patients is being increasingly recognized, e.g., Mayo Clinic's Center for Innovation (http://www.mayo.edu/center-for-innovation/), IDEO-Stanford MedX partnerships (http://medicinex.stanford.edu/stanford-medicine-x-ideo-design-challenge-workshop/), the IHI's "What matters to you?" framework (http://www.ihi.org/Topics/PFCC/Pages/default.aspx). Encouraging all levels of health systems players to further probe the question of how else might understanding of the patient experience be acquired is essential to designing for sustainable change, particularly concerning underserved populations; those funding and designing healthcare innovation are rarely those who need the innovations most (Horn & Mendoza, 2014).

Designing for patient engagement

Relatively new, but inarguably central, to health systems reform is the pivotal concept of directly involving patients and their representatives (families, caregivers) in active roles to improve health and healthcare. Accumulating evidence suggests that better health outcomes, quality and safety

increases, and cost control can be realized more readily when patients, as the core of the system, are considered part of the solution (Carman et al., 2013).

"Patient engagement" may refer to individual behaviors, such as the framework outlined by the Center for Advancing Health as "actions people take for their health and to benefit from health care," or extend to systems levels including organizational design, governance, and policy-making. Understanding engagement as a continuum characterized by information flow and influence on care, organizational and/or policy decisions (Carman et al., 2013), or in relation to the settings in which it occurs, e.g., during the care experience, within the microsystems of clinics or hospital wards, and larger health care and community ecosystems systems (Conway et al., 2006), may be particularly useful for directing change, especially when embraced as a new value of care delivery value rather than an endpoint (Oldenburg, 2014).

While currently considered the most promising area for widespread improvements of health delivery systems (Chaudhry et al., 2006), health information technology (HIT) presents both massive opportunities and vexing challenges to designing for patient engagement. Electronic health or medical records (EHR, EMR) and patient portals aim to afford direct and active healthcare participation for patients, but often suffer from a multitude of issues including fragmentation, lack of communication or integration between various platforms, and prohibitive costs. In 2009, the U.S. Health Information Technology for Economic and Clinical Health (HITECH) act was authorized to provide funding and incentives intended to assist dissolution of these barriers and support a smoother transition. Importantly, the emphasis is on "meaningful use" of HIT – payments are contingent upon demonstrating achievements and advances in processes and outcomes (Blumenthal & Tavenner, 2010).

Contrary to the panacea it is sometimes viewed as, HIT has also been considered a major hindrance to increasing patient engagement, particularly regarding issues of privacy, security, and accessibility, as well as a direct impact on in-person interactions, e.g., data entry by providers during timeconstrained visits. Some argue that patients, especially those with active illness, are already engaged; the focus of system redesign should instead be on engaging providers to improve patient relationships via "bedside skills," e.g., open demeanor, caring attitude, reflective listening and empathy. Others have seen measurable engagement benefits from the increased physician or provider interactions afforded by email, text, and other electronic communication, with reductions in medical errors and increases in perceived "whole-person" care (Bechtel & Ness, 2010). Either way, meaningful patient engagement, i.e., that leading to sustainable health behavior choices, emerges from strong interpersonal relationships, which will continue to be a critical focus for healthcare design even amidst extensive technological utilization.

Designing for personalization

The challenges of healthcare organizations stand alone in terms of the complexity and ever-changing needs, wants, and expectations of those they serve. Unlike a business, which targets a specific population segment with a defined, narrow set of customer demands, most healthcare providers cannot be particular about who and how they serve. Even specialists who address a few conditions in depth cannot anticipate how the scenario of engagement will unfold with any given patient; each situation involves a complex web of medical histories, environmental conditions, behaviors,

technological savvy, self-awareness, health knowledge and wellness expectations, in addition to the variable expression of the same disease in different people.

Given the persistently dynamic context that providers and health seekers must navigate, designing for an optimal patient experience will likely include infrastructure that supports constant discovery, responsive and adaptable care, and consistent, reliable, bidirectional communication. For example, a flexible scaffold can be constructed, suitable for a broad range of patient experiences or health engagements, and include available prompts to aid improved situational understanding. Opportunities to actively involve an individual patient in their own care can be built into the scaffold, thereby acting to minimize human shortcomings, e.g., oversight caused by a taxed provider who might make assumptions or overlook individual needs when restricted by time and resources.

The whole area of patient engagement presents an opportunity to design for personalization. It may not necessarily be better or appropriate for every patient to move toward more engagement in every setting; patients have widely varying willingness, capabilities, interests, and goals for their own healthcare, each of which is affected by multiple factors. Viewing engagement on a continuum allows for aligning the characteristics of the person to the given situation to define and create the optimal degree of participation (Carman et al., 2013).

Overall, there is a strong call to design for personalization in many aspects of healthcare delivery, from one-on-one interactions, to highly technological advances such as genetic testing. Thus, seeking to understand how knowledge gathered from populations and over time can best be applied, yet tailored, to different health systems, materials, communications, relationships, and treatments is key for effective redesign. While a useful starting point, the one-size-fits-all model is no longer, perhaps was not ever, appropriate in healthcare.

Facilitating change

Health systems redesign is frequently addressed at the level of mega-organizations and institutions, e.g., large hospital and academic medical centers, national or state-level payers, pharmaceutical and biotech industries. Disease is managed, and health created and maintained, however, almost entirely within the communities where individuals actually live. Pervasive emphasis on HIT implementation may be creating a digital divide between large urban health systems with extensive financial and technical resources and smaller practices or rural systems that cannot absorb the steep costs of systemic change. Small-scale providers represent a sizeable proportion of health systems nationwide, and are likely to need a variety of suitable options and ongoing support to make substantive progress since they are frequently already overburdened in providing direct care.

Lasting transformation involves the collective, incremental steps of individuals. Thus, an organization can be an especially high-leverage target, and includes a powerful frame, e.g., "how we do things here," for initiating change (Jones, 2013). It is rightfully assumed that players on the provider side of health systems act toward a goal of improved patient health. However, it is quite rare that smallerscale healthcare organizations, especially solo practitioners, articulate or assess the strategies they use to meet these goals. Similarly, organization members do not usually reflect on whether their individual strategies are compatible with those of the group; indeed, most players remain unaware of their use of any strategy at all. Most importantly, it is highly unusual that these organizational values, even if well-articulated, are evaluated aside those of the patients they seek to help. As such,

concerted attention to identifying the values underlying care delivery strategies of any health organization and each of its members, and authentic consideration of how well these align with those of patients (in the their own words), is critical to facilitating appropriate, effective, and sustainable change in health systems of all sizes.

The canvas as a design tool for health system transformation

The creation of a template to initiate and enable large organizational changes or generate entirely new ventures has been a highly successful strategic tool for business (Osterwalder, Pigneur & Clark, 2010). Formatted as a visual chart, or canvas, the building blocks for key elements and areas of development can be described, developed, and mapped out according to the specifics of any individual business. Attesting to the canvas format's utility and ease, numerous versions have since been introduced for particular entrepreneurial niches, including social good and service-based. To our knowledge, however, very few, if any, similar resources are available to address the needs of health organizations (for an exception, please see http://imaginego.com/modelh/modelh-what/).

To this end, we developed a canvas focused entirely on the distinct characteristics, needs, and purpose of healthcare organizations. Their nature as hybrids of business, social, and service enterprises lends well to adaptation from the canvases and principles mentioned above, especially toward a goal of aligning the diverse values of multiple players that are frequent sources of conflict and adversity in healthcare practice and delivery (Jones, 2013). Like others, the health canvas is structured in a clean visual format to afford flexible application to various organizational sizes and scopes of change. Similarly, the format is approachable for diverse users and situations ranging from individual providers to administrative staff or clinic managers, as well as consultants and designers who are increasingly involved as agents and implementers at various levels of health systems change. Sections and building blocks are simple in appearance, yet each is inquiry-driven, requiring research, deep thinking and iteration to incorporate and maintain focus on the individualized perspectives and needs of patients.

A critical goal of the canvas is to reframe the context of health relationships. Use of alternate terms such as 'health-seeker' and 'health-advisor' instead of 'patient' and 'provider' (Jones, 2013) can diffuse assumptions of hierarchy, agency or unequal responsibility, and make progress in shifting cultural attitudes even during the redesign process. With an emphasis on communication, the canvas guides users to describe the information flow between parties, and identifies both barriers and potential solutions for improvement, including suitable opportunities for HIT implementation. Similarly, the infrastructure required to support collaboration on treatment plans and ongoing care outside the facility can be readily identified, and integrated with goals drafted by the patient (in their own words). Acting as a coordination tool, the canvas promotes clarification of the optimal action steps for reconfiguring clinic processes and procedures to deliver truly patient-centered care.

The canvas allows for an engagement continuum (Carman et al., 2013), and guides groups to define an ideal range for different types of patients, relationships, or stages of treatment. In some cases, it may be more appropriate for patients to have limited power or decision-making authority, with input sought after a care agenda has already been drafted. Other times, distributing more power and responsibility for active patient partnership with organizational leaders, front-line managers, and clinicians in care plan, delivery, and evaluation may lead to better outcomes.

Making change in our highly complex interconnected health systems can be daunting, especially for small-scale organizations. Even the task of identifying which first step to take can be paralyzing when the problems or needs seem far in excess of available resources. Like all processes, however, picking a starting point, no matter how small, is key to initiating a shift. Using a design tool like the healthcare canvas that guides collaborative strategizing with guidance, support, and a clear vision of desired outcomes can be pivotal in helping providers approach and follow through with even large systemic changes.

The canvas is currently undergoing usability testing at a mid-sized (12 practitioner) integrative facility (Sunnyside Collaborative Care, http://www.sunnysidecocare.com/) where naturopathic, Chinese medicine and acupuncture, massage therapy, and midwifery are provided in conjunction with conventional evidence-based allopathic and behavioral medicine treatment. Not only will further improvements to the overall functionality and utility for the intended goals of the canvas be identified, but this unique setting also provides an exciting opportunity to apply and refine the canvas for alternative and complementary healthcare practices.

A free downloadable version of the canvas will be released in Sept 2015 and available at DROdesign.com

DeAunne Denmark, M.D., Ph.D.

Assistant Professor MFA Program in Collaborative Design Pacific Northwest College of Art, Portland, OR ddenmark@pnca.edu

Danielle Olson, M.F.A.

Visual Strategist Principal at DROdesign, LLC Danielle@drodesign.com

References

Bechtel, C. & Ness, D.L. (2010). If you build it, will they come? Designing truly patient-centered health care." Health Affairs, 29(5), 914-920.

Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: care, health, and cost. Health Affairs, 27(3), 759-769.

Blumenthal, D., & Tavenner, M. (2010). The "meaningful use" regulation for electronic health records. New England Journal of Medicine, 363(6), 501-504.

Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. Health Affairs, 32(2), 223-231.

Chase, D. (2012). Patient engagement is the blockbuster drug of the century. Forbes.com. Sep 9. Retrieved from: http://www.forbes.com/sites/davechase/2012/09/09/patient-engagement-is-theblockbuster-drug-of-the-century/

Chaudhry, B., Wang, J., Wu, S., Maglione, M., Mojica, W., Roth, E., Morton, S.C. & Shekelle, P.G. (2006). Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. Annals of Internal Medicine, 144(10), 742-752.

Conway, J., Johnson, B., Edgman-Levitan, S., Schlucter, J., Ford, D., Sodomka, P. & Simmons, L. (2006). Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future. Institute for Family-Centered Care. Retrieved from: http://www.hsi.gatech.edu/erfuture/images/1/1f/IHIIFCCPartneringwithPatientsandFamilyPaperJun e06.pdf

Dweck, C.S. (2006). Mindset: the new psychology of success. New York: Random House.

Heath, C. & Heath, D. (2010). Switch: How to Change Things When Change is Hard. New York: Random House.

Horn, I. B., & Mendoza, F. S. (2014). Reframing the Disparities Agenda: A Time to Rethink, a Time to Focus. Academic pediatrics, 14(2), 115-116.

Jones, P.H. (2013). Design for Care. New York: Rosenfeld Media.

Institute of Medicine. (2001). Envisioning the national health care quality report. Washington (DC): National Academies Press.

Nelson, E.C., Fisher, E.S., & Weinstein, J.N. Institute of Medicine. (2011). "A perspective on patientcentric, feed-forward collaboratories." In Engineering a learning healthcare system: A look at the future: Workshop summary by the Institute of Medicine, Washington, DC: National Academies Press.

Oldenburg, J. (2014). From Compliance to Engagement: Reimagining the Patient Relationship. blog.himss.org. May 28. Retrieved from: http://blog.himss.org/2014/05/28/from-compliance-toengagement-reimagining-the-patient-relationship/.

Osterwalder, A., Pigneur, Y., & Clark, T. (2010). Business model generation: A handbook for visionaries, game changers, and challengers. Hoboken, NJ: Wiley.

Ponemon Institute. (2014). The Imprivata Report on the Economic Impact of Inefficient Communications in Healthcare. Published online Jun 2014. Retrieved from: http://www.ponemon.org/local/upload/file/2014%20Imprivata%20Report%20FINAL%203.pdf.

Wu, R. C., Tran, K., Lo, V., O'Leary, K. J., Morra, D., Quan, S. D., & Perrier, L. (2012). Effects of clinical communication interventions in hospitals: a systematic review of information and communication. technology adoptions for improved communication between clinicians. International Journal of Medical Informatics, 81(11), 723-732.