

# Organizational and Network Initiatives on Patient and Family Engagement that Accelerate Healthcare Improvement

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“If an organization is narrow in the images that it directs toward its own actions, then when it examines what it has said, it will see only bland displays. This means in turn that the organization won't be able to make much interesting sense of what's going on or of its place in it. That's not a trivial outcome, because the kind of sense that an organization makes of its thoughts and of itself has an effect on its ability to deal with change. An organization that continually sees itself in novel images, images that are permeated with diverse skills and sensitivities, thereby is equipped to deal with altered surroundings when they appear.” (Weick 1979: 249)

**I** was reminded of the above quotation from Karl Weick when first reading this timely collection of 10 case studies of healthcare organizations. In their ongoing efforts to better engage with the patients and families they seek to serve, each organization included here has a unique story to tell. Necessarily, only certain perspectives are drawn on and only specific “chapters” of those stories can be represented. However, for those of us seeking insights into how to embed patient and family engagement in healthcare delivery, this collection highlights how – as Weick suggests – each organization not only began its journey by seeking to make sense of what and why it is, but continued to do so as it travelled.

What is particularly striking is how staff, patients and family members in each of the organizations have grappled – together – with figuring things out along the way. And rather than interpreting their shared experiences solely through the narrow lens of efficiency and effectiveness of clinical and technical processes, they have brought Weick’s “diverse skills and sensitivities” to bear on the challenge of aligning such (necessary, but not sufficient) processes with broader human and social considerations. In this regard, at the beginning of this book the editors offer the intriguing proposition that there can be “no sustainable changes in system performance ... without effective co-design” (Baker et al. 2016: 12). It is perhaps worth pausing to reflect here on the definition of co-design provided by Bradwell and Marr, which centres on four elements:

- *Participation*: Co-design is a collaborative process in which as many stakeholders as possible have input.
- *Development*: Co-design evolves as a process, maturing and adapting as it takes place.
- *Ownership and power*: Co-design involves a transformation of ordinary power relations between stakeholders and aims to generate collective ownership.
- *Outcomes and intent*: Co-design has a practical focus, notwithstanding the fact that unplanned processes and transformations are likely to occur as collateral effects of the process (Bradwell and Marr 2008: 17).

The emergent, still evolving, “engagement-capable environments” identified by the editors seem to me to be striving to embody these underlying elements of co-design. How the case-study organizations have nurtured such environments bears testimony to Weick’s observation that “the kind of sense that an organization makes of its thoughts and of itself” is key to being able to “deal with change” – change represented in this case by the increasingly complex and demanding context of healthcare provision both in North America and in the UK.

Yet, despite the promise held out by the exemplar organizations described in these pages, there remains a certain fragility to the patient-centred care movement of which these organizations are clearly a part. With the notable exceptions of the Augusta University Health System and the Cincinnati Children’s Hospital Medical Center, the remainder of the case studies still retain a certain sense of newness, of novelty. The work to increase and assimilate patient engagement into their day-to-day healthcare practices begins – as described by the interviewees themselves – as recently as the mid/late 2000s. Perhaps it is not surprising, therefore, that the editors sound words of caution: there is “still insufficient evidence that increasing/improving efforts of patient-centred care ... will yield results.” It appears that in terms of the “business case for quality,” interventions to improve patient-centred care and patient engagement are typically still “not systematically evaluated, [limiting] their application elsewhere.” Those of us long convinced of the case for patient-centred care and greater patient and

family engagement have been too slow in building a robust evidence base with which to convince policy makers and senior decision-makers of the relative importance of these issues in the face of so many other competing resource demands.

But this may soon change. For example, in England our National Institute for Health Research recently commissioned no less than seven major national studies – at a cost of £3.5 million – to explore the use and usefulness of patient experience data (in all its myriad forms). Research now underway is exploring, among other issues, how front-line staff use patient experience data to support service improvement, how to optimize organizational strategies and practices for improving patients’ experiences of care and how to use digital data capture and improved analysis of narrative data to enhance the usefulness of patient-experience data in services for people with long-term physical and mental health conditions. And researchers internationally are beginning to use increasingly sophisticated evaluative study designs to explore the impact of co-production and co-design approaches in terms of improved clinical outcomes.

But that is all in the future. Returning to the stories of the 10 leading organizations presented here, the editors note “there are substantial challenges to successful engagement” (Baker et al. 2016: 12). Perhaps, however, the next stage of the journey towards accelerating healthcare improvement through patient-centred care and patient engagement needs to attend more closely to a further “novel image,” one that is more distant from the “bland displays” of narrowly focused organizations. That image is not of staff striving to engage patients in ever more meaningful ways, but of patients and staff having collective ownership of efforts to improve their shared healthcare services; power residing not in any stakeholder group, but within the process of co-production/co-design. Certainly, there will be challenges; however, to return to Karl Weick: “[I]n the last analysis, organizing is about fallible people who keep going” (Weick 2001: xi). The 10 case-study organizations described in these pages keep going.

## References

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