

COMMENTARY

Engagement for Research and Quality Improvement – More Than Just Words

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Abstract

We reflect on the paper from Hahn-Goldberg et al. (2024) who shared key learnings from a pan-Canadian quality improvement (QI) and patient engagement care transition initiative called Bridge-to-Home. In considering the approach and outcomes presented in their paper, we have generated reflections and practical suggestions on how to amplify engagement work even further: (1) patient engagement and QI are about relationships; (2) seamlessly implementing complex interventions across siloed organizations continues to be a challenge, which engagement alone cannot solve; (3) it is time for a paradigm shift; (4) QI is about human behaviour change and is inherently messy; and (5) embedding fulsome evaluation of engagement is essential.

Introduction

We appreciate having the opportunity to read the paper by Hahn-Goldberg et al. (2024), sharing the results of a pan-Canadian improvement initiative that centralized patient and care partner (e.g., family, friends, neighbours) engagement to advance the spread of the Bridge-to-Home (B2H) program (Hahn-Goldberg et al. 2015). B2H is a bundled intervention aimed at making transitions from hospital more patient-centred by including standardized discharge summaries, teach-back to overcome communication barriers to high-quality transitions (Brach 2024) and post-discharge follow-up

(Black et al. 2021) and embracing the patient and caregiver as part of the care team. As research chairs with a focus on patient-oriented research and who are embedded in complex integrated care networks, we were intrigued by the opportunities this project provided for advancing the science and practice of patient and family engagement at scale. Similar to our experiences as part of networks committed to care delivery innovation using engaged communities, Hahn-Goldberg et al. (2024) noted that quality improvement (QI) and patient engagement were mutually reinforcing – the quality of the care transitions were enhanced through partnerships with patients and care partners (i.e., family and friend caregivers) who informed the design and implementation of the interventions. By involving patients and care partners, the teams – even those that were less experienced with engagement – could speak to the value of these partnerships in producing more meaningful outputs.

Discussion

The B2H initiative was designed to activate each of the three components of the engagement-capable environments (ECE) framework (Baker et al. 2016; Fancott et al. 2018) with built-in support from a centralized hub throughout the project. The ECE framework, with a focus on roles and tangible support for leadership, staff and patient partners, provides a

holistic context to amplify the potential for success in implementing and sustaining health system improvements, particularly those that engage communities, patients and caregivers. In considering the approach and outcomes presented by Hahn-Goldberg et al. (2024), we have generated some reflections and practical suggestions on how to amplify this kind of engagement work even further to inform meaningful partnerships for research and QI in the future.

Reflection #1: Patient engagement and QI are about relationships

The importance of engaging with patients and care partners for health system improvement and research is more recognized than ever (Rowland et al. 2018), prompting evolutions in expectations of research funders and of how care delivery innovations are designed in Canada and elsewhere. Engagement of patients and care partners is no longer considered an afterthought or a “nice to have,” but has become a required competency for healthcare providers, leaders, staff, researchers and patients themselves. As such, this requires the development of engagement knowledge, skills and attitudes at every level of the health system to yield success.

By applying the ECE framework in the co-design of the B2H intervention, specifically in the selection of improvement teams and in the support provided to the patients, providers and leaders, Hahn-Goldberg et al. (2024) present the practical way in which they employed an *engagement first* approach to their project. One key feature of this framework is the recognition of the importance of relationships among knowledge users to the success, or failure, of any improvement activity, be it research or QI.

We see an opportunity for the ECE framework to be paired with a learning health systems (LHSs) approach to support implementation, evaluation and adaptation (Greene et al. 2012; Lee-Foon et al. 2023a, 2023b; Reid 2016; Reid and Greene 2023; Reid et al. 2024). In an LHS, communities, researchers and health system operators come together to define, understand and tackle complex healthcare problems (Reid et al. 2024). In an LHS, the team moves through problem identification, evidence gathering and co-design of service improvements, implementation and evaluation in a continuous cycle (Reid et al. 2024). As the complexity of healthcare delivery and the problems associated with it evolve, so too does the importance of early and meaningful engagement relationships with the patients, care partners and community members served (Lee-Foon et al. 2023b). It is with this realization that more advanced LHS models in Canada and elsewhere have integrated engagement as a foundational pillar of an LHS, ensuring active and meaningful partnerships throughout the LHS cycle (Lee-Foon et al. 2023b; Reid et al. 2024). Early engagement prompts improvement teams to take a realist approach: to understand what works for whom and why and

continue to iterate and evolve approaches. Meaningful engagement also prompts keen attention to how and why improvement happens, not only whether it did or did not. This is both a strength and a limitation of the approach presented by Hahn-Goldberg et al. (2024), where it was not clear to us whether the potential of the engagement first approach was fully realized in practice. While patients and caregivers were involved as partners in the B2H projects, it was not clear whether this reflected the representation of the diversity of the communities served by the organizations involved. In our experiences, diversity of patient and community perspectives is one key to meaningful and sustained engagement.

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Reflection #2: When it comes to the implementation of interventions, how to seamlessly implement complex interventions across siloed organizations continues to be a challenge, which engagement alone cannot solve

Implementing complex, multi-faceted interventions is challenging at the best of times and even more so in the middle of a global pandemic. This was evidenced by the loss to follow-up in the B2H initiative, where nine of 16 teams reported on the experience or partnership outcomes by the end of the collaborative. Another interesting outcome was the differential success in the implementation of the individual B2H interventions. It seems that the components of the intervention bundle that were least likely to be implemented were those components that crossed multiple sectors, such as the patient-oriented discharge summary and post-discharge follow-up, whereas teach-back was adopted by 80% of the teams that reported their implementation outcomes (Hahn-Goldberg et al. 2024: Table 2). In terms of active participation of patients and caregivers, 59% of the teams involved the family and caregiver in the transition in care teaching and 42% completed post-discharge activities with patients (Hahn-Goldberg et al. 2024: Table 2). Whether this was an artifact of the B2H intervention itself or the timing of the collaborative was not discussed. It would be interesting to know whether the underlying issues contributing to low adoption were measured. We appreciate that implementing cross-sectoral initiatives, such as moving in-hospital approaches into the community and sustaining them, is difficult to do. The high degree of variability in the adoption of individual B2H interventions signals that engagement as a lever may not be enough given both the complexity of the intervention and the fragmentation of our care system. If not already collected, we encourage the B2H teams to capture data regarding why the implementation of the cross-sectoral components of the intervention had reduced success in

addition to learning from teams what additional evaluation supports would have been helpful. It is this kind of formative evaluation and discussion of the findings with patient partners where further co-design or co-revision of programs can be very impactful.

Reflection #3: It is time for a paradigm shift in how we think about engagement

While patient engagement in pre-defined QI projects is essential – and several excellent examples exist – it tends to promote somewhat decontextualized work, like rearranging the deck chairs on the Titanic. Engagement with end-users of the system must also happen at a higher level – i.e., unpacking our understanding of how the system as a whole is ill-designed to meet the needs of patients, families and, in some cases, providers. This will require a major paradigm shift not only in how we think about patient and family engagement but also in how we think about what and who healthcare is for and why we perpetuate the silos we do.

Projects such as B2H are an encouraging example of a progressively more macro approach to patient engagement and QI by focusing on care transitions; however, the impact of the siloing of health sectors still rears its ugly head. What is interesting is that the silos, which are too often recognized as the issue, are socially constructed – the system is “perfectly designed to get the results it gets” – to quote one of the grandfathers of QI, Paul Batalden (Carr 2008). The deconstruction of the silos and the wholesale system redesign is, in fact, where patient, family and community engagement are most needed. With no intended disrespect to all of the amazing people doing hard work in localized healthcare QI, we are tweaking at the fringe and celebrating more consultative patient engagement efforts as the panacea to a much bigger problem. Impactful engagement starts with how the problems are even defined in the beginning. How patients, families and community partners see or problematize the challenges in the healthcare system is often very different from the views of internal QI teams. It is here that Hahn-Goldberg et al. (2024) have it right. Moving the ECE framework to a macro health delivery system lens is the logical next step to advance health system delivery innovation in partnership, not simply engagement, with patients and care partners in decision-making roles at the policy and payment tables.

Reflection #4: QI is about human behaviour change and, therefore, is inherently messy

In reviewing the success factors of the B2H initiatives, these particular elements stood out: having a trans-disciplinary team working together across sectors, including patient partners; use of patient stories to ground the work; patient input into tool development; building on previous success (e.g., in line with an LHS model, some of the initiatives were layering onto

previous work); and, importantly, support for change management. Healthcare is constantly evolving and the *people aspect* requires particular support and attention, particularly when new groups of individuals (in this case, health system staff and patient partners) start working together for the first time. For the B2H project, it was wonderful to see built-in change management support for project teams. As described by Hahn-Goldberg et al. (2024), it seemed that engagement of patients and care partners fell into the planning, ideation and co-design phases and it was less clear what engagement looked like in the implementation and evaluation stages. Given that engagement was a key lever for the B2H collaborative project, the lack of implementation results from almost half of the teams leaves us asking, “why?”

From our collective experience straddling research and QI in complex healthcare systems, moving beyond engagement to *storytelling* can be an incredibly strong strategy to support team motivation, to support accountability for promises made and to foster long-term sustainability of QI efforts. Within our local contexts, we have also observed that robust engagement can even help to defray some of the challenges experienced by the rapid pace of change in healthcare resulting from the COVID-19 pandemic and its lingering aftermath. Future large-scale implementation efforts should consider carefully how to support and sustain robust and meaningful patient and care partner engagement and evaluation throughout the full, and often messy, lifecycle of change.

Reflection #5: Embedding fulsome evaluation of engagement is essential

A reflection that evaluation is essential is probably not surprising in a commentary authored by three research chairs; however, let us explain. The knowledge we have on patient engagement experiences is largely made up of reports from individual study teams or single-site QI experiences and often focuses on the classic *barriers to and facilitators of* engagement. Hahn-Goldberg et al. (2024) provide a rich description of a complex project with robust patient engagement and descriptive report-style data. They used the Public and Patient Engagement Evaluation Tool (McMaster University 2024) to evaluate engagement; however, they only report what we would call satisfaction-oriented results. This seems to be a common approach of QI projects and reflects a missed opportunity to really dig into more participant-reported outcome measures that could inform our understanding of how engagement actually functions – the missing link in engagement science.

Moreover, QI projects rarely discuss an evaluation framework that includes key performance indicators or program outcome measures, which are patient-reported or metrics that reflect things that matter to patients and families. We would love to learn more about how patient and caregiver partners

defined success in the B2H projects and whether these outcomes were realized. This begs the question: “How is person-centredness reflected in the definition of ‘success’ or ‘effectiveness’?” If a project makes patients feel safer receiving care at home but does not reduce emergency department visits or hospitalizations or save money, is that not still successful? Involving patients, families and communities in co-designing how evaluation frameworks and outcome measures are selected for QI is definitely where engagement work needs to go in the future (Abelson et al. 2023).

Conclusion

In summary, these reflections represent key areas of focus that are needed to take patient engagement in QI to the next level. The B2H initiative demonstrates a cross-sectoral improvement initiative that mobilized teams from different sectors and patient and caregiver partners to work together to improve the quality-of-care transitions. While many benefits were realized, some elements of the intervention proved challenging potentially as a product of competing priorities and because of the

difficulty in creating integrated interventions in a system that is historically siloed. In this commentary, we push on the importance of evaluation and system-level redesign and the system supports that are needed to sustain and evolve system improvements in full partnership with communities. As we continue to evolve our co-design efforts, we also need to move from the individual perspective – where patients and their clinicians co-design care plans and pathways together – to the macro level, where communities of end-users are co-designing integrated systems of care with the service delivery organizations. To get there, our understanding of patient and community engagement also needs to transform, moving away from projects that we bring to patients, families and communities to transferring the power of change whereby our communities take the helm and lead health systems transformation (Russell and McKnight 2022). We have come so far with patient and family engagement in QI in the past decade that we are beginning to understand what is possible; pushing ourselves to unlock the next level of partnership will make the next decade of QI (and programs such as B2H) truly transformational. **HQ**

References

- Abelson, J., L. Tripp, M. MacNeil, A. Lang, C. Fancott, R. Ganann et al. 2023. Development of the Engage With Impact Toolkit: A Comprehensive Resource to Support the Evaluation of Patient, Family and Caregiver Engagement in Health Systems. *Health Expectations* 26(3): 1255–65. doi:10.1111/hex.13742.
- Baker, G.R., M. Judd, C. Fancott and C. Maika. 2016. Creating “Engagement-Capable Environments” in Healthcare. In G.R. Baker, M. Judd and C. Maika, eds., *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare* (pp. 11–34). Longwoods Publishing.
- Black, A.T., S. Nixon, M. Meghan, C. Wallsworth, L. Cuthbertson, B. Parappilly et al. 2021. Implementing PODS (Patient Oriented Discharge Summary) in an Acute Medical Urban Health Setting in Vancouver, Canada. *Patient Experience Journal* 8(3): 117–24. doi:10.35680/2372-0247.1565.
- Brach, C. 2024. Use the Teach-Back Method: Tool 5. *Health Literacy Universal Precautions Toolkit (3rd ed.)* (pp. 15–18). Agency for Healthcare Research and Quality.
- Carr, S. 2008. A Quotation With a Life of Its Own. *Editor’s Notebook*. PSQH. Retrieved May 16, 2024. <<https://www.psqh.com/analysis/editor-s-notebook-a-quotation-with-a-life-of-its-own/>>.
- Fancott, C., G.R. Baker, M. Judd, A. Humphrey and A. Morin. 2018. Supporting Patient and Family Engagement for Healthcare Improvement: Reflections on “Engagement-Capable Environments” in Pan-Canadian Learning Collaboratives. *Healthcare Quarterly* 21(SP): 12–30. doi:10.12927/hcq.2018.25642.
- Greene, S.M., R.J. Reid and E.B. Larson. 2012. Implementing the Learning Health System: From Concept to Action. *Annals of Internal Medicine* 157(3): 207–10. doi:10.7326/0003-4819-157-3-201208070-00012.
- Hahn-Goldberg, S., A. L’Espérance, B. Comeau, A. Harrison and C. Fancott. 2024. Bridge-to-Home: A Case Study of the Mutually Reinforcing Benefits of Patient Engagement-Focused Quality Improvement Initiatives for Transitions out of Hospital. *Healthcare Quarterly* 27(1): 42–50. doi:10.12927/hcq.2024.27323.
- Hahn-Goldberg, S., K. Okrainec, T. Huynh, N. Zahr and H. Abrams. 2015. Co-Creating Patient-Oriented Discharge Instructions With Patients, Caregivers, and Healthcare Providers. *Journal of Hospital Medicine* 10(12): 804–07. doi:10.1002/jhm.2444.
- Lee-Foon, N.K., R.J. Reid and A. Brown. 2023a. Fairness for Whom? Learning Health Systems’ Approach to Equity in Healthcare. *Healthcare Policy* 19(2): 15–20. doi:10.12927/hcpol.2023.27237.
- Lee-Foon, N.K., M. Smith, S.M. Greene, K. Kuluski and R.J. Reid. 2023b. Positioning Patients to Partner: Exploring Ways to Better Integrate Patient Involvement in the Learning Health Systems. *Research Involvement and Engagement* 9(1): 51. doi:10.1186/s40900-023-00459-w.
- McMaster University. 2024. Public and Patient Engagement Evaluation Tool. Retrieved May 2, 2024. <<https://ppe.mcmaster.ca/resources/public-and-patient-engagement-evaluation-tool/>>.
- Reid, R.J. 2016. Embedding Research in the Learning Health System. *Healthcare Papers* 16(Special Issue): 30–35. doi:10.12927/hcpap.2016.24724.
- Reid, R.J. and S.M. Greene. 2023. Gathering Speed and Countering Tensions in the Rapid Learning Health System. *Learning Health Systems* 7(3): e10358. doi:10.1002/lrh2.10358.
- Reid, R.J., W.P. Wodchis, K. Kuluski, N.K. Lee-Foon, J.N. Lavis, L.C. Rosella et al. 2024. Actioning the Learning Health System: An Applied Framework for Integrating Research Into Health Systems. *SSM-Health Systems* 2: 100010. doi:10.1016/j.ssmhs.2024.100010.

Rowland, P., M. Brosseau and C. Houle. 2018. Patient Roles in Engagement-Capable Environments: Multiple Perspectives. *Healthcare Quarterly* 21(SP): 45–49. doi:10.12927/hcq.2018.25639.

Russell, C. and J. McKnight. 2022. *The Connected Community: Discovering the Health, Wealth, and Power of Neighborhoods*. Berrett-Koehler Publishers.

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