



TOP 10

LESSONS LEARNED

In a nut shell, designing and implementing community-based, cross-sectoral, multi-partner provision of health services, with patients and families as part of the team, is not a straight-forward process. However, with the positive impacts on clinical outcomes and safety in organizations that have a patient-centred culture⁵, there is growing interest in this approach. Furthermore, it is aligned with the direction in which the Ontario health system is moving.

⁵ <http://isqua.org/docs/default-source/education-/glenn-robert-isqua-webinar-slides-jan-2014.pdf?sfvrsn=0>



TOP 10

LESSONS LEARNED

IF YOU ARE ABOUT TO EMBARK ON A CO-DESIGN OR PATIENT ENGAGEMENT PROCESS, WE HAVE CREATED THIS TOP TEN LIST OF THE KEY ISSUES AND POINTS TO BEAR IN MIND:

- 1 Both the role of the funder and the relationship between funder and community need to be explicit, transparent and constructive. A project charter outlining accountabilities, roles and responsibilities is a critical starting point, however ongoing nurturing of the relationship is needed over the course of the project.
- 2 The relationship must be built on openness, trust and a willingness to “fail forward” together. Agreeing up front that there is always something to be learned even when things don’t go according to plan, gives permission for open dialogue and course correction.
- 3 There is an opportunity to revisit the actual winning proposal before agreements are signed and the work begins. This is the time for an open dialogue between the funder and the project team, now that it is clear you are partners. What exactly do you want to accomplish? Does the project team have other ideas? Were there things they didn’t put in their proposal because they might be considered too off-the-wall? Are there things that you, as the funder, hoped to see, but didn’t, which could now be put on the table? Has anything changed since the proposal was submitted that affects the approach?
- 4 Initial orientation, training and capacity building needs to be delivered with patients, family caregivers and providers together. Making time for these joint sessions will be harder for some providers, patients and caregivers than others, but it is imperative. This needs to be taken into account when designing and scheduling the sessions. Questions of timing and compensation will come into play. For issues of compensation, refer to our *Should Money Come Into It?* report.
- 5 Do not underestimate the power of storytelling. Use it to start the process, and at the beginning of any meeting. What may initially seem to be isolated problems, add up to a picture of system issues. There is a tipping point and everyone in the room knows when it has been reached.
- 6 There is a clear pattern of great enthusiasm and momentum as work gets off the ground – this is particularly true for the patients and families, as this is often the first time they have been involved in this kind of work. As the project moves from design to implementation, most of the day-to-day work swings more to the provider organizations and staff. During this period there is a danger that the patients and

families become disengaged, as the team process becomes more about reporting on results, than it is about collaboration and creating new ideas. Right from the outset, it is important to anticipate this shift and create an expectation of it from the start, through clear and ongoing communication. It is normal, and it does not diminish the importance of the patient and family contributions. The reality is that the intensity of engagement changes over the life of the work. We began to think of it as a pendulum. Being upfront about the ebbs and flows of the engagement process helps avoid disappointment.

7 Pay attention to the balance between the time and energy spent engaging with patients and families and the time and energy spent engaging with providers. This is particularly important as it relates to providers and staff who work in partner organizations other than the lead one (in PATH's case, the hospital). When a project deliberately sets out to bring patients and families into the centre of decision-making, it will naturally spend a lot of time establishing that process. However, further into the project, the implementation of change will rely on staff and provider commitment to the vision. If this is not secured at the start, success will be harder to achieve.

8 A concerted focus on the spread of engagement capacity across the partner organizations should be explicit from the beginning of the project. This should not be left until later to think about, once there is proof of concept in the lead partner organization.

9 At the mid-point of the work the team should have some sense of where things are heading. This is a good time for a brainstorming session to identify any system barriers that could be a problem once the external funding comes to an end. Barriers could include payment mechanisms, organizational-specific accountability agreements, LHIN rules, MOHLTC policy or any other system legacies that the team thinks may get in the way of continuation and spread. The Ministry has recently indicated a willingness to relax some rules or tolerate a low-rules environment for some collaborative efforts. This should be capitalized on if appropriate.

10 Identify, early on, who the likely champions are for sustainability and spread and bring them into the tent as early as possible.



The Change Foundation is enormously proud of the work of the PATH project and the west Northumberland community. Watching the enthusiasm, capacity development and commitment of all involved, was a true honour. As the work continues, Ontario's health system will benefit from all that has been learned, and Ontario patients, family caregivers and health care providers will benefit from better health care experiences.