Advancing Patient-Partnered Research: Empowerment, Innovation and Evolution

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Abstract

From the perspective of patient partners, the Ontario SPOR SUPPORT Unit Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach Awards have facilitated successful patient-partnered research projects, which, in turn, have led to an evolution in patient partnerships and engagement strategies. The 15 projects profiled in this special issue point to the beneficial impacts of patientpartnered research.

Introduction

As experienced patient partners, we welcome the opportunity to reflect on the Ontario Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit's (OSSU) Engaging Multistakeholders for Patient Oriented-research Wider Effects and Reach (EMPOWER) Awards, now in their fourth round of funding. Can we say that they are aptly named? And more importantly, has patient-partnered research in Ontario truly been empowered? Was this empowerment manifested in research that responded to the untapped opportunity to encourage and support knowledge translation activities that would build relationships and "push the results to those who can use them to effect real impact and change in Ontario" (OSSU n.d.)?

Discussion

With the SPOR ideals and vision for patient-partnered research, this special edition of the EMPOWER Award studies demonstrates the evolution in patient partnerships and innovative engagement strategies in diverse healthcare research. The EMPOWER Awards were meant to motivate teams to take their patient engagement to a new level. The breadth and depth of the 15 projects reveal the growing appetite to further develop patient engagement strategies and, more significantly, the extent and reach of patient-partnered research. This special edition represents the following topics: priority setting and best practices, equity in patient partnerships, co-designing interventions and tools, tools for patient engagement and patient-driven or community-driven projects.

These studies bring to light three fundamental impacts on health research:

- In partnering with patients, research benefits from identifying unanswered questions, patient-relevant topics and new areas of research.
- Patient-partnered research influences and shapes knowledge translation strategies and activities.
- Established patient-researcher relationships provide impetus to continue collaborating.

In this special edition, we witness researchers successfully partnering with patients using co-creation, co-design and co-leadership, and we get a glimpse of the evolution of patientpartnered research. In one project, an empowered patient brought the grant opportunity forward; in another, the community saw the need. We note novel approaches to address equity, diversity and inclusion through strategic equity lenses and by partnering with more diverse populations. There is also the acknowledgement that much work remains to be done in this area. One thing that resonates is that these partnerships have a good dose of generosity, commitment and originality, resulting in innovative strategies for patient partnership that will serve Canadian society.

Since 2012, when a literature search on patient engagement yielded only 34 results, to the present, where a plethora of more than 12,000 articles is available, the growth of patient partnership in research has exploded and is charting new territory (Marlett 2022). When researchers' passion for discovery and innovation is combined with the power of committed and enthusiastic patients and caregivers with the unique expertise of lived experience, both the transformative aspect and the hope for the future as we democratize and revolutionize health research together takes root. The EMPOWER Awards have enabled research teams to push their patient-oriented research further and build on these essential patient partnerships.

We believe that the EMPOWER Awards are aptly named. This special issue highlights proof of empowerment on multiple levels: stronger and more diverse patient-researcher partnerships, knowledge translation that has a greater reach and impact and innovative strategies for patient-partnered research. Empowerment is realized through meaningful collaboration and co-production. As patient partners ourselves, we look forward to more patient partner-initiated applications as ideas for end-of-grant translation can be generated by any of the team members.

Conclusion

It has been inspirational to see the optimism of people working hard to attain the ultimate results from the SPOR partnership. This special edition also emphasizes that we need to share our successes and challenges with one another and learn from our missteps as we develop patient partnerships and strategies that truly enable patients and caregivers to be an integral part of the research that has an incredible impact on our lives. HQ

References

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