

Patient Engagement in TRIC Grant Applications

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Overview

- TRIC Grant: Brief overview
- Patient voice
- Patient engagement
 - Patient research partners

- Discussion and examples



TRANSLATING RESEARCH INTO CARE

Overview of TRIC Grants

- To support research, at the point of care, that will facilitate the translation of clinical science into improved delivery of services and patient care
- TRIC grants aim to change care **NOW** at NSHA and IWK through implementation science research projects.

TRIC Levels

- **Level 1:** Gain evidence that will support preparation of level two or three proposal
- **Level 2:** Comprehensive research project to improve healthcare
- **Level 3:** Similar to level 2, only broader in scope and complexity

Priority projects...

- Improve patient-reported outcomes
- Improve safety of healthcare
- Improve access for under-served populations
- Reduce unnecessary interventions

Patient Voice

- Personal statements of impact from patients or family members
- Letters of support from charities or advocacy groups
- Video resources to share stories



PATIENT ENGAGEMENT

Definitions: Patient

An overarching term inclusive of individuals with **personal experience** of a health issue and informal **caregivers, including family and friends.**

(SPOR, ND, P.5)

Definitions: Patient Engagement

Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation.

(SPOR, ND, p.5)

Engagement is two-way, involves the transparent exchange of information, seeks common understanding ... and leads to trust-based, sustainable **relationships**.

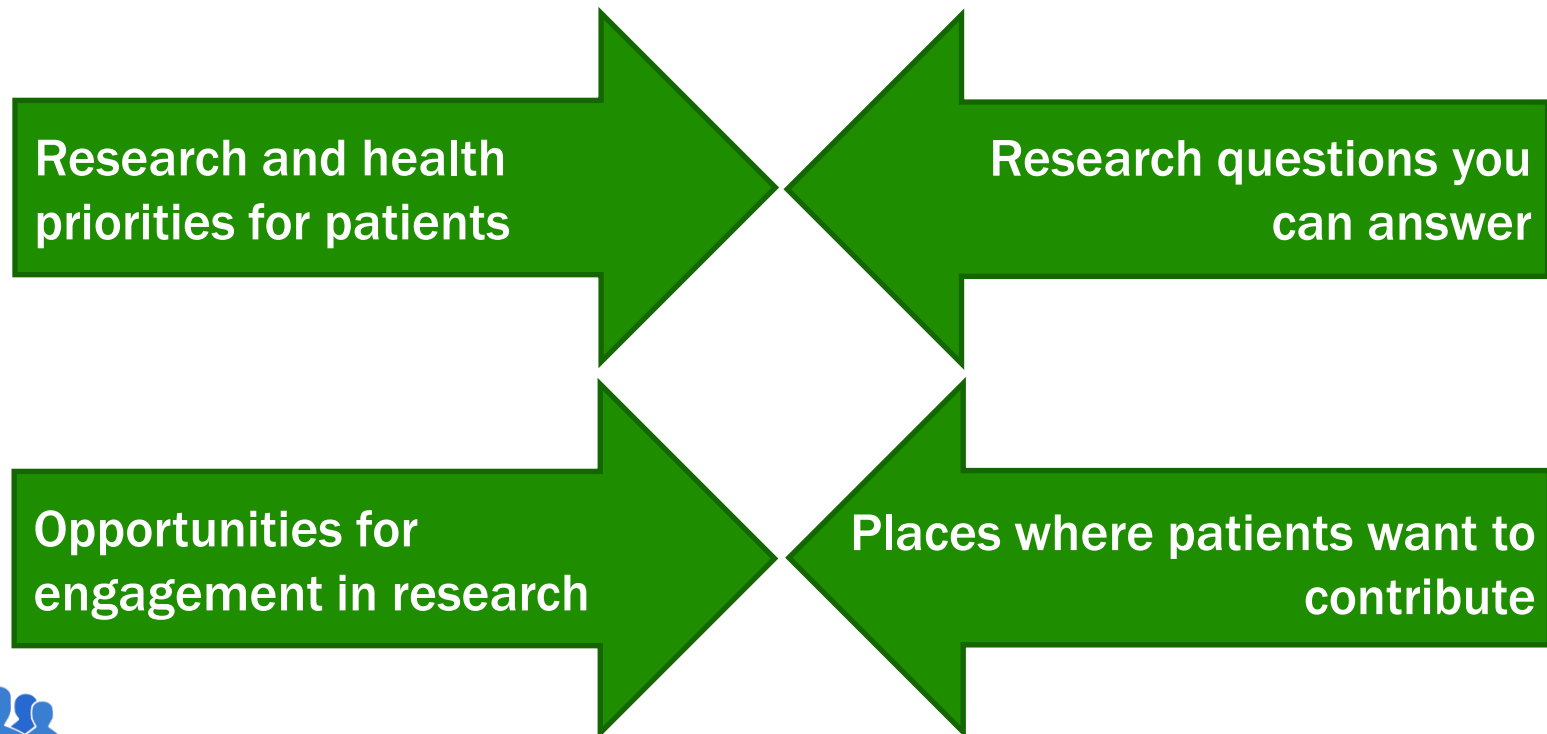
(NSHA, ND, p.2)

Rationale for Engaging Patients

- **Moral argument:** Patients have the right to contribute to research
- **Methodological argument:** Involving patients can lead to better, more relevant research
- **‘Pragmatic’ argument:** Some patient groups and funding competitions require it

Meaningful Engagement

- Inclusiveness, support, mutual respect and co-building (CIHR, ND)



Tokenism and Other Challenges

- Patients are present, but not actively engaged
- Managing expectations and keeping promises
- Building and maintaining relationships

**Time, planning, assessing readiness
and connecting with patients early**

Planning

- What decisions are there to be made?
- What impact will patients have on decision-making?
- Who is differently affected?
- Budget: reimbursement vs compensation

How and when do you involve patients in planning?

Assessing Readiness

- Are you willing to work in a new and challenging way?
- Can you commit time and resources?
- Are you comfortable with things taking longer than you are used to?

**What about other members
of your team?**

Levels of Engagement

What impact do patients have on decision-making?

- International Association for Public Participation: <http://www.iap2.org/>
 - Promises to the public
- Carman et al (2013): *A framework for understanding the elements and developing interventions and policies*

Carman et al., 2013; IAP2, ND; NSHA, ND; Snow et al., 2013

Types of Engagement Activities

	Focus Group	Patient Advisory Group
Definition	Facilitated discussion with people affected by issue in question	Patients and family members who help researchers make decisions
Possible purpose	Identify questions for future research	Maintain accountability to patients and family members
Contribution to research	Feedback from patients on what topics should be studied	Research process is consistent with values of patients and family members
Level of engagement	Consult	Collaborate

Patient Research Partners

- Patients or family members who join research team as experts
- Ground research in lived experience
- Planning research and engagement
- Recruiting participants, analyzing data and interpreting findings
- Collaborate, empower

Summary

- Engagement can take many forms but must be carefully planned
- Which TRIC level are you applying for?
- How could you involve patients, and how might that develop over time?

Patient Engagement Consultations

- Maritime SPOR SUPPORT Unit
 - <http://www.spor-maritime-srap.ca/>
- Brian Condran, Patient Engagement Coordinator
 - (902) 473-4546
 - Brian.Condran@nshealth.ca
- Please book consultations one or two weeks in advance of competition deadline

Thank you!



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New Brunswick Health Research Foundation



Fondation de la recherche en santé du Nouveau-Brunswick



References

- Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeny, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2),223-231. doi: 10.1377/hlthaff.2012.1133
- Strategy for Patient-Oriented Research / Canadian Institutes of Health Research. (ND). *Strategy for patient-oriented research: Patient engagement framework*. Retrieved from http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf
- Degeling, C., Carter, S. M., Rychetnik, L. (2015). Which public and why deliberate? A scoping review of public deliberation in public health and health policy research. *Social Science and Medicine*, 131, 114-121. Retrieved from <http://www.journals.elsevier.com/social-science-and-medicine>
- Domec, J. P., Prutsky, G., Elraiya, T., Wang, Z., Nahban, M., Shippee, N., ... & Murad, M. H. (2014). Patient engagement in research: A systematic review. *BMC Health Services Research*, 14:89. doi: 10.1186/1472-6963-14-89
- International Association for Public Participation (2014). *IAP2's public participation spectrum*. Retrieved from <http://www.iap2.org/?page=A5>
- Health Research Authority / INVOLVE. (2016). *Public involvement in research and research ethics committee review*. Retrieved from <http://www.invo.org.uk/posttypepublication/public-involvement-in-research-and-research-ethics-committee-review/>

References

- Newfoundland and Labrador SUPPORT. (ND). *Patient and public engagement planning template*. Retrieved from Memorial University website: <http://www.nlsupport.ca/getattachment/8dc1f539-d225-46fa-ba8d-2d06da934486/Patient-and-Public-Engagement-Planning-Template.pdf.aspx>
- Nova Scotia Health Authority. (ND). *Involving patients and citizens in decision making: A guide to effective engagement*. Retrieved from <http://www.cdha.nshealth.ca/involving-patients-citizens/our-strategies>
- Shippee, N. D., Domecq-Garces, J. P., Prutsky Lopez, G. J., Wang, Z., Elraiyah, T. A., Nabhan, M., ... & Murad, M. H. (2013). Patient and service user engagement in research: A systematic review and synthesized framework. *Health Expectations*, 18(5), 1151-1166. doi: 10.1111/hex.12090
- Snow, B., Tweedie, K., Pederson, A., Shrestha, H., & Bachmann, L. (2013). *Patient engagement: Heard and valued. A handbook for meaningful engagement of patients that have not traditionally been heard in healthcare planning*. Retrieved from Canadian Foundation for Healthcare Improvement website: http://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome_handbook-fraserhealth.pdf?sfvrsn=2