

# Patient and Public Engagement Tools & Resources

Peer-reviewed publications, lay language blog posts,  
guides, templates, workbooks, and videos

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## CHI Patient and Public Engagement Resources

- General information about CHI: <https://umanitoba.ca/centre-for-healthcare-innovation/>
- Preparing for Research by Engaging Patient and Public Partners (PREPPP) Award: <https://umanitoba.ca/centre-for-healthcare-innovation/funding-opportunities-and-awards#preparing-for-research-by-engaging-public-and-patient-partners-preppp-award>
- Patient and Public Engagement Lunchtime Learning Series: <http://chimb.eventbrite.com>
- KnowledgeNudge blog: <https://medium.com/knowledgenudge>
- PE Lunchtime Learning - The Collaborative Partnership (*One hour video*): <https://www.youtube.com/watch?app=desktop&v=OVEggRm2FdA&list=PLwqeP6dbRSC50TUb1n-7cq7a12FYgEiuc&index=3>
- Engaging people with lived experiences in patient-reported measurement initiatives (*PDF*): <http://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2021-11/engaging-people-with-lived-experiences-in-patient-reported-measurement-initiatives.pdf>
- Free and low-cost counselling and support resources in Manitoba (*PDF*): <http://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2021-11/covid-19-counselling-resources.pdf>

## Introduction to Patient and Public Engagement

- What is Patient Engagement in Health Research? (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/pe-1-what-is-patient-engagement-health-research-a2df904a245d>
- The Value of Patient Engagement in Health Research (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/pe-2-the-value-of-patient-and-public-involvement-in-health-research-aa27727a9749>
- Patient Engagement 101 (*One hour video*): <https://www.youtube.com/watch?v=QZsjN4OWLWo>
- The Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework: <https://cihr-irsc.gc.ca/e/48413.html>
- Patient Engagement in Data Science, Technology and Engineering (*One-hour video*): <https://www.youtube.com/watch?v=mug4K05r8q4>

## Patient and Public Engagement in Manitoba

- Experiences and Motivations for Engaging (*KnowledgeNudge blog + short videos*): <https://medium.com/knowledgenudge/patient-engagement-in-manitoba-video-series-part-1-86103e55b9be>
- Impact and Aspirations for Patient Engagement (*KnowledgeNudge blog + short videos*): <https://medium.com/knowledgenudge/patient-engagement-in-manitoba-video-series-part-2-2f12dab1e899>

- Crockett L. et al. (2019) Engaging patients and the public in health research: experiences, perceptions and training needs among Manitoba health researchers. *Research Involvement and Engagement*, 5(18). (Peer-reviewed publication – results informed CHI programs and services, including the PREPPP Award and PE Lunchtime Learning series): <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0162-2>

### Partners vs. Participants

- Doria N. et al. (2018). Sharpening the focus: differentiating between focus groups for patient engagement vs. qualitative research. *BMC Research Involvement and Engagement*. 4(19). (Journal Article) <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0102-6>
- PE Lunchtime Learning - Practical Engagement: Focus Groups and Discussion Groups (One-hour video): <https://www.youtube.com/watch?v=xjCjD3yV96k&list=PLwqP6dbRSC5phnDYeCMsjEShIAiSXKx&index=4&t=31s>
- Discussion Groups vs. Focus Groups (*KnowledgeNudge* blog post): <https://medium.com/knowledgenudge/methods-in-patient-engagement-discussion-focus-groups-d6081d80f8d2>

### Levels of Engagement

- The Levels of Patient and Public Involvement (*KnowledgeNudge* blog post): <https://medium.com/knowledgenudge/pe-3-the-levels-of-patient-and-public-involvement-77026a547f2b>
- Levels of Engagement and Appropriate Methods (One-hour video): <https://www.youtube.com/watch?v=1sbJVCiPmTg>
- International Association for Public Participation (IAP2) Spectrum of Engagement (PDF): [https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20\(1\).pdf](https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20(1).pdf)

### Assessing Readiness to Engage

- Readiness to Engage Workbook (Fillable PDF): <http://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2021-11/readiness-to-engage-workbook.pdf>
- Are You Ready for Patient Engagement? Assessing Expectations (*KnowledgeNudge* blog post): <https://medium.com/knowledgenudge/pe-4-are-you-ready-for-patient-engagement-assessing-expectations-4c84e09f3ba1>
- PE Lunchtime Learning - Assessing Readiness to Engage (One-hour video): <https://www.youtube.com/watch?v=AV-BX2vpyNA>

## Methods of Engagement (Participatory Approaches)

- Methods of Patient and Public Engagement: A Guide (PDF): <http://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2021-11/methods-of-patient-and-public-engagement-guide.pdf>
- Manafo et al. (2018). Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research. *Health Res Policy Syst.* 7(16). (Peer-reviewed publication): <https://pubmed.ncbi.nlm.nih.gov/29415734/>
- Methods in Engagement: The World Café (KnowledgeNudge blog post): <https://medium.com/knowledgenudge/methods-for-patient-engagement-the-world-caf%C3%A9-8f58b84577a>
- James Lind Alliance (KnowledgeNudge blog posts):
  - Introduction to the James Lind Alliance: <https://medium.com/knowledgenudge/introduction-to-the-james-lind-alliance-a-participatory-approach-to-engage-patients-caregivers-94d38e4df718>
  - The James Lind Alliance Method: <https://medium.com/knowledgenudge/part-ii-the-james-lind-alliance-767a378e6b58>
- PhotoVoice (KnowledgeNudge blog posts):
  - What is it? <https://medium.com/knowledgenudge/photovoice-blog-series-96477db68e05>
  - Community Partnership and Hard-to-Reach Populations: <https://medium.com/knowledgenudge/photovoice-blog-series-331a8fadd0b>
  - The Research Process: <https://medium.com/knowledgenudge/photovoice-blog-series-9736dfec1664>
- Tips and Tricks for Establishing an Advisory Group (One-hour video): <https://www.youtube.com/watch?v=kpurBYgyr1Y&t=1s>

## Recruitment of Patient and Public Partners

- Information to include in a call for partners (PDF): <http://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2022-02/call-for-patient-and-public-partners.pdf>
- Purpose of Engaging Patient Partners (KnowledgeNudge blog post): <https://medium.com/knowledgenudge/pe-5-purpose-of-engaging-patients-and-the-public-f4b1118c2348>
- What Influences/Motivates Someone to Become a Patient Partner? (KnowledgeNudge blog post): <https://medium.com/knowledgenudge/pe-6-what-influences-someones-motivation-to-get-involved-in-health-research-5438438bdf81>

- How Do I Find People to Engage in Health Research? (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/pe-7-how-do-i-find-people-to-involve-in-my-health-research-4d6f1b163419>
- PE Lunchtime Learning - Where Are All the Patients At? Recruitment for Engagement (*One-hour video*): <https://www.youtube.com/watch?v=30D-296ic10&list=PLwqeP6dbRSC50TUb1n-7cq7a12FYgEiuc&index=6>

### Patient and Public Engagement in Practice

- Five Point Checklist When Planning for Patient Engagement (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/pe-8-five-point-checklist-when-planning-for-patient-engagement-c0c604c8639a>
- Greenhalgh, T, et al. (2019). Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. *Health Expect.* 22(4): 785-801. (*Peer-reviewed publication*). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6737756/>
- The Importance of Relationship Building (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/the-importance-of-relationship-building-guest-blog-with-rishma-chooniedass-ae5348299a04>
- SPOR Capacity Development Framework : <https://cihr-irsc.gc.ca/e/49307.html>
- Practical Tools for Ethical Engagement in Health Research (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/practical-tools-for-ethical-engagement-in-health-research-56fbf0733d37>
- Community Engagement and Power Dynamics (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/practical-tools-for-ethical-engagement-in-health-research-c8d759f11bc5>
- The Rules of Partnerships (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/practical-tools-for-ethical-engagement-in-health-research-1ffd8058bedb>
- Navigating Conflict in Engagement Using Strengths-Based Approaches (*one-hour video*): <https://youtu.be/JCd5rTyIOAM>

## Case Studies

### PE Lunchtime Learning Series

- Dr. Dylan McKay – Engaging in Clinical Trials (*One-hour video*):  
<https://www.youtube.com/watch?v=6UmevIN8yLU&list=PLwqeP6dbRSC5phnDYeCMsjEShIAiSXKxx&index=6>
- Dr. Anna Chudyk - Engaging in Scoping Reviews (*One-hour video*):  
<https://www.youtube.com/watch?v=Rrsh5k2asqc&list=PLwqeP6dbRSC5phnDYeCMsjEShIAiSXKxx&index=8>
- Dr. Maya Jeyaraman - Engaging in Scoping Reviews (*One-hour video*):  
<https://www.youtube.com/watch?v=Rrsh5k2asqc&list=PLwqeP6dbRSC5phnDYeCMsjEShIAiSXKxx&index=8>
- Dr. Kristy Wittmeier – Collaborating to Improve Health Services for Children and Teens with Chronic Pain (*One-hour video*):  
[https://www.youtube.com/watch?v=TF3Duh\\_asPY&list=PLwqeP6dbRSC7cCbUG\\_OkhiV16xdfISKqu&index=6](https://www.youtube.com/watch?v=TF3Duh_asPY&list=PLwqeP6dbRSC7cCbUG_OkhiV16xdfISKqu&index=6)
- Dr. Sadeesh Srinathan – Engagement in Thoracic Surgery Research (*One-hour video*):  
[https://www.youtube.com/watch?v=AiV\\_x7Tv5Y&list=PLwqeP6dbRSC7cCbUG\\_OkhiV16xdfISKqu&index=3](https://www.youtube.com/watch?v=AiV_x7Tv5Y&list=PLwqeP6dbRSC7cCbUG_OkhiV16xdfISKqu&index=3)
- Dr. Nathalie Riediger – Community Engagement and Transformative Research About a Controversial Food Policy (*One-hour video*):  
<https://www.youtube.com/watch?v=gGEZwuQjgqs&list=PLwqeP6dbRSC50TUb1n-7cq7a12FYgEiuc>
- Monika Kowatsch - Community Engagement Prior to Basic Science Research (*One-hour video*):  
<https://www.youtube.com/watch?v=Zb-X9gfeP50&list=PLwqeP6dbRSC50TUb1n-7cq7a12FYgEiuc&index=4>

### KnowledgeNudge blog posts

- Patient Advisory Groups in Diabetes Research Series (*KnowledgeNudge blog posts*):
  - A Caregivers Perspective: <https://medium.com/knowledgenudge/patient-advisory-groups-in-diabetes-research-a-caregiver-perspective-4fb9e9155480>
  - A Youth Perspective: <https://medium.com/knowledgenudge/patient-advisory-groups-in-diabetes-research-the-perspective-of-a-youth-advisor-6e46d5522822>
  - A Clinician Perspective: <https://medium.com/knowledgenudge/building-a-patient-advisory-group-within-diabetes-research-q-and-a-with-dr-brandy-wicklow-ab62516d082a>

## Budgeting and Compensation

- CHI Patient and Public Engagement Budget Builder (.xlsx file): [http://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2022-02/2020-01-29\\_chi\\_pe\\_budget\\_tool\\_v2.8-3.xlsx](http://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2022-02/2020-01-29_chi_pe_budget_tool_v2.8-3.xlsx)
- How to Use CHI's Patient and Public Engagement Budgeting Tool (*KnowledgeNudge* blog post): <https://medium.com/knowledgenudge/how-to-use-chis-new-patient-and-public-engagement-budgeting-tool-f051a55369ca>
- Budgeting for Patient Engagement (*KnowledgeNudge* blog post): <https://medium.com/knowledgenudge/budgeting-for-patient-public-engagement-in-health-research-d70f5ce8fca9>
- Richards D., et al. (2018). Patient partner compensation in research and healthcare: the patient perspective on why and how. *Patient Experience Journal*. 5(3) (Peer-reviewed publication): <https://pxjournal.org/cgi/viewcontent.cgi?article=1334&context=journal>
- CIHR – Considerations when paying patient partners in research: <https://cihr-irsc.gc.ca/e/51466.html>

## Online Engagement

- PE Lunchtime Learning - Patient and Public Partner Panel Series:
  - Pre-Assessing Needs for Inclusive Online Engagement (*One-hour video*): [https://www.youtube.com/watch?v=f7cvjywWD6Q&list=PLwqeP6dbRSC7cCbUG\\_QkhiV16xdfISKqu&index=7](https://www.youtube.com/watch?v=f7cvjywWD6Q&list=PLwqeP6dbRSC7cCbUG_QkhiV16xdfISKqu&index=7)
  - Engaging Online with Indigenous and Newcomer Communities (*One-hour video*): [https://www.youtube.com/watch?v=ErUfilyHcuU&list=PLwqeP6dbRSC7cCbUG\\_QkhiV16xdfISKqu&index=8](https://www.youtube.com/watch?v=ErUfilyHcuU&list=PLwqeP6dbRSC7cCbUG_QkhiV16xdfISKqu&index=8)
  - Practical Tips and Tools for Online Engagement (*One-hour video*): [https://www.youtube.com/watch?v=ErUfilyHcuU&list=PLwqeP6dbRSC7cCbUG\\_QkhiV16xdfISKqu&index=8](https://www.youtube.com/watch?v=ErUfilyHcuU&list=PLwqeP6dbRSC7cCbUG_QkhiV16xdfISKqu&index=8)
  - Addressing Barriers to Meaningful Engagement (*One-hour video*): <https://www.youtube.com/watch?v=PC5tvxYQFf0>
  - CHI Grand Round: Lessons Learned Engaging Virtually in a Pandemic (*One-hour video*): <https://www.youtube.com/watch?v=ei-cY27ieUA>
- Pre-Assessing Needs for Inclusive Online Engagement (*KnowledgeNudge* blog post): <https://medium.com/knowledgenudge/pre-assessing-needs-for-inclusive-online-patient-engagement-e17416755fe5>

- Patient Engagement in the Covid-19 Pandemic. (*KnowledgeNudge* blog post about the evaluation done of our Collaborative Partnership when they transitioned online): <https://medium.com/knowledgenudge/engaging-during-covid-19-evaluating-remote-online-methods-bd60ab8d1b5a>
- Preparing for Hybrid Engagement (*One-hour video*): <https://www.youtube.com/watch?v=8HjJdALo9v4>

### Evaluating Patient and Public Engagement

- The Canadian Centre for Excellence on Partnerships with Patients and Public (CEPPP) Patient and Public Engagement Evaluation Toolkit (*Website*): <https://ceppp.ca/en/collaborations/evaluation-toolkit/>
- Staniskewski et al. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Res Involv Engagm.* 3(13). (*Peer-reviewed publication – helps them to lay out a manuscript to publish about the engagement afterwards*): <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5611595/>
- Boivin et al. (2018). Patient and public engagement in research and health system decision making: A systematic review of evaluation tools. *Health Expect.* 21(6). (*Peer-reviewed publication*): <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6250878/>

### Engagement and Allyship

- CHI Grand Round - What Every Health Researcher Needs to Know About Health Equity: Privilege, Oppression and Allyship with Stephanie Nixon (*One-hour video*): <https://www.youtube.com/watch?v=yiWZK2AxF7M>
- Nixon, SA. (2019). The coin model of privilege and critical allyship: implications for health BMC Public Health. 19. (*Peer-reviewed publication*): <https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-7884-9>
- Academic Health Sciences Leadership Program Keynote - The Imperatives of Anti-Racism in Leadership: Dr. Marcia Anderson (*Two-hour video*): <https://www.youtube.com/watch?v=4jbGROZd02I>
- Decolonizing Community Engagement in the ‘Era of Reconciliation’ with Dr. Derek Kornelsen (*KnowledgeNudge VLOG/blog series*):
  - Why Researchers Need to Rethink How They Work with Indigenous Communities: <https://medium.com/knowledgenudge/decolonizing-community-engagement-in-the-era-of-reconciliation-why-researchers-need-to-rethink-9e310ab619b2>

- What is Decolonization? <https://medium.com/knowledgenudge/decolonizing-community-engagement-in-the-era-of-reconciliation-part-2-what-is-decolonization-79d3e66fded7>
- Decolonizing Community Engagement: <https://medium.com/knowledgenudge/decolonizing-community-engagement-85ee3ad5369d>
- Introduction to the Indigenous Healthcare Quality Framework (One-hour video): <https://www.youtube.com/watch?v=kpurBYgyr1Y&t=1s>

### The Valuing All Voices Framework

- Shimmin et al. (2017). Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma-informed intersectional analysis. *BMC Health Services Research*. 17. (Peer-reviewed publication): <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2463-1>
- Five Reasons Why We Need Trauma-Informed Intersectional Analysis in Public and Patient Engagement (KnowledgeNudge blog post): <https://medium.com/knowledgenudge/5-reasons-why-we-need-trauma-informed-intersectional-analysis-in-patient-public-engagement-5afeec311c0d>
- Roche et al. (2020). Valuing All Voices: refining a trauma-informed, intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach. *Research Involvement and Engagement*. 6(42). (Peer-reviewed publication): <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00217-2>
- PE Lunchtime Learning – The Valuing All Voices Framework (One-hour video): <https://www.youtube.com/watch?v=XpTS2-AITUY&list=PLwqeP6dbRSC5phnDYeCMsjEShIAiSXXkxx&index=3>

### Trauma-Informed Engagement

- PE Lunchtime Learning - The Importance of Trauma-Informed Engagement (One-hour video): <https://www.youtube.com/watch?v=oCyiAu30IR8>
- Trauma-Informed Engagement (KnowledgeNudge blog series):
  - What is Trauma? <https://medium.com/knowledgenudge/trauma-informed-engagement-part-1-understanding-trauma-96f35fb00252>
  - The Effects of Trauma: <https://medium.com/knowledgenudge/trauma-informed-engagement-part-2-the-effects-of-trauma-99c72d6db9e6>
  - Safety and Trustworthiness: <https://medium.com/knowledgenudge/trauma-informed-engagement-part-3-safety-and-trustworthiness-4cc9386b6102>

- Bearing Witness: <https://medium.com/knowledgenudge/trauma-informed-engagement-part-4-bearing-witness-7bfb6d4d922e>
- Empowerment: <https://medium.com/knowledgenudge/trauma-informed-engagement-part-5-empowerment-5efa6bf217d1>
- Canadian Foundation for Healthcare Improvement - How to Engage and Support Diverse Patient Partnerships During a Crisis Part 2 (*One-and-a-half-hour video*):  
<https://www.youtube.com/watch?v=tGWazas2xb4&list=PL4kAZziQlydN9mWjRVuMf8VxFY3fpIVi5&index=6&t=2483s>
- Why Bodies Matter in Patient Engagement in Health Research (*KnowledgeNudge blog post*):  
<https://medium.com/knowledgenudge/why-bodies-matter-in-patient-and-public-engagement-in-health-research-84339b4daa85>
- Suggestions for Integrating Embodied Reflexivity in Patient Engagement in Health Research (*KnowledgeNudge blog post*): <https://medium.com/knowledgenudge/suggestions-for-integrating-embodied-reflexivity-in-patient-and-public-engagement-in-health-70b3a0ca1584>
- Why Bodies Matter in Patient Engagement in Health Research (*One-hour video*):  
<https://www.youtube.com/watch?v=WB7eORw4EJY>