**Supplementary Information**

Table 1. Texts analyzed after being suggested or implied by informants

| Documents reviewed and analyzed | Citation or location of document | Illustrative informant extract mentioning text from this category |
| --- | --- | --- |
| **Organizational Documents**CADTH website, including sections relevant to the Strategic plan; technology prioritization criteria; public available budgets from previous years; advertisement for nominations for public members, profiles for patient members of the committees; patient liaison forum meetings minutes; (page not longer available) (report) cardiac monitors, (report) dialysis; (report) sleep apnoea; (report) water fluoridation; patient engagement: submissions template; conflict of interest forms and guidelines for patient organizations; process and timelines; CADTH’s History Board of Directors composition, profiles, roles; Symposium(s); Common Drug Review: (engagement); pCODR: pCODR submission template and feedback https://www.cadth.ca/drr/patient-input-and-feedback | https://www.cadth.ca/ including: https://www.cadth.ca/news/cadth-2018-2021-strategic-plan; https://www.cadth.ca/about-cadth/how-we-do-it/planning-documents; https://www.cadth.ca/patients-experiences-cardiac-monitors-stroke-atrial-fibrillation-and-heart-failure-rapid-qualitative; https://www.cadth.ca/dialysis-modalities-treatment-end-stage-kidney-disease; https://www.cadth.ca/news/cadth-recommendations-sleep-apnea; https://www.cadth.ca/community-water-fluoridation-clinical-and-cost-effectiveness-0; https://www.cadth.ca/patient-and-community-engagement; https://www.cadth.ca/about-cadth/who-we-are/history; https://www.cadth.ca/about-cadth/who-we-are/board-of-directors | *Informant extract* “But to go back to something XX said at the X conference, I think a large part of it is … a) **there are no goals or clear objectives** guiding these activities across the organization, [and] there are not b) **theoretically informed either**. So it hasn’t connected with the appropriate theory…there are lots of people thinking about how to do this [patient engagement] well, but if you look even **the HTA book on patient involvement**, you know many of the people involved in developing these processes have very little knowledge of the relevant academic areas, or scholarly areas that underpin most of this work.”*Informant extract “*It's uncomfortable for me, I really was disappointed by the way the **strategic plan** was rolled out for example, there was no input, there was a half hour webinar without and Q&A and this is a strategic plan …”*Informant extract “*Yeah, I mean we’re involved as a member of **their patient liaison group**. And of course we do **regular submissions** in the process, right.”*Informant extract “…*you have a **bunch of pharmacists** that have **epidemiology training** when you’re hammer, everything looks like a nail, you’re looking for **quantitative information**.”*Informant extract* “…patients would **submit things**, and – my understanding is sometimes **a digestive view** of that would be presented by the patient experts like X [name]” |
| **Patient related texts**The Best Medicine Coalition – patient involvement and relationship with CADTH- /Health Charities Coalition of Canada- Patient engagement in British Columbia (BC), Patient engagement in HQOntario Patient engagement in Quebec ISPOR EUPATI Patient associations (small or big) or groups; health-related charities in Canada (national and other); history; relation to other health system stakeholders; goals; capacity to fill patient submissions; “conventional methodology”; capacity to advocate¸(Culture of) patient and health professional relationship; patient knowledge and decision making; pharmaceutical power in decision making for patients; healthy system and patient choices"What is this patient evidence," Presentation “moving from the survey to the narrative” Power structures at hospital, LHIN, CADTH and other situations where patients are sought | https://bestmedicinescoalition.org http://www.healthcharities.ca/ https://bcsupportunit.ca/events-training/patient-engagement-evolution-health-technology-assessments-different-contexts https://www.hqontario.ca/Patient-Partnering/Patient-Partnering-Framework https://www.inesss.qc.ca/en/methodology/methodology-documents.html https://www.ispor.org/strategic-initiatives/patient-initiatives https://eupati.eu/ http://www.healthcharities.ca/about/history.aspx | *Informant extract* “You know government funded the **Canadian Medical Protective Association** back in 1901 by an **act of Parliament**, it’s funded out of that; so the doctors got protected and we're paying huge fees - our governments are paying huge fees to maintain the Canadian Medical Protective Association so that doctors don’t have to pay liability fees, but patient and the patient interests are left at the whim and whimsy of government, business and other private interests. How practical is that in 2018 or 2019 especially if we're moving towards some kind **of pharma‑care plan**.*Informant extract* “I got to tell you, no one sends **us letters of thanks** for input and sends along messages from the CDEC or other committees thanking us. And the CDRs CADTH does it regularly and we love it.” *Informant extract “*are looking at helping CADTH improve what they’re doing you can certainly look at the **BC SUPPORT Unit** for some good lessons I think.”*Informant extract “*I did host several **ISPOR patient round tables** – North American, European patient roundtables and I developed a course on helping patients understanding HTA for EUPATI, for the European Union Patient Academy, which was developed by me for **ISPOR for EUPATI**.” |
| **Reference to organizations, resources, polices, best practices associated to PPE**NICE and Scotland models of engagement SIGN- Health Canada – Ministry of Health The University of Toronto, Centre for Interprofessional Education - patient partnership program - The Beryl Institute as Chair of their Global Patient Family Advisory Council- Toronto Central LHIN - Canadian Medical Association - University of Toronto Public Health Healthcare Industry Pharma-care plan - Health Quality Ontario; HQO Transformation patient advisors; https://www.hqontario.ca/Patient-Partnering/Patient-Partnering-FrameworkJames Lind Alliance - CIHR (Canadian Institute for Health Research) - Cochrane organization patient engagement- HTAi website patient engagement framework, FDA; Drug assessment process;  model of engagement/patient participation – asthma projectStanding Committee Report, Health Act, - Local Health Systems Integration Act, 2006 - European Medical Association-  | https://www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/public-involvement-programme/patient-public-involvement-policy https://www.sign.ac.uk/patient-and-public-involvement/ https://ipe.utoronto.ca/about-us/ipe-patient-partners https://www.theberylinstitute.org/page/GPFABhttp://www.torontocentrallhin.on.ca/ https://www.cma.ca/ https://ihpme.utoronto.ca/research/research-centres-initiatives/ihpme-patient-engagement-committee/patient-engagement-committee-members/ https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/implementation-national-pharmacare/final-report.html https://www.jla.nihr.ac.uk/ https://cihr-irsc.gc.ca/e/45851.html https://training.cochrane.org/online-learning/consumer-involvement https://htai.org/interest-groups/pcig/values-and-standards/ input template https://www.jstor.org/stable/26661150?seq=1#metadata\_info\_tab\_contents https://www.ourcommons.ca/Committees/en/HESA https://www.ontario.ca/laws/statute/s06004https://emanet.org/ | *Informant extract* “ **The Beryl Institute** is a global community of patient experience professionals*Informant extract* “we talk about CADTH as this independent body – it isn’t, it’s an arm of **the government, it works on behalf of the government**. The biggest mandate they’ve got is how do we ensure that we’re going to be able to not overly impact on **the budgets** and that we’re going to be choosing drugs that give us the highest return of quality adjusted life here on the dollar.”*Informant exctract “*Two weeks ago a committee of **NICE**, that deals with highly specialised technologies, had its regular monthly meeting… And I had the opportunity to register in advance for that meeting, and I had the opportunity to attend that meeting, and I had the opportunity to not to participate in the discussion, but to listen to the discussion of the advisory committee on highly specialised technologies. And then the part of the process, which cannot have, either at pCODR or at the common drug review under CADTH...”*Informant exctract* “I mean it does do it, or it attempts to, as part of its broader assessment of – you know, its five-year evaluation for **Health Canada**.” *Informant extract* “the **CIHR, one of their standing committees** … there’s the governing council, as you may know, and then there’s the standing committee on ethics. And I feel really quite fortunate to have been asked to join the standing committee on ethics as a patient member” |
| **Scientific Publications**Kleinman, Arthur. The Illness Narratives: Suffering, Healing, and the Human Condition. New York: Basic Books, 1988.Forest PG and Martin D 2018, Fit for Purpose: Findings and Recommendations of the external review of the Pan-Canadian Health Organizations. Berglas, S., Jutai, L., MacKean, G. *et al.* Patients’ perspectives can be integrated in health technology assessments: an exploratory analysis of CADTH Common Drug Review. *Res Involv Engagem* **2,**21 (2016). https://doi.org/10.1186/s40900-016-0036-9 Weeks L, Polisena J, Scott AM, Holtorf AP, Staniszewska S, Facey K. Evaluation of patient and public involvement initiatives in health technology assessment: A survey of international agencies. Int J Technol Assess Health Care. 2017 Jan;33(6):715-723. doi: 10.1017/S0266462317000976. Epub 2017 Nov 10. PMID: 29122048.Bond K, Weeks L Using the INTEGRATE-HTA guidance: experience from CADTH - Int J Technol Assess Health Care. 2017 Jan;33(5):591-596. doi: 10.1017/S0266462317000940. Epub 2017 Nov 16. PMID: 29143698. | *Book*Report -https://www.canada.ca/en/health-canada/programs/external-advisory-body-pan-canadian-health-organizations.html*Journal article**Journal article**Journal article* | *Informant extract* “… I understand the goal to be adding a face to an illness... Almost like - and it’s a reflection on **Arthur Kleinman's work from the '80s or whatever on illness narratives** where introducing this idea that we - unless it’s stories from people to know what it feels like to be a patient; but then that's where our engagement sort of stops, is we're eliciting a story and then engaging with what that story is trying to tell us.”  |