

GRIPP2-Short Form Checklist for the Reporting of Patient Engagement in Research

Section and topic	Item	Reported on page No
1: Aim	<p><i>Report the aim of PPI in the study</i></p> <p>Researchers and patient leaders from three national joint- and skin-disease organisations co-developed and distributed an online survey to benchmark the views of people in Canada about using large, routinely-collected datasets in health research.</p> <p>The patient partners are co-investigators on a multidisciplinary team grant and co-develop projects to engage the public about the conduct of health research. From their frequent interactions with fellow patients, investigators, clinicians, and the public-at-large about the Canadian health research landscape, they identified a need to increase people's awareness and understanding about the use of routinely-collected data in health research.</p> <p>As a first step, the patients wanted to conduct a survey to benchmark people's current understanding, support, and willingness to learn more about this type of research. They approached researchers who had in-depth knowledge of health data, and expertise in survey design and implementation science, to collaborate on this project.</p>	5, 6-7
2: Methods	<p><i>Provide a clear description of the methods used for PPI in the study</i></p> <p>This was a patient-initiated study conducted at all stages through a partnership with researchers at Arthritis Research Canada. Throughout each phase of the research process, patients and researchers corresponded regularly by e-mail and held progress meetings (in-person or via teleconference) several times per year.</p> <p>The questionnaire was co-developed by the lead patient-partner and two of the researchers, with all patients contributing questions. The patient-partners then reviewed and provided iterative feedback on the drafts to ensure the title and content would be accessible, understandable, and interesting to lay audiences. The patients subsequently tested the online version of the questionnaire and provided additional feedback about its user-friendliness.</p> <p>The patient-partners played a key role in the recruitment effort. They promoted the survey through their personal Twitter feeds and their organisations' websites, e-mail lists, and social media channels. Of note, one patient-</p>	6-9, Figure 1

	<p>partner interviewed the first author about the survey for her organisation's newsletter.</p> <p>Once the survey was closed and responses analysed, the patient partners reviewed and affirmed the results, and discussed their possible impact for policymakers, researchers, and the public. They contributed to a meeting abstract and manuscript on this study (on which they were included as co-authors) and led the preparation of a lay summary. Along with the researchers, they are now co-developing educational materials for the public that incorporate patients' perspectives on this type of research.</p>	
3: Study results	<p><i>Outcomes—Report the results of PPI in the study, including both positive and negative outcomes</i></p> <p>Patient partners contributed to the study in many ways. They provided valuable feedback on drafts of the questionnaire, identifying phrases that could be misconstrued by the public. While they did not carry out the statistical analysis, they reviewed and affirmed the analyses presented to them at in-person meetings by one of the researchers. They subsequently discussed the possible impact of the findings for policymakers, researchers, and the public, and developed and implemented a dissemination plan.</p> <p>Patient partners reviewed and edited the abstract and manuscript the researchers drafted, and (along with the researchers) co-presented a poster on this study at a major scientific meeting. They also led the preparation of a lay summary of the survey findings and identified areas for future research; for example, which wording (i.e. "deidentified" vs. "coded" data) patients and the public are most comfortable using.</p>	9, Figure 1
4: Discussion and conclusions	<p><i>Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects</i></p> <p>The patient partners' involvement added credibility to the study and its findings. It may have appeared self-serving for health services researchers to conduct this survey on their own and report a favourable result about the level of support for this type of research from those outside the academic research community.</p> <p>The research trainees gained valuable experience in collaborating with patient partners and developed a better understanding of partners' roles, such as researchers' role in maintaining scientific rigor and patient partners' role in driving study accessibility. They additionally gained experience in discussing authorship for this paper. In turn, patients learned more about the research process, including how researchers go-about accessing</p>	15-16

	administrative data, and even co-presented the findings at a major scientific meeting.	
5: Reflections/critical perspective	<p><i>Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience</i></p> <p>Despite the survey being open for more than six months, and enthusiastic recruitment efforts of the patients and researchers, only 151 responses were received. A prior, though much-shorter, survey conducted by the patient partners received 636 online responses over three weeks. For the current survey, we suspect many potential respondents, especially those who found the survey through social media, reviewed the consent page and perceived the survey as too long or formal.</p> <p>Still, responses were submitted by > 80% of those started the survey and, on-the-whole, there was meaningful variation in the responses to different questions within surveys. For example, 95% reported being familiar with the term “electronic health/medical record” but only 58% were familiar with the term “administrative health data(base)”.</p> <p>The sample was also somewhat selected; for example, 67% reported having a chronic illness and 58% were university graduates. Recruitment was carried out mainly through patient groups for arthritis and skin disease, and individuals living with other conditions (and the public-at-large) may have different privacy and security concerns. As such, our findings cannot be generalised to the entire Canadian population. Further investigation is needed with more population-based sampling strategies, so the views of people of different ages, races/ethnicities, socioeconomic backgrounds, languages, and health status are better represented.</p>	14-16