

Towards a more user-centred research literacy platform: Protocol for usability study with patient partners

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Context

- In primary care, patient engagement in research can improve credibility, value, relevance, quality, appropriateness, applicability
- Major barrier: lack of common language & shared understanding
- Potential facilitator: research methods training
- The Quebec SPOR SUPPORT Unit developed a research literacy workshop that became an online platform *Understanding Research* using the Open Science Framework (OSF)

Study objectives

- Understand the experience of patient partners navigating the platform
- Identify usability issues

Methods

- Qualitative usability study
- 2 focus groups (5 participants per group, minimum recommended to identify most usability problems)
- Participants will be asked about perceptions, feelings and attitudes regarding the platform and participate in a card sorting activity
- Focus groups will be video recorded, transcribed, thematically analysed (using Nvivo software)

Future research

- Testing with other stakeholders (e.g., decision makers, clinicians)
- Pilot RCT to test the effectiveness of *Understanding Research* as an educational intervention

"Patients have been partnering as co-researchers for several years. However, something has been amiss: patients, as lay researchers, were not familiar with basic research language and concepts.

The Research Literacy training fills this void as it provides an indispensable tool for untrained patients, among other lay researchers, that helps them get further engaged and be included in a democratic scientific process."

- Mario Di Carlo, patient partner

Identifying patient partners' needs and concerns

Improving the *Understanding Research* platform

Anticipated results

Increasing research literacy for participation in research projects

Potentially facilitating patient partners' engagement in primary care research

Research literacy is defined as being sufficiently familiar with scientific ethics and methods to understand basic research concepts (knowledge), communicate with researchers and research participants (behavior), and respect research ethics (attitude).

(definition adapted from Nebeker and López-Arenas, 2016).

Understanding Research platform

- Co-developed with patient partners
- Organized in modules
- Offers content as PowerPoint slides, text, and video tutorials
- Built using the Open Science Framework (a free open source system)

What is OSF?

- OSF is a free open source platform to manage research projects
- Structured storage for many types of resources
- Different people can have different access permissions
- Built-in version control
- <https://osf.io>



References:

Nebeker C, López-Arenas A. Building research integrity and capacity (BRIC): an educational initiative to increase research literacy among community health workers and promoters. *Journal of Microbiology & Biology Education*. 2016 Mar;17(1):41.

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Main Partners:

Canadian Institutes of Health Research
Ministère de la Santé et des Services sociaux du Québec
Fonds de recherche du Québec - Santé

University Partners:

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