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Article abstract

Engaging patients in research conduct and agenda setting is increasingly considered as an ethical imperative, and a way to transcend views of patients as passive subjects by fostering their empowerment. However, patient engagement in research (PER) is still an emerging approach with debated definitional and operational frameworks. This song addresses the sometimes difficult encounter and elusive mutual understanding between researchers and patients. “What is PER?” is an impressionistic illustration of the challenges and issues that can be found in the universe of patient engagement in research.



ART, CULTURE ET OEUVRE DE CRÉATION / ART, CULTURE & CREATIVE WORKS

“What Is PER?” Patient Engagement in Research as a Hit

Jean-Christophe Bélisle-Pipon^{1,2}, Claudio Del Grande^{3,4}, Geneviève Rouleau^{4,5}

Résumé

Impliquer les patients dans la conduite de la recherche et dans l'établissement des agendas de recherche est de plus en plus considéré comme un impératif éthique de même qu'un moyen de transcender la vision classique des patients en tant que sujets passifs en favorisant leur autonomisation. Cependant, l'engagement des patients en recherche est encore une approche émergente avec des cadres définitionnels et opérationnels débattus. Cette chanson aborde la rencontre parfois difficile et l'insaisissabilité de la compréhension mutuelle entre chercheurs et patients. « What is PER? » est une illustration impressionnante des défis et enjeux rencontrés dans l'univers de l'engagement du patient en recherche.

Mots clés

engagement des patients, travail artistique fondé sur la recherche, savoir expérientiel, autonomisation des patients, recherche axée sur les patients, résultats centrés sur les patients, implication des patients

Abstract

Engaging patients in research conduct and agenda setting is increasingly considered as an ethical imperative, and a way to transcend views of patients as passive subjects by fostering their empowerment. However, patient engagement in research (PER) is still an emerging approach with debated definitional and operational frameworks. This song addresses the sometimes difficult encounter and elusive mutual understanding between researchers and patients. “What is PER?” is an impressionistic illustration of the challenges and issues that can be found in the universe of patient engagement in research.

Keywords

patient engagement, research-based artistic work, experiential knowledge, patient empowerment, patient-oriented research, patient-centered outcomes, patient involvement

[Researcher] What is PER?
Patients explain me, explain me
Once more

[Researcher] Patients explain me, explain me
Once more

What is PER?
Hey Hey

[Patients' back vocals]
Whoa ooh whoa ooh

[Patients] I don't know why you're not fair
I give you my insights, but you don't bear
So, am I right? What is wrong?
Gimme a plea

[Patients] What is PER?
Researchers explain me, explain me
Once more

[Patients] What is PER?
Researchers explain me, explain me
Once more

[Researchers' back vocals]
Whoa ooh whoa ooh whoa ooh whoa oh
oh ooh whoa ooh whoa oh oh oh oh (Bis)

[Patients] Oh, I can help, what can I do?
[Researcher] I'm applying for grants and I need you
[Both] I know we're a team, me and all of you
[Researcher] I can't press Send

[Researcher] What is PER?
Funders explain me, explain me
Once more

[Researcher] What is PER?
Funders explain me, explain me
Once more

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		<i>[Researchers' back vocals]</i> <i>Whoa ooh whoa ooh whoa ooh whoa oh oh ooh whoa ooh whoa oh oh oh oh (Bis)</i>
<i>[Researcher]</i>	What is PER?	
	What is PER?	<i>[Researchers' back vocals]</i> <i>Whoo ooh whoo ooh whoo ooh</i>
	What is PER?	<i>[Researchers' back vocals]</i> <i>Whoo ooh who ooh whoo ooh</i>
<i>[Both]</i>	What is PER? No one can tell me, can tell me At once	
<i>[Researcher]</i> <i>[Researcher]</i>	Explain me Just tell me	
<i>[Patients]</i> <i>[Researcher]</i> <i>[Patients]</i> <i>[Researcher]</i> <i>[Both]</i>	I want no other, no other advisor This is our care Our affair We are together, I need you forever Is it PER...	
<i>[Both]</i>	What is PER? Won't you explain me, explain me Once more	
	What is PER? Funders explain me, explain me Once more Hey Hey	<i>[Patients' back vocal]</i> <i>Whoa ooh whoa ooh whoa ooh whoa oh oh ooh whoa ooh whoa oh oh oh oh (Bis)</i>
	What is PER? Patients explain me, explain me Once more	<i>[Researchers' back vocal]</i> <i>Whoa ooh whoa ooh whoa ooh whoa oh oh ooh whoa ooh whoa oh oh oh oh (Bis)</i>
	What is PER? Researchers explain me, explain me Once more	
	What is PER?	

Afterword

Patient engagement in research (PER) is increasingly recognized and considered as an ethical imperative, based on the predication that research must serve those on whom and for whom it is conducted [1]. Seeking to transcend a paternalistic view of the involvement of patients in research (as objects and subjects of research), PER's objective is to value their knowledge and their experiences as being able to guide and orient research conduct and priority setting, so that it is more relevant and of greater impact [2]. Historically, researcher-patient relationships were not easily qualified as being founded on comradeship, equality and inclusivity [3]. Therefore, such a new approach to health research is laudable and likely necessary, but not without difficulty. PER requires, to some extent, the transformation of relationships between the various parties involved. An important change of culture and mentalities is needed to allow patients to join research teams and to be considered as important and valued partners [4].

“What is PER?”

This song – pastiche of the highly successful hit “What Is Love” performed by Haddaway in the 90s¹ – addresses themes related to PER operationalization as well as the obstacles and pitfalls in rebalancing the researcher-patient relationship; one of its critical obstacles being the meaningful and effective involvement of patients in research. “What Is PER” returns to the root of this concept and questions its foundations and implications based on both patients' and researchers' perspectives. The

¹ The song was released in 1993 on the label Coconut. Written and produced by Dee Dee Halligan and Junior Torello (<https://www.youtube.com/watch?v=HEXWRTEbj1I>).

song focuses on the challenges to reach a genuine, mutually beneficial researcher-patient relationship. But, achieving mutual understanding is not easy. On the one hand, research carries its share of imperatives and constraints (e.g., never-ending quest for funds and publications) that can easily escape patients. On the other hand, patients' realities and experiences with their disease, the health care system and research endeavour may sometimes seem trivial or biased (uncontrolled experiences vs. controlled experiments) to researchers. Too often, patients and researchers live in parallel realities. This is evoked by the repetition of the same questions and incessant requests to get an explanation of what PER really is and what actually goes wrong. Both are seeking to have a common understanding of what unites them, of the terms of their relationship.

PER, as a (new) research approach [5], seeks to intermingle patients and researchers, particularly by valuing patients as partners, and their experiential knowledge as complementary to scholarly knowledge. The choir of patients stress that they want to contribute to research and share their perspective that forms a "communal body of knowledge exceed[ing] the boundaries of individual experiences" [6]. However, in the song, researchers are only involving them superficially – minutes before submitting a grant application – leaving patients dissatisfied with their involvement: "I don't know why you're not fair. I give you my insights, but you don't bear". Researchers also are dissatisfied with and puzzled by funder expectations regarding their involvement of patient partners in research. In essence, "What is PER" focuses on miscommunication and Augean expectations between patients, researchers and funders. The song evokes a need for a frank and open dialogue within the research community, including patients, researchers, funders and so on.

Towards answering the question "What is PER?"

Whether in the context of patient-oriented research (Canadian model, established by the Canadian Institutes of Health Research, CIHR) [7], patient-centred outcomes research (American model as defined by the Patient-Centered Outcomes Research Institute, PCORI) [8], or public involvement in research (British model championed by INVOLVE, funded by the National Institute for Health Research, NIHR) [9], engaging patients in research is complex. It requires researchers to balance their expertise and quest for evidence-based knowledge with the perspectives and the subjectivity of patients. It entails recognizing that patients have experiential knowledge that can potentially increase the relevance and validity (both internal and external) of research projects. To achieve this, it is necessary to have a common vision of PER as well as a clear understanding of respective expectations and limitations.

As some funding opportunities (and increasingly scientific journals²) are now requiring the involvement of patients, this nudges researchers to engage in PER approaches. The instrumentalization of patients to gain access to these funds is real and represents a pressing ethical issue [1], yet even well-intentioned researchers are facing difficulties in authentically conducting PER. The song conveys that researchers' and patients' narratives are still tangential, highlighting that these communities have not yet established the necessary dialogue [13]. The terms of their relationship (or of their *affair*) are not yet established, nor has agreement been reached on what they should expect from each other; this is potentially one of the most pressing operational dimensions of PER.

Much remains to be done to address the issues of communication and genuine and mutually beneficial relationships. When researchers and patients ask each other and research funding agencies what PER entails, the answers they receive – the back vocals in the song – are heartfelt but remain elusive. It is as if the words are lacking for them to truly understand each other at this early stage of their new partnership. Making them still wonder what PER is.

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Conflicts of Interest

JCBP is cofounder and former Executive Editor of *BioéthiqueOnline*, and is member of the *Canadian Journal of Bioethics* Editorial Advisory Board. CDG and GR have nothing to declare.

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² The number of journals explicitly welcoming articles about PER is growing. For instance, the British Medical Journal (BMJ) and the Canadian Medical Association Journal (CMAJ) both seek to publish scholarship about PER [10,11]. The BMJ (since 2015) and BMJ Open (since 2018) now require that articles submitted be accompanied by a patient and public involvement statement describing whether and how patients were involved in the research [12].

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