

Stakeholders' experiences of HIV patient engagement within the I-Score patient-reported outcome Study: benefits and challenges



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The I-Score Study and Patient Engagement (PE)

PE was integrated in the I-Score Study through the I-Score Consulting Team and its activities.

Introduction

Patient engagement (PE) in research is recognized as a valuable approach to improve the quality, applicability, and relevance of health research and its benefits for accountable and accessible healthcare^{1,2}. PE implies, in part, **partnerships and mentorship between multidisciplinary investigators and patients**, given the importance and complementarity of their respective perspectives.

However, **how different stakeholders experience these partnerships and how these experiences evolve, is little documented**^{3,4}.

Aim: To address this gap by presenting three stakeholders' perspectives on their experience of PE

The I-Score Study

Objective: to develop and validate the clinical use of a digital HIV-specific patient-reported outcome measure of antiretroviral therapy adherence barriers.

So far, work on the **conceptual framework** included:

- a synthesis of qualitative studies on adherence barriers to antiretroviral therapy
- 27 semi-structured interviews with PLHIV.

A **Delphi** will be conducted to translate and adapt the conceptual framework for PLHIV, clinicians, and other relevant stakeholders,

An **adaptive trial** will evaluate how the implementation of the I-Score measure into HIV care.

The I-Score Consulting Team

- was formed by a **PE coordinator**
- initially a group of **ten diverse people living with HIV (PLHIV)** living in Montreal, Canada

5 men:	4 White MSM (one anglophone; one European) 1 African MSW	5 women:	2 White WSM (one anglophone; one ex-IDU) 3 African women
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Members' age : between 28 and 55 years old.
Number of years on ART : < 3 years to > 10 years.

- is engaged in **each step of the I-Score Study** by holding meetings to discuss its advancements
- collaborates in **knowledge-transfer activities (KTAs)** to disseminate results to concerned communities
- is involved as participants in research concerned with the patient perspective and the evaluation of PE in the I-Score Study

Materials and Methods

The table below presents the **experiences of PE** of three distinct types of stakeholders who participated in the I-Score Study:

- 1) clinical investigators
- 2) a PE coordinator
- 3) a patient-investigator

Using a reflexive and deliberative exercise, stakeholders identified the challenges they encountered while implementing and pursuing PE in the context of the I-Score Study and their implications

Results: Stakeholders' challenges and solutions at three key moments of the Patient Engagement Project

Moments of the PE project	Initiation of PE Project design, recruitment of patients	Implementation of PE Conducting Consulting Team meetings and integration with I-Score Study	Expansion of PE Integration of PE in all research projects affiliated with a Mentorship Chair in innovative clinical trials (awarded to BL by the Canadian Institutes of Health Research)
Stakeholders			
Investigators Role: conduct of the I-Score Study	<p>Challenge: Facing the possibility of limited patient interest in the PE Project</p> <p>Solution: Deciding to play it by ear</p> <p>Challenge: Understanding the boundaries between PE and research, for example, given overlap in methods</p> <p>Solution: Making provisions in the protocol for engaged patients to also be participants in I-Score-related research</p>	<p>Challenge: Determining what patient input can/cannot do</p> <p>Solution: Considering multiple sources of input in research decision-making (e.g., research evidence, engaged patients' feedback)</p> <p>Challenge: Tension with the PE coordinator around the urgency to see concrete use of patient input and the perceived inaction of investigators</p> <p>Solution: Communication between investigators and PE coordinator to clarify perspectives on the timeline of patient input integration</p>	<p>Challenge: Negative (and positive) impacts on the study timeline and budget, as PE becomes a necessary component of research</p> <p>Solution: Finding ways to compensate /catch up, seeking additional funding</p> <p>Challenge: Ensuring transparency and documentation of how patient input is used or not in practice</p> <p>Solution: Formalizing the process of receiving and responding to patient feedback within the Mentorship Chair</p>
PE coordinator Role: organization of PE activities, and liaison between the Consulting Team and I-Score investigators	<p>Challenge: Deciding who we should recruit</p> <p>Solution: Using maximum variation sampling, considering, for example, research experience, community involvement, and the main groups affected by HIV in Quebec :</p> <p>Challenge: Determining how to evaluate the PE Project</p> <p>Solution: Using a convergent mixed method design and involving PE Project participants</p>	<p>Challenge: Having difficulty reporting the 'patient perspective' to investigators, given multiple view points within the Consulting Team</p> <p>Solution: Meeting regularly with investigators to convey the complexity of the patient perspective</p> <p>Challenge: Making the Consulting Team's engagement as easy for its members as possible</p> <p>Solution: Attending to engaged patients' preferences</p>	<p>Challenge: Having a heavier workload due to increasing demand to engage patients in new projects</p> <p>Solution: Drawing on previously gained experience and skills</p> <p>Challenge: Fearing that PE in the new projects may become less meaningful</p> <p>Solution: Clarifying with interested investigators their expectations of PE and guiding them, as necessary</p>
Patient-investigator Role: provision of patient and academic/scientific expertise through involvement in PE activities (patient Team meetings) and research	<p>Challenge: Managing a recent HIV diagnosis and its consequences, including difficulty accessing medication, depression, feeling useless as a PLHIV, and confidentiality concerns</p> <p>Solution: Getting involved in the PE Project to discuss these issues with a group of investigators and other PLHIV</p> <p>Challenge: Feeling demotivated with academic life</p> <p>Solution: Seeking opportunities in the PE Project to share academic expertise</p>	<p>Challenge: Not seeing the value of the patient perspective to clinical research</p> <p>Solution: Participating regardless, and gradually realizing its value</p> <p>Challenge: Not wanting to be a 'passive' member of the Consulting Team</p> <p>Solution: Taking on a 'hybrid' patient-investigator role</p>	<p>Challenge: Juggling PE, academic research, and professional life</p> <p>Solution: Establishing priorities</p>

Conclusion

Through PE with PLHIV, stakeholders affiliated with the I-Score Study faced unanticipated personal and professional impacts, illustrating PE's potential to challenge and change existing research practices and experiences of living with HIV. Despite initial doubts and lack of experience with the integration of patient expertise in research, PE has become an unavoidable and key component of investigators' research activities.

ACKNOWLEDGMENTS: DL and IT are postdoctoral trainees of a Strategy for Patient-Oriented Research (SPOR) Mentorship Chair in Innovative Clinical Trials awarded by the Canadian Institutes of Health Research (CIHR) (www.cihr-irsc.gc.ca) to BL (#383427). DL and IT were supported by Mitacs through the Mitacs-Accelerate Program (#IT05857). DL received an Interdisciplinary Postdoctoral Award of the Health Research Foundation, and BL by a clinician-researcher award of the Quebec Health Research Funds (FRQ-S) (#28899). Partial funding for the I-Score Study was received from the CIHR's HIV Clinical Trials Network (CTN 283), from the Quebec SPOR Support Unit (M606), and from a research grant from the Investigator Initiated Studies Program of Merck Canada Inc. (IISP-53538). The Patient Engagement Project is supported by an unrestricted grant from Gilead Sciences Canada Inc. The opinions expressed in this manuscript are those of the authors and do not necessarily represent those of Merck Canada Inc., Gilead Sciences Canada Inc., or their affiliates or related companies.

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