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

Lessard D1,2,3, Engler K1,2,3, Vicente S1,2,3, Toupin J1,2,3, Cox J1,2,3, Kronfli N1,2,3, Routy JP1,2, Lebochëu B1,2,3,4
1. McGill University Health Centre for Outcomes Research and Evaluation, Montreal, Canada; 2. University of Montreal Department of Mathematics and Statistics, Montreal, Canada; 3. McGill University Health Centre-CHU Sainte-Justine Research Centre, Montreal, Canada; 4. McGill University Department of Family Medicine, Montreal, Canada. 5. Canadian Institutes of Health Research Strategy for Patient-Oriented Research Partnership Chair in Innovative Clinical Trials, Montreal, Canada

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.

The I-Score Consulting Team
- initially a group of ten diverse people living with HIV (PLHIV) living in Montreal, Canada

The I-Score Consulting Team
- 4 White MWM
- 1 African MWM
- 2 White WSM
- 1 African WSM
- 5 men:
- 1 White WSM
- 1 African WSM
- 5 women:
- 1 White WSM
- 1 African WSM
- Members' ages: between 26 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

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 healthcare1,2. 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 documented1,4. 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.

Stakeholders
Project design, recruitment of patients

Challenge: Facing the possibility of limited patient interest in the PE Project
Solution: Deciding to play it by ear

Challenge: Understanding the boundaries between PE and research, for example, given overlap in methods
Solution: Making provisions in the protocol for engaged patients to also be participants in I-Score-related research

Challenge: Deciding who we should recruit
Solution: Using maximum variation sampling, considering, for example, research experience, community involvement, and the main groups affected by HIV in Quebec:

- 2 White WSM
- 1 African MWM
- 5 men:
- 1 White WSM
- 1 African WSM
- 5 women:
- 1 White WSM
- 1 African WSM

Challenge: Determining how to evaluate the PE Project
Solution: Using a convergent mixed method design and involving PE Project participants

Challenge: Having difficulty reporting the ‘patient perspective’ to investigators, given multiple view points within the Consulting Team
Solution: Meeting regularly with investigators to convey the complexity of the patient perspective

Challenge: Making the Consulting Team’s engagement as easy for its members as possible
Solution: Attending to engaged patients’ preferences

Challenge: Not seeing the value of the patient perspective to clinical research
Solution: Participating regardless, and gradually realizing its value

Challenge: Not wanting to be a ‘passive’ member of the Consulting Team
Solution: Taking on a ‘hybrid’ patient-investigator role

Patient-investigator
Role: provision of patient and academic/scientific expertise through involvement in PE activities (patient Team meetings) and research

Challenge: Managing a recent HIV diagnosis and its consequences, including difficulty accessing medication, depression, feeling useless as a PLHIV, and confidentiality concerns
Solution: Getting involved in the PE Project to discuss these issues with a group of investigators and other PLHIV
Challenge: Feeling demotivated with academic life
Solution: Seeking opportunities in the PE Project to share academic expertise

Investigators
Role: conduct of the I-Score Study

Challenge: Not wishing to be a ‘passive’ member of the Consulting Team
Solution: Being a member of the Consulting Team and actively sharing the feedback

Solution: Taking on a ‘hybrid’ patient-investigator role

Challenge: Not seeing the value of the patient perspective to clinical research
Solution: Participating regardless, and gradually realizing its value

Challenge: Not wanting to be a ‘passive’ member of the Consulting Team
Solution: Taking on a ‘hybrid’ patient-investigator role

Expansion of PE
Integration of PE in all research projects affiliated with a Mentorship Chair in innovative clinical trials

Challenge: Negative (and positive) impacts on the study timeline and budget, as PE becomes a necessary component of research
Solution: Finding ways to compensate /catch up, seeking additional funding

Challenge: Ensuring transparency and documentation of how patient input is used or not in practice
Solution: Formalizing the process of receiving and responding to patient feedback within the Mentorship Chair

Challenge: Having a heavier workload due to increasing demand to engage patients in new projects
Solution: Drawing on previously gained experience and skills

Challenge: Having the PE in new projects may become less meaningful
Solution: Clarifying with interested investigators their expectations of PE and guiding them, as necessary

Challenge: Juggling PE, academic research, and professional life
Solution: Establishing priorities

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.

REFERENCES