



Engaging Patients, Caregivers and the Community Co-Designing What the Future Holds for IHPME

Summary of Priorities Set at June 7, 2018 Meeting

These notes focus on the priority areas identified by the attendees of the June 7th event on patient engagement hosted by Institute of Health Policy Management and Evaluation (HPME). The 4 priority areas identified were: 1) *education*, 2) *organizational culture*, 3) *partnerships*, and 4) *research*.

The four priority areas are divided into overarching summary points as well as core activities that may help us move ahead in the shorter term.

1. Education

For students

- Curriculum development (why we need to do patient engagement, how to do patient engagement and what the impact is)
- Connect students to the practice community (e.g., identify patients/caregivers that have a specific problem and partner with students to work on a concrete problem together)
- Contribute to practice, quality improvement and implementation

For faculty, larger IHPME Community and beyond

- Education on engagement (and co-design) so that it can be built into coursework
- Be a learning hub for others (e.g., community partners, other faculties)
- Explore and teach philosophical and epistemological tensions that exist in patient engagement – power dynamics, culture, representation, representativeness
- Unpack underpinnings of democratic vs. technocratic model for engagement

IHPME has a role to start training leaders who will push beyond the status quo and change the system

Some specific activities that can start to move the education agenda forward

- Invite patients and caregivers to be guest speakers in IHPME courses (e.g., course on strategy, health care systems, etc.)
- Invite patients and caregivers to design IHPME strategic plan
- At alumni events – pair up speakers with patients and caregivers
- Look at what's happening in other fields, not just healthcare. E.g., human-centered design
- Critically evaluate existing patient engagement evidence & experience
- Integrate modules within existing courses to promote use of patient data and critical evaluation
- Develop an online course or module (potential to generate revenue)
- Start small – such as introducing a new course at IHPME and gradually gain faculty buy-in



2. Organizational Culture

- Make IHPME equal, transparent, respectful regardless of title/role – create an environment of bringing everyone together respectfully; shift the power dynamic to one of equality
- Be mindful of the language we are using around patient engagement. IHPME should think about where it is focusing – patient engagement or public/citizen engagement? Participants noted that each requires different strategies
- Cultural shift- involving patients in highest level of policy and governance and break down internal hierarchies within organizations
- *Equal* representation of end users on governance boards
- Demonstrate value of engagement- grant submissions, increase buy-in for patient engagement with policy makers

Some specific activities that can start to move the organizational culture agenda forward

- Assess the level of commitment for patient engagement among IHPME community (do we want to be a centre or take another approach?)
- Structurally embed patient engagement in governance in IHPME
- Compensate patients fairly
- Set and assess goals on a yearly basis

3. Partnerships and Networking

- Strengthen and broaden relationships beyond traditional relationships in academia – reaching out to primary care facilities, social/ non-profit sectors, work with community in a real way.
- Stay abreast of what community leaders and community organizations need; develop resources to support them
- Bring partnerships into the core of IHPME's priority setting and strategic plan

Some specific activities that can start to move the partnerships agenda forward

- Take an inventory of traditional partners (e.g., MOHLTC Patient and Family Advisory Committee) and non-traditional partners (e.g., YMCA, Housing, municipalities), and expert organizations that do citizen engagement/co-design work (open labs)
- Partner with international organizations, e.g., international models for integrated care and engagement; IPFCC

4. Research

- Work with patients and policy makers to drive research agenda
- Focus on knowledge translation
- Continue the conversation about patient engagement in research; there are frameworks but rules of engagement in research aren't clear. IHPME can lead the conversation on that.
- How can IHPME play a role in helping organizations assess impact, evidence, and analysis on engagement?
- Healthcare equity – how to evaluate impact?
- Have respect for patient partners in research. Set expectations, communicate regularly and continually revisit goals.