

# *Participatory research in citizenship psychiatry: let's grow together!*

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# Who we are



International Program for Participatory Action Research (IPPAR) in Citizenship Psychiatry

- International: Montreal-Lille-New Haven
- Participatory Action Research: Integrated Knowledge Translation = Translation of the experiential knowledge of mental illness
- Citizenship Psychiatry: Full citizenship for everyone

# What we do

- At Hôpital Louis-H. Lafontaine
  - Research as an inclusive workplace
  - Where patients can learn new skills
  - A different way of looking at people with mental illnesses
  - Presentations
  - Publications

# The Patient Expertise

- PAR is an approach to research that involves persons of primary interest in all aspects of the process, from conceptualization through data collection, interpretation and sharing of findings.
- Co-learning, a strength-based approach, and acknowledgement of privilege and power are hallmarks of PAR.
- This collaborative research approach is particularly well suited to research on full citizenship because persons with primary interest are fully **included in all aspects** of the project.

# Postulates

➤ (a) all types of knowledge are *a priori* equal;

... but ...

➤ (b) the lived experience of mental health problems or illnesses deserves special attention.

## (a) all types of knowledge are a priori equal

- The Actor Network Theory is also known as the sociology of translation (ST).<sup>\*</sup> Central to ST is the *principle of generalized symmetry* that assigns equal amounts of agency among different *actors* of a network.
- The uptake of new knowledge and innovations can only take place if they are being carried by a network.
- A network is always composed of actors that do not initially have a common perspective or knowledge about a problem to be solved.

<sup>\*</sup> Latour, Bruno (1987) *Science in action. How to follow scientists and engineers through society*. Cambridge: Harvard University Press.

## (b) the lived experience of mental health problems or illnesses deserves special attention

- For centuries, people with mental health problems or illnesses have been marginalized\*;
- What an individual thinks or says can often be seen as a symptom to be treated, a treatment that may begin, at times, precisely with the suspension of rights and freedoms ;
- Mental health services themselves have also been found to perpetuate stigma about mental health problems and illnesses – what about research?

\*Foucault, M. (1972). Histoire de la folie à l'âge classique, Paris : Éditions Gallimard

# A study on participation



- September 1st, 2010, the Institutional Review Board of Louis-H Lafontaine Hospital in Montreal gave approval for a study titled: *Evaluating the feasibility of electronic data collection with psychiatric patients and understanding their experience of human-computer interaction.*
- 120 individuals were recruited, equally distributed in three sub-groups:
  - People with Anxiety and mood diagnoses;
  - People with Psychosis Diagnoses;
  - and people from the Emergency Room.



# Assessing the added value of PAR

- A list of 30 possible research topics was produced—the *Checklist for participatory research in mental health*\*
- 27 focus group participants were asked, for each of these topics, if it was *very important, important, somehow important or not important* to conduct research on that topic.

\* Pelletier, Delorme, Lesage, Macaulay, Salsberg, Vallée (2011) User-led research, a global and person-centred initiative, *International Journal of Mental Health Promotion*

# Results to the *Checklist* (n=27)

Possible research topic	%
Breaking free from poverty	88
Facilitate the recognition of competencies	86
Improving access to information	85
Taking responsibilities	84
Facilitate the recognition of the need for accommodations	83
Overcoming multiple bereavements	83
Fighting stigma in the workplace	82
Facilitate the recognition of credentials and work experiences	82
Access to housing	82
Access to transportation	81
Supporting decision making and one's voice and influence	81
Supporting social integration (work, volunteering etc)	80

# Discussing together the results

- A focus group was held with 9 out of the 27 participants (3 from each sub-group) to discuss the results to the Checklist.
- They were told about the results of the Checklist and asked what they gained from participating in a focus group.
- They were asked what they thought they would gain from getting even more actively involved in future research activities, for example as Co-research team-members.

# Discussing together the results



- Overall, participants stated that involvement as focus group participants and co-researchers
  - improves their economic situation
  - is a concrete recognition of competencies
  - improves their access to first-hand information
  - supports them in assuming some responsibilities.


# Results - Themes



## ➔ Becoming free from poverty:

“Becoming free from poverty is the ultimate goal for many, once the symptoms are in control and that the recovery process is under way. If we are economically better off, our mental health will improve. Being paid as research partners is a concrete way to help us financially, for us to make some money out of research about us”.

# Results - Themes



➔ Recognition of competencies:

“Being paid to actively participate in a focus group is a recognition of our valued, specific competencies and contributions. We, consumers, are in the best possible situation to know what our needs are”.

# Results - Themes



## ➔ Taking responsibilities:

“To be invited to join a focus group is a way to be recognized as important contributors. Even as a simple participant, we have to get up early and that makes us feel that we have the responsibility to be there on time and to get engaged”.

# Results - Themes



## ➔ Improving access to information:

“We like to have access to first-hand information by being part of the very process of knowledge generation. For example: having experienced a new and stimulating technology (iPad), made us feel part of this technological world”.



# Summing Up – NIMH – The 4 P's

- ➔ According to the National Institutes of Mental Health (NIHM 2008) the “4 P's” of research are about: “increasing the capacity to Predict who is at risk for developing disease; developing interventions that Preempt (or interrupt) the disease process; using knowledge about individual biological, environmental, and social factors for Personalized interventions; and ensuring that clinical research involves Participation from the diversity of people and settings involved in health care.”



# Summing Up – NIMH – The 4 P's

- Focus groups participants were told about the 4 'P's of research according to the National Institute of Mental Health.
- They were asked in what type of research they would like to be involved and when their lived experience seemed more relevant with regards to the '4Ps'.



# Summing Up – NIMH – The 4 P's

- Obviously, the “4P's” are not in an alphabetical order. There is an implicit hierarchy, with participation being last of those P's.
- From a PAR point of view, it would make more sense to reverse the order: Participation, Personalization, Preempt, Predict.



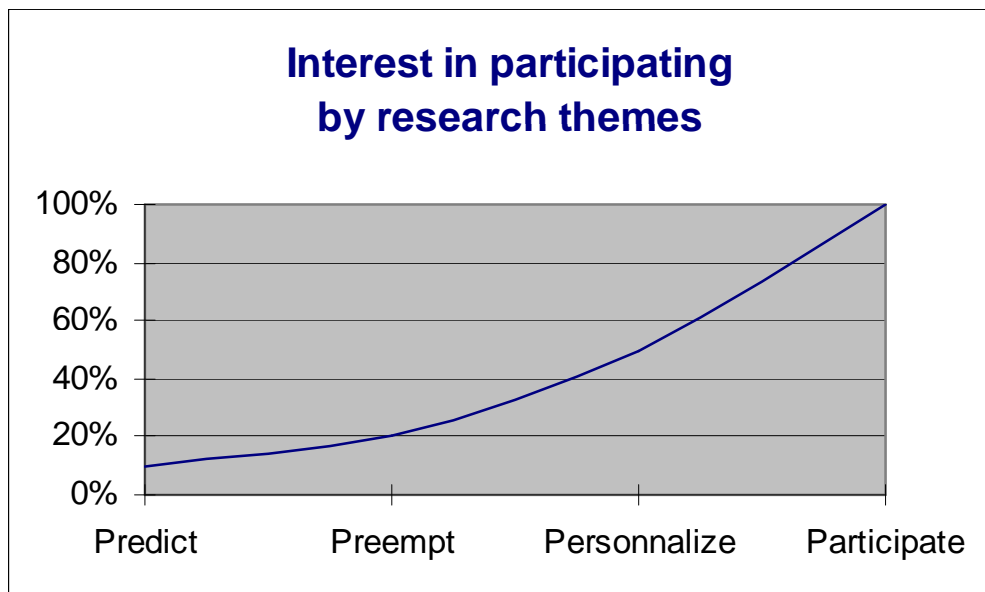
# Summing Up

- ➔ The more a research project is participatory, the more relevant it is in addressing research priorities dear to PAR and consumers.
- ➔ The more a project is about participation, the more consumers are interested in participating.

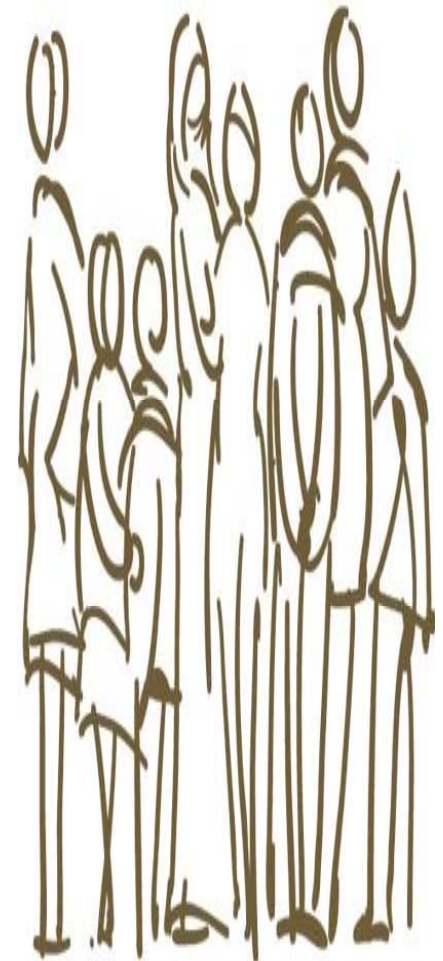


# Summing Up

## ➔ The “P” gradient:



➔ Research on community inclusion, for example, can be research *as* community inclusion.



# What we do

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September 27, 2011

**Speaker:** Jean-Francois Pelletier,  
Hopital Louis-H Lafontaine

**Topic:** Participatory research in  
citizenship psychiatry: let's grow  
together!

[Listing of past seminars](#)

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presentations](#)

**Were you at the last seminar?**

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**Please add your [comments!](#)**

## Participatory Research @ Lunch

Please join us each month for our brown bag seminar series. Guest speakers will discuss topics of interest to Participatory Research

Unless otherwise noted, All talks are at the McGill Department of Family Medicine, 515 Pine Ave West, Montreal, QC [\[map\]](#)

Talks are at **12:00 PM**, followed by a discussion period. Please RSVP by email or phone!

Seminars...

2010 - 2011 Seminars

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- **September 27, 2011 - Jean-Francois Pelletier, Hopital Louis-H Lafontaine**
  - Participatory research in citizenship psychiatry: let's grow together!.
- **October 11, 2011 - TBA,**
  - TBA.
- **November 22, 2011 - Dr. Anne Crocker, Douglas Mental Health University Institute**
  - TBA.
- **December 13, 2011 - Susan Law, St Marys Hospital**
  - JRA

Questions ?

