

# **PATIENT ENGAGED RESEARCH: WHEN BARRIERS BECOME FACILITATORS & VICE VERSA**

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# OVERVIEW





Patient  
Engagement  
Platform



## Goal: AbSPORU PEP

- ▶ “The goal of the Patient Engagement Platform is to support meaningful engagement of patients and researchers at one or more stages across the health research process to promote patient-oriented research”.



Patient  
Engagement  
Platform

## Goal: Canadian Depression Research & Intervention Network (CDRIN)

- ▶ “CDRIN will mobilize Canada’s mental health community, including people with lived experience, to address important issues associated with mood disorders and post-traumatic stress disorder (PTSD) through research network development, capacity building and knowledge translation in order to improve the lives of people with mood disorders and their families”.

# Facilitators & Barriers to Patient Engaged Research

## ▶ Areas of Focus

- Ways of Knowing
- Established Cultures (handout)
- Researcher's Guide to Patient Engaged Health Research (handout)
- Identifying Facilitators & Barriers

# Categories of Ways of Knowing

## Tacit knowledge

- Is difficult to transfer efficiently from one person to another even if written down or verbalized.
- Best thought of as experience
- Described as practical, know-how, context specific and “emergent, fluid, and person-specific”.

## Codified knowledge

- Can be written down, transmitted and understood
- e.g. recipes, blueprints, instruction manuals – but also lesson plans in classrooms.

# Tacit Knowledge: Characteristics

- ▶ Telling stories, observing, showing
- ▶ Non-linear, circular, evolving
- ▶ Includes emotions, visceral reactions, scents, sounds, touch
- ▶ Contextualized – utility depends on context
- ▶ Acquired through direct experience
- ▶ “Subjective”
- ▶ Embraces complexity and is unbothered by it



# Tacit Knowledge: Characteristics cont'd

- ▶ Passed on directly by those with experience
- ▶ Skills acquired through being shown in real time
- ▶ Mastery is incremental
- ▶ Competence not measured but experienced and lack of competence can have mild to severe life consequences (e.g. loss of job .... loss of life....).

# Value of Tacit Knowledge

- Evolving, expanding, adaptable to context, flexible
- Adaptable to change, context
- Holistic – includes physical and meta-physical
- Defines human experience and life
- Utilitarian, practical, action-oriented

# Disadvantages of Tacit Knowledge

- ▶ Requires contact to transmit
- ▶ Oral, fragile, can be lost, may die out
- ▶ Often not written at all – remains verbal or within activities that “show”
- ▶ May have to be re-invented in each generation
- ▶ Much harder to build upon
- ▶ Situation and context specific – hard to translate to different situations

# Codified Knowledge: Characteristics

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- ▶ Can be decontextualized - decoupled from context
- ▶ Encoded: Passed on (in text and in numerals) in books, lectures, diagrams, tables, and other materials. May be communicated by charts, graphs, diagrams, blueprints, instructional manuals etc.
- ▶ Passed on formally and within formal social structures
- ▶ Tell (as opposed to show)
- ▶ Can be independent of experience or practice.
- ▶ “Objective”

# Codified Knowledge: Characteristics cont'd

- Competence can be measured and assigned a score
- Systematic – seeks to break down complexity
- Compartmentalized
- Knowledge for the sake of knowledge (it is an end in and of itself)
- Intellectual
- Underlies career, profession, commerce, discoveries

# Value of Codified Knowledge

- Systematically organized
- Can be replicated
- Can be communicated and passed on – at great distances to people who have never met.
- Translates into different languages if need be
- Can be applied in different situations
- Can be built upon because it is not easily lost – also is available from generation to generation
- Has led and continues to lead to knowledge advancement for humankind – along with the benefits of this advancement

# Disadvantages of Codified Knowledge

- ▶ Can be blind to the value of other versions and sources of knowledge – and ways of knowing
- ▶ Segmented and non-holistic– focused on one subject and one subject only
- ▶ Can be rigid – can be slow to adopt change and new ideas
- ▶ Hegemonic - non-inclusive of diversity and other cultural ways

# Facilitators & Barriers to PE Health Research

- ▶ Is inclusive
- ▶ Is conducted in an atmosphere of equity
- ▶ Involves shared decision-making
- ▶ Takes time and money – over and above a standard research project
- ▶ Involves networking, outreach, forming and sustaining relationships among many people.
- ▶ Appreciates but at the same time balances different viewpoints and agendas – people with lived experience are diverse. Families often have divergent views from people with lived experience. When they don't agree, things can get tense.



# Facilitators & Barriers to PE Health Research

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- Requires managing disagreement – your views and all these other views may collide.
- Requires the researcher to be culturally competent and able to bridge between the culture of research and that of people with lived experience and caregivers – and possibly other cultures.
- Needs the researcher to be a facilitator – encouraging, reconciling (likely) and capturing the many views and ideas of people with lived experience and caregivers.
- Requires the researcher to be a translator who is able to convert these diverse views into a viable research focus/project.

# Facilitators & Barriers to PE Health Research

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- ▶ Requires the researcher to identify and utilize the talents and strengths of people with lived experience and caregivers for the good of the research – for example – as data gathers and as knowledge translators.
- ▶ Means that the researcher and his or her team are not alone with their data. Even analysis can be shared. It doesn't have to be but it may be.
- ▶ Means that the researcher(s) are not alone throughout the whole process.

# Questions?



спасибо  
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