

## BACKGROUND

The World Health Organization has declared non-adherence to medications an epidemic, only 50% of adults adhere to treatment and those with inflammatory arthritis are no exception. Reported adherence rates as low as 30% for disease-modifying anti-rheumatic drugs in patients with RA or 10% for urate-lowering therapy in gout highlight the importance of targeting and improving adherence to treatment. **Research on interventions to help arthritis patients better take their medications has been disappointing and inconsistent.** However, prior studies have not explored patient perspectives on adherence strategies which may contribute to disappointing results of research on adherence interventions.

## OBJECTIVES

- To describe the conception, development, and implementation of a research project which demonstrates the value of **arthritis patients' involvement and collaboration**
- To report preliminary research findings and update on progress

## PATIENT INVOLVEMENT IN RESEARCH

### Conception

On February 11th, 2014, we presented our research program on medication adherence in arthritis at a meeting of the **Arthritis Research Canada's (ARC) Patient Advisory Board (APAB)**. Composed of men and women living with arthritis, the APAB participates in arthritis research decision-making with ARC researchers. From APAB input on rationale (*'arthritis patients are willing to, and should be consulted when it comes to what adherence interventions to study'*), approach (*'focus groups with patients'*), the focus group-based research study **INflammatory arthritis patients' perspectives, priorities, and opinions on interventions FOR MEDication adherence (INFORMED study3)** was borne.

### Design and Development

We proposed a qualitative study using focus groups with patients with inflammatory arthritis to gain insights on patients' perspectives on medication adherence interventions, including their attitudes and willingness to use them. APAB involvement at this stage included having a member as a co-investigator on the research team and grant proposal, providing feedback on the research proposal, as well as a letter of support.

### Implementation

**Preparation of Study Materials:** APAB members provided feedback and comments on various study materials, including the focus topic guide.

**Recruitment:** APAB has provided channels to support study recruitment including The Arthritis Newsletter, a booth at the 2014 eROAR, and individual members' efforts.

## PILOT INFORMED STUDY FOCUS GROUP WITH APAB

Prior to launching the INFORMED study, six APAB members agreed to participate in a pilot focus group. This was designed to test study methods, identify any potential issues, and provide an opportunity to generate preliminary research findings. The session was digitally recorded and transcribed verbatim. We applied an iterative, thematic approach using a constant comparative approach informed by aspects of grounded theory and analyzed the transcript using the constant comparison method. Four study team members independently read and annotated the transcript and after discussion agreed on an initial coding framework.

### I. Emerging Categories

- Relationships-trusts-access
- Stage of Illness
- Strategies
- Beliefs/attitudes
- Side effects/complications/medication effects
- Peer Relationships
- Medication Taking
- Daily life /self-management
- Education/information
- Medications for arthritis
- Other Medications
- Other

### Preliminary Findings

#### II. Emerging Themes

- The first year of diagnosis is the most difficult

"When you're newly diagnosed it's so much information ... it was horrible... And you've got the brain fog so you're trying to learn and manage and advocate for yourself at the same time. So the first year was really trying."

- Peer support is absolutely essential to aid with difficulties in taking medications as prescribed

"The power of peer relationships in coping with any of the arthritis diseases is, you can't overstress how important it is to have somebody that has walked the walk and talked the talk."

- Trust in the qualifications of the health care provider and in the quality of information received is essential to supporting patients taking their medications as prescribed.

Trust, I guess. Trust is a big thing for me.. feel it's okay to be vulnerable and when you have severe arthritis diseases, you are vulnerable.



### Individuals living with INFLAMMATORY ARTHRITIS:

What are your experiences and opinions on medication taking?

#### WE WANT TO HEAR FROM YOU.

For many patients living with arthritis, medication taking is a part of everyday life. Dr. Mary De Vera, Assistant Professor at the Faculty of Pharmaceutical Sciences in the University of British Columbia, and the researchers at Arthritis Research Centre of Canada are conducting focus group sessions to find out patients' experiences with medication taking. We also hope to gain opinions regarding strategies that may help patients improve medication taking.

Patients with **Rheumatoid Arthritis, Lupus, Polyarthritis, Psoriatic Arthritis, Ankylosing Spondylitis** and **Gout** who are **19 years old or older** are being invited to participate in a 2 hour focus group session. You will receive an honorarium for your participation.

For more information about the study, please contact Pavan Mehat at 604-880-9312 or pmehat12@mail.ubc.ca.

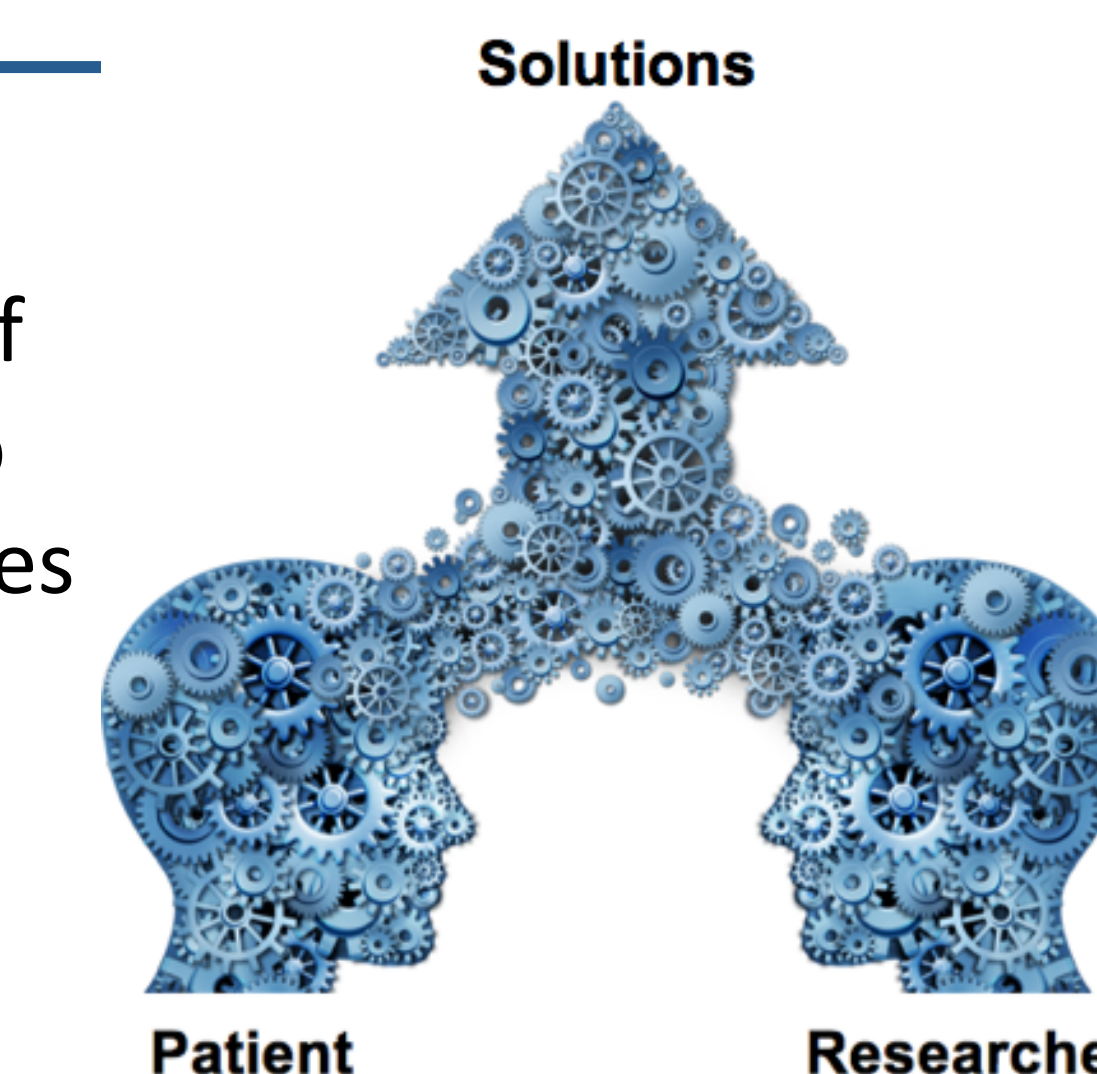
a place of mind  
THE UNIVERSITY OF BRITISH COLUMBIA  
Faculty of Pharmaceutical Sciences



Arthritis Research Centre of Canada  
Arthritis Research Canada  
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## IMPLICATIONS

It is clear from the conception, development, and implementation of the INFORMED study that patient/researcher collaboration needs to become commonplace and the standard to conduct patient outcomes research. The goal of all of our research is to improve patient outcomes. Therefore it is essential that we are allowing the patient to guide research questions so that it most benefits them.



## ACKNOWLEDGEMENTS

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### Questions?

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