



**CHÉOS**

Centre for Health Evaluation & Outcome Sciences

# Perspectives of Patients, First Degree Relatives, and Rheumatologists

## Around Preventative Treatments for Rheumatoid Arthritis

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### PURPOSE

- To identify relevant attributes for a discrete choice experiment representing the factors that influence the preferences of patients, first-degree relatives of patients, and rheumatologists about a preventative treatment for rheumatoid arthritis

### BACKGROUND

- Rheumatoid arthritis (RA) affects more than 330,000 Canadians and generates \$16.1 billion in direct health care costs<sup>1</sup>
- RA is thought to have an identifiable pre-clinical phase which predicts the development and progression of disease<sup>2</sup>
- Screening using auto-antibodies and other biomarkers offers the opportunity to identify and treat those at high risk in an effort to prevent the development of rheumatoid arthritis

### METHODS

- Qualitative study design
- Setting: Urban community in British Columbia
- Data Collection: semi-structured focus groups were conducted with:
  - Patients diagnosed with rheumatoid arthritis
  - First degree relatives of people with rheumatoid arthritis
  - Rheumatologists
- Focus groups were transcribed, analyzed, interpreted and then reduced to a potential list of attributes using a Framework analysis<sup>3</sup>

### TABLE 1: PARTICIPANT GROUPS

<b>Patients</b>	<b>13 (3 Male, 10 Female)</b>
<b>First Degree Relatives</b>	<b>5 (2 Male, 3 Female)</b>
<b>Rheumatologists</b>	<b>7 (2 Male, 5 Female)</b>

### TABLE 2: FRAMEWORK ANALYSIS OF SELECTED FACTORS INFLUENCING UPTAKE OF A PREVENTATIVE TREATMENT

	Living with Rheumatoid Arthritis	Wanting a Better Quality of Life	Trying to Avoid the Side Effects of Medication	Having Concerns about the Impact of the Test	Needing More Evidence	Implementing Preventative Treatment for Rheumatoid Arthritis in the Health System
 <b>Patient</b>	"I had a son and was a single mom. I was just devastated, I couldn't even, for an afternoon, I couldn't get dressed, couldn't pull up the zipper on my pants, and I just lost so much weight."**	"I had a very rich, very full no-limits life previously. I had no indication that that would change ... And I would like to not have had that impeded by any kind of thoughts ... I would probably choose not to try find out."*	"And of course the medication is effecting all the other things, the liver, the kidneys. Your skin, your hair, like everything. Eyes."**	"I'm in for taking all the tests I can get my hands on, because every little bit of knowledge helps me understand what is going on with my body. ...I want to know for my own benefit these different things."**	"If we don't know the cause [of RA], everything is suspect that we do. You know? And especially all the treatments that are -- the regimen, or the procedure from the drug companies do."*	None
 <b>First Degree Relative</b>	"She [family member] had a life and then once the disease came and took it from her, she didn't anymore. She couldn't do things."**	"If that was a risk for the medication, it's also a risk for the RA. You're almost guaranteed to get serious infections and TB is completely likely. So would I rather get those now when I'm strong enough and healthy enough to fight them"***	"Especially because of watching my mom with prednisone, if there's anything that increase the mental risk, that would be like huge for me."*	"And for me adding any kind of anxiety to it, not because [a test result] necessarily jars me into a realism that I'm not comfortable with, but because I don't think it adds anything."**	"If it was that kind of drug where it had already been used in the market place, with you know, other people taking it. That'd be great. But if it was something that was newly developed for this and perhaps the experimental trial, no."*	None
 <b>Rheumatologist</b>	None	None	None	"Well, if I know I'm going to have Lupus then my insurance goes into the toilet, you know, and I don't want that, so I don't want to know. I don't want my family to know."**	"I think that I really, really strong, good solid scientific placebo control or analyzed control, let's do it, I'll push for it. But before that it is do no harm and that is how I approach my patient."**	"I barely have time to address the issues and the patients and when you say 25 percent already have erosive disease by the time they come, I tell you my practice in the middle of British Columbia is 50 percent, so there is no time to address the why."**

\*\* Frequent theme; \* Infrequent theme

### TABLE 3: ATTRIBUTES ELICITED FOR A DISCRETE CHOICE EXPERIMENT

Accuracy of test	Who recommends looking into treatment	Rheumatoid arthritis risk and risk reduction with treatment	Method of administration	Chance of side effects	Certainty in estimates	Opinion of healthcare provider (or patient for the rheumatologist)
How accurate is the test in predicting rheumatoid arthritis	Whether it is a health care provider, patient, or relative who recommends it	The risk of developing Rheumatoid arthritis without vs. with treatment	Whether it is an infusion, injection, tablet.	The risk of a side effect from treatment	How strong is the evidence for the test and preventative treatments	Whether a healthcare provider or patient supports/wants to take test and/or preventative treatment

### RESULTS

- Patients and first-degree relatives tended to focus on impacts on their quality of life including activities, relationships, health, and wealth.
- Rheumatologists mainly focused on the evidence for preventative treatments, the ability to predict who would develop rheumatoid arthritis, and the implementation challenges at a health system level
- First-degree relatives valued the availability of options for treatment after screening, whereas patients viewed screening as obtaining intrusive personal knowledge on their health

### CONCLUSIONS

- Through qualitative analysis, we highlighted key themes in this discussion which informed the attributes to be included in a discrete choice experiment
- Our findings suggest that there are important differences in how uncertainties surrounding the potential benefits of a preventative treatment for rheumatoid arthritis are valued from the perspectives of patients, FDRs and rheumatologists.

### FUNDING

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### CITATIONS

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- Gale, BMC Med Res Methodol. 2013;