

Development and Pilot Testing of the Arthritis Health Journal for Rheumatoid Arthritis

Paul Adam¹, Linda Li^{2,3}, Erin Carruthers³, Gwen Ellert⁴, Beverly Mitchell⁵ & Diane Lacaille^{3,6}
 1. Mary Pack Arthritis Program, Vancouver Coastal Health 2. Department of Physical Therapy, UBC 3. Arthritis Research Centre of Canada 4. Trelle Enterprises Inc. 5. IMITS, PHSA/VCH/PHC 6. Department of Medicine, UBC

Background

- In rheumatoid arthritis (RA) it is recommended that treatment is escalated until a target is reached and promptly modified when the target is no longer met.
- The active involvement of people with RA in monitoring their own disease activity could facilitate this approach by providing early warning when targets are not being met.
- An existing, paper-based chronic disease journal was chosen as the framework upon which to build the online Arthritis Health Journal (AHJ)

"Well if I could get a little chart that looked like this that kind of gave me an overview...then it would show me week to week how things are changing...you don't pay so much attention so you don't realize that it's worse than it was a year ago, you know you just kind of get used to it." (Elizabeth)

"So my expectation is certainly that patients will call me, and they -- they normally do if they aren't doing well, if you can give them some more alerts, 'cause clearly for every patient who calls, there's somebody else who's toughing it...out 'cause they're not...appropriately aware...of the fact that their disease is misbehaving." (Dr. Osler)

Objectives

- To adapt a chronic disease journal to the needs of patients with RA.
- The usability and pilot testing phases of this study are ongoing.

Methodology

- 9 adults with RA and 5 rheumatologists were recruited from the Greater Vancouver area.
- Structured interviews were conducted to understand how patients and rheumatologists would use an online AHJ, which would be adapted from an existing chronic disease journal. Feedback was solicited in relation to care needs and how it would be used in day-to-day disease management.
- Interview data were taped, transcribed and analyzed using a thematic approach to identify key ideas and recurrent themes.

Findings

Theme 1: Enhancing Self Care - Both individuals with RA and rheumatologists identified several ways in which the AHJ could enhance self care including:

- Establishing a record of successful and unsuccessful disease management strategies.
- Increasing the self-awareness of individuals with RA by helping to identify factors that may be making an individual's condition worse or better.

"No, I think that basically a patient having gone through this just makes them much more aware of where they're at. There are obviously, there always are patients who are so vague and this allows them to have a more objective measure of how they're really doing. And if they're doing it regularly, they can then say oh yeah, I am feeling better you know and this is why I'm feeling better...so that's what's great about this is that the patients a) are more aware. They can monitor themselves better. They have a better idea of how they're doing and then we can address..." (Dr. Stone)

"With having the data in place, you can actually see, if you create a diary of what you did that particular day or what you did out of the regular norm that particular day, then you can see you know my pain here, what am I doing? Oh, these are, that's me cutting the grass...you can control them by saying okay, well maybe you know instead of trying to do the whole yard in one day, how about we do the yard in two days." (John)

- Educating people with RA overtly (e.g., messaging about the importance of treating to target) or covertly (e.g., distinguishing the three types of exercise).

Figure 1: Screenshot from AHJ Health Diary

What types of exercises did you do in the last 7 days?

- Stretching eg. yoga, Tai Chi, physiotherapist-prescribed exercises
- Strengthening eg. weight-training, physiotherapist-prescribed exercises
- Aerobic eg. walking, StairMaster

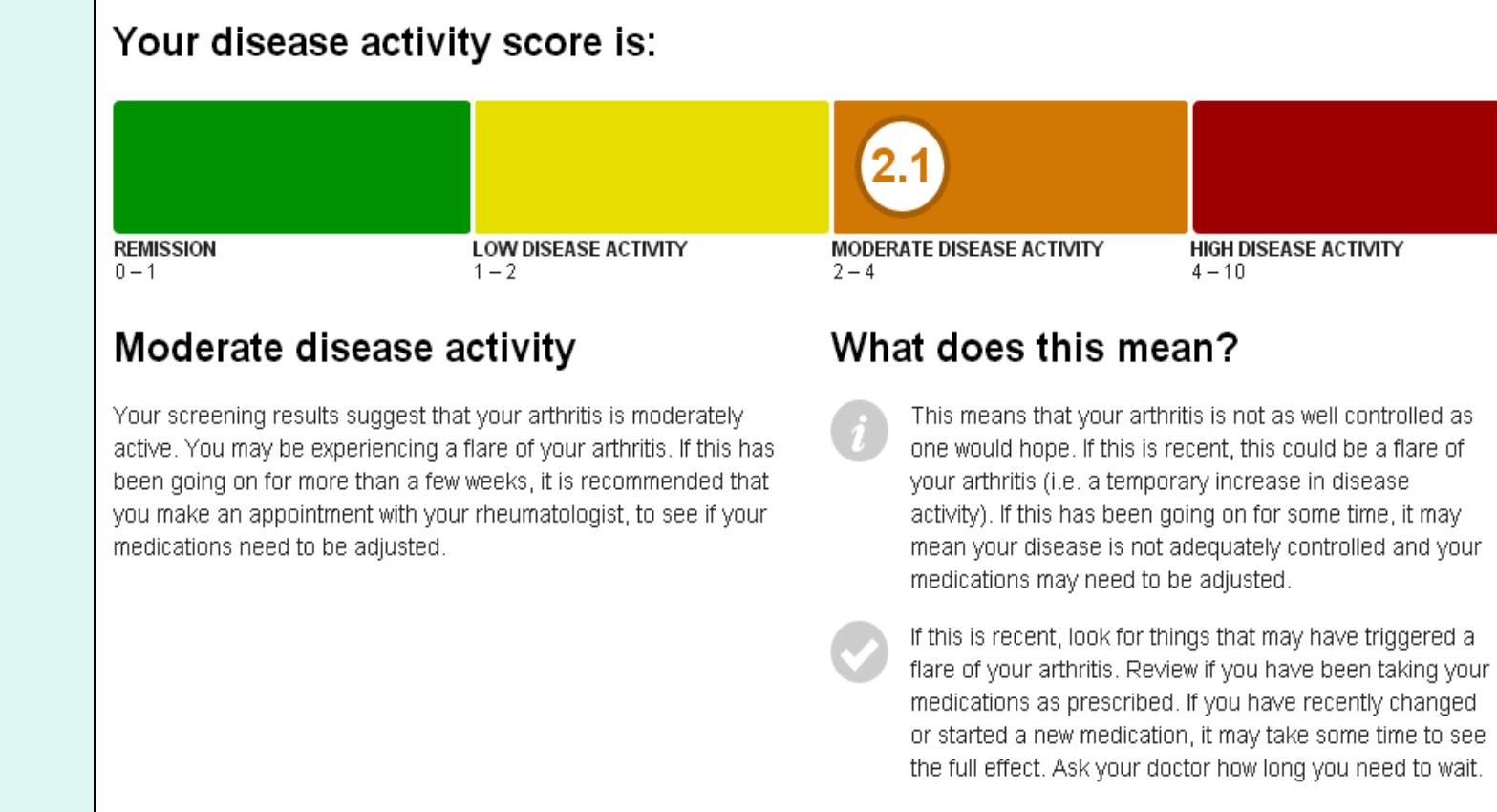
Rheumatologists were ambivalent in that they identified the importance of patients being more involved in their own care, yet some felt that this could lead to a heightened patient anxiety, if patients focused on and worried about changes in their health based on scores in the AHJ that were not clinically meaningful.

Theme 2: Enabling Care As Needed - Individuals with RA identified the challenges faced in managing their disease and obtaining timely access to their rheumatologist.

Importance of care as needed versus routine care – care when needed was thought to be beneficial if appropriate and could free up time if it precluded unnecessary, routine care appointments. Other rheumatologists felt that routine care catches things that may be missed by a tool or patient self-assessment.

Rheumatologists feared the AHJ would not be sufficiently sophisticated or accurate to discern poor disease control from other factors that can cause increased pain or a short-term flare of the disease. The AHJ would be perceived as being beneficial if it could guide patients to make this discernment.

Figure 2: Screenshot from AHJ Disease Activity Assessment

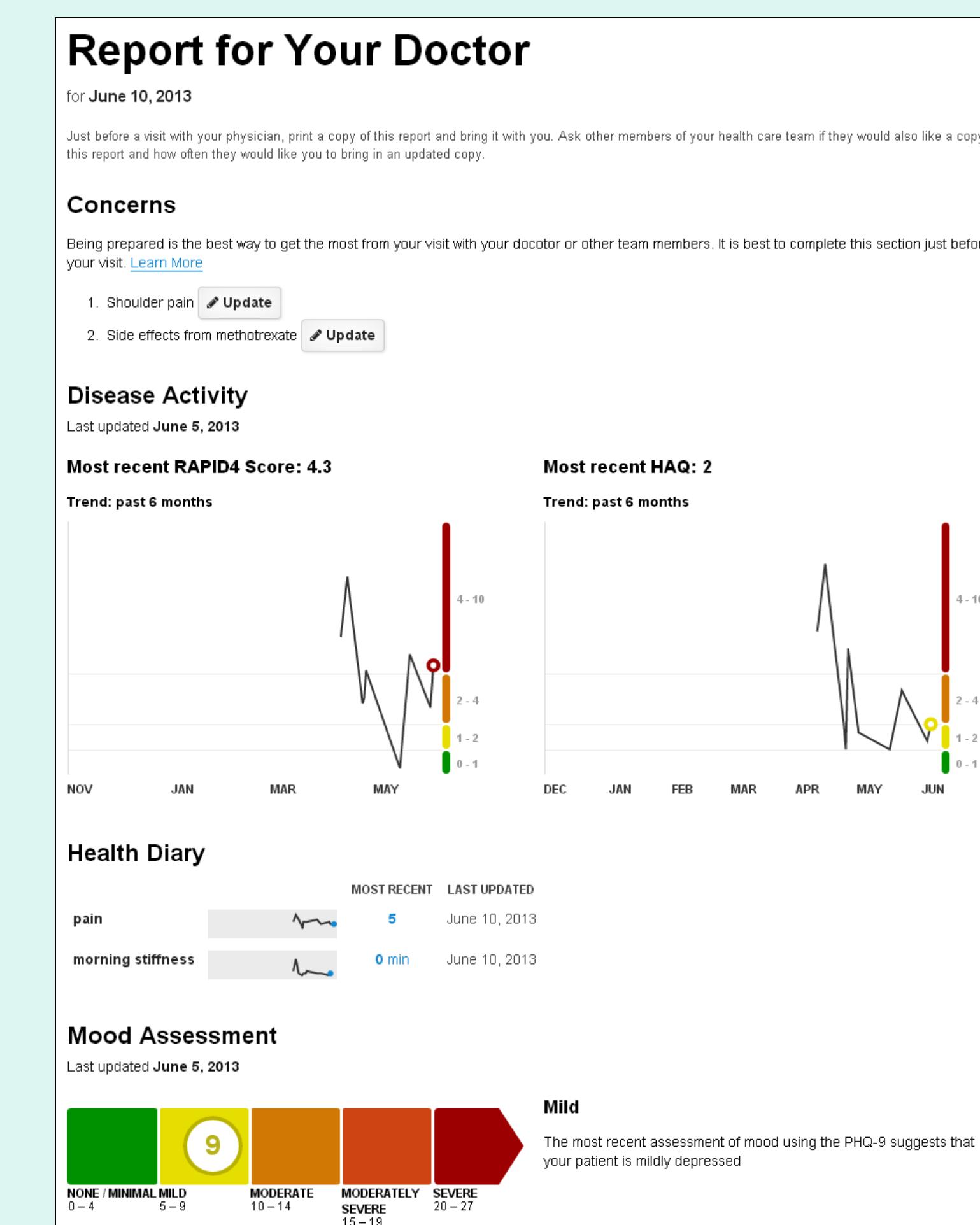


Theme 3: Saving Time or Creating More Work - By providing information that succinctly summarizes how a patient is managing in a way that rheumatologists can easily understand, it was thought that the tool may save time.

"I suspect a rheumatologist would really like it because as I say, it provides an empirical framework around which the discussion you need to have with the rheumatologist can happen. I mean, he's going to have in his folder your lab reports and he's going to leaf through them. He may do a homunculus with you. But if you can go in there with the stuff already kind of pre-digested, everybody's time is going to be saved. And the appointment can get down to its focal point much more rapidly." (Glasgow)

Rheumatologists also expressed fears that patient's use of the AHJ could be overwhelming to them either with the amount of information that patients brought in for review or that it could lead to increased questions and concerns.

Figure 3: Screenshot from AHJ Physician's Report



Study Significance

- Understanding the difference in patient and physician expectations for online applications such as the AHJ is beneficial for those developing and marketing similar applications.
- Further testing for usability, satisfaction and how it will influence care is required.

Conclusion

- Concerns raised by both the individuals with RA and the rheumatologists will be taken into consideration in the design of the online AHJ.