

## Background

Patients' Internet use for health purposes is regarded as potentially transformational. The use of online resources is associated with the emergence of the e-patient, broadly defined as someone who is an involved and empowered partner in care and is engaged in informed decision-making. We know little, however, about how Internet use influences help-seeking, the patient-clinician consultation and informed decision-making in early rheumatoid arthritis (RA).

## Purpose

This qualitative study examines patient accounts of their Internet use during the 12 months following their diagnosis of RA, how it impacted patient help-seeking and how it evolved over time.

## Methods

Twenty-two participants (17 women, 5 men), age range 30s-70s, were recruited within 12 months of a RA diagnosis from rheumatologist and family physician offices and online patient advocacy groups.

A series of 3-4 in-depth interviews were conducted over 12 months to track illness experiences and behaviours over time.

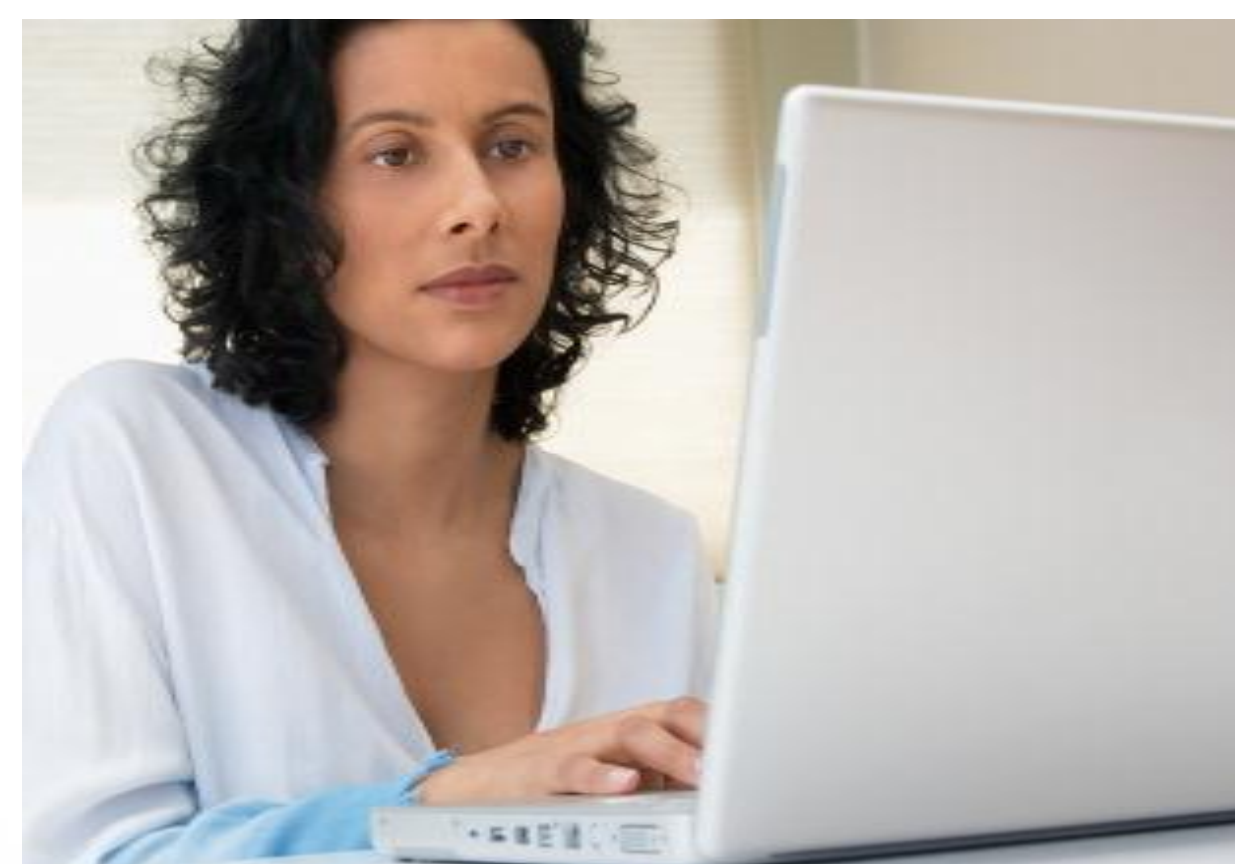
The interview guide is based on 3 areas:

- 1) Pre-diagnosis symptoms, impact and management;
- 2) Experiences with health professionals leading to the diagnosis;
- 3) Post-diagnosis experience of symptoms, management and the health care system.

Analysis is informed by grounded theory.

Early analysis is concurrent with data collection enabling new and salient questions to be introduced to the interview schedule.

The impact of Internet use on illness behaviours emerged as an early theme and was subsequently included as a topic for inquiry in all interviews.



## Results and Discussion

### 3 themes that emerged from the interview accounts:

#### E-Patient

- Empowered
- Equipped
- Enabled
- Engaged

"I've researched it and... the faster you get on... medication, the better off you're going to be. And if every place you ever read says the same thing, then there must be something to it. [I search] the internet... Multiple sites... because I think that knowledge is power and I like to control the things that I can and it's one thing you can do for yourself is to learn everything that you can learn. So yeah, multiple sites, multiple resources" (Cher).

#### Theme 1: Assessing Trustworthiness

Participants compared different sites to validate information and favoured institutional sites offering factual information over personal blogs. Cher expressed how this gave her control over her illness.

#### Theme 2: Help-Seeking Support

The Internet provided participants with information that some discussed with their family doctor, e.g. to gain a specialist referral, or to gain a 'second opinion.

"I went to the GP and he gave me Prednisone. But because it's only 10 milligrams, it didn't really help me... he said it looks like you've got rheumatoid arthritis. So I [went] home and started researching on the Internet and went back to him in two days. And I asked him to refer me to a specialist... I have an active role" (Canoe).

#### Interview 1

"Going on the [Arthritis] Facebook site and getting in contact with other people... it was good to see... there's other people out there... with it and their different methods ... they're dealing with a lot of, like, heavier medications for the pain..."

#### Interview 3 (10 months later)

"Not as much any more... the computer- I would go on it quite frequently, especially the Internet to research stuff, hang out on Facebook... Now I'm hardly on Facebook... When I was sick I guess I was researching Arthritis" (Mary).

#### Theme 3: Evolving strategies

Over time participants changed the way they used the Internet; e.g. some used it less as they secured knowledge and support from their doctors, and others used it for targeted or selective purposes.

#### Discussion

Our findings illustrate aspect of the e-patient. Some participants felt empowered and enabled e.g. some felt able to take control of their medication use due to Internet knowledge gained (e.g. Cher); some were actively engaged in gaining a speedy rheumatologist appointment and diagnosis (e.g. Canoe). There was also evidence that the Internet e.g. Facebook (Mary) equipped them to cope with new symptoms, pain and medications as they faced the diagnosis of an ongoing condition through learning about the experience of others.

**Conclusion:** As Internet use becomes a key feature of help-seeking, it influences help-seeking. This has implications for both the patient's and clinician's role in managing RA. More research is needed to identify the ways in which health professionals can best support patient Internet use for optimum outcome, and encourage patients to become more informed partners in care.

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