

NHS Charities Together: Online resource for self-management of inflammatory rheumatic disease (IRD)

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Summary of the project:

Bristol Bones and Joints Health Integration Team was funded £23,880 by NHS Charities Together in a 2-year project to develop an online resource for self-management of inflammatory rheumatic disease (IRD). They worked with tech company Living With to develop a self-management app. This resource was meant for people who were newly diagnosed with IRD. The app was developed and piloted between September 2022 - March 2023. A full launch and adoption into rheumatology clinics at University Hospitals Bristol & Weston NHS Foundation Trust (UHBW) and North Bristol NHS Trust (NBT) took place in April 2023. Currently, only clinical teams can invite patients to use the app. 223 patients have been invited to use the app and 171 patients registered and accessed the app. At the time of this report there was no explanation as to why other patients did not go on and register on the app.

Aim:

The aim of this project was to develop self-management knowledge and skills for patients newly diagnosed with IRD through providing information and support. The long-term goal was to empower patients to make adaptive behaviour changes, which will improve their health and reduce healthcare utilisation.

App development:

This was a collaborative effort which included rheumatology patients, clinicians from NBT and UHBW, BNSSG Integrated Care Board (ICB) MSK programme lead, researchers from University of the West of England and University of Bristol, Living With tech company development team and project support from Bristol Health Partners.

The app was developed using an iterative process and feedback from the patient focus group and BNSSG MSK patient groups was actioned and then reviewed again by the patient groups until the final version was agreed. Information on the app now includes explanation of rheumatology conditions, advice on ways to physically and emotionally manage the condition, support and care resources and information on the commonly used medications. There are also videos on the app which have guidance on medication, exercise and wellbeing including videos of personal stories from patients sharing their lived experience with IRD. Information on the app was written in a way that is more accessible to the general public. The team also worked very closely with Versus Arthritis during content development.

Project evaluation:

This project was evaluated using online survey and one to one interviews, following the full launch of the app in April 2023. Below is a report that will be divided into two sections:

Section A: Online survey

Section B: One to one semi-structured interviews.

Section A:

Online survey report:

An online survey was created as part of an evaluation plan for the self-management app for patients with rheumatic conditions. To maintain patients' confidentiality, the link to the survey was distributed by the Living With company who had email details from patients who had downloaded the app. Feedback was collected over a six week period from 22 June 2023. A total of 50 people accessed the survey, 35 people submitted a complete survey response and 25 people submitted an incomplete survey response. The 35 complete survey responses will be used in this report.

Results from the survey are as follows:

Question 1:

Did you experience any issues with downloading the app on your device?

91.43% reported that they did not experience any problems in accessing the app on their devices; and 8.57% reported that they did experience issues in downloading the app. The following explanations were given:

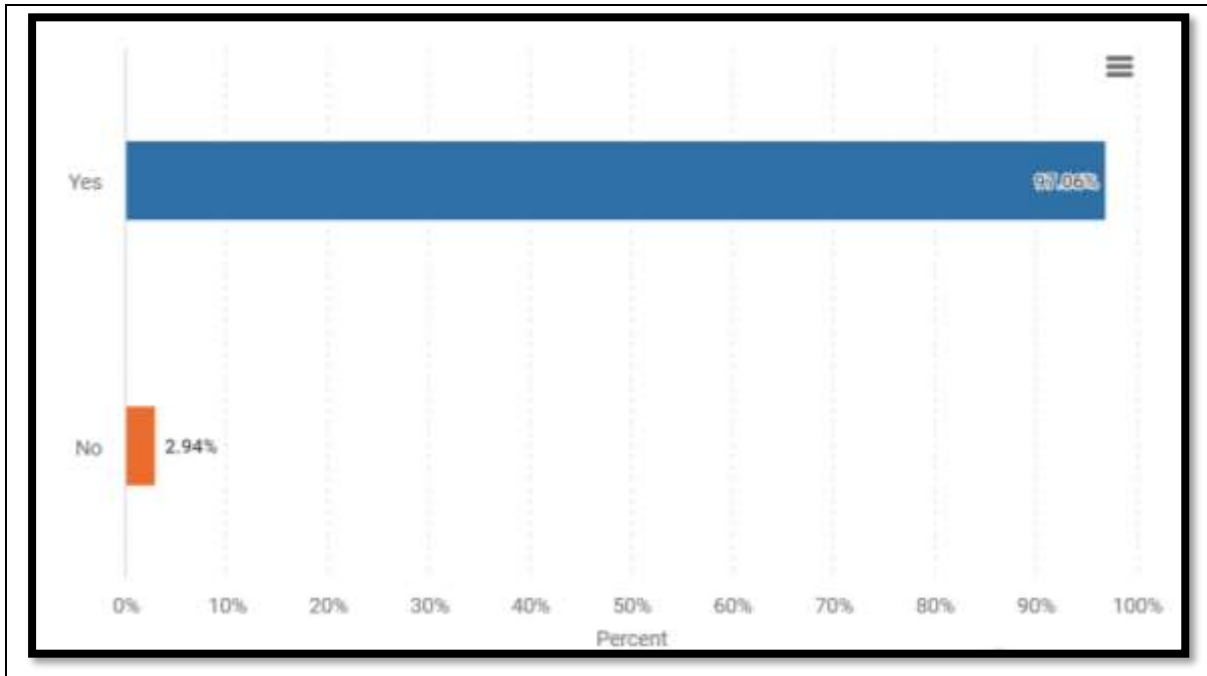
"But only because I initially thought that I could download onto my PC. It worked fine when downloaded to my phone."

"This is the first time I have been able to access the app."

Question 2:

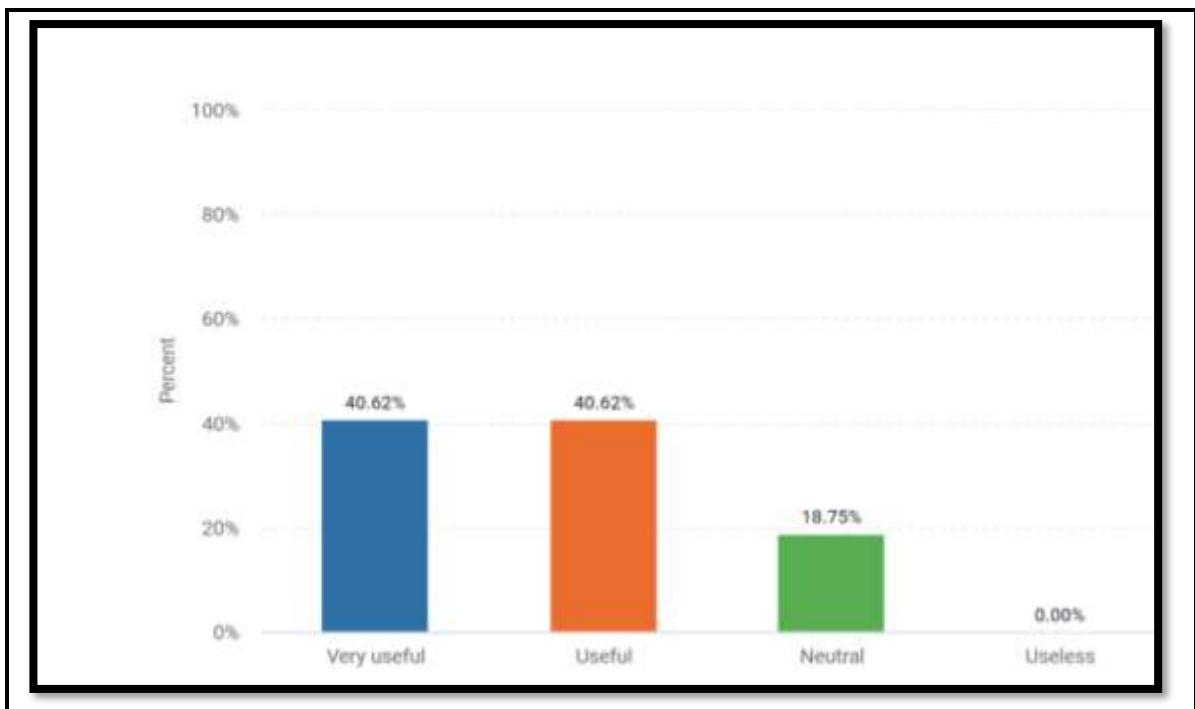
Was it easy to find your way around the app?

The majority of participants reported that they found it easy to use the app.



Question 3:

How useful did you find the information on the app?



"Some information that I didn't know".

"I liked the videos explaining things".

"Things were explained in ways that I understood with very helpful diagrams. At no point was it suggested that my pain and problems were all down to my stupidity and lack of care and that I had brought the condition on myself which is something that I have experienced so often in the last 50 years (though not in the last few at SMD where I have found the consultant currently caring for me very kind and helpful) that I have been afraid of asking doctors the questions for which the app provided answers."

"It's been very useful looking up symptoms relating to my condition, and giving me additional information."

"So much clear, useful information that's easy to find and really appropriate. Great access to hospital contact information and support groups."

"Really good information. Helps a lot"

"Great for feeling involved and the take your tablets reminder is very useful"

"A good place to find reliable information on rheumatoid arthritis which is something I knew very little about before I had it."

"very straight forward".

"It's not anything I hadn't already read online"

"Useful to start but no new information or 'news' added."

"The information is useful but not all is relevant to me. So searching riddles my busy mind more. This reply is only specific to me as I get overwhelmed".

Question 4:

Is there any additional information, features or improvements you would like to see on the app? If so, please provide more details here.

Information on condition:

"How to manage the condition better What to do when you have a flare etc"

"Being able to differentiate between pain and stiffness when answering as stiffness can still affect daily life"

"I found the personal stories very interesting, but would have liked more detail. I would also have liked more details (with pictures) of the aids that are available. It is difficult to know what is available and would help without making costly mistakes going to commercial websites."

"It would be useful for guidance on the distinction between swollen and tender joints. I had assumed that if a joint was tender that was because it was swollen, whereas it was explained that this was more an indication of relative malfunction/pain."

The app:

"I am unable to change information about medication unless I remove it completely and re add it."

"Maybe the contracts page can be colour coordinated For example if it's pain I have then the Number, the font, the indicators should all follow the same colour. I don't know if this is possible But just an idea".

"I think the app is great and can't think of anything extra needed yet."

"Make it easier to use as someone with dyslexia It's sometimes hard to read."

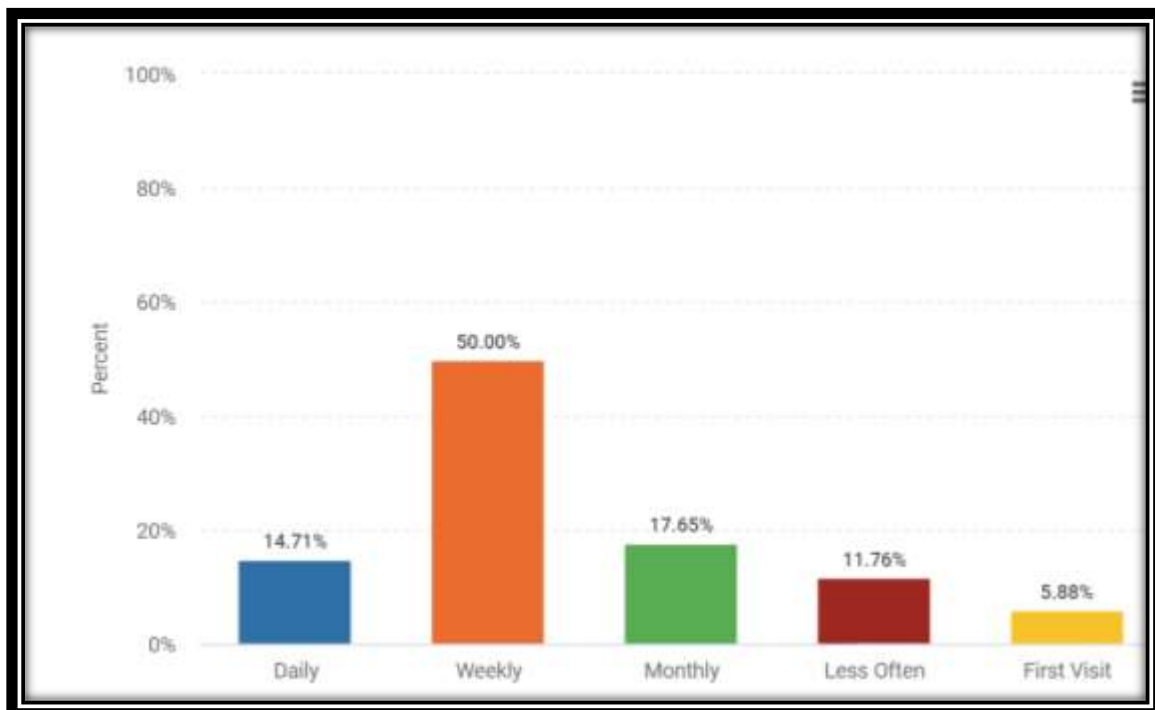
"Future hospital appointments and new information (like a what's new section) would be useful."

"I'm not sure I have been using the app long enough and I have yet to see how the questionnaires I complete weekly are of benefit to me or the RA team."

"Maybe a forum or chat room? I have never had a response through the messaging section from consultants so it is redundant. I have not used the app recently as I keep forgetting, part of my condition is brain fog! I set the reminder within the app but it doesn't pop up consistently or stay on the notification bar as a reminder. When I miss a week it doesn't pop up the next time. If I'm using my phone the reminder doesn't appear or if it does"

Question 5:

How frequently have you used the app?



50% of the participants reported to have used the app weekly.

Section B:

One to One semi-structured interviews:

App users who completed that online survey were given the option to participate in one to one semi-structured interviews. Willingness to be interviewed was indicated by entering telephone number and email address on the online survey. 36.36% (n =12) left their email address and mobile numbers and 63.64% (n =23) declined.

Only 7 out of 12 people were interviewed as 5 were not contactable. All had been diagnosed between June 2020 and May 2023. Interviewees were aged between 38 and 74 with two male and five female. Consent to be interviewed was recorded on the day of the interview including consent to be audio-recorded. Interview media used was determined by participant preference. 5 interviews were done via MS Teams, one on Zoom platform and another via telephone. Although they were all scheduled for an hour the longest interview lasted 28 mins. Original transcriptions were done verbatim using the audio recording and was analysed and coded as below:

Theme 1: App usability:

The app was reported to be easy to download, easily accessible, a convenient resource and the language was simple to understand.

"I found it pretty straightforward to download"

"Yeah, I think language is, yeah so the articles are clearly written. Easy to understand.."

"I think it's a brilliant resource. I think it's fantastic. You've got everything just in one place. You don't have to go looking for it, and also you know that it's all, you know, ..and you're not gonna get random things that you might if you were sort of scrolling through the Internet, looking up things. So I think it's been brilliant. I've used it a lot."

"Well..as I said I do find it very easy to access and its very convenient when I go into the messages and it says your clinic and I click on it you can actually ring clinic via the app which I find is very useful without me finding the number and dialing it I think that is a big assert actually"

"No, actually it seems to be honest. It's pretty good, to be honest. From what.. for the bits I've used, it's really easy to use and nice and straightforward. To be honest, you don't have to like you don't have to ever like press anything to like, get help or anything because it's all so self-explanatory.."

Although the app was widely reported as easy to use there were some who experienced difficulties in editing their entrance and general use:

“..if I tap randomly as I would do because there's no instructions and then I actually want to delete that, I can't there's no delete button. You have to, once you've clicked something.. that's it.

“It's not easy to use. It's not easy to update. It's not easy to understand, like it's just very difficult to use. And yeah, so for those three main and reasons like I don't see this being useful to me personally anyway.”

Theme 2 : Fatigue diary:

The fatigue diary was the most used tool on the app although with different views on its usage and functionality. Some app users used the fatigue diary as a monitoring tool to manage their fatigue symptoms:

“I mean the fatigue one was really quite good because it was quite good to be able to look at it and see. Where the fatigue was more and where it was less and see whether there was any correlation with what I was doing.”

“I suppose for me. See the bits that sort of where I can look back and see the differences in how I'm doing on different bits. So when I've done.. the fatigue diary and I could see that actually I am sleeping a bit better and that helps me. And then maybe I can think about what why is that? Is there something I've done that's helped me to sleep better or to feel a bit better or not have so much stiffness or whatever? So yeah, it's those things that have helped me out.”

“At the beginning, because I was having a lot of sleep disturbance with the pain and stuff I was having, I used the fatigue part of it where you can register your...Uh, the bits about when you've slept and when you're busy, and there's two sections to the fatigue bit aren't there? So there was that bit. And then I also used to keep a little diary bit of how I felt at the time and a disturbed my sleep and I haven't used that so much recently as my sleep has improved”.

Other app users reported negative experiences from using the fatigue diary:

“.. then in terms of the diaries.. Like I found those not super intuitive and not very easy to use...I think diaries can be really useful for tracking, but just the, you know, the current setup.. I didn't find particularly helpful,,the fatigue diary where you.... I'm like clicking on it now. Yeah, it's kind of hard to understand and like a bit ambiguous. Yeah, like there isn't something that tells you how to use it.”

Theme 3: Ability to track symptoms:

The ability to track symptoms was said to be helpful in aiding follow-up appointments with the clinical team.

"I can see how that's moving. So whereas if you ever just reporting something when you go and see the doctor your first reaction is to say yeah I am very unwell or yes I am fine but that gives you the details of how things are within the whole period I think it works well for that."

Although symptom tracking was reported as useful as a self-management app it is not linked to the clinical team and some users felt that the functionality needed to be there to give patients reassurance of clinical monitoring.

"Plus, I've used a fair up thing to report when my hips been hurting as well, so that's quite useful. But one thing one thing it could do one thing would be nice is when you filled in, you've got no idea if anybody looked at it, so it be nice if you could actually go in and there be a thing that actually could tell you whether someone was actually actioned what you've written on there."

Theme 4: App content:

Generally, information in the app was said to be very useful which enabled patients to have knowledge and confidence in managing their conditions. This included information on rheumatoid conditions, common drug treatment and social support.

Rheumatoid arthritis conditions:

"So if I were newly diagnosed. I would be looking for this kind of fundamental information. And I think I would, and because it's trustworthy, I think it's like a useful summary of all the headline in terms to think about. I think that's helpful."

"Just because getting poorly during COVID means that there are great big gaps in my knowledge and things that people think that I know I don't know because everything you know, treatment was so random at that point. So it's been really quite good to go through doing as much as I can to help myself."

"You know, I think, yeah, the libraries like a good high level summary of a lot of kind of useful..Items that often come up with these conditions."

Information on medication:

"That's really useful because my drugs are changing quite often and I'm getting different drugs given to me, and obviously it's quite useful to have something at your fingertips that you can just go in and find out what the new drug is or what they're suggesting and what the side effects are and...because honestly, if you get the leaflet out of the drug package and read all that, you'd never take anything. I read it through last lot and thought, Oh my goodness, to really want to do this? So it was then quite good to go to the app, because then it process it down to just the key things."

“So like today I was looking at some of the drug leaflets. With which are like... nice summaries like easy to access just because I mean I have because I'm on maternity.. So I think it's like a helpful compilation..”

Social support:

“And it links into all the social support as well and all the support groups. I think that's really, really important because it took me years to find different support groups that would help”

Theme 5: Relatability of lived experience:

The app includes videos of people narrating their personal journeys from diagnosis, treatments and living with a rheumatology condition. These videos were reviewed as important in managing the conditions given other people's lived experiences which were relatable.

“Yeah, I think they're quite positive, I think.. it's quite nice to know people have been in the same position and then they've been able to move forward because this has been one heck of a struggle for me.”

“So it's quite useful to see all the different adaptations and all the different options and people giving their opinion. You know, even things as simple as if you can manage it, get extra leg room at the front of the aeroplane.”

Theme 6: Health care utilisation:

App users reported an increase in their ability to self-manage and decreased utilisation of healthcare services:

“You know everything is quite tricky to access, but when you can open an app and you can answer your own questions, I think it'll cut down on an awful lot of patients making appointments with doctors and hospitals and things because they can find their own information that they know is the information that the hospital or the doctor would give. And it's just there at your fingertips.”

“I think, for people that are newly diagnosed then to have all of this at their fingertips, this is going to take pressure off the NHS.. make people feel more self-empowered, you know.”

“Yes, I can do things to help myself. Yes, I can see other people have been through this. Yes, I can see options and so rather waiting for a hospital appointment for an OT for something that might help you sit in the car without an awful lot of pain. You can go into the app and you can find it yourself.”

Theme 7: Barriers to app use:

Although the app was widely accepted there were some people who still preferred information in paper copies as this was more accessible due to visual impairments:

"Yeah, if I'm reading information, I do prefer to look in like if I've got it in like in front of me, but that's just my personal preference I don't like reading stuff of screens..because of my glasses, it's just easier for me to read it off paper"

Limitation of this evaluation:

Evaluation resource was not costed in the original funding bid which made it difficult to collect evaluation data for a longer period as initially intended. Patients from North Bristol NHS Trust were given access to the remote monitoring app during COVID-19, this made it difficult for some interviewees to distinguish between the two (remote monitoring and self-management app) in their responses to interview questions.

Conclusion:

From the feedback collected through the survey and interviews, the self-management app was said to be a useful resource, with reliable information from a trusted source. Participants reported that the content was easy to read and understand. General information on the rheumatoid conditions, common drug treatments, support groups and videos were said to be the most useful information on the app. App users reported that accessibility of the information enabled them to self-help, resulting in the decrease of healthcare utilisation. However, the app was reported not to be user friendly for people with dyslexia and visual impairments.

Despite the inaccessibility issues in view of dyslexia and visual impairments, both the online survey and the interviews showed that the app as a resource was able to fulfil its original aim. The aim was to produce a resource that provides information and support with the long-term goal of empowering patients to make adaptive behaviour changes to improve their health and reduce healthcare utilisation.

App overview:

Data in the appendix gives an overview of the app usage between 1 September 2022 to 31 August 2023. It also shows how many people were given access to the app and how many registered, app usage (Southmead refers to NBT and Bristol refers to UHBW), most opened articles and article interaction.

Appendix :

Data overview

The data is based on the following clinics:

- Bristol Royal Infirmary EIA Clinic
- Weston General Hospital Rheumatology Clinic (No patients)
- Southmead Hospital Rheumatology Department

The data covered in this report:

- 01 September 2022 - 31 August 2023
- Product: Living With Arthritis

Terminology:

- "Invited" refers to patients added to the platform by an HCP.
- "Registered" refers to patients completing the invitation process (incl. accepting Ts & Cs).
- "Discharged" refers to patients moved by an HCP out of the main list, using the built-in 'discharge' function (i.e. no longer treated / monitored using the app).

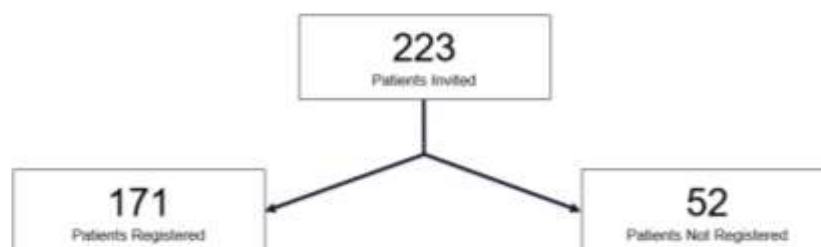
Notes:

- Some patients are assigned multiple products. Therefore, there may be content here associated with products other than 'Living With Arthritis'

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Patient Journey



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App Usage

Users opening app	→	23 Patients - Bristol	102 Patients - Southmead
Total sessions* recorded	→	307 Sessions - Bristol	4,449 Sessions - Southmead
Average** number of sessions* per user	→	13 Sessions per user - Bristol	44 Sessions per user - Southmead

Notes:

* A session is a group of interactions recorded when a user visits your website within a given period. After 30 minutes of inactivity, a new session is recorded.

** The average here is only considering patients who are opening the app

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Most Opened Articles

Article	Total number of times opened by all patients	Number of patients opening articles
symptoms	51	29
management-how-can-help-myself	47	11
welcome	44	21
what-is-as	33	14
fatigue	31	23
myths-debunked	31	21
newly-diagnosed-patients	29	14
drugs	28	14
what-is-ra	26	17
body-fitness	23	14
tests-assessments	22	12
hci-health-and-care-videos	20	11
what-is-rheumatoid-arthritis	19	12
causes	19	13
diet-food	16	9

Note:

* Some patients are assigned multiple products. Therefore, there may be content here associated with products other than 'Living With Arthritis'

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Article Interactions

13 Bristol Patients Opening Articles	66 Southmead Patients Opening Articles	79 Total Patients Opening Articles
107 Total Articles Opened by Bristol Patients	880 Total Articles Opened by Southmead Patients	987 Total Articles Opened
8 Articles per Patient for Bristol*	13 Articles per Patient for Southmead*	12 Articles per Patient* (All Patients)

Note:

* The average here is only considering patients who are opening articles.

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