Is social media the answer to the support desired by people with Rheumatoid Arthritis? A qualitative exploration

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Statement of Purpose
The aim was to identify the use of social media by people with RA and to determine if these current methods of technology could aid the development of a more patient-centred model of care.

Literature Review
Social media and the use of smartphone and tablet ‘apps’ are part of daily life for many, with diverse roles ranging from entertainment to education with increasing potential for sharing health information and providing support. Users can create and link into networks of people with shared interests or experiences in real-time, which may have an important role to play in health care. In contrast, outcomes in rheumatoid arthritis (RA) have too often been associated with loss of mobility and reduced quality of life, leading to loss of independence, anger, frustration and depression. Although recent advances in pharmacological management have improved outcomes for many, it often adds to the overall complexity of disease management for the individual.

Methodology
Semi-structured interviews were carried out with 14 people with RA to explore their lived experience of their disease, identify the current use of social media and ‘apps’ and specifically how they would like to see this technology used in their future care. Interviews were recorded and transcribed verbally by an independent transcriber; data were analysed using NVivo.

Results
Six key themes were identified from the analysis with an overarching theme of ownership of their disease: whereby social media could be used to provide support. Interestingly, at the point of diagnosis, respondents reported being overwhelmed by existing online resources. The desire for more patient-centred social media and a tool such as an ‘app’ tailored to the individual was noted. Such technology could be used to allow the sharing of similar experiences by people who are geographically distant, together in a meaningful way, e.g. through blogs. The respondents felt they needed a source of reference for disease management and/or a resource when attending appointments e.g. tracking symptoms. Moreover, because of the hand pain and deformities experienced by respondents (Figure 1) the use of touch-screen technology (e.g. smart phones and tablets) were reported to be a much easier way of navigating health resources. Finally, the immediacy of support and information that can be provided by social media and ‘app’ use is something respondents desired.

Conclusions
The range of social media technology that people with RA would find most useful does not yet appear to exist. The data has been used to aid the creation a multi-platform ‘app’, patient-centred ‘app’ that can be used to aid patients’ ownership of their disease and health.

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Annex
Figure 1: A respondent’s hand deformity from her RA. Age 26.

...that’s what my condition’s done to me, it’s destroyed me, because I am just so angry with it because I am a young girl...

"I live on my own so you can’t just phone people up, you know people are busy, and it was like there was always somebody there that would just kind of have a similar story. I often found it was a good way of supporting me when I was feeling a bit lonely and in a lot of pain"

"I want to be in control, desperate to be in control"

"I sometimes wish I could stab myself in the arm and just send it in the post or something, because you’ve either got to take a day off, you’ve then got to go and have it done...

"I want to be an average 29 year old girl, doing everything that I want to do...I want to be in control of everything myself..."

"Thank God I have the internet because now obviously I’ve got more understanding of what to do, but talking to other people who do have it, they’ve got that other sort of understanding..."

"Never Google anything health related, because you will scare the life out of yourself"

"If your rheumatologist said to you ‘here’s an app you can use to help you’ it would be great"

"...at the moment I do it (record information) in 17 different places..."