

Resource

# Creating Additional Patient Value in RA Pathways

Blog by Ailsa Bosworth, MBE, NRAS National Patient Champion

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Maximising the potential impact of revised pathways of care including remote monitoring digital applications, health apps and patient initiated follow up in Inflammatory Arthritis.

Many rheumatology services are reviewing their pathways of care, primarily as a response to dealing with issues resulting from the pandemic. Whilst COVID might be the catalyst for initiating such service reviews now, the need for improved care pathways, more effective use of clinical time and better patient outcomes, was there well before COVID struck in 2020. If any good is to come out of the devastating statistics of the last two years, surely a more efficient health service where the right patient is seen by the right health professional at the right time, has to be worth striving for even though this might seem unachievable in the short term when faced with the backlogs and workforce shortages many services are experiencing.

Use of Patient Held Records (PHR), Patient Initiated Follow up pathways (PIFU), a hybrid mix of face-to-face and remote appointments, the application of digital technology including health apps and

remote monitoring platforms are all on the table when considering how best to improve care for all, but especially those with chronic, long term conditions who require to be monitored long-term by specialist care teams.

Understandably people are raising concerns about the possibility of technological solutions and PIFU driving rather than solving health inequalities and we are right to be aware of and caring about those who are unable or unwilling to engage in these service reforms for whatever reason, including language and cultural barriers as well as health literacy and social deprivation causes. However, the same can be said about the introduction of many new and disruptive technologies but these are not reasons to put the brakes on. We need to ensure that the system accommodates the needs of all and by making services more efficient for 'the many' I agree in principle with the argument that new ways of working should create capacity to see those whose needs are greatest and who may not be in a position to adopt such service reforms. This is not going to be easy and is going to take time, but I sense there is currently a groundswell of commitment amongst both patients and health professionals to make change happen and to adapt which I don't think was anything like as apparent before the pandemic.

These service reforms, though needed, are all disruptive and no-one welcomes change when they are fire-fighting on numerous fronts. From the research I've done and the focus groups we have run in NRAS on a variety of relevant subjects, my impression is that many patients are ready and willing to embrace new ways of accessing and receiving care, including use of digital technology. In 2020, statistics show that 84% of UK adults owned a smartphone and 53% of people over the age of 65 had one. Also in 2020, on average, Brits spent 2 hours and 34 minutes online on their smartphones every day. I imagine that in spring 2022 these statistics will be even higher and in fact growth of smartphone ownership is predicted to reach 93.7% by 2025. The following table shows generational access to the internet via a mobile phone from stats taken from 2020.

Table 1 – Generational access to the internet via mobile phone:

| Age Group | Has access to the internet via mobile phone | Does not have access to the internet via mobile phone |
|-----------|---|---|
| 16-24     | 98%   | 2%  |
| 25-34     | 96%   | 4%  |
| 35-44     | 97%   | 3%  |
| 45-54     | 95%   | 5%  |
| 55-64     | 77%   | 23%   |
| 65+       | 53%   | 47%   |

Table showing generational access to the internet via a mobile phone, from 2020.

These growing statistics underline that by the second half of this decade the vast majority of people will be in a position to manage an electronic health record on their phone. Changes to the numbers of people working from home in the last 2 years will also accelerate this growth. By then, I imagine remote monitoring with relevant patient reported outcomes on your phone set at intervals to suit, with reminders nudging you to fill them in, will be the norm rather than the exception. We will be used to having our consultations (where appropriate) remotely, perhaps with more use of video by then, rather than by telephone as is the case currently. And, hopefully, the small minority without access to the internet, as well as those with urgent need and/or who may have language or cultural barriers, will

be able to be seen in person.

Will it all work seamlessly though? Will patients be better off and with improved outcomes? This is the bit I struggle with. There are so many great things to be proud of in terms of what the NHS has achieved. There are the improvements reported in the NEIAA national audit, 2022 winners of BSR Best Practise Awards and much more. There are also greater numbers of people with MSK conditions being treated appropriately in the community, supposedly leaving more availability for those with inflammatory and connective tissue conditions to be seen in hospital, and yet we still have many inappropriate referrals which are sent down the wrong route wasting their and clinic time. There are also no easy answers to the severe workforce shortages as reported in the BSR Report on this subject: A Workforce in Crisis<sup>2</sup>. There are backlogs of frightening proportions in most areas as rheumatology was one of the specialist areas of medicine called to the COVID front line (and is still being affected). Just last week I listened to a consultant rheumatologist saying he was really worried about so many people needing to be seen and no appointment slots for months. It is though a mixed picture, as some units are saying that they are able to see people and seem to be managing OK, but the GIRFT (Getting it Right First Time in Rheumatology) process and report has also reinforced the challenges faced by many units, including rising demand for services, limited resources and an overstretched workforce.

It's true that we have never had so many options to treat people with IA – a positive cornucopia of treatments (by comparison to what I had access to over 40 years ago!). However, despite advances in treatment that have helped to improve outcomes for rheumatology patients, treatment goals, hopes and expectations are not always met for patients and health professionals and inflammatory arthritis like RA continues to present a considerable human and economic burden.

The complexities of this subject are more than can be tackled in this blog in any detail. However I wanted to conclude on a positive note as in spite of my above ramblings, I am hopeful about the future and at NRAS we spend considerable time and energy in looking at 'system' difficulties and trying to come up with solutions that will support not only the individual, but the health professionals who treat us and the NHS system they operate within.

We have had input to a number of teams who are re-designing their IA pathways and we are always prepared to support rheumatology teams in this way. Our 21 years as the national specialist RA patient organisation ensures we are able to provide up to date and relevant data and feedback about patients' real world needs and expectations when designing new pathways of care. We are supporting researchers in many different ways, who are looking at new ways of delivering care. We have services and resources which help health professionals to meet their responsibilities in respect of NICE RA Guideline and Quality Standards as well as EULAR Recommendations for the implementation of Self-Management Strategies in Inflammatory Arthritis. These include services healthcare professionals and clinicians can refer patients to directly via an online form on our website – specifically: New2RA Right Start (for those diagnosed within the last 12 months) and 'Living with RA' (for those with existing disease), and the NRAS e-learning programme SMILE-RA already has approaching 1,000 registrations since launch in September, 2021. Ensuring that people living with inflammatory arthritis are educated about their disease and are properly equipped to self-manage and self-monitor is going to be critical in this new, more remote system of care delivery. You can find out more about all these resources on the [self-management area](#) of our website.

We see ourselves as partners to the rheumatology workforce, 'part of the MDT'. Our goals align with

the rheumatology health professionals when it comes to best evidence-based care for people with RA and JIA. Interestingly we are currently looking to introduce a similar service to Right Start in JIA which we think will be of massive benefit to families, New2JIA Right Start.

We are currently just starting to recruit patients from 5 UK Rheumatology units in order to carry out a service evaluation on the New2RA Right Start service in order to gather empirical data on its value both to individuals diagnosed with RA as well as the NHS. This service evaluation is being carried out in collaboration with University of Manchester.

We have our biggest stand ever at this year's BSR congress and we will be there in force and in person presenting posters on the above services and resources, so please if you're attending the 2022 BSR Conference do come and see us and find out how we can help you to help your patients live 'life without limits'.

## References

1. Source: <https://www.finder.com/uk/mobile-internet-statistics> Analysis conducted by finder.com.
2. British Society for Rheumatology Workforce Report, 2021 : A Workforce in Crisis.
3. Disease impact of rheumatoid arthritis in patients not treated with advanced therapies; survey findings from the National Rheumatoid Arthritis Society.

Elena Nikiphorou, Hannah Jacklin, Ailsa Bosworth, Clare Jacklin, Patrick Kiely.

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