

## Editorial

# An uncomfortable truth: the long-term impact of COVID-19 on the clinician–patient relationship

The impact of COVID-19 will reverberate long after the acute phases of the pandemic. Healthcare delivery has been profoundly impacted, with hospital waiting lists not predicted to return to baseline until 2025, even on the most optimistic estimates [1]. Delays in diagnosis, best studied in cancer but seen across the board, will lead to potentially avoidable morbidity and mortality for years to come [2].

To understand the impact in our specialty, all rheumatology teams must read the publications by Melanie Sloan's team. They have produced ground-breaking qualitative research that is relevant to us all. We must listen to the stories that they describe.

Their latest paper demonstrates the effect of the pandemic on patients and clinical teams. Using mixed-methods research, they have created an evidence-base from 1543 people living with rheumatic diseases and 111 clinicians, with in-depth interviews of 73 contributors and detailed follow up of 139 people with rare autoimmune rheumatic disease patients.

Their findings make for uncomfortable reading because, despite the efforts of clinicians, the impact on our patients has been profound. The proportion who felt medically supported reduced from 74.4% pre-pandemic to 39.7% during it. There was a reduction in healthcare-seeking behaviours, with patients feeling 'abandoned' by clinicians in the face of cancelled appointments, persistent difficulties accessing care and a switch to remote consultations. This was exacerbated by Government messaging 'to protect the NHS', which frequently left patients feeling like a 'burden' and 'guilty' when requesting advice. Clinicians significantly under-estimated these effects, while over-estimating the degree of healthcare avoidance among patients for fear of contracting infection.

Increased self-management was reported but this was often through necessity and was not always accompanied by an increase in education or clinical support. Rheumatology specialist nurses and patient charities were praised for stepping into the breach, providing valuable support and information.

The likelihood of reporting of mental health symptoms, poor even before the pandemic (although again over-estimated by clinicians), dropped even further.

Both patients and clinicians described delays in care leading to irreversible damage and possibly even contributing to deaths. Concerningly, patients described ongoing doubts about future access to care, especially about receiving prompt treatment for severe flares. Some of those who had been unable to access support

described reduced willingness to report symptoms in the future. This has the potential to delay treatment, with all the attendant consequences.

The impact on clinicians was no better. Healthcare reconfigurations and redeployment both contributed to high-stress work environments. Respondents described low morale, compassion fatigue and feeling burnt out. Of the clinicians surveyed, 23% felt that their mental health had sustained long-term damage. There was no significant difference in well-being scores between those who were and were not redeployed.

Similar to previous studies across different specialties, both pros and cons to telemedicine were identified. Benefits include increased flexibility and reduced travel time and costs [3, 4], along with positive environmental impacts [5]. However, as Sloan *et al.* highlight, telemedicine was felt to be inferior in many aspects by both patients and clinicians [6, 7]. Patients described a perception of reduced clinician empathy and listening, and clinicians expressed fears that ongoing targets for telemedicine appointments were crude and took insufficient account of the complexity of some rheumatological conditions [6, 7]. They have also previously identified concerns about the reliability of assessment, particularly where physical examination is required [6].

## So, what is the significance of these findings?

As the authors have previously demonstrated, changes in patient–clinician relationships have the potential to influence not only healthcare quality but also patient health behaviours and outcomes [8, 9]. Given the detrimental impact of the pandemic on many clinicians, there is also a real risk of further attrition from the already depleted rheumatology workforce [10]. The full effect of the pandemic has yet to be felt.

More crucially, what needs to be done? Helpfully, the authors identify some barriers and facilitators for accessing care that we can reflect on.

Barriers were often administrative, with inefficient systems and technology frustrating the efforts of individuals to access or provide care. Helplines were frequently cited, both as barriers to care where they were not functioning as intended and as facilitators to excellent care where they were. Worryingly, clinicians did not always have awareness of these issues. Helplines are a key area for improvement, with a focus on streamlining procedures for those that exist or pulling together business

cases for them where they do not. Many clinicians will also recognize the negative impact of healthcare reconfiguration and social distancing on the ad hoc, informal methods of communication that many teams relied on. It is important that all departments consider the communication methods currently in place, both formal and informal, to ensure that robust mechanisms to exchange clinical information continue.

The primary–secondary care interface is also highlighted as dysfunctional, with patients often stuck in the middle as both sides perceive the other to be limiting access and ‘passing the buck’. With all elements of the health service feeling overburdened, respectful, considerate communication between individuals and careful planning of local services is required. Telemedicine also offers a unique opportunity for case conferences, and innovative approaches such as joint patient consultations with both primary and secondary care physicians [11]. This collaborative way of working has the potential to enhance both working relationships and patient outcomes.

For patients, the most notable barriers included the ‘fear of being a burden’, with respondents acutely aware of the pressures on the healthcare service and mindful of government messaging that it could be overwhelmed. It is vital that we acknowledge and address these concerns, or we risk reduced patient engagement and access to healthcare, particularly in the current context of encouraging patient-initiated follow-up.

For clinicians, the barriers include time pressure and a backlog of patients requiring care. Remote consultations were cited by many, building on findings from the authors’ recent pioneering research into the impact and risks of telemedicine [6]. Notably, other studies have suggested both patient and clinician preference for video rather than telephone consultations, with greater impacts on wellbeing and improved confidence in clinical assessments and appointment outcomes [3, 12, 13]. Selecting cases appropriate for virtual follow-up has long been recognized as important in order to avoid inadvertently increasing both demand and costs [11, 14]. The NHS must continue to provide care tailored to the individual, and efforts to ‘build back better’ must not distract from the fact that the ‘right’ type of consultation is dependent on the individual and their circumstances, rather than taking a ‘one size fits all’ approach. Making use of resources such as the virtual consultation toolkit, as described in the England Rare Diseases Action Plan 2022 [15], can also improve the telemedicine experience. Specifically designed for managing complex, multi-system rare diseases, the aims of the toolkit are to improve both clinic design and patient outcomes.

Facilitators included providing clear information on how to access support (e.g. business cards containing contact information/helpline numbers) and individuals/departments being perceived as approachable and contactable. Simple acts of kindness and personable behaviour go a long way.

This study is a significant addition to the fields of rheumatology and health service research, and adds to

Sloan *et al.*’s growing body of research demonstrating the impact of the pandemic on people living with rheumatic diseases, the negative consequences to their health and well-being and risk of deteriorating outcomes in the future. It is important to acknowledge the contribution of patient charities to funding COVID-19 research, particularly Lupus UK whose funding of the earlier LISTEN study allowed this study to be realized.

As the authors so poignantly finish: ‘The feeling of abandonment will remain for longer than the memories of the chaos of Covid’ [clinician quote]. All rheumatology departments should reflect on the contents of this paper and its implications.

**Funding:** M.R. is funded by a Versus Arthritis Clinical Research Fellowship, as well as grant funding from Lupus UK and Scleroderma and Raynaud’s UK. F.A.P. is funded by an NIHR Advanced Fellowship. F.A.P. and P.C.L. are recipients of a grant from Vifor Pharma. Vifor Pharma had no influence on the design, conduct or interpretation of this study.

**Disclosure statement:** F.A.P. and P.C.L. are recipients of a grant from Vifor Pharma. Vifor Pharma had no influence on the design, conduct or interpretation of this study.

## Data availability statement

No new data were generated or analysed in support of this research.

**Megan Rutter** <sup>1,2,3</sup>, **Fiona A. Pearce** <sup>1,2,3</sup> and **Peter C. Lanyon**<sup>1,2,3</sup>

<sup>1</sup>Department of Lifespan and Population Health, School of Medicine, University of Nottingham, <sup>2</sup>Department of Rheumatology, Nottingham University Hospitals NHS Trust, Nottingham and <sup>3</sup>National Congenital Anomaly and Rare Disease Registration Service (NCARDRS), NHS Digital, Leeds, UK

Accepted 22 March 2022

Correspondence to: Megan Rutter, University of Nottingham, Clinical Sciences Building, City Hospital Campus, Nottingham NG5 1PB, UK.

E-mail: meghan.rutter@nottingham.ac.uk

## References

- 1 Health and Social Care Committee. Clearing the backlog caused by the pandemic. London: House of Commons, 2021.
- 2 Maringe C, Spicer J, Morris M *et al.* The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study. *Lancet Oncol* 2020;21:1023–34.
- 3 Akintomide E, Shah B, Sridharan S *et al.* Clinical perception of effectiveness of virtual appointments and comparison with appointment outcomes at a specialist children’s hospital. *Future Healthcare Journal* 2021;8: e660–5.

- 4 Dullet NW, Geraghty EM, Kaufman T *et al.* Impact of a university-based outpatient telemedicine program on time savings, travel costs, and environmental pollutants. *Value Health* 2017;20:542–6.
- 5 Ravindrane R, Patel J. The environmental impacts of telemedicine in place of face-to-face patient care: a systematic review. *Future Healthc J* 2022;9:28–33.
- 6 Sloan M, Lever E, Harwood R *et al.* Telemedicine in rheumatology: a mixed methods study exploring acceptability, preferences and experiences among patients and clinicians. *Rheumatology* 2021; doi: 10.1093/rheumatology/keab796.
- 7 Pooni R, Ronis T, Lee T; The CARRA Investigators. Telemedicine use by pediatric rheumatologists during the COVID-19 pandemic. *Pediatr Rheumatol* 2021;19:93.
- 8 Sloan M, Gordon C, Lever E *et al.* COVID-19 and shielding: experiences of UK patients with lupus and related diseases. *Rheumatol Adv Pract* 2021;5:rkab003.
- 9 Sloan M, Gordon C, Harwood R *et al.* The impact of the COVID-19 pandemic on the medical care and healthcare-behaviour of patients with lupus and other systemic autoimmune diseases: a mixed methods longitudinal study. *Rheumatol Adv Pract* 2021;5:rkaa072.
- 10 British Society of Rheumatology. Rheumatology workforce: a crisis in numbers. 2021. <https://www.rheumatology.org.uk/Portals/0/Documents/Policy/Reports/BSR-workforce-report-crisis-numbers.pdf?ver=2021-06-16-165001-470> (5 April 2022, date last accessed).
- 11 Williams OE, Elghenzai S, Subbe C, Wyatt JC, Williams J. The use of telemedicine to enhance secondary care: some lessons from the front line. *Future Healthcare J* 2017;4:109–14.
- 12 Lai FHY, Yan EWH, Yu KKY *et al.* The protective impact of telemedicine on persons with dementia and their caregivers during the COVID-19 pandemic. *Am J Geriatr Psychiatry* 2020;28:1175–84.
- 13 Golash V, Athwal S, Khandwala M. Teleophthalmology and COVID-19: the patient perspective. *Future Healthcare J* 2021;8:e54–9.
- 14 Imison C, Castle-Clarke S, Watson R, Edwards N. Delivering the benefits of digital health care. London: Nuffield Trust, 2016.
- 15 Department of Health and Social Care UK Government. England rare diseases action plan 2022. London: UK Government, 2022.