

Digital exclusion as a potential cause of inequalities in access to care: a survey in people with inflammatory rheumatic diseases.

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Abstract

Objectives: COVID-19 led to rapid uptake of digital healthcare. We sought to examine digital access, health and digital literacy, and impact on confidence and satisfaction with remote consultations in people with inflammatory rheumatic diseases (IRDs).

Methods: People with IRDs (n=2,024) were identified from their electronic health record and invited to participate in a cross-sectional survey, using short message service (SMS) and postal approaches. Data were collected on demographics, self-reported diagnosis, access to and use of internet-enabled devices, health and digital literacy, together with confidence and satisfaction with remote consultations. Ethical approval was obtained (Ref 21/PR/0867).

Results: Six hundred and thirty nine (639) people completed the survey (mean (sd) age 64.5 (13.1) years, 384 (60.1%) female). 287 (44.9%) completed it online. One hundred and twenty-six (19.7%) people reported not having access to an internet-enabled device. Ninety-three (14.6%) reported never accessing the internet; this proportion was highest (23%) in people with rheumatoid arthritis (RA). One hundred and seventeen (18%) reported limited health literacy. Even in those reporting internet use, digital literacy was only moderate. People with limited health or digital literacy or without internet access were less likely to report confidence or satisfaction with remote consultations.

Conclusion: Limited health and digital literacy, lack of digital access and low reported internet use were common, especially in older people with RA. People with limited health literacy or limited digital access reported lower confidence and satisfaction with remote consultations. Digital implementation roll-out needs to take account of people requiring extra support to enable them to access care digitally or risks exacerbating health inequalities.

Key words: Digital exclusion, digital access, health literacy, digital literacy, rheumatoid arthritis, axial spondyloarthritis, psoriatic arthritis, inflammatory rheumatic diseases

Key messages:

- Many older people with inflammatory rheumatic diseases do not have access to the internet or use it infrequently
- Limited health and digital literacy is common and impacts on confidence and satisfaction with telemedicine
- Clinical services need to take account of people unable to access services digitally

Background

The COVID-19 pandemic led to an overnight shift in healthcare delivery and rapid uptake of digital technology. This digital transformation is supported in the NHS Long Term Plan [1] which encourages “digital-first” approaches where people are encouraged to use digital tools to manage their own health, stay well and recognise important symptoms early. In parallel with the digital approach, the pandemic led to rapid adoption of remote consultations by telephone or video. Long-term adoption of some of these technologies is likely given the perceived convenience and environmental sustainability [1,2].

Whilst adoption of these technologies was of necessity at the start of the pandemic, such rapid implementation bypassed any assessment of accessibility, leading to concerns around digital access and exclusion. The Centre for Ageing Better and Citizens Online [3] explored the digital experiences of people aged 50-70 during the pandemic using a combination of telephone and online surveys and qualitative interviews. The report recognised that there were emotional and mental health benefits from being online but concluded that the digital divide was widened during the pandemic, especially in people on low incomes who may be already at risk of poorer health outcomes.

Digital inclusion requires both digital access (to appropriate devices and reliable internet connectivity) and digital *literacy* i.e., the skills, confidence and willingness to be able use the internet to access appropriate health information. Digital or eHealth literacy describes “the ability to read, use computers, search for information,

understand health information and put it into context” [4] and thus is influenced by both general literacy levels and digital skills.

Rheumatology services need to understand more about digital inclusion amongst their local populations to ensure their services are designed and delivered in ways that address the needs of all service users and do not inadvertently widen health inequalities. Given that the majority of long term follow up outpatient consultations - which may be informed by the use of patient reported outcome measures, often delivered digitally – are with people who have inflammatory rheumatic diseases (IRDs) we sought to examine digital access, use, health and digital literacy, and satisfaction and confidence with remote consultations during the pandemic in people with IRDs.

Methods

Study design

Potential participants were identified from the rheumatology patient DIAGnostic and MONitoring Database (DIAMOND) at Midlands Partnership NHS Foundation Trust. This database contains clinical information about diagnoses, patient encounters, and medications on a cohort of >20,000 patients [5]. Using the patient diagnosis term, a list of patients with a rheumatology clinician diagnosis of one of the four diagnoses of interest (rheumatoid arthritis (RA), ankylosing spondylitis/axial spondyloarthropathy (AS/AxSpA), psoriatic arthritis (PsA), or systemic lupus erythematosus (SLE) was assembled. Patients had to be under active follow up, i.e. had a clinical contact within the last 2 years and not been discharged from follow-up. 2024 patients with one of the diagnoses of interest and under active followup were randomly selected from the database via computer. Of the 2024, providing patients had a mobile telephone number on record, they were randomly selected to be invited to participate either by via SMS text message (which included the option to complete the questionnaire via online link, email, paper or by telephone with a researcher) or postal letter, with reminder SMS being sent at one week, and reminder letters at 2 and 4 weeks. Those people without a mobile telephone number on their records were sent a postal invitation directly.

Data collection

People were invited to complete a single cross-sectional questionnaire in August 2021 (to coincide with the relaxation of national COVID restrictions, for full survey see Supplementary data). Data were collected on age, gender, self-reported IRD diagnosis (characterised as RA, PsA, AS/AxSpA), SLE and “other”), and access to and use of digital technology. People were asked to indicate whether they had access to the internet (using a checklist of basic mobile phone, smartphone (with access to internet), computer and/or tablet) and the frequency of internet use (never, sporadically (< 1 day/week), regularly (1-3 days/week), frequently (4-6 days/week), or daily). Those reporting internet use were asked about their self-perceived e-health literacy using the e-Health Literacy Scale (eHEALS) [3]. This is an 8-item measure (using a 5-point Likert scale response) of eHealth literacy developed to measure people’s combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic information to health problems. A higher total eHEALS indicates greater perceived digital literacy with a score of <26 considered to represent limited digital literacy [6]. Health literacy was assessed using the single-item literacy screener [7] which asks: “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” Responses were dichotomized into limited (often, always, sometimes need help) and adequate (rarely, never need help) health literacy [7].

Participants were asked which services they had used to manage their arthritis during the pandemic using a checklist. They were asked to separately rate their confidence and satisfaction with talking to their rheumatology clinician on the telephone or on a video call (5 options, from very satisfied/confident to very unsatisfied/confident). People were also asked about their preferences for accessing future care (telephone, video or face-to face) for either a routine review appointment, an urgent problem or for a new or first appointment about a problem. These questions were informed by our previous qualitative work which indicated that some people had low confidence in communicating on the telephone and that preferences for future consultation type was influenced by personal circumstances, such as work or family commitments [8]. Ethical approval was obtained (Surrey Borders REC Ref 21/PR/0867) and all participants provided informed consent.

Statistical analysis was performed using Stata 17.0. The sample of responders was summarized using frequencies and percentages with means and standard deviations

(SD) or medians and quartile values as appropriate. The Wilcoxon rank-sum, t-tests, analysis of variance and chi-squared tests were used to compare continuous and categorical responses as appropriate.

Results

The survey was conducted in August 2021 to coincide with relaxation of England national restrictions. Six hundred and thirty-nine people completed the survey, of whom 287 (44.9%) completed it online. Mean (standard deviation (SD)) age was 64.5 (13.1) years and 384 (60.1%) were female. Six hundred and twenty-eight (98.3%) reported themselves to be of Caucasian ethnicity. The majority (492, 77%) of participants reported having RA, with 130 (20%) reporting psoriatic arthritis, 50 (8%) AS or axial spondyloarthritis, and 36 (6%) SLE or other, with 33 (5%) reporting more than one diagnosis.

One hundred and twenty-six (19.7%) responders reported no access to an internet-enabled device (Table 1) and this proportion was highest in people with RA. Those without access an internet enabled device were older (mean (SD) age 73.2 (10.5) vs 62.3 (12.8) years $p<0.001$), and less likely to be in current employment (10 (6.9%) vs 110 (24.1%) $p<0.0001$).

Three hundred and eighty-four people (63%) reported accessing the internet frequently or daily, but 93 (15.3%) reported never accessing the internet. Limited health literacy was common ($n=117$, 19.3%). This proportion was lower in those employed (14 (10%) vs 101 (22.4%), $p=0.001$ and those without internet access (35 (28.7%) vs 82 (16.9%), $p=0.003$).

Limited digital literacy was also common with 124 (26.1%) of people reporting an eHEALS of < 26 and this was reported even in people with access to an internet device. This proportion was higher in those not in employment (30.8% v 13.3%, $p<0.0001$) and ≥ 65 years (33.8% v 19.2%, $p<0.0001$). Furthermore, looking at the individual domains of the eHEALS (Figure 1) illustrates that whilst 73% of people agreed they knew how to find health information online, just over half (53%) felt confident to use information from the internet to help make health decisions.

This was reflected in the self-management strategies that people used for their arthritis, with less than a third reporting using websites for arthritis information (Table 1) and many using telephone helplines to manage their symptoms.

Experiences of and preferences for remote consultations

People were asked whether their most recent rheumatology consultation was face-to-face (n=153), telephone (n=134) or video (n=2). Type of consultation did not differ significantly whether people had internet access or limited health or digital literacy.

Considering perceived confidence and satisfaction with remote consultations, those without internet access or who had limited health or e-health literacy were more likely to rate themselves as being unconfident or very unconfident about both telephone and video consultations (Table 2). This was most marked for video consultations where 41.4% of those with limited health literacy reported being unconfident or very unconfident compared with 30.3% of the survey responders. Similar findings were seen with perceived satisfaction with both telephone and video consultations (Table 2). There was no difference in confidence or satisfaction with use of telephone consultations in relation to age or employment status. Older age and not being employed were associated with less perceived confidence and satisfaction for video consultations. People with limited health literacy or limited digital literacy were less confident and less satisfied with both types of remote consultation than people with adequate health and digital literacy. Gender was not associated with confidence or satisfaction with either telephone or video calls.

The majority of people preferred face-to-face consultations in the future, although for urgent problems (such as an arthritis flare) or for a routine review appointment more people would consider a telephone consultation than would consider this for a new/first appointment about a problem (Table 3). Those preferring a telephone consultation were similar to those preferring video, face-to-face or a choice at the time in terms of age, gender, employment status and health literacy. The same pattern was seen across IRD groups.

Discussion

This survey demonstrates that in a population of people with IRDs one in five people do not have access to an internet enabled device and 15% report never using the internet. Furthermore, even in patients who have access to an internet enabled device up to one in five people report limited health or digital literacy. People without access to the internet or with limited health or digital literacy are also less likely to be confident or satisfied with remote consultations. This may be a significant barrier to longer term uptake of remote consultations. Given that the NHS long term plan [1] is moving to “digital-by default”, this risks digital exclusion and widening inequalities for people without access to or confident with digital technology [9-11]. This is a particular concern for people with IRDs who are high users of health and social care [12].

Whilst we studied patients attending a single secondary care centre, potentially limiting generalisability (especially regarding ethnicity), our results are similar to general population data which suggest that the UK digital divide is influenced by age, socioeconomic status, and whether a person has a disability [13]. Stoke-on-Trent has high levels of socioeconomic deprivation [13] and significant levels of limited health literacy [14], both of which may negatively impact on digital access and skills. However, it is possible that our figures may underestimate the problem, since people with limited literacy may be less likely to complete surveys, although we attempted to mitigate this by offering multiple methods of survey completion, including by telephone with a researcher. We identified one in five responders had limited health literacy, which is similar to other studies [7]. However, although the single item screener for health literacy performs moderately well at identifying those with limited reading difficulty [7], it may identify less than half of people who lack competency to interpret and understand written health information [15].

In common with general population data [13] we found that with increasing age, internet access and usage decreases: 100% of respondents in the 16–34 age group reported going online daily or almost daily, compared with only 67% in the 65+ age group. However, surveys of internet use in older people suggest that whilst internet use increased significantly during the pandemic, many older people or those on low incomes remain offline, and of these, many felt they did not need to be able to use the internet and valued non-digital approaches [3]. Thus, whilst the sociodemographics of our area may mean that the rates of digital exclusion are higher than in other areas, the impact of age on digital exclusion still needs to be considered when developing

services to prevent worsening health inequalities in people at highest risk of poor outcomes [12].

Most previous studies in this area have focused on people with RA. A French, multicentre, cross-sectional study [16] showed that 82% of participants had digital access (compared to 77% of our cohort with RA) although only 29% reporting using it specifically for RA-related reasons. In contrast, a single-centre German study of people with inflammatory arthritis showed that whilst 91% of their cohort had access to a smartphone, and 75% reported accessing the internet for health information, eHealth literacy was low [17]. Our survey is novel in including a broader range of IRDs than RA.

Our digital literacy results are similar to those seen in an international cross-sectional study of people with poorly controlled RA, [18] with limited digital literacy seen in nearly two-thirds of people and only one-third reporting finding the internet useful to help inform decisions about their health. In contrast, a Canadian study of adults aged over fifty with a recent fracture [19] showed whilst digital access was similar, levels of digital literacy were higher, and a significant proportion reported using the internet to look for medical information for themselves or others. Thus, whilst the single-centre nature of our results is a weakness and limits generalisability, comparison of our results with other published cohorts provides confidence in our findings. A strength of our findings is the broad recruitment strategy enabling people to participate either online or via paper survey (with 56% completed as hard-copy) in addition to the use of validated tools (such as eHEALS [4]) for examining digital literacy.

Reflecting other published data on telemedicine in rheumatology [20] our results suggest a strong preference for face-to-face appointments, especially for first appointments [20] although our responders were more likely to consider telephone appointments for routine reviews or urgent appointments. This study further adds to the findings of Sloan et al [20] in two ways. First our respondents expressed a preference for telephone over video consultations, which may be reflective of the level of health literacy in our population. Second, 1 in 5 people reported wanting to have choice of consultation modality at the time of the appointment. The notion that patient preferences for remote consultations vary depending on their context and situation at

the time of appointments was highlighted in our previous qualitative studies [8] and has important ramifications for service design.

To our knowledge this is the first UK study to examine the impact of internet access, and digital and health literacy with preferences and confidence for telemedicine. Whilst digital access and literacy skills did not seem to influence preferences for a particular consultation type, our results suggest that people without digital access or with limited health literacy were likely to report perceived lower confidence and satisfaction with both telephone and video consultations. In a small US study health literacy was not associated with willingness to undertake video consultations, although their population was younger than our cohort and all reported access to an internet enabled device [21]. Nearly 2 million people in the UK alone report being unable to explain symptoms and feelings on the phone and our qualitative studies also identified that in addition to reduced confidence in being able to talk on the phone, some participants described conversations as stressful and more hurried [8, 22]. Given that people without access to the internet or with limited health literacy are more likely to be socioeconomically deprived and therefore at risk of poorer health outcomes [23], it is important to increase awareness and address these factors in healthcare delivery to prevent worsening existing health inequalities.

In summary, our results emphasise the challenge of digital inclusion for people with IRDs and demonstrate that even with digital access, people may need support to enhance their digital literacy and skills to support more effective telemedicine consultations and promote digital arthritis self-management. Service providers need to consider the impact of digital exclusion and support efforts to enable people to access care digitally where appropriate, whilst considering patient preferences and continuing to provide alternative non-digital ways for people to access care services for those not online.

References

1. NHS long term plan. <https://www.longtermplan.nhs.uk/online-version/chapter-5-digitally-enabled-care-will-go-mainstream-across-the-nhs/>
2. Royal College of Physicians. Outpatients: the future – adding value through sustainability. London: RCP, 2018.

3. Centre for Ageing Better/Citizens Online. Digital Skills to Connect report published July 2021.
4. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *J Med Internet Res*. 2006 Nov 14;8(4):e27. doi: 10.2196/jmir.8.4.e27. PMID: 17213046; PMCID: PMC1794004.
5. Grove, M.L.. (2001). Adverse reactions to disease-modifying anti-rheumatic drugs in clinical practice. *QJM*. 94. 309-319. 10.1093/qjmed/94.6.309.
6. Richtering SS, Hyun K, Neubeck L, et al. eHealth literacy: predictors in a population with moderate-to-high cardiovascular risk. *JMIR Hum Factors*. 2017;4(1):e4. doi:10.2196/humanfactors.6217
7. Morris, N.S., MacLean, C.D., Chew, L.D. et al. The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Fam Pract* 7, 21 (2006). <https://doi.org/10.1186/1471-2296-7-21>
8. Paskins Z, Bullock L, Manning F, Bishop S, Campbell P, Cottrell C, Jinks C, Narayanasamy M, Scott I, Sahota O, Ryan S (2022) Acceptability of, and preferences for, remote consulting during COVID-19 among older patients with two common long-term musculoskeletal conditions: findings from three qualitative studies and recommendations for practice. *BMC Musculoskelet Disord* 23, 312 (2022). <https://doi.org/10.1186/s12891-022-05273-1>
9. Fang ML, Canham SL, Battersby L, Sixsmith J, Wada M, Sixsmith A. Exploring Privilege in the Digital Divide: Implications for Theory, Policy, and Practice. *Gerontologist*. 2019 Jan 9;59(1):e1-e15. doi: 10.1093/geront/gny037. PMID: 29750241.
10. Turner A. Morris R. Rakhra D. Stevenson F. McDonagh L. Hamilton F et al, Unintended consequences of online consultations: a qualitative study in UK primary care. *British Journal of General Practice* 2022; 72 (715): e128-e137. DOI: <https://doi.org/10.3399/BJGP.2021.0426>
11. Sheikh, Aziz et al. Health information technology and digital innovation for national learning health and care systems. *The Lancet Digital Health*, Volume 3, Issue 6, e383 - e396
12. <https://www.versusarthritis.org/media/24238/state-of-msk-health-2021.pdf>
13. Office for National Statistics Survey 2020. <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics>

14. Protheroe J, Whittle R, Bartlam B, Estacio EV, Clark L, Kurth J. Health literacy, associated lifestyle and demographic factors in adult population of an English city: a cross-sectional survey. *Health Expect*. 2017 Feb;20(1):112-119. doi: 10.1111/hex.12440. Epub 2016 Jan 15. PMID: 26774107; PMCID: PMC5217902.
15. Rowlands G, Protheroe J, Winkley J, Richardson M, Seed PT, Rudd R. A mismatch between population health literacy and the complexity of health information: an observational study. *Br J Gen Pract*. 2015 Jun;65(635):e379-86
16. Magnol M, Eleonore B, Claire R, Castagne B, Pugibet M, Lukas C, Tournadre A, Vergne-Salle P, Barnetche T, Truchetet M, Ruysse-Witrand A. Use of eHealth by Patients With Rheumatoid Arthritis: Observational, Cross-sectional, Multicenter Study. *J Med Internet Res* 2021;23(1):e19998.
17. Knitza J, Simon D, Lambrecht A, Raab C, Tascilar K, Hagen M, Kleyer A, Bayat S, Derungs A, Amft O, Schett G. Mobile health usage, preferences, barriers, and eHealth literacy in rheumatology: patient survey study. *JMIR mHealth and uHealth*. 2020;8(8):e19661.
18. Taylor PC, Ancuta C, Nagy O, de la Vega MC, Gordeev A, Janková R, Kalyoncu U, Lagunes-Galindo I, Morović-Vergles J, de Souza MPGUES, Rojkovich B, Sidiropoulos P, Kawakami A. Treatment Satisfaction, Patient Preferences, and the Impact of Suboptimal Disease Control in a Large International Rheumatoid Arthritis Cohort: SENSE Study. *Patient Prefer Adherence*. 2021 Feb 17;15:359-373. doi: 10.2147/PPA.S289692. PMID: 33633444; PMCID: PMC7900444.
19. Cherid C, Baghdadli A, Wall M, Mayo NE, Berry G, Harvey EJ, Albers A, Bergeron SG, Morin SN. Current level of technology use, health and eHealth literacy in older Canadians with a recent fracture-a survey in orthopedic clinics. *Osteoporos Int*. 2020 Jul;31(7):1333-1340. doi: 10.1007/s00198-020-05359-3. Epub 2020 Feb 28. PMID: 32112118.
20. Sloan M, Lever E, Harwood R, Gordon C, Wincup C, Blane M, Brimicombe J, Lanyon P, Howard P, Sutton S, D'Cruz D, Naughton F. Telemedicine in rheumatology: A mixed methods study exploring acceptability, preferences and experiences among patients and clinicians. *Rheumatology (Oxford)*. 2021 Oct 26:keab796. doi: 10.1093/rheumatology/keab796. Epub ahead of print. PMID: 34698822; PMCID: PMC8689882.

21. Dekker AB, Bandell DLJI, Kortlever JTP, Schipper IB, Ring D. Factors Associated with Patient Willingness to Conduct a Remote Video Musculoskeletal Consultation. Arch Bone Jt Surg. 2020 Nov;8(6):656-660. PMID: 33313344; PMCID: PMC7718570.
22. Health literacy Matters 0621 Update (pifonline.org.uk)
23. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. 2011 Jul 19;155(2):97-107.

Figure 1: Self-reported e-health literacy using eHEALs.

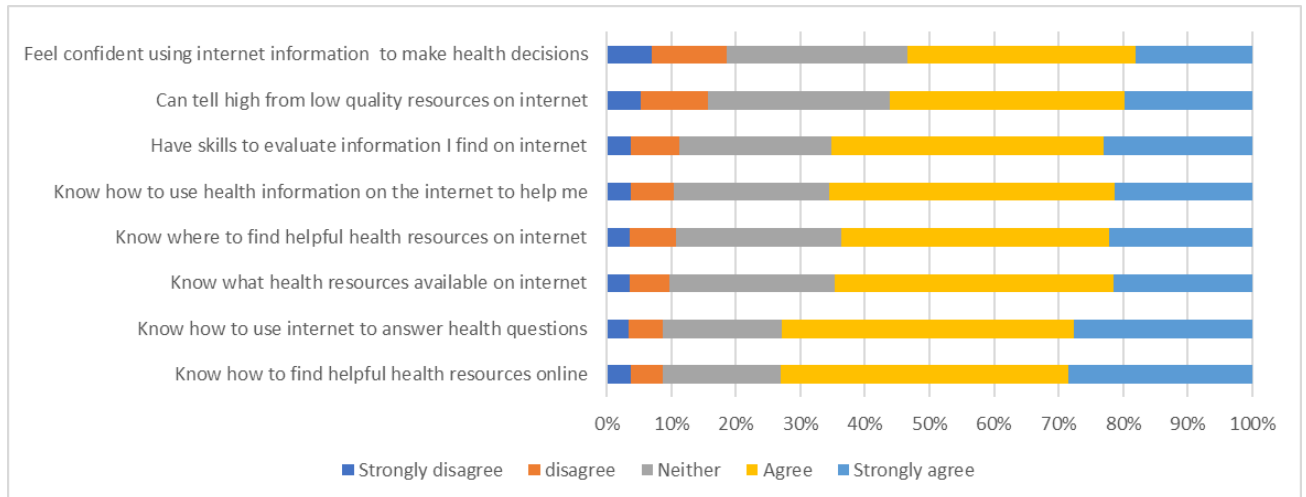


Table 1: Survey Demographics and Internet Access and Use

N (%) unless otherwise stated	Total N=612	No internet device N=126	Internet device ^c N=486	P
Age group				
Age < 65 years	273 (45.6)	21 (16.6)	252 (52.5)	<0.0001
Age ≥ 65 years	326 (54.4)	99 (78.5)	227 (46.7)	
Female gender	384 (64.7)	70 (55.5)	314 (64.6)	0.177
Employment status				
Employed	144 (24.0)	10 (7.9)	134 (27.5)	<0.0001
Other (incl retired)	456 (76.0)	110 (87.3)	346 (71.2)	
Arthritis diagnosis^a				
RA	492 (77.0)	109 (86.5)	366 (75.3)	
Psoriatic arthritis	130 (20.3)	16 (12.7)	105 (21.6)	
AS or Axial SpA	50 (7.8)	8 (6.3)	39 (8.1)	
Other	23 (3.6)	4 (3.1)	19 (3.9)	
Frequency of internet use				
Never	93 (14.6)	82 (66.7)	11 (2.3)	<0.0001
< 1 day/week	64 (10.5)	15 (12.2)	49 (10.1)	
1-3 days/week	68 (11.2)	8 (6.5)	60 (12.4)	
4-6 days/week	83 (13.6)	5 (4.1)	78 (16.1)	
Everyday	301 (49.7)	13 (10.6)	288 (59.3)	
Limited health literacy	117 (19.3)	35 (28.7)	82 (17)	0.003
eHEALS median (IQR)^b	31 (25, 34)	26 (24, 32)	31 (26, 34)	0.0236
Limited digital literacy^b (eHEALS < 26)	124 (26.1)	15/31 (48.4)	109/351 (24.6)	0.003
Limited health and digital literacy	31 (6.6)	6 (19.4)	25 (5.7)	0.003
Sources of arthritis advice				
Websites	176 (28.8)	3 (2.3)	173 (35.6)	<0.0001
GP appointment	151 (24.7)	23 (18.3)	128 (26.3)	0.061
Telephone advice line	286 (46.7)	57 (45)	229 (47.1)	0.706
Rheumatology appointment	297 (48.5)	57 (45)	240 (49.4)	0.407
Rheumatology email advice	66 (10.8)	2 (1.2)	64 (13.2)	<0.0001

^a arthritis diagnosis groups not mutually exclusive as some people indicated more than one diagnosis

^b 475 patients completed eHEALS fully and could be included in analysis. 612 people answered question regarding device access.

^cInternet device was defined as a smartphone or desktop or laptop computer with internet access.

Data presented as N(%) in columns unless otherwise specified.

Table 2: Impact of internet access, health and e-health literacy on confidence and satisfaction with remote consultations

	Internet access (n=612)		Limited Health literacy (n=606)		Limited Digital literacy (n=475)		Total
	No N=126	Yes N=486	Yes N=117	No N=489	Yes N=124	No N=351	
Most recent rheumatology consultation							
Telephone	24 (46.2)	110 (46.6)	24 (49.0)	109 (46.4)	22 (41.5)	82 (46.6)	134 (46.5)
Video	0	1 (0.4)	0	1 (0.4)	0	1 (0.6)	1 (0.4)
Face to face	28 (53.9)	125 (53.0)	25 (51.0)	125 (53.2)	31 (58.5)	93 (52.8)	153 (53.1)
Confidence for a telephone consultation							
Very confident	33 (27.7)	178 (37.1)	27 (23.3)	181 (37.9)	39 (31.7)	132 (37.9)	211 (35.2)
Confident	51 (42.9)	194 (40.4)	41 (35.3)	20 (42.7)	42 (34.2)	153 (44.0)	245 (40.9)
Neither	11 (9.2)	48 (10.0)	16 (13.8)	42 (8.8)	19 (15.5)	28 (8.1)	59 (10.0)
Unconfident	18 (15.1)	50 (10.4)	27 (23.3)	40 (8.4)	19 (15.5)	29 (8.3)	68 (11.4)
Very unconfident	6 (5.0)	10 (2.1)	5 (4.3)	11 (2.3)	4 (3.3)	6 (1.7)	16 (6.7)
Confidence for a video consultation							
Very confident	7 (6.9)	106 (22.5)	15 (13.5)	98 (21.3)	8 (6.6)	92 (26.7)	113 (19.7)
Confident	22 (21.6)	166 (35.2)	32 (28.8)	155 (33.7)	36 (29.8)	133 (38.7)	188 (32.8)
Neither	22 (21.6)	77 (16.3)	18 (16.2)	81 (17.6)	32 (26.5)	45 (13.1)	99 (17.3)
Unconfident	30 (29.4)	89 (18.9)	31 (27.9)	87 (18.9)	32 (26.5)	53 (15.4)	119 (20.7)
Very unconfident	21 (20.6)	34 (7.2)	15 (13.5)	39 (8.5)	13 (10.7)	21 (6.1)	55 (9.6)
Satisfaction for a telephone appointment							
Very satisfied	32 (27.6)	139 (29.1)	23 (20.0)	145 (30.6)	24 (19.7)	107 (30.8)	171 (28.8)
Satisfied	41 (35.3)	198 (41.4)	41 (35.7)	198 (41.8)	38 (31.2)	149 (42.9)	239 (40.2)
Neither	16 (13.8)	59 (12.3)	19 (16.5)	56 (11.8)	27 (22.1)	37 (10.7)	75 (12.6)
Unsatisfied	20 (17.2)	68 (14.2)	22 (19.1)	64 (13.5)	25 (20.5)	46 (13.3)	88 (14.8)
Very unsatisfied	7 (6.0)	14 (2.9)	10 (8.7)	11 (2.3)	8 (6.6)	8 (2.3)	21 (3.5)
Satisfaction for a video appointment							
Very satisfied	6 (6.0)	79 (16.7)	11 (9.9)	74 (16.1)	8 (6.6)	69 (20.1)	85 (14.8)
Satisfied	18 (18.0)	168 (35.5)	25 (32.5)	150 (32.7)	34 (27.9)	127 (37.0)	186 (32.5)
Neither	30 (30.0)	108 (22.8)	28 (25.2)	110 (24.0)	35 (28.7)	77 (22.5)	138 (24.1)
Unsatisfied	22 (22.0)	83 (17.6)	21 (18.9)	83 (18.1)	31 (25.4)	49 (14.3)	105 (18.3)
Very unsatisfied	24 (24.0)	35 (7.4)	16 (14.4)	42 (9.2)	14 (11.5)	21 (6.1)	59 (10.3)

Table 3: Impact of internet access, health and e-health literacy on preferences for future care

	Internet access		Limited health literacy		Limited digital literacy		Total
	No N=126	Yes N=486	Yes N=117	No N=489	Yes N=124	No N=351	
Preference for future first appointment/new problem							
Telephone	19 (15.8)	46 (9.5)	12 (10.3)	52 (10.9)	7 (5.7)	40 (11.5)	65 (10.8)
Video	0	7 (1.5)	1 (0.9)	6 (1.3)	0	7 (2.0)	7 (1.2)
Face to face	81 (67.5)	328 (68.1)	87 (74.4)	318 (66.4)	88 (72.1)	231 (66.2)	409 (67.9)
Choice at the time	20 (16.7)	101 (21.0)	17 (14.5)	103 (21.5)	27 (22.1)	71 (20.3)	121 (20.1)
Preference for future urgent problem							
Telephone	25 (21.4)	80 (16.5)	20 (17.1)	84 (17.5)	14 (11.4)	64 (18.3)	105 (17.5)
Video	0	11 (2.3)	2 (1.7)	9 (1.9)	1 (0.8)	10 (2.9)	11 (1.8)
Face to face	77 (65.8)	294 (60.7)	78 (66.7)	290 (60.5)	85 (69.1)	201 (57.4)	371 (61.7)
Choice at the time	15 (12.8)	99 (20.5)	17 (14.5)	96 (20.0)	23 (18.7)	75 (21.4)	114 (19.0)
Preference for future routine review appointment							
Telephone	35 (29.4)	125 (25.9)	25 (21.4)	134 (28.0)	22 (17.9)	95 (27.2)	160 (26.6)
Video	1 (0.8)	17 (3.5)	2 (1.7)	16 (3.3)	1 (0.8)	17 (4.9)	18 (3.0)
Face to face	67 (56.3)	236 (48.9)	74 (63.3)	224 (46.8)	72 (58.5)	161 (46.1)	303 (50.3)
Choice at the time	16 (13.5)	105 (21.7)	16 (13.7)	105 (21.9)	28 (22.8)	76 (21.8)	121 (20.1)

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Disclosures

The authors declare no conflicts of interest.

Data Sharing statement

The data underlying this article will be shared on reasonable request to the corresponding author.

Lay Summary

The COVID-19 pandemic led to rapid changes in how healthcare was delivered and a shift to remote consultations. Many of these changes need access to the internet (known as digital access) and confidence in using internet (called digital literacy). To study the impact of digital access and literacy in people with inflammatory rheumatic diseases (like rheumatoid arthritis (RA)) we asked people (by post or SMS text) to complete a survey. 639 people responded. The average age was 64.5 years and 60.1% of people were female. Almost 20% of people reported not having access to an internet-enabled device. Ninety-three (14.6% of people) reported never accessing the internet; this was highest (23%) in people with rheumatoid arthritis (RA). One hundred and seventeen (18%) had limited health literacy. Even in those reporting internet use, digital literacy was only moderate. People with limited health or digital literacy or without internet access were less likely to report they were confident or satisfied with remote consultations. Roll out of digital innovations needs to take account of people who may need extra support to access care digitally.