

Health information use by patients with systemic lupus erythematosus (SLE) pre and during the COVID-19 pandemic

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To cite: Cardwell FS, Elliott SJ, Chin R, *et al.* Health information use by patients with systemic lupus erythematosus (SLE) pre and during the COVID-19 pandemic. *Lupus Science & Medicine* 2022;**9**:e000755. doi:10.1136/lupus-2022-000755

► Additional supplemental material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/lupus-2022-000755>).

Received 17 June 2022
Accepted 12 October 2022



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ABSTRACT

Objective We conducted an international survey of patients with SLE to assess their access, preference and trust in various health information sources pre-COVID-19 and during the COVID-19 pandemic.

Methods Patients with SLE were recruited from 18 observational cohorts, and patients self-reporting SLE were recruited through five advocacy organisations. Respondents completed an online survey from June 2020 to December 2021 regarding the sources of health information they accessed in the 12 months preceding (pre-11 March 2020) and during (post-11 March 2020) the pandemic. Multivariable logistic regressions assessed factors associated with accessing news and social media post-11 March 2020, and self-reporting negative impacts from health information accessed through these sources.

Results Surveys were completed by 2111 respondents; 92.8% were female, 76.6% had postsecondary education, mean (SD) age was 48.8 (14.0) years. Lupus specialists and family physicians were the most preferred sources pre-11 March 2020 and post-11 March 2020, yet were accessed less frequently (specialists: 78.5% pre vs 70.2% post, difference -8.3%, 95% CI -10.2% to -6.5%; family physicians: 57.1% pre vs 50.0% post, difference -7.1%, 95% CI -9.2% to -5.0%), while news (53.2% pre vs 62.1% post, difference 8.9%, 95% CI 6.7% to 11.0%) and social media (38.2% pre vs 40.6% post, difference 2.4%, 95% CI 0.7% to 4.2%) were accessed more frequently post-11 March 2020 vs pre-11 March 2020. 17.2% of respondents reported negative impacts from information accessed through news/social media. Those outside Canada, older respondents or with postsecondary education were more likely to access news media. Those in Asia, Latin America or younger respondents were more likely to access social

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The spread of misinformation/disinformation has been amplified during the COVID-19 pandemic, yet little is known about how patients with SLE access and trust health information.

WHAT THIS STUDY ADDS

- ⇒ We surveyed an international sample of patients with SLE and found that lupus specialists and family physicians are the most preferred and trusted health information sources, yet were accessed less frequently during the COVID-19 pandemic.
- ⇒ News media and social media—less trusted sources—were accessed more frequently during the COVID-19 pandemic.
- ⇒ Those in Asia, older respondents or males were less likely to report being negatively impacted by information accessed through news or social media.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Results suggest that increasing accessibility to lupus specialists and family physicians both in person and virtually will be important to reduce the consequences of accessing and acting on misinformation/disinformation.

media. Those in Asia, older respondents, males or with postsecondary education in Canada, Asia or the USA were less likely to be negatively impacted.

Conclusions Physicians, the most preferred and trusted sources, were accessed less frequently, while news and social media, less trusted sources, were accessed more frequently post-11 March 2020 vs pre-11 March 2020. Increasing accessibility to physicians,

in person and virtually, may help reduce the consequences of accessing misinformation/disinformation.

INTRODUCTION

The spread of health-related false information, either unintentionally (misinformation) or deliberately (disinformation), through news or social media can have serious consequences. Conflicting or unfounded messages can undermine trust in health institutions,¹ influence patient decision-making and contribute to fear and anxiety.^{2,3} The spread of misinformation/disinformation has been amplified during the COVID-19 pandemic (ie, the infodemic),^{1,2,4} emphasising the need for accessible and credible health information. This is particularly true for individuals with complex diseases like SLE as those with active/untreated disease, a high comorbidity burden and/or on immunosuppressive therapies may be at higher risk of severe COVID-19.⁵

With the exception of small Spanish (n=150)⁶ and American (n=56)⁷ studies that found that 67.3% and 80% of patients with SLE, respectively, use the internet to search for health information, there is limited research on how patients with SLE access and trust health information. We surveyed an international sample of patients with SLE on how they accessed health information and their preferred sources and level of trust in each source prior to and during the COVID-19 pandemic. We explored determinants of accessing health information through news and social media during the pandemic, and self-reporting perceived negative impacts of accessing health information through these sources.

METHODS

Recruitment

Individuals aged ≥ 18 years were recruited from the following two sources between June 2020 and December 2021:

1. Those fulfilling the American College of Rheumatology⁸ and/or Systemic Lupus International Collaborating Clinics (SLICC) Classification Criteria for SLE⁹ were recruited from observational research cohorts (n=18) in SLICC (Asia: Seoul, South Korea, Singapore; Canada: Toronto, Montreal, Calgary, Winnipeg, Quebec City, Halifax; Europe: Bilbao, Spain, Manchester, UK, Pisa, Italy; Latin America: Rosario, Argentina, Mexico City, Mexico; USA: Baltimore, Pittsburgh, Chicago, New York City, Los Angeles).
2. Those self-reporting an SLE diagnosis were recruited from SLE advocacy associations (n=5) (Lupus Canada, Lupus Foundation of America, Spanish Lupus Federation, Lupus Europe, Argentine Lupus Association).

Respondents recruited from research cohorts were approached in clinic or sent, via email or hard copy, an invitation to participate in an online survey regarding where they accessed their health information in the 12

months preceding (pre-11 March 2020; the date WHO declared a pandemic) and during (post-11 March 2020) the COVID-19 pandemic. Advocacy organisations distributed the survey link to their registries via email and shared the link on their social media platforms (eg, Facebook, Instagram).

Health information survey

The survey was designed by the research team and rooted in the social amplification of risk¹⁰ and environment and health risk perception literature.¹¹ The survey was translated and back-translated from English into Canadian French, European French, Italian, Spanish and Korean, and pilot tested with Canadian patients as well as researchers at each site to ensure comprehension and applicability in each international context.

Respondents were asked how frequently they accessed various health information sources (ie, lupus specialists, family physicians, pharmacists, alternative care providers, peers, advocacy organisations, news media, social media) preceding and during the COVID-19 pandemic. They were also asked their level of trust in each source (ie, sources listed above and specifically among news and social media sources, trust in newspaper, online news media, radio, television, Facebook, Instagram, internet blog, Twitter, YouTube, LinkedIn, Pinterest, Reddit, TikTok) pre-11 March 2020 and post-11 March 2020. Frequency of access and level of trust were measured on a 5-point Likert scale (for access, options included: never, rarely, sometimes, often or always; for trust, options included: very untrustworthy, somewhat untrustworthy, neutral, somewhat trustworthy or very trustworthy). Respondents also ranked their top three preferred news and social media sources pre-11 March 2020 and post-11 March 2020.

Respondents self-reported if they perceived their health had been negatively impacted because of health information accessed through news or social media (ie, respondents were asked to respond yes/no to each question: “Do you feel that your health has been negatively impacted because of health information you accessed through news media?”; “Do you feel that your health has been negatively impacted because of health information you accessed through social media?”). Respondents also self-reported sociodemographic information as of the date of survey completion (ie, age, gender, race and ethnicity, education, household size, relationship status, employment status, region of residence), SLE disease characteristics as of the date of survey completion (ie, disease duration, SLE medications taken in the past year) and COVID-19 disease characteristics ever (ie, diagnosis, hospitalisation).

Statistical analysis

Descriptive statistics were used to calculate the percentage of respondents accessing and trusting each source and the percentage self-reporting that

Table 1 Respondent characteristics (n=2111)

Characteristic	Total sample
Region*, %	
Asia	9.5%
Canada	40.2%
Europe	17.1%
Latin America	5.6%
USA	27.6%
Age (years)†, mean (SD) (n=2089)	48.8 (14.0)
Female, % (n=2105)	92.8%
Non-white race and ethnicity‡, % (n=2028)	34.8%
Postsecondary education§, % (n=2065)	76.6%
Household size, mean (SD) (n=2088)	2.7 (1.4)
Relationship status—partnered¶, % (n=2043)	65.1%
Employed**, % (n=2069)	55.5%
Recruited through research cohort††, %	79.9%
Survey completed by 31 December 2020	72.0%
Time elapsed from 11 March 2020 to survey completion, in days (SD)	264.9 (96.1)
SLE disease duration‡‡, mean years (SD) (n=2079)	16.7 (12.0)
SLE medications taken in the past year§§, % (n=2106)	
Antimalarials, and corticosteroids and/or immunosuppressive drugs and/or biologics	56.9%
Corticosteroids and/or immunosuppressive drugs and/or biologics	11.5%
Antimalarials only	25.6%
None	6.0%
Self-reported positive COVID-19 test and/or doctor diagnosis, %	2.6%
Self-reported hospitalisation for COVID-19, %	0.4%

*Region: Asia (Seoul, Singapore); Canada (Toronto, Montreal, Calgary, Winnipeg, Quebec City, Halifax, Lupus Canada); Europe (Bilbao, Manchester, Pisa, Spanish Lupus Federation, Lupus Europe); Latin America (Rosario, Mexico City, Argentine Lupus Association); USA (Baltimore, Pittsburgh, Chicago, New York City, Los Angeles, Lupus Foundation of America).

†Age (years) at time of survey completion.

‡Non-white race and ethnicity includes respondents who selected a race and ethnicity option other than, or in addition to, white/Caucasian.

§Postsecondary education includes completion of certificate, diploma or degree greater than a high school diploma or equivalent.

¶Partnered includes common-law partnership or legally married (and not separated).

**Employed includes full-time, part-time or self-employment.

††Research cohort: observational cohorts in established research networks. Does not include SLE advocacy organisations.

‡‡SLE disease duration=age at survey completion–age of SLE diagnosis.

§§Corticosteroids and/or immunosuppressive drugs and/or biologics include: azathioprine, belimumab, colchicine, cyclophosphamide, ciclosporin, intravenous immunoglobulin, leflunomide, methotrexate, mycophenolate mofetil or mycophenolic acid, rituximab, steroids, tacrolimus, ustekinumab or other immunosuppressive drugs.

their health had been negatively impacted because of health information accessed through news or social media. To simplify the analysis, we collapsed the Likert frequency of access/level of trust ratings into accessed/did not access and trusted/did not trust. Patients responding accessing a source sometimes/often/always were considered to access the source, whereas those responding never/rarely were considered to not access the source. Similarly, those responding somewhat trustworthy/very trustworthy were considered to trust the source, whereas those responding very untrustworthy/somewhat untrustworthy/neutral were not considered to trust the

source. Those self-reporting that their health had been negatively impacted because of health information accessed through either news or social media were considered to have been negatively impacted.

McNemar tests were used to compare the percentage accessing (reported as sometimes/often/always) and reporting trust (reported as somewhat/very trustworthy) in each source pre-11 March 2020 and post-11 March 2020. Results are expressed as proportions with differences and 95% CIs.

Preference ranking scores were averaged across patients for each health information source, with the most preferred sources having the lowest score. Preference

rankings are reported for each source pre-11 March 2020 and post-11 March 2020.

Multivariable regression analysis

Multivariable logistic regression analysis was used to examine the associations between the outcomes: (1) accessing news media post-11 March 2020, (2) accessing social media post-11 March 2020 and (3) self-reporting perceived negative impacts from health information accessed through news or social media and a variety of determinants.

Selection of determinants was clinically and theoretically informed by our understanding of SLE and COVID-19 as well as through the involvement of observational cohort and advocacy association representatives. Determinants (see online supplemental table 1) include:

1. Sociodemographics as of the date of survey completion: age in years (continuous), gender—female (reference: male gender), non-white race and ethnicity (reference: white only), postsecondary education (reference: high school diploma or equivalent or less), household size (continuous), relationship status—partnered (reference: grouped all non-partnered including never legally married; separated, but still legally married; divorced; widowed), employment status—employed (reference: grouped all non-employed including student; retired; not employed, looking for work; not employed, not looking for work; unemployed; unable to work) and region of residence (reference: Canada).
2. SLE disease characteristics as of the date of survey completion: disease duration in years (continuous); antimalarial use (reference: no antimalarial use) and corticosteroid and/or immunosuppressive drugs and/or biological use (reference: no corticosteroid, immunosuppressive drugs or biologic use). Respondents reported the medications they had taken over the year prior to the date of survey completion or were currently taking. This served as a proxy for disease severity and those self-reporting no medications or antimalarials only over the year prior to survey completion were considered to have less severe disease.
3. COVID-19 disease characteristics: diagnosis ever (reference: no diagnosis ever) and hospitalisation ever (reference: no hospitalisation ever).
4. Time elapsed in days between date of survey completion and 11 March 2020 (continuous).
5. Access variables: reporting access (sometimes/often/always post-11 March 2020; reference: never/rarely) in each health information source.
6. Trust variables: reporting trust (somewhat/very trustworthy post-11 March 2020; reference: very untrustworthy/somewhat trustworthy/neutral) in each health information source. For trust in news and social media, the individual news and social media sources (news media: newspaper, online news media, radio, television; social media: Facebook, Instagram, internet blog, Twitter, YouTube, LinkedIn, Pinterest, Reddit, TikTok) were grouped to create single trust in news media

and trust in social media variables. Respondents were considered to trust news media or social media if they reported any of the individual news or social media sources as somewhat/very trustworthy (reference: very untrustworthy/somewhat untrustworthy/neutral).

Age, gender, postsecondary education and region are known determinants to influence actual and perceived health status,¹² and were included in all models. Each of the three outcomes were first modelled using blocks of determinants: sociodemographics; SLE disease characteristics; COVID-19 disease characteristics; time elapsed in days between date of survey completion and 11 March 2020; access variables; trust variables. Determinants for which an association with the outcome was likely (based on $p < 0.1$) were considered as potential determinants, after eliminating variables least likely to be associated with the outcome within each block based on backward stepwise selection. An interaction term between region and postsecondary education was also considered. Forced and potential determinants were included in the final model, and the most parsimonious model with significant covariates for which an association remained statistically significant at the 95% confidence level, after eliminating variables least likely to be associated with the outcome, was presented.

For all models, we adjusted for the missingness in the determinants as follows: missing values for continuous variables (ie, age in years, household size, SLE disease duration in years) were imputed using the mean value calculated from non-missing responses (imputation); for non-continuous variables (ie, gender—female, non-white race and ethnicity, postsecondary education, relationship—partnered, employment status—employed, antimalarial use, corticosteroid and/or immunosuppressive drugs and/or biological use), we set their missing values to 0 and included dummy variables to indicate if the value was missing (missing indicator method).

For multivariable logistic regression models (1) and (2), there were no missing outcome values. For regression model (3), those reporting ‘prefer not to answer’, ‘I don’t know’ or who skipped the question were not included in the analysis, and no imputation for the outcome values was done (complete case analysis).

Sensitivity analysis

All of the above analyses were also completed excluding those recruited from advocacy associations. All analyses were conducted using Stata V.15.1.

RESULTS

Sample characteristics

Surveys were completed by 2111 respondents, 1686 were recruited from patient cohorts (26.0% response rate) and 425 were recruited through advocacy organisations (response rate cannot be calculated as a denominator is not available) (table 1). The mean (SD) age was 48.8 (14.0) years, 92.8% were female,

Table 2 Health information source access* and trust†, pre-11 March 2020 and post-11 March 2020 (n=2111)

Health information source	Access			Trust		
	Pre‡ %	Post‡ %	% Difference (95% CI)	Pre‡ %	Post‡ %	% Difference (95% CI)
Lupus specialists	78.5	70.2	-8.3 (-10.2 to -6.5)	91.5	91.3	-0.2 (-1.3 to 1.0)
Family physicians	57.1	50.0	-7.1 (-9.2 to -5.0)	75.7	75.7	0.0 (-1.6 to 1.6)
Pharmacists	45.7	40.0	-5.7 (-7.6 to -3.7)	68.5	67.0	-1.4 (-2.9 to 0.1)
Alternative care providers	20.1	13.6	-6.5 (-8.0 to -5.0)	27.9	25.0	-2.9 (-4.3 to -1.6)
Peers	40.6	42.4	1.8 (-0.2 to 3.7)	27.3	28.7	1.4 (-0.3 to 3.0)
Advocacy organisations	36.4	37.4	1.0 (-0.8 to 2.7)	58.7	54.3	-4.4 (-5.9 to -2.8)
News media	53.2	62.1	8.9 (6.7 to 11.0)	56.3§	51.2§	-5.1 (-6.7 to -3.5)
Newspaper	-	-	-	32.4	29.3	-3.1 (-4.7 to -1.4)
Online news media	-	-	-	44.1	40.9	-3.2 (-4.8 to -1.6)
Radio	-	-	-	29.7	25.6	-4.1 (-5.5 to -2.6)
Television	-	-	-	39.3	36.9	-2.3 (-3.9 to -0.7)
Social media	38.2	40.6	2.4 (0.7 to 4.2)	30.4¶	27.8¶	-2.6 (-4.1 to -1.1)
Facebook	-	-	-	14.2	13.3	-0.9 (-2.1 to 0.3)
Instagram	-	-	-	8.0	7.7	-0.3 (-1.3 to 0.7)
Internet blog	-	-	-	11.3	9.9	-1.4 (-2.6 to -0.3)
Twitter	-	-	-	7.0	7.0	0.0 (-0.8 to 0.9)
YouTube	-	-	-	15.5	14.4	-1.1 (-2.4 to 0.1)
Other social media**	-	-	-	8.1	7.0	-1.1 (-2.1 to -0.2)

Significant differences in bold. 95% CIs using McNemar tests.

*Respondents who reported health information source access sometimes/often/always.

†Respondents who reported source as somewhat/very trustworthy.

‡Pre and post refer to 11 March 2020.

§Respondents were not asked to identify level of trust in news media overall. Value derived from grouping four news media sources (newspaper, online news media, radio, television) included in the survey to create a single trust in news media variable. Respondents were considered to trust news media if they reported any of the individual news media sources as somewhat/very trustworthy.

¶Respondents were not asked to identify level of trust in social media overall. Value derived from grouping social media sources (Facebook, Instagram, internet blog, Twitter, YouTube, LinkedIn, Pinterest, Reddit, TikTok) included in the survey to create a single trust in social media variable. Respondents were considered to trust social media if they reported any of the individual social media sources as somewhat/very trustworthy.

**Other social media include LinkedIn, Pinterest, Reddit and TikTok.

34.8% were of self-reported non-white race and ethnicity and 76.6% reported completing postsecondary education.

Health information source access

During the pandemic, 62.1% of respondents reported accessing health information sometimes/often/always through news media and 40.6% reported accessing health information sometimes/often/always through social media (table 2). Seventeen per cent (17.2%) of respondents reported being negatively impacted by health information accessed through these sources.

The most frequently accessed sources (reported as sometimes/often/always) post-11 March 2020 and pre-11 March 2020 were lupus specialists (post: 70.2%, pre: 78.5%), family physicians (post: 50.0%, pre: 57.1%) and news media (post: 62.1%, pre: 53.2%) (table 2). Lupus specialists (post: 70.2% vs pre: 78.5%, difference -8.3%, 95% CI -10.2% to -6.5%), family physicians, pharmacists and alternative care providers were accessed less

frequently, while news media and social media were accessed more frequently post-11 March 2020 vs pre-11 March 2020.

Trustworthiness of health information sources

The most trusted sources (reported as somewhat/very trustworthy) post-11 March 2020 and pre-11 March 2020 were lupus specialists (post: 91.3%, pre: 91.5%), family physicians (post: 75.7%, pre: 75.7%) and pharmacists (post: 67.0%, pre: 68.5%) (table 2). Trust in many sources decreased post-11 March 2020 vs pre-11 March 2020, including alternative care providers (post: 25.0% vs pre: 27.9%, difference -2.9%, 95% CI -4.3% to -1.6%), advocacy organisations, news media (overall and for newspapers, online news media, radio and television) and social media (overall and for internet blogs and other social media). No sources were considered more trustworthy during pandemic versus pre-pandemic.

Preferred health information sources

Lupus specialists and family physicians were ranked as the first and second most preferred sources both post-11 March 2020 and pre-11 March 2020. While news media was ranked the third most preferred source post-11 March 2020 and pre-11 March 2020, social media was ranked less highly during pandemic versus prepandemic (seventh post vs sixth pre), and peers were ranked more favourably during the pandemic (sixth post vs seventh pre). Advocacy organisations and pharmacists were ranked fourth and fifth both post-11 March 2020 and pre-11 March 2020, respectively, while alternative care providers were the least preferred source (eighth post and pre).

Multivariable logistic regression results

Older (vs younger) respondents, those residing in Asia, Europe, Latin America or the USA (vs those residing in Canada), or those with postsecondary education (vs without) were more likely to access health information through news media (table 3). Those accessing peers, advocacy organisations or social media sometimes/often/always (vs never/rarely) were also more likely to access news media. While respondents reporting news media as somewhat/very trustworthy (vs very untrustworthy/somewhat trustworthy/neutral) were more likely, those reporting trust in family physicians or social media were less likely to access news media.

Table 3 Multivariable logistic regression results*†: determinants of: (1) accessing‡ news media for health information, (2) accessing‡ social media for health information and (3) self-reporting perceived negative impacts from health information accessed‡ through news/social media

Explanatory variables	News media (n=2111)		Social media (n=2111)		Negative impacts (n=1866)	
	Adjusted OR	95% CI	Adjusted OR	95% CI	Adjusted OR	95% CI
Region						
Canada (ref)	1.00	–	1.00	–	1.00	–
Asia	3.19	(1.94 to 5.25)	2.26	(1.50 to 3.39)	0.31	(0.16 to 0.61)
Europe	3.04	(2.17 to 4.26)	1.09	(0.79 to 1.51)	0.97	(0.55 to 1.72)
Latin America	2.32	(1.34 to 4.01)	2.26	(1.35 to 3.79)	0.69	(0.26 to 1.83)
USA	1.36	(1.04 to 1.79)	0.71	(0.54 to 0.95)	1.38	(1.01 to 1.89)
Sociodemographics						
Age	1.01	(1.001 to 1.02)	0.97	(0.96 to 0.98)	0.98	(0.97 to 0.98)
Female	1.00	(0.65 to 1.53)	1.49	(0.93 to 2.37)	2.23	(1.17 to 4.24)
Postsecondary education	1.55	(1.18 to 2.04)	0.92	(0.70 to 1.21)	0.66	(0.44 to 0.98)
Europe×postsecondary education§	–	–	–	–	3.05	(1.57 to 5.91)
Latin America×postsecondary education§	–	–	–	–	4.05	(1.34 to 12.25)
Access‡/Trust¶ in health information sources						
Access—peers	2.88	(2.27 to 3.66)	1.93	(1.54 to 2.49)	–	–
Access—advocacy organisations	1.61	(1.25 to 2.07)	1.96	(1.55 to 2.49)	–	–
Access—news media	–	–	6.93	(5.30 to 9.05)	–	–
Access—social media	8.65	(6.51 to 11.50)	–	–	–	–
Access—alternative care providers	–	–	1.43	(1.03 to 1.97)	1.59	(1.14 to 2.22)
Trust—family physicians	0.74	(0.56 to 0.97)	–	–	–	–
Trust—news media**	5.85	(4.59 to 7.45)	–	–	0.59	(0.46 to 0.76)
Trust—social media††	0.62	(0.46 to 0.84)	4.68	(3.65 to 6.00)	–	–

Significant covariates in bold.

*Sociodemographics, disease characteristics, number of days to survey completion since 11 March 2020, and access to and trust in sources were considered in the models. Only significant variables are presented here.

†Variables with a ‘–’ were not included in the final model. Region, age, gender and postsecondary education were forced into the models, and other variables were chosen through backwards stepwise selection.

‡Respondents accessing source for health information sometimes/often/always post-11 March 2020.

§Interaction between region and postsecondary education was added to explore the relationship of postsecondary education in different regions. Only significant interactions included in the final model.

¶Respondents reporting source as somewhat/very trustworthy post-11 March 2020.

**Respondents were not asked to identify level of trust in news media overall. Value derived from grouping four news media sources (newspaper, online news media, radio, television) included in the survey to create a single trust in news media variable. Respondents were considered to trust news media if they reported any of the individual news media sources as somewhat/very trustworthy.

††Respondents were not asked to identify level of trust in social media overall. Value derived from grouping social media sources (Facebook, Instagram, internet blog, Twitter, YouTube, LinkedIn, Pinterest, Reddit, TikTok) included in the survey to create a single trust in social media variable. Respondents were considered to trust social media if they reported any of the individual social media sources as somewhat/very trustworthy.

Respondents in Asia or Latin America were more likely, and those in the USA were less likely to access health information through social media (table 3). Older respondents were less likely to access this source. Respondents accessing peers, advocacy organisations, news media or alternative care providers were more likely to access social media. Those reporting trust in social media were also more likely to access social media.

Older respondents or those residing in Asia were less likely to be negatively impacted by health information accessed through news or social media, and those in the USA and females (vs males) were more likely to be negatively impacted (table 3). While those in Canada, Asia or the USA with postsecondary education were less likely to be negatively impacted, those with postsecondary education in Europe or Latin America were more likely to report negative impacts. Respondents accessing alternative care providers were more likely, while those reporting trust in news media were less likely to report negative impacts.

Sensitivity analysis

Characteristics of respondents recruited from observational cohorts only (n=1686) were similar to the full sample (online supplemental table 2). Among the sample recruited from observational cohorts only, the percentages accessing health information sometimes/often/always through news (63.2%) and social media (38.8%) post-11 March 2020 (online supplemental table 3) were similar to the percentages accessing health information sometimes/often/always through news (62.1%) and social media (40.6%) post-11 March 2020 in the full sample. The percentage reporting being negatively impacted by health information accessed through these sources was also similar (observational cohorts only: 14.6%; full sample: 17.2%). While access to and trust in most sources were similar between the samples, the percentage of those accessing (observational cohorts only: post: 28.1%, pre: 27.1%; full sample: post: 37.4%, pre: 36.4%) and trusting advocacy organisations (observational cohorts only: post: 46.9%, pre: 51.2%; full sample: post: 54.3%, pre: 58.7%) was lower among those recruited from the observational cohorts (online supplemental table 3). The top three most preferred sources (lupus specialists, family physicians, news media) post-11 March 2020 and pre-11 March 2020 were the same for both samples (online supplemental table 4). Factors associated with accessing news or social media post-11 March 2020 or self-reporting negative impacts from health information accessed through these sources were relatively similar between the samples (online supplemental table 5), although notably postsecondary education was not associated with self-reporting negative impacts among those recruited from observational cohorts only.

DISCUSSION

This study is the first to report how individuals with SLE access, prefer and trust various health information

sources pre-COVID-19 and during the COVID-19 pandemic. Although lupus specialists and family physicians were ranked the most preferred and trustworthy sources both pre-11 March 2020 and post-11 March 2020, access to these sources decreased, and access to news and social media—less trusted sources—increased during the pandemic. This is likely due to decreased accessibility of in-person sources coupled with concern about transmission of COVID-19, particularly during the first year of the pandemic when most data were collected.

In the full sample including respondents recruited from observational cohorts and advocacy associations, advocacy organisations were less accessed than other less trusted sources (eg, peers, social media) both pre-11 March 2020 and post-11 March 2020, and with the exception of the aggregated trust in news media variable, advocacy organisations had the largest decrease in trust (by 4.4%) post-11 March 2020. This is surprising given advocacy organisations exist to support and promote the interests of those affected by SLE, and collaborate with physicians, researchers and patients to mobilise informational and other resources. As expected, access and trust of advocacy associations were lower among the observational cohort (which excludes those recruited from associations) than the full sample.

We observed that those accessing social media and trusting news media were more likely to access news media, and those accessing news media and trusting social media were more likely to access social media. This is not surprising given those who trust a source (eg, social or news media) are more likely to access that source. Those accessing peers and advocacy organisations were also more likely to access both news and social media. These findings emphasise the complementary nature of news and social media and indicate that individuals accessing news or social media are also more likely to seek health information from a range of sources. Unsurprisingly, younger respondents were more likely to access health information through social media.

Respondents in Asia were less likely to report negative impacts from health information accessed in news or social media, perhaps due to regional variations in the style/content of news and social media sources. While those in Canada, Asia and the USA with postsecondary education were less likely to report negative health impacts, respondents in Europe (88.1% from Spain) and Latin America (ie, Argentina and Mexico) were more likely to report negative impacts. This is generally consistent with data from the World Values Survey,¹³ which reports lower confidence in the press in Spain (32.7%), Argentina (29.1%) and Mexico (26.8%) compared with Canada (42.6%), Singapore (54.9%) and South Korea (49.5%). Females and those accessing alternative care providers were also more likely to report negative impacts. These groups may be more likely to seek and act on information from various sources.¹⁴ Finally, those trusting news media were less likely to report negative impacts, possibly because being negatively impacted by

health information accessed through news media could lead to decreased trust in this source. The associations between age, gender, education and region across the models emphasise the importance of targeting health messaging based on demographics to improve communication with patients and reduce the adverse impacts of misinformation/disinformation.

Our results emphasise the need to improve accessibility to the most preferred and trusted health information sources. Access to news and social media increased during the pandemic, and news media was the second most accessed source post-11 March 2020; engaging preferred and trusted sources (eg, physicians) to disseminate health information through these communication channels, particularly during times of scientific uncertainty, can help increase access to trusted sources. To further increase direct accessibility to physicians, virtual access is critical particularly when in-person appointments are not possible. Establishing the infrastructure to support a hybrid model of care beyond the pandemic will be useful for future clinical practice. Although clinical,^{15 16} financial, technological and cultural¹⁷ challenges associated with telerheumatology exist for both patients and healthcare providers, virtual appointments can reduce geographic barriers¹⁸ and improve access to specialised care.¹⁶ During the pandemic, telerheumatology¹⁵ and other digital interventions (eg, professionally moderated electronic applications^{19 20}) were well-received by patients,^{15 16 21} and fewer missed appointments were reported compared with in-person visits during and prior to the pandemic.²² Integrating remote appointments into clinical practice is a feasible and accessible option to improve patient-centred care and communication with trusted health information sources.

Our study has several potential limitations. First, our sample may not be representative of the general population with SLE. A high proportion of patients self-reported high income and postsecondary education and most were recruited through observational patient cohorts, representing those who have access to high quality care. While we also recruited through advocacy organisations, our sample is less likely to include patients who do not have access to adequate care or do not have internet access. Second, those recruited through advocacy organisations may differ from those recruited through observational cohorts as they may not have a physician confirmed diagnosis and may be more engaged in the SLE social media community. We have performed a sensitivity analysis excluding those recruited from advocacy organisations and observed few differences between the two samples. Third, a COVID-19 diagnosis may influence the experiences and perspectives of respondents and those who experienced serious illness or death due to a COVID-19 diagnosis may not have participated, which may affect the generalisability of the results.

There are also limitations related to data collection. First, the response rate for respondents recruited from observational cohorts was only 26.0%, which is consistent

with other surveys conducted during the pandemic.²³ We cannot accurately report a response rate for respondents recruited through advocacy organisations as these sources used a multimodal approach (eg, newsletter, social media) for recruitment and the number of potential respondents reached through social media is unknown. Second, we did not collect physician or patient-reported data on SLE disease activity or damage, and medication use served as a proxy for SLE severity in our regression models. Third, we cannot characterise any changes in disease severity throughout the course of the pandemic as we asked about medications taken over the year prior to the date of survey completion and not prepandemic and during the pandemic. Fourth, surveys were completed over an 18-month period and frequency of access and trust in health information sources may have changed over this interval. Although a small number of sites collected data throughout 2021, most responses (72.0%) were collected from June 2020 to December 2020. In multivariable analysis, we accounted for this 18-month interval by considering time elapsed between date of survey completion and 11 March 2020. Fifth, respondents may access news media through social media (eg, if a news media article is posted on social media). Due to the granularity of our survey questions, we cannot accurately tease out these occurrences. Sixth, we did not assess other factors (eg, political leanings, specific news sources, whether respondents are accessing scientifically correct information) that could influence how they access, prefer and trust various health information sources and how they may be negatively affected by the health information accessed.

Finally, there are also limitations related to missing data. To deal with missing data, we used imputation for continuous variables and indicator variables for non-continuous variables. However, given that no variable has >3.9% of values missing we are confident that this did not influence interpretation of results. Next, 245 respondents did not self-report if their health had been negatively impacted because of health information accessed through news or social media; to account for this missing data in our third regression model, we assessed whether there were differences between those who answered they experienced negative impacts versus those with a missing response. While there are minor systematic differences between the groups (eg, those with postsecondary education or who trust news media were less likely to have a missing response, and those who were of non-white race and ethnicity or who accessed social media were more likely to have a missing response) (data not shown), we did not undertake any imputation for this outcome variable. Of the 245 respondents with missing values for whether their health had been negatively impacted, 79.6% were due to the respondent reporting “I don’t know” rather than ‘prefer not to answer’ or skipping the question. Therefore, we were reluctant to impute values for these respondents. Furthermore, our understanding of how exposure to misinformation/disinformation in the news or on social media can impact (self-reported)

health status remains limited and imputation of values for this outcome would be purely speculative.

Our findings demonstrate that lupus specialists and family physicians are the most preferred and trusted sources of health information for individuals with SLE, and news media and social media—less trusted sources—were accessed more frequently during the pandemic. Our results suggest that increasing accessibility to lupus specialists and family physicians both in person and virtually will be important to reduce the consequences of accessing and acting on misinformation/disinformation.

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Acknowledgements The authors thank all the respondents who provided their time for this research.

Contributors FSC, SJE, RC, YSP and AEC contributed to study design, data collection, data analysis and interpretation and preparation of the manuscript. All authors were involved in collecting or supervising data collection, and critically reviewed and approved the final version of the manuscript. FSC and AEC serve as guarantors and are responsible for the overall content.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests S-CB's work was supported in part by Basic Science Research Program through the National Research Foundation of Korea (NRF) funded by the Ministry of Education (NRF-2021R1A6A1A03038899). SB holds a James McGill Research Chair. The Montreal General Hospital Lupus Clinic is partially supported by the Singer Family Fund for Lupus Research. INB has received consulting fees, speaking fees, and/or honoraria from Eli Lilly, GlaxoSmithKline, AstraZeneca, UCB and Bristol Myers Squibb (<US\$10 000 each) and research support from GlaxoSmithKline. INB is an NIHR Senior Investigator and is supported by Versus Arthritis UK, the NIHR Manchester Biomedical Research Centre and the NIHR Manchester Clinical Research Facility. MYC has received consulting fees from Janssen, AstraZeneca, Mallinckrodt Pharmaceuticals and MitogenDx (<US\$10 000). AEC has received consulting fees from AstraZeneca/MedImmune, Bristol Myers Squibb and GlaxoSmithKline (<US\$10 000 each). AEC holds the Arthritis Society Chair in Rheumatic Diseases at the University of Calgary. PRF has received consulting fees from AstraZeneca and GlaxoSmithKline (<US\$10 000 each) and holds a tier 1 Canada Research Chair on Systemic Autoimmune Rheumatic Diseases at Université Laval. JGH's work was supported by the Canadian Institutes of Health Research (grant MOP-88526). The Hopkins Lupus Cohort is supported by the NIH (grants AR-43727 and AR-69572). AM has received consulting fees from Janssen, Astellas and GlaxoSmithKline (<US\$10 000 each), and a research fund from GlaxoSmithKline for investigator-sponsored research through the GSK Supported Studies Programme (proposal ID 10743). AM's work was supported in part by the Ministry of Health, Republic of Singapore (grant reference: R-172-000-524-733). SM has received consulting fees from Exagen Diagnostics, Cugene, GlaxoSmithKline and Lilly, and has served on the Board of AstraZeneca and Lupus Foundation of America. MM has received consulting fees from AstraZeneca, AbbVie, GlaxoSmithKline and UCB. CP has received consulting fees from AstraZeneca and GlaxoSmithKline. RR-G has received consulting fees from AstraZeneca, Biogen, ThermoFisher and Aurinia Pharmaceuticals (<US\$10 000 each). RR-G's work was supported by the NIH (grants 5UL1-TR-001422-02 (formerly 8UL1-TR-000150 and UL1RR-025741), K24-AR-02318 and P30-AR-072579 (formerly P60-AR-064464 and P60-AR-48098)). She is the Gallagher Research Professor of Rheumatology at the Feinberg School of Medicine, Northwestern University. GR-I's work was supported by the Department of Education, Universities and Research of the Basque Government. DJW has received consulting fees from Merck, EMD Serono, Pfizer, Lilly and Glenmark (<US\$10 000 each). The rest of the authors declare that they have no relevant conflicts of interest.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study was approved by the Research Ethics Boards at the University of Calgary (REB20-0522), University of Waterloo (#42115) as well as each additional collaborating site. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request.

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