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Concise report

Estimation of the burden of shielding among a cross-section of patients attending rheumatology clinics with SLE—data from the BSR audit of systemic lupus erythematosus

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Abstract

Objectives. We aimed to estimate what proportion of people with SLE attending UK rheumatology clinics would be categorized as being at high risk from coronavirus disease 2019 (COVID-19) and therefore asked to shield, and explore what implications this has for rheumatology clinical practice.

Methods. We used data from the British Society for Rheumatology multicentre audit of SLE, which included a large, representative cross-sectional sample of patients attending UK Rheumatology clinics with SLE. We calculated who would receive shielding advice using the British Society for Rheumatology's risk stratification guidance and accompanying scoring grid, and assessed whether ethnicity and history of nephritis were over-represented in the shielding group.

Results. The audit included 1003 patients from 51 centres across all 4 nations of the UK. Overall 344 (34.3%) patients had a shielding score $\geq$3 and would have been advised to shield. People with previous or current LN were 2.6 (1.9–3.4) times more likely to be in the shielding group than people with no previous LN ($P < 0.001$). Ethnicity was not evenly distributed between the groups (chi-squared $P < 0.001$). Compared with White people, people of Black ethnicity were 1.9 (1.3–2.8) and Asian 1.9 (1.3–2.7) times more likely to be in the shielding group. Increased risk persisted after controlling for LN.

Conclusion. Our study demonstrates the large number of people with SLE who are likely to be shielding. Implications for clinical practice include considering communication across language and cultural differences, and ways to conduct renal assessment including urinalysis, during telephone and video consultations for patients who are shielding.

Key words: systemic lupus erythematosus, infection, COVID-19, coronavirus, health services, epidemiology, shielding.

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Rheumatology key messages

- More than a third of patients with SLE may be shielding during the coronavirus disease 2019 (COVID-19) pandemic.
- Patients from Black and minority ethnic (BAME) backgrounds are over-represented in the shielding group.
- Half of patients with previous LN are shielding and may miss urinalysis due to telephone consultations.

Introduction

Coronavirus disease 2019 (COVID-19) presents a unique challenge in that it poses a threat to the entire population. However, there is a subset of the population who have been defined by the UK's Chief Medical Officers to be 'extremely vulnerable' to severe illness from COVID-19. The defined criteria for identifying the 'extremely vulnerable' group includes 'People on immunosuppression therapies sufficient to significantly increase risk of infection' [1], which is likely to apply to many people with autoimmune rheumatic diseases. In order to protect their health, these people have been advised to adopt extreme social distancing measures termed 'Shielding'.

Patients in this shielding category were identified in England using data accessed and searched by National Health Service (NHS) Digital, and patients were contacted by letter through this national process. General practitioners and hospital clinicians in each NHS Trust were asked to identify and contact additional patients who would meet clinical criteria for shielding but who were not identified by NHS Digital. The UK devolved nations (Scotland, Wales, Northern Ireland) used similar country-specific methodology [2–4].

In order to guide identification of these 'extremely vulnerable' patients by clinicians, the British Society for Rheumatology (BSR) established a working group to define immunosuppression therapies sufficient to significantly increase risk of infection in the context of patients treated by rheumatologists [5]. The group produced a risk stratification guide and an accompanying scoring grid, where a score of 3 or more meant that people should be advised to 'shield' themselves [6]. Both resources reliably identified those needing to shield, although the scoring grid has now been removed from the BSR website, because of some minor discrepancies between this and the stratification guide [7].

Rheumatology services have been made aware of the concern caused by shielding and inconsistent information from different health providers, not least through the greatly increased number of calls to rheumatology advice lines. LUPUS UK (a patient charity) describe receiving numerous reports from people with lupus who are shielding and experiencing hardship and difficulty accessing essential support [P. Howard, CEO Lupus UK, 2020 (personal communication)]. The solitary confinement experienced by those advised to shield is a heavy burden. Patients who are shielding are told they should not leave their home even for shopping, and either the whole household shields, or they should isolate themselves from other people in their home, keeping 2 m away at all times and eating alone in their room [8].

The requirement to shield is likely to be disproportionately high among people with rare autoimmune rheumatic diseases, such as SLE, because of frequent long-term CS and immunosuppressant use in these conditions, and high levels of comorbidity. However, what is not known is the burden of shielding amongst different groups of people with autoimmune rheumatic diseases.

We used data from the BSR multicentre audit of SLE, which included a large and representative cross-sectional sample of patients attending UK Rheumatology clinics with SLE, to calculate their shielding scores, and to explore what implications this has for rheumatology clinical practice now and in the future.

Methods

Full methods for the audit are described in 'BSR Guideline on the Management of Adults with SLE 2018: Baseline MultiCentre Audit in the UK' (submitted with this paper). In brief, 51 rheumatology units in the 4 nations of the UK retrospectively audited care at the preceding clinic visit of prevalent SLE cases attending during a 4-week period in February–June 2018. Data including patient demographics, medications (including CS dose) and comorbidities were collected using web-based survey software. For this analysis, ethnic groups containing fewer than 50 people were categorized as other, resulting in ethnic group categories of White, Asian or Asian British, Black or Black British, Other ethnic groups, or not stated.

We applied the BSR risk stratification (scoring) grid to find out who would have qualified for shielding advice according to the COVID-19 guidance. This allocated points for CS dose (0 points if no steroids or daily dose <5 mg daily, 2 points if daily dose ≥ 5 mg and <20 mg, and 3 points if daily dose ≥ 20 mg daily), number of immunosuppressants (1 point if one DMARD or biologic and 2 points if two or more DMARDs or biologics; excluding HCQ and SSZ), CYC (3 points if given in the past 6 months) and 1 point if any one or more of: age >70 years, diabetes mellitus, pre-existing lung disease, renal impairment, history of ischaemic heart disease or hypertension. Scores for each category are summed, and a person with a score ≥ 3 should be advised to shield.

We applied all of the risk factors in the BSR's 'Risk stratification of patients with autoimmune rheumatic diseases' [6]. However, the audit data recorded CS dose at

a single time-point at the end of the preceding clinic visit, whereas the risk stratification grid allocated points for dose over the preceding 4 weeks. We assumed that patients were on the steroid dose we recorded for at least 4 weeks, because most steroid courses for SLE last at least this long. We did not have data on the least frequent of the listed comorbidities, namely pre-existing lung disease, so could not include this stratification. We conducted sensitivity analyses to assess what impact our assumption about length of CS courses, and the omission of pre-existing lung disease, might have had on our results.

We assigned each patient a shielding score and a shielding status (yes/no). We used ethnicity reported in the audit (taken from the self-reported ethnicity collected at inpatient and outpatient attendances to hospital and recorded on hospital computer systems). We also included presence or absence of previous LN. We compared the distribution of shielding status with the distribution of ethnicity, and with whether a patient had previously had LN using chi-squared testing and logistic regression. We included a multivariable regression analysis to estimate the adjusted odds ratio for the effect of ethnicity on shielding status, while controlling for LN.

This manuscript is based on clinical audit data and so ethical approval and informed consent was not required. Participating units registered the audit with their local audit departments. Data collection was hosted by the Audit department at the Dudley Group NHS Foundation Trust.

Results

The audit included 1003 patients. Patients were aged a median age of 48 (interquartile range 36–58) years, and 935 (93%) were female. Overall, 586 (58.4%) were White, 157 (15.7%) Asian or Asian British, and 147 (14.7%) Black or Black British; Other ethnic groups each contributed $<5\%$. A total of 497 (48.7%) patients were on prednisolone. This included 95 (9.5%) on a dose <5 mg daily, 347 (34.6%) on a dose ≥ 5 mg and <20 mg daily, and 55 (5.5%) on a dose ≥ 20 mg daily.

Overall 344 (34.3%) patients had a shielding score ≥ 3 and would have been advised to shield. The distribution of scores is shown in Table 1.

Ethnicity was not evenly distributed between the shielding and not shielding groups (chi-squared $P < 0.001$), and people of Black, Asian and minority ethnic (BAME) ethnicities were more likely than those of White ethnicity to be in the shielding group. Compared with White people, people of Black ethnicity were 1.9 (1.3–2.8) and Asian 1.9 (1.3–2.7) times more likely to be in the shielding group (Table 2). Mixed ethnicity and Other ethnic groups did not show statistically significant differences from White people, but the numbers were small. People with previous or current LN were 2.6 (95% CI 1.9, 3.4) times more likely to be in the shielding group than people with no previous LN. Overall, 243 (24.2%) patients in the audit had had LN, and of these 124 (51.0%) were in the shielding group compared with 220 (28.9%) of 760 patients without previous LN ($P < 0.001$).

Table 1 Shielding scores in the 1003 people included in the British Society for Rheumatology multicentre SLE audit

Shielding score	Number (%)	Shielding indicator	Number (%)
0	204 (20.3)	No	659 (65.7)
1	312 (31.1)		
2	143 (14.3)		
3	202 (20.1)	Yes	344 (34.3)
4	121 (12.1)		
5	20 (2.0)		
7	1 (0.10)		
Total	1003		

Multivariable regression analysis was performed to estimate the adjusted odds ratio for the effect of ethnicity on shielding status, while controlling for LN. This confirmed increased odds of being asked to shield in the Asian or Asian British, and Black or Black British groups, independent of their history of LN. Asian or Asian British people were 1.7 (95% CI 1.2, 2.5) times more likely than White people to be in the shielding group, and Black or Black British people were 1.7 (95% CI 1.1, 2.4) times more likely. The odds ratio for Other ethnic groups was not significant.

Discussion

In a large representative sample of people living with SLE in the UK we found that just over a third would be eligible for shielding. This illustrates the large burden of shielding and of perceived risk being carried at this time by people with SLE in the UK, and around the world.

Our study included a large and representative sample of people with lupus living in the UK. It included people from all four nations of the UK, attending both large and small hospitals. Demographics were similar to other published UK cohorts of people with SLE [9–12]. Our paper contains good quality data, collected by doctors from medical notes from the clinic visit prior to the audit time frame to avoid bias. There were no missing data because the web-based survey software did not allow submission until all fields were completed. Data were collected in 2018, and it is likely that the clinical characteristics and management of cohorts of patients with SLE are similar today.

There are of course some limitations. We did not have data on whether each patient had been on their current dose of steroids for at least 4 weeks, and we assumed that they had. However, we think this had a negligible effect on the shielding status. We tested whether in people on doses of prednisolone >20 mg daily we were over-estimating the number who would be eligible for shielding by giving them 3 points. We thought it almost certain that someone on 20 mg of prednisolone would

Table 2 Ethnicity and LN in the shielding/non-shielding groups

Characteristic	*N* (%) in audit	*N* (%) in shielding group	*N* (%) in non-shielding group	Crude odds ratio (95% CI) for shielding	Adjusted odds ratio (95% CI) for shielding
Ethnicity					
White	585 (58.3)	167 (28.6)	418 (71.4)	1	1
Asian or Asian British	157 (15.7)	68 (43.3)	89 (56.7)	1.9 (1.3–2.7)	1.7 (1.2–2.5)
Black or Black British	145 (14.5)	63 (43.5)	82 (56.6)	1.9 (1.3–2.8)	1.7 (1.1–2.4)
Other ethnic groups	66 (6.6)	26 (39.4)	40 (60.6)	1.6 (0.96–2.8)	1.5 (0.9–2.6)
Not stated (or unknown)	50 (5.0)	20 (40.0)	30 (60%)	1.7 (0.9–3.0)	1.5 (0.8–2.7)
LN					
Never had LN	760 (75.8)	220 (28.9)	540 (71.1)	1	1
LN (ever)	243 (24.2)	124 (51.0)	119 (49.0)	2.6 (1.9–3.4)	2.3 (1.7–3.2)

be on a dose of $\geq$5 mg for at least 4 weeks and so would be awarded at least 2 points. If all the people on prednisolone >20 mg had received only 2 points for steroid dose, then only 13 people would have moved from the shielding group into the non-shielding group (because all except 13 people on high-dose steroids qualified for shielding for other reasons in addition). We also did not have data to estimate the number of people who had pre-existing lung disease, and it is possible that a small number who did not already receive a point for being aged >70 years and other comorbidities could have gained an extra point. Potentially, this means that up to 75 (7.5%) people who had a total shielding score of 2 and were <70 years with no comorbidities should be in the shielding group, but we think in reality that this group is likely to be very small, as pre-existing lung disease is not common in SLE.

This is the first report we are aware of describing the burden of shielding on patients with SLE or other rare autoimmune rheumatic diseases in the UK.

This paper describes a high requirement for shielding amongst people with SLE during the COVID-19 pandemic. It highlights that a high proportion of people living with SLE have been identified as being at high risk of severe disease if they are infected with COVID-19. It also alerts us to a challenge for how we reduce harm by maintaining healthcare services for this group. We found that shielding was disproportionately indicated in people with previous LN compared with those who have never had LN. An increased chance of shielding was also seen among people with SLE of BAME background compared with people of White ethnicity, and this effect persisted despite controlling for history of LN. Most rheumatology services in the UK have switched to offering telephone or video consultations, rather than face-to-face follow-up, following the National Institute for Health and Care Excellence (NICE) rapid guidance [13]. The shielding groups have been advised to stay at home for at least 12 weeks, and will require telephone consultations for this 3-month period, and possibly longer. For people from BAME backgrounds we need to address barriers to accessing healthcare that may be exacerbated by telephone consultations [14–16]. For everyone with SLE we need to complete renal assessment including urinalysis, renal function by blood tests and blood pressure check alongside telephone consultations. Although the NICE rapid guidance advises that services plan remote blood monitoring for DMARDs there is no mention of remote urine or blood pressure monitoring. This is essential to detect LN, which is often asymptomatic, is potentially organ or life-threatening, and is more common in people with previous nephritis.

Whilst there is an evolving picture around the use of CS and COVID-19, the multi-speciality Clinical guide for the management of patients with musculoskeletal and rheumatic conditions on CS during the coronavirus pandemic describes the theoretical risks of more severe COVID-19 infection amongst this group [17]. It is notable that nearly half of the people in the audit were on prednisolone, and over a third were on a dose of 5 mg daily, which is currently thought to be sufficient to increase the risk of severe infection with COVID-19. There is clear advice not to stop CS suddenly, due to the risk of Addisonian crisis and lupus flare, but to taper the dose if possible. An urgent research priority should be to investigate the safety of steroid usage in lupus and other rare autoimmune rheumatic diseases, and how to maintain disease remission with a lower steroid burden.

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Health NHS Foundation Trust, Great Western Hospital NHS Foundation Trust, Heart of England NHS Foundation Trust, Kettering NHS Foundation Trust, King's College Hospital NHS Foundation Trust, Kingston Hospital NHS Foundation Trust, Lancashire and South Cumbria NHS Foundation Trust, Lewisham and Greenwich NHS Trust, London North West University Healthcare NHS Trust, Manchester University NHS Foundation Trust—Manchester Royal Infirmary, Trafford General and Wythenshawe Hospital sites, NHS Greater Glasgow & Clyde, NHS Lanarkshire, Newcastle upon Tyne Hospitals Foundation Trust, North Bristol NHS Trust, Northampton General Hospital NHS Trust, Northumbria Healthcare NHS Foundation Trust, Nottingham NHS Treatment Centre, Pennine Acute NHS Foundation Trust, Pennine Musculoskeletal Partnership, Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust, Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust, Royal Liverpool & Broadgreen University Hospitals NHS Trust, Royal United Hospitals Bath NHS Foundation Trust, Royal Wolverhampton Hospitals NHS Trust, Salford Royal NHS Foundation Trust, Sandwell and West Birmingham Hospitals NHS Trust, Sheffield Teaching Hospitals NHS Foundation Trust, Sherwood Forest Hospitals NHS Foundation Trust, South Tees Hospitals NHS Foundation Trust, South Warwickshire NHS Foundation Trust, Staffordshire and Stoke on Trent Partnership NHS Trust, Stockport NHS Foundation Trust, Tameside Hospital NHS Foundation Trust, University Hospitals Birmingham NHS Foundation Trust, University Hospitals Coventry and Warwickshire NHS Trust, University Hospitals of Leicester NHS Trust, University Hospitals of Morecambe Bay—Furness General and Royal Lancaster sites, and Worcestershire Acute Hospitals NHS Trust. We would also like to acknowledge Paul Howard, CEO of LUPUS UK, for his contribution in highlighting the issues of shielding.

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Data availability statement

The data underlying this article cannot be shared publicly for the privacy of individuals included in the audit.

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