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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Key messages (up to 3, maximum 15 words each)

1) More than a third of patients with SLE may be shielding during COVID-19
2) Patients from Black and minority ethnic (BAME) backgrounds are over-represented in the shielding group
3) Half of patients with previous lupus nephritis are shielding and may miss urinalysis due to telephone consultations

Abstract

Objectives: We aimed to estimate what proportion of people with systemic lupus erythematosus attending UK rheumatology clinics would be categorised as being at high risk from COVID-19 and asked to shield, and explore what implications this has for rheumatology clinical practice.

Methods: We used data from the BSR multi-centre audit of systemic lupus erythematosus (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 BSR'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 ≥3 and would have been advised to shield. People with previous or current lupus nephritis were 2.6 (1.9-3.4) times more likely to be in the shielding group than people with no previous lupus nephritis ($p<0.001$). Ethnicity was not evenly distributed between the groups (chi-squared $p<0.001$). Compared to 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 lupus nephritis.

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.

Keywords

Systemic lupus erythematosus
Infection
COVID
Coronavirus
Health services
Epidemiology
Shielding

Introduction:
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 United Kingdom'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 NHS Digital, and patients were contacted by letter through this national process. GPs 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, 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 (patient charity) describe receiving numerous reports from people with lupus who are shielding and experiencing hardship and difficulty accessing essential support(8). 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 two metres away at all times and eating alone in their room.

The requirement to shield is likely to be disproportionately high among people with rare autoimmune rheumatic diseases, such as systemic lupus erythematosus (SLE), because of frequent long-term corticosteroid and immunosuppressant use in these conditions, and high levels of co-morbidity. 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 multi-centre audit of systemic lupus erythematosus, which included a large and representative cross-sectional sample of patients attending UK Rheumatology clinics with SLE, to calculate their shielding scores, and 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 Systemic Lupus Erythematosus (SLE) 2018: Baseline Multi-Centre 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 February–June 2018. Data including patient demographics, medications (including corticosteroid dose) and co-morbidities were collected using web-based survey software. For this analysis, ethnic groups containing fewer than 50 people were categorised as other, resulting in ethnic group categories of White, Asian or Asian British, Black or Black British, Other ethnic groups, and not recorded.
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 corticosteroid dose (0 points if no steroids or daily dose <5mg daily, 2 points if daily dose ≥5mg and <20mg and 3 points if daily dose ≥20mg daily), number of immunosuppressants (1 point if 1 DMARD or biologic and 2 points if ≥2 DMARDs or biologics; excluding hydroxychloroquine and sulfasalazine), cyclophosphamide (3 points if given in the past 6 months) and 1 point if any one or more of: age >70, diabetes mellitus, pre-existing lung disease, renal impairment, history of ischaemic heart disease or hypertension. Scores for each category are summed, scoring 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 corticosteroid 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 co-morbidities, namely pre-existing lung disease, so could not include this stratification. We conducted sensitivity analyses to assess what impact our assumption about length of corticosteroid 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 lupus nephritis. We compared the distribution of shielding status to the distribution of ethnicity, and to whether a patient had previously had lupus nephritis using chi-squared testing and logistic regression. We included a multi-variable regression analysis to estimate the adjusted odds ratio for the effect of ethnicity on shielding status, while controlling for lupus nephritis.

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. 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 less than 5%. 497 (48.7%) patients were on prednisolone. This included 95 (9.5%) on a dose <5mg daily, 347 (34.6%) on a dose ≥5mg and <20mg daily and 55 (5.5%) on a dose ≥20mg 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 to 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 lupus nephritis were 2.6 (95% CI 1.9-3.4) times more likely to be in the shielding group than people with no previous lupus nephritis. Overall 243 (24.2%) patients in the audit had had lupus nephritis, and of these 124 (51.0%) were in the shielding group compared to 220 (28.9%) of 760 patients without previous lupus nephritis (p<0.001).

Multi-variable regression analysis was performed to estimate the adjusted odds ratio for the effect of ethnicity on shielding status, while controlling for lupus nephritis. 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 lupus nephritis. 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 4 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 was 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 >20mg 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 20mg of prednisolone would be on a dose of ≥5mg for at least

4 weeks and so would be awarded at least 2 points. If all the people on prednisolone >20mg 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 a small number who did not already get a point for age >70 years and other co-morbidities could have gained an extra point. Potentially this means up to 75 (7.5%)people who had a total shielding score of 2 and were <70 years with no co-morbidities should be in the shielding group, but we think in reality 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 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 lupus nephritis compared to those who have never had lupus nephritis. An increased chance of shielding was also seen among people with SLE of BAME background compared to people of White ethnicity, and this effect persisted despite controlling for history of lupus nephritis. Most rheumatology services in the UK have switched to offering telephone or video consultations, rather than face-to-face follow up following the 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 which 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 lupus nephritis, 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 corticosteroids and COVID-19, NHS England's Clinical guide for the management of patients with musculoskeletal and rheumatic conditions on corticosteroids 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 5mg daily which is currently thought sufficient to increase the risk of severe infection with COVID-19. There is clear advice not to stop corticosteroids 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 RAIRD, and how to maintain disease remission with a lower steroid burden.

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