

1 Inequalities in access to specialist allergy services in the United Kingdom: a report from the
2 BSACI Registry for Immunotherapy (BRIT)

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4 Short title: Inequalities in access to specialist allergy services

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1 **Data Availability Statement**

2 The data that support the findings of this study are available from the British Society for
3 Allergy & Clinical Immunology. Restrictions apply to the availability of these data, which
4 were used under license for this study. Data are available on application to BSACI with the
5 review and permission of the Registry Steering Committee.

6 **IRB statement**

7 BRIT is a research database approved by the West of Scotland Research Ethics Committee 4
8 (IRAS Number 249481).

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1 **Key messages**

- 2 • There may be geographical inequality in access to specialist allergy services and
3 biologics
- 4 • Results suggest reduced access to specialist care for the most deprived and minority
5 ethnic groups
- 6 • Registry data is limited by those who consent to participate and may have selection
7 bias

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1 **Abstract**

2 Background:

3 There is an unmet need for specialist allergy treatment in the United Kingdom. Allergen
4 immunotherapy and treatment with Omalizumab for Chronic Spontaneous Urticaria (CSU)
5 are key markers for these services. The British Society for Allergy and Clinical Immunology
6 (BSACI) Registry for Immunotherapy (BRIT) is a national project to record the real-world
7 effectiveness, safety and access to treatment for aero-allergen, venom and peanut
8 immunotherapy as well as Omalizumab for CSU.

9 Methods:

10 We described participant demographics, Index of Multiple Deprivation (IMD) and access to
11 treatment from registry launch. Data for 1835 participants were available for analysis from
12 63 centres enrolled between 1st October 2018 and 24th August 2023.

13 Results:

14 96.5% (1771/1835) were living in England with only 3.5% (64) being from the devolved
15 nations. 14.4% (251/1748) were in the most affluent IMD decile compared to 4.5%
16 (78/1748) in the most deprived IMD decile. White participants were 1.74 times more likely
17 to be referred directly from primary care compared to people of Asian, black, mixed or
18 other minority ethnic groups. Instead, these groups were referred more frequently from
19 secondary or tertiary hospital services. The median distance travelled from home to
20 treatment centre was 15.2 miles with evidence of clustering around specialist centres.

21 Conclusions:

1 We have described disparities and unwarranted variation in the provision of treatment
2 around the UK. The data suggest that there is limited access to immunotherapy in the
3 devolved nations. Access is also reduced by socio-economic deprivation. White participants
4 were more likely to receive a direct referral from primary care than those from other ethnic
5 groups whose referral pathways were more complex. Registry data is limited by participant
6 enrolment and may have selection bias. Nevertheless, BRIT has highlighted inequity in
7 access to specialist allergy services in the UK.

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1 Introduction

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3 For decades there has been a desire to improve coverage in allergy services (1). Allergists
4 are trained to manage a variety of diseases that are also the remit of other organ-based
5 specialists. Specific allergen immunotherapy is one area of practice that is unique to allergy
6 medicine, where allergists would be expected to lead practice and develop guidelines.
7 Immunotherapy is much less accessible in the United Kingdom than in other European
8 countries and despite state funded services being free at point of care (2). In continental
9 Europe allergists are mainly office-based specialists practising within a primary care
10 environment, whilst in the UK specialists are limited to hospital-based centres. Several
11 treatments are used by allergy specialists in the UK, these include aero-allergen
12 Immunotherapy (AIT) to common environmental allergens such as grass pollen and house
13 dust mite, and venom immunotherapy (VIT) for those who have experienced systemic
14 allergic reaction to insect stings (3,4). Allergists also prescribe high cost drugs for biological
15 immune modulation, such as the use of anti-immunoglobulin E (Omalizumab, OMA) for the
16 treatment of Chronic Spontaneous Urticaria (CSU) and asthma (5). Peanut oral
17 immunotherapy (PIT) has also recently been licensed and approved for prescription through
18 public funded services (6). Mapping specific allergen immunotherapy practice and use of
19 high tariff immunomodulation in the UK could be a useful marker for allergy services as a
20 whole and help to define the “unmet need” and unwarranted variation (7).
21 It is important to note that the exact number of centres offering paediatric and adult
22 immunotherapy is not known. Other groups have looked at provision of allergen
23 immunotherapy and biologicals in the UK. Most recently a nationwide survey of paediatric
24 allergy services showed 60 centres offered AIT, 18 VIT and 25 OMA and most had small

1 numbers of patients (7). Over a decade ago Rajakulasingham and colleagues surveyed 22
2 adult allergy centres in the UK, and reviewed care of 1731 allergen immunotherapy patients
3 (8). They found that half of these centres were led by consultants who did not practice
4 allergy as their main specialty. Vance et al. surveyed practice with results from 12 paediatric
5 centres and data from over 300 children receiving allergen immunotherapy (9). Both surveys
6 described the piecemeal provision of allergen immunotherapy in line with estimates
7 suggesting that the UK lags behind other European countries in delivery of allergen
8 immunotherapy (10). The use of Omalizumab for treatment of CSU has been described in
9 multicentre surveys and as part of prospective international AWARE collaboration and the
10 international CURE registry (11–14). None of these surveys addressed access to therapy,
11 reporting instead on formulation, route of administration and safety in clinical practice.
12 Previous surveys of VIT in the UK have had good responses with up to 95% of surveyed
13 centres contributing to a questionnaire on clinical practice (15,16). About half of surveyed
14 centres had less than ten or no patients under current treatment. With multiple small
15 throughput centres practicing independently, a national registry can help to benchmark
16 services against national trends, improve adherence to clinical guidelines and best practice,
17 and provide more comprehensive picture across the UK when all treatments are registered
18 in one place.

19

20 We developed a participant registry to record the access to treatment, safety and real-world
21 effectiveness of allergen immunotherapy and high-cost immunomodulatory treatment by
22 allergists in the UK. A registry allows collection of data about patients that have a common
23 disease or have received certain treatments across multiple sites (17). Web based patient
24 registries are a well-tested tool for collecting data on the real world use of specialist

1 treatments (18). They have been used successfully across a wide variety of clinical settings
2 (19). They are increasingly recognised as an important source of valuable real-world
3 evidence to inform practice. A recent review placed their contribution second only to
4 randomised clinical trials (20).

5

6 The BSACI Registry for Immunotherapy (BRIT) was launched five years ago and has grown
7 steadily over time. The registry records episodes of treatment (rather than individual
8 appointments) and allows the participants themselves to enter effectiveness and quality of
9 life data, as well as adverse reactions particularly those that lead to treatment
10 discontinuation. In this article we describe the geographic, demographic and some socio-
11 economic factors that are associated with access to specialist immunotherapy care.

12 [Methods](#)

13

14 BRIT is a web-based registry that can be accessed securely using a standard web browser.
15 Its use is voluntary and is available free of charge to all Consultant members of BSACI. It is
16 open to participants who are resident in the UK. The registry allows clinicians to enter
17 participant information onto a database whether in hospital, or from an office-based
18 practice. It collects data for both NHS and private practice users. BRIT is a research database
19 approved by the West of Scotland Research Ethics Committee 4 (IRAS Number 249481). The
20 data used for the analysis were collected between 1st October 2018 until 24th August 2023.

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22 *Participant enrolment*

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1 Patients are invited to join the registry by their supervising consultant or their delegated
2 users such as clinical nurse specialists, clinical administrators, and doctors both of
3 consultant and non-consultant grade working in the immunotherapy clinic. There is a range
4 of participant information leaflets available for adults, and children and their parents.
5 Participants must provide written informed consent to join the registry, which is then kept
6 in local medical notes. The registry collects personal identifiable information including their
7 home postcode and self-identification of gender and ethnic group with the specific
8 permission of the participant. Ethnicity categories were mapped to those of the 2011
9 National Census ([Ethnicity and National Identity in England and Wales - Office for National](#)
10 [Statistics \(ons.gov.uk\)](#)). Participants are contacted by the registry at intervals to record
11 safety and effectiveness data and monitor their own care by the completion of online
12 patient related outcome measures (PROM).

13

14 *Statistical analysis*

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16 In this paper we describe how patient demographics, socioeconomic factors, ethnicity and
17 distance travelled are factors in accessing the real-world use of immunotherapy. We
18 employed descriptive statistical techniques for the analysis. No inferential statistics are
19 produced as ideally the registry should contain full coverage of all treatment episodes
20 across the UK during the given period and therefore there should be no need to generalise
21 findings to the wider population of the patients in the UK. Additionally, the registry data are
22 not collected using probability-based sampling approach and therefore it is sufficient to
23 produce relevant descriptive statistics and comment on missing data points.

24

1 Results

2 Data for this analysis was provided by the clinical teams supporting 96 consultants from 63
3 sites across the United Kingdom (UK). Our analytical sample contained 1835 participants for
4 whom full information was available, all of whom were receiving various forms of
5 immunotherapy or immunomodulating treatment. The demographic characteristics of
6 registry participants are shown in Table 1. Children made up 45.0% (832/1835) of
7 participants. Most patients were living in England (96.5% (1771/1835)), with 65% of the
8 sample living outside London and 31.5% living within Greater London. The devolved nations
9 were poorly represented with 0.4% of participants from Scotland, 1.7% from Wales and
10 1.4% from Northern Ireland. In our sample 1296 (71.0%) received allergen immunotherapy,
11 318 (17.0%) venom immunotherapy, 172 (9.0%) Omalizumab for the management of
12 chronic spontaneous urticaria and 49 (3.0%) peanut oral immunotherapy. There were only
13 two venom participants recorded in Wales with no registered participants otherwise for VIT,
14 OMA or PIT in the devolved nations. 97.7% were being treated by the National Health
15 Service (NHS). Consequently, private practice made up 2.3% of immunotherapy services
16 overall, except for peanut immunotherapy where private episodes of care represented
17 30.6% (15/49) of all treatments.

18 *Index of Multiple Deprivation (IMD)*

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20 We employed the index of multiple deprivation (IMD) based on home postcode for
21 participants being treated in England and Wales (21). (The IMD is not available for people
22 living in other parts of the UK, although other tools are available but were not employed
23 due to the small number of participants in those regions). There was a clear disparity
24 between the proportion in the upper socio-economic deciles compared to those in the most

1 deprived deciles (Figure 1). In the registry 14.4% (251/1748) were found to be in the most
2 affluent decile compared to only 4.5% (78/1748) in the most deprived. Participants were 3.2
3 times more likely to receive immunotherapy in the most affluent decile than the least. This
4 trend was most marked for VIT at 21.0 (42/2), AIT 3.7 (182/49), and PIT 9.0 (9/1 from
5 second decile as no participants in first) but not for OMA 0.7 (18/27)(Figure 2). The IMD is
6 made of several component rankings including health, employment, education and skills,
7 and income. At 4.9 (328/67) health deprivation deciles showed the most marked difference
8 between most and least affluent participants. Differences between most and least affluent
9 were also seen in the employment deciles (3.9 (277/71)). Other IMD indicators showed
10 similar ratios to those seen overall: 3.4 (288/85) for education and skills deciles, and 3.3
11 (273/82) for income deciles.

12

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14 *Referral pathways to access care*

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16 There were differences in referral pattern to specialist allergy services observed between
17 different ethnic groups (Figure 3). All groups were more likely to be referred from a
18 secondary or tertiary hospital service than directly from primary care (referral ratio of
19 primary to secondary OR tertiary care of 0.71 (676/952)) (Table 2). This ratio varied
20 between ethnic groups and the primary care referral rate was higher for white and Asian
21 participants. Primary care referral ratios were 0.79 for white, 0.59 for British Asian, 0.41 for
22 black British, and 0.40 for those of mixed or other ethnicities. White participants were 1.35
23 times more likely to be referred from primary care than British Asians, 1.92 times more
24 likely than black British and 2.25 times more likely than people of mixed or other ethnic

1 groups. Overall white participants were 1.74 times more likely to be referred directly from
2 primary care compared to other ethnic groups.

3

4 *Distance travelled between home and specialist care centre*

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6 We calculated the distance travelled between home postcode and participant's specialist

7 allergy centre (Figure 4). The median travel distance to access services was 15.2 miles.

8 Travel was shortest in Greater London at 9.1 miles median distance (IQR 17.3), compared to

9 11.4 miles (IQR 32.9) in Scotland, 12.6 miles (IQR 12.8) in Wales, 14.3 miles (IQR 11.3) in

10 Northern Ireland and 18.7 miles (IQR 24.0) in England outside London. We divided distances

11 into terciles and assessed the empirical density to adjust the percentiles to represent three

12 main clusters. The final terciles were defined as short travel distance under 9.2 miles (0 –

13 35.0%), middle 9.3-19.9 miles (35.1 – 60.0%), and long over 20 miles (60.1 - 100%). Half of

14 respondents (50.3%) travelled a short distance in London compared to 24.8% in England and

15 34.8% in the devolved nations. Participants were more likely to travel longer distances if

16 they lived outside of London, in England (48.1%), devolved nations (30.3%) compared with

17 only 26.8% in London. Participants receiving venom immunotherapy travelled furthest with

18 median distance travelled of 25.5 miles (IQR 27.0) as did those of white ethnicity with

19 median of 16.8 miles (IQR 24.4) to receive care (Figure 4).

20

21 Discussion

22

23 The results suggest inequality in access to specialist allergy treatment in the UK. Not all

24 forms of allergen immunotherapy and biological treatment are available throughout the UK.

25 Access to care is related to geography and socio-economic deprivation. Patients who were

1 black or from mixed or minority ethnic backgrounds were less likely to be referred directly
2 from primary care and are more likely to be referred from secondary or tertiary services.
3 Difficulty in accessing treatment is also reflected by the distance travelled between home
4 and hospital for specialist allergy care. Nearly 20 years after the House of Lords report of the
5 unmet need of allergy sufferers in the UK, there are still inequalities in access to care (22).

6

7 *Geographical disparities*

8

9 There is disparity in treatment around the UK. Using data from the 2021 census the
10 population of London is estimated at 7.5 million, compared to a combined population of
11 10.5 million in the devolved nations of Scotland, Wales and Northern Ireland (23). Based on
12 similar access to services in London we would expect over 800 participants to have been
13 registered from the devolved nations, instead we had just 64. Similarly, using services in
14 London as a benchmark, less than a third of the expected participants were accessing
15 services from England outside of London in our sample (30.5%, 1193 of an estimated 3776).
16 The London focus is related to the higher number of allergists in the capital (10).

17

18 Access to peanut oral immunotherapy was similarly underserved. Palforzia peanut OIT has
19 not been approved for use in Scotland but has NICE approval for England and Wales.

20 Approximately a quarter of a million (or 2% of 12.7 million) children in the UK have peanut
21 allergy (24). Using a conservative treatment rate of 2% of the 2% of children with peanut
22 allergy, there should be 5,000 children registered for PIT (25). Instead, there were only 49 in
23 the dataset we used for the analysis and of those a third accessed care through private
24 services rather than state funded healthcare. The proportion of peanut allergic children is

1 also likely to be higher among minority ethnic groups. This is related to the increased risk of
2 allergic disease and also due to barriers in access to dietary peanut allergy prevention in
3 infancy (26,27). The almost complete absence of state funded PIT reported only increases
4 the inequity for disadvantaged groups.

5

6 *Socioeconomic status and ethnicity*

7

8 Deprivation and ethnicity are also associated with access to services. The most affluent
9 participants in our sample were three times as likely to access immunotherapy care within
10 the NHS when compared to the most deprived. This is despite the NHS *Long Term Plan* to
11 take action on those very inequalities and reduce unwarranted variation, although tackling
12 the burden of severe allergic disease is not specifically mentioned in these goals (28). The
13 trend in treatment toward the more affluent was not seen in access to OMA for CSU. Access
14 to OMA was evenly spread through socioeconomic status in keeping with the demographic
15 characteristics of the disease (29).

16

17 There were differences in referral pathways between ethnic groups: those of black, black
18 British and mixed or other minority ethnic groups were more likely to require referral from a
19 secondary or tertiary care physician, whereas white and Asian or British Asian ethnic groups
20 were more likely to be referred directly from their primary care providers. Ethnic minorities
21 are more likely to experience significant allergic disease in the UK (30). Similar inequalities
22 of provision of healthcare to ethnic minorities have been described in referral to mental
23 health services and in routes to diagnosis for cancer (31,32). Whilst language barriers and
24 cultural differences in presentation may be part of the reason for these differences, we

1 cannot exclude physician bias influencing referral (33). The data suggests longer and more
2 convoluted treatment pathways for patients who are at the greatest risk of severe disease,
3 where prevention strategies and prompt referral for specialist care is most needed.

4

5 *Cluster effect around specialist centres*

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7 There was a cluster effect of primary care referrals around specialist centres. It is likely that
8 local primary care providers are aware of local specialist centres and make appropriate
9 referrals, whereas those further away from centres do not know of their existence. This
10 would suggest an education gap in primary care to know both how, and where to refer for
11 specialist allergy care. There is a need for targeted education, allergy aware primary care
12 practices, and regional referral networks, which could be fulfilled in part by patient support
13 groups. The distance travelled for treatment is also important as most patients requiring
14 allergen immunotherapy require multiple visits to a specialist centre. For some allergen
15 immunotherapy shared care models are available using sublingual immunotherapy that can
16 be administered in any healthcare setting, but this would require appropriate trained
17 physicians within primary care.

18

19 *Limitations*

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21 Registry data has several limitations related to missing participants (unit non-response) and
22 data points (item non-response). Participants need to give consent to be included in
23 registry and there may be selection bias amongst those who enrol to participate. Several of
24 the investigators have observed that BME participants were less likely to consent to have
25 their data shared with the registry, and that this was also true of the most affluent.

1 However, the proportions of ethnic groups in the registry are broadly similar to those of the
2 2021 Census where 9.3% Asian/Asian British (c.f. 8.1% in the registry), 4.0% black/black
3 British (c.f. BRIT 3.3%) and 5.0% mixed or other minority ethnic groups (c.f. BRIT 7.8%).
4 There is no record kept of those who do not consent to participate, mainly because there is
5 no ethical framework for holding such data. Not all centres contribute data to the registry,
6 this may be more marked within the private sector. Use of BRIT is recommended as good
7 practice by Improving Quality in Allergy Services (IQAS) the accreditation programme for
8 allergy services managed by the Royal College of Physicians. Although there are allergy
9 specialist centres for adults and children in all of the devolved nations, not all offer
10 immunotherapy (7). Based on analysis of services held by BSACI, it can be estimated that the
11 registry covers two thirds of AIT centres at present although the exact denominator is not
12 known (34).

13 Missing data points are also common in clinical registries as unlike clinical trials they do not
14 undergo the same level of data scrutiny. As this is a voluntary registry, we have attempted
15 to keep data collection requirements to a minimum to reduce the burden on participants
16 and practitioners (35).

17 Omalizumab was perhaps the least well reported of the treatment domains, this may be due
18 to the use of OMA by dermatologists as well as allergists. There may also be competition
19 from international registries like CURE (13), and that some treatment centres may prefer to
20 reserve their own data for their own research. There are advantages to being part of this
21 project. Within BRIT each centre and clinicians have access to their own data for their own
22 use, and by contributing data to the registry they are also able to benchmark their practice
23 against the registry as a whole using a real-time dashboard. However, despite the

1 limitations, this registry allows a detailed description of specialist allergy treatments in the
2 UK.

3

4 *Next steps*

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6 All centres practicing allergen immunotherapy and biologic support for Chronic
7 Spontaneous Urticaria in the UK should be encouraged to engage with the registry for the
8 benefit of their patients and services. Commissioners should consider funding based upon
9 contribution to this national dataset. To improve referral, there is a need for increased
10 visibility of allergy centres to primary medical care with clear commissioning pathways in
11 place.

12

13 Children are well represented amongst BRIT participants. This reflects the expansion of
14 provision of paediatric allergy care. There is a need to increase adult allergy training posts
15 across the UK to lead development of the specialty [1, 10, 35]. Ethnic minorities in the UK
16 are more likely to have significant allergic disease (30). The need to improve engagement is
17 multifactorial and has been discussed recently highlighting the issues associated with urban
18 deprivation in the United States of America (36). There is a need to work with minority
19 ethnic communities to understand the barriers to access specialist services and develop
20 appropriate interventions (37).

21

1 Conclusion

2 This is the largest and most comprehensive data on the use of allergen immunotherapy in
3 the UK. There are disparities in the provision of treatment around the UK and particularly
4 the absence of registry participants from the devolved nations. Access to NHS care is
5 influenced by geography, socio-economic deprivation and ethnicity. There were differences
6 in referral pathways to specialist allergy services based upon ethnicity: with black people,
7 those of mixed ethnicity and other minority ethnic group participants less likely to be
8 referred directly from primary care. The BSACI Registry for Immunotherapy has highlighted
9 inequity in access to specialist allergy services in the UK.

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