
NHS 10-year plan for health consultation 2024

British Society for Immunology Clinical Immunology Professional Network (BSI-CIPN) submission

December 2024

Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

The British Society for Immunology Clinical Immunology Professional Network (BSI-CIPN) is an integrated and impactful professional network for individuals working within clinical immunology. The BSI-CIPN's membership includes over 155 professionals in the clinical immunology space including clinical immunologists, healthcare scientists, allergists, pharmacists and immunology specialist nurses. The Network is used to share best practice and guidelines and to foster collaboration, ultimately improving care for patients.

Our organisation would like to see this critical and increasingly relevant speciality recognised within a 10-year plan for health, alongside and within a greater focus on supporting pathology sub-specialties broadly within the NHS. Although pathology and its sub-specialties are not always as visible as other specialties, pathology underpins every aspect of patient care and is core to a functioning, effective, healthcare service. Clinical immunology (which in many areas also includes specialist allergy services) is a small but growing specialty and is gaining more visibility within medical and scientific spheres as we come to understand more about the role the immune system plays in a vast range of conditions. Rising patient demand¹ and the growing pipeline of immune therapies² used to treat an increasing number of conditions across many clinical specialties from oncology to rheumatology, to gastroenterology, and geriatric medicine, warrant an increased national drive and focus to support this vital area of clinical practice. Clinical immunologists also hold valuable expertise in the advancing field of immunogenomics, which will become increasingly relevant in the fast-growing area of personalised medicine.

Furthermore, the specialty plays a critical role in immunoglobulin stewardship, with reductions in use seen in recent years despite growing demand.³ The effective stewardship demonstrated in this area is only possible with the input of clinical immunology, and the 21 Sub-Regional Immunoglobulin Advisory Panels (SRIAPs) across England are critical for ensuring appropriate and cost-effective use of immunoglobulin – supporting targeted use of this scarce resource.

Below we have detailed some key cross cutting themes that are of significant importance to the specialty, and which we would hope to feature within a comprehensive long-term plan.

Growing the clinical immunology workforce to meet rising service demand and countering current workforce vulnerability (cross-cutting)

Greater national and regional ownership of long-term workforce planning for pathology and its sub-specialties needs to be established. Within clinical immunology and allergy, currently, there are a number of services across the country that are at risk of collapse if one or two consultants leave the workforce, with many others at risk of being unable to cope if one consultant is on a period of leave⁴.

As specialist clinical immunology and allergy services are provided at a sub-regional level, and not every Integrated Care Board (ICB) will commission a service within their patch, many patients already travel long distances to access care. For services with only one or two consultants, the pressure is not only challenging for the clinical team but also negatively affects patients and compounds inequities in access to care.

The range of professional groups who provide and support care within these services are all impacted by workforce challenges, including medics, healthcare scientists, nurses, pharmacists, and psychological practitioners. There are specific challenges also existing around progression and succession planning, for example, for clinical scientists, the main funded training route is only three years long, with no support for progression into senior posts following training, meaning large numbers of newly qualified clinical scientists leave the NHS. For medics, there is a general lack of nationally funded training places in clinical immunology, which means responsibility for adequately staffing these specialist services falls to individual trusts, who are already under huge financial pressure.

Immunology and allergy is an area for which the scientific landscape is constantly and quickly evolving, and therefore clinical academic posts are much needed and valued for the specialty. However, the numbers of these posts have been dwindling for several years now, and urgent action is needed as part of a wider drive on research and clinical academia within the NHS. Having adequate clinical academic expertise within immunology will be important to allow the NHS to reach its potential for clinical research delivery and clinical trial implementation, and to deliver on the recommendations from the O'Shaughnessy review⁵.

We are aware the government is currently looking to refresh its long-term workforce plan and we recommend it heeds input from the Royal College of Pathologists, the Royal College of Physicians and others on adequate national workforce planning at a specialty level. We would also want to see clearer responsibility for specialty level workforce planning within NHSE Workforce Training and Education, so that our specialty has a point of contact and can genuinely and openly collaborate with our arm's length bodies on this important issue.

We are also aware that some challenges can be mitigated through more creative multidisciplinary working, with professionals working to the top of their license, competency-based frameworks, and integrated service models. However, basic workforce planning and supply must be part of the long-term workforce, and 10-year plan, with explicit inclusion of pathology and its sub-specialties.

While clinical immunology expertise, for now, is largely focused on primary and secondary immunodeficiency and allergy, within the coming 10 years and beyond there is predicted to be a

greater strain on the specialty as new immune therapies, many of which result in secondary immunodeficiency are rolled out for a greater number of conditions. Any long-term planning for the NHS should take account of this very quickly evolving context for the specialty, which could have a huge impact on workload.

Improving and sustaining access to services and improving equity through increased national resourcing and support for local commissioning (cross-cutting)

Specialist clinical immunology and allergy commissioning is currently overseen within the National Blood and Infection Programme of Care, within which the Specialised Immunology and Allergy Clinical Reference Group (CRG) sits. Although significant expertise is held within the CRG, resourcing for this programme within NHS England is limited, and there are areas of work of national value that are not currently able to be addressed.

There is widely acknowledged to be a pressing need for improved data on patient outcomes within the specialty at a national level. The lack of data makes it impossible, currently, to understand how services are meeting demand and need across the country, and makes crucial monitoring – for example of patients being treated with plasma products – challenging. There are also a number of relevant patient registries, such as the UK Primary Immunodeficiency Registry, which are currently supported via external, time-limited funding, despite their clear national value and application. Although there is work currently ongoing around a new quality dashboard for specialist services which should give an indication of waiting lists across the country, there are a number of areas relating to data which could be built upon for a better understanding of the national picture, and therefore more targeted interventions to support services, for example – crucially – in workforce planning for the specialty.

Furthermore, nationally co-ordinated clinical forums, such as multi-disciplinary teams, have vital importance for patient care and treatment. This is especially true for rare immune-mediated conditions (such as complex common variable immunodeficiency) for which expertise on care and treatment can only be found at a national level, and therefore should be nationally supported.

There has also been calls from the clinical immunology and allergy community for an established national lead for the specialty for some time, akin to the National Clinical Directors that provide leadership in other specialties⁶. We would hope this position could cover both allergy and clinical immunology.

With commissioning responsibility for both immunology and allergy due to be fully delegated to ICBs from 2025 it is critical that national oversight and leadership is adequately resourced to support equity of care and counter the postcode lottery that already exists in the specialty. For smaller specialties such as these, support for the ICBs in commissioning and appropriate performance management is critical, as lack of specialist commissioning knowledge within ICBs and at a regional level can mean there is a disconnect between commissioning and provider teams, with diluted support for small but vital services such as these as a result of ambitious mainstream performance targets around elective and urgent and emergency care. It will be essential that funding for smaller specialist services such as these is ringfenced at the ICB level.

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

As the BSI-CIPN represents clinical immunology and allergy as a specialty, our biggest enablers centre on access to community services and support for primary care.

Improvement in allergy care within primary care settings and coping with rising demand (hospital to community)

Although a minority of patients with allergy will need referral to secondary or tertiary services, for many patients with allergy, their main point of contact will be within primary care. It is acknowledged that GPs and their primary care colleagues are working in a very challenging context currently, and we also know that diagnoses for allergies (including severe and complex allergies) are rising significantly, with providers across different care settings faced with increasing demand. It is therefore critical that GPs and other primary care professionals are better supported in allergy care, with accredited expertise in management of common allergic diseases. Improved knowledge of allergy would mean more patients will have their allergy recognised and treated and the burden of disease reduced.⁷ There is also scope for improved allergen immunotherapy provision in primary and community settings.

Supporting equitable access to allergen immunotherapies through standardised integrated care agreements (hospital to community)

The provision of immunotherapy in the UK is the only disease modifying treatment for allergy, yet many patients are unable to access this treatment. Despite being a highly efficacious treatment, it is underused, with a lack of national policy exacerbating variation in access. There is evidence that permissions for prescribing of allergen immunotherapies vary substantially between different localities and across different professional groups. Currently, there is variation between, and across, local systems on whether a patient experiencing a severe allergen burden is offered sublingual immunotherapy (SLIT - oral therapies) on the NHS, as opposed to subcutaneous immunotherapy (SCIT - a course of injections). This variation is currently driven by differential local clinical standards and funding flows to acute hospitals providing SCIT or SLIT in hospitals, as opposed to a whole care pathway that could enable SLIT to be provided solely through primary, community and homecare settings.

An integrated commissioning model – which plans services with the totality of resources available for the whole local population and patients – could remove current (financial) barriers faced by commissioners, providers and clinicians, which incentivises SCIT activity to take place in hospital settings. This should support a reduction in inequalities, improvement in patient acceptance of treatment and therefore outcomes, release secondary care capacity and the burden in hospital and acute settings, and release cost savings for the NHS.

Moving care out of hospital through community phlebotomy services (hospital to community)

For immunology, many patients are under the care of a specialist immunology centre. Part of ongoing care and review often involves blood testing, and so community diagnostic hubs are of

vital importance to ensuring patients get timely care, and specialist staff/GP time is used in most efficient way possible. There is appreciation within specialist services for the immense pressure that GPs are under in the current context, and equitable and widespread access to community phlebotomy services can support care provision without needing to unnecessarily add to the workload of busy GP practices. This of course also is a key example of where government can act to move key services away from secondary or tertiary care, and into the community.

We would like to see an expansion in these community phlebotomy services, with a commitment to supporting the digital transformation needed to underpin this. Due to the geographical spread of immunology centres, and the fragile state of the workforce (across professional groups) for this small speciality, there is already a postcode lottery for patients. We cannot afford to further exacerbate this with unequal access to helpful and much anticipated initiatives such as the community diagnostic hubs. It should also be noted that many hospital services use these hubs, and so expansion and improvement would mean benefit is felt widely across multiple secondary care specialties.

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

Improving IT infrastructure to support community care and reduce inequity of access (analogue to digital, hospital to community)

One reason for inequity in provision affecting patients is because clinicians are trying to operate across clinical settings where there is no IT interoperability. There is a need for development of integrated digital systems to facilitate medical record access across systems boundaries to speed up clinical assessments and allow better co-ordination of care by different clinicians treating the same patient.

For example, in immunology, we could reduce unnecessary testing in pathology by improving digital access to results from other providers and care settings – for example if a patient attends a regional clinic, the consultant may order a lesser number of tests if they are able to view previous results from the patient's local hospital. Improved access to care records would benefit all specialties, and so is in the interest of patients broadly. It would improve care, shorten patient pathways and release cost savings.

In order to support integrated care within clinical immunology, digital and IT infrastructure needs to be in place, across clinical settings, as is the case – across the board – for the whole NHS. We know we are not alone in this, and the government will have high numbers of examples submitted on this subject. We are in support of digital modernisation being at the core of a 10-year plan for health.

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Supporting earlier diagnosis of hereditary angioedema and primary immunodeficiency (sickness to prevention)

Currently, diagnoses in primary immunodeficiency and hereditary angioedema can be difficult for patients to obtain, leading to potentially life-changing symptoms and damage, such as organ damage. These diagnostic delays could potentially be improved with data solutions; for example, laboratory results can suggest antibody deficiency and if linked to antibiotic prescribing in primary care could identify patients before they have organ damage.⁸ Improvements could also be made through the use of more effective triage and clinical education; for example, urgent or primary care presentations with swelling may highlight hereditary angioedema earlier.⁹

Access to specialist psychological support embedded within services (sickness to prevention)

The mental health implications of living with an allergy or immunodeficiency can often be devastating for patients. These conditions are often rare and not well understood within wider society, making living day-to-day an exhausting and challenging experience. Furthermore, as many of these conditions are genetic, and therefore present from birth, the impact on paediatric patients can be huge. These conditions can often mean sudden and debilitating symptoms, reactions or infections, which can cause severe illness and significantly interfere with everyday life, and result in heightened anxiety and stress¹⁰.

Due to the number of rare conditions these services see, psychological support needs to be specialist and informed, as the specialty moves very quickly, with advances in diagnostics and treatment a constantly changing landscape. Each specialist service should have a specially trained psychological practitioner embedded within the multi-disciplinary team, as this should be a core and critical element of care for these patient groups.

Q5. Please share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in.

SHORT TERM (1-2 years)

1. Growing the clinical immunology workforce to meet rising service demand and countering current workforce vulnerability (cross-cutting)

Please see further context within Question 1. We would wish to see an increase in training and consultant positions across professional groups for immunology, organised and planned at a national level, and a commitment in adequate funding to increase the clinical immunology workforce overall to counter service vulnerability. These commitments should continue to be built upon over the medium and long term (for example with increased training places planned through the duration of the long-term NHS workforce plan), with associated planning and review.

Workforce planning should also consider all professional groups involved, including medical, healthcare science, nursing, pharmacy, psychology and clinical academia.

2. Improving and sustaining access to services and improving equity through increased national resourcing and support for local commissioning (cross-cutting)

Please see further context within Question 1. We would like to see a commitment to increased resourcing and funding for pathology broadly beyond the pathology transformation networks, as well as increased resourcing for clinical immunology at a national level (through the National Blood and Infection Programme of Care), alongside a review of current service provision across England in support of local commissioning, reducing inequities, and reducing the current postcode lottery that exists. It will be essential that funding for smaller specialist services such as these is ringfenced at the ICB level once commissioning for both specialist immunology and allergy services has been delegated to the ICBs. There should also be an officer responsible at ICB level for commissioning local allergy pathways and accountable for ensuring patients have clear pathways to local care where appropriate, and specialist opinion within reasonable geographical distance.

We would also like to see a new national leadership position established to provide direction and external visibility for the specialty. These commitments should continue to be built upon over the medium and long term, with associated planning and review. National planning must take into account the future demand on the specialty as a result of the introduction of a significant number of new immune therapies in other clinical areas.

In addition to the wider issues we have raised for the specialty in Q1-4, we would recommend the following policy initiatives that would support substantial initial improvements in how we can provide safe and effective care for the patient cohorts we see.

3. Clinical Immunology and Allergy: Implementing newborn screening for SCID (sickness to prevention)

The government has been consulting for several years on introducing newborn screening for Severe Combined Immunodeficiency (SCID) to be offered alongside the current 9 other newborn blood spot conditions using the same blood spot sample.¹¹ Catalysing implementation of this screening nation-wide is critical in improving outcomes for newborns with SCID. We would urge that the introduction of the screening should not be further delayed.

4. Improved access to targeted therapeutics for rare immune-mediated diseases through reviewing NICE thresholds (cross-cutting)

Current NICE processes are not fit for purpose to enable approval and use of targeted therapies for rare diseases. The current burden of evidence needed for NICE approval is simply often not possible for rare diseases. These patients already have huge challenges in accessing diagnosis and care due to the rarity of their conditions, and this is compounded by a rigid and inflexible approval processes, which can result in a lack of access to suitable treatments and therapeutics. Work to expedite solutions to this issue should be supported at the national level and prioritised.¹²

5. Supporting improved data collection on clinical immunology through national support for patient registries (cross-cutting)

It is acknowledged that an inadequate level of service data is held at a national level for specialised immunology and allergy, despite the often-serious complications of allergic and immune-mediated illness for the patients who live with them. Aside from immunoglobulin provision via the National Immunoglobulin Database we do not currently have national, or regional level data that is reliable and gives an indication of the prevalence of these conditions, demand and capacity of services, service activity, or patient outcomes. Although multiple registries exist in the area, for example the UK Primary Immunodeficiency Registry, NHSE cannot mandate reporting through the registries from services as it does not fund them. It is not a sustainable solution to have these kind of registries resourced by individual trusts or charities, given their huge implications for what we understand about how we are serving these patient groups at a national level.

6. Contributing to improved care and reduced antimicrobial resistance through penicillin de-labelling (sickness to prevention)

It is well acknowledged within expert allergy networks and organisations that penicillin de-labelling should be a matter of national priority, and there is ongoing work to continue to build the already compelling evidence base in this area to demonstrate the significant number of people within England who are incorrectly identified as having a penicillin allergy¹³. Guidelines to expedite penicillin de-labelling across care settings have recently been published.¹⁴ Penicillin de-labelling is both important for improving patient care and reducing antimicrobial resistance.

MEDIUM TERM (2-5 years)

7. Clinical immunology and allergy: safeguarding immunoglobulin supplies (sickness to prevention)

Despite the excellent work of the 21 SRIAPs across England in ensuring immunoglobulin is used appropriately, immunoglobulin can still be notoriously difficult for NHS providers to access. Although there is an acknowledgement that immunoglobulin supplies in the past have been substantially impacted due to challenges in the UK with contaminated blood, these supplies can be particularly vulnerable to changes within the external environment that affect donation rates and market availability. More must be done to safeguard against shortages of this vital treatment. The risk of patient harm from a lack of treatment is severe, and the impact of switching products when there is a disruption in supply further affects services' limited capacity. NHS Blood and Transplant must be adequately resourced to enable long-term growth in the number of plasma donors at a domestic level.

LONG TERM (5 years +)

8. A considered and ethical framework and long-term plan for further genetic screening (sickness to prevention)

Current and past work on genetic screening can be built upon to establish an approach for a longer term ethical framework and strategy around genetic testing, which has been identified as a key gap that is vital to address urgently due to the ethical complexities of this work.

9. Longer-term workforce planning and future service design in the context of the growing pipeline of immune therapies (cross-cutting)

The pipeline for cell-based therapies is rapidly growing, and these therapeutics have a huge potential to treat a wide variety of different diseases. However, these are also treatments that will require significant resources to provide to individuals and there are likely to be a number of challenges to overcome.

Local and national workforce planning is key to this – these treatments are likely to require a multi-specialty effort with immunology providing input and expertise at a scale not currently seen in the NHS. Therefore, there will be challenges to overcome in not only workforce planning, but also in service design. Providing targeted education initiatives to deliver training on the immunology of these treatments will also help to advance patient care and outcomes in immune-mediated conditions.

¹ Natasha Allergy Research Foundation (2024). *Allergies – The Facts*. Accessed: <https://www.narf.org.uk/the-allergy-explosion>

² Patel, S et al (2019). The Expanding Field of Secondary Antibody Deficiency: Causes, Diagnosis, and Management. *Frontiers in Immunology*, 10: doi: [10.3389/fimmu.2019.00033](https://doi.org/10.3389/fimmu.2019.00033).

³ NHS England (2024). *National Immunoglobulin Database Annual Report 2022/23*. Accessed: https://igd.mdsas.com/wp-content/uploads/Igd_AnnualReport_202223.pdf

⁴ British Society for Immunology (2024). *Find a clinical immunologist*. Accessed: <https://www.immunology.org/public-information/find-clinical-immunologist>

⁵ UK Department of Health & Social Care et al. (2023) *Commercial clinical trials in the UK: the Lord O'Shaughnessy review*. Accessed: <https://www.gov.uk/government/publications/commercial-clinical-trials-in-the-uk-the-lord-oshaughnessy-review>

⁶ British Society of Allergy and Clinical Immunology (2023). *Leading allergy charities call for Allergy Tsar on eve of parliamentary debate*. Accessed: <https://www.bsaci.org/leading-allergy-charities-call-for-allergy-tsar-on-eve-of-parliamentary-debate/>

⁷ The All-Party Parliamentary Group for Allergy and the National Allergy Strategy Group (2021). *Meeting the Challenges of the National Allergy Crisis*. Accessed at: <https://www.nasguk.org/wp-content/uploads/2021/10/Meeting-the-challenges-of-the-national-allergy-crisis-2021.pdf>

⁸ Jolles, S et al (2014). *Calculated globulin (CG) as a screening test for antibody deficiency*. *Clinical & Experimental Immunology*, 117: 671–678. Doi: [10.1111/cei.12369](https://doi.org/10.1111/cei.12369).

⁹ Betschel, S. et al (2020). Development of the Hereditary Angioedema Rapid Triage Tool. *Journal of Allergy and Clinical Immunology*, 8: 310–317. Doi: [10.1016/j.jaip.2019.05.056](https://doi.org/10.1016/j.jaip.2019.05.056)

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- ¹⁰ Immune Deficiency Foundation (2024). *Addressing mental health*. Accessed: <https://primaryimmune.org/living-primary-immunodeficiency/addressing-mental-health#:~:text=Research%20shows%20that%20people%20with,daily%20stressors%2C%20and%20negative%20thinking>.
- ¹¹ Public Health England (2021). *Evaluation launches of newborn screening for SCID in the NHS*. Accessed: <https://phescreening.blog.gov.uk/2021/09/06/evaluation-launch-newborn-scid-screening-nhs/>
- ¹² Clarke, S. et al (2021). The impact of rarity in NICE's health technology appraisals. *Orphanet Journal of Rare Diseases*, 16: 218. Doi: [10.1186/s13023-021-01845-x](https://doi.org/10.1186/s13023-021-01845-x)
- ¹³ British Society for Antimicrobial Chemotherapy (2024). *The surprising truth about penicillin allergies*. Accessed: <https://bsac.org.uk/the-surprising-truth-about-penicillin-allergies/>
- ¹⁴ Savic, L. et al (2022) BSACI guideline for the set-up of penicillin allergy de-labelling services by non-allergists working in a hospital setting. *Clinical & Experimental Allergy*, 52: 1135–1141. Doi: [10.1111/cea.14217](https://doi.org/10.1111/cea.14217)