

Quality in Primary Immunodeficiency Services

2025 QPIDS Census

2025 QPIDS census questions

Section One: Introduction

Thank you for taking time to participate in the Clinical Immunology Census 2025. This survey is being carried out by the Quality in Primary Immunodeficiency Services (QPIDS) accreditation programme at the Royal College of Physicians (RCP).

By completing and submitting the information for your service you will be participating in a national collection of data that can be used to build a picture of Clinical Immunology services across the UK. This data will be collated, and a report generated, which we will share with you. We will also look to publish the results and create a narrative that can be used to highlight the development of immunology provision in the UK.

Please answer all questions which are relevant to your service. We rely on receiving data from as many services as possible to continue to provide high quality census reports to the immunology community.

Questions which are not relevant to your service can be skipped. Services completing this census should not provide any patient-identifiable data. Only one member of your team needs to complete the survey on behalf of your service.

*Q1 Please enter your email address, this will be for the purpose of sharing final data.
[]

*Q2 Please enter the name of your hospital (main site where service is delivered) and Trust.
[]

*Q3 Are you completing this survey for...

If you would like to complete this survey for an additional service, please contact the office team on askqpids@rcp.ac.uk.

- Adult services
- Paediatric services

Q4 Do you give permission for your survey data to be collated and presented anonymously?

*Data collected will not be linked to a named service when reported/presented

- Yes
- No



Section Two: Staffing

Please skip questions that do not apply to your service.

Q5 Immunology consultants

Number of consultant immunologists in your centre?]Number of unfilled consultant immunologist posts?]Number of immunology consultants retiring in the next 5 years?]

Q6 For each consultant, please indicate the job planned direct clinical care (DCC) allocated for care of clinical immunology patients. Please give this as PAs (sessions) to the nearest 0.5 (1.0 PA = 4 hours).

Please also indicate the total contracted NHS sessions within each consultant's job plan.

	Clinical Immunology DCC PAs	Total NHS PAs in job plan
Consultant 1		
Consultant 2		
Consultant 10		

Q7 If you would like to add additional information, please do so here.

[]

Q8 Immunology nursing team

Number of nurses working in the immunology service in your centre? [] Number of unfilled immunology nursing posts? (Please indicate total number of vacancies and the banding for each of these, e.g. 2 vacancies, 1x Band 5, 1x Band 6). []

Q9 Please complete the below for all nurses working in the immunology service based on contracted sessions. (ANP- Advanced nurse practitioner \ AfC – Agenda for Change.

	ANP	Prescribing	Clinics	Filled/Unfilled	AfC band	Hours/WTE equivalent
Nurse 1						
Nurse 2						
Nurse 12						

Q10 Other immunology team members

	Number (WTE)	AfC band (select highest if multiple)	How is it funded?
Psychologist			
Physiotherapist			
Physician associate			

Tel: 020 3075 1407 Email: <u>askqpids@rcp.ac.uk</u> Website: <u>https://www.qpids.org.uk/</u> Page **4** of **8**

Medical secretary		
CLinical pharmacist		
Dietician		
Other roles 1		
Other roles 2		

Q11 If you would like to add additional information, please do so here. []

Please include details of any vacancies or posts not included above. []

Q12 Immunology trainees

Do you have immunology specialty trainees?

- Yes
- No

Q13 If yes,

How many immunology trainees do you have in post? []

How many immunology trainee post(s) at your service are unfilled at present? [] How many immunology trainees are expected to complete training in the next 12 months? 1

[

Q14 If applicable, how many trainees are on: ACI pathway [] ACLI pathway []

Q15 Immunology staffing

Does the service have an allocated pharmacist within the department structure?

- Yes
- No

Q16 If yes, are they prescribing pharmacists?

- Yes
- No

Q17 Does the service have dedicated psychology support for immunology?

- Yes
- No •

Q18 If no, is there an effective referral pathway for patients with immunodeficiency requiring psychological support?

- Yes
- No

Tel: 020 3075 1407 Email: askqpids@rcp.ac.uk Website: https://www.qpids.org.uk/ Page 5 of 8



Section Three: Patient activity

Q19 Please enter data for the time period 01 June 2024 – 31 May 2025. *Please provide current numbers or close estimate*

Total number of patients seen [] Total number of new referrals for suspected immunodeficiency (PID + SID new patients) including those not seen in clinic (number of patients) [] Total number of patients seen in nurse-led clinics [] Total number of patients seen in clinician-led clinics []

On the next page, we will ask for the following data: (please note, remote refers to telephone/video)

	Total number of patients	Remote clinic	Face-to-face clinic
New patients seen in nurse-led clinic			
New patients seen in clinician-led clinic			
Follow-up patients seen in nurse-led clinic			
Follow-up patients seen in clinician-led clinic			

*Q20 Please indicate whether you will be entering the current data or estimates for your service. (*You can return to this page to edit your response*).

- Current data
- Estimates

Q21/22 Please enter the following data.

If providing estimates, please estimate the split across columns 2 and 3 as percentage in relation to the estimated total in the first column.

For example, 30% F2F, 70% remote (of 20 new patients seen in nurse-led clinics).

	Total number of patients	Remote clinic	Face-to-face clinic
New patients seen in nurse-led clinic			
New patients seen in clinician-led clinic			
Follow-up patients seen in nurse-led clinic			
Follow-up patients seen in clinician-led clinic			

If totals exceed 150, please list below:

Q23 On 31 May 2025:

Total number of primary immunodeficiency (PID) patients under care with your service (estimate to the nearest 50 if data not available) []

Total number of secondary immunodeficiency (SID) patients under care with your service (estimate to the nearest 50 if data not available) []

Tel: 020 3075 1407 Email: <u>askqpids@rcp.ac.uk</u> Website: <u>https://www.qpids.org.uk/</u> Page 6 of 8



Q24 Immunoglobulin replacement therapy Number of patients receiving intravenous therapy (IV therapy) treatment in hospital [] Number of patients receiving IV therapy treatment at home [] Number of patients receiving subcutaneous (SC) pump in hospital [] Number of patients receiving SC pump at home [] Number of patients receiving rapid push at home [] Number of patients receiving facilitated subcutaneous (SC) in hospital [] Number of patients receiving facilitated subcutaneous (SC) at home []

Q25 Please provide the total number of hereditary angioedema (HAE) patients Type 1/2: [] Type 3: []

Q26 Are patients offered the option to contact the service directly for advice during the working week (Monday-Friday and in normal working hours)?

- Yes
- No

Q27 Are patients offered the option to contact the service directly for advice out-of-hours including over weekends and bank holidays?

- Yes
- No

Q28 How quickly is your service able to respond to requests for advice?

- <4 hours
- Same working day
- Next working day
- Within 2 working days/next working day
- Over 2 working days





Section Four: Research

Q29 In the last 3 years has your service been involved in

- Commercial research/trials for immunodeficiency
- Non-commercial research/trials for immunodeficiency
- Commercial research/trials for HAE
- Non-commercial research/trials for HAE
- None of the above

Q30 Genetics

Does your service have a policy for selecting patients for genetic testing?

- Yes
- No

```
If yes, what is the policy?
```

```
[ ]
```

Q31 CVID

Does your service have a policy for identifying patients with CVID liver disease?

- Yes
- No

Q32 If you responded yes to Q31, what screening investigations are included in this policy?
[]

Q33 If you responded yes to Q31, what criteria is used for referral to hepatology?

Q34 If you would like to add any additional comments, please do so here.

Thank you for taking the time to complete this census.

We will be collating responses throughout August and September for publication later in the year. We will share this with you via email and on our website once it becomes available.

If you have any questions, email the RCP office team at askQPIDS@rcp.ac.uk.



