# **QPIDS census 2023**

Thank you for taking time to participate in the immunology census 2023. 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 immunology services across the UK. These 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.

Services completing this census should not provide any patient-identifiable data.

1. Please enter your email address, this will be for the purpose of sharing final data

2. Please enter the name of your hospital (main site where service is delivered) and Trust.

**3.**Are you completing this survey for...

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

○ Adult services ○ Paediatric services

**4.**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

# Staffing

\*Please skip the questions that do not apply to your service.

## **5.Immunology consultants**

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

**6.**Please complete the below table for all consultants working in the immunology service based on sessions in job plans. If the job plan does not specify distinction between direct clinical care (DCC) activities, please estimate the split. Please report contracted (ie job planned) activity.

	Immunology DCC	Allergy DCC	Supporting professional activity (SPA)	Other specialty DCC	Lab DCC	Other contracted activity (eg university, college, management etc)
Consultant 1						
Consultant 2						
Consultant 3						
Consultant 4						
Consultant 5						
Consultant 6						
Consultant 7						
Consultant 8						
Consultant 9						
Consultant 10						

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

### 8.Immunology nursing team

Number of unfilled immunology nursing posts ..... Number of unfilled allergy nursing posts ....

**9**.Please complete the below for all nurses working in the immunology service based on contracted sessions. (ANP- Advanced nurse practitioner \ AfC – Agenda for Change. Please select the most recent qualification. If this is currently in progress, please also select 'working towards')

	ANP (Y/N)	Prescri bing (Y/N)	Clinics (Y/N)	Filled/U nfilled	AfC band	Hours/W TE equivalen t	Qualificatio n (most recent)	Working towards (Y/N)
Nurse 1								
Nurse 2								
Nurse 3								
Nurse 4								
Nurse 5								
Nurse 6								
Nurse 7								
Nurse 8								
Nurse 9								
Nurse 10								

# **10.**Other immunology team members

Please complete the below for the immunology service.

Role	Number (WTE)	AfC band	How is it funded? (short term/soft or long term/departmental)
Psychologist			
Psychology			
technician			
Physiotherapist			
PT support			
Physician			
associate			
Data manager			
Research nurse 1			
Research nurse 2			
Service co-			
ordinator			
Medical secretary			
Admin 1			
Admin 2			
Admin 3			
Other roles 1			
Other roles 2			

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

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

# **12.Immunolgy trainees**

Do you have immunology specialty trainees?

 $\bigcirc$  Yes  $\bigcirc$  No

13. 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? .....

**14.**If applicable, How many trainees are on: i) ACI pathway..... ii) ACLI pathway .....

## **15.** Immunology staffing

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

 $\bigcirc$  Yes  $\bigcirc$  No

### 16. Pharmacy

	AfC band	Hours/WTE equivalent
Pharmacist 1		
Pharmacist 2		
Pharmacist 3		

17. If yes, are they prescribing pharmacists?

⊖Yes ⊖No

18. Does the service have dedicated psychology support for immunology?

⊖Yes ⊖No

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

 $\bigcirc$  Yes  $\bigcirc$  No

20. Immunology Clinical Scientists directly supporting ID clinics:

Consultant (frcpath) \_\_\_ : Number (WTE):

Non frcpath: number (WTE):

Trainee HST number of training posts:

# **Patient activity**

**21.**Please enter data for time period 01 April 2022 – 31 March 2023 *Please provide current numbers or a close estimate to the nearest 10 patients/appointments* Total number of **new referrals** for suspected immunodeficiency (PID + SID new patients) - including those not seen in clinic .....

Total number of **new patients** seen in consultant led clinic face-to-face ..... Total number of **new patients** seen in consultant led clinic remotely\* ..... Total number of **follow-up patients** seen in a consultant led clinic face-to-face ..... Total number of **follow-up patients** seen in a consultant led clinic remotely\* ..... Total number of **new patients** seen in nurse-led clinics face-to-face ..... Total number of **new patients** seen in nurse-led clinics remotely\* ..... Total number of **new patients** seen in nurse-led clinics remotely\* ..... Total number of **follow-up** patients seen in nurse-led clinics face-to-face ..... Total number of **follow-up** patients seen in nurse-led clinics face-to-face ..... Total number of **follow-up** patients seen in nurse-led clinics remotely\* ..... \*telephone/video

22. On 31 March 2023..

Total number of primary immunodeficiency (PID) patients ..... Total number of secondary immunodeficiency (SID) patents .....

23. Immunoglobulin replacement therapy
Number of patients receiving intravenous therapy (IV therapy) treatment in hospital .....
Patients IV therapy treatment at home .....
Patients receiving subcutaneous (SC) pump in hospital .....
Patients receiving SC pump at home .....
Patients receiving rapid push at home .....
Patients receiving rapid push in hospital .....
Patients receiving facilitated subcutaneous (SC) in hospital....
Patients receiving facilitated subcutaneous (SC) at home .....

24. Total number of hereditary angioedema (HAE) patients .....

Type1/2:

Type 3:

25. HAE long term prophylaxis

Please provide the total number of HAE patients on the following treatments for long term prophylaxis

**26.** How many patients with SPAD are treated with replacement immunoglobulin (any route of administration)?

# Research

27. In the last 3 years has your service been involved in...
Commercial research/trials for immunodeficiency .....
Non-commercial research/trials for HAE .....
Non-commercial research/trials for HAE .....

## 28. Genetics

Does your service have a policy for selecting patients for genetic testing? (Y/N)

If yes, what is the policy?

## 29. CVID

Does your service have a policy for identifying patients with CVID liver disease? (Y/N)

If yes, what are the additional investigations/referral pathway?

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

Thank you for taking time to complete this census. If you have any questions, email the RCP office team at askqpids@rcp.ac.uk