

Quality in Primary Immunodeficiency Services

QPIDS Census 2021: Analysis

Dr W Bermingham QPIDS StR representative

UK coverage

- > 26 centers returned data to the census (32 responses in 2018)
- > 25 centers with broad distribution across the United Kingdom and 1x center from the Republic of Ireland.



https://www.nationalarchives.gov.uk/do c/open-government-licence/version/3/ Centres returning data represented by •

Quality in Primary Royal College Physicians

Immunodeficiency Services

Staffing: Consultant Immunologists (22/26 returned data)

- > 22 centres reported 58 consultants in post. The median number of consultants per centre was 3 with a range of 1-6
- > Average work plan distribution is demonstrated in figure 1. However, there was broad variation for each domain, figure 2.
- > 6x consultant vacancies were reported with a further 6 consultants being reported to be 'nearing retirement.' Note that from the trainee section, 3x trainees were reported to be due to complete training in the next 12 months.

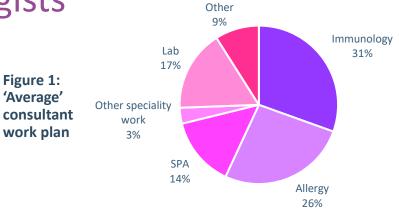
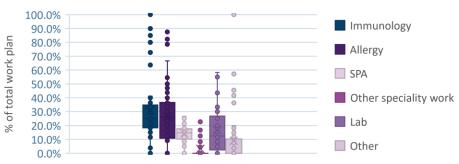


Figure 2: Variation of each domain between reported work plans



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Staffing: Immunology Nursing Staff (1) (22/26 returned data)

- > There were a total of 95 Immunology nurses in post across the 22 centres returning data. The median number pre centre was 3.5 with a range of 1-10.
- > Grade/Grade mix of nursing posts varied widely between centres as shown in figure 1

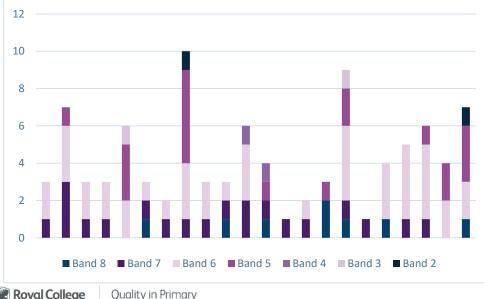


Figure 1:

Grade mix of Immunology nurses by centre Band 6 nurses were the most common.

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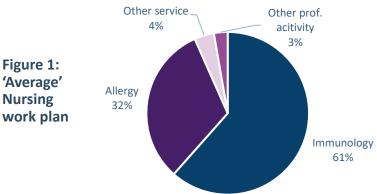
Staffing: Immunology Nursing Staff (2) (22/26 returned data)

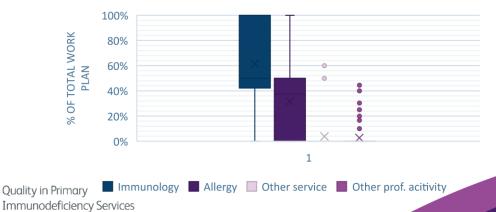
- > The average immunology work plan involved 61% immunology time and 32% time in allergy.
- > As with consultant, there was variation between centres, with some nurses reported to have 100% of their work plan allocated to clinical immunology.

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Physicians

Figure 2: Variation of each domain between reported work plans





Other healthcare professionals (1)

> StRs

- 17/23 centres reported Specialist Registrar (StR) training posts
- The median number of StRs was 2/centre with a range of 0-5.
- There were 5x unfilled StR posts and 3 StRs in post were expected to complete training in the next 12 months.
- > Pharmacy
 - 15/22 centres reported dedicated pharmacy support for clinical immunology





Other healthcare professionals (2)

> Psychology

- 2/22 centres reported a dedicated psychologist in post for clinical immunology. This comprised on 1x 8C (0.8 FTE) and 1x 8A (0.4 FTE) practitioner.
- Of the remaining 20 centres who reported on this category, 8/20 reported an 'effective' psychology referral pathway was available

> Physio

• 4/22 centres reported a dedicated physiotherapist and 15 of the remaining 20 centres reported an effected physiotherapy referral pathway.

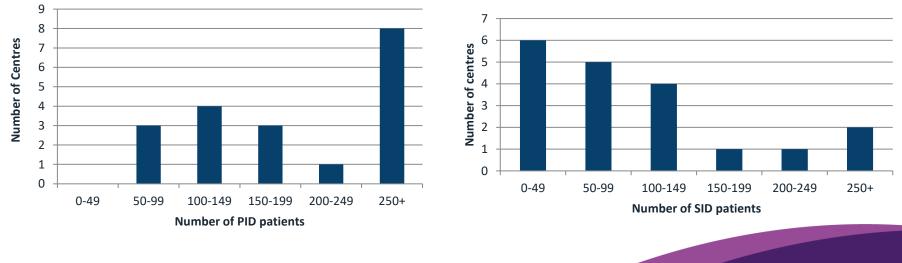




Number of PID/SID patients (19 responses)

Number of PID patients under care of centre

Number of SID patients under care of centre



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Service access

- > Are patients offered the option to contact the service directly for advice during the working week (Monday-Friday and in normal working hours)? YES 22/22
- > Are patients offered the option to contact the service directly for advice out-of-hours including over weekends and bank holidays? YES 2/22
- > How quickly is your service able to respond to requests for advice?
 - <4 hours: 1/22
 - Same working day: 9/22
 - Next working day: 4/22
 - Within 2 working days/next working day:10/22
 - Over 2 working days: 2/22

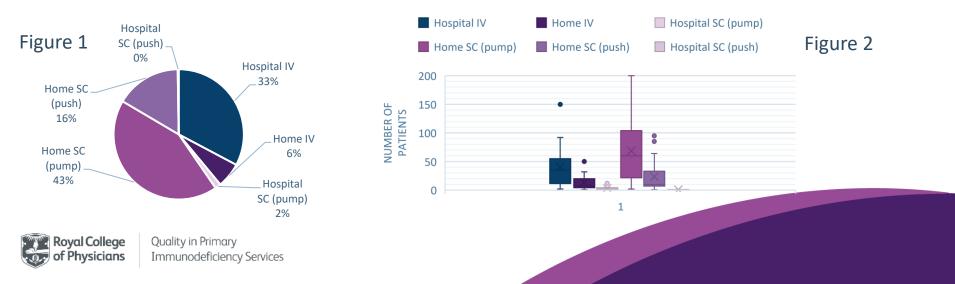




Immunoglobulin therapy delivery

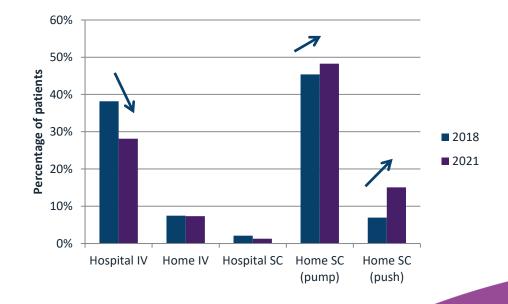
> 22/26 centres returned data

- > Subcutaneous immunoglobulin delivered by pump was the most common form of delivery (figure 1), but there was significant variation between centres (figure 2).
- > Of 18 centres reporting subcutaneous delivery of immunoglobulin, 16/18 had patients on both pump and push forms of delivery. 3/16 had the majority of patients on push delivery.



2018 vs 2021 immunoglobulin delivery

> The proportion of patients on home, subcutaneous modes of delivery was increased in 2022 (post-pandemic).



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Hereditary angioedema (HAE)

- > 19 centres returned data on HAE
- > The mean number of patients per centre was 46 with a range of 9- '>200'
- > 18 centres provided data on the therapies prescribed for HAE patients for long term prophylaxis (note, berotralstat was not included in this survey)
 - Danazol and tranexamic acid were reported to be in use for the most patients in this survey
 - There were 62 patients reported to be receiving lanadelumab across these centres



Research

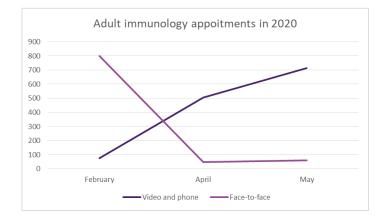
- > Commercial immunodeficiency research: 4/19
- > Non-commercial immunodeficiency research: 16/21
- > Commercial research for HAE: 8/20
- > Non-commercial research for HAE: 5/13

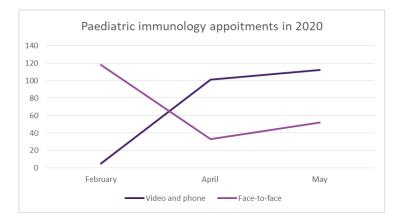




COVID19 pandemic effects on clinic delivery

> There were significant increases in telephone/video consults in response to the COVID19 pandemic in 2020



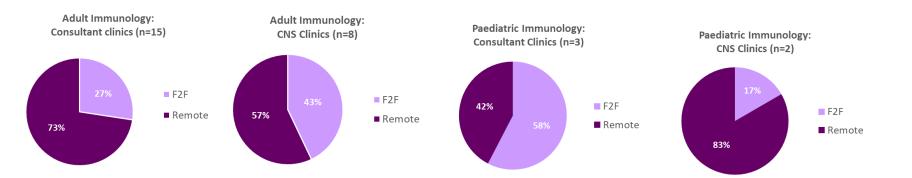






Development of clinics through 2021

> The majority of adult immunology and paediatric CNS appointments remained remote in 2021. Paediatric consultant appointments had a small majority of face-to-face appointments.

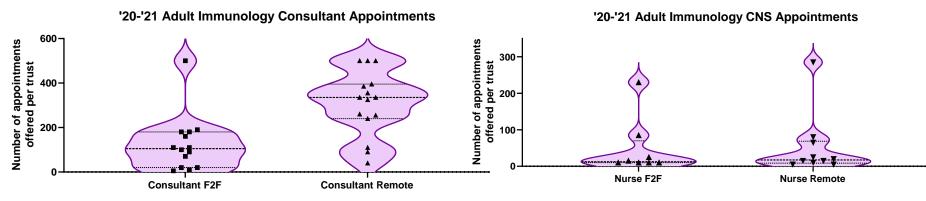


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Variation in appointments offered

> There was wide variation in the number of remote/face-to-face appointments offered between centres





Centres participating in the survey

- > St James's , Dublin
- > University Hospitals of Leicester NHS Trust
- > University College London Hospitals
- > Royal Victoria Hospital, Belfast
- > UCLH
- > Addenbrookes Hospital
- > Newcastle Hospitals NHS Trust
- > Russells Hall Hospital, Dudley Group Foundation Trust
- > St James Hospitals, Leeds Teaching Hospitals
- > Epsom & St Helier University Hospitals NHS Trust
- > Royal Free Hospital
- > Royal papworth NHS Trust

- > NHS Grampian
- > Ninewells Hospital and Medical School, NHS Tayside
- > Southmead Hospital
- > University Hospital of Wales
- > University Hospitals Plymouth (Derriford Hospital)
- > Nottingham University Hospitals NHS Trust
- > Salford Royal NHS Foundation Trust
- > Royal Preston Hospital, Lancashire Teaching Hospitals NHS Foundation Trust
- > Royal Stoke Hospital
- > Sandwell and West Birmingham NHS Trust
- > Royal Brompton Hospital

- > Royal London Hospital, Barts Health NHS Trust
- > Birmingham Heartlands Hospital, University Hospitals Birmingham NHS Foundation Trust
- > Northern General Hospital, Sheffield Teaching Hospitals
- > Manchester Foundation Trust





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