

UK Cystic Fibrosis Service Resourcing 2019 to 2021

Based on findings from the annual Cystic Fibrosis Trust Staffing Tool

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Summary

Participation

In October 2021, 49 of 60 CF centres across the UK completed the Cystic Fibrosis Trust's staffing tool. This included 26 paediatric and 23 adult CF centres, the highest level of participation in the staffing tool since it began. Staffing information, which is submitted by centre staff themselves, provides us with a snapshot of CF service staffing levels each year.

This report summarises the staffing tool findings from three years of data collection (2019 to 2021).

Key insights

- Not all people with cystic fibrosis consistently have access to a full multi-disciplinary team (MDT) at their CF centre, particularly when it comes to psychosocial support, pharmacy and research staff; in October 2021:
 - 1 in 5 participating CF centres reported not having a clinical psychologist as part of their MDT
 - More than 1 in 2 participating CF centres reported not having a social worker as part of their MDT
- A larger proportion of paediatric CF services appear to lack access to certain staff groups for their MDT, particularly social workers and research staff, compared to adult CF centres
- Satisfaction with staffing levels remained relatively low year-on-year, with fewer than half of the services that responded saying they were 'satisfied' with staffing in their service
- In October 2021, median staffing levels were similar across paediatric and adult CF centres in most staff groups; however, several CF centres reported being without certain staff groups, and there was a lot of variation in staffing levels and availability between centres
- Overall staff time available to the CF population across participating centres appears to have reduced year-on-year and it will be vital to monitor this trend in future
- More medical, nurse, physiotherapy and dietetics time is available to the paediatric population, whereas the adult population has more social worker and research staff time available
- In late 2021, vacancy rates in CF services had increased compared to previous years and were reflective of vacancy levels in the NHS as a whole
- Services for children appear to struggle more than adult CF centres to secure suitably qualified staff, as vacancies in paediatric centres remained unfilled for longer and were more often covered by staff less senior than the substantive post
- While the COVID pandemic exacerbated staffing shortages in 2020, CF services continued to face significant challenges in October 2021
- Teams and services innovate to meet the needs of people with CF despite challenges with staffing, vacancies and the pandemic

Background

People with cystic fibrosis (CF) living in the UK receive care from a range of healthcare teams and services, including specialist CF multidisciplinary teams (MDTs). These MDTs are made up of different specialist CF health professionals, including doctors, nurses, dietitians, physiotherapists and other staff, so that they can holistically manage the physical as well as mental health and wellbeing of people with CF under their care. The Cystic Fibrosis Trust's Standards of Care¹ and NHS England's CF Service Specifications for Children and Adult services^{2,3} provide consensus guidance on the composition of CF MDTs, as well as recommended qualifications and banding of MDT staff.

The multidisciplinary, specialist approach to CF care has resulted in huge improvements in care and, most importantly, the health outcomes and experiences of people with CF and their families. In the decade from 2010 to 2020, the proportion of people with CF aged 16 or over has increased, with the median age of the CF population in 2020 reaching 21 years⁴. Furthermore, median predicted survival age has increased steadily, so that half of the people with CF born in 2020 are expected to live into their fifties.

To continue this trend of ongoing improvement, it is essential to ensure that CF centres have sufficient staff to meet evolving population needs, provide safe, high-quality care, and that this care can be accessed in a timely manner by those who need it. CF increasingly needs to be treated as a multi-system condition, as lung function improvements from modulator therapies are shifting the focus of many patients' concerns onto other aspects of their physical and mental health. Additionally, cost of living pressures could result in increased demand for financial and benefits advice, as well as mental health and crisis support. High-quality CF care, therefore, requires appropriate resourcing for all specialties in the MDT, access to suitably qualified staff, and effective recruitment and retention of such staff (low vacancy rates), all of which are key priorities in the NHS generally^{5,6,7}.

The Cystic Fibrosis Trust seeks to ensure that people with CF can access the expertise and support they need to lead long, healthy lives. We monitor this in a number of ways, including collecting and publishing information on patient outcomes (via the UK CF Registry), staffing levels and patient experiences, feeding this information back to services to stimulate Quality Improvement (QI), and sharing our findings more widely to increase reach and impact.

1 Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 2nd edition; 2011: www.cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents

2 NHS England, Service Specification A01/S/b Cystic Fibrosis Children; 2018: www.england.nhs.uk/wp-content/uploads/2018/07/a01Sb-spec-cystic-fibrosis-child.pdf

3 NHS England, Service Specification A01/S/a Cystic Fibrosis Adults; 2018: www.england.nhs.uk/wp-content/uploads/2018/08/Cystic-fibrosis-adult.pdf

4 UK CF Registry Annual Reports for 2010 and 2020: www.cysticfibrosis.org.uk/registryreports

5 NHS England & NHS Improvement, We are the NHS: People Plan for 2020/21 – Action for us all; 2020: www.england.nhs.uk/publication/we-are-the-nhs-people-plan-for-2020-21-action-for-us-all/

6 The Health Foundation, A Critical Moment; 2019: www.health.org.uk/sites/default/files/upload/publications/2019/A%20Critical%20Moment_1.pdf

7 Nuffield Trust, NHS Workforce; 2019: www.nuffieldtrust.org.uk/resource/the-nhs-workforce-in-numbers

Scope of the report

This report presents an overview of staffing information collected once annually for three years (2019–2021) from participating CF centres across the UK. The report is designed to stimulate discussion about the resourcing of CF services and encourage participation in future rounds of data collection. We hope that the insights from this, and future reports, will be useful to understand how staffing levels in CF services change over time, especially as CFTR⁸ modulators are introduced to increasing proportions of the population, alongside dramatic changes in digital health offerings and the wider NHS funding landscape.

Information within this report is drawn from three years of staffing data. The most recent findings from 2021 are presented, alongside data from previous years, where relevant, to facilitate comparisons and to enable early identification of any changes that may positively or negatively impact CF care delivery.

Services can use the information in this report alongside their own staffing data to review staffing levels and reflect on how their service compares. However, when exploring staffing levels, it is important to also consider the patient population that a service serves, access to support from community and other non-CF services, such as GPs, as well as additional factors that could impact on staff cover needed.

Data collection

Each year since 2019, the Cystic Fibrosis Trust invites all specialist CF services to complete our dedicated 'staffing tool' to share detailed information about staff groups, contract types, banding, vacancies and satisfaction with staffing levels. The tool collects this information directly from CF services via an online platform each October, as such it provides an annual snapshot of staffing levels.

While services are not required to complete the staffing tool, the majority of specialist CF centres have contributed data in the last three years. Participation varied year-on-year but remained high throughout the COVID pandemic (Table 1). Clinics that enter their own Registry data could individually contribute to the tool, but responses were combined with their network centre in analyses and reporting.

Table 1: Participation in staffing tool by service type and year

	2019	2020	2021
Paediatric services	72.7% (24 of 33)	63.6% (21 of 33)	81.3% (26 of 32)
Adult services	82.1% (23 of 28)	78.6% (22 of 28)	82.1% (23 of 28)
Total participating services	77.0% (47 of 61)	70.5% (43 of 61)	81.7% (49 of 60)*

*In 2021 there were 60 services: 56 CF centres (with local networks) and 4 stand-alone sites; one former paediatric centre joined another's network and hence is no longer counted as a centre in its own right.

8 Downey, Damian & Taylor-Cousar, Jennifer. (2019). Letter to the editor: Challenges and opportunities in the development of future CFTR modulator options for people with CF. *Journal of Cystic Fibrosis*.

Notes and limitations

When reviewing the findings presented in this report, it is important to keep in mind the following limitations.

Well over 70% of CF centres in the UK contributed to the staffing tool most years, but we do not have staffing information from all active CF services. This report is based on data collected from 49 of 60 CF centres (81.7%) across the UK in 2021, and also draws in staffing information from previous years, which were based on slightly different numbers and combinations of centres (see Table 1). While there is some overlap in the samples year-on-year, the number of participating services varied between 2019 and 2021, and fewer services took part in 2020 than in other years, likely due to the pandemic.

The data collected constitute a snapshot of staffing resource available within CF centres at specific points in time (once per year, in October). Staffing levels can fluctuate throughout the year, as staff leave or as vacancies are filled, and readers are encouraged to keep this in mind when reviewing the findings, particularly with regards to the impact of temporary vacancies on staff availability. The picture may look different at other times of the year.

Staffing levels are presented as Whole-Time Equivalents (WTEs) per 75 patients in this report. For core MDT members, such as doctors, nurses and dietitians, these levels may be compared to recommended levels in the Standards of Care. However, direct comparison of staffing levels for admin, research and other staff groups is not recommended, because the Standards focus on CF specialist staff only, while this report also counts other staff in these groups who may be providing services to CF patients, such as healthcare assistants and social welfare advisors.

Finally, capturing accurate CF team staffing information can be difficult due to the different ways in which CF teams are set up. In our first round of data collection for the staffing tool, we found that there was great variation in the way that CF teams described their structures and resources, making it difficult to pool data together and to compare configurations across services. Attribution of patients under shared care arrangements, for example, is complex, because these individuals may receive varying proportions of care from the central specialist CF team, while also receiving some care from local teams.

Since 2019, we have worked to improve how we capture information on staffing resources, bed availability, as well as full- versus shared-care patients, in order to make our staffing information more accurate. For example, we now attribute shared care patients proportionately, where possible. We have also followed up with services to ensure the information we have is as complete as it can be. This is why there may be some discrepancies between findings from 2019 and later years, as we improved our data collection and analysis. For example, shared care patients were not included in 2019, which means findings from that year likely overestimated the availability of staff to the CF population.

We will continue to develop and improve our staffing tool and reports in future, and we welcome feedback at QI@cysticfibrosis.org.uk

Section 1

Staff groups available within MDT

The staffing tool asks services to provide details about members of their multi-disciplinary team (MDT), to better understand the staff groups that are available and the composition of MDTs within CF centres.

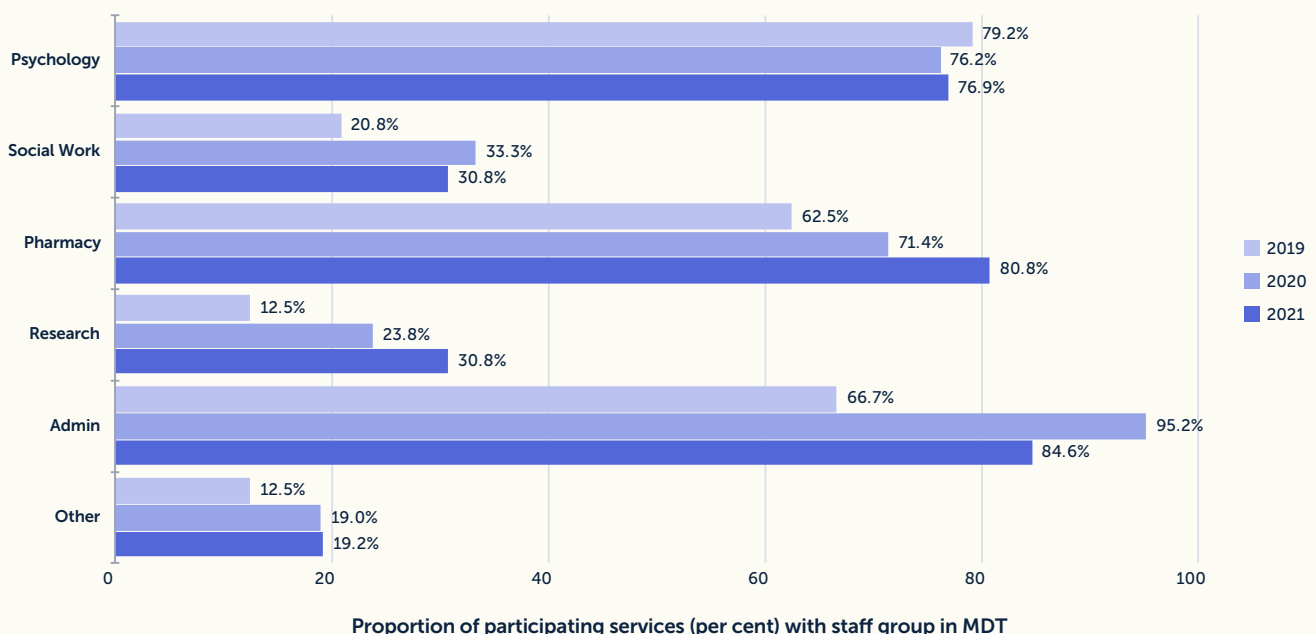
Table 2: Proportion of paediatric centres that have each staff group in MDT

NB: The below is based on currently available staff in a staff group only, vacant roles are not included

	October 2019		October 2020		October 2021	
	Percent	Centres	Percent	Centres	Percent	Centres
Medical (Doctors)	95.8%	23 of 24	100%	21 of 21	100%	26 of 26
Nursing	100%	24 of 24	100%	21 of 21	100%	26 of 26
Physiotherapy	91.7%	22 of 24	100%	21 of 21	100%	26 of 26
Dietetics	95.8%	23 of 24	100%	21 of 21	100%	26 of 26
Psychology	79.2%	19 of 24	76.2%	16 of 21	76.9%	20 of 26
Social Work	20.8%	5 of 24	33.3%	7 of 21	30.8%	8 of 26
Pharmacy	62.5%	15 of 24	71.4%	15 of 21	80.8%	21 of 26
Research	12.5%	3 of 24	23.8%	5 of 21	30.8%	8 of 26
Admin	66.7%	16 of 24	95.2%	20 of 21	84.6%	22 of 26
Other ⁹	12.5%	3 of 24	19.0%	4 of 21	19.2%	5 of 26

While paediatric services confirmed they have medical, nursing, physiotherapy and dietetics staff, not all children with CF had access to a full MDT at their CF centre. This particularly applies to psychologists, social workers, pharmacists and research staff, whose availability could change year-on-year and varied by centre.

Figure 1: Proportion of paediatric centres that have psychology, social work, pharmacy, research, admin and other staff within their MDT



⁹ "Other" represents roles such as: Health Care Assistants, Pulmonary Physiologists, Respiratory Technicians, Welfare Advisors and Youth Workers

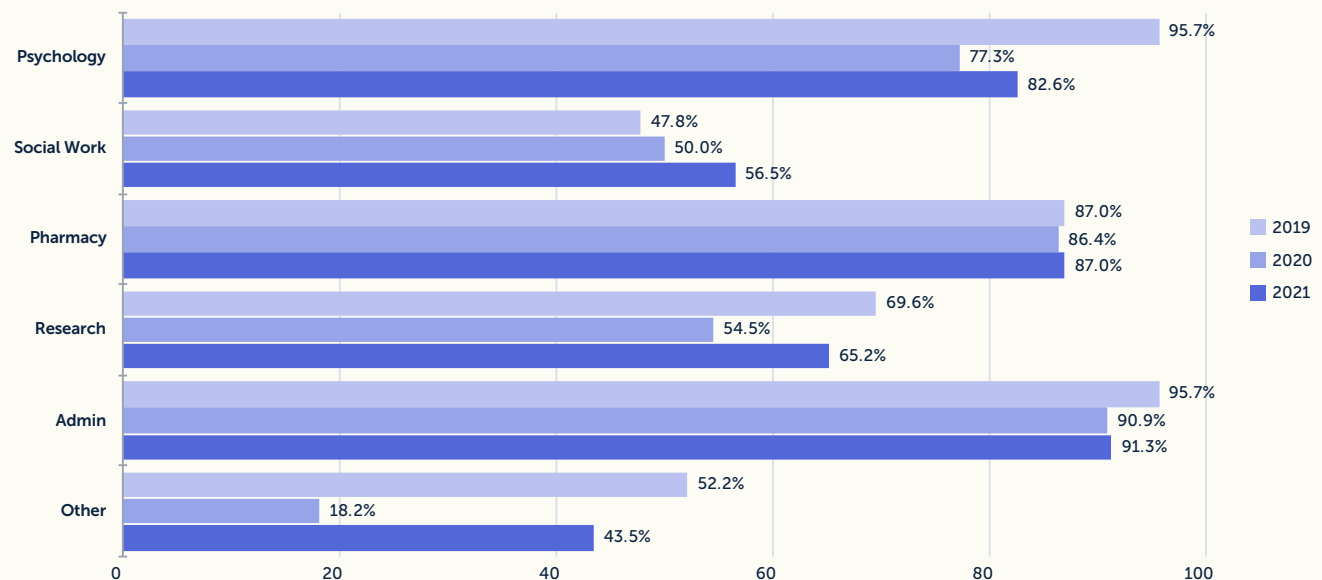
Table 3: Proportion of adult centres that have each staff group in MDT

NB: The below is based on currently available staff in a staff group only, vacant roles not included

	October 2019		October 2020		October 2021	
	Percent	Centres	Percent	Centres	Percent	Centres
Medical (Doctors)	100%	23 of 23	100%	22 of 22	95.7%	22 of 23
Nursing	100%	23 of 23	95.5%	21 of 22	95.7%	22 of 23
Physiotherapy	100%	23 of 23	95.5%	21 of 22	95.7%	22 of 23
Dietetics	100%	23 of 23	95.5%	21 of 22	95.7%	22 of 23
Psychology	95.7%	22 of 23	77.3%	17 of 22	82.6%	19 of 23
Social Work	47.8%	11 of 23	50.0%	11 of 22	56.5%	13 of 23
Pharmacy	87.0%	20 of 23	86.4%	19 of 22	87.0%	20 of 23
Research	69.6%	16 of 23	54.5%	12 of 22	65.2%	15 of 23
Admin	95.7%	22 of 23	90.9%	20 of 22	91.3%	21 of 23
Other ¹⁰	52.2%	12 of 23	18.2%	4 of 22	43.5%	10 of 23

Similar to services for children, nearly all participating adult services confirmed that their MDT included medical, nursing, physiotherapy and dietetics staff in October 2021. However, access to psychologists, social workers, pharmacists and research staff varied. Some adult centres reported that their MDT did not include these staff groups, although a higher proportion of adult services overall reported having access to these groups compared to children’s services. One participating adult centre reported a complete lack of staff for their CF MDT, with all available roles in the service standing vacant in October 2021.

Figure 2: Proportion of adult centres each year that have psychology, social work, pharmacy, research, admin and other staff within their MDT



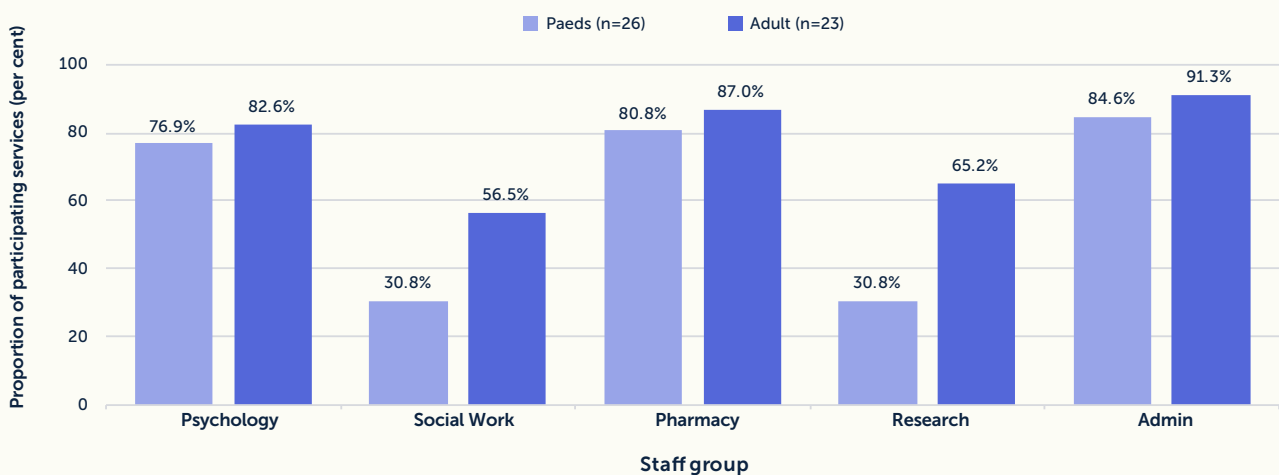
¹⁰ "Other" represents roles such as: Health Care Assistants, Pulmonary Physiologists, Respiratory Technicians, Welfare Advisors and Youth Workers

Nearly all participating CF centres, whether for children or adults, confirmed that their MDT included medical, nursing, physiotherapy and dietetics staff. This is crucial, because these staff groups are also the groups that people with CF say they need and access the most¹¹. However, other expertise considered to be important for CF MDTs was not always available. This means that some people with CF may struggle to access certain staff groups when they need them.

Insight: Not all people with cystic fibrosis consistently have access to a full multidisciplinary team at their CF centre, particularly when it comes to psychosocial support, pharmacy and research staff.

When comparing availability of staff groups within paediatric and adult services, there was a higher proportion of CF centres for adults reporting access to psychologists, social workers, pharmacy and research staff in their MDT. This difference is particularly pronounced for social workers and research staff, where fewer than 1 in 3 children’s centres reported having access to these groups in their MDT, compared to well over half of adult centres.

Figure 3: Comparison of proportion of paediatric and adult centres reporting access to psychology, social work, pharmacy, research and admin staff in 2021



While exact proportions vary year-on-year, the discrepancies between paediatric and adult services in terms of availability of the above staff groups within MDTs is a relatively consistent finding over three years of data collection.

Insight: A larger proportion of paediatric CF services appear to lack access to certain staff groups for their MDT, particularly social workers and research staff, compared to adult CF centres.

11 Cystic Fibrosis Trust, Patient-Reported Experience Measures; 2022 www.cysticfibrosis.org.uk/QI

Section 2

Staffing configurations

The make-up of CF teams can differ between paediatric and adult centres, and even between the same types of services. This may be entirely appropriate, depending on service size, characteristics of the patient population, as well as other factors, such as access to support and services in the community. However, it is important to monitor staffing levels within CF services, as these can be linked to ability to meet professional standards and improved clinical outcomes. Staffing information provides important insights to help teams explore whether the level of staffing in their service is appropriate, and to track how it changes over time.

In order to compare staffing levels across centres of differing sizes, we use the total Whole-Time-Equivalents (WTE) available within each staff group at a centre and work out the centre's WTE cover per 75 patients from this. This approach takes into account that centres serve different numbers of people and therefore require different staffing levels to cater for their population. The WTE per 75 patient calculation provides us with a figure that can be compared more readily.

Table 4: Median centre-level staff time available by staff group in 2021

NB: The table below shows the median WTE available per 75 patients in participating paediatric and adult centres in October 2021; vacant roles are not included in this calculation unless they were covered, where a vacant role was covered at a different level to the usual role, the WTE of the cover arrangement was used in the table below to ensure the table only includes staff actually available within services at the time

	Paeds Services (n=26)		Adult Services (n=23)	
	Median* WTE / 75 patients	Range** Lowest – Highest	Median* WTE / 75 patients	Range** Lowest – Highest
Medical (Doctors)	0.8	(0.5 – 2.0)	0.7	(0.0 – 1.5)
Nursing	1.6	(0.5 – 3.3)	1.3	(0.0 – 3.3)
Physiotherapy	1.4	(0.3 – 2.1)	1.2	(0.0 – 2.2)
Dietetics	0.6	(0.3 – 1.1)	0.5	(0.0 – 0.7)
Psychology	0.3	(0.0 – 0.8)	0.3	(0.0 – 0.6)
Social Work	0.0	(0.0 – 0.8)	0.1	(0.0 – 0.7)
Pharmacy	0.3	(0.0 – 0.8)	0.4	(0.0 – 1.0)
Research	0.0	(0.0 – 0.5)	0.2	(0.0 – 1.3)
Admin	0.6	(0.0 – 1.4)	0.5	(0.0 – 1.3)
Other	0.0	(0.0 – 1.4)	0.0	(0.0 – 1.0)

* A median of zero means that half or more of participating services reported not having any available staff within the respective staff group (they may have had vacant posts in these staff groups)

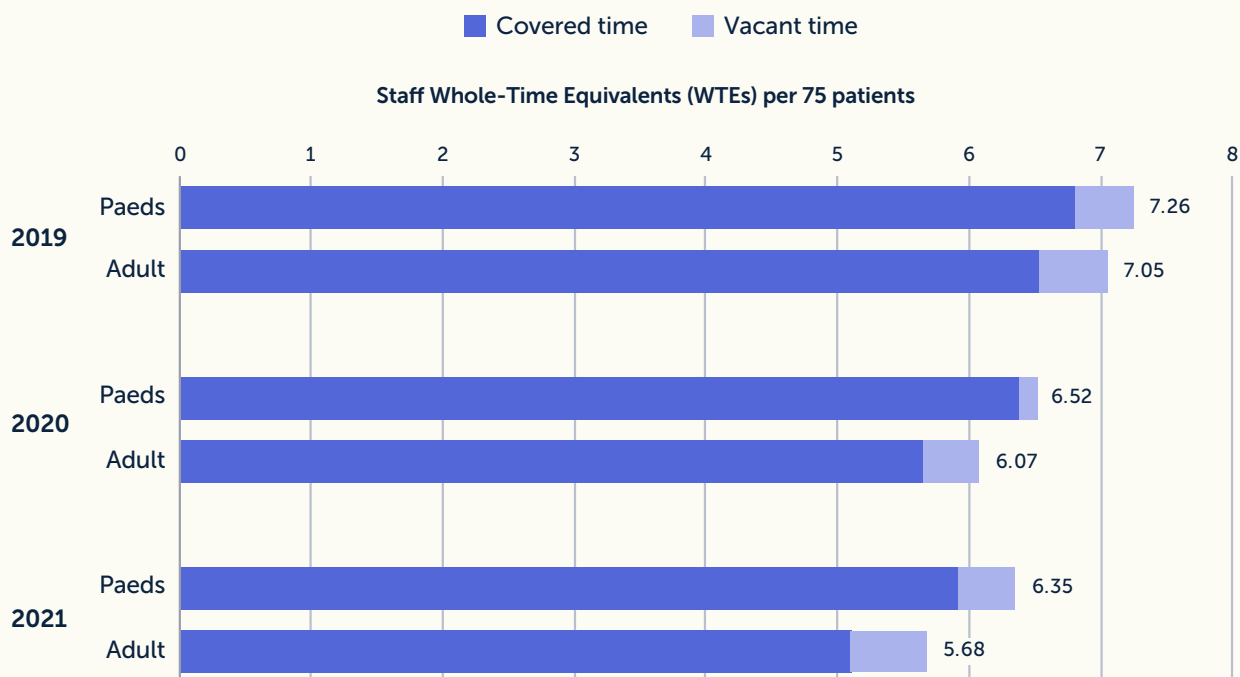
** The range shows the lowest and highest staffing level seen among participating centres for each staff group (as WTE per 75 patients); it gives an idea of the differences in level of cover between different centres, but does not take fully into account differences in patient population characteristics or complexity, nor external / other factors that can impact on required staffing levels

Insight: In October 2021, median staffing levels were similar across paediatric and adult CF centres in most staff groups; however, several CF centres reported being without certain staff groups and there was a lot of variation in staffing levels and availability between centres.

The different amounts of staff time available across participating centres (see ranges in Table 4) show that there appears to be variation in staffing levels between services. Availability of staff can also fluctuate over time. It is therefore useful to consider how much staff time was available on average across the population that was being cared for by participating CF centres.

Figure 4: Average staff time available in October 2019, 2020 and 2021

NB: Average staff time was calculated based on all posts (incl. vacant/covered posts) and total population in sample; where a vacant post was covered at a different level to the usual role, the WTE of the available cover was included in 'covered time', any remaining vacant time is included in 'vacant time' (tinted)



The overall staff time available to the paediatric and adult population across participating CF centres was relatively similar, although adults appeared to have slightly less staff time available on average.

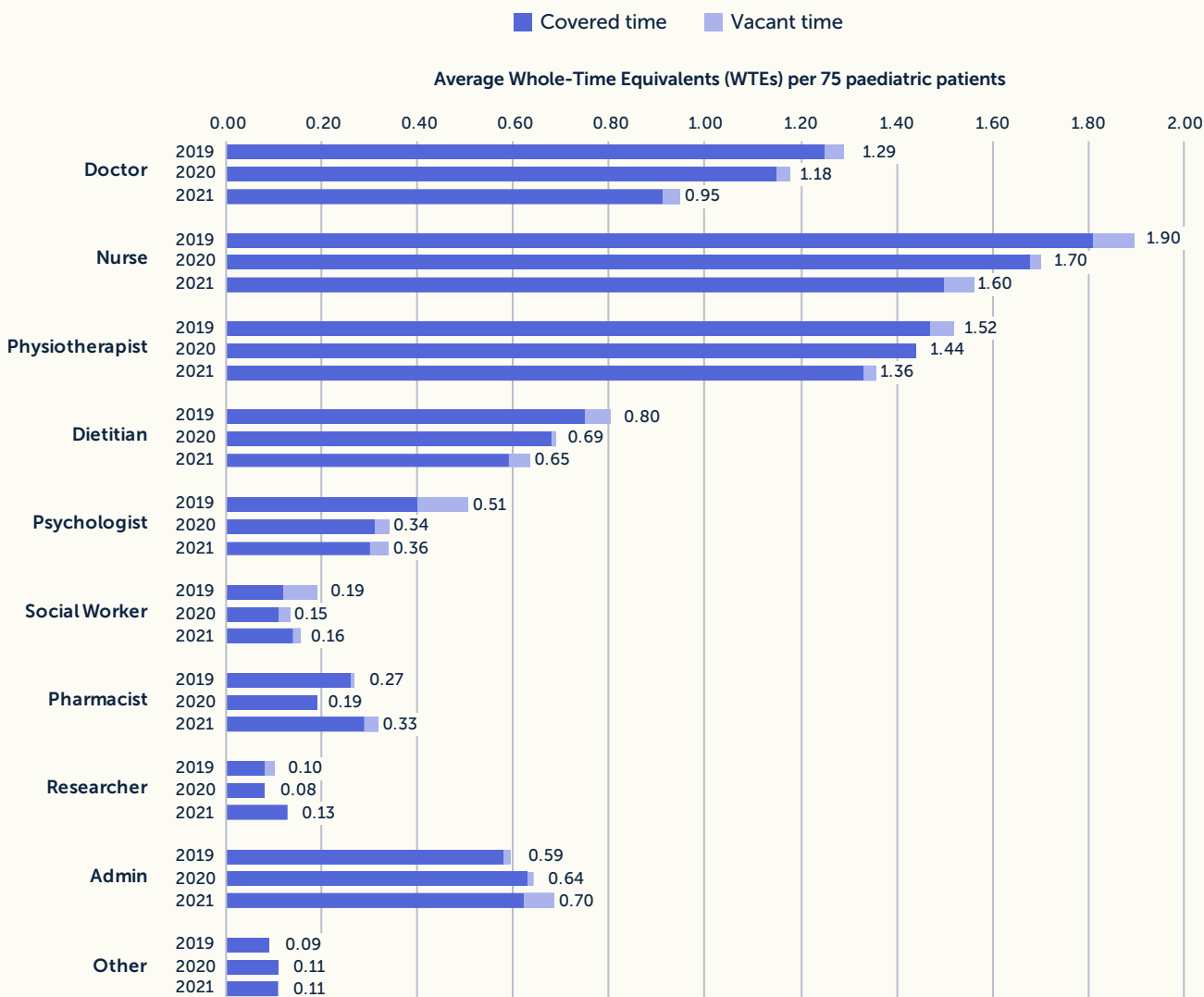
There appeared to be a reduction in overall staff time available to both populations year-on-year. It is important to keep in mind that levels in 2019 may be an overestimate due to shared care patients not having been included that year. Future rounds of the staffing tool will help explore whether these trends continue, but it is concerning to see that staff availability reduced also between 2020 and 2021, when shared care patients were included.

Insight: Overall staff time available to the CF population across participating centres appears to have reduced year-on-year and it will be vital to monitor this trend in future

To explore how staff time is distributed across different specialties, Figures 5 and 6 provide a breakdown of WTE per 75 patients by staff group for paediatric and adult populations.

Figure 5: Average staff time for paediatric population, by staff group

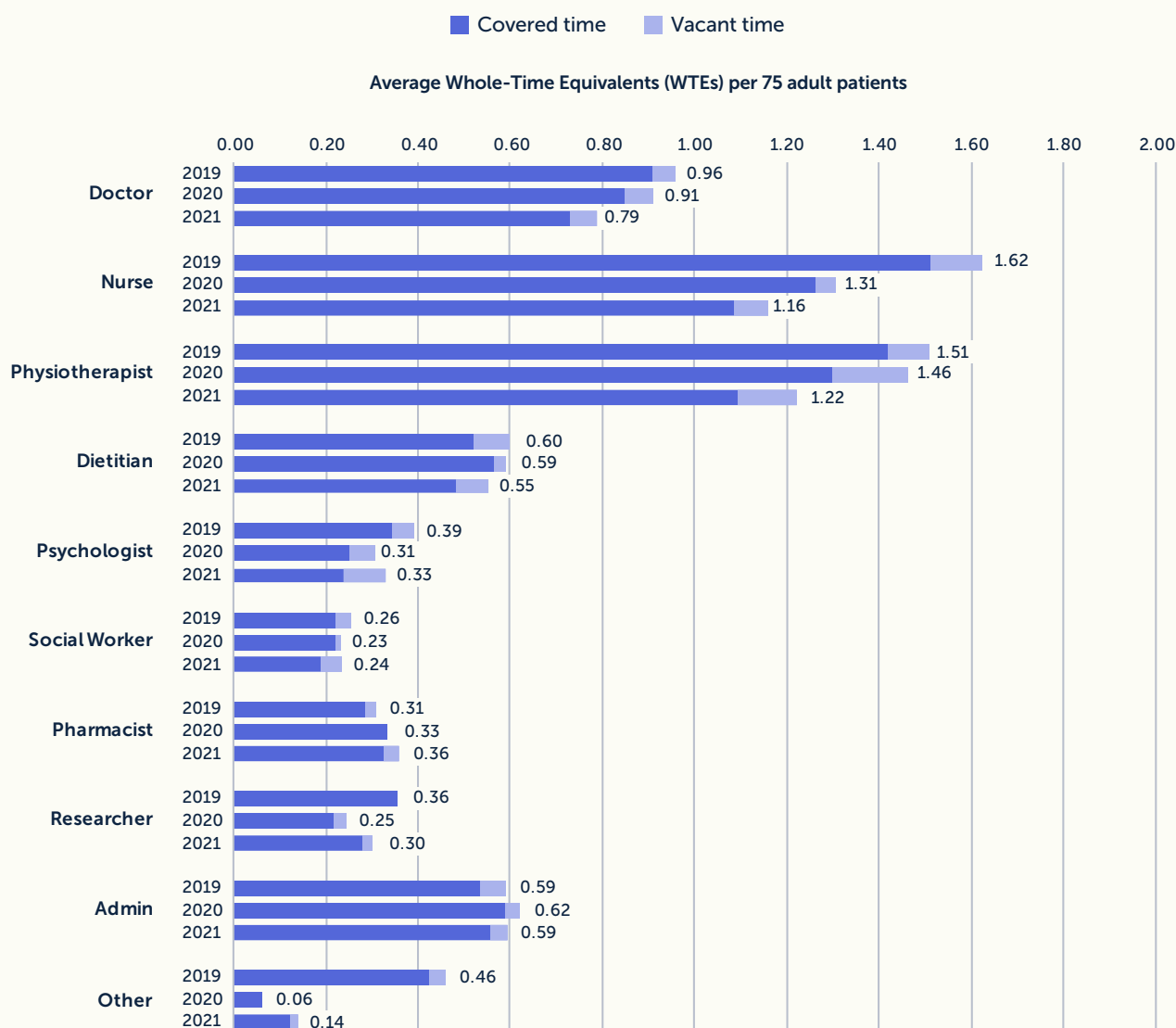
NB: Average staff time was calculated based on all posts in a staff group (incl. vacant/covered posts) and total population in sample; where a vacant post was covered at different hours to the usual role, the WTE of the available cover was included in 'covered time', any remaining vacant time is included in 'vacant time' (tinted)



The average WTE medical, nurse, physio and dietetics cover available to the paediatric CF population in participating services appeared to have reduced year-on-year. This is particularly notable for doctors. In other areas, including social work and research, staffing levels appear to have remained relatively stable, but often at lower levels than seen in adult centres.

Figure 6: Average staff time for adult population, by staff group

NB: Average staff time was calculated based on all posts in a staff group (incl. vacant/covered posts) and total population in sample; where a vacant post was covered at a different level to the usual role, the WTE of the available cover was included in 'covered time', any remaining vacant time is included in 'vacant time' (tinted)



Average medical, nurse, physio and dietetics staff time available to the adult CF population in participating services was lower than for the paediatric population most years. This aligns with findings from our first staffing report¹².

Medical, nurse and physio staff time also appeared to have reduced for the adult population year-on-year. Availability of other staff groups remained relatively stable over time for adults, and the average social worker and researcher time available was consistently higher than for the paediatric population.

Insight: More medical, nurse, physiotherapy and dietetics time is available to the paediatric population, whereas the adult population has more social worker and research staff time available.

12 Cystic Fibrosis Trust, Staffing Report 2019; 2020: Cystic Fibrosis Trust_UK Staffing Report_2019.pdf

When looking at the average staff time available, it is important to consider context. For example, in October 2020 and 2021, the COVID pandemic might have been affecting staffing levels in various ways. It may have led to temporary reductions in staffing levels due to staff absences or staff being drafted in to support the COVID response, or it might have increased retention as staff may have wanted to support their service during this difficult time. Our data show that participating centres reported lower vacancy rates in 2020 (see Section 3), and that satisfaction with staffing levels was higher that year (see Section 4). However, fewer centres took part in the staffing tool in 2020 and this could have affected the findings, as services that were struggling may have been less likely to contribute, hence impacting our findings around vacancies and satisfaction.

Future information on staffing levels post-pandemic will help us to understand how the pandemic affected findings in 2020 and 2021 and how levels change. Other factors that may impact staffing levels in future include changing patient needs due to more widespread use of CFTR modulator drugs, as well as the digitalisation of the NHS and increased use of remote consultation formats.

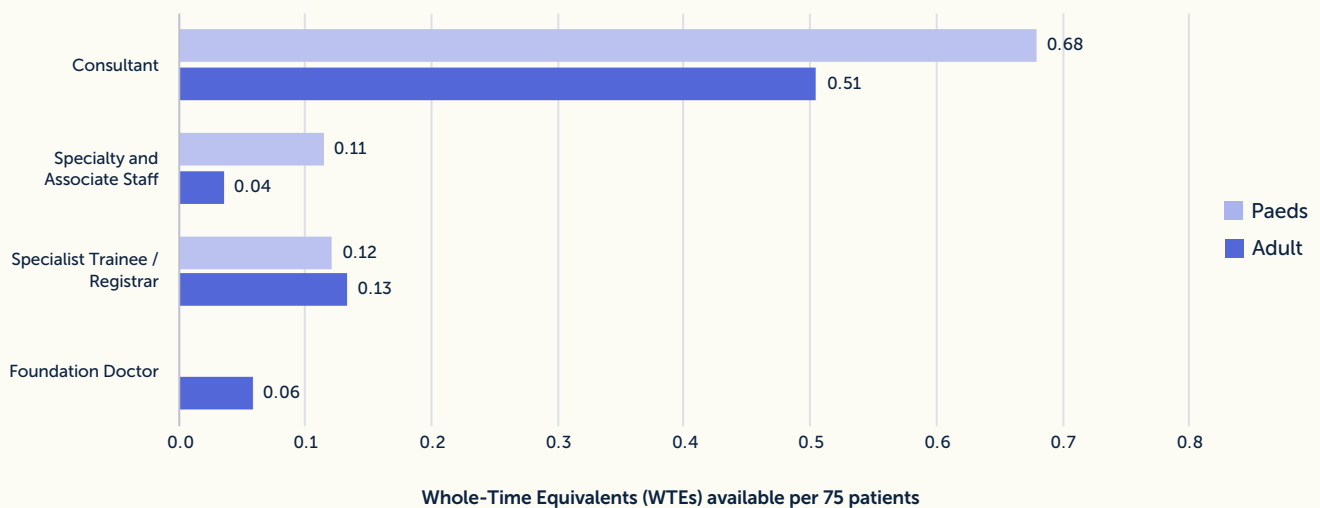
Staff seniority

Staffing levels vary not only by the types of roles and overall staff time available, but also by the seniority of such roles. In 2019, participating adult centres had a significantly higher proportion of lower banded posts than paediatric centres (24.1% vs. 12.8%). While adult centres still had a larger proportion of posts at Band 5 or below in 2021 (18.9% vs. 17.6%), this difference is no longer as pronounced.

Figures 7 to 15 show the average WTE staff time available to children and adults with CF under the care of participating services in October 2021. This is presented for each staff group individually (as WTE per 75 patients) and split by seniority (NHS banding)¹³. Open vacancies are not included in the figures below, but covered WTEs are. Average values have been rounded to two decimals in all figures below, unless the value for a band was below 0.005 WTE, in which case three decimals are shown.

Figure 7: Medical staff time available per 75 patients by banding Oct 2021

NB: Based on 0.914 (paeds) and 0.731 (adult) WTE per 75 patients medical staff time



¹³ NHS England, Agenda for Change; 2021: www.healthcareers.nhs.uk/working-health/working-nhs/nhs-pay-and-benefits/agenda-change-pay-rates/agenda-change-pay-rates

Figure 8: Nursing staff time available per 75 patients by banding Oct 2021

NB: Based on 1.497 (paeds) and 1.084 (adult) WTE per 75 patients nurse staff time

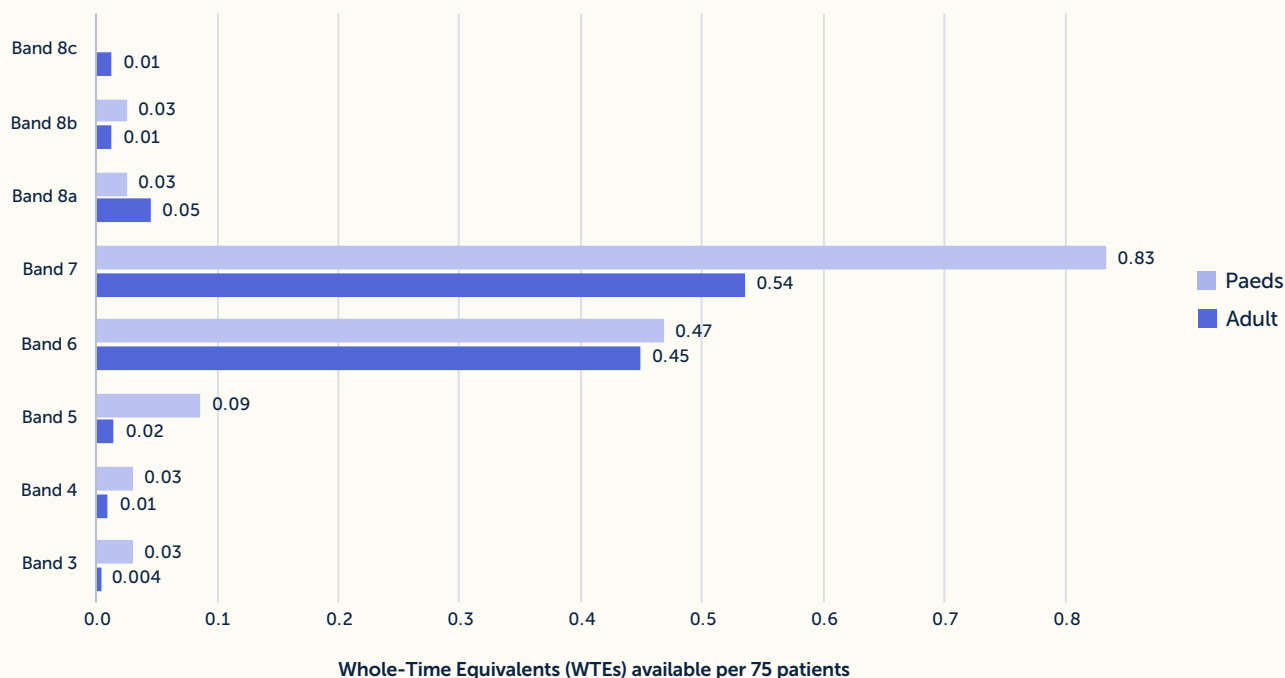
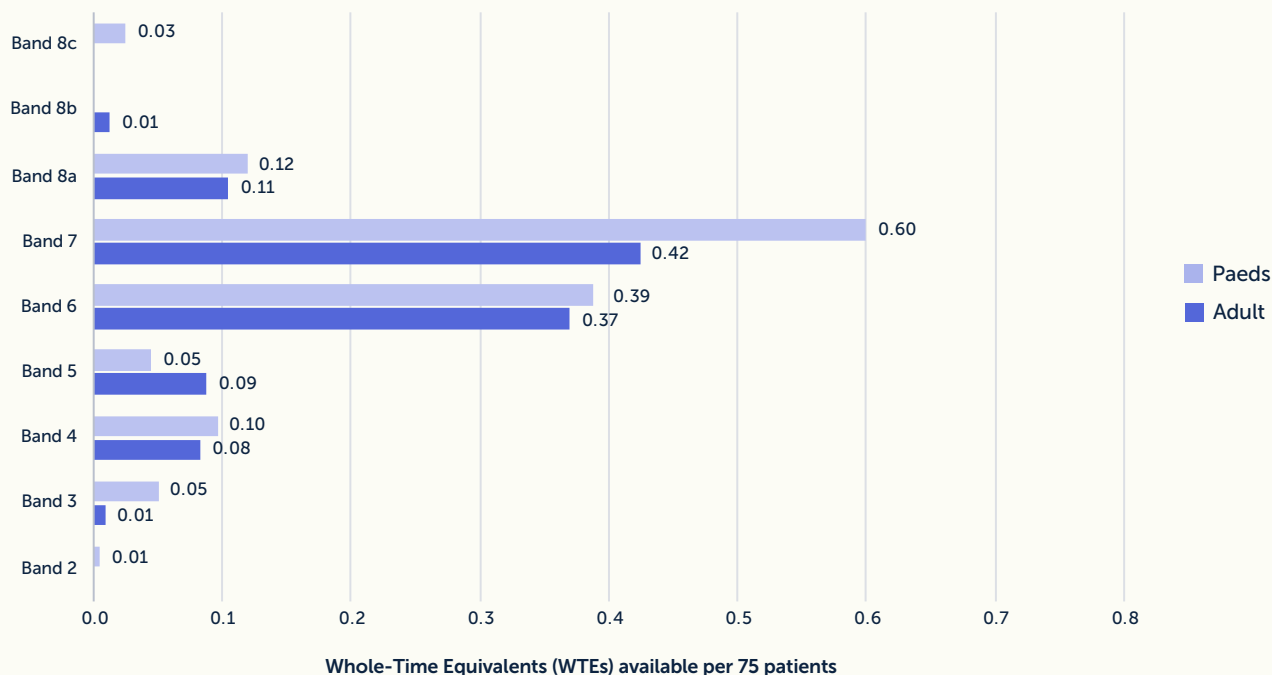


Figure 9: Physiotherapy staff time available per 75 patients by banding Oct 2021

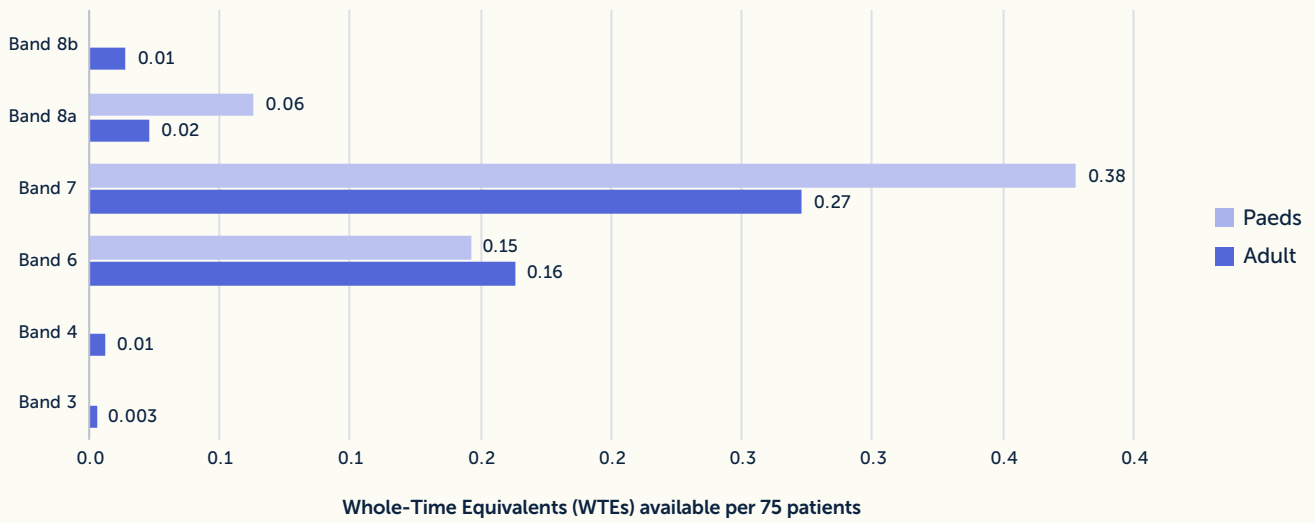
NB: Based on 1.328 (paeds) and 1.092 (adult) WTE per 75 patients physio staff time



Medical, nursing and physiotherapy staff were the three groups with the most staff time available overall. Banding for doctors differs from other NHS staff banding, with most medical staff in CF centres employed at consultant level (Figure 7). Similar to our findings in 2019, the majority of nurses and physiotherapists were employed in Bands 6 and 7. For all three groups, our findings show that there was more senior staff time available to the paediatric population, compared to adults.

Figure 10: Dietetics staff time available per 75 patients by banding Oct 2021

NB: Based on 0.587 (paeds) and 0.482 (adult) WTE per 75 patients dietetics staff time



Similar to nurses and physios, dietitians tended to be employed at Bands 6 or 7, with more senior staff time available in paediatric services at Bands 7 and 8a.

Figure 11: Psychology staff time available per 75 patients by banding Oct 2021

NB: Based on 0.297 (paeds) and 0.239 (adult) WTE per 75 patients psychology staff time

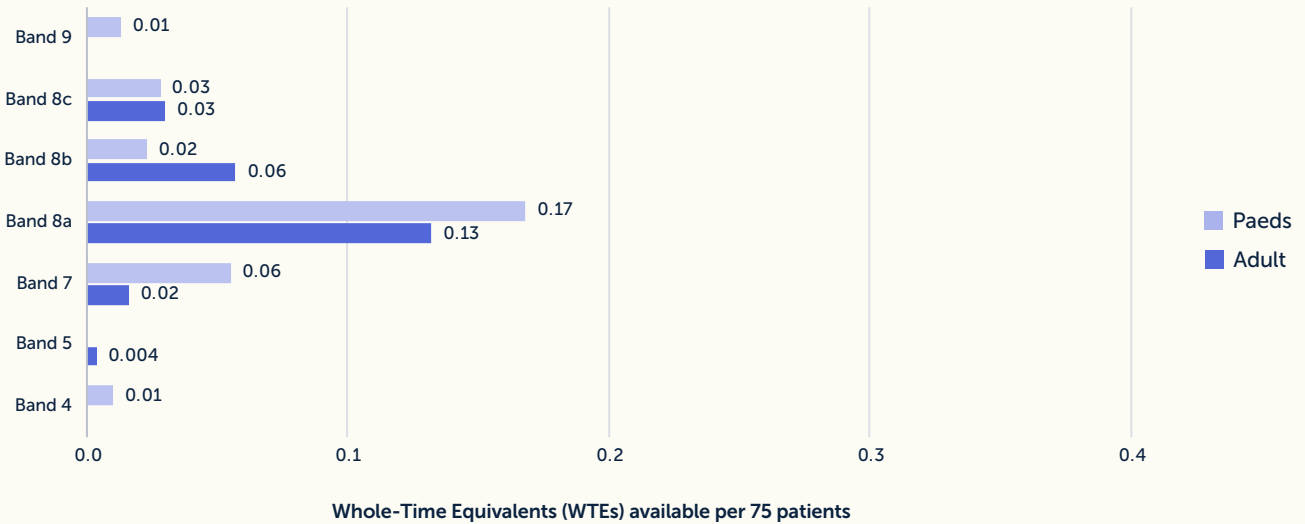


Figure 12: Social work staff time available per 75 patients by banding Oct 2021

NB: Based on 0.144 (paeds) and 0.189 (adult) WTE per 75 patients social work staff time

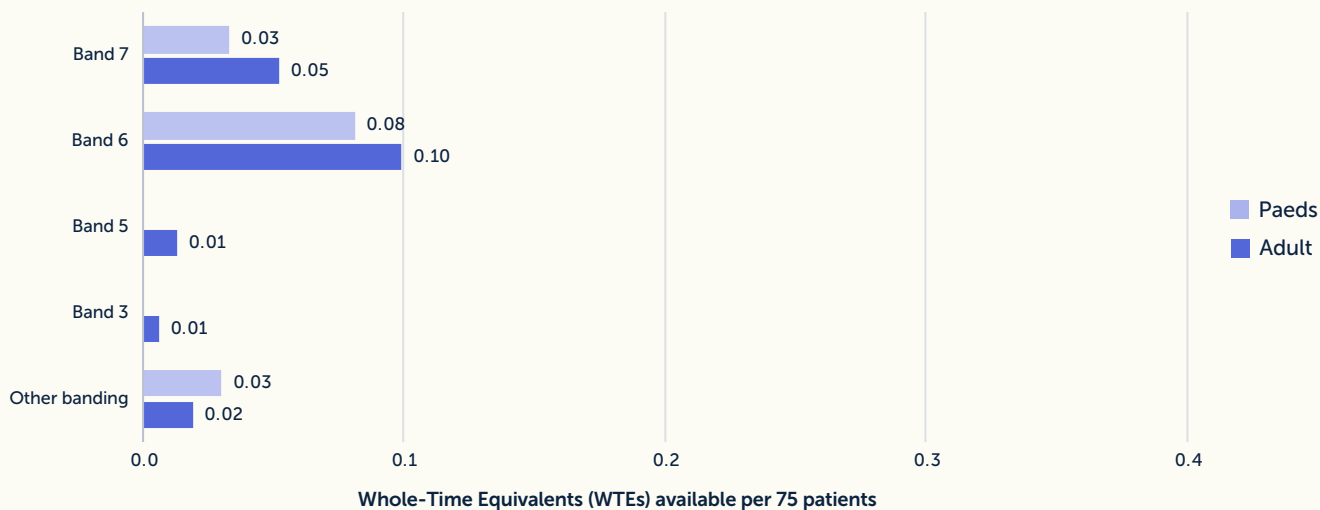
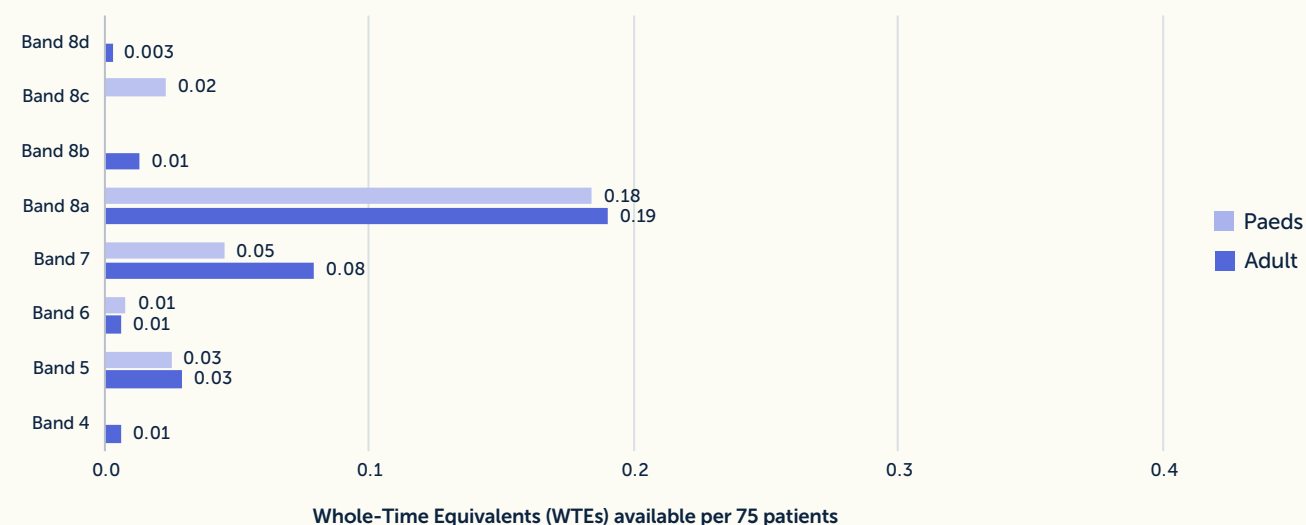


Figure 13: Pharmacy staff time available per 75 patients by banding Oct 2021

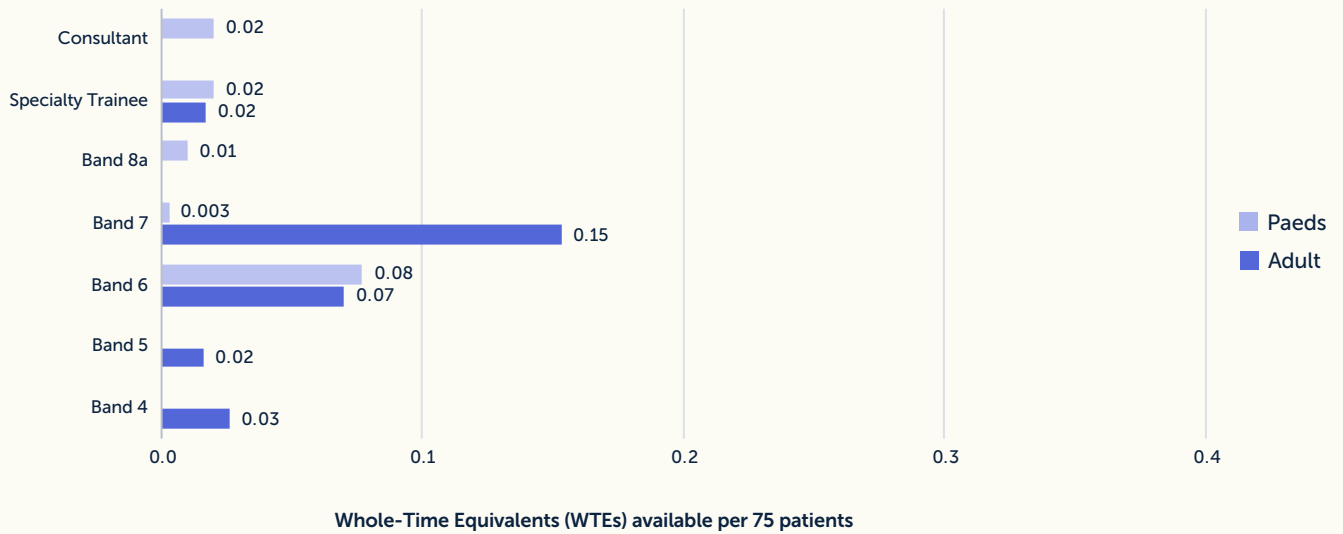
NB: Based on 0.285 (paeds) and 0.326 (adult) WTE per 75 patients pharmacy staff time



For psychologists, social workers and pharmacists, banding distribution of staff was similar across paediatric and adult services. Psychology and pharmacy staff appeared to accumulate at higher bandings than other staff groups, with most employed at Band 8a or 8b. In contrast, most social workers were employed at Band 6. However, it is important to remember that these are average figures and not all participating services said that they had access to psychologists, social workers or pharmacists as part of their MDT in October 2021 (Figure 3).

Figure 14: Research staff time available per 75 patients by banding Oct 2021

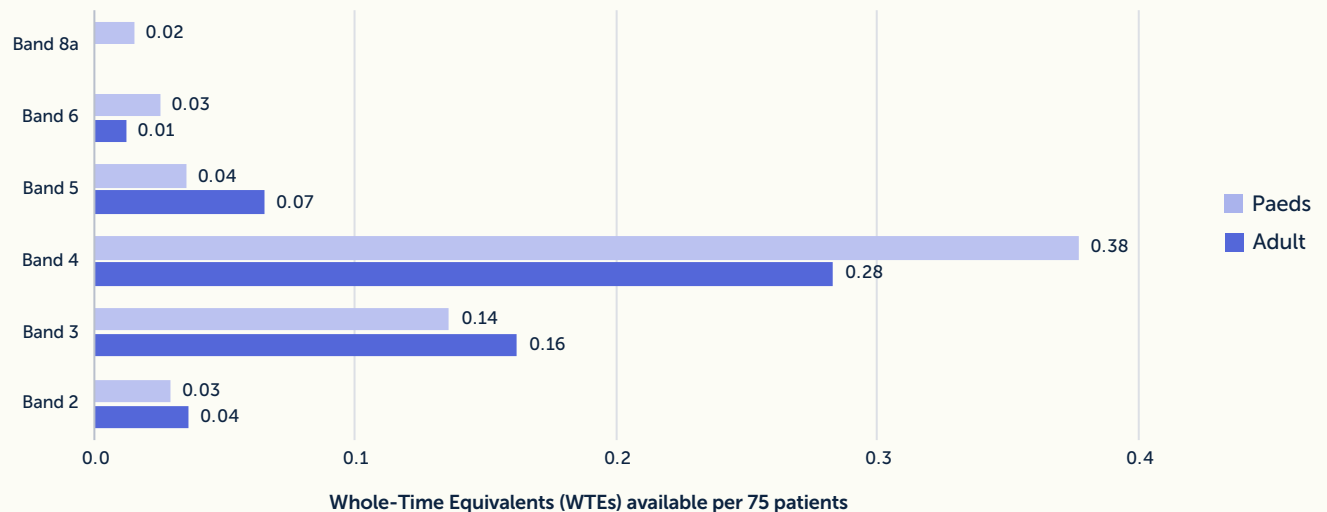
NB: Based on 0.130 (paeds) and 0.282 (adult) WTE per 75 patients research staff time



The adult CF population had more dedicated research staff time overall than was available to the paediatric population. However, our data show that dedicated research staff working in services for children tended to be more senior.

Figure 15: Admin staff time available per 75 patients by banding Oct 2021

NB: Based on 0.617 (paeds) and 0.558 (adult) WTE per 75 patients admin staff time



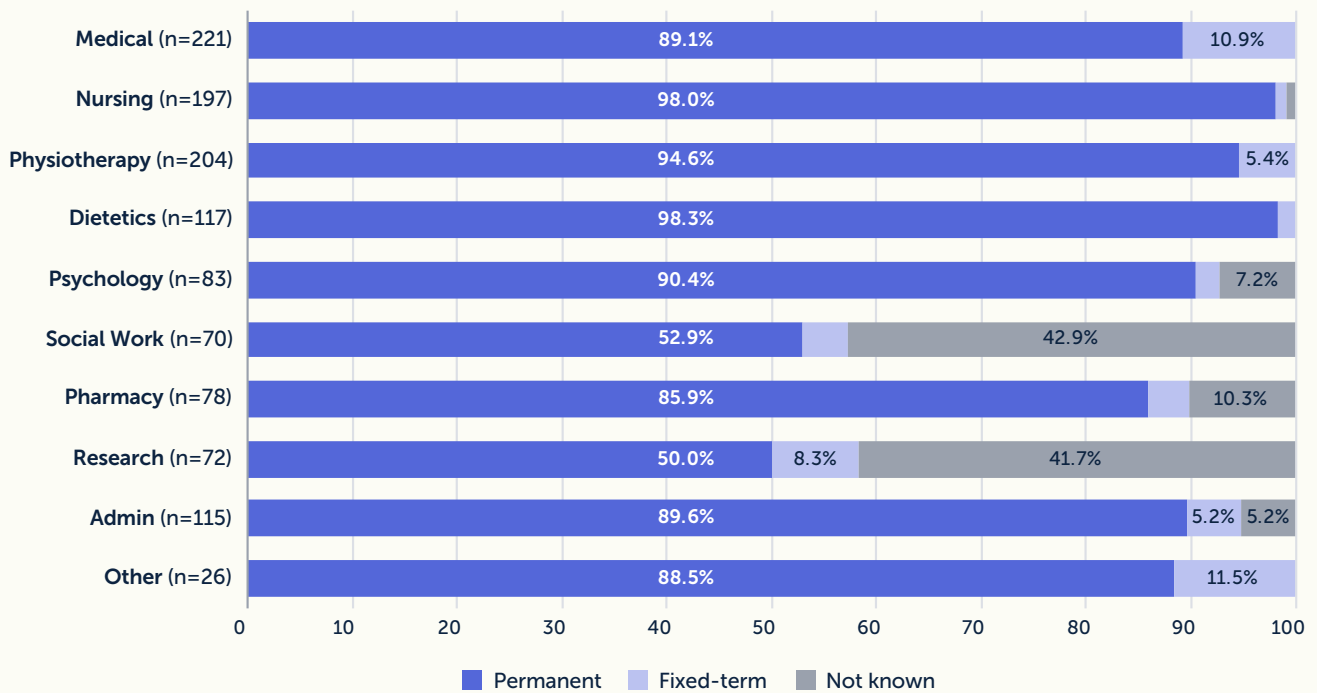
Administrative staff, such as secretaries and database coordinators, concentrated at Bands 3 and 4, with slightly more senior admin staff time available for the paediatric population compared to adults.

Contract types

While most posts in CF services are permanent, some staff are on fixed-term contracts (FTCs), which do not guarantee that a post will remain available when the fixed term ends. The proportion of FTCs in October 2021 was 5.2%, with 87.8% on permanent contracts and 6.9% not known. While five percent of staff on FTCs might not seem like much, it means 1 in 20 roles were only fixed term.

Figure 16: Contract types by staff group in 2021

NB: Based on 1,183 posts, regardless of hours worked (WTE); percentage labels <5% are not shown



Most staff groups had more than 85% permanent posts with only a minority of staff being on FTCs. However, for large proportions of social workers and research staff, the contract types were not known and therefore no conclusions can be drawn for those groups, which may be on entirely different contract types, funded or employed through external organisations, or simply missing.

Section 3

Vacancies

Even when a centre has staff in each group, it may not be fully staffed. This is exemplified by physiotherapist vacancies in 2021 (15 across 49 participating centres) despite nearly all centres reporting access to physiotherapists. Hence, it is important to consider vacant posts that have funding but remain uncovered.

To better understand how vacancy rates compare with the NHS overall, and to explore where posts remain empty for long periods of time, the staffing tool collects information on currently active staff in each service, as well as vacancy rates and cover arrangements, in the form of Whole Time Equivalents (WTE).

Table 5: WTE workforce and vacancy rates across participating UK CF centres

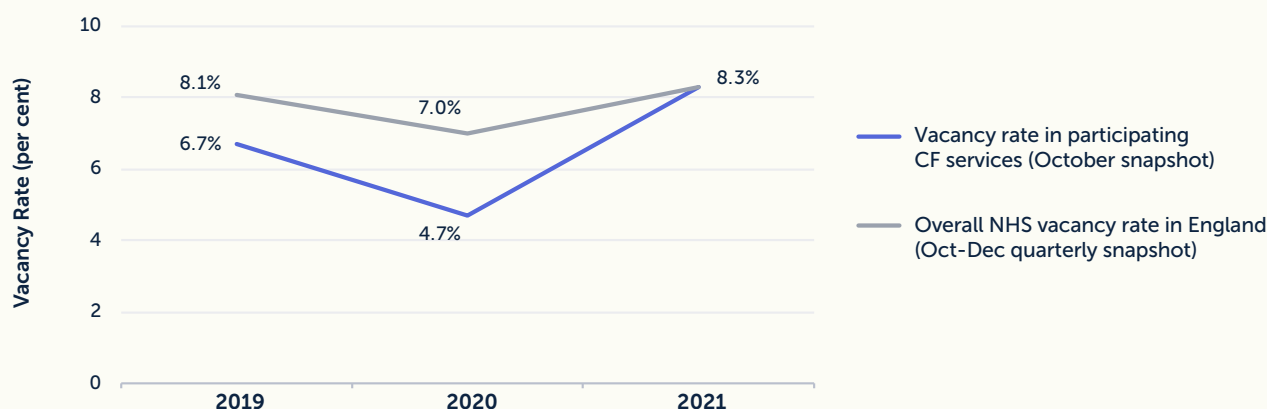
	2019	2020	2021
Active CF Workforce (WTE)	628.9	580.9	631.4
Vacancies (WTE)	45.2	28.8	57.2
Vacancy Rate* (%)	6.7%	4.7%	8.3%

*The vacancy rate is the proportion of WTEs that are vacant out of the total planned / budgeted WTEs for the CF workforce across participating centres (incl. active workforce WTE plus vacancies WTE), i.e. Vacancy Rate (%) = (Vacant WTE ÷ Planned Total WTE) x 100.¹⁴

Information from the staffing tool shows that vacancy rates in CF services fluctuate year-on-year, as do overall NHS vacancy rates.

Figure 17: Vacancy rate changes over time, 2019-2021

In October 2019 and 2020, vacancy rates in participating CF centres were lower than the corresponding quarterly vacancy rate in the NHS overall. In the last quarter of 2021 (October to December), official NHS Vacancy Statistics¹⁴ showed a WTE vacancy rate of 8.3% across NHS providers in England, which matched the vacancy rate reported by participating CF centres in October 2021.



Insight: In late 2021, vacancy rates in CF services had increased compared to previous years and were reflective of vacancy levels in the NHS as a whole.

¹⁴ NHS England, NHS Vacancy Statistics England; 2022: digital.nhs.uk/data-and-information/publications/statistical/nhs-vacancies-survey/april-2015---december-2021-experimental-statistics

Table 6: Vacancies* unfilled for more than six months by staff group in 2021

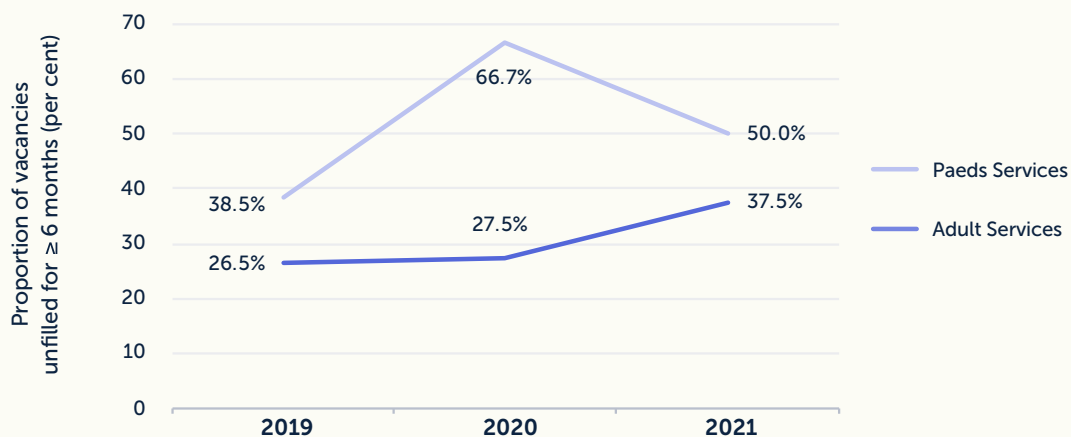
	Paeds Services (n=26)		Adult Services (n=23)	
	Vacant over six months	Total vacant posts	Vacant over six months	Total vacant posts
Medical (Doctors)	1	2	5	8
Nursing	2	5	1	7
Physiotherapy	1	2	5	13
Dietetics	1	3	2	8
Psychology	4	5	2	10
Social Work	2	2	4	6
Pharmacy	1	3	2	4
Research	0	0	1	3
Admin	1	4	1	3
Other	0	0	1	2
Total	13	26	24	64
Proportion of vacancies unfilled for more than six months	50%		37.5%	

* Vacancies that are being covered are excluded from number of vacancies unfilled for ≥ 6 months and further information about cover arrangements is shown in Table 7

Adult CF services had more vacancies than paediatric services overall, but also serve a bigger population. Across participating paediatric and adult CF centres, most vacant social worker posts (6 of 8, 75%) and many psychology posts (6 of 15, 40%) had been unfilled for six months or more in October 2021. Reasons for this may include difficulties establishing a supervisory structure for such roles, how a service advertises the post(s), or problems finding suitably qualified staff.

Overall, a higher proportion of vacancies in participating children’s services remained unfilled for more than six months compared to adult services. This finding was consistent over the three years for which we have staffing data. However, in 2021, the proportion of posts unfilled for more than six months had increased in participating adult services but decreased in paediatric services.

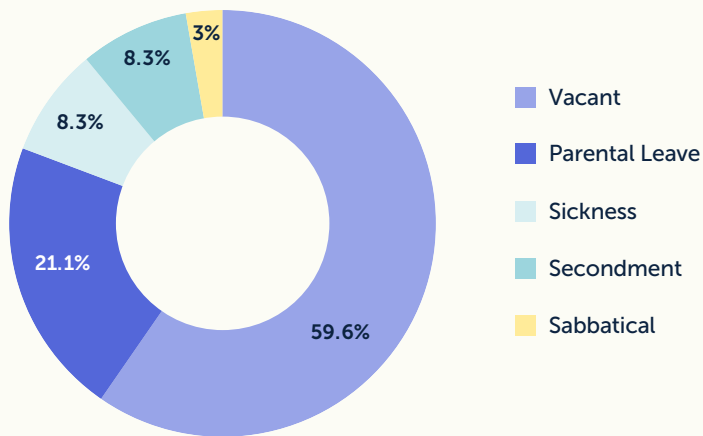
Figure 18: Proportion of vacancies that remain unfilled for ≥ 6 months



Vacancy reasons

Posts may be vacant for a number of different reasons, for example, due to staff moving on or retiring, or due to existing staff being on longer term leave.

Figure 19: Vacancy reasons provided in 2021



Most posts were vacant due to staff having left, but 40.4% were vacant due to a contracted member of staff on parental or sick leave, secondment or sabbatical.

Cover arrangements

In some cases, vacancies can be covered by existing staff, although such staff may not be as qualified and/or available to cover a role fully. Cover staff can be a lower banding or work fewer hours than the staff they are filling in for. To better understand if and how vacant roles are backfilled, the staffing tool collects information about cover arrangements for vacant posts.

Of 109 vacant posts in October 2021, 19 were covered (17.4%), but only nine (8.3%) were covered at the same or higher level/banding than the vacant role.

Table 7: Vacancy cover arrangements

	Paeds Services			Adult Services		
	Covered at \geq banding & WTE level	Total covered posts	Proportion covered at same level	Covered at \geq banding & WTE level	Total covered posts	Proportion covered at same level
2019	0	3	0%	10	16	62.5%
2020	4	10	40.0%	8	17	47.1%
2021	2	6	33.3%	7	13	53.8%

Generally, paediatric services seemed to have relatively low proportions of vacancies that were covered at the same level or higher in terms of staff banding and WTE. This aligns with earlier findings that a higher proportion of vacancies within paediatric centres remained unfilled for six months or more (Figure 18).

Insight: Services for children appear to struggle more than adult CF centres to secure suitably qualified staff, as vacancies in paediatric centres remained unfilled for longer and were more often covered by staff less senior than the substantive post

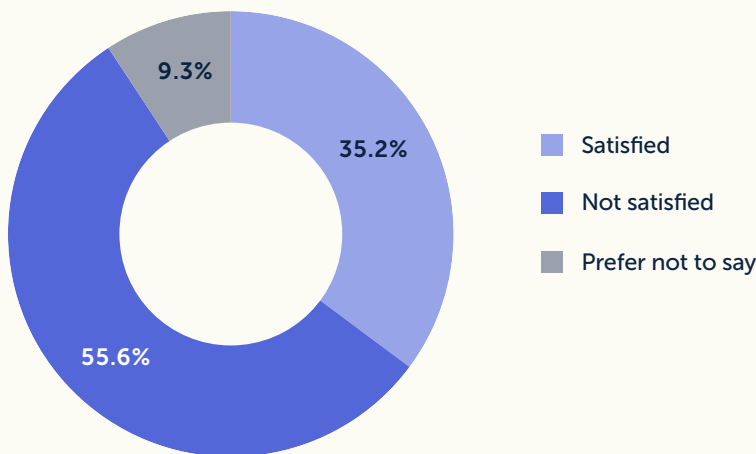
Section 4

Satisfaction with staffing levels

To understand how staff perceive the levels of staffing within their own services, our staffing tool offers respondents an opportunity to share whether or not they are satisfied with the levels of staffing in their service.

Figure 20: Overall satisfaction with staffing levels in October 2021

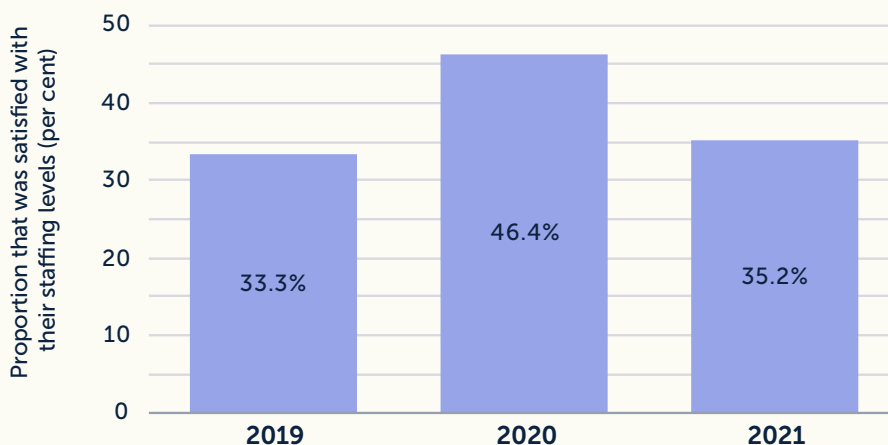
NB: Responses from clinics were counted individually in this calculation; total responses included: 54



In October 2021, satisfaction with staffing levels in CF services was relatively low. More than half of respondents (55.6%) said that they were not satisfied with staffing in their service, and only about a third (35.2%) said they were satisfied.

Figure 21: Proportion satisfied with staffing levels each year, 2019-2021

NB: Based on responses received from participating services, incl. individual clinics, by year



Insight: Satisfaction with staffing levels among respondents remained relatively low year-on-year, with fewer than half saying they were 'satisfied' with staffing in their service.

Each year, fewer than half of respondents across participating services reported that they were satisfied with their staffing levels. Satisfaction seemed to improve in 2020, when it increased to 46.4% and dissatisfaction dropped to 48.2%. Interestingly, this correlates with the finding that vacancy rates reported among participating services had been lower in 2020. However, in 2021, overall satisfaction appeared to have returned to pre-pandemic levels.

As paediatric and adult centres serve different populations, it is also important to consider this information individually. Satisfaction levels followed comparable patterns in paediatric and adult services, with satisfaction higher in 2020 than 2019 or 2021. However, the proportions of respondents saying they were satisfied with staffing levels differed between paediatric and adult centres over time.

Figure 22: Satisfaction with staffing levels in paediatric services over time

NB: Responses from clinics were counted individually in this calculation, which is why service numbers differ from those in previous sections, where clinic responses had been included under their network centre

NB: Percentages below 10% have been rounded to the nearest whole number

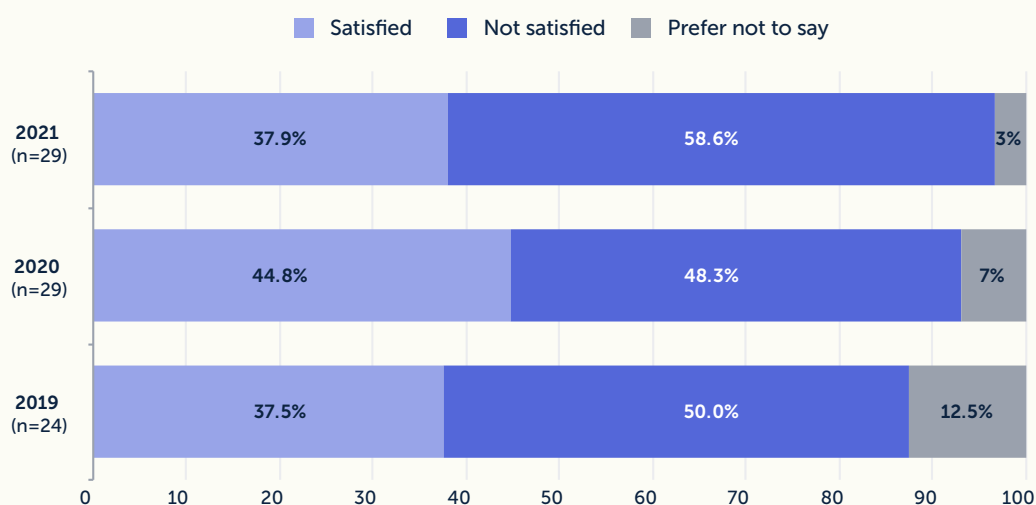
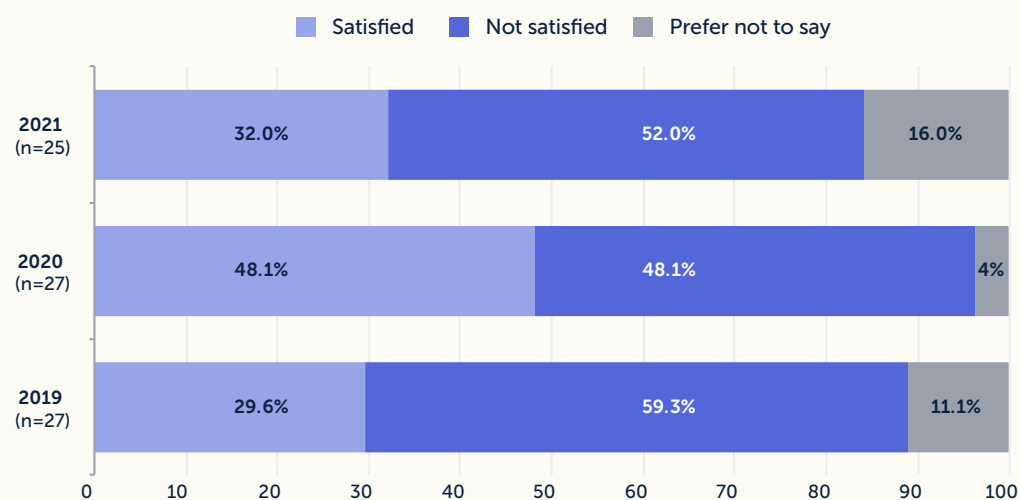


Figure 23: Satisfaction with staffing levels in adult services over time

NB: Responses from clinics were counted individually in this calculation, which is why service numbers differ from those in previous sections, where clinic responses had been included under their network centre

NB: Percentages below 10% have been rounded to the nearest whole number



Section 5

Challenges and Innovations

The staffing tool explores satisfaction with staffing levels and asks respondents to share reflections on challenges and innovations in their service.

Staffing challenges

In 2019, some services reported specific challenges with certain staff groups, including doctors, nurses, psychologists and pharmacists.

"We have no junior medical staff attached to the CF team. It would be really helpful to have additional medical and nursing time, but the main shortage is the lack of CF pharmacist time." Paediatric service

"Our staffing levels in particular for nursing and psychology are woefully inadequate." Paediatric service

Others were concerned about the impact of new treatments on their workload, particularly during the initial roll out.

"The implementation of the CFTR modulator therapies will impact considerably on our workload." Paediatric service

Unsurprisingly, in 2020, several services shared that they faced challenges with staffing due to the COVID pandemic.

"We are broadly satisfied, although there are gaps exacerbated by COVID and physio gaps which are short term and again due to COVID." Adult service

"The COVID pandemic this year has also meant we have had to change the way we work. Many members of the CF team were redeployed to other areas during the real peak of the pandemic." Adult service

In 2021, challenges were again more focused on shortages in specific staff groups, this time more often referencing a lack of social workers specifically. Some centres shared that certain staff, such as pharmacists, also covered other specialties and this meant competing pressures and a potential lack of time for CF work, even when staffing levels were adequate in theory.

"We do not have a social worker and we are very short on consultant and medical time." Paediatric service

"Currently no pharmacist – this post did exist but has been lost after several years of non-recruitment." Paediatric service

"We do not have a social worker and are stretched from a physiotherapy and pharmacy viewpoint as they have to cross cover other specialties." Paediatric service

"Although the staffing levels within our CF budget meet the standards for 100 patients, other clinical pressures mean that this time is not fully realised." Adult service

Insight: While the COVID pandemic exacerbated staffing shortages in 2020, CF services continued to face significant challenges in 2021.

Service innovations

Many CF centres and teams adapt and innovate to overcome staffing and other challenges and deliver the best possible care for people with CF. Our analysis of free text comments in the staffing tool identified a number of different approaches to addressing staff shortages and arising challenges, such as during the pandemic. Mitigating actions taken ranged from seeking additional funding for new posts and expanding existing roles, to working with technologies, other teams and community organisations to change the way care is delivered.

Virtual clinics and remote monitoring

In 2019, some centres had already started to trial remote monitoring and virtual appointments, but this was still a relatively small number. Reported use of virtual clinics increased dramatically as a result of the COVID pandemic in 2020 and 2021, with platforms such as NHS Attend Anywhere facilitating this change. Many CF centres also reported introducing new technologies, such as NuvoAir, to remotely monitor patients at home.

“We have moved to a significant number of appointments being virtual and are utilising remote monitoring following the pandemic.” Adult service

“We have used NHS Attend Anywhere for local and network patients and [...] have provided NuvoAir, weighing scales, postal respiratory culture kits, and all these will continue.” Paediatric service

“We as a team during the pandemic have used ‘Near Me’ technology, NuvoAir and oxygen saturation probes to help monitor patients.” Paediatric service

“Introduced (co-designed with patients) a patient facing app and clinician facing portal for home monitoring plus video conferencing for virtual clinics (spirometry, weight, activity, mood, symptom score). This is now shared with CF and other respiratory disease services around the world.” Adult service

One centre reported offering remote glucose monitoring and virtual reviews to support decision making and prescribing.

“Clinical nurse specialist and dietitian run Freestyle Libre review clinic (virtual) weekly (clinical decision making and prescribing).” Adult service

Another service shared that they had introduced joint virtual transition clinics for young people who are moving from paediatric into adult services to reduce the time normally needed to run such clinics face to face and to limit need for travel.

“To reduce the backlog of young people transitioning to adult care, we have developed and initiated joint virtual transition clinics, which reduced the need for adult CF centres, young people and their families to travel and take more time out of their day to attend [in-person] joint clinics.” Paediatric service

Care at home and in the community

Even before the COVID pandemic, many CF centres had been offering services in the community and/or at home. During the pandemic, more aspects of care were moved into the community and a greater number of participating centres said that they were providing at least some form of care at home when it was safe to do so. This included services such as nurse and physiotherapist home visits, as well as remote monitoring, and various tests for annual reviews.

“Increase in community service to include physio and nurse home visits.” Adult service

“Nursing is part hospital and part community-based.” Paediatric service

“We have introduced community physio since the beginning of the pandemic to avoid travel to hospital for patients. We have also piloted a remote monitoring project to allow patients to carry out vital signs and lung function when unwell, pre clinic visit or for ongoing health monitoring.” Adult service

Several services also said they had started to offer exercise classes online through their physiotherapy team.

"[We offer] virtual general exercise classes and antenatal classes, including Pilates and yoga (physiotherapists and exercise practitioner)." Adult service

"Home support for physio and exercise – including video support." Paediatric service

One service shared that they were rolling out a Hospital at Home programme to be able to deliver more IV antibiotics in people's homes.

Non-medical prescribing

Many CF centres reported that they had non-medical prescribers working in their service. Most were nurse and physiotherapist prescribers, although some services also had pharmacist and dietitian prescribers. A few centres mentioned existing staff who were undergoing training to become non-medical prescribers.

"Both CF nurse specialists and our CF pharmacist are independent prescribers." Paediatric service

"We have one additional nurse prescriber and another one currently in training, which will result in all of our CF nurse specialists being non-medical prescribers." Paediatric service

Distributed prescribing responsibilities offer an effective way to reduce reliance on medical prescribers. Due to the specialised nature of CF care, use of non-medical prescribers may be more common in CF than in other fields.

Expanded or alternative roles

Apart from non-medical prescribing, existing CF service staff also took on other additional responsibilities, and/or agreed to work extra hours, to cover staff shortages. Advanced practice roles, for example, allow physiotherapists to take bloods and carry out port flushes. Several services also mentioned that they had implemented nurse-led, rather than consultant-led, clinics. And one service shared that a nurse was acting as database coordinator in the absence of administrative support.

"[Staff are] working across roles where appropriate e.g. physiotherapist accessing of ports, nurse and dietitian managed continuous glucose monitoring." Adult service

"Upskilling [our] MDT to become CF practitioners (i.e. able to cross cover basics of other specialisms; taking blood, doing spiro, discussing diet and diabetes)." Adult service

In some services, non-specialist staff were asked to step in to deliver certain aspects of care. This included the use of Welfare Rights / Social Welfare Advisors to cover vacant social worker posts, asking respiratory Advanced Nurse Practitioners to support annual reviews, and use of a Physiotherapist Technician to free up specialist CF physiotherapist time.

"Welfare rights adviser employed to cover vacant social work role, as unable to recruit 0.25WTE social worker." Adult service

"[Our] Band 4 Physio Technician has had a positive impact on the physio service taking on less specialised aspects." Paediatric service

One paediatric centre, which had noted a need for more psychologist time, had introduced a joint youth worker to support transition from children to adult services.

"Would like more psychologist time – recently a joint youth worker [was] appointed with adult service which helps to bridge some of the social and psychological problems faced by paediatric patients especially around adolescence." Paediatric service

A challenge with this approach is that such alternative staff are rarely specifically trained in CF care, and hence those covering the posts may lack the in-depth understanding of the condition that specialist CF staff would bring. Non-specialist roles are therefore only useful in some circumstances and cannot replace a fully qualified CF specialist.

However, gaps in CF knowledge could be at least partially mitigated through close working with CF teams. For example, one centre said that they had a Band 5 ward nurse supporting their CF team for a time to help build the ward nurse's CF knowledge, which could then be shared with other ward staff. Furthermore, the service felt that this approach could support succession planning to avoid future clinical nurse specialist (CNS) shortages.

"Band 5 ward nurse works 3 days a week with the CF team for 6 months to provide ward staff with a universal knowledge of CF from diagnosis to transition and not just knowledge gained from CF patients who are admitted for treatment. This also will support succession planning for future CNS posts." Paediatric service

Close working with others

Some CF centres also mentioned working with other health professional groups to provide care. This included working with primary care in communities, as well as other specialist teams, such as the diabetes team and the palliative care service. It also included liaison with midwives and maternity services, where relevant.

"Improved links with Diabetic Team [and] developed links with GI service." Paediatric service

"We have strong links with a palliative care consultant, which has greatly benefited the service." Adult service

"Increased liaison with midwives and new CF record/documentation during pregnancy." Adult service

Some centres also mentioned links to local organisations and sports clubs to support exercise programmes in the community.

Proactive research and quality improvement

Several CF centres, most of them adult services, specifically mentioned involvement in research and quality improvement to ensure high quality care. Some even confirmed that they were securing additional roles or freeing up staff to support these activities, or were regularly reviewing opportunities for improvements.

"Permanent Adherence and QI Lead developed from CF Health Hub programme." Adult service

"[We have] weekly QI meetings to review service and systems." Adult service

This included use of the CF Health Hub, an online platform to support medication adherence and behaviour change.

"Active involvement with Health Hub research study delivered by physiotherapist and pharmacist. Training and QI work integrated into the clinical service." Adult service

Other innovations

Participating CF services also talked about a number of other innovative approaches they used to address challenges, particularly those faced during the COVID pandemic. Often, these approaches used technology to overcome barriers created by the pandemic. One service, for example, established a private social media space for families under its care to make communication and information exchange easier.

"Development of private Facebook page to support families during COVID." Paediatric service

Another CF service, which had only recently started to register patients, created a video to help people with CF and their families explore the new service remotely.

"As we have recently become a CF centre, due to pandemic, we created a video showing our service to help families make their transition from previous CF centre." Paediatric service

Another service used a community nurse with CF expertise to deliver education and training in the community. Due to the pandemic, this centre moved its offer online to continue educating those who work with people with CF, such as teachers, about the condition and its challenges.

“School staff CF education/training is now completed virtually, which reduced the amount of time taken by the CF Community Nurse to travel to schools in different areas.” Paediatric service

Further approaches to managing staffing and other challenges that were mentioned by CF centres included securing charitable funding for a fixed term ‘CF Medicines Interventionist’ post and seeking funding to develop sufficient in-patient en-suite facilities.

Insight: Teams and services innovate to meet the needs of people with CF despite challenges with staffing, vacancies and the COVID pandemic.

Recommendations and next steps

UK-wide recommendations

Engagement with the staffing tool has remained high despite the COVID pandemic, with 49 of 60 CF centres contributing in 2021. This, together with the relatively low satisfaction levels recorded year-on-year, indicates that CF services worry about their staffing levels and are keen to review them.

Findings from our Patient-Reported Experience Measures¹⁵ show that CF teams are still delivering high quality care, but there is clear evidence that teams are stretched. The staffing tool found that CF MDTs often do not have dedicated psychosocial input, nor do they consistently have pharmacy or research staff. While existing or alternative staff may take on some of these responsibilities, such cover arrangements often cannot fully replace a dedicated CF specialist.

High vacancy rates, particularly for social workers and psychologists, are concerning, given the crucial role that psychosocial support plays in holistic CF care. We may also see an increasing need for this type of support in coming years due to financial pressures linked to the rising cost of living, and due to the impact of new modulator therapies on those who can and those who cannot take them. The fact that many services report struggling to recruit and/or retain qualified psychosocial staff is worrying, especially where posts remain vacant long term.

Paediatric and adult services have different staffing configurations and face diverse staffing challenges. Consideration of service type, centre size and population needs is important when trying to address staffing challenges at local and regional levels. Furthermore, each centre's staffing data should ideally be considered in the context of other, complementary intelligence, including data on patient experiences and outcomes, for example from the UK CF Registry.

However, from the insights in this report, we can make some general recommendations that apply across the UK:

- Sufficient resourcing of CF services is essential to ensure staffing levels are adequate to cater for the evolving needs of the population and to ensure all people with CF can access the right professional(s) at the right time
- Exploring issues around staff recruitment and retention at national level is important to avoid vacancies remaining unfilled for long periods of time, particularly where there appear to be common challenges with attracting suitably qualified staff, such as in psychology and social work
- Continuous monitoring of staffing levels in CF centres and across the CF population as a whole is warranted to better understand how these change over time and to identify and explore early any trends that could impact on CF care delivery
- Many services innovate to address staffing challenges and should be encouraged and enabled to share learning from the changes they made with others¹⁶

¹⁵ Cystic Fibrosis Trust, Patient-Reported Experience Measures; 2022 www.cysticfibrosis.org.uk/QI

¹⁶ The Cystic Fibrosis Trust Quality Improvement team is looking to develop a series of innovation case studies; contact the team at QI@cysticfibrosis.org.uk

Service-level recommendations

All CF centres that contributed to the staffing tool have been issued with a tailored report showing staffing and vacancy levels in their service, compared to average levels from across the full sample. Centre staff can review the UK-wide report alongside their centre-level report to better understand how their staffing levels compare.

If a service identifies any specific issues with their staffing levels, it is important to consider the cause of any shortages in order to address them. For example, a lack of funding for posts needs to be tackled differently to issues with recruitment to existing, but vacant posts. A service might also be fully staffed for some staff groups but lack others entirely.

When exploring staffing challenges, consideration should be given to the needs of a centre's population, which may also change over time. This could be facilitated by regularly capturing and reviewing patient outcomes and experiences, for instance through ongoing contribution to the Trust's CF Registry and participation in the staffing tool, as well as future cycles of patient-experience surveys.

Depending on local needs and challenges identified, CF centres could consider steps they could take to address these. For example:

- If a centre has recognised that it needs additional funding for new posts, it could use evidence from its staffing report and the UK-wide findings, in addition to other intelligence, to develop a business case
- If a centre has longstanding vacancies in a staff group and is struggling to recruit to these posts, it could review the recruitment process, including job descriptions and how roles are advertised, seeking advice from professional bodies and others to attract candidates
- If a centre has identified specific pressures, it could explore innovative solutions to relieve some of these pressures, e.g.:
 - use of virtual and joint clinics to reduce travel time
 - upskill existing staff to become non-medical prescribers to reduce pressure on existing prescribers
 - increase provision of services such as remote monitoring and home IVs in the community to relieve pressures on inpatient facilities
 - use alternative roles to deliver some aspects of care, to free up specialist CF staff time for more specialised aspects of care

Our next steps

The Cystic Fibrosis Trust Quality Improvement team will continue to monitor staffing levels in CF centres through our annual staffing tool. We will publish our findings annually from now on to help identify trends, changes and challenges, and to share the innovative approaches CF centres use to ensure they can provide the best care for people with CF. We will continue to improve our staffing tool and will encourage all CF centres across the UK to participate to give as clear a picture as possible of staffing levels and any changes over time.

Working with our Quality Improvement Working Group, made up of people with CF, family members and CF health professionals, we will support centres to explore and try to address staffing challenges. We will also work with our Policy team and others to better understand the particular challenges in recruiting and retaining social workers and psychologists, and to advocate for more psycho-social support for people with CF.

The team can be contacted at: QI@cysticfibrosis.org.uk

Glossary

Word/phrase	Meaning
Centre	Hospital providing expert care and specialised disease management to people living with cystic fibrosis
CF	Cystic Fibrosis
Clinic	Regional hospital or site where treatment is provided locally for people with CF; clinics are linked to a centre hospital / CF team via a network.
CNS	Clinical Nurse Specialist
Community support	Care that is delivered locally or at home
Cystic Fibrosis Service Specification	Standard of care issued by NHS England that adult and paediatric CF centres in England are working to
FTC	Fixed-Term Contract, a time limited type of employment
Home IVs	Intravenous antibiotic therapy given in the patient's home
Median	The middle value (number) when all values in a series are arranged from smallest to largest.
MDT	Multi-Disciplinary Team; your CF team made up of each discipline i.e. nurse, physio, social worker, dietitian.
Network	A CF centre and its linked clinics form a network
PREMs	Patient-reported experience measures
QI	Quality Improvement – a framework we use to systematically improve the ways care is delivered to patients
QI WG	Quality Improvement Working Group – a group of health professionals and patients/parents working to improve the way care is delivered to those living with cystic fibrosis
Range	Smallest to largest value
Standards of Care	The Cystic Fibrosis Trust's recommended best practice guidelines for CF services (2011)
WTE	Whole-Time Equivalents

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

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