Cystic Fibrosis Trust

UK cystic fibrosis service resourcing 2019

Preliminary report

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Fighting for a Life Unlimited

Introduction

Since the mid-1990s, people with cystic fibrosis (CF) living in the UK have been cared for by specialist multidisciplinary teams, with their recommended composition detailed in the Cystic Fibrosis Trust's 2011 Standards of Care[1]. Since 2000 the median age of the population has increased from 15.3 years to 21.0 years, with the proportion of people with CF aged 16 or over increasing from 48.0% to 60.6% between 2000 and 2019[2]. Today 10,655 people in the UK are living with CF, with specialist clinical teams providing care across 57 centres and 76 clinics in 2019.

The multidisciplinary, specialist approach to CF care has seen huge improvements in the provision of care, production of research and, most importantly, the health outcomes and experience of care by people with CF and their families. To continue this trend of improvements, it is essential to ensure that CF centres have sufficient staff to provide high quality and safe care, and that this care can be accessed in a timely manner. Recruitment and retention of staff within the NHS has become a key priority, as set out in the recently released NHS People Plan[3] and numerous high-profile reports published in the last few years by leading think tanks, such as the Health Foundation[4] and Nuffield Trust[5]. These have highlighted areas of concern in the NHS staffing situation, particularly daily or weekly gaps in hospital medical cover and shortages in nursing staff. Overall, data has shown that NHS providers have seen an increase in their vacancy rate that is attributed to increased demand and higher leaver rates. As this first round of staffing data was collected before the UK left the EU, future reports will provide a useful insight into areas such as levels of staffing vacancies pre- and post-Brexit.

A priority of the Cystic Fibrosis Trust is to, in close collaboration with our independent Clinical Advisory Group, 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 the UK CF Registry, and collecting Patient Reported Experience Measures (PREMs). In 2019, we undertook to gather information on the staffing levels across CF services around the UK via an online survey. Our objective is to measure staffing levels in CF over time to identify early any changes that may positively or negatively impact CF care delivery.

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

[2] UK CF Registry Annual Reports: www.cysticfibrosis.org.uk/registryreports

[3] NHS England & NHS Improvement, We are the NHS: People Plan for 2020/21 – action for us all, July 2020: https://www.england.nhs.uk/publication/we-are-the-nhs-people-plan-for-2020-21-action-for-us-all/

[4] The Health Foundation, A Critical Moment, February 2019: https://www.health.org.uk/sites/default/files/upload/publications/2019/A%20Critical%20Moment_1.pdf

[5] Nuffield Trust, The NHS Workforce in Numbers, May 2019: https://www.nuffieldtrust.org.uk/resource/the-nhs-workforce-in-numbers

Scope of the report

This 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 particularly useful during a period of dramatic change in the CF landscape, as CFTR[6] modifiers are introduced to increasing proportions of the population, further altering the demographics of CF alongside dramatic changes in digital health offerings and the wider NHS funding landscape.

Using the snapshot data collected in year one, we are publishing this initial report to document insights drawn from our first data collection. As recommended by the Clinical Advisory Group, all staffing groups within UK CF centres will be incorporated. We will include the level of engagement in this voluntary exercise by CF teams and areas where the data collection process and tools require development, as well as the configuration and whole-time equivalent (WTE) resourcing of CF teams, and innovations in resource allocation.

This report is not intended as a substitute for the Cystic Fibrosis Trust 'Standards of Care'[1] recommended staffing levels, although it is hoped that providing baseline levels in core staff groups will help in future reviews of appropriate staffing levels.

Methodology

In June 2019 the Cystic Fibrosis Trust's Quality Improvement team contacted all 60 CF centres or stand-alone clinics across the UK, inviting them to participate in the Staffing Tool survey during the month of October 2019. 49 centres agreed to participate, with 47 ultimately completing the survey. Centres were asked to complete a secure online tool that captured staff group, WTE, contract types, vacancy reasons and vacancy cover (Appendix 1). This covered the period 1-31 October 2019, although some data entry was completed by the Quality Improvement (QI) team post-lockdown of the tool, based on Staffing Tool proformas completed by the centres.

Key messages

Capturing CF team staffing configuration is complex

Creating a tool to collect detailed information on staffing levels in a standardised manner was difficult. Despite issuing guidance and extensive consultation with the Clinical Advisory Group, some data elements were not completed in a consistent manner. This is particularly true with regards to beds and nursing staff. There is great variation in the way that CF teams describe their structures and resources. Teams manage limited staffing resources by sharing staff across adult and paediatric centres and local and regional networks. Many services rely on non-specialist staff and have different funding sources, even for their specialist staff. These factors, together with the difficulty in pinpointing monthly WTE dedicated to CF by different

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[6] 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.

team members, make gathering a comprehensive view of human resourcing challenging

Not all people with CF have access to a full multidisciplinary team

Table 1: Proportions of centres that have each staff group
(24 Paediatric centres, 23 Adult centres)

	Paediatric	Adult
	% (N)	% (N)
Medical	95.8 (23)	100 (23)
Dietetics	95.8 (23)	100 (23)
Nurse	100 (24)	100 (23)
Physiotherapy	91.7 (22)	100 (23)
Admin	70.8 (17)	95.7 (22)
Other*	16.7 (4)	42.8 (11)
Pharmacy	70.8 (17)	91.3 (21)
Psychology	91.7 (22)	100 (23)
Research	12.5 (3)	69.6 (16)
Social Work	33.3 (8)	60.9 (14)

*"Other" represents the following job titles: Health care assistant, Microbiologist, Support time and recovery worker, Quality Improvement Officer, Pulmonary Physiologist, Social Welfare Advisor, Respiratory Technician, Clinical Support Worker, Youth Worker, Housekeeper.

There appears to be a difference between access to the four largest staffing groups in paediatric and adult centres. While participating adult centres have 100% coverage, two paediatric centres are without CF physiotherapists, with one of these centres also missing specialist dietetics staff and a separate paediatric centre stating they were missing CF specialist medical staff. Further investigation in future data rounds is required to understand whether this potential finding is an artefact of data collection practices, or due to other factors integral to the different cohorts being cared for.

Looking across all staff groups, a lower proportion of paediatric centres have access to admin, other, pharmacy, psychology, research and social work staff, although the psychology difference is relatively small as based on two paediatric centres missing access. The levels of access to social workers, identified as a key member of the CF multidisciplinary team in the Cystic Fibrosis Trust's 'Standards of Care'[1], appears particularly low. However, in the cumulative graph above (Figure 1), which breaks down staffing levels by band and WTE per 75 patients, we can see that paediatric centres appear to have slightly more medical, nursing and dietetics staffing time compared to adult centres (equivalent to 1 WTE nursing staff more for a centre of 300 patients).

CF services have high vacancy rates and some services and staff groupings are affected more than others

A recent NHS Improvement report showed a WTE vacancy rate of 9.2% across all NHS providers[7], compared to 7.1% for participating UK CF centres. This indicates that although the CF centres have a vacancy rate that is lower than the overall NHS rate and adult social care, it is still higher than vacancy rates for other public sector areas[8]. The overall WTE vacancy rate in participating UK CF centres is lower in paediatric compared to adult services (6.2% vs 7.5%).

Table 2: WTE and Vacancy rate in participating UK CF centres*

	Oct '19
Total workforce WTE	628.9
Vacancy Rate (%)	7.1
WTE Vacancies	44.8

*The WTE for vacancies is not included in the current workforce WTE eg the vacancy rate denominator does not include vacancy WTE, to ensure comparability with NHS Improvement Staffing Reports. This makes the vacancy rate higher than if vacancy WTE was included in the denominator and so care should be used when comparing this rate with other sectors.

Table 3: Number of vacancies unfilled for more than six months out of Total Open Vacancies, per staff group

	UK Adult average	**UK Paeds average**
	N	**N**
Nursing	2/5	1/3
Physiotherapy	0/6	0/3
Dietetics	1/5	1/3
Psychology	1/4	3/6
Social work	5/5	2/3
Pharmacy	0/2	1/1
Research	0/0	1/1
Admin staff	2/5	0/2
Other	0/1	1/1
Medical	2/6	0/2
Number of posts covered at same banding & WTE or higher**	0/3	10/16

NB: Vacancies that are being covered are excluded from number of vacancies unfilled for more than six months. **Number of posts covered at same banding and WTE or higher/number of posts covered

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[7] NHS Improvement, Performance of the NHS provider sector for the quarter ended 30 June 2018. 2018.https://improvement.nhs.uk/documents/3209/Performance_of_the_NHS_provider_sector_for_the_month_ended_30_June_18_FINAL.pdf

[8] Office for National Statistics, What are the vacancy trends in the public sector? August 2019: https://www.ons.gov.uk/economy/governmentpublicsectorandtaxes/publicspending/articles/whatarethevacancytrendsinthepublicsector/2019-08-06

Across both adults and paediatrics, the majority of social worker posts were vacant for six months or more. We are unable to identify from the data if long-term vacancies are due to a decision by the centre to not advertise for cover*, difficulties establishing a supervisory structure for a social work role within a medical team, or issues finding staff to cover the post.

As shown above, cover is not always possible to find and where cover staff are in place, they are often at a lower banding and/or WTE than the staff they are replacing.

It should be highlighted that although a centre has a CF staff member in each staff group, they may not be fully staffed in that area. This is highlighted by the number of psychology vacancies (10 across 47 participating centres) despite 100% of adults and 91.7% of paediatric centres having access to a CF psychologist.

Adult and Paediatric teams have different staffing configurations

Table 4: Staffing Tool - Staff WTE per 75 patients.

	Adult	**Paediatrics**
Admin	0.7	0.5
Medical	1.0	1.2
Dietetics	0.6	0.8
Nurse	1.8	2.0
Other	0.4	0.1
Physio	1.7	1.4
Pharmacy	0.4	0.2
Psychology	0.4	0.5
Research	0.4	0.1
Social Worker	0.2	0.2

Based on 1,066 obs.

Adult and paediatric centres appear to have comparable levels of staffing (within 0.2 WTE per 75 patients) across all staff groups apart from physiotherapy, research and other, where adult staffing levels are higher. Comparison of Staffing Tool WTE levels per 75 patients to the Trust's 'Standards of Care' document[1] is not possible, as the 'Standards of Care' document provided levels for CF specialist staff, not all staff proving a service to CF patients.

Staffing levels may be linked to ability to meet professional standards and clinical outcomes. The UK CF Dietetics Group surveyed 16 adult dietitians to investigate how perceptions of sufficient and insufficient levels of adult dietetics staffing relates to number of patients per WTE dietitian. They also explored how these factors related to the ability to provide a full service for patients, with items such as ability to contact patients within a few weeks of sending oral nutritional samples or do home visits higher in the group that felt they had sufficient staffing.

*The UK psychosocial group have advised they were unaware of these vacancies being advertised.

The study also found the BMI of 71% of the centres perceived as having adequate dietetics staffing was above the mean, in direct contrast to the 'insufficiently staffed' centres where 71% had a BMI below the mean.[9]

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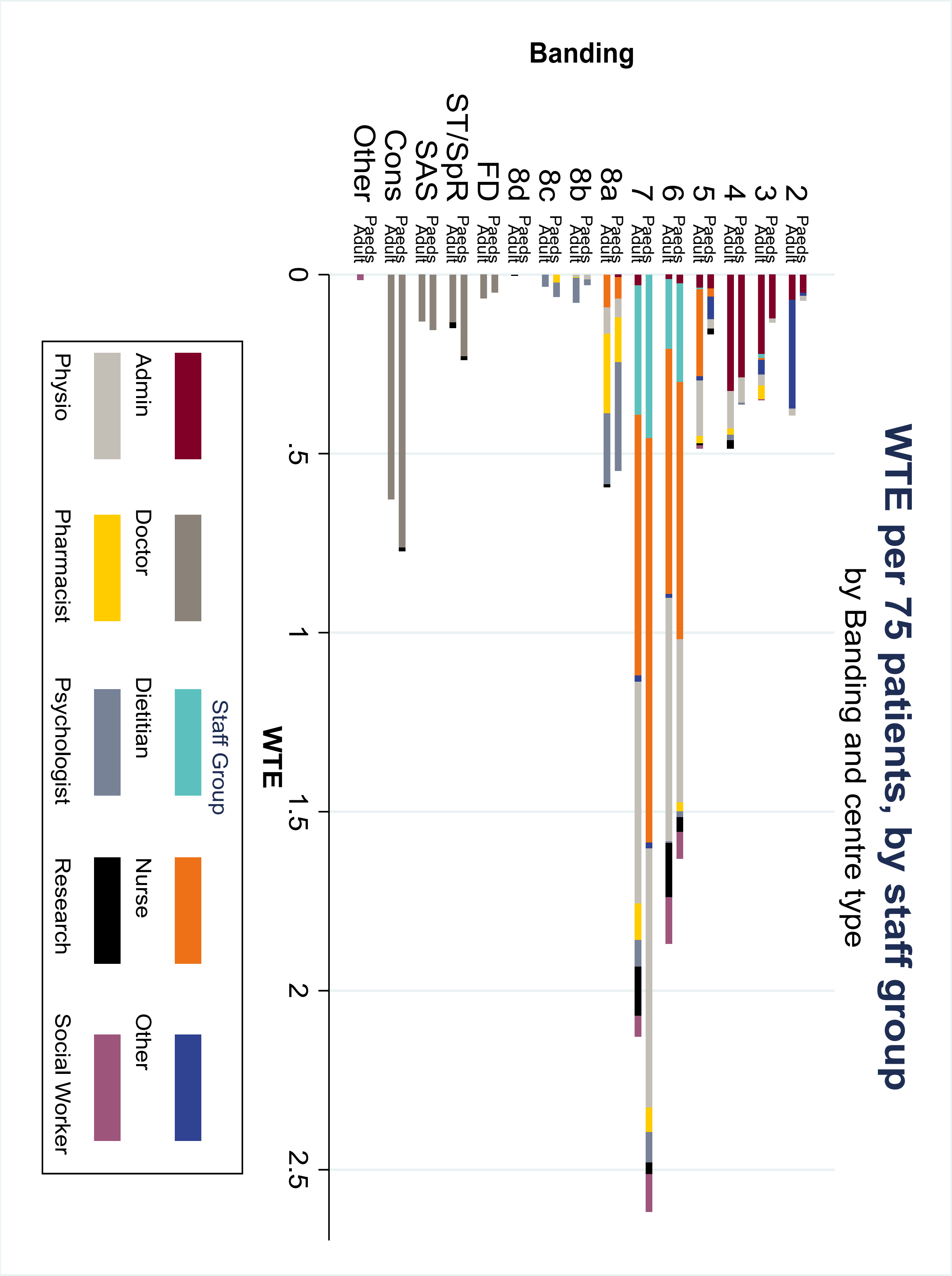
[9] Bara, V. (2019). Variations in dietitian service provision across UK adult cystic fibrosis centres. ECFS e-poster.


WTE per 75 patients, by staff group
by Banding and centre type
Banding
2
3
4
5
6
7
8a
8b
8c
8d
FD
ST/SpR
SAS
Cons
Other
Paeds
Adult
0
.5
1
1.5
2
2.5
WTE
Staff Group
Admin
Doctor
Dietitian
Nurse
Other
Physio
Pharmacist
Psychologist
Research
Social Worker

One interesting observation is that adult staff appear to have a statistically significant higher proportion of lower banded staff than paediatric centres (22% of staff at Banding 5 or lower in adult centres against 12% in paediatric centres, P<0.001). See Appendix 2. One potential explanation may be that in paediatrics, CF staff often work in smaller teams and may be more likely to take on management responsibilities compared to adult centres, which have a larger variation in grades.

For both adult and paediatric centres different staffing groups appear to accumulate at different bandings, with admin staff concentrated at bands 2, 3 and 4 (the ‘Other’ staff at Band 2 that can be seen in higher levels in the adult bar are predominantly health care assistants). Nurses and physiotherapists make up the majority of staffing time at bands 5, 6 and 7, with dietitians and social workers concentrated at Bands 6 and 7. Psychologists and pharmacy staff are the largest proportion of staff at bands 8a-8d. In general, the composition of staff for each banding is similar between adult and paediatric centres with one exception. Nursing staff tended to be more qualified in paediatric centres than adult centres, with 97% of paediatric nursing staff at Band 6 or above, compared to 83% of adult nursing staff.

Over half of CF centres are not satisfied with their staffing levels

Figure 2: Satisfaction with staffing levels

3 obs were excluded due to missing data

1 obs was excluded due to missing data

57% of participating services reported that they are not satisfied with the staffing levels in their CF service. 31% reported satisfaction, with the remaining 12% preferring not to respond to this question. Levels of satisfaction reported were similar between adult and paediatric services.

*Clinical psychologists post-training enter the NHS at Band 7.

CF teams innovate to meet the needs of people with CF

In the face of challenges associated with post provision and vacancies, CF teams innovate and adapt in order to provide the best possible care for people with cystic fibrosis. Common themes are provided in the graph below.

- Providing care in the community, either through home IV services*, exercise programmes or support for families at key moments such as immediately after diagnosis.
- Non-medical prescribing appears to be particularly well-developed in CF services across nursing, pharmacy, dietetics and physiotherapy staff, perhaps due to the specialised nature of the field.
- Use of non-specialist staff to deliver certain aspects of care eg physiotherapy technical instructors providing exercise programmes and support.
- New collaborations including working with a charity to deliver paediatric exercise programmes and developing closer links with palliative care teams, diabetes services and establishing link tertiary consultants in areas such as gastroenterology.
- Research and QI, encompassing areas such as the CFHealthHub work on service improvement and adherence.

Other staffing innovations that have not been included in the table (less than two comments) are a rapid response physio unit and staff from one centre working across two Hospital Trusts. We can see that at the point this Staffing survey was completed, although some centres had started to trial remote monitoring and virtual appointments, this was still a relatively small number and in contrast, one centre described developing satellite clinics to be closer to patients and their families. It is likely that adaptations from the sites to support patients at home during the COVID-19 pandemic will lead to an increased number of centres using remote appointments in the next survey.

Workarounds

Some centres are using welfare advisors or volunteers to cover certain aspects of the CF social worker role, but this is a partial, short-term solution to the lack of qualified social workers in CF care.

“In CF teams, if a CF social worker is not integrated within the team, issues such as inequality, vulnerability and crisis will be at risk of not being managed safely. Or another staff group will attempt managing it, which is not their integral job responsibility.”
UK CF Psychosocial group, 2020

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* How homecare is provided varies. Some centres reported use of private companies to provide homecare while another adult centre stated they had reduced their use of homecare companies and increased use of their Trust pharmacy to reduce costs.

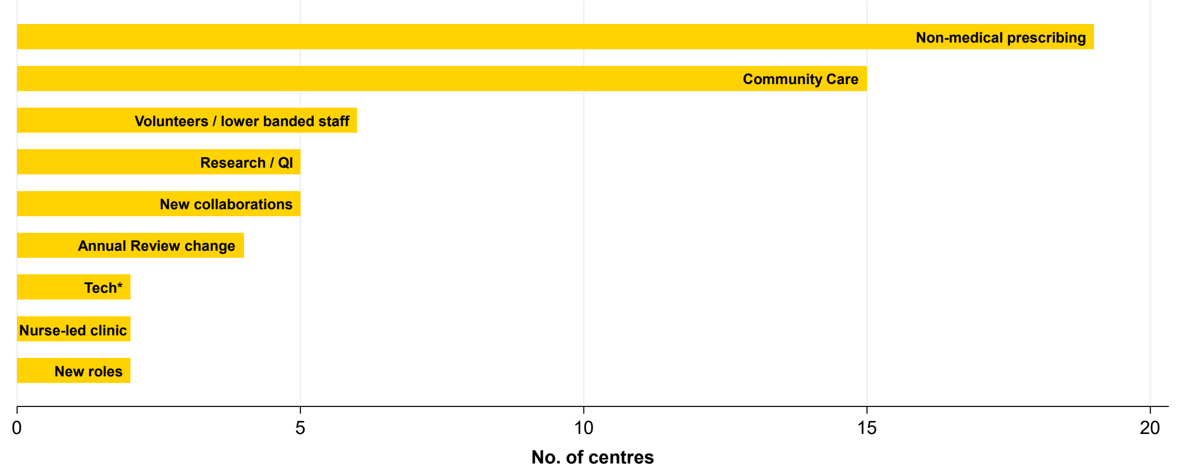

Figure 2: Innovations in UK CF centres

*Tech incorporates any use of remote monitoring, virtual appointments or apps.

32 out of 47 specialist centres provided comments on innovations that they have implemented to handle service pressures. Some centres also took the opportunity to describe other issues. Several centres expressed concerns regarding a lack of time and/or resource to implement CFTR modulator therapies, particularly if their network clinics have different funding arrangements. Also mentioned was the difficulty for some centres in accessing space or funding to develop sufficient inpatient en suite facilities for their patients.

Bed availability

When reporting bed availability, it was difficult for sites to report all the beds available for people with CF, particularly distinguishing between beds solely available for CF patients versus those where people with CF take priority. The complexities apparent in bed allocation have made it difficult to get a clear picture of bed availability for people with cystic fibrosis. It is clear that high levels of variation are present across centres in this area, with several centres reporting having received funding to develop new CF wards, one with up to 20 single beds with en suite facilities, while some centres have limited or no en suite facilities, despite current NICE guidance[10].

Discussion

Engagement with the staffing tool was high, representing 47 out of 60 CF centres. This possibly reflects concerns about the future resourcing of CF care in an increasingly challenging funding environment. As COVID-19 accelerates the move towards virtual appointments and home monitoring, it will be interesting to see how, or if, this affects staffing levels.

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[10] NICE Quality statement 2: Preventing cross-infection during hospital admissions. https://www.nice.org.uk/guidance/qs168/chapter/Quality-statement-2-Preventing-cross-infection-during-hospital-admissions

As this data is a snapshot of staffing levels, it is possible that the staffing situation is different at other times of the year. The longitudinal data gathered as the Staffing Tool is repeated annually will help gain an overview of how staffing levels are altered with the potential introduction of new commissioning arrangements and the impact of CFTR modulator roll-out.

It is hard to determine the impact of low or missing staff levels in some staff groups. Although it is likely that centres have access to non-CF specialist staff within their Hospital Trust, the quote below highlights the importance of CF specialist staff.

> "The level of expertise required to treat the complex multi-system symptoms and complications in CF can only be acquired by a multidisciplinary team of trained, experienced, specialist health professionals who routinely see a critical mass of patients at a specialist CF centre." Cystic Fibrosis Trust Standards of Care, 2011.

Paediatric and adult centres appear to have some different staffing issues, as paediatric centres have proportionally less access to key CF specialist staff members while adult centres have higher WTE vacancy rates and lower staffing time per 75 patients against recommended levels. The two centre types are likely to be affected differently by access to CFTR modifiers and should continue to be analysed seperately.

Next Steps

1. All CF centres will be encouraged to participate in future years, to give as clear a picture as possible of staffing levels and any changes over time.
2. The data collection tool will be amended in line with feedback from CF centres, the Clinical Advisory Group, and the Quality Improvement team. It is noted that centres have particular need of high-quality beds data for benchmarking purposes.
3. Staffing data should be considered in the context of other intelligence, including the UK CF Registry reports and forthcoming reports on Patient Reported Experience Measures (PREMs). This can be split into two strands. **Reporting**: The Quality Improvement Team will incorporate how satisfied patients were with access to their multidisciplinary team, together with staffing levels and clinical outcomes, to help centres make the case for more staffing. **Data impact**: The Trust's new Quality Improvement Working Group will support centres to use the staffing data with other data sources, to ensure maximum impact on improving quality of care.
4. Non-medical prescribing and community care could be considered by CF services as a useful strategy to manage pressure on inpatient beds and CF clinics.
5. The Cystic Fibrosis Trust will facilitate discussions between the UK CF Psychosocial Group and centre directors to identify where the social worker recruitment bottleneck lies and steps that could be taken to resolve it.
6. Some paediatric centres don't have access to a CF specialist pharmacist. The Cystic Fibrosis Trust's Quality Improvement team will support researchers to use the staffing data to investigate whether staffing levels may affect the roll out of new therapies.

7. The Cystic Fibrosis Trust’s Quality Improvement team will validate the staffing data using data checks with centres. Included in this process will be identification of ‘work-arounds’ used by centres who do not have CF specialist support in particular staff groups.

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