Cystic Fibrosis Trust

UK Patient Reported Experience Measures (PREMs) Survey

Adult CF Services Report

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Uniting for a life unlimited

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Acknowledgements

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Cystic Fibrosis Trust

UK Patient Reported Experience Measures (PREMs) Survey

Adult CF Services Report

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Summary and key data

Participation and feedback

We would like to thank people with cystic fibrosis, as well as clinical teams, for promoting and completing our patient experience survey. Overall, 1,285 responses were received from adults with CF under the care of 25 of 28 UK CF centres/networks. This represents approximately 21% of the CF population in adult care in the UK. All CF centres that took part have received a bespoke, anonymised summary of their local data.

Key data insights

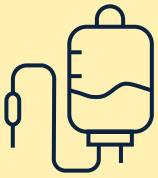
Access and support from the CF team

Over 99.5% of respondents who had needed CF specialist doctors, nurses, physiotherapists or dietitians said they had been able to access these professions.

11% of respondents who had needed support from a CF social worker said they could not access this, as no one was available. For CF clinical psychologists, this was 5.7%.

96.3% of ratings for support received from the different professions in the CF team were excellent or good.

IV antibiotics



66.4% of respondents had always started urgent IV antibiotics within 24 hours.

77.5% of respondents had never experienced delays (>7 days) in admissions for planned IV antibiotics.

52.8% of respondents who had home IV antibiotics accessed these from a homecare company. 43.1% received them from their hospital pharmacy.

59.2% of respondents said they preferred home IVs, 26.5% favoured hospital IV treatment, and 14.3% had no preference.

Communication with and seeing the CF team

98.9% of respondents knew how to contact their CF team during working hours, falling to 75.5% out of hours.

93.9% of respondents had had outpatient contact with their CF team in the last year, with 96.2% rating their experiences of such consultations as excellent or good.

38.6% of respondents said they would prefer a combination of virtual and hospital care, while 33.3% favoured hospital clinics and 22.9% wanted primarily virtual care.

88.7% of respondents confirmed they were satisfied with the time taken to communicate test results.

Care at home and in the community

86.6% of respondents used some form of home monitoring equipment, with most able to measure lung function at home.

79.8% of respondents confirmed they used airway clearance equipment at home, with most receiving this through their CF team.

21.2% of respondents had access to care at home or in the community, with 84.6% of these confirming that this was provided by their CF team.

Annual reviews

84% of respondents had an annual review in the last 12 months and most completed their annual review as an outpatient appointment.

Over 90% of respondents had lung function and blood tests done or discussed at their annual review, but there was some variation in other types of test carried out.

Over 90% of respondents confirmed they had seen a CF nurse, physiotherapist and dietitian at their last annual review. However, the proportions who had seen a CF psychologist, social worker or pharmacist were much lower.

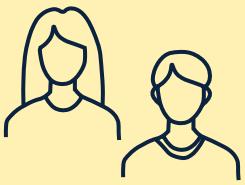
82.9% of respondents confirmed they had received written feedback from their last annual review, but 17.1% could not recall having had feedback.

Experiences of support with managing CF

Most people with CF who responded felt that their care was individualised to their needs, though a few respondents also shared disappointing experiences.

88.5% of ratings for support received from CF teams at key times and with key issues were excellent or good.

93.6% of ratings given for support with physical health and hospital care were excellent or good. In contrast, 80.2% of ratings for support with social, mental and wellbeing issues were excellent or good.



Infection control and prevention

98.5% of respondents felt infection control measures were sufficient at their CF centre or clinic, but some raised concerns about infection control, particularly in other areas of hospitals, such as x-ray and pharmacy departments.

Hospital care

21.1% of responses indicated that people with CF had waited in a waiting room on at least one occasion when they visited their outpatient clinic.

29.7% of responses indicated that height and weight were measured in the same room for all patients. For lung function, this was 16%.

78.7% of responses confirmed admissions to CF wards (or wards with experienced CF staff), but a few respondents said they had been admitted to a non-CF ward on at least one occasion as a bed on the CF ward was not available.

91.5% of responses confirmed stays in private rooms with en suite bathrooms during hospital admissions, but a few respondents had to use bathrooms that may be accessed by others with CF, or shared rooms or bays.

89.1% of respondents rated ward care during inpatient stays as excellent or good, but other aspects of care were rated less positively. 11.7% and 12.3%, respectively, rated access to additional food and receipt of drugs to take home as poor.

Recommendations

Responses from people with CF highlight a need for:

- equitable access to specialists with CF expertise, particularly social workers, clinical psychologists, and pharmacists
- enhanced person-centred approaches to CF care, considering people's individual needs and preferences, offering choice and involving patients in decisions
- greater collaboration and coordination within and beyond CF teams to support a growing and diversifying adult population with CF
- improved communication, specifically timely feedback from tests and annual reviews
- equitable and high-quality access to care in the community, including specialised medicines, such as modulators, and home IV antibiotic therapy.

Introduction

The Patient Reported Experience Measure survey (PREMs) allows cystic fibrosis (CF) centres and their network clinics to capture patients' experiences and satisfaction with CF care in a systematic way. Listening to the voices of people with CF is critical to ensure that services can respond to and meet needs now and in future. We are incredibly grateful for the support of the CF community and clinical teams in promoting and completing the PREMs survey.

We hope this report will help CF centres, their clinics, and other stakeholders to better understand experiences of adult CF care in the UK, existing best practices, what patients value about their care, as well as areas for quality improvement. With repeating survey cycles, the findings will also provide important information to help us understand how experiences may change over time.

About the survey

The PREMs survey questions were developed with input from Cystic Fibrosis Trust's Clinical Advisory Group (CAG) and Quality Improvement (QI) working group, which is made up of people with CF, family members and CF health professionals. The survey is reviewed between cycles to ensure it still asks questions about the most important aspects of CF care and reflects any changes in care due to new treatments, guidelines, or other developments.

From 1 November 2023 to 31 March 2024, people with CF under the care of participating centres were invited to complete the survey by their CF teams, either online or on paper. It asked them to reflect on the care they had received in the 12 months prior to completing the survey. Other questions explored preferences for the future and asked for suggestions for improvements people with CF wanted to see based on their experiences.

All CF centres/networks that supported the project were provided with a bespoke summary of their local insights and feedback in July 2024, thus allowing them to evidence good practice and identify local priority areas for quality improvement. In 2026/27, the adult survey will be repeated to help us explore how experiences change with time. While we will aim to provide longitudinal information that can be compared over time, the survey process is iterative, and some questions may be refined, replaced or added in future.

About this report

This report provides an overview of the findings from the second cycle of the adult PREMs survey, which explored experiences of CF care in 2023/24. The report is based on 1,285 responses from people with CF cared for at 25 of 28 adult CF centres in the UK.

Survey respondents were allowed to skip questions where they did not feel well placed to answer, or something did not apply to them (these are recorded as 'missing' in figures within this report). The number of responses that were included in the analyses, and responses that were excluded, are provided for reference alongside each figure. Where respondents had provided free text comments, these were analysed and grouped into themes. General written feedback and suggestions for improvements provided by respondents are summarised within this report. The report also contains example quotes from free-text responses to illustrate themes and findings, where relevant. These quotes have been anonymised, with any references to the names or locations removed or replaced with neutral terms (in square brackets).

Where there was variation between centres for the topics explored in the survey, information about the median and range are included in this report. The median is the value at the midpoint, with half the CF centres in the survey falling below this, and half above it. The range shows the lowest and the highest finding at centre-level.

Where comparisons were possible, findings from the 2023/24 cycle of the adult survey are discussed in the context of results from the first cycle, which ran during the pandemic in 2020/21. The report also features summaries of relevant sections within the recently published third edition of the Standards for the clinical care of children and adults with cystic fibrosis in the UK (August 2024)[1]. These are included in light blue boxes at the start of most sections and outline the relevant recommendations for organisations that provide specialised CF care.

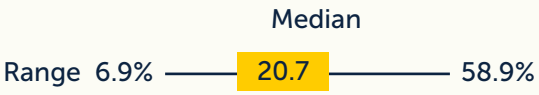
Participation

All adult CF centres in the UK were invited to take part in the PREMs survey as a service evaluation exercise. Twenty-five of 28 CF centres/networks (89.3%) decided to participate. Participation in the survey is voluntary, and three CF centres chose not to take part in 2023/24. Two of these centres had recently completed internal patient experience surveys and therefore declined to take part; one service did not respond to our invitation.

Participating services could choose to hand out paper surveys, send an email invite, or use a combination of the two. Between 1 November 2023 and 1 April 2024, 1,285 valid responses were received from adults with CF under the care of participating CF centres and some of their network or outreach clinics. This represents insights from approximately 21% of the CF population in adult care in the UK.

The number of survey responses received varied by centre/network, with a median of 52 responses and a range from 10 to 123. As centre sizes differ, it is also important to consider how the number of responses from each centre/network corresponds to its list size. For example, a centre with a list size of 50 patients that received 25 survey responses would have a response rate of 50%, whereas a centre with 250 patients and 25 responses would only have a response rate of 10%. The higher the response rate, the more representative and insightful the survey findings are for a centre or network. In the adult PREMs survey, response rates varied by centre, with a median response rate of 20.7% and a range from 6.9% to 58.9% (the mean was 25.9%). Response rates can be impacted by how and when CF teams share the survey with people under their care. Teams with higher response rates usually use paper and email invitations, with occasional reminders, to drive up the number of responses.

Centre-level insight: Proportion of centre's patients that responded to the survey



1 Cystic Fibrosis Trust, August 2024: **Standards for the clinical care of children and adults with cystic fibrosis in the UK**

Section 1
Access to and support from the CF team

Accessing the CF team

CF multidisciplinary teams (MDTs) usually consist of staff from a range of medical and allied health professions with expertise in cystic fibrosis. This should include doctors, nurses, physiotherapists, dietitians, and pharmacists, as well as clinical psychologists and social workers. Every person with CF should have access to a full MDT so that they can get the specialist care and support they need.

What do the Standards of Care say?

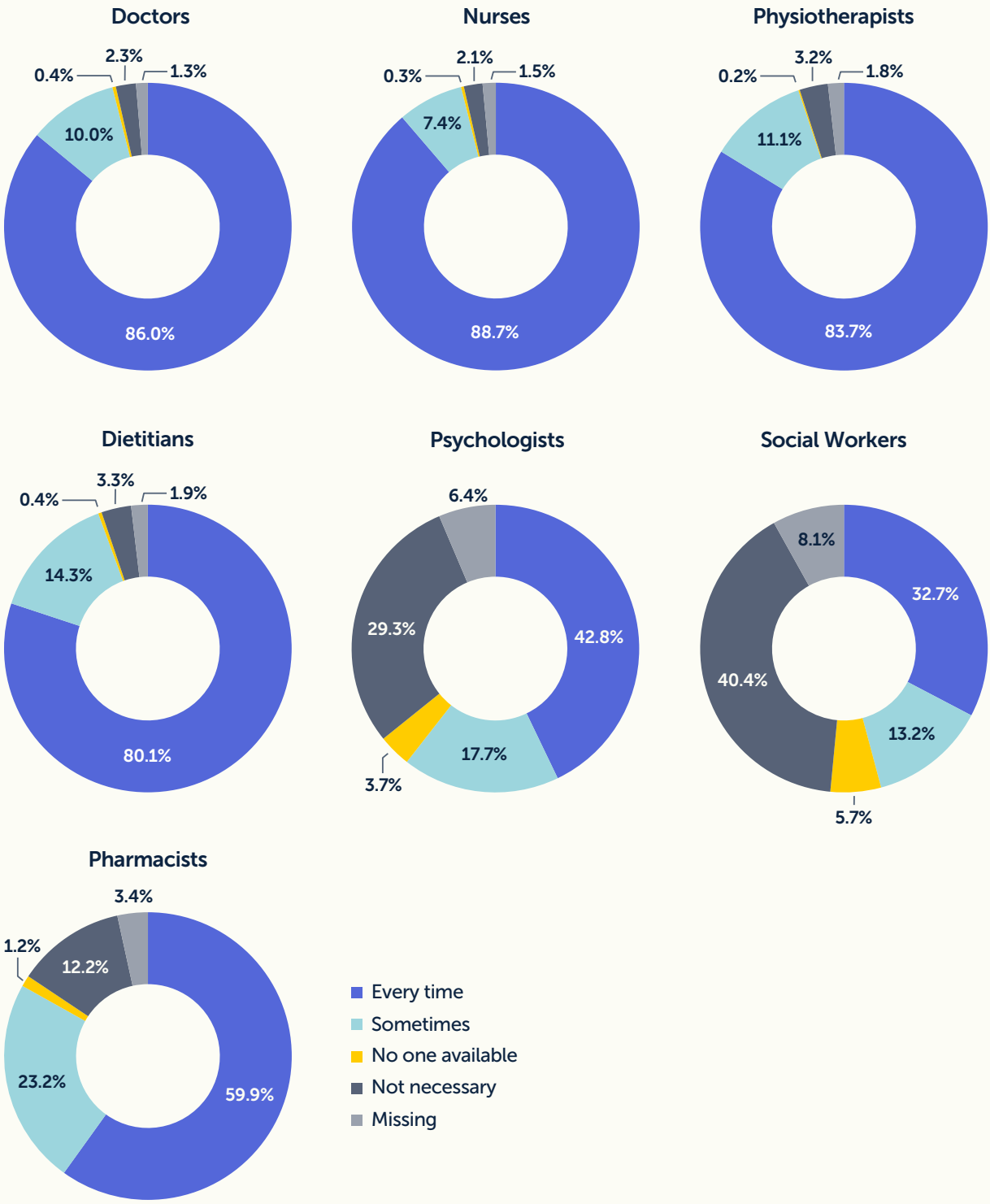
- All people with CF must have access to specialist advice and care from their CF centres at all times (3.1).
- CF centres must have a core MDT of trained and experienced CF specialists, including consultants, CF nurses, physiotherapists, dietitians, clinical psychologists, social workers, and pharmacists (2.3).
- CF centres must have an MDT of an appropriate number for the amount of patients at the centre (2.3).

Generally, access to different professions within the CF team was good (Figure 1). Most survey respondents confirmed that they had been able to access staff from each profession every time they needed to in the last year, with some saying they could access staff sometimes but not every time. Access to dietitians improved slightly compared with the previous survey. In 2023/24, 94.4% of respondents confirmed they could access support from this profession when needed, compared to 89.8% previously.

Survey question: Have you had access to each member of the CF multidisciplinary team (MDT) when you needed them in the last 12 months?

Figure 1: Access to different professions in the CF team

Note: all survey respondents included (n=1,285).



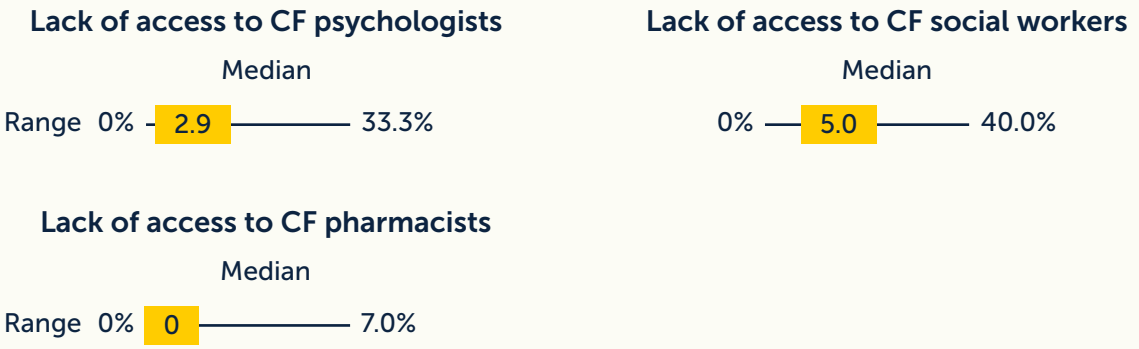
There were differences in the proportions of respondents who felt they needed to access certain professions. Over 94% of respondents said they had needed support from CF specialist doctors, nurses, physiotherapists and dietitians at some point in the last 12 months. However, 12.2%, 29.3% and 40.4% of respondents said they had not felt they needed CF specialist pharmacist, psychologist or social worker support, respectively. These proportions are lower than in the previous survey, when 20.2%, 35.3% and 45.0% said they had not needed to access the respective professions. This could be driven by changes in support needs within the adult CF community. For example, it could be that people's physical and mental health needs are shifting due to the increasing use of modulator drugs, with many adults with CF having to look after themselves and their CF while growing older and planning for a future they may not have considered before. Other factors that may impact the number of people with CF who feel they need support from a social worker are ongoing inflation and the cost of living crisis.

Very few survey respondents reported problems accessing doctors, nurses, physiotherapists or dietitians (0.4%, 0.3%, 0.2% and 0.4%, respectively). Slightly larger proportions said they had been unable to access CF pharmacists (1.2%), psychologists (3.7%), or social workers (5.7%) when required, as no one from these professions was available. These proportions have remained relatively stable compared to the 2020/21 survey cycle, when 1.4%, 2.1% and 5.1%, respectively, reported issues with access to these professions.

The proportions of respondents who said they had been unable to access support from CF psychologists, social workers or pharmacists when they had needed to varied by centre. In some CF centres, there were no survey respondents reporting a lack of access to these professions, while in others, more than a quarter of respondents said no one was available to support them when needed.

Centre-level insight: Proportion of respondents unable to access CF psychologists, social workers and pharmacists when needed

Note: based on all participating CF centres (n=25).



Only looking at those who said they had needed support, excluding all missing responses and those who said support was 'not necessary', we found that 99.5% of those who had needed CF doctors, nurses, physiotherapists or dietitians said they could access these professions. However, 11% of respondents who had needed CF social worker support said they had been unable to access this (72 of 662), for psychologists this was 5.7% (46 of 824), and for pharmacists this was 1.5% (16 of 1,084). These proportions are again similar to findings from our previous survey in adult care in 2020/21, when this was 10.8% for social workers, 3.7% for psychology and 1.9% for pharmacy. This indicates that some people with CF continue to experience problems accessing professions in the CF team, which particularly applies to CF specialist social workers, but also to psychologists and pharmacists.

We know from our staffing tool[2] that some CF centres/networks do not have these professions available. Sometimes, this can be due to a temporary vacancy within the team, but in other cases, there is no funding available for such roles. For example, several CF centres do not have embedded roles for CF social workers, and even in centres that have such roles they are often not available full time.

Centres without CF specialist psychologists, social workers or pharmacists may refer patients to general hospital psychology and pharmacy services or community social work, but staff in these departments do not usually have a good understanding of the complexities of CF and there may be long waiting times to get an appointment, which is also impacted by ongoing NHS-wide workforce issues.

Problems accessing support from certain professions when required could have a negative impact on people with CF, as they might miss out on specialist help and advice when they need it. A lack of access to CF clinical psychologists and social workers specifically may be even more impactful in the current financial climate and cost of living crisis, with more people than ever potentially needing financial and wellbeing support. Where survey respondents had reported issues accessing one or more professions, the survey asked if and how this had impacted them.

Survey question: If you said that you were unable to access any member of the MDT when you needed them, please tell us how this impacted on you.

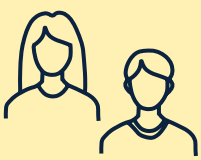
Overall, 139 respondents left comments regarding the impact of limited access to certain professions in the CF team. Some said that this had not directly impacted them, or that they had received support from other professions in the CF team instead.

> "Very little impact as my health is relatively stable at the minute."
>
> "It did not impact me at all, as I didn't need any support from CF specialist social worker."
>
> "Although [my CF team] don't have a CF specialist psychologist, the specialist nurses fill in as best they can. I don't feel this has impacted greatly on myself."

However, others who had issues accessing the CF team generally, or certain professions, reported a range of ways in which they had been impacted. Some felt that they would have benefitted from CF psychologist support, particularly during periods of stress, anxiety or poor mental health.

> "I was having very bad issues with stress and health anxiety, which was also causing me some physical symptoms. I managed to get into clinic very quickly to discuss the physical symptoms but was told there was a three-month waiting list to see the CF psychologist. This felt extremely stressful at the time on top of other issues."
>
> "With Kaftrio, I am having far more mental health and wellbeing issues, and access to a psychologist would be very helpful."
>
> "Not being able to access a psychologist while suffering with severe phobia of needles has made treatment more difficult."

Over 99.5% of respondents who had needed CF specialist doctors, nurses, physiotherapists or dietitians said they had been able to access these professions.



11% of respondents who had needed support from a CF social worker said they could not access this as no one was available. For CF clinical psychologists, this was **5.7%**.

2 Cystic Fibrosis Trust, March 2024: **UK Cystic Fibrosis Service Resourcing 2021-2023**

Other survey respondents reflected that access to a CF social worker would have been helpful to discuss various social and welfare issues, including help with benefits, finances, housework, self-care, and a house purchase.

> "Never seen a social worker the whole time I've been at the unit. Struggling to pay bills, make ends meet, and get to clinics."
>
> "Social worker – I'm not well enough for college/training/work and have no support with options that may be available."
>
> "Hoped to see a social worker about getting funding for some help with heavy housework."
>
> "CF specialist social worker could have been useful with assistance dealing with council and government financial assistance."

Only one comment specifically referenced problems accessing pharmacy advice.

> "Pharmacist available on request but I have a few issues with Kaftrio and unable to contact."

Finally, a few others commented on other access issues, including a lack of responsiveness when they had contacted the team for support.

> "There can be delays to speaking with specialist nurses and doctors, due to the service being overstretched. This can lead to exacerbations taking hold more."
>
> "My email to the CF nurses was not answered so after three days I had to ring them."

Support from members of the CF team

All members of the CF MDT have defined roles and responsibilities to ensure people with CF can access staff with relevant expertise to get specialist advice and care.

What do the Standards of Care say?

Specialist multidisciplinary care is essential in the management of children and adults with CF (3)

- **Clinical specialists and consultants:** Lead on planning and delivery of CF care for patients attending CF Centre / network clinics; act as lead clinician or Centre Director.
- **Clinical nurse specialist:** Provide advocacy and psychosocial support; provide home-based care and support; provide education about CF to others; act as a link to primary care, community services and hospitals.
- **Physiotherapist:** Assess issues; ensure access to appropriate treatment; review and adapt treatment; support with equipment.
- **Dietitian:** Provide full nutritional advice and assessment to both in- and outpatients; follow clinical dietetic practice.
- **Clinical psychologist:** Undertake psychological screening; take a preventative approach to mental health; provide evidence-based psychological therapies.
- **Social worker:** Understand the psychosocial impacts of living with CF; contribute to annual review; provide expertise in applying social work models and approaches; identify and provide early intervention to manage health inequalities.
- **Pharmacist:** Provide a prescription monitoring and medication review service with full review at annual review; assist in optimising adherence; aid in the resolution of any medication supply problems.

When survey respondents said they had accessed staff in the CF team, the survey then asked them to rate their overall satisfaction with the support they had received from each profession.

Survey question: If you have accessed [members of the MDT], please rate your experience of support received.

The vast majority of ratings provided were either excellent or good (96.3%; 5,875 of 7,249 ratings across seven defined professions). There was only minor variation by centre, showing that support from all professions is generally rated highly regardless of centre.

Centre-level insight: Proportion of respondents at each centre who rated support from any profession in the CF team they had seen as excellent or good

Note: based on all participating CF centres (n=25).

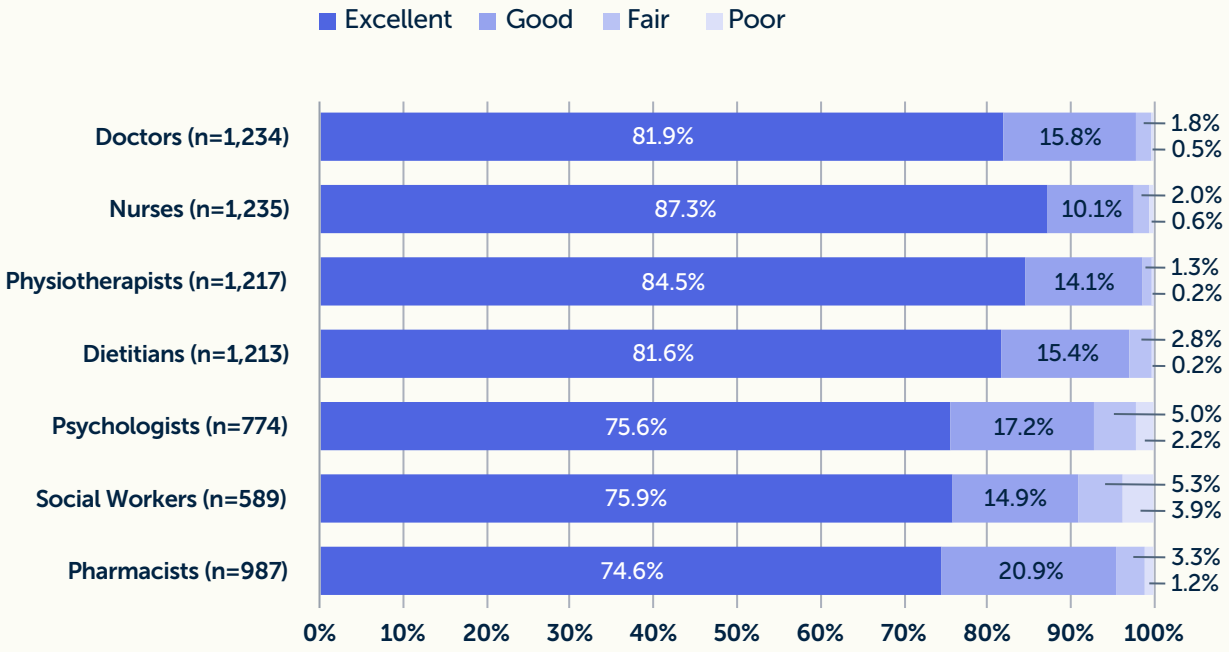
Median

Range 90.0% — 97.0 — 98.9%

However, the proportion of excellent and good ratings provided varied by profession. Figure 2 shows the proportions of responses and ratings for each profession from those who had accessed respective staff at some point in the last 12 months. It excludes missing respondents as well as those who did not access support, either because they did not need to or because no one from the respective profession was available.

Figure 2: Ratings of support received by profession

Note: number of valid survey responses included is provided for each profession.



All those who had accessed specialist CF doctors, nurses, physiotherapists, dietitians and pharmacists rated support from these groups particularly highly (over 95% excellent/good ratings). This aligns with findings from the previous survey cycle, which showed similarly high ratings for these professions. While support from psychologists and social workers was rated slightly less positively, both professions still received over 90% excellent or good ratings, again demonstrating that most patients rate support from all professions in the CF team highly.

> "Some members of CF team go above and beyond to support me, [such as] social worker, specialist nurses, dietitian. They help me get through the pressures that living with CF puts me under."
>
> "Efficient, friendly nurses and physiotherapists get to know you really well as a person with a life. Social worker and psychologist are great too."
>
> "Good and clear responses and directions from my consultants."

96.3% of ratings for support received from the different professions in the CF team were excellent or good.

Section 2
Person-centredness and support with managing CF

Person-centredness

CF teams should provide holistic, person-centred care to all people with CF, taking into account individual clinical need, but also personal perspectives and preferences, as well as the wider context of people's lives that could impact health and wellbeing. People with CF should be empowered to share in decisions about their health and treatment.

What do the Standards of Care say?

The care people with CF receive must consider both their clinical needs and a range of non-clinical factors. Their care plan must be reached through shared decision-making, with partnership between the person with CF, their parents or carers (in the case of children and young people), and their clinical team (2.2).

As the needs of the CF community change and diversify, person-centredness is becoming increasingly important. The patient experience survey explored respondents' views on whether and how their care is individualised to their needs.

Survey question: Do you feel that your MDT give you individual care, according to your needs? Please explain.

Figure 3: Word cloud of person-centredness feedback

Note: based on 878 comments; to produce word cloud, some common terms (such as 'and', 'to', 'but') were excluded.

Overwhelmingly, survey respondents felt that their CF teams provided care that was individualised to their needs and most comments were positive and full of praise for person-centred approaches to care.

> "Definitely, my MDT support whatever decisions I make around treatments and tailor their care around my needs [and] lifestyle."
>
> "Yes, they are very understanding and open to flexibility with regards to how I go about my life. I always feel supported and that I can ask them about anything."
>
> "Absolutely, it's a great two-way relationship and they understand me and my needs deeply."

However, some respondents fed back that, while certain aspects of care are individualised, others are not. Some also shared that, while there was a person-centred approach in the past, this no longer feels the case for them now.

> "Yes, I do feel my care is tailored to my needs, in terms of treatments and what is best for my health. I feel like there could be more support [and] understanding when it comes to impact on relationships, children and work."
>
> "Mostly. Sometimes I feel that issues related to aging and maintaining quality of life not always fully understood."
>
> "Not any more no. It's turned into a normal department of care. Like asthma or ENT etc."
>
> "No. I would say the care I receive now is poor compared to the care I used to receive. I think most of this is down to not visiting the hospital for [face-to-face] consultations."

A few respondents also shared negative or disappointing experiences with regards to individualisation of care and treatments. These touched on topics such as not being listened to or involved in decisions, feeling like a 'tick box', and not having specific personal needs met.

> "No, for somebody doing so well following Kaftrio the team need to adjust to this. I want to lead a normal life. I know if I need support who to contact and appreciate the team want tick box contact, but this needs to be telephone."
>
> "No, I have been deeply disappointed by the healthcare provided by my service the last two years. There has been inconsistent support, [and] ignorant comments made by members of staff."
>
> "No. It's always the same default approach decided in five minutes and without my input. Sometimes [they] don't seem to even look at the test data beyond today, and definitely don't try to understand my life situation."

Most people with CF in the survey felt that their care was individualised to their needs, though a few respondents also shared disappointing experiences.

Support with key aspects of CF

CF MDTs should support people with CF in all aspects of managing cystic fibrosis, including managing physical and mental health, as well as general wellbeing.

What do the Standards of Care say?

There is an increasing expectation that people with CF can live long, fulfilling lives largely unlimited by CF. It is important for CF teams to support people CF and their families and carers with their life expectations, hopes, and goals (5.6).

CF teams should work to support people with CF to:

- develop self-management strategies, focusing on independence, autonomy, and decision-making skills
- attain goals that are important to them throughout their lives
- access information and make informed decisions regarding sexual health, fertility, family planning, pregnancy and parenthood (5.6.4).

The survey asked respondents how satisfied they were with the support they had received from their CF team over the last 12 months at key times and with important issues, including diagnosis, managing treatments and inpatient care, benefit applications, emotional health, and dealing with school or work.

Survey question: Using the list below, please rate the support you have received from your CF MDT in these key areas in the last 12 months.

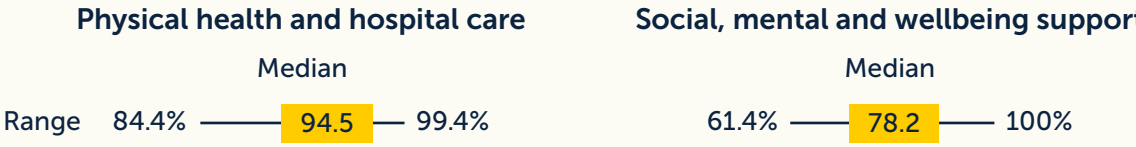
Overall, 6,056 ratings were provided for different aspects of CF care by 1,207 survey respondents (78 skipped this section of the survey). Most ratings given for aspects of CF care were either excellent or good (88.5%; 5,360).

When looking at ratings of support with physical health and hospital care (Figure 4a), these were very positive, with 93.6% of ratings given for support in these areas excellent or good. But overall ratings for support with social, mental and wellbeing issues (Figure 4b), were slightly less positive, with 80.2% being excellent or good.

There was limited variation between centres in terms of overall ratings of support with physical health issues and hospital care. However, there was more variation at centre level when it came to ratings of support for social, mental and wellbeing issues.

Centre-level insight: Proportion of respondents who rated support in key areas and with important issues as excellent or good

Note: based on all participating CF centres (n=25).

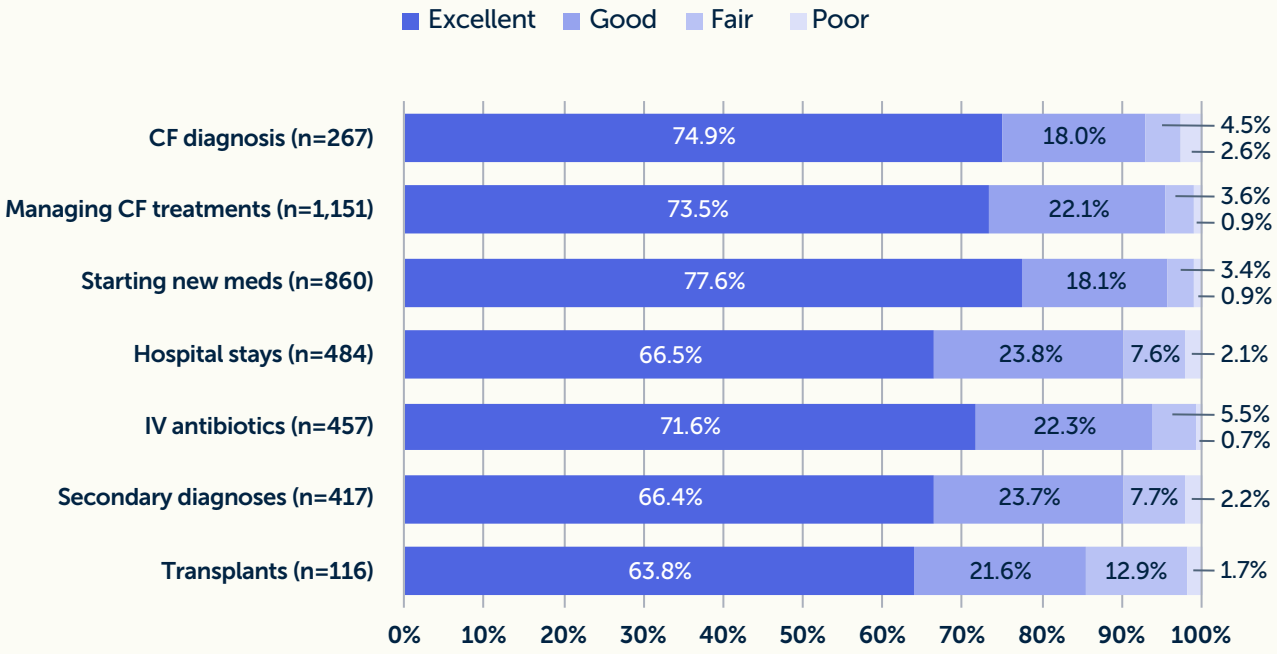


Support with physical health and hospital care

Support with starting new treatments, managing treatments, IV antibiotics, and hospital stays were all rated highly by those who had needed support with these (Figure 4a). 95.7%, 95.6%, 93.9% and 92.9% of respondents, respectively, said their CF team did an excellent or good job supporting them in these areas. Ratings for other aspects of managing physical health were similarly positive. Support and advice around transplants was rated the least highly in this group, though 85.3% of ratings were still excellent or good.

Figure 4a: Ratings of support with physical health and hospital care

Note: number of valid survey responses included is stated for each aspect of care.

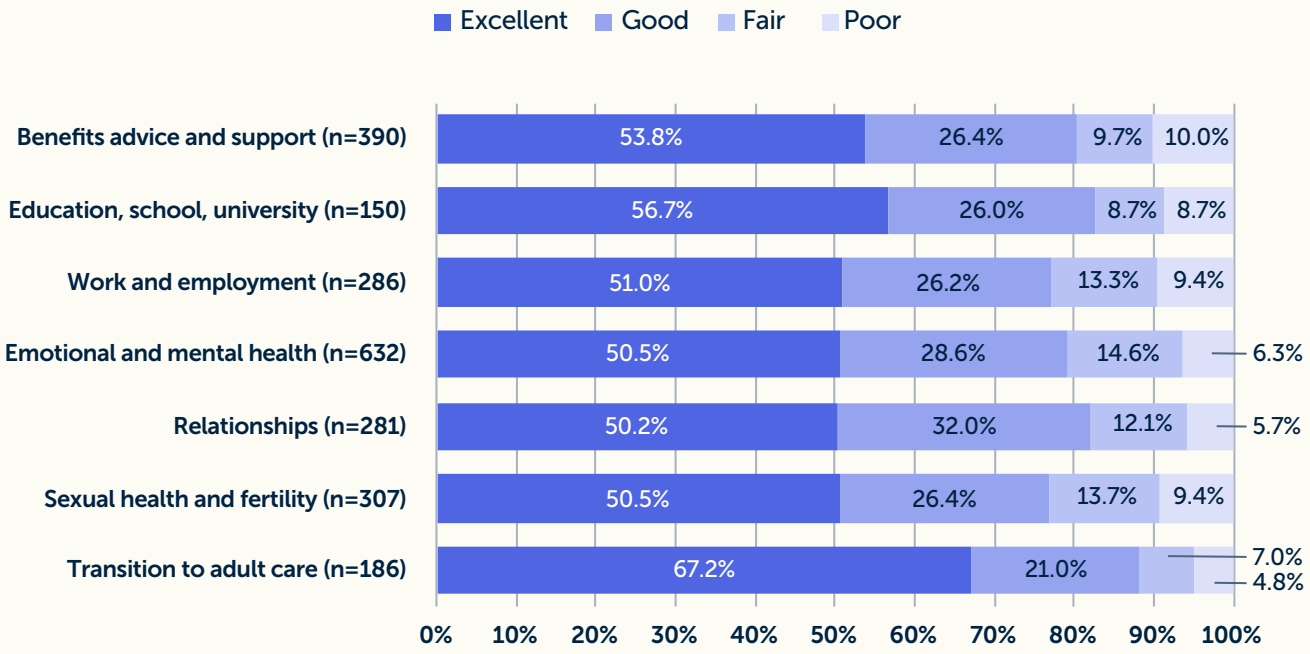


Support with social issues, mental health and wellbeing

In contrast to ratings for support with physical health, experiences of support with emotional wellbeing, relationships, benefits, work, or education were rated less positively (Figure 4b). It should be noted that there were fewer respondents who commented on these aspects of care (n number provided in y-axis for each aspect).

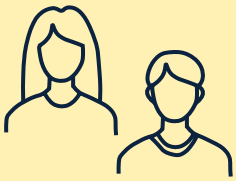
Figure 4b: Ratings of support with social issues, mental health and wellbeing

Note: number of valid survey responses included is stated for each aspect of care.



The slightly less positive ratings for social and wellbeing issues, including benefits, work, and education, may be linked to the lack of or limited access to CF clinical psychologists and social workers highlighted by respondents in the previous section.

Not all these social and wellbeing issues were explored in the previous survey. However, where questions were included in both surveys, a comparison of the two shows a mixed picture. Support with benefits and fertility and sexual health were rated similarly between the two survey cycles, whereas the proportion of 'excellent' ratings was higher for support with education in the more recent survey. In contrast, the proportion of 'excellent' ratings for support with relationships decreased between 2020/21 and 2023/24.



88.5% of ratings for support received from CF teams at key times and with key issues were excellent or good.

93.6% of ratings given for support with physical health and hospital care were excellent or good. In contrast, only 80.2% of ratings for support with social, mental and wellbeing issues were excellent or good.

Referrals to other specialties

To provide comprehensive and holistic care, CF teams must also have good relationships with and clear referral pathways to other specialties, such as diabetes, hepatology (liver and pancreas care) and transplant teams, as well as primary care. It may not always be necessary to refer people with CF to other specialist departments; therefore, mechanisms to consult with and obtain advice from other specialists must also be in place.

What do the Standards of Care say?

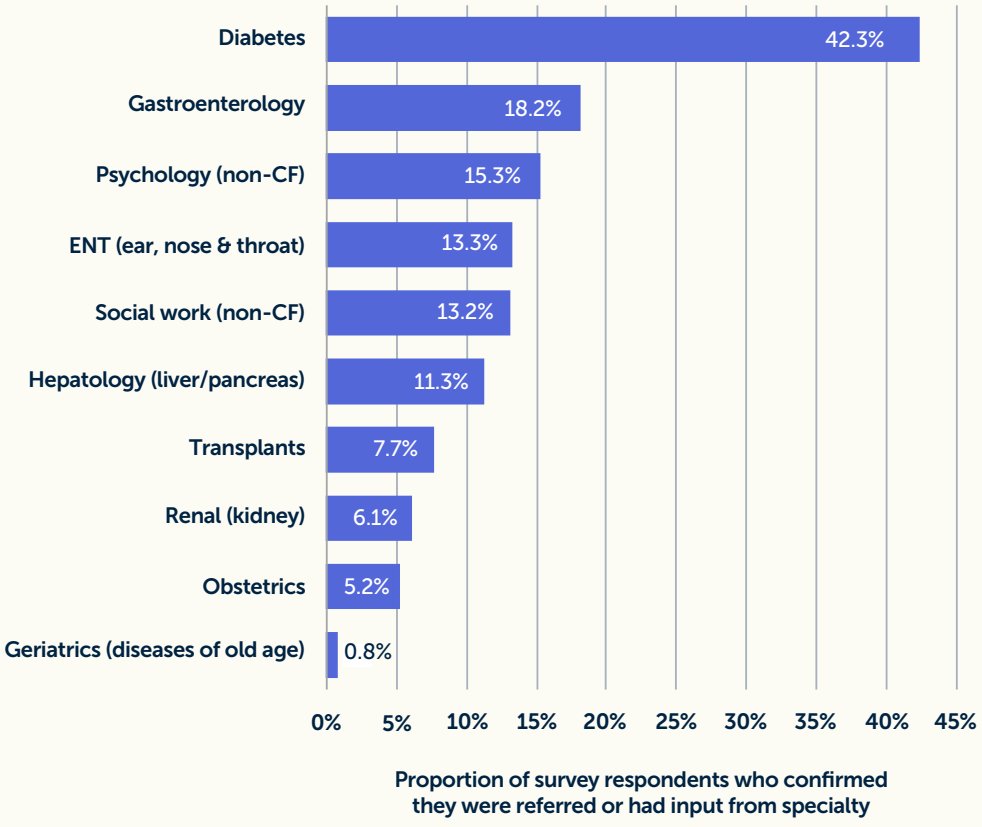
CF centres must have access to other medical and surgical specialists when required (2.3) who are familiar with the complications of CF. These services should develop their experience in managing CF-related complications in close liaison with the core CF MDT. Referral pathways with SLAs must be established. Where appropriate, joint clinics should be established, particularly for CFD [CF diabetes] and antenatal clinics (3.1).

The survey looked at how many people with CF had required input from or referral to other specialists in the last year.

Survey question: In the last 12 months, if needed, have you received advice and/or follow-up from one of the specialities listed?

Figure 5: Advice from or referral to other specialties

Note: based on 1,285 respondents; graph shows proportion of full sample who confirmed they had advice from or referral to respective non-CF specialty.



The most common specialty adults with CF had needed input from or referral to was diabetes care, with 42.3% of respondents in the survey confirming they had received this. This finding is unsurprising, given the link between CF and diabetes. While some CF teams have dedicated CF diabetes staff within their MDT, others have to refer to Diabetes services within the hospital.

Psychology and social work support from outside the CF team was obtained by 15.3% and 13.2% of respondents, respectively. This links to findings in Section 1 regarding a lack of access to CF specialist clinical psychologists and social workers, which may impact the number of input and referral requests to non-CF psychology and social work services.

Other specialties needed relatively frequently by people with CF were gastroenterology (18.2%), ear, nose and throat services (13.3%) and hepatology (11.3%), showing that even in the modulator era, CF is a multi-system disease, with many people requiring ongoing support and input not just from their CF team but also from other specialties.

Good relationships and close collaboration and coordination between CF teams and other specialties, including joint multidisciplinary discussions where appropriate, are therefore highly recommended. These help to ensure a shared understanding of patients' needs, as well as the complexities of CF, and a more seamless experience of care for people with CF. It is likely that collaboration beyond the CF team will become increasingly important in future as the needs of the CF community change and diversify.

Section 3
Communicating with and seeing the CF team

Contacting the CF team

As people with CF can experience issues, such as exacerbations and infections, at any time, it is important they are aware of how to get specialist help and support when required.

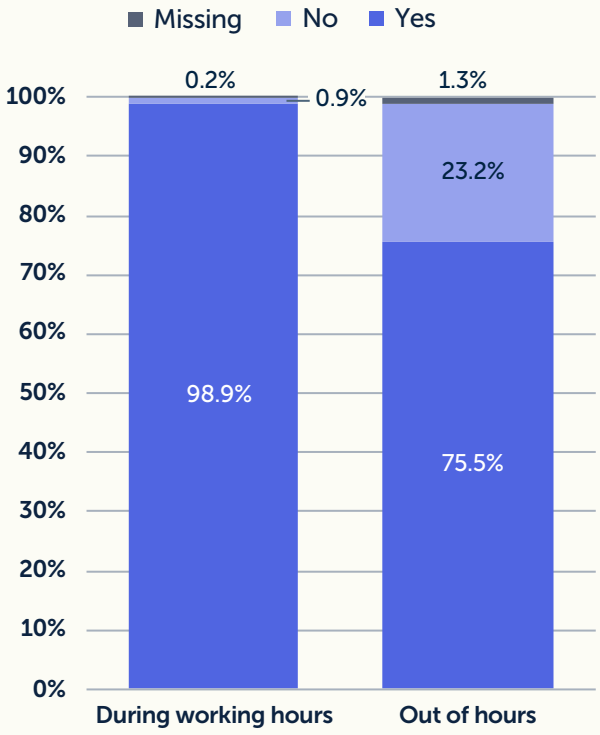
What do the Standards of Care say?

All people with CF must have access to specialist advice and care from their CF Centres at all times (3.1). Contact details, including telephone numbers for the CF team, should be provided (5.1.3). Teams must have the ability to provide advice for urgent needs on a 24-hour basis, 7 days per week (2.3.2).

Survey question: Do you know who to contact if you have concerns about your CF?

Figure 6: Awareness of how to contact the CF team

Note: based on 1,285 survey respondents, including those who skipped the question (missing).



Awareness of who to contact was excellent during working hours. However, nearly a quarter of respondents (23.2%) were unsure how to contact their CF team outside of their usual working hours. These findings are only very slightly better than in the 2020/21 survey, when 24.6% of respondents said they did not know how to contact their CF team out of hours.

98.9% of respondents knew how to contact their CF team during working hours, falling to 75.5% out of hours.

Centre-level insight: Proportion of respondents who said they know how to contact their CF team

Note: based on all participating CF centres (n=25).

During working hours

Median

Range 94.7% — 100 — 100%

Outside of hours

Median

59.4% — 75.6 — 100%

Some respondents left more detailed comments about their ability to contact the team, explaining how difficulties with reaching the team affected them and sharing ideas for improvement.

> "The phone numbers keep changing for who to contact. [This] causes anxiety and worry."
>
> "I am not always sure who to contact and have many times had to chase up responses. This can be frustrating if you are reaching out over a health concern and would like advice on the issue."
>
> "Communication needs work. [I] would really love a one-pager on how to contact them when I need, including out of hours, as well as emails for appointments, not letters."

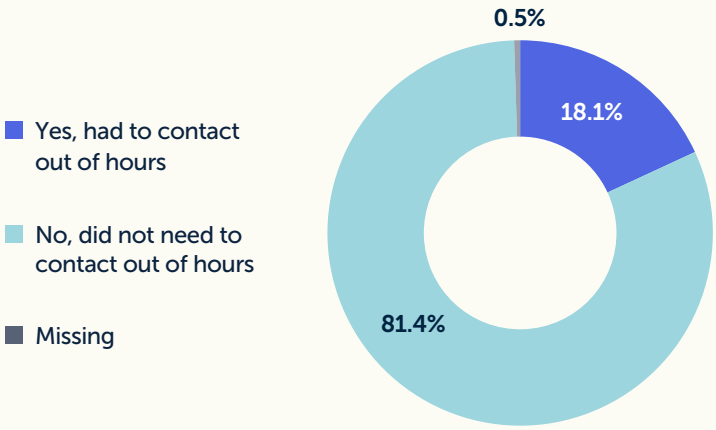
To understand the importance of having up-to-date contact details for the CF team, including for out of hours support, the survey also explored if survey respondents had needed to access the CF team outside their usual working hours.

Survey question: In the last 12 months, have you needed to contact the team out of hours?

Just under one in five respondents (18.1%; n=232) confirmed they had needed to contact their CF team out of hours in the last year, indicating an ongoing need to ensure a clear point of contact for CF-related needs during and out of hours.

Figure 7: Need to access CF team out of hours in the last 12 months

Note: based on 1,285 survey respondents, including 7 who skipped the question (missing).



Contact with the CF team

CF services are diversifying the ways in which they communicate with and see people with CF, making increased use of remote methods, such as telephone consultations, video conferencing and email, as well as increasing the use of home visits.

What do the Standards of Care say?

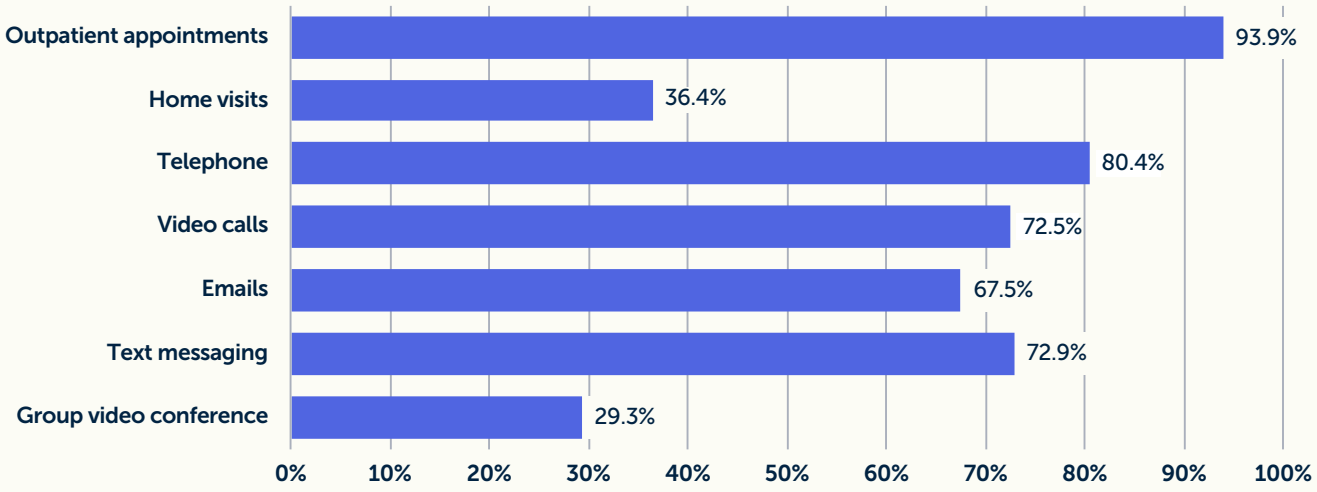
- The use of virtual consultations and remote monitoring plays an important role in access to care. Although many aspects of a consultation can be achieved virtually, it is important that people with CF have clear routes of communication with their CF team and access to urgent face-to-face review if required (2.2.1).
- People with CF should be reviewed regularly, with a frequency appropriate to their individual needs (5.2.1).
- A home-based care service can support many aspects of clinical and social care (5.5.1).

The survey explored which communication methods and appointment formats had been used and asked respondents to rate their experience of each.

Survey question: In the last 12 months, please indicate how you have communicated with your CF MDT. Please tick all that apply, rating your experience.

Figure 8: Types of contact with the CF team

Note: based on 1,228 respondents (excluding 57 who skipped this section); each respondent could select multiple answer options.

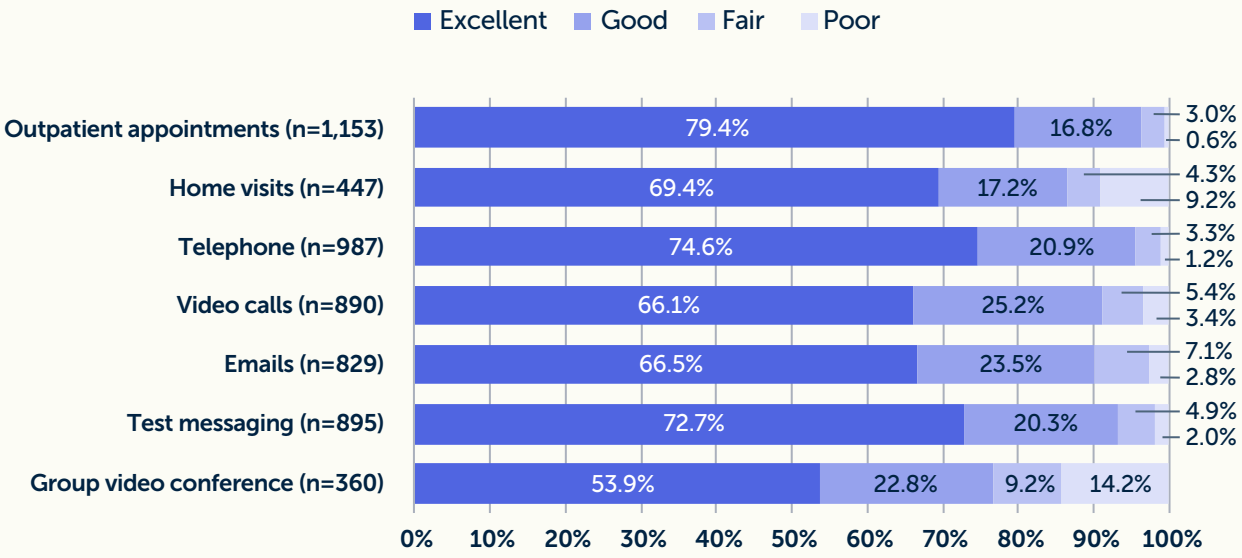


The vast majority of respondents (93.9%) confirmed they had had face-to-face contact with their CF team in outpatient clinic settings in the last year. Most respondents also said that they had used remote communication methods, such as phones (80.4%), text messaging (72.9%) and video conferencing (72.5%) to communicate with their CF team in the last 12 months. Only about a third of respondents (36.4%) confirmed that they had had a home visit.

Satisfaction with the different ways to see and communicate with the CF team varied. Figure 9 outlines the ratings given by people with CF for the different methods.

Figure 9: Ratings of communication methods and appointment formats

Note: based on 1,228 respondents (excluding 57 who skipped this question); each respondent could rate each communication methods that they had used.



All communication methods and appointment formats were mostly rated positively. Outpatient appointments were the highest-rated format, with 96.2% rating their experiences as excellent or good. However, most other methods, including remote options, such as phone and video, were rated similarly positively by more than 90% of respondents. In contrast, home visits and group video sessions were rated least positively and received 9.2% and 14.2% poor ratings, respectively.

93.9% of respondents had had outpatient contact with their CF team in the last year, with **96.2%** rating their experiences of such consultations as excellent or good.

Future appointment preferences

Survey respondents were asked about their future preferences for how they see their CF team for clinic appointments.

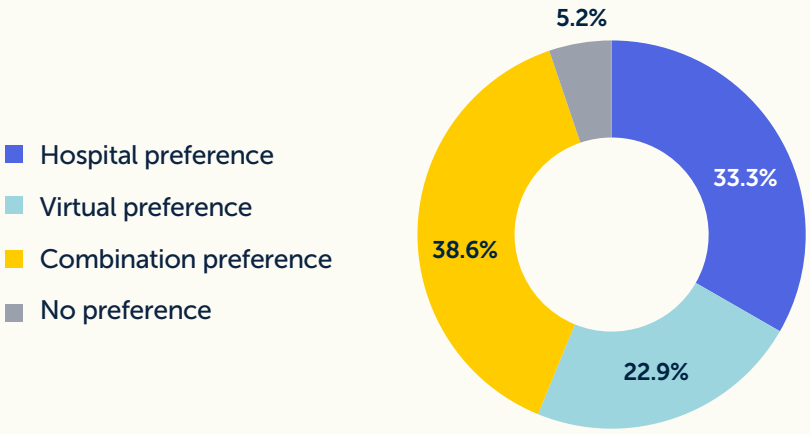
What do the Standards of Care say?

The needs of most people with CF are likely to be met by a 'blended model' of virtual and face-to-face appointments. A bespoke approach should be considered on a case-by-case basis (2.2.1)

Survey question: If given the choice between virtual clinics versus hospital clinics for routine appointments, which would you prefer and why?

Figure 10: Future appointment preferences

Note: based on 1,229 respondents (excluding 56 who skipped this question).



Preferences for appointment formats were split, with 38.6% wanting a hybrid approach, 33.3% preferring hospital appointments, and 22.9% favouring virtual care. This has shifted since the previous survey, which collected data at the height of the pandemic, when only 22.2% had preferred hospital care, with 46.9% favouring a combination and 25.7% wanting virtual care. This shows preferences can be influenced by personal and external factors, and there is no one-size-fits-all format. It is therefore essential to discuss options and preferences with people with CF.

38.6% of respondents said they would prefer a combination of virtual and hospital care, while 33.3% favoured hospital clinics and 22.9% wanted primarily virtual care.

Many respondents provided reasons for their preference. Those who favoured a hybrid model of care, with some virtual and some hospital appointments (38.6%), often stated that virtual clinics were more convenient and less disruptive but also said they valued the personal contact during hospital visits.

> "I like virtual because I keep so healthy I don't feel I need to be in hospital, but I also like the personal side of things meeting and speaking in person."
>
> "Virtual clinics are great when there are no issues. [...] However, face-to-face means I can talk to each person alone if I wish, talk about problems, there is more time and [I] have more of a connection with the team."
>
> "It's much easier to do phone calls and miss less time from work. Not always easy to talk about personal stuff on the phone."

Some of these respondents also noted specifically that their health influenced their preference; when they were feeling relatively well, they preferred virtual care, but when they were unwell, they wanted to be seen.

> "Happy to attend clinic now and again to keep in personal touch with the team. Otherwise, if well I'm quite happy to save the journey and discuss over the phone or by video call."
>
> "We mostly need to go in, as I have frequent IVs, but on the rare occasions I am well, I prefer video."
>
> "Sometimes it is necessary to see the people physically so that they can do the necessary examinations, but when things are going well a virtual appointment covers all the necessary parts without having to drive an hour down to the clinic."

Those with a preference for hospital appointments (33.3%) often discussed the more in-depth, personal nature of hospital clinic appointments and better ability to communicate face-to-face.

> "I much prefer in-person, you get a greater rapport and I find it much easier and more comfortable to talk face-to-face. [It] feels much more personal."
>
> "I find it difficult to communicate over the phone and prefer to talk face to face for my appointments."

Others cited the reassurance gained from being seen in person or from having physical examinations or hospital tests as reasons for their preference.

> "Easier to get reassurance face to face."
>
> "I prefer to have all the proper tests in a visit and think they are more effective (ie, liver/kidney function tests/bloods). [It's] always better to see doctors in person."
>
> "Virtual clinics are good, but how can a health professional expect to notice any other potential issues over a device screen? I know from personal experience that other issues concerning my own health have been picked up on during hospital outpatient clinics."

In contrast, those with a preference for virtual care (22.9%) put greater emphasis on avoiding travel time and costs, and or disruption to their lives, with many mentioning work or caring responsibilities.

> "[Virtual care] helps massively with work-life balance and also reducing travel costs."
>
> "I live quite far from the hospital and CF clinic, and also have a young child; thus, virtual clinics are much easier and more convenient."

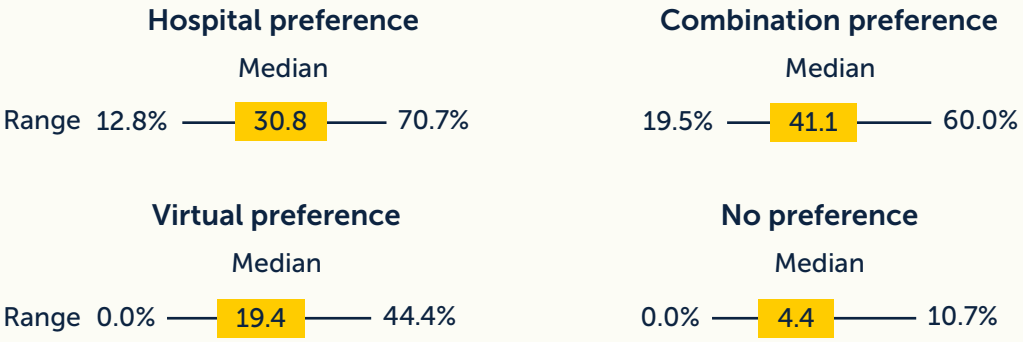
Others with a preference for virtual care also mentioned the risk of infection in hospital settings.

> "I am keen to avoid exposure to Covid, flu or any other respiratory infection. To reach the CF clinic you have to walk through busy hospital corridors."
>
> "I think [I prefer] virtual because [I] don't have to worry about cross-infection [from] going to the hospital."

The proportions of respondents who preferred one format over another also varied by centre. This may in part be driven by differences in centres' location and population; for example, centres serving large rural areas may have larger proportions of respondents who prefer hybrid and virtual models of care to avoid travelling long distances.

Centre-level insight: Proportion of respondents at each centre who preferred hospital or virtual appointments, or a hybrid approach

Note: centres with fewer than 10 respondents to this question were excluded (two centres).



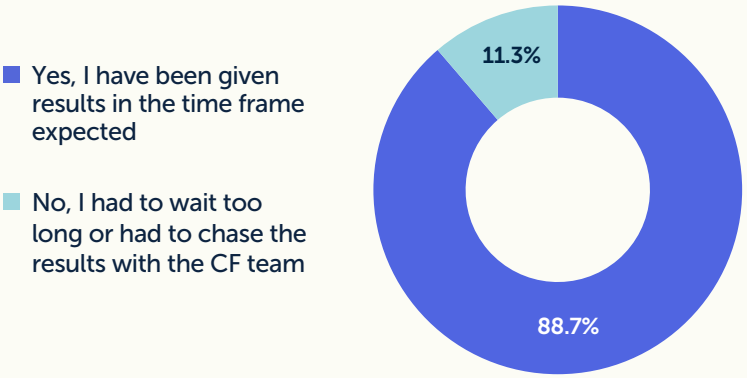
Communication of test results

In our previous survey, communication of test results was mentioned as an area for improvement. Survey respondents fed back that they sometimes had to chase test results, and would value being informed of all results for reassurance, including those that showed everything was fine. Our most recent survey again asked about respondents' satisfaction with the communication of test results.

Survey question: Were you satisfied with the time taken to communicate test results in general?

Figure 11: Satisfaction with time taken to communicate test results

Note: based on 1,087 respondents (excluding 198 who skipped this question).



The majority of respondents (88.7%) confirmed that they were satisfied. However, about 1 of 10 respondents (11.3%) said they had to wait too long or had to chase results, and there was variation by centre.

Centre-level insight: Proportion of respondents at each centre who were satisfied with the time taken to communicate test results

Note: centres with fewer than 10 respondents to this question were excluded (1 centre).

Comments left by some survey respondents illustrate that people with CF value timely feedback from tests and assessments, even if nothing untoward is found.

> "[At] my last two annual assessments, I have not been spoken to about my results until a few appointments down the line. I would prefer to be told as soon as they get the results."
>
> "[I would prefer my centre to] call with results from swab. Even if it's all clear, it's nice peace of mind to be told, rather than wait [until] next appointment months later."
>
> "I only receive results if the results were bad. Letting me know what all results of all tests [are] would be appreciated."

88.7% of respondents confirmed they were satisfied with the time taken to communicate test results.

Section 4
Annual reviews

Annual review formats

Current guidance recommends that all adults with CF have an annual review with their CF team. These meetings should include a review of results from tests and assessments looking at key health outcomes, conversations with different specialists in the CF MDT, as well as screening for any psychological or social support needs. Feedback from annual reviews should be provided in a timely manner to ensure that people with CF have a record of discussions and the healthcare plan going forward.

What do the Standards of Care say?

Outpatients; Frequency (5.2.1): Adults and children with CF must be reviewed face-to-face at least once a year (including annual review) by the full Specialist CF Centre MDT, which may take place at either the Network CF Clinic or Specialist CF Centre hospital.

Annual review (5.3):

- The annual review is a detailed assessment of every aspect of the person with CF's condition and therapies, to assess changes over the last year, identify where treatments can be improved, and produce a management programme for the following year.
- An annual review is a process, and does not necessarily need to happen all in one day, but will always include some in-person contact.

The survey explored how annual reviews were conducted in the previous 12 months, as well as asking about the tests and assessments carried out and the staff seen.

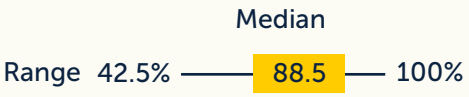
Survey question: In the last 12 months, did you have an annual review?

Approximately 84% of respondents (1,079 of 1,285) confirmed that they had had an annual review in the last year. It is unclear why some respondents did not have an annual review in that timeframe. However, as an annual review can be a prolonged process, it is possible that some respondents had not been explicitly informed that they had an annual review and had deemed it just a usual clinic appointment.

The proportion of respondents with an annual review in the last 12 months varied by centre.

Centre-level insight: Proportion of respondents with annual review in last year

Note: based on all participating CF centres (n=25).

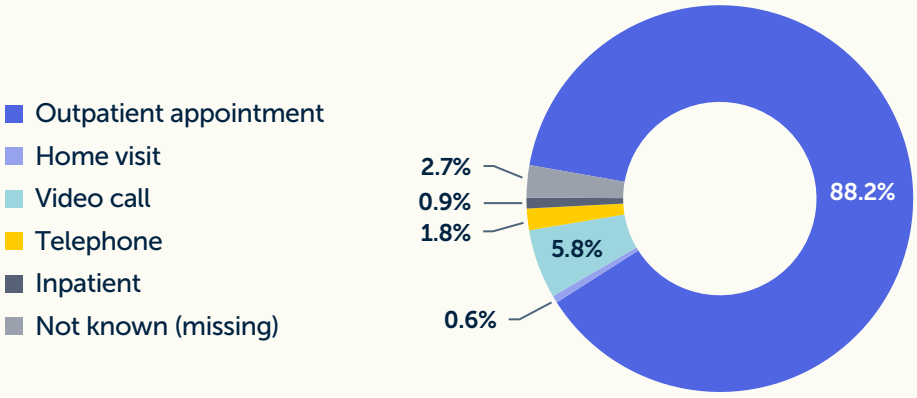


The remainder of this section focuses only on those who had confirmed they had an annual review in the last 12 months and excludes 206 survey respondents who did not confirm this.

Survey question: Please tell us how your last annual review was done.

Figure 12: Format of annual reviews

Note: based on 1,079 survey respondents with an annual review in the last 12 months, including those who skipped the question (missing).



The vast majority of annual reviews were completed as outpatient appointments (88.2%, 952 respondents), though 5.8% (63 respondents) and 1.8% (19 respondents) had remote annual reviews via video conference or phone, respectively. Other formats included annual reviews during home visits and in inpatient settings.

84% of respondents had an annual review in the last 12 months and most completed their annual review as an outpatient appointment.

Tests and assessments for annual review

What do the Standards of Care say?

Annual review; Investigations (5.3.2): Centres may do additional investigations, but those listed below are the minimum expected:

- Lung function.
- Exercise testing, when clinically indicated.
- Oxygen saturation measured by pulse oximetry.
- Respiratory sample such as sputum or a cough swab for microbiology.
- Chest radiograph.
- Ultrasound of liver and spleen [...] Routine repeat ultrasounds may not be necessary in adults with CF with previous normal scans.
- Screening for reduced BMD with DEXA scan should be considered.
- Assessment of glucose metabolism.
- Blood.

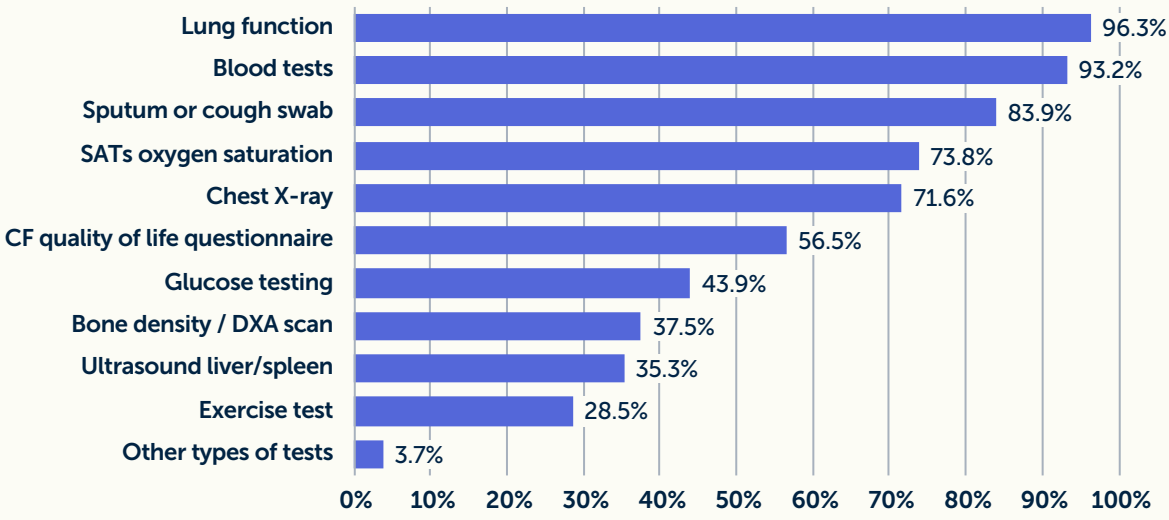
Respondents with an annual review were asked about investigations they had for their last review.

Survey question: Did you have any tests/assessments done for your annual review?

This question relies on respondents accurately recalling which tests and assessments had been carried out for their annual review, which is a limitation. However, we provided a list of common tests carried out at annual reviews in CF care to aid recall.

Figure 13: Tests and assessments for annual review

Note: based on 1,052 respondents with an annual review (excluding 27 who skipped this question).



Lung function and blood tests were the most common types of assessments respondents recalled having, with 96.3% and 93.2% reporting having these rests for their last annual review, respectively. Sputum or cough samples, SATs oxygen saturation and chest x-rays were also frequently completed and discussed at annual review, with 83.9%, 73.8% and 71.6% recalling having these assessments, respectively. More than half of respondents (56.5%) also reported having completed a CF quality of life questionnaire for their annual review.

Use of other assessments varied. As outlined in the standards of care, some tests should be considered but not necessarily completed at annual review, depending on the individual patient, their health, history and previous results. This includes bone density scans, ultrasounds, and exercise testing. It is therefore to be expected that the proportions of respondents with these tests will be lower than for standard tests such as lung function and bloods.

Over 90% of respondents had lung function and blood tests done or discussed at their annual review, but there was some variation in other types of test carried out.

Staff seen for annual review

The survey also explored which members of the team people with CF had seen at their last annual review.

What do the Standards of Care say?

People with CF will see the members of the multidisciplinary CF team, who should be present at every clinic (5.2.3).

In addition to the consultations carried out in standard clinics [refer to 5.2.3], the following are included in the annual review:

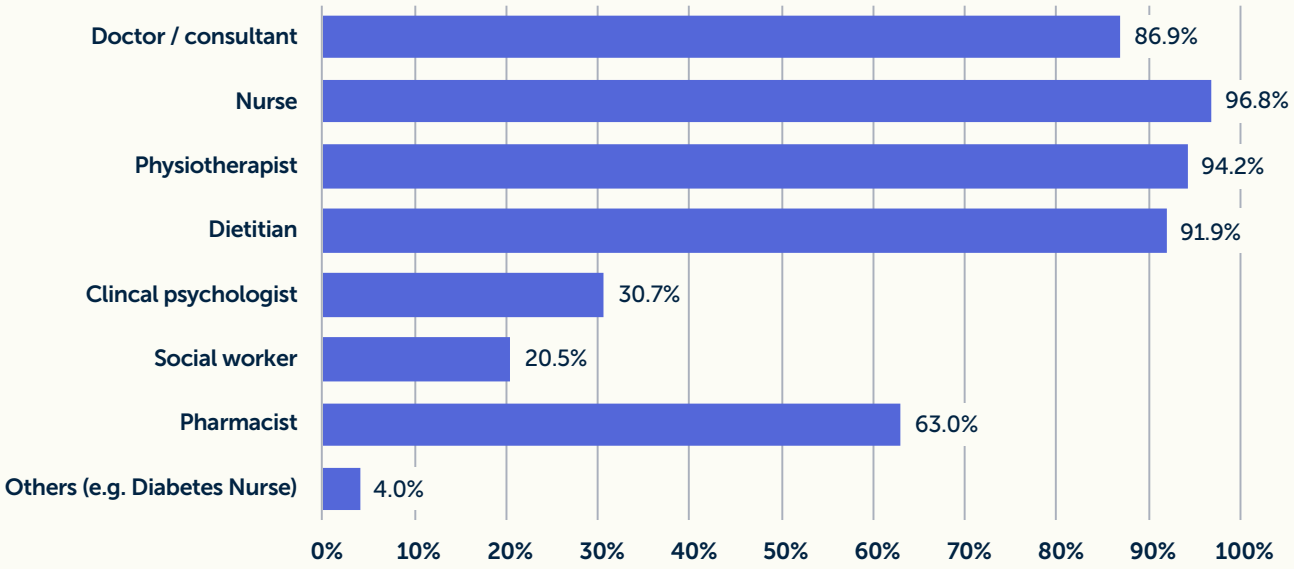
- Physiotherapy review of airway clearance techniques, exercise, and inhaled medication regimens.
- Comprehensive nutritional assessment.
- Screening of the person with CF and their family/carers by a clinical psychologist and by a social worker.
- Pharmacist review and discussion of all medication taken (5.3.1).

Survey question: Which team members did you see for your annual review?

This question also relies on recall, though familiarity with the CF team and different specialists within it means that most survey respondents should have been able to answer this question accurately.

Figure 14: CF professions seen at annual review

Note: based on 1,057 respondents with an annual review (excluding 22 who skipped this question).



More than 9 of 10 respondents confirmed they had seen a CF nurse, physiotherapist and dietitian for their annual review, with 86.9% also confirming they had seen a consultant or other doctor. This aligns with findings from the question about access to CF MDT staff (Section 1), which showed that these four groups were often easily accessible when people with CF needed them.

The proportion of respondents who recalled seeing a CF pharmacist, psychologist or social worker was much lower, with 63%, 30.7% and 20.5%, respectively. Again, this finding aligns with survey responses on the accessibility of these professions, as well as the fact that large proportions of respondents felt they had not needed support from a psychologist or social worker. While screening by a CF psychologist and social worker is recommended at annual review, this may be done in different ways, and not all people with CF may see a psychologist or social worker face-to-face for their annual review.

Where people with CF feel they do not need psychological or social support, or where screening does not show a need for this, differences in who is seen for annual review are warranted, as this means care is adapted around the patient. However, from the CF staffing tool, we know that roles for CF psychologists and social workers do not exist in all CF centres. This is also demonstrated in the variation by centre in the proportions of respondents who confirmed they had seen these professions at annual review. Therefore, some of the variation in staff seen (Figure 14) is likely driven by a lack of such roles, rather than patient need, which is concerning.

Centre-level insight: Proportion of respondents who had seen CF psychologists, social workers and pharmacists at their last annual review

Note: centres with fewer than 10 respondents to this question were excluded (one centre).

Over 90% of respondents confirmed they had seen a CF nurse, physiotherapist and dietitian at their last annual review. However, the proportions who had seen a CF psychologist, social worker or pharmacist were much lower.

Feedback from annual review

Finally, the survey also asked whether those whose annual review had been completed more than a month ago had received written feedback from the meeting.

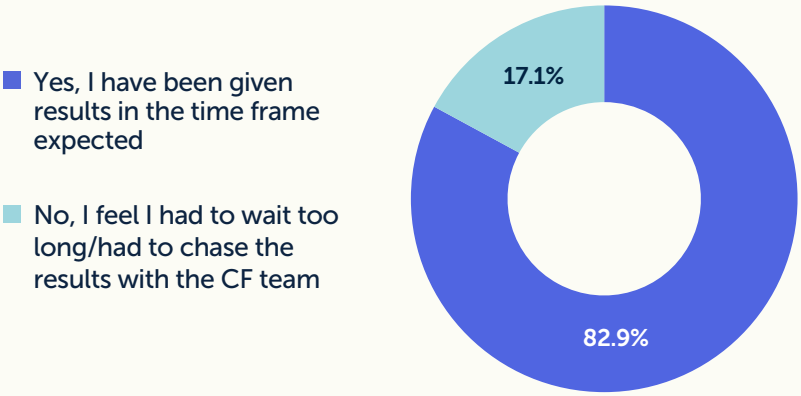
What do the Standards of Care say?

- A report should be written once all results are available, and sent to the GP, Network consultant, and person with CF or their family/carers.
- The report should be discussed with the person with CF or their family/carers and the treatment plan agreed (5.3).

Survey question: Did you receive written feedback from your annual review (via letter or online portal)? Please only answer if annual review was more than one month ago.

Figure 15: Written feedback from annual review

Note: based on 909 survey respondents with an annual review, excluding 170 who skipped this question; their review may have been <1 month previously.



Among those who answered this question (n=909), more than 8 in 10 respondents (82.9%) confirmed that they had received written feedback from their last annual review. However, just under two in 10 (17.1%) said that no written feedback had yet been shared with them. This is a slightly higher proportion than in the previous survey, in which 13.1% said they did not recall having had feedback from their annual review.

There was variation by centre in the proportions of respondents who said they had had feedback from their annual review.

Centre-level insight: Proportion of respondents who had received written feedback from their last annual review

Note: centres with fewer than 10 respondents to this question were excluded (two centres).

82.9% of respondents confirmed they had received written feedback from their last annual review, but 17.1% could not recall having had feedback.

Section 5
Infection control and prevention

Due to the risk of cross-infection, people with CF should be kept apart from each other when visiting any area of the hospital. All settings in which care is provided should have clear protocols in place to minimise the risk of infection.

What do the Standards of Care say?

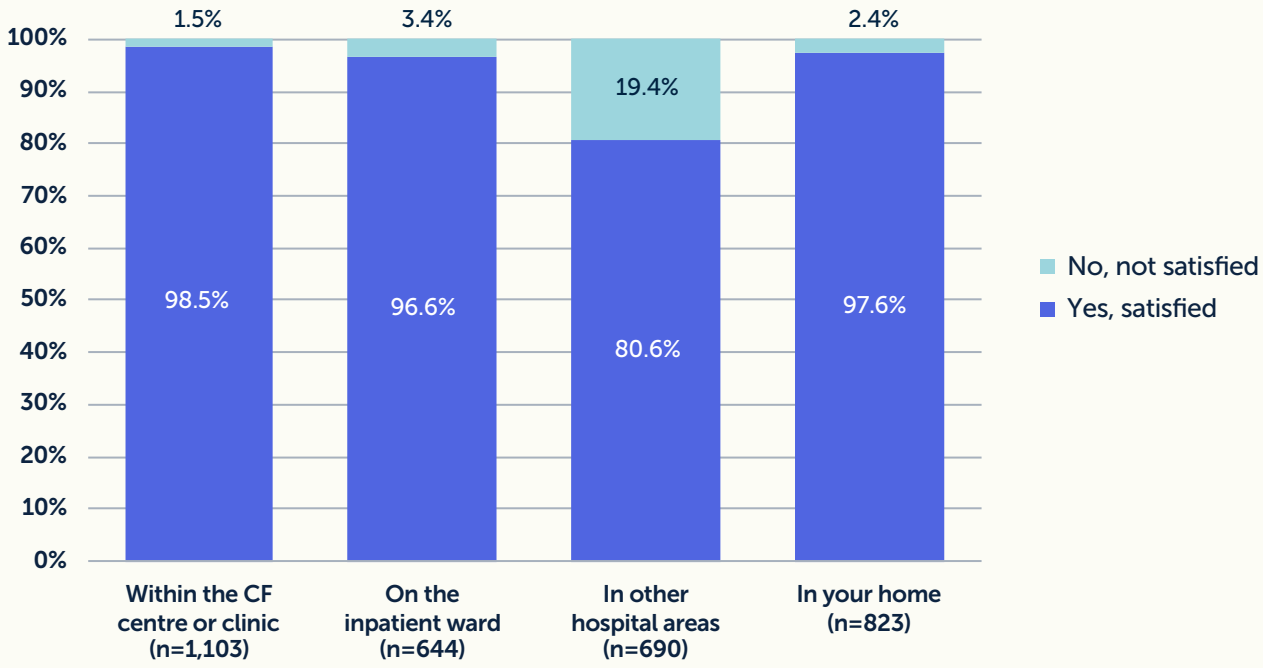
- People with CF must be isolated from each other.
- Every person with CF who's admitted to hospital must be in their own room with en suite facilities.
- Hospital facilities must maintain a high standard of cleanliness.
- Processes should be in place to avoid people with CF being in contact with each other in waiting rooms.
- A high standard of hygiene should be practised by staff at all times, in particular hand washing (4.4).

The survey asked about satisfaction with infection control in a variety of settings, including respondents' main CF centre or clinic, but also inpatient wards, other hospital areas, and people's homes.

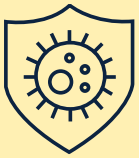
Survey question: In the last 12 months do you feel that the measures put in place are sufficient to help stop the spread of infection?

Figure 16: Satisfaction with infection control measures in different settings

Note: based on valid responses only (excluding those who said 'don't know' and who skipped this question); number of valid survey responses for each setting is provided in x-axis.



Overall, survey respondents were mostly satisfied with infection prevention and control measures. The number of respondents able to provide feedback about each setting varied, depending on whether they had had care in that setting in the last 12 months. For example, not all respondents would have had an inpatient stay or a home visit in the last year. Those who did respond were overwhelmingly satisfied, with very few 'no' responses recorded for CF clinic, inpatient and home environments. However, when asked about other areas of the hospital, such as x-ray, pharmacy and cafés, nearly 2 of 10 respondents who gave a rating (19.4%, n=134) felt infection control could be improved.



98.5% of respondents felt infection control measures were sufficient at their CF centre or clinic, but some raised concerns about infection control, particularly in other areas of hospitals, such as x-ray and pharmacy departments.

Those who said they were not fully satisfied with infection control measures in any setting were asked to provide more information. One hundred and fifty-three comments were received, the majority of which focused on concerns about infection control in hospital settings other than the CF clinic and inpatient ward, such as x-ray and pharmacy.

> "Masks don't need to be worn in other areas of the hospital and there's no way of knowing if I'm [sitting] next to a fellow CF sufferer as everybody can mix in x-ray departments, pharmacy, etc."
>
> "Throughout the respiratory waiting areas CF patients are put into private rooms; however, when waiting for imaging or other specialities we are expected to [wait in] waiting room with everyone else but asked to wear a mask which can draw attention to us."
>
> "Other areas, like the x-ray waiting area, were extremely busy and cramped. I waited outside the room to avoid infection."

However, there was also some feedback regarding inpatient settings and infection control on hospital wards. Several of these respondents felt ward staff' awareness and understanding of CF care needs and infection risk could be improved.

> "Hospital inpatient ward needs more awareness of CF infection control procedures, portacath care, etc."
>
> "Inpatients ward is severely lacking in experience caring for CF patients. To the point I feel unsafe and actively avoid inpatient admissions for as long as I can."

Others had concerns about hygiene and cleaning protocols in hospital settings.

> "My hospital is filthy. I do not feel it is cleaned thoroughly and is very easy to catch infections. The individual rooms are not cleaned between patients."
>
> "Things are not cleaned frequently enough within hospital and clinic."

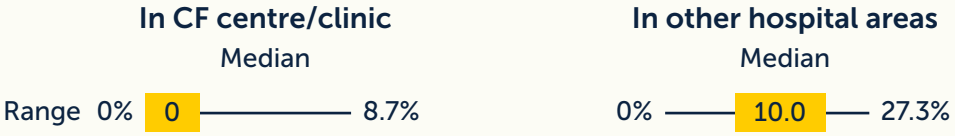
Some respondents also shared worries about infection prevention and control in their home environment.

> "I live in a very old house that I cannot afford to heat sufficiently. Other members of the household are not as conscious about infection risks and do not clean surfaces, leave standing water and mouldy food."

Given the risk of infection, and the anxiety this can cause when people with CF feel infection control is insufficient, CF centres and wider hospitals should make an effort to adhere strictly to the measures outlined in the standards of care and other guidance.

Centre-level insight: Proportion of respondents who felt that infection control measures were not sufficient in their centre/clinic or other areas of the hospital

Note: based on all participating CF centres (n=25).



Section 6
Hospital care

Outpatient clinic experiences

To more fully understand the experiences of people with CF when they attend outpatient appointments in their CF centre or clinic, we asked them to tell us what happens on arrival, when being seen by the team, and when having lung function, height, and weight measured.

What do the Standards of Care say?

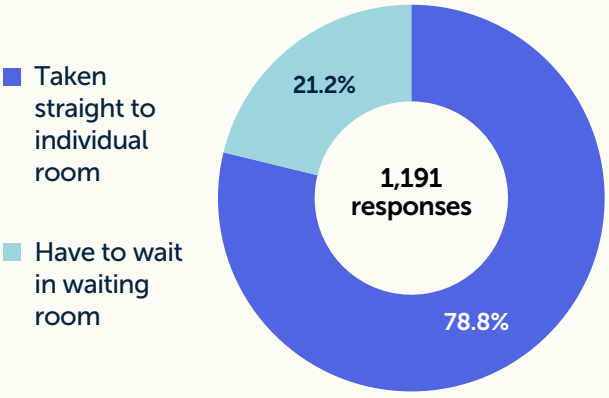
- People with CF must be isolated from each other.
- Processes should be in place to avoid people with CF being in contact with each other in waiting rooms (4.4).
- Infection control principles must be strictly maintained in clinic (5.2).

Survey question: For each question below, please tick the boxes that best describe your hospital experience in the last 12 months.

Note: figures 17–20 show the proportions of responses/instances and not respondents. This is because some respondents may have had multiple outpatient appointments and had different experiences at each appointment, therefore providing more than one response to the below questions.

Figure 17: "In CF outpatient clinic, what happens on arrival?"

Note: based on 1,191 survey responses provided by 1,164 respondents, 27 had experienced both scenarios in the last 12 months; excludes 121 who skipped this question; graph is out of responses.



In most instances, and in line with the standards of care, people with CF were taken straight to an individual room upon arrival at CF outpatient clinics and did not have to remain in communal waiting areas. However, 21.2% of responses indicated that some people with CF are asked to wait in communal areas on occasion. The distribution of responses to this question was slightly different to findings from the previous survey in adult CF care in 2020/21, when 85.9% said they were taken to an individual room and 16.4% said they had to wait in communal areas.

21.1% of responses indicated that people with CF had waited in a waiting room on at least one occasion when they visited their outpatient clinic.

There was variation by centre in the proportion of responses confirming adults with CF were taken straight to an individual clinic room upon arrival.

Centre-level insight: Proportion of respondents who went straight to an individual room upon arrival

Note: centres with fewer than 10 respondents to this question were excluded (one centre).

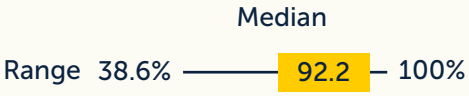
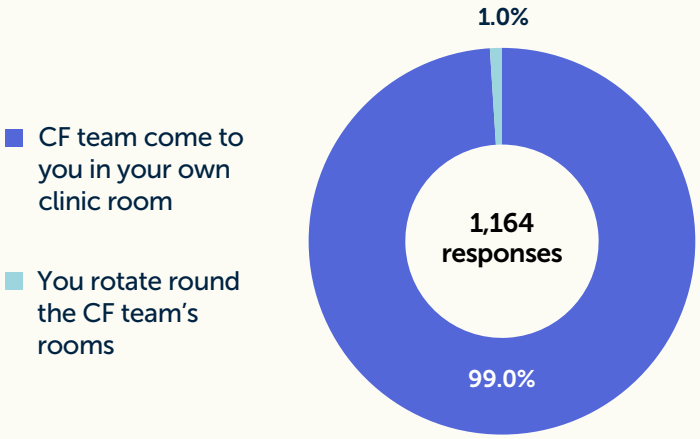


Figure 18: "In CF outpatient clinic, how is care delivered?"

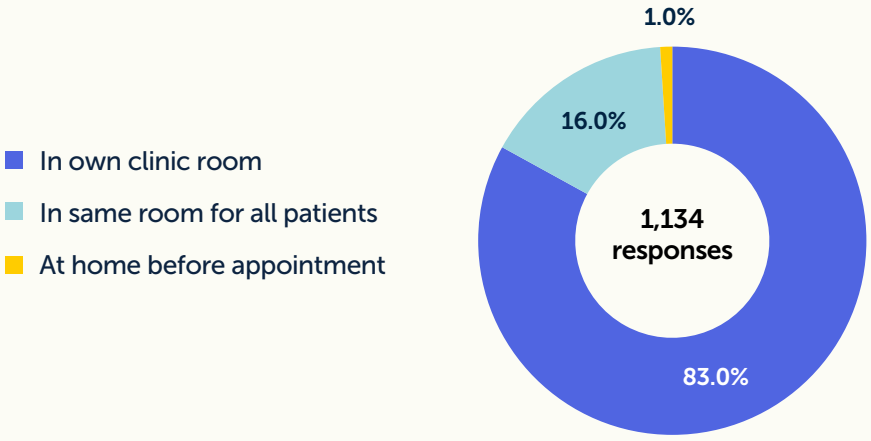
Note: based on 1,164 survey responses provided by 1,163 respondents, one had experienced both scenarios; excluding 122 who skipped this question; graph is out of responses.



In line with recommended best practice, most people with CF are seen in their own clinic room every time they attend outpatient clinics, with CF professionals coming to patients in their individual rooms. The distribution of responses for this question is the same as it was in the 2020/21 survey. Only 12 respondents (1%) from seven different centres reported ever rotating around their CF teams' rooms.

Figure 19: "In clinic, where is lung function measured?"

Note: based on 1,134 survey responses provided by 1,121 respondents, 13 had experienced both scenarios; excluding 164 who skipped this question; graph is out of responses.



Not all respondents to the survey had lung function tests for outpatient clinic appointments, with 164 skipping the question entirely. Of 1,134 responses received from 1,121 people, the majority of responses (83.0%, n=941) shows that most lung function measurements were taken in individual clinic rooms, with 16% of responses (n=182) indicating that measurements were carried out in the same room for all. In the previous survey, a higher proportion of lung function measurements were reportedly taken in individual rooms (93.6%). A few responses in 2023/24 indicated these assessments may also be completed at home prior to an outpatient visit (1%, n=11).

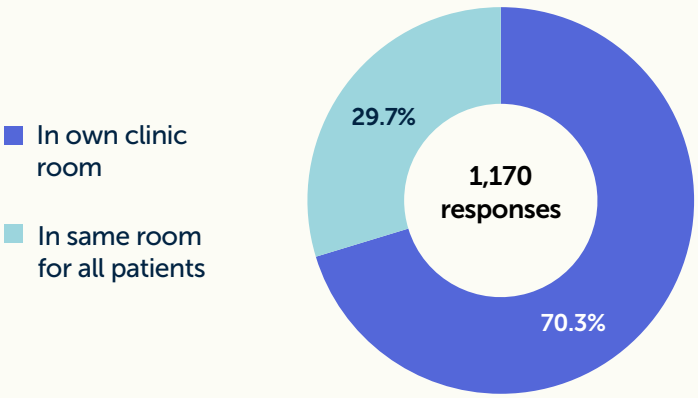
However, there was variation by centre in the proportion of responses confirming lung function was measured in patients' own rooms.

Centre-level insight: Proportion of responses indicating that lung function was measured in patients' own clinic rooms or at home prior to appointment

Note: centres with fewer than 10 respondents to this question were excluded (one centre).

Figure 20: "In clinic, where are height and weight measured?"

Note: based on 1,170 survey responses provided by 1,152 respondents, 18 had experienced both scenarios; excludes 117 who skipped this question; graph is out of total responses.



In contrast to measurement of lung function, survey data about the approach to height and weight measurements show that a larger proportion of these is done in the same room for all patients. While the majority of responses (70.3%, n=823) shows that most height/weight measurements were taken in individual clinic rooms, just under a third (29.7%, n=347) were carried out in the same room for all. This is a higher proportion than in the previous survey when this was 24.9%.

There was variation by centre in the proportion of responses confirming that these measures were taken in patients' individual rooms.

Centre-level insight: Proportion of responses indicating that height and weight were measured in patients' own clinic rooms

Note: centres with fewer than 10 respondents to this question were excluded (one centre).

29.7% of responses indicated that height and weight were measured in the same room for all patients, and for lung function this was 16%.

Inpatient facilities

People with CF may occasionally require hospital inpatient treatment; for example, during exacerbations and for intravenous (IV) antibiotics. During hospital stays, all people with CF should ideally be looked after by experienced CF professionals and have their own room and en suite bathroom to prevent cross-infection.

What do the Standards of Care say?

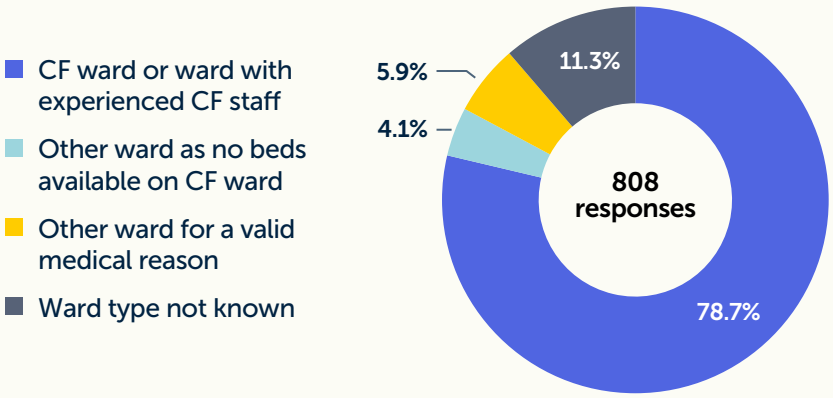
- Every person with CF admitted as an inpatient will be in their own room with en suite facilities, to minimise the risk of cross-infection and to give them as much privacy as possible. Hospital facilities must maintain a high standard of cleanliness (4.4).
- Principles of infection control must be strictly adhered to in the hospital [see 4.4] (5.4).

Note: Figures 21 and 22 show the proportions of responses/instances and not respondents. This is because some respondents may have had multiple inpatient stays and had different experiences during each stay, therefore providing more than one response to the below questions.

Survey question: When staying in hospital – what type of ward did you stay on?

Figure 21: Type of ward

Note: based on 808 survey responses provided by 784 respondents, 24 had experienced more than one scenario; excludes 501 respondents to whom this was not applicable or who skipped the question; graph is out of responses.



In line with recommended best practice, most responses confirmed admissions for adults with CF to wards with experienced CF staff (78.7%, n=636). This was a slightly lower proportion than in our previous survey in 2020/21 when this was 82%. The proportion of responses indicating admissions to other wards due to a lack of beds decreased from 14.2% in the 2020/21 survey to just 4.1% in the 2023/24 survey. However, the proportion of responses in the 'ward type not known' category increased from 0.9% to 11.3% in our most recent survey. Only 33 respondents (4.1% of responses) in the most recent survey said they had stayed on another ward on at least one occasion due to a lack of beds on the CF ward in our most recent survey.

There was some variation in response distribution between centres.

Centre-level insight: Proportion of responses confirming that people with CF had to stay in a non-CF ward due to a lack of beds

Note: centres with fewer than 10 respondents to this question were excluded (three centres).

Median

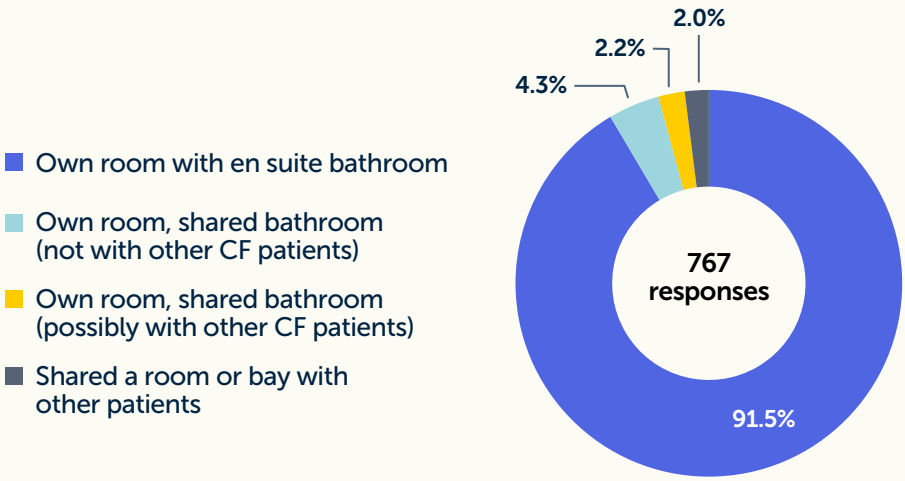
Range 0% - 2.7 ——— 20.0%

78.7% of responses confirmed admissions to CF wards (or wards with experienced CF staff), but a few respondents said they had been admitted to a non-CF ward on at least one occasion as a bed on the CF ward was not available.

Survey question: When staying in hospital – what type of bedroom and bathroom did you have?

Figure 22: Type of room

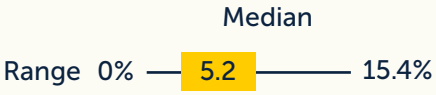
Note: based on 767 survey responses provided by 744 respondents, 21 had experienced more than one scenario; excludes 541 respondents to whom this was not applicable or who skipped the question; graph is out of responses.



The majority of responses (91.5%, n=702) indicate that people with CF are usually admitted to a private room with en suite bathroom, as recommended in the standards of care. Only 2.2% (n=17) of responses indicated that people with CF had to use shared bathrooms potentially also accessed by others with CF, and 2.0% of responses (n=15) indicated stays in shared rooms or bays, which are not appropriate for people with CF. These findings are similar to the previous survey, although proportions indicating use of bathrooms shared with others with CF decreased (from 6.2% to 2.2%), while the proportion indicating use of shared rooms or bays increased (from 0.3% to 2%).

Centre-level insight: Proportion of responses confirming that people with CF had to share a bathroom or bay with others, potentially including CF patients

Note: centres with fewer than 10 respondents to this question were excluded (three centres).



91.5%
of responses confirmed stays in private rooms with en suite bathrooms during hospital admissions, but a few respondents had to use bathrooms that may be accessed by others with CF or shared rooms or bays.

Inpatient care experiences

During inpatient stays, people with CF should have access to additional food, equipment for their side room, as well as hospital education for those under 18. Furthermore, other aspects of care, including the timing of intravenous (IV) antibiotics and receipt of drugs to take home, should be well organised.

What do the Standards of Care say?

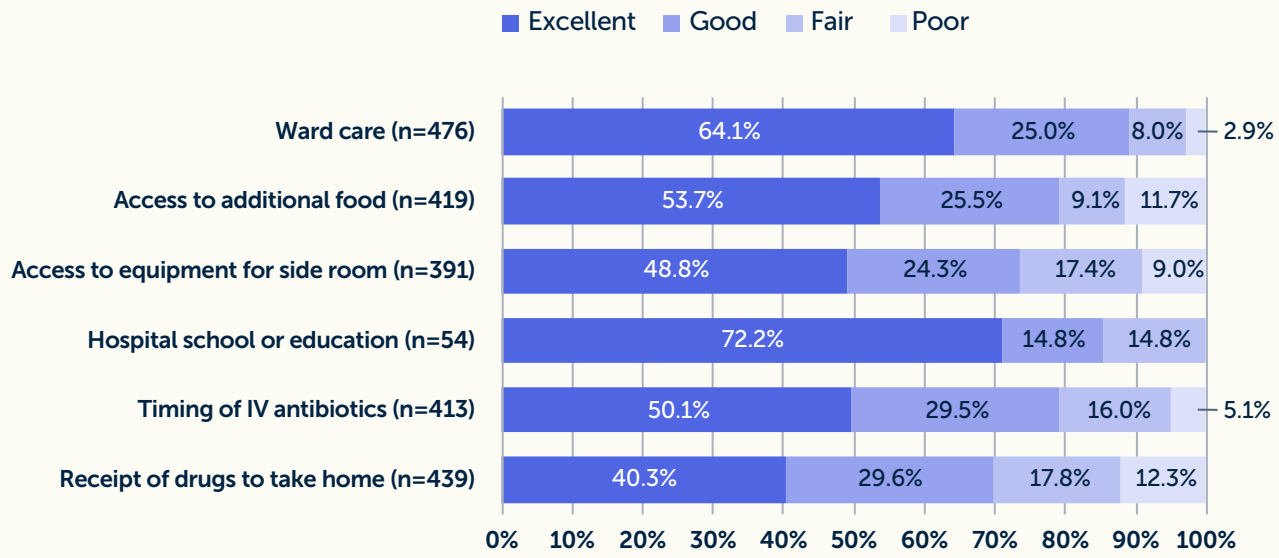
- Beds in a ward suitable for CF care should always be available for emergency admissions.
- There should also be enough beds to ensure elective and urgent admissions can be managed appropriately.
- Local authorities have a duty to provide suitable education to children who cannot attend school due to illness. This education might be provided in a number of ways, including hospital schools.
- There should be access to appropriate play and/or recreation, with facilities for studying.
- Inpatients should have a choice of high-quality food and fluids to meet their individual requirements (5.4.1).

The survey explored experiences of inpatient stays. Overall, 496 of 1,285 respondents (38.6%) provided one or more rating(s) for aspects of inpatient care.

Survey question: Thinking about when you had to stay in hospital (either for IVs or something else related to CF) in the last 12 months, how good were the care aspects listed below?

Figure 23: Experiences of inpatient care

Note: based on responses from 496 respondents who had had a hospital stay (excluding 789 who replied 'not applicable' or skipped this question); number of valid survey responses for each aspect of inpatient care is provided in x-axis.



Many aspects of inpatient care were rated positively by survey respondents, with 89.1% of those responding to this question confirming that ward care had been excellent or good. Similarly, the 54 respondents who provided a rating for hospital education rated this highly, with 87% excellent and good ratings.

Around three-quarters of respondents rated IV antibiotic timing, access to additional food, and access to equipment highly, with 79.7%, 79.2% and 73.1% excellent or good responses, respectively. However, 1 in 10 respondents rated access to additional food as 'poor' (11.7%).

Receipt of drugs to take home was the least positively rated aspect of inpatient care, with 12.3% 'poor' and 17.8% 'fair' ratings. However, even this aspect of care received 69.9% excellent or good ratings, indicating that overall experiences of inpatient care were relatively positive with a few exceptions.

The previous survey did not ask this question in the same way and it is therefore not possible to compare.

89.1% of respondents rated ward care during inpatient stays as excellent or good, but other aspects of care were rated less positively. 11.7% and 12.3%, respectively, rated access to additional food and receipt of drugs to take home as poor.

Section 7
Intravenous antibiotic therapy

Access to IV antibiotics

Timely access to intravenous (IV) antibiotic therapy is crucial to managing infection and exacerbations in people with CF.

What do the Standards of Care say?

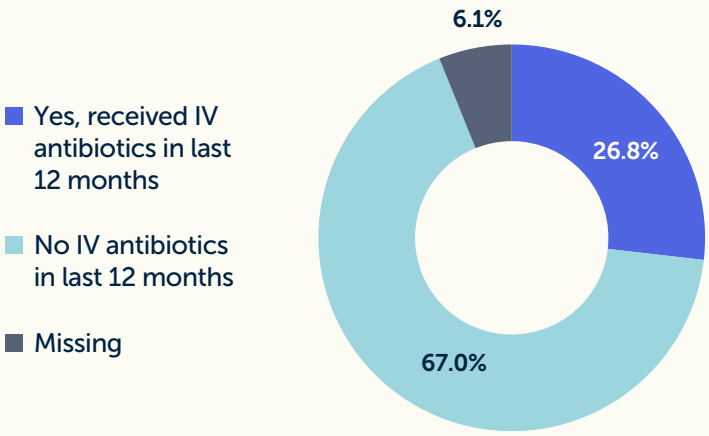
Inpatients (5.4): The majority of admissions are for IV antibiotics, either for a chest exacerbation or as part of routine management.

- An urgent course of treatment should be implemented within a maximum of 24 hours of the decision being made. There should not be a delay of longer than seven working days of the proposed admission date for a non-urgent course of treatment.
- Discharge planning is essential, especially if the person with CF is finishing the course of IV antibiotics at home.

Survey question: In the last 12 months, have you received intravenous (IV) antibiotic therapy either at home or when staying in hospital?

Figure 24: Intravenous antibiotic therapy in the last 12 months

Note: all survey respondents included (n=1,285).

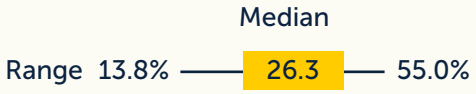


Just over a quarter of people with CF in the survey (26.8%, n=345) confirmed that they had received IV antibiotics in the last 12 months. This is a slightly smaller proportion than in the 2020/21 survey, in which 30.5% reported having had IVs. The decline in the proportion of survey respondents who had needed IV antibiotics in the last year may in part be due to improved health for many people with CF on modulator therapies. Data from the UK CF Registry also show an overall decline in IV days in the adult CF population[3]. The proportion of adults with CF who had had IVs in the last 12 months varied by centre.

3 UK CF Registry, September 2023: 2022 Annual Data Report

Centre-level insight: Proportion of respondents who received IV therapy in the last year

Note: based on all participating centres (n=25).

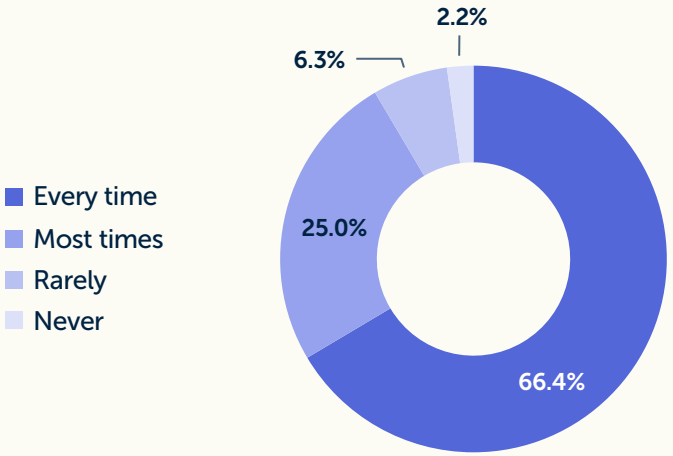


Respondents who confirmed they had IV antibiotics in the last year (n=345) were shown several follow-up questions to further explore their experiences with timeliness and location of antibiotic therapy. The remainder of this section focuses on these respondents only.

Survey question: If you were told that a course of IV antibiotics was necessary in the next 24 hours, did treatment start within that time frame?

Figure 25: Urgent IV antibiotic therapy started within 24 hours

Note: based on 268 respondents who had received urgent IV antibiotics, excluding 77 not applicable and missing responses (did not need to start antibiotics within 24 hrs).



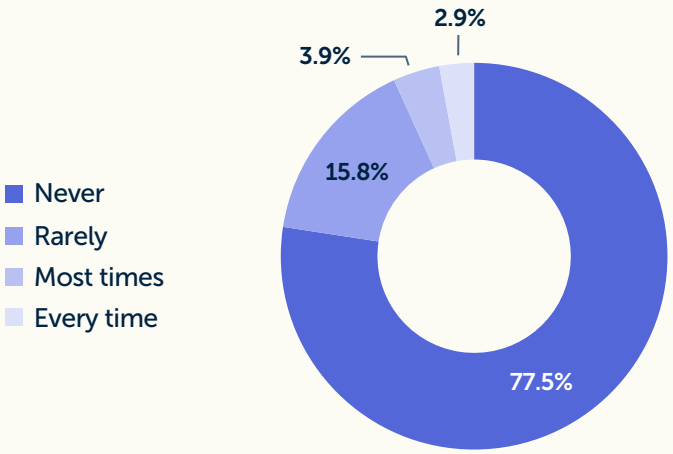
The vast majority of respondents (91.4%) confirmed that, where indicated, urgent IV antibiotics were started within 24 hours, every time or most times. This is a slight increase from the previous survey when this was 87.2%. The proportion confirming urgent IVs were started on time 'every time' increased from 40.2% in 2020/21 to 66.4% in 2023/24.

Where IV antibiotic treatment is routine or planned, this should be started on or as close to the proposed admission date as possible. The survey asked those on routine or planned IV antibiotic therapies about delays to their scheduled admission to better understand when and how delays occurred in this setting during the pandemic.

Survey question: Have you had a delay of longer than 7 working days from your proposed admission date for planned or routine IV antibiotics?

Figure 26: Planned IV antibiotics delayed more than 7 working days

Note: based on 311 respondents who had received routine IV antibiotics, excluding 34 not applicable and missing responses (did not need routine IV antibiotics).



More than 3 in 4 respondents (77.5%) confirmed that their routine or planned antibiotics were never delayed more than seven days from the originally scheduled admission date. This is an increase compared to the previous survey when this was 69.7%. Only 21 people (6.8%) in the 2023/24 survey said they had started routine IV antibiotic therapy with more than seven working days' delay every time or most times, with another 49 (15.8%) saying delays happened rarely.

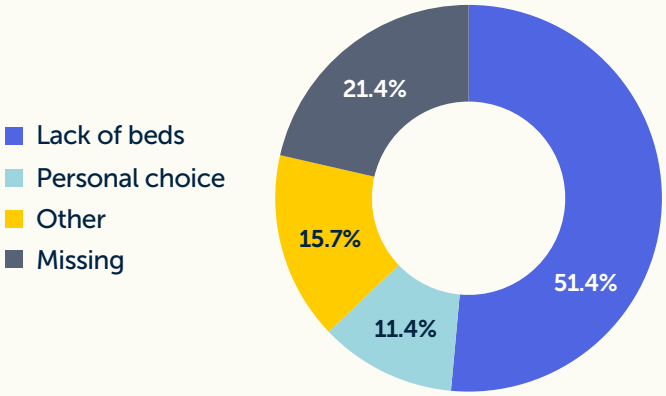
66.4% of respondents had always started urgent IV antibiotics within 24 hours.

77.5% of respondents had never experienced delays (>7 days) in admissions for planned IV antibiotics.

Survey question: If you had a delay of longer than 7 working days to planned/routine antibiotics, what was this due to?

Figure 27: Reasons for delay to planned IV antibiotics

Note: based on 70 respondents who had experienced a delay of more than 7 working days, including missing responses (unknown).



Of the 70 individuals in the survey who had experienced a delay of more than seven days to planned IV antibiotic therapy, more than half (51.4%) said that a lack of suitable beds had caused the delays to their scheduled admission date(s) for routine IV antibiotics. Twelve respondents provided other reasons for the delay to planned antibiotics, which included medicine supply issues and problems with vascular access, as well as instances where respondents felt there was not one single reason, but where delays were caused by a mixture of different circumstances, including lack of beds, personal choice, and others.

> "Vascular access [was] not available, as well as lack of clinic space."
>
> "3rd party antibiotic supplier."
>
> "Both. Lack of beds as CF ward is being used as a "normal" ward a lot of the time and staff are not able to move patients to a different ward. And my choice, as it wasn't a good day for me going in hospital."

Home IV antibiotic therapy

The use of IV antibiotic therapy at home has increased significantly in recent years. Where these are appropriate, home IV antibiotic therapies can reduce or avoid inpatient stays.

What do the Standards of Care say?

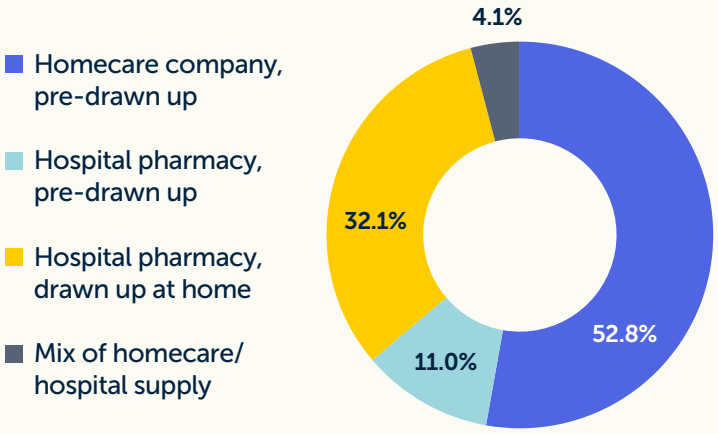
- Home IV antibiotics may be suitable for some people with CF. CF teams need to evaluate their appropriateness.
- When a person with CF is receiving IV antibiotics at home, close monitoring is required.
- Home delivery of pre-prepared IV antibiotics should be considered and when appropriate offered to people with CF.
- Appropriate training to administer IV antibiotics must be given to the person with CF or their family/ carers, and written competency checks recorded (5.5.2).

Of 345 survey respondents who said they had had IV antibiotic therapy in the last 12 months, 218 (63.2%) confirmed that this had included home IVs. These respondents were asked to share information on access arrangements for home IV antibiotics, as well as their experience with home IVs.

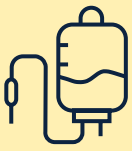
Survey question: In the last 12 months, have you received intravenous (IV) antibiotic therapy either at home or when staying in hospital?

Figure 28: Access arrangements for home IV antibiotics

Note: based on 218 respondents who had received home IV antibiotics.



Half of those who had received home IVs (52.8%) said these were delivered pre-drawn up by a homecare company. A third (32.1%) said they received their home IVs via their hospital pharmacy but had to draw these up themselves at home. Only 11% received pre-drawn up antibiotics from their hospital pharmacy.



52.8% of respondents who had home IV antibiotics accessed these from a homecare company, and 43.1% received them from their hospital pharmacy.

Survey question: What was your experience of home IVs?

The survey then asked respondents to describe their experiences with home IVs in the last year. Two hundred comments were received, many of which were positive, describing experiences with IVs at home as 'excellent', 'great', 'very good', 'fantastic' and 'amazing'.

> "Home IVs are excellent, having done home IVs for many years, it means that you can be surrounded by your own things, minimise risk of further infection, eat food that you like, etc. It also minimises homesickness, which I have previously had with admissions."
>
> "Brilliant – I am a full-time carer for my spouse and wouldn't have been able to go into hospital."
>
> "Very easy, better than staying in hospital as I can carry on with day-to-day activities with family, [and] even go to work for lighter duties."

Some also specifically described how well supported they had felt by their CF team.

> "Excellent. CF nurse[s] sort out all the drugs from hospital pharmacy and Lloyds homecare. They are on the end of the phone if I need them."
>
> "It gave me independence and meant I could go home. They gave me a refresher (I had done them before) and observed me doing it to make sure I was doing it properly."

However, others fed back they had found home IVs 'tiring' and 'exhausting', although many still remarked that they preferred home treatment to staying in hospital.

> "Time consuming and laborious when unwell."
>
> "Hard work but good if I don't want to stay on the ward."
>
> "Exhausting! We wish we could have pre-mixed drugs which we could use quickly, safely, and on the move."

Some had experienced issues with receiving deliveries.

> "Not a good delivery company, always late deliveries or doesn't come in time, missing items."
>
> "Generally good although had to chase for missing items."

The responses clearly show that many people with CF value having the option of home IVs and have positive experiences with this approach, which allows them to enjoy home comforts and routines while on treatment. However, responses also highlight that support from the CF team is crucial to ensure adequate training as well as access to drugs and equipment. Some also reported finding home IVs tiring or exhausting and may prefer to stay in hospital for their IV treatment.

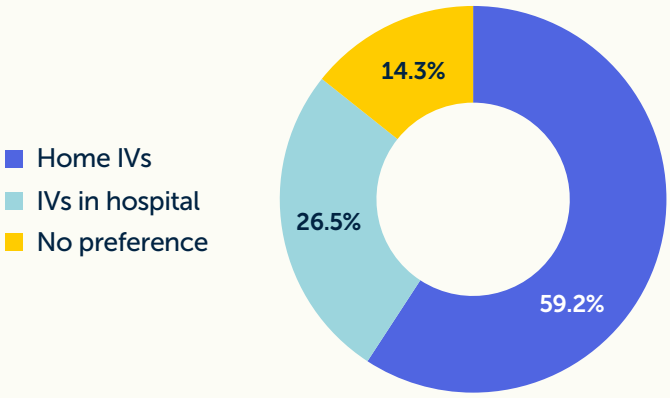
Future IV preferences

Given experiences with home IVs can vary, the survey asked people with CF who had needed any IV antibiotics over the last 12 months to reflect on their future preferences for where they would like to complete courses of IV antibiotics. It not only explored what their preference would be but also asked respondents to share the reason(s) for their answer.

Survey question: In future, if given the choice of completing IVs in-hospital or at home, which would you prefer and why?

Figure 29: Future preferences for location of IVs

Note: based on 336 respondents who had received any IV antibiotics, excluding 9 missing responses.

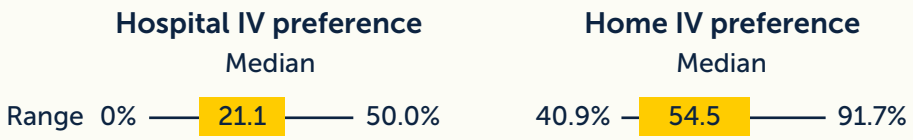


More than half of respondents (59.2%) preferred home IVs, a quarter (26.5%) favoured hospital IVs and 14.3% said that they had 'no preference'. The proportion with a preference for home IV treatment reduced compared to the 2020/21 survey when 68.1% had this preference, whereas the proportion favouring hospital IVs increased from 22.6% in the previous survey. This may, in part, have been due to the COVID-19 pandemic impacting on preference in 2020/21, with many people with CF preferring to remain at home.

There was some variation in the proportion of respondents with preferences for home versus hospital IVs at centre level.

Centre-level insight: Proportion of respondents stating a preference for hospital or home IV antibiotic therapy

Note: centres with fewer than 10 respondents to this question were excluded (10 centres).



59.2% of respondents said they preferred home IVs, 26.5% favoured hospital IV treatment, and 14.3% had no preference.

Two hundred and thirty-four respondents shared reasons for their preference. In line with the feedback from those who had positive experiences with IVs at home, those who favoured home IV treatment valued creature comforts, being in their own surroundings and keeping up routines with work or education.

> "Prefer my own surroundings. I am able to rest more without constantly being disturbed. My IVs are administered at [the] right times as I'm doing them myself."
>
> "Much prefer being at home. I am more active at home, have access to more things at home and feel I do much better at home, even when unwell."
>
> "Home IVs allows me to work from home. It's difficult working from hospital as the MDT come in at random times throughout the day and also the WiFi isn't good enough."
>
> "If I have college that is easier for me and sometimes hospital isn't the best with food."

Some also specifically mentioned the reduced risk of infection with home versus hospital treatment.

> "It's much easier and less risk of infection."
>
> "Lower risk of infection, lower risk of deconditioning [physical decline following inactivity or bedrest], control over infection control."

Others highlighted the impact of hospital stays on their mental health or wellbeing and noted that home IVs would be less disruptive and stressful for them.

> "Would be great to carry on normal life – look after my kids and sleep in my own bed. Being in hospital meant I needed to organise a lot of care for my kids, caused my kids stress and I struggled mentally being apart from them."
>
> "Less intrusive to my humanity. Only people I know are dealing with me, strangers are not coming into my room at night when I am asleep, and strangers don't ask me questions about my body or suddenly decide I need a blood test."

In contrast, those with a preference for hospital IVs put greater emphasis on being able to rest, have treatments administered by health professionals, and have direct access to medical staff.

> "Less stress. I prefer being taken care of and support with meals etc. Also, it's reassuring somebody's always there on the ward at a press of alarm button than home alone."
>
> "I want the break and not have to sort my own IVs. I want to be in hospital resting and being taken care of."

In line with feedback from those who had more negative experiences with home IVs, some also said they found these tiring and stressful, hence preferring hospital treatment.

> "Too tiring to do at home, and I don't rest, I continue my usual daily life."
>
> "Live on my own. Too much equipment. Hard to do alone. Very tiring."

Others said they preferred being admitted to reduce the burden on others, specifically spouses or family.

> "Less burden on family."
>
> "The burden on my wife to care for me at home would be too great and it would involve more than just home IVs; for example, blood tests and scans."

Those who had no immediate preference often said their preference would depend on their health and might also change as they start to feel better.

> "I prefer a mix. It is good to start in hospital to get the help with diet, physio, and bloods, and it ensures you rest and not do jobs at home. By the second week I'm ready to go home as I'm feeling better and want to do more."
>
> "It varies, sometimes I feel unwell enough to want the physio's extra support in hospital, but other times I want to continue working or having some sort of life around the IV treatments."

Section 8
Care at home and in the community

Home monitoring

The use of technologies to empower people with CF to self-monitor at home and or share their data remotely with the CF team has increased rapidly over the years. A wide range of clinical information can now be collected remotely. This should always be the choice of the person with CF, but can be hugely reassuring for some.

What do the Standards of Care say?

- Remote monitoring is the ability to monitor certain aspects of the health of a person with CF from their own home (2.2.1).

The survey asked about home monitoring equipment people with CF used in their own homes, finding that 1,113 of 1,285 (86.6%) of survey respondents use some form of monitoring equipment at home. While the proportion of respondents who used such devices, and the types of devices in use, varied by centre, there were no centres in the survey where no one used home monitoring, showing that this is widespread among the CF community.

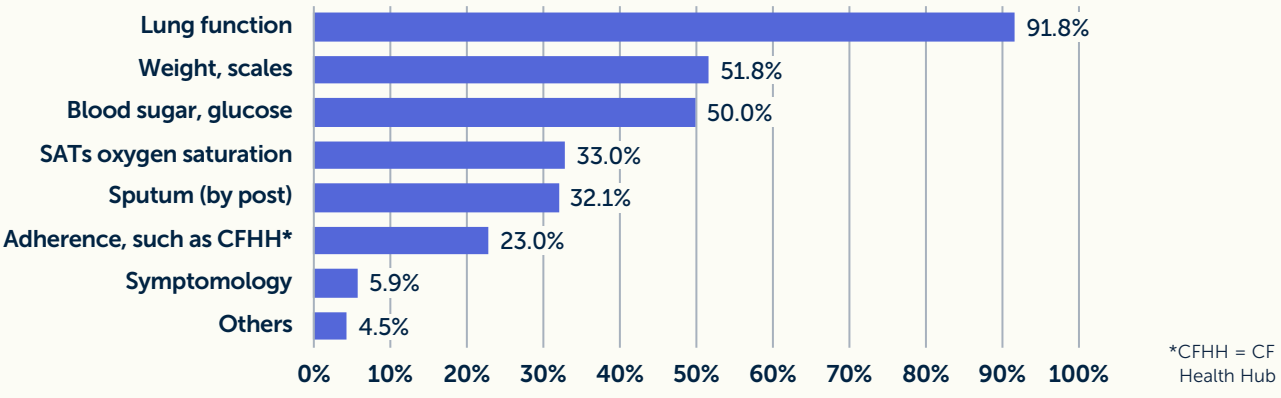
Centre-level insight: Proportion of respondents using any type of home monitoring equipment

Note: based on all participating centres (n=25).

Survey question: What home monitoring equipment do you have/use at home?

Figure 30: Use of home monitoring equipment

Note: based on 1,113 respondents who confirmed use of any home monitoring equipment, graph shows proportion using each type.



Nine of 10 respondents (91.8%) who used home monitoring equipment were able to measure lung function at home. Five of 10 respondents also monitored weight and blood sugar at home. Use of other home monitoring equipment, including oxygen saturation, adherence and symptomology was less frequent.

86.6% of respondents used some form of home monitoring equipment, with most able to measure lung function at home.

Airway clearance

Many people with CF have different types of airway clearance equipment at home to help manage cystic fibrosis.

What do the Standards of Care say?

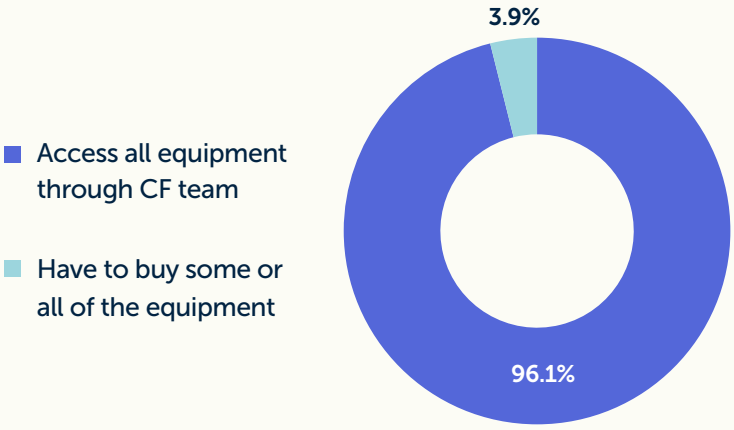
Specific therapies used to treat CF include antibiotics for acute exacerbations and chronic infection, and use of airway clearance techniques and mucolytics to improve airways clearance (4.5.2.2).

The survey explored access to airway clearance equipment, as well as types of equipment in use. Of 1,285 survey respondents, 1,025 (79.8%) confirmed that they used airway clearance equipment at home. The remainder of this section is based on those who had access only.

Survey question: Were you able to access all of the airway clearance and nebuliser equipment that you need?

Figure 31: Access to airway clearance at home

Note: based on 995 respondents who had access to airway equipment, excluding 30 who skipped this question.



The vast majority of respondents (96.1%) confirmed that they obtained their airway clearance equipment through their CF team, which aligns with findings from our previous survey. Only 39 respondents (3.9%) said they had to buy some or all of their equipment.

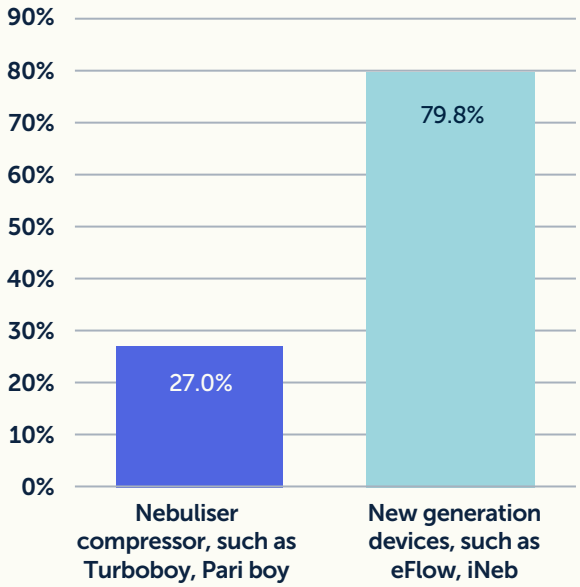
There was only slight variation at centre level in the proportion of respondents who said they received all their equipment through their CF team, with the highest proportion at any centre being 11.1% of respondents saying they have to buy some or all of their equipment.

79.8% of respondents confirmed they used airway clearance equipment at home, with most receiving this through their CF team.

Survey question: What type(s) of equipment do you use?

Figure 32: Types of airway clearance equipment

Note: based on 958 responses by 897 respondents who had access to airway equipment, excluding 128 who skipped this question; 61 respondents selected both options; graph shows proportion of respondents who use each type, as there is overlap, this may add up to more than 100%.



Use of airway clearance equipment at home is still common, including more traditional models. Around a quarter (27%) of those who confirmed they had access to airway clearance used nebulisers or compressors, while 79.8% used new generation models such as the eFlow and iNeb devices, which can also include electronic data capture.

Specialised medications

Apart from airway clearance equipment, people with CF may have access to other treatments to help manage CF at home, including specialised medicines such as modulators, pancreatic enzymes and antibiotics. The survey enquired about respondents' experiences with specialised medications at home, including delivery arrangements.

What do the Standards of Care say?

- CF teams should work with people with CF, or their families or carers, to ensure they understand how to get their medicines.
- If there are problems getting medicines, CF teams should resolve these, liaise with other providers to ensure an ongoing supply, and suggest alternatives where necessary (4.2.5).
- Home delivery of pre-prepared IV antibiotics should be considered and when appropriate offered to people with CF. (5.5.2).

Survey question: If you have been prescribed specialised medicines, such as inhaled antibiotics/ modulators for use at home, what was your experience with these?

Seven hundred (54.5%) respondents provided a response to this question. Overall feedback on specialised medications at home was positive, with survey respondents describing their experiences as 'excellent', 'very good', 'good' and 'fine'. Many of these respondents reported prompt deliveries of medications to their homes.

> "Excellent experience. Home delivery is always on time."
>
> "All good, home delivery is a good system to keep on top of medicines."

Others, however, reported problems with deliveries of specialised medicines by homecare companies. These ranged from communication issues and inconvenient delivery arrangements to missed or delayed deliveries.

> "Home delivery has been inconvenient as I do not work at home. Past experience with delivery to workplace has been poor. Deliveries have been cancelled last minute which impacted back-up stock."
>
> "Using Lloyds clinic homecare is very frustrating as the communication between staff is poor and the delivery hours are unrealistic."
>
> "Sciensus are supposed to deliver, but their communication is poor, and I have often been left with short supply."

Those who had to collect medication from pharmacies also reported some issues.

> "My pharmacy is a nightmare, very unorganised and always forgot to order my medication."
>
> "Generally good. Communication between hospital, GP surgery and pharmacy sometimes a little slow."
>
> "The medicines are excellent; have improved my health and quality of life. It is frustrating that I have to collect medicine in 3 different ways, and they cannot all be collected from one pharmacy."

Despite some respondents reporting negative experiences, many also fed back that the specialised medicines they could access in the community setting (either via pharmacies or homecare companies) were benefitting their health and that they appreciated the service on offer.

Our survey results show that there is variation in how such medicines are accessed and suggest improvements are needed in home delivery as well as pharmacy collection arrangements to ensure uninterrupted access. In particular, communication from homecare companies and communication between CF teams, GPs and pharmacies were highlighted as areas for improvement.

Homecare

Access to care at home and in the community is important to help manage CF on a day-to-day basis and to avoid unnecessary exacerbations and hospital admissions.

What do the Standards of Care say?

- Homecare encompasses a range of activities related to CF care provided at home, from routine clinical care to the CF virtual ward.
- Most specialist CF centres in the UK offer a home-based care service. (5.5.1).

The survey explored if people with CF had access to community support and care in their homes, who provided this and what their experiences were.

Survey question: Do you have access to any community support or care delivered in your home such as physio, port flushes, etc?

Around 1 in 5 (21.2%) survey respondents (n=272) confirmed they had access to community care, either through their specialist CF team or community staff.

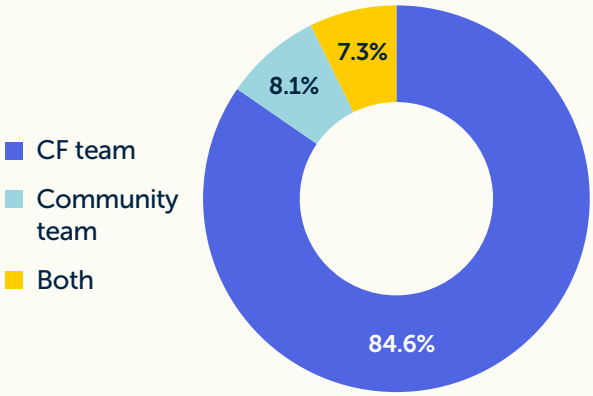
Centre-level insight: Proportion of respondents with access to community/homecare

Note: based on all participating centres (n=25).

Survey question: If you have access to any community support or care at home, who provides it?

Figure 33: Homecare provider

Note: based on 259 respondents with access to community care, excluding 13 who had access to community care but skipped the question.



Most respondents confirmed that care in the community was provided through their specialist CF team (84.6%), with just 8.1% saying they received care through community-based staff and 7.3% reporting that community support was shared between both teams.

21.2% of respondents had access to care at home or in the community, with 84.6% of these confirming that this was provided by their CF team.

Survey question: What do the team delivering community care do?

To better understand the kind of services offered at home and in the community, people with CF were asked to give details about the services they could access. From an analysis of free text comments (n=190), the most common services provided at home were port flushes, blood tests, physio and nurse visits, though other services were also offered through CF and community teams, including checks of and support with equipment, medication and exercise techniques.

> "Bloods, port flushes, start IVs – nurses [and] physio at home as often as required."
>
> "Physio techniques, SATs monitoring, exercise sessions and tips, muscle pain advice and exercise. Prescribe medicine."
>
> "CF team for port flush and bloods. Nutricia [homecare service provider] nurses oversee PEG management."
>
> "Support worker helps am/pm medication routine. Mainly prompting, encouraging, monitoring."

Survey question: Do you have any comments or concerns about the support or care given at your home?

Figure 34 : "Do you have any comments or concerns?"

Note: Word cloud based on free text answers left by 129 respondents; common words were excluded to create the word cloud (such as 'to', 'and', 'if', etc).

The vast majority of respondents said they had no concerns or comments about the care they could access in their home or in the community. Several also specifically left positive feedback about their homecare services.

> "I think it's very handy and great."
>
> "No concerns, my MDT are great! I appreciate all they do for me."

Section 9
Transplants

What do the Standards of Care say?

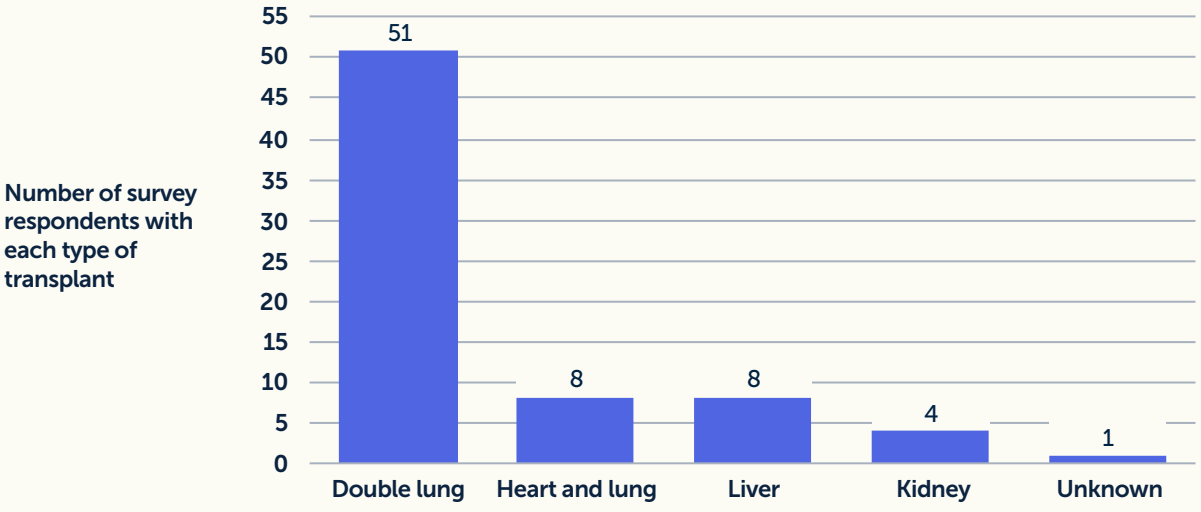
- People with CF who have undergone lung transplant still have CF, with its systemic complications, and should be managed with collaborative working between the CF MDT and transplant teams.
- There should be a clear agreement which areas of care are the primary responsibility of which team. (5.7.2).
- Other solid organ transplants, in particular liver, kidney, and pancreas, may be required by some people with CF. The CF MDT should have a working relationship with one of the NCG designated centres for liver, pancreas and renal transplantation. (5.7.3).

Overall, 65 of 1,285 survey respondents (5.1%) confirmed that they had a transplant. This is the same proportion as we saw in our previous survey. Seven respondents with a transplant said that they had more than one type of transplant.

Survey question: What type of transplant have you had?

Figure 35: Types of transplants

Note: graph shows the number of survey respondents with each type of transplant (some respondents had more than one type of transplant and are therefore counted more than once).



The most common type of transplant received by people with CF in the survey was a double lung transplant (51 of 65). Other types of transplants respondents had received were heart and lung, liver, or kidney transplants. There were no respondents with a pancreas transplant or other types of transplants in the 2023/24 survey.

Experiences of post-transplant care

The survey asked all respondents who had had a transplant about the care they receive from the CF and transplant teams following their transplant.

Survey question: What sort of things does your CF team or your transplant team do to help care for you after your transplant?

In part, the response to this question depended on the type of transplant(s) people with CF had received. For example, those with lung transplants often noted that their transplant team would focus on lung monitoring and care, but the CF team would deal with any other CF-related issues.

Post-transplant care from CF team

Fifty-nine transplant recipients (90.8%) shared comments about the care they could access from their CF team following their transplant. In line with best practice recommendations, most reported that the CF team continued to provide many or all aspects of care to help them manage life with cystic fibrosis, including physio exercise and airway clearance, CF diabetes care, nutritional advice, as well as emotional and wellbeing support.

> "Management of everything CF related (x-rays, six-weekly transplant blood tests, digestion, dietary advice, bowels, bone density, diabetes, six-weekly portacath flushes, annual bone density treatments, exercise advice, blood pressure, mental health, hernia monitoring, emotional help, specialist referrals), except my lungs, which are monitored by my transplant centre." Double lung transplant recipient
>
> "Airway clearance, physio, exercise, antiglobulin, lung function monitoring. Essentially everything needed has been provided." Double lung transplant recipient
>
> "Regular clinics - in person and phone/video. I see the diabetes nurse and physio and dietitians. They offer psychological and social work advice." Double lung transplant recipient
>
> "Holistic approach to treatment, generally look after me." Heart and lung, liver, and kidney transplant recipient

Others also specifically mentioned how their CF team worked with the transplant team to coordinate care and advise about the complexities of CF.

> "[They] assisted the transplant team with recommending appropriate antibiotics treatments immediately post-transplant, as well as continuing to monitor and treat non-lung related CF symptoms." Double lung transplant recipient
>
> "They work together with the transplant team, they deal with my drugs and keep each other well informed regarding my weight my diabetes and keeping me fit and well." Double lung transplant recipient
>
> "They liaise with [transplant team] on anything lung related to agree the best care, but most is done by [transplant team] in regard to transplant." Double lung transplant recipient

Three transplant recipients left comments noting that they received little care from their CF teams post-transplant and felt this needed improvement.

> "Not much, I hardly see them, sadly." Double lung transplant recipient
>
> "I wish that they remember despite having a transplant that I am still their patient. And that it would be beneficial if we were under one main consultant who made main decisions about my care." Double lung transplant recipient

> "[Do] not forget about post-transplant patients. [Do] not pass the buck and refer to transplant team for obvious CF related things." Double lung transplant recipient

Post-transplant care from transplant team

Fifty-eight transplant recipients (89.2%) also shared comments about the care from their transplant team after they had their transplant. Most of these comments noted that care related directly to the transplant, such as monitoring and immunosuppression, was provided by transplant teams.

> "They keep an eye on lung function and kidney function and help with treating or arranging treatment for any transplant side effects." Double lung and kidney transplant recipient
>
> "Things directly linked to transplant/lungs and I did access psychology service through them too." Double lung transplant recipient
>
> "Monitoring lung, heart and liver function, setting anti-rejection medication dose, advice on Covid. Management of essential interventions with transplanted organs." Heart and lung and liver transplant recipient

Only three transplant recipients stated that their transplant team did not see them much, but that they instead received most or all care from their CF team post-transplant.

> "Nothing. They do if I'm an inpatient, but my CF team has more to do with me." Double lung transplant recipient
>
> "They do not give a lot of support constantly; have to chase them up. Left hanging all the time. [CF team] offer me more support than the transplant team." Double lung transplant recipient

The survey findings indicate that most post-transplant care is delivered in line with best practice recommendations, which endorse clearly defined roles for each team and good communication and collaboration between CF and transplants teams. However, there are some cases where people with CF report little contact with their CF team or their transplant team post-transplant, showing that there may be variation in practice that should be addressed.

Section 10
Praise and areas for improvement

Excellence in care provided by CF teams

Adult CF care, delivered by multidisciplinary teams in CF centres across the UK, seeks to provide holistic, person-centred care for all people with CF. To explore areas where respondents felt their teams had excelled, the survey asked them about the best aspect(s) of care received from their CF team.

Survey question: What does your CF team do best?

Over 942 comments were received outlining things CF teams did particularly well according to people with cystic fibrosis under their care.

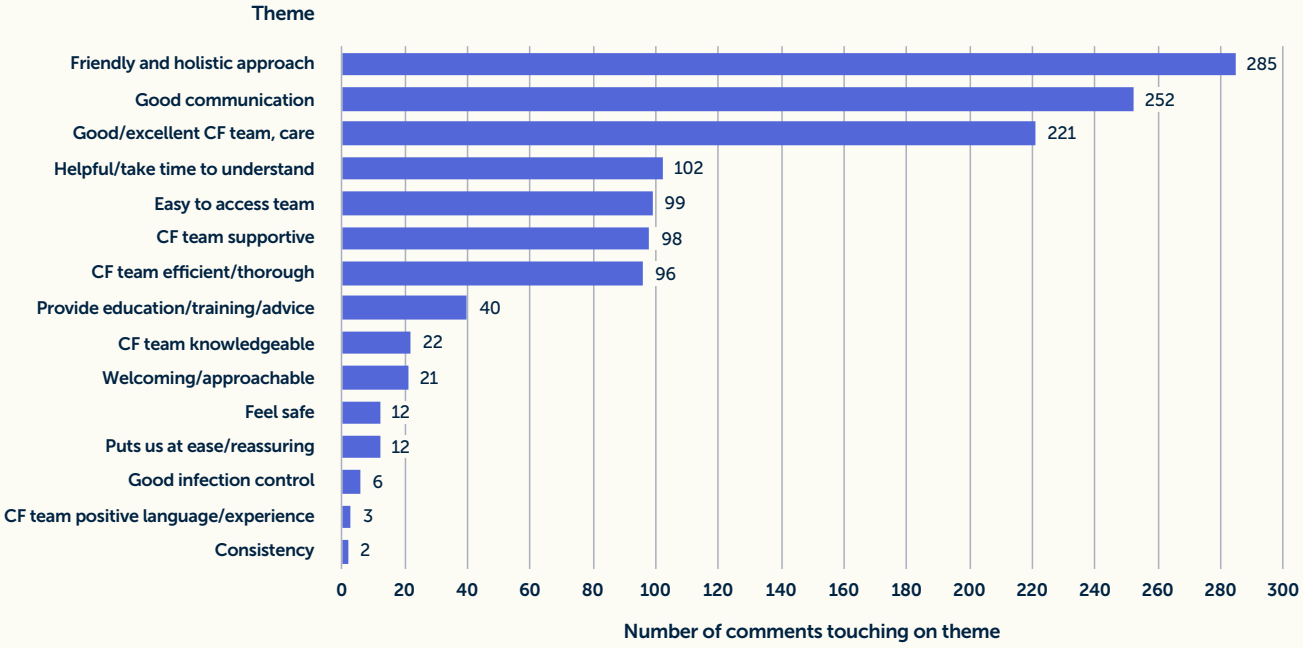
Figure 36: Word cloud from praise comments

Note: based on 942 comments; to produce word cloud, common terms (such as 'and', 'to', 'but', 'them', 'me', etc) were excluded.

While Figure 36 gives an overview of words commonly used in praise comments, it is necessary to analyse free-text responses in more detail to better understand aspects of care that are being praised and identify common themes. This is because people do not necessarily use the same words when describing the same or similar aspects of care. Figure 37 shows a breakdown of themes touched upon in free text comments and how frequently these themes were found.

Figure 37: Thematic analysis of comments on best aspects of CF care

Note: based on 942 free text comments; some comments fit with more than one theme and were categorised more than once, hence counts may add up to more than this.



The three most common themes positive comments centred around were approaches to care and communication. Many respondents praised their CF teams' friendly and holistic approach.

> "They provide holistic care and are always accessible."
>
> "Holistic care – the care from all members of the MDT is excellent. I feel secure knowing that I can ask for help when I need it which makes a huge difference to how I feel about living with CF."

Communication was another area that received a lot of positive feedback. Many of these comments particularly praised CF teams' listening skills (95 comments).

> "My CF team are best at listening to your issue and giving you advice."
>
> "Listening to your needs about treatment and discussing the best way to move forwards whilst taking your view into account."
>
> "They are very patient with me. Due to my autism I tend to have a lot of questions when I go to clinic and they are all very good at listening to and answering said questions."

Other comments in the communication theme focused on how teams were responsive, approachable and communicated in clear and understandable ways, explaining things well.

> "They are very responsive and always ready to listen and give great advice."
>
> "Communication between team members and myself, openness and availability of team members for questions and queries. Everyone is friendly, approachable and helpful."
>
> "They are all very helpful. Explain things clearly, friendly and welcoming, and put you at ease. Always answer any questions or concerns quickly and make sure you understand."

Another theme centred around general feedback for the teams, in which respondents often described their CF team as 'excellent', 'brilliant' and 'fantastic'.

> "They are a fantastic team of professionals who are thoughtful, kind and robustly cheerful. Nothing is too much trouble."
>
> "They are amazing at everything. Any problem I have they are able to solve and they make clinic enjoyable."
>
> "They have provided a high level of care. [...] I have a good relationship with them. They have always been there to help me any time we needed them. They are all excellent."

Other comments noted how the team took time to understand each individual and deliver person-centred care according to their needs.

> "They know me as a person and always go that extra mile. They are very approachable and put you mind at ease if you are feeling a little anxious."
>
> "Personable, interested in me as an individual, knowledgeable. Explain clearly what I could do to be better but always give me options, so I am involved in my care."

Access to the CF team generally, or specific professions within the team, was also praised by many people with CF. Several of these respondents mentioned different ways to access the CF team, including using the phone or virtual appointments.

> "I love how easy it is to access each member of the team. I love that nothing is too much trouble and any issue or concern I have is not a problem for them."
>
> "I normally have easy access to CF nurses with regards to any issues which they escalate to appropriate medical team."
>
> "They are very accessible if I have concerns, they are also very accommodating with virtual appointments."

CF teams were often described as 'supportive', 'caring', 'efficient' and 'knowledgeable', with several respondents especially praising the advice and education their teams provide.

> "Proactive and supportive, provides prompt and excellent care and guidance."
>
> "Provides knowledgeable information and an environment that alleviates any stress or anxiety about hospital visits. Also, very quick and efficient."

The themes were similar to those in 2020/21, though there was an upward shift in references to holistic and person-centred care. The overall volume of positive comments shows clearly that CF teams are delivering exceptional care that is valued by those who receive it, with many different aspects of CF care covered within the feedback.

Improvements

As the previous chapter showed, the majority of survey respondents were happy with the care that they receive and felt well supported by their CF team. However, several respondents made suggestions for improvements when asked where their CF team could do better. These suggestions do not indicate that a team is providing sub-standard care. Instead, they pinpoint specific issues and situations, based on individual experiences, where there may be opportunities for positive change that services should explore. Almost all services that participated in the project received praise for many aspects of their care, as well as some suggestions for areas to improve.

Survey question: What could your CF team do better?

Overall, 362 comments on aspects of care that could be improved were received, some of which may be outside the direct control of CF teams. In addition, 334 respondents answered 'nothing' or something to this effect in response to this question. While the latter responses have been excluded from the analysis below, which focuses on improvement areas, it should be noted that this is almost the same number of respondents as provided actual improvement suggestions.

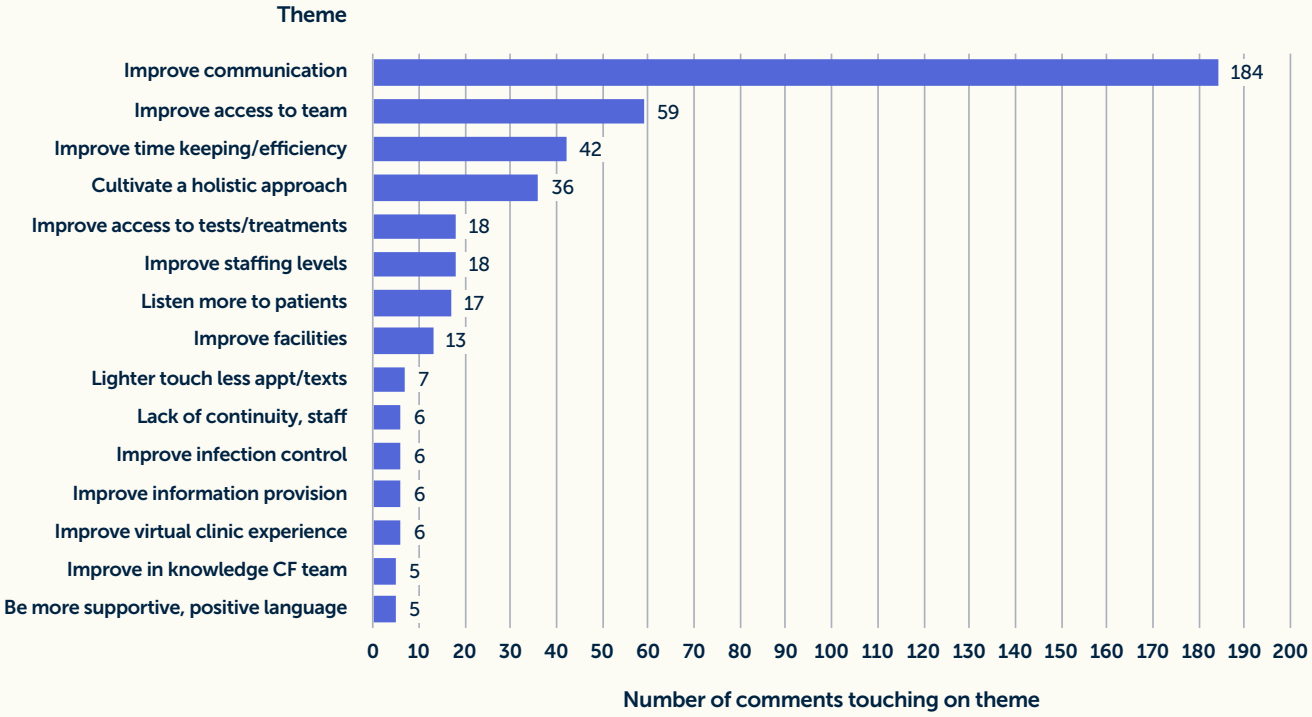
Figure 38: Word cloud from improvement suggestions

Note: based on 362 comments; to produce word cloud, common terms (such as 'and', 'to', 'but', 'them', 'me' etc) were excluded.

Figure 38 shows an overview of common terms used by survey respondents within their suggestions for improvements. As before, it is necessary to analyse free text feedback further to more fully understand common themes, as people can use different words to express similar concerns and improvement ideas (Figure 39).

Figure 39: Thematic analysis of comments on best aspects of CF care

Note: based on 362 free text comments; some comments fit with more than one theme and were categorised more than once, hence counts may add up to more than this.



Ideas for improvements often focused on communication, which was also one of the aspects most praised by survey respondents. This is similar to our previous survey and shows that experiences of communication can vary. Looking more closely at comments in the communication theme reveals that many focus on communication of test results.

> "Ensure test results are provided in a succinct and timely manner."
>
> "Provide test result quicker and online."

Others highlight issues with communication between different members of the CF team, other hospital teams or community services. Some of these respondents felt that they had to repeat information they had already shared, or that they received opposing information from different staff.

> "The communication between the different departments of my CF team could be better. I'm constantly having to relay the same information to every different specialist I see."
>
> "Communication between staff wasn't always efficient. Sometimes I would receive different information from different staff, regarding my progress, which could then be confusing and sometimes cause anxiety."
>
> "Communication between other areas of treatment specialist, eg gastroenterology."
>
> "Communication could be better. Communication between the team and me, and communication between the team and my transplant team."

Other improvement comments in this theme touched on responsiveness and communication of care plans and treatment decisions, or offers, such as exercise classes. Some respondents also discussed communication formats, with several suggesting that email would be preferable to letters.

Some respondents felt their CF team could take a more holistic, person-centred approach to care, with a few also noting that they did not currently feel listened to.

> "Post-Kaftrio, the focus needs to move to aging with CF, with a more holistic approach."
>
> "Sometimes I feel that they don't hear me and how it's all about numbers, not about me as a person."
>
> "Listen more and take what I say onboard rather than shrugging things off or not listening."

Another area for improvement often mentioned was access to the CF team, which was also linked to staffing in the team. In line with findings presented in Section 1 of this report, some respondents had experienced problems accessing certain professions and felt this could be improved, particularly mentioning psychologists and social workers.

> "CF social worker could be better, not great at getting in contact with."
>
> "The psychologist availability could be better. Having them available is good; however, not if there is only availability one afternoon per week."
>
> "Psychology has been under supported frequently. Social work support needs improvement."

Other respondents highlighted that waiting times in clinics could be long and felt their CF teams could improve their efficiency and time keeping. This applied to both outpatient and virtual settings.

> "My only issue is the waiting times to see each team member at my appointments."
>
> "Virtual clinics are great, but sometimes you are left waiting ages between seeing people."

Advice on and offers of medications, equipment, access to facilities or community services was also mentioned by a few respondents.

> "They have limited access to some facilities compared to other units I have attended. I'm not sure if this is a funding issue but items some as home spirometry and body fat measuring are not available. I miss having these options at home."
>
> "They should give more information and help guide to make life easier for example activities, things I can access for help or ways to get the help more effectively."

Some respondents also made specific suggestions of areas where information and support could be improved, such as fertility and the menopause.

> "More specific information on different co-factors of CF, ie liver disease/diabetes/pregnancy."
>
> "Women's health in CF, particularly how menopause can affect CF. The ability to prescribe types of HRT with support of a women's health advisor rather than having to go separately to the GP would be fantastic."

Improvement comments also touched on a wide range of other topics, from staff continuity and infection control to inpatient bed availability and hospital parking.

The range of different comments and experiences shared demonstrates that it is valuable for CF teams to have local data about the feedback from people under their care to help them identify and prioritise areas for improvement within their service. All centres that supported the survey have been issued with a bespoke summary of their local responses to help them with this.

Recommendations and next steps

Recommendations

Overwhelmingly, adults with CF who responded to the survey perceived that they were well looked after by their CF teams. However, insights highlight some variation in experiences regarding the availability of certain specialists, approaches to communication, processes at annual review, and infection control measures, as well as access to specialised medications and care in the community. Furthermore, the survey showed clear preferences for continued face-to-face contact with CF teams and access to home IVs. However, patient preference must be considered as the results indicate there is no one-size-fits-all approach to care and preferences can differ depending on the situation and context.

Some of the key findings in this survey reflect issues and variations already evident in our previous surveys, indicating priority areas that people with CF repeatedly highlighted for improvement, including:

- consistent access to CF specialist psychologists and social workers, which has been flagged as an issue by respondents from multiple different centres in our adult and paediatric surveys
- communication, especially of test results and feedback from annual review, which many respondents in our adult and paediatric surveys felt was not timely
- access to and coordination with specialties beyond the CF team (including diabetes, hepatology, ENT, transplant, and obstetrics teams), which adults with CF repeatedly said can vary and will likely become increasingly important in future.

Several general recommendations for CF services and care can be made from the insights shared by people with CF in the survey. These recommendations are generalised and based on feedback from adults with CF who attend different CF centres across the UK. Many of the recommendations below align with the standards of care and other relevant guidance documents, reemphasising the importance of implementing such guidelines consistently to avoid unwarranted variation.

Recommendations for CF care from patients' experiences and feedback:

Access to CF team and other support:

- Ensure all people with CF see a psychological and social professional at least once per year at annual review and/or have their case reviewed by psychological and social professionals with expertise in CF.
- Ensure all people with CF are aware of how they can access support from clinical psychologists and social workers, should they need it.
- Ensure staff can provide information and advice on benefits, education, emotional wellbeing, and other areas where families may need support; this may include appropriate signposting or referral to external services and resources, such as Cystic Fibrosis Trust.[4]
- Ensure all people with CF see a pharmacist with expertise in CF at least once per year at annual review and/or have their medication regimen reviewed by a CF pharmacist.

Communication, collaboration and person-centredness:

- Ensure all patients know how to access support outside of working hours; for example, by sending out annual reminders of out-of-hours contact details.
- Endeavour to provide all patients with timely feedback on tests, assessments and annual reviews, and communicate any changes in care plans clearly.
- Ensure effective communication among members of the CF team and a shared understanding of each person's needs and preferences.

4 https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/support-available and https://www.cysticfibrosis.org.uk/the-work-we-do/information-resources/publications

- Establish person-centred approaches to CF care; consider people as individuals; and offer choice and involve patients in decisions, including, but not limited to, how they are communicated with and seen.
- Work towards greater collaboration and coordination with specialties beyond CF teams to support a growing, ageing and diversifying adult population with CF.

Annual reviews and hospital care

- Endeavour to provide a full review by all professions in the CF team at annual review, including pharmacy, psychology and social work.
- Ensure there are processes in place to share test results and written feedback from annual reviews in a timely manner.
- Ensure infection control protocols are up to date and followed at all times.
- Schedule and run annual review clinics in a way that minimises wait times for people with CF, including waits at x-ray and pharmacy departments.
- Endeavour to measure lung function as well as height and weight in individual clinic rooms rather than in a shared space; this may require additional equipment to be purchased for individual rooms.
- Ensure patients with CF have their own room with an en suite bathroom during all inpatient stays, including when staying on non-CF wards.

Care at home

- Endeavour to support people with CF to receive services in the community, including home IVs where possible and appropriate, with full training and ongoing support. Ensure people with CF feel confident to administer home IVs and know who to contact if there are any issues, including outside of normal working hours.
- Empower people with CF to use home monitoring equipment to monitor their own health as well as share data with their CF team, if they wish.
- Ensure equitable and high-quality access to care and specialised medicines at home; where medications are delivered by external homecare services, consider regular review of experiences and put processes in place to support people with delivery issues.

CF service-level improvement work

There are a number of quality improvement (QI) activities that could be considered by participating CF centres, depending on challenges and priorities identified from their local survey responses. All CF centres that took part in the survey have received a bespoke data summary with the feedback from people under their care.

Reviewing their bespoke centre summary against the findings from the full sample analysis and recommendations within this report can help services to highlight existing good practice, and to identify local challenges and priority areas to target with QI efforts. CF centres that did not participate in this work, and therefore do not have their own bespoke summary, could use locally gathered patient feedback and the insights presented in this report as a starting point to reflect on how care is delivered locally and where QI efforts might focus.

Depending on the priority area(s) identified in a centre, a service could, for example:

- Review how the CF team communicate internally to find opportunities to ensure all CF staff have access to the same notes and a shared understanding of the patient.
- Consider how the team provides advice on emotional wellbeing, mental health, benefits and financial support, and identify opportunities to make people with CF aware of the support it can offer in these areas, or signpost to external resources such as those available from Cystic Fibrosis Trust[5].
- Map out the process for annual review clinics and identify opportunities to enhance person-centredness.
- Undertake a QI project to implement a new online portal for people with CF to receive timely feedback about the results of their tests and investigations.
- Develop a business case to apply for funding for a dedicated CF social worker to support people with CF accessing the service.

Bespoke support is available for all CF teams that wish to discuss patient experience data, explore a local challenge, or implement a change within their service. Facilitated sessions use evidence-based QI methods to help centres identify and explore improvement priorities and plan quality improvement projects. Contact Cystic Fibrosis Trust's QI team at **QI@cysticfibrosis.org.uk** to get started.

Future surveys

The adult patient-reported experience survey is not run every year to allow CF centres time to implement and embed changes and so as not to overwhelm people with CF with requests for feedback via surveys. The Quality Improvement team at Cystic Fibrosis Trust will re-run the survey again in 2026/27 and publish an updated report on experiences of adult CF care in the autumn of 2027.

In the meantime, we welcome any feedback on this publication, as we are keen to continuously improve how we report on our findings, so that these publications are as useful as possible for the clinical CF community and beyond. To share your suggestions, simply email us at **QI@cysticfibrosis.org.uk**.

5 https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/support-available and https://www.cysticfibrosis.org.uk/the-work-we-do/information-resources/publications

Glossary

Word/phrase	Meaning
Annual review	A full health review undertaken by the specialist CF centre once a year.
CAG	Clinical Advisory Group for Cystic Fibrosis Trust.
Centre	Hospital providing expert care and specialised disease management for people living with cystic fibrosis.
CF	Cystic fibrosis.
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.
Home IVs	Intravenous antibiotic therapy given in the patient's home.
Hospital IVs	Intravenous antibiotic therapy given in a hospital ward.
Infection control	Special measures to keep patients safe, such as segregation, cleaning, and disinfecting.
IVs	Intravenous antibiotic therapy – a course of antibiotics given through the vein to treat an infection.
Median	The middle value (number) when all values in a series are arranged from smallest to largest. In this report, the median shows the middle value when the proportions of responses for each participating centre are arranged from smallest to largest.
MDT	Multidisciplinary Team: your CF team is made up of each discipline, such as nurse, physio, social worker, and dietitian.
NICE	National Institute of Clinical Excellence – provides guidance, advice and information services for health professionals.
PREMs	Patient-reported experience measures.
Range	Smallest to largest value in a series. In this report, the ranges refer to the lowest and the highest proportion of respondents that were recorded for a question in participating centres.
Respondents	Adults living with cystic fibrosis and their parents who responded to the paediatric PREMs survey.
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, people with CF and parents working to improve the way care is delivered to those living with cystic fibrosis.

Cystic Fibrosis Trust

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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