

UK Patient Reported Experience Measures (PREMs) Survey

Children's CF Services Report

Data collection period

1 November 2022 – 31 March 2023

Publication date

September 2023

Data collection, analysis and reporting led by

Jana Witt, Clinical Quality Improvement Manager, Cystic Fibrosis Trust

Sophie Lewis, Clinical Quality Improvement Advisor, Cystic Fibrosis Trust

With input and advice from

Nicole Lyster, Cystic Fibrosis Trust Involvement Network

Esther Valentine, Cystic Fibrosis Trust Involvement Network

Jacqueline Lowdon, CF dietitian (paediatrics)

Anirban Maitra, CF paediatrician

Fiona Dowdall, CF social worker (adults), Cystic Fibrosis Trust Clinical Advisory Group

Marie Donnelly, CF social worker (paediatrics)

Fiona McKirdy, Quality Improvement Impact Officer, Cystic Fibrosis Trust

Sarah Clarke, Associate Director of Data and Quality Improvement, Cystic Fibrosis Trust

Keith Brownlee, Director of Medical Affairs, Cystic Fibrosis Trust

Clare Corbett, Director of External Affairs, Cystic Fibrosis Trust

Members of the Cystic Fibrosis Trust Quality Improvement Working Group

Acknowledgements

Firstly, the Cystic Fibrosis Trust Quality Improvement team would like to thank children with CF and their families for responding to the survey and for sharing their experiences. We are also grateful to all paediatric cystic fibrosis centres and clinics that participated in the project and distributed the survey to their patients. Finally, we would like to thank anyone who has generously donated to Cystic Fibrosis Trust.

Contact information

For more information or feedback about this report, or for advice and support with quality improvement work, please contact us: QI@cysticfibrosis.org.uk

UK Patient Reported Experience Measures (PREMs) Survey Children's CF Services Report

Contents

Summary and key data	5
Participation and feedback	5
Key data insights	5
Recommendations	7
Introduction	8
About the survey	8
About this report	8
Participation	9
Section 1	
Access to and support from the CF team	10
Accessing specialists in the CF team	10
Support from specialists in the CF team	14
Section 2	
Experiences of support with managing CF	17
Support with physical health and hospital care	19
Support with social issues, wellbeing and mental health	20
Section 3	
Communicating with and seeing the CF team	21
Contacting the CF team	21
Communicating with and seeing the CF team	23
Future appointment preferences	25
Communication of test results	27
Section 4	
Annual reviews	29
Tests and assessments for annual review	31
Staff seen at annual review	32
Feedback from annual review	33

Section 5	
Infection control and prevention	34
<hr/>	
Section 6	
Hospital care	37
<hr/>	
Outpatient clinic experiences	37
Inpatient facilities	40
Inpatient care experiences	42
Section 7	
Intravenous antibiotic therapy	44
<hr/>	
Access to IV antibiotics	44
Home IV antibiotic therapy	47
Future IV preferences	49
Section 8	
Care at home and in the community	51
<hr/>	
Airway clearance at home	51
Community care	53
Section 9	
Praise and areas for improvement	56
<hr/>	
Excellence in care provided by CF teams	56
Improvement suggestions	59
Recommendations and next steps	63
<hr/>	
Recommendations	63
CF centre-level improvement work	65
Future surveys	66
Glossary	67
<hr/>	

Summary and key data

Participation and feedback

We would like to thank children with cystic fibrosis and their parents, as well as clinical teams, for promoting and completing the patient experience survey. Overall, 828 responses were received from children with CF and parents attending 28 of 32 UK paediatric CF centres/networks. This represents approximately 18.4% of the CF population in paediatric care in the UK. All CF centres that took part have received bespoke feedback.

Key data insights

Access to and support from CF multidisciplinary team (MDT)



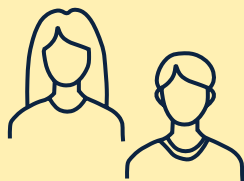
Over 95% of respondents said they had been able to access CF specialist doctors, nurses, physiotherapists and dietitians when they had needed them in the last 12 months.

13.0% of respondents said they could not see a CF social worker in the last 12 months, as no one was available. For pharmacists, this was 9.2%, and for psychologists, this was 7.4%.*

96.1% of ratings for members of the CF MDT seen in the last 12 months were excellent or good.

Experiences of support with managing CF

89.9% of ratings for support received from CF teams at key times and with key issues were excellent or good.



94.9% of ratings given for support with physical health and hospital care were excellent or good. In contrast, only **81.1%** of ratings for support with social and wellbeing issues were excellent or good.

Care at home and in the community

83.7% used airway clearance equipment at home, with most receiving this through their CF team.



22.9% of respondents confirmed they had access to care at home and/or in the community.

Annual Reviews

90.3% of respondents had had an annual review in the last 12 months; most had this as an outpatient appointment.



Over 90% of respondents had had chest x-rays, blood tests and sputum/cough swabs done or discussed at their annual review, but there was variation in other types of tests carried out.

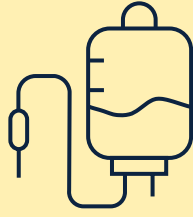
Over 90% of respondents confirmed they had seen a CF doctor, nurse, physiotherapist and dietitian at their last annual review. However, the proportions who had seen a CF psychologist, social worker or pharmacist were much lower.

89.5% of respondents confirmed they had received written feedback from their last annual review, while **10.5%** could not recall having had feedback.

*These figures are explained further in the text on page 12-13

IV Antibiotics

65.2% of respondents had always started urgent IV antibiotics within 24 hours.



73.6% of respondents had never experienced a significant delay (>7 days) for an admission for planned/routine IV antibiotics.

60.5% of respondents said they prefer home IVs to hospital IVs.

Communicating with and seeing the CF team

99.0% of respondents knew how to contact their CF team during working hours, falling to **82.9%** out of hours.



91.7% of respondents had outpatient contacts with their CF team in the last year, with **96.2%** rating their experiences of such consultations as excellent or good.

47.6% of respondents said they would prefer to be seen in hospital clinics, while **40.3%** preferred a combination of virtual and hospital appointments in the future.

88.5% of respondents overall were satisfied with the time taken to communicate test results in general.

Hospital care



24.4% of children with CF and their parents said they had waited in a waiting room on at least one occasion when they visited their outpatient clinic.

63.8% of children with CF and parents said that they had experienced height and weight being measured in a shared room for all patients on at least one occasion, whereas for lung function, this was just **21.5%**.

16.1% of 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.

6.0% of respondents said they had potentially shared a bathroom with other CF patients on at least one occasion, and **1.8%** said they had shared a bay with others.

88.5% of respondents rated ward care generally as excellent or good, but respondents rated other aspects of inpatient care less positively, with **26.3%** saying that access to additional food during inpatient stays had been poor.

Infection Control

86.4% of respondents felt infection prevention measures were sufficient at their CF centre or clinic, but some raised concerns about infection control, particularly in other areas of hospitals, including x-ray and pharmacy departments.



Recommendations

The survey findings highlight a need for:

- Equitable access to specialists with CF expertise, particularly clinical psychologists, social workers and pharmacists.
- Continued access to face-to-face appointments in paediatric care and consideration for families' preferences in how they are seen.
- Good quality communication, particularly during virtual clinics, and timely feedback from tests, assessments and annual reviews.
- Better infection control in hospital areas outside the CF clinic, specifically x-ray and pharmacy departments, as well as inpatient wards.
- Equitable and high-quality access to care in the community, including home IV antibiotic therapy and specialised medicines.

All CF centres that took part in this project have been provided with a bespoke data summary of their local feedback to help them evidence existing good practice and identify priority areas for quality improvement.

Cystic Fibrosis Trust will re-run the Paediatric PREMs project in 2025/26 to understand how the experiences of children with CF and their families change over time.

Introduction

The Patient Reported Experience Measure survey (PREMs) allows cystic fibrosis (CF) centres and their network clinics to capture patient experience and satisfaction with their CF care in a systematic way. Listening to the voices of children with CF and their parents/carers 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 network clinics, and other stakeholders to better understand experiences of paediatric CF care, existing best practice, what patients and their families 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 change over time, for example, as highly effective modulator therapies become available to younger patients and as the digitisation of NHS services continues.

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 2022 to 31 March 2023, children and parents under the care of participating CF centres were invited to complete the paediatric PREMs survey by their CF teams. The survey 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 they 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, thus allowing them to evidence good practice and identify local areas for quality improvement. In 2025/26, the paediatric PREMs project will be repeated again 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 paediatric PREMs survey, which collected data in 2022/23. It is based on 828 responses from children with CF, and their parents cared for at 28 of 32 CF centres/networks across 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 analysis, and responses that were excluded, are provided for reference alongside the figures. 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. The report also contains example quotes from free-text responses to illustrate findings where relevant. These quotes have been anonymised, with any references to the names or gender of children with CF replaced with neutral terms (in square brackets).

Where relevant, findings from the 2022/23 cycle of the paediatric survey are compared to the previous cycle, which ran in 2019/20. You will also see references to quality standards, aims or objectives drawn from the paediatric Cystic Fibrosis Service Specification¹, the NICE Quality Standard for CF², as well as occasional reference to the Standards of Care³. These are included in light blue boxes at the start of most sections and define the standards expected from organisations that provide specialised CF care. Although it should be noted that an update to the Standards and specifications is expected in 2024. For further explanation of the service specifications, please go to our website where you will find full details: cysticfibrosis.org.uk/laysummaries

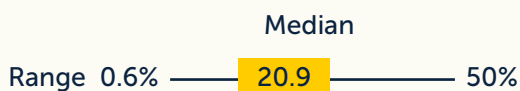
Participation

In the summer of 2022, Cystic Fibrosis Trust invited all paediatric CF networks via their main centre to take part in the PREMs survey as a service evaluation exercise. Twenty-eight of 32 CF centres/networks in the UK (87.5%) decided to participate and were issued bespoke survey invitations to share with their patients. Participation in the survey is voluntary, and four CF centres chose not to take part in 2022/23.

Participating services could choose to hand out paper surveys, send an email invite, or use a combination of the two. Between 1st November 2022 and 1st April 2023, 828 responses were received from children and parents under the care of participating paediatric CF centres and some of their network clinics. Surveys were often completed by parents/carers of children with CF but may also have been completed by children and teenagers with CF themselves. This represents insights from approximately 18.4% of the CF population in paediatric care in the UK⁴, and 19.3% of the population cared for by participating CF centres.

The number of survey responses received varied by centre, with a median of 26.5 (range: 2 to 121). As centre sizes differ, it is also important to consider how the number of responses per centre 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 have a response rate of 10%. The higher the response rate, the more representative and insightful the survey findings are for a centre/network. In the PREMs survey, response rates varied by centre, with a median response rate of 20.9%.

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



- 1 NHS England, 2018: www.england.nhs.uk/wp-content/uploads/2018/07/a015b-spec-cystic-fibrosis-child.pdf
- 2 National Institute for Health and Care Excellence (NICE) QS168, 2018: [Cystic fibrosis \(nice.org.uk\)](https://www.nice.org.uk)
- 3 Cystic Fibrosis Trust, 2011: www.cysticfibrosis.org.uk/sites/default/files/2020-12/Cystic%20Fibrosis%20Trust%20Standards%20of%20care.pdf
- 4 UK Cystic Fibrosis Registry 2021

Section 1

Access to and support from the CF team

Accessing specialists in the CF team

CF multidisciplinary teams (MDTs) usually consist of different specialist staff with expertise in cystic fibrosis, including doctors, nurses, physiotherapists, dietitians, pharmacists and psychological and social staff. All children with CF and parents should ideally have access to a full MDT so that they can get the specialist advice and support they need.

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.1: Aims and objectives of service: The service will deliver the aims of improving life expectancy and quality of life for children with CF by [...] ensuring equity of access to services for the CF population.

Section 3.2: Outpatient care: Outpatient clinics are multidisciplinary with all patients being reviewed by the doctor and a CF nurse specialist, physiotherapist and dietitian at all routine reviews. There will be access to psycho-social support.

Quality Standards Domain 2: Enhancing the quality of life of people with long-term conditions: All children should have access to psychological support at annual review.

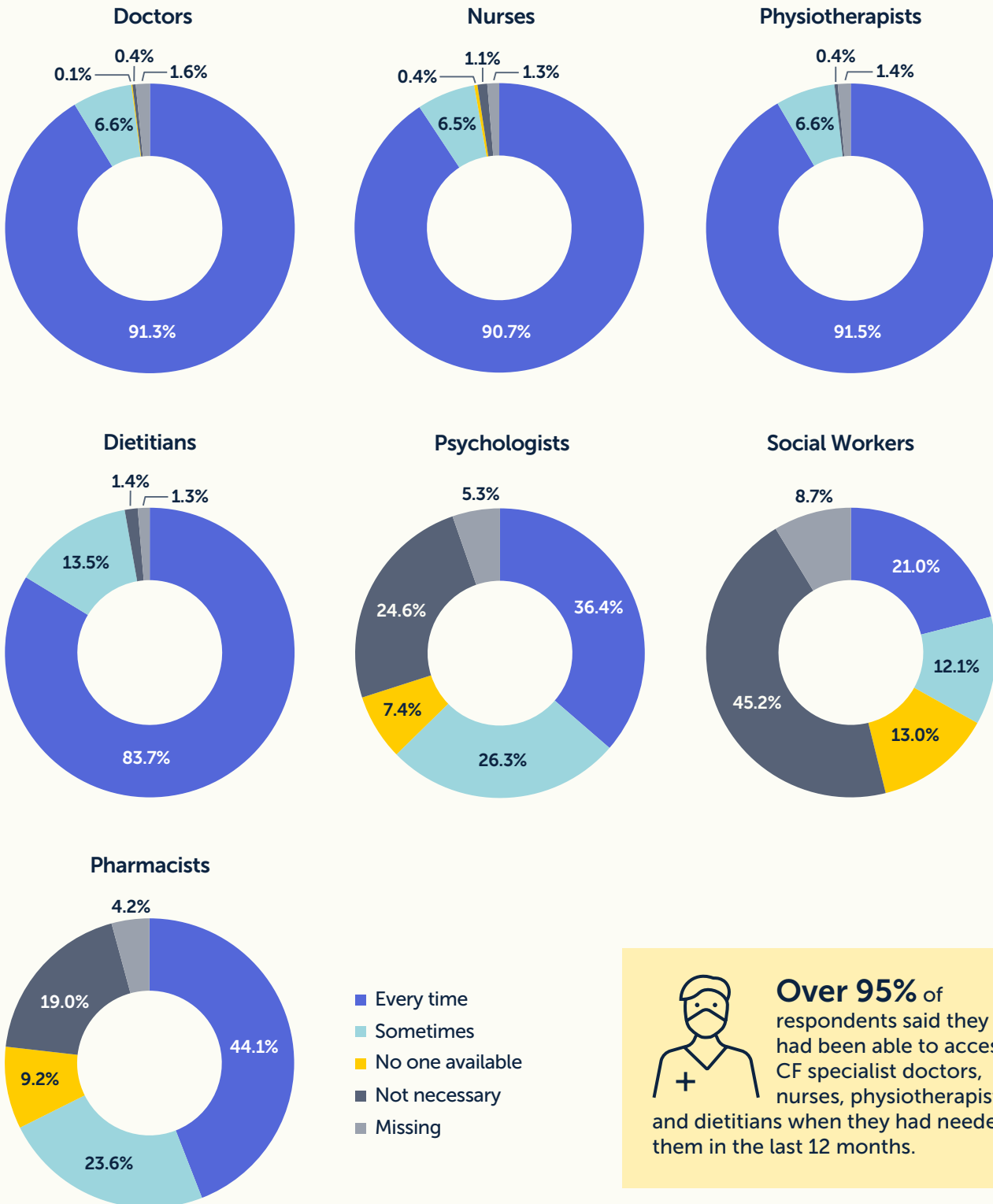
Quality Standard Cystic Fibrosis QS168 (NICE):

Quality measures (Structure): a) Evidence that cystic fibrosis multidisciplinary teams have professionals with specialist expertise in the condition including a paediatrician or adult physician, nurse, physiotherapist, dietitian, pharmacist and a clinical psychologist.

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

Figure 1: Access to specialists in the CF team

Note: All survey respondents included (n=828)



Over 95% of respondents said they had been able to access CF specialist doctors, nurses, physiotherapists and dietitians when they had needed them in the last 12 months.

Generally, access to different staff groups within the CF MDT was good. Most survey respondents confirmed that they had been able to access most specialist staff every time they needed to, with some saying they could access staff sometimes but not every time. Over 95% of respondents confirmed they had access to doctors, nurses, physiotherapists and dietitians, which aligns with findings from the 2019/20 survey. For dietitians, the proportion reporting access 'sometimes' but not 'every time' was slightly higher (13.5%) than for the other three specialist groups.

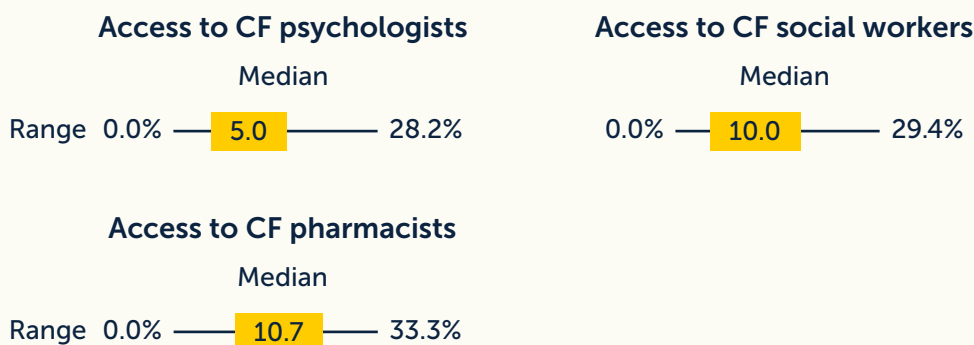
There were differences in the proportions of respondents who felt they needed to access certain staff groups. Nearly all respondents said they had needed support from CF specialist doctors, nurses, physiotherapists and dietitians at some point in the last 12 months. However, 19.0%, 24.6% and 45.2% of respondents said they had not felt they needed CF specialist pharmacists, psychologists or social workers, respectively. For psychologists and social workers, these proportions are similar to what was seen in the 2019/20 survey. However, the proportion of respondents who said they did not require support from CF pharmacists declined from 32.5% in 2019/20 to 19.0% in 2022/23, which may reflect the added importance of pharmacovigilance in children on CFTR modulators, which became available between survey cycles.

Very few survey respondents reported problems accessing doctors and nurses (0.1% and 0.4%, respectively), and none said they had regular issues accessing physiotherapists or dietitians. Slightly larger proportions said they had been unable to access CF psychologists (7.4%), pharmacists (9.2%) or social workers (13.0%) when required, as no one was available. For psychologists, this proportion had remained relatively stable compared to the 2019/20 survey, when 7.9% had reported a lack of access to CF psychology. However, for CF pharmacists and social workers, the proportion unable to access these two specialties decreased from 18.3% and 21.7%, respectively, in 2019/20.

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 specialties, 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: Centres with fewer than 10 respondents were excluded (7 centres totalling n=37 responses)



Looking at those who reported a lack of access but excluding those who said they had not needed support from these specialist groups and any missing responses, we find that 28.3% of respondents who had needed CF social worker support (n=382) said they had been unable to access this, for pharmacists this was 11.9% (of n=636), and for psychologists, this was 10.5% (of n=580).

We know from our staffing tool⁵ that some paediatric CF centres/networks do not have CF specialist psychologists, social workers or pharmacists available within their CF MDT. Sometimes, this can be due to a temporary vacancy within the team, but in other cases, there is no funding available for such roles⁵. Many paediatric CF centres do not have embedded roles for social workers, and there is a limited number of specialist CF social workers working within paediatric CF care in the UK⁶. Furthermore, even in centres that have CF social workers within their CF MDTs, such roles are often not available full time and the ability of staff to see all children and families may therefore be limited^{5,6}.

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, also in light of ongoing NHS-wide workforce issues.

Problems accessing support from certain staff groups when required could have a negative impact on children with CF and their parents, as they might miss out on the specialist help and advice they need. 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 families than ever potentially needing financial and wellbeing support. Where survey respondents had reported issues accessing one or more staff groups, the survey asked if and how this had impacted them.

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

Responses indicated that a lack of access to CF clinical psychologists and social workers could lead to anxiety, exacerbate mental health issues and result in concerns that families may be missing out on certain benefits and support.

“Several requests made to help with forms to apply for disability benefit. No attempt to arrange meeting with patient when marriage breakdown of [their] parents.”

“With minimal social work support, I am having lots of issues getting school to allow [my child] on school trips and getting into issues with attendance etc. With no psychology seen when [my child] said [they] wanted to die [...] I have no evidence of any mental health struggles [my child] has had as a result of CF to put towards an EHCP [Education, Health and Care Plan].”

“I believe we may have missed out on support, benefits etc. due to not having access to this [a CF social worker].”

Some respondents reported having to seek and fund support privately, which puts an additional burden on parents and may result in inequity for those unable to afford private care.

“Our clinical psychologist retired [...] and we have had no replacement available. The team could only offer a referral to the psychology team (for which there was a 4 months waiting timeline). I eventually sought support privately. It was distressing and upsetting for all parties involved.”

“We have sourced own private therapy. Costs of this could be spent on other things. Our team suggest speaking to the CF social worker or nurse but she is not trained in counselling or psychology. It is disappointing to not have this service.”



13.0% of respondents said they could not see a

CF social worker in the last 12 months, as no one was available. For pharmacists, this was **9.2%**, and for psychologists, this was **7.4%**.

5 Cystic Fibrosis Trust, CF Staffing Report UK 2020-2022, published March 2023: UK Cystic Fibrosis Service Resourcing - Report March 2023

6 Information provided by CF social worker colleagues in August 2023 via email

Other respondents described how access to CF pharmacists would be useful.

“There have been a few occasions where we’ve discussed meds and it would have been handy to talk to a specialist CF pharmacist.”

“Specialist pharmacist would have been helpful when there was a Creon shortage, and when our GP has struggled with antibiotic prescriptions.”

Occasionally, those who had experienced problems getting advice from certain staff managed to get support from other staff within the CF MDT.

“No social worker. We managed alone with all these aspects, sometimes some advice was given by the CF nurse (much appreciated).”

“I made several phone calls to dietitian regarding loose stools. I didn’t get any response, resulting in me having to raise it with another member of MDT to get a plan in place.”

It is evident from these responses that a lack of access to certain specialist staff groups can impact children with CF and their families.

Support from specialists in the CF team

Specialists within CF MDTs have defined roles and responsibilities to ensure holistic care is provided to children and families affected by CF.

Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK (2011):

3.1 Principles: Specialist multidisciplinary care is essential in the management of children and adults with CF. [...] Continuity of care is essential. All patients should have a named consultant even though the CF centre may work with a team of consultants. [...] CF centres must have access to other specialists who are familiar with the complications of CF.

3.4 Clinical nurse specialist:

- Provide advocacy and psychosocial support [...]
- Provide home care support particularly for home intravenous antibiotic therapy.
- Provide education to others about CF including nurseries, schools, places of higher education and work places.
- Act as a link between the patient and family, primary care/community services and hospital

3.5 Physiotherapist:

- Be responsible for a full assessment [...] on admission to and discharge from hospital, at every outpatient appointment and at annual review.
- Maintain community contact when necessary.

3.6 Dietitian:

- To be responsible for providing full nutritional advice and assessment [...] as appropriate to both in- and outpatients

3.7 Clinical psychologist:

- Undertake psychological review as part of annual review including an assessment of behaviour, emotions and family functioning.
- Provide psychological therapies [...]

- Respond to referral of inpatient for specialist psychological input [...]
- Provide a psychology service in parallel with CF clinics [...]
- Provide support for newly diagnosed patients.

3.8 Social worker:

- Maintain up-to-date knowledge on all significant welfare and benefit changes and understand and apply relevant and current legislation to support patients.
- Have knowledge of chronic illness and how this impacts on patients and their families both day to day and long-term [...]

3.9 Pharmacist:

- Provide a prescription monitoring and medication review service, to include education and counselling to patients and carers.
- Provide a full review at annual review and disseminate information to GP and community pharmacist.

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 speciality.

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

Overall, satisfaction with support from all different specialties within the CF MDT was high. More than 9 in 10 responses provided (96.1%) rated support received as 'good' or 'excellent' (based on 4,562 responses across all staff groups from 828 individuals).

However, there was variation by centre in the proportions of respondents who felt the support they had received from specialist staff had been excellent or good.

Centre-level insight: Proportion of respondents who rated support from any members of the CF MDT they had seen as either excellent or good

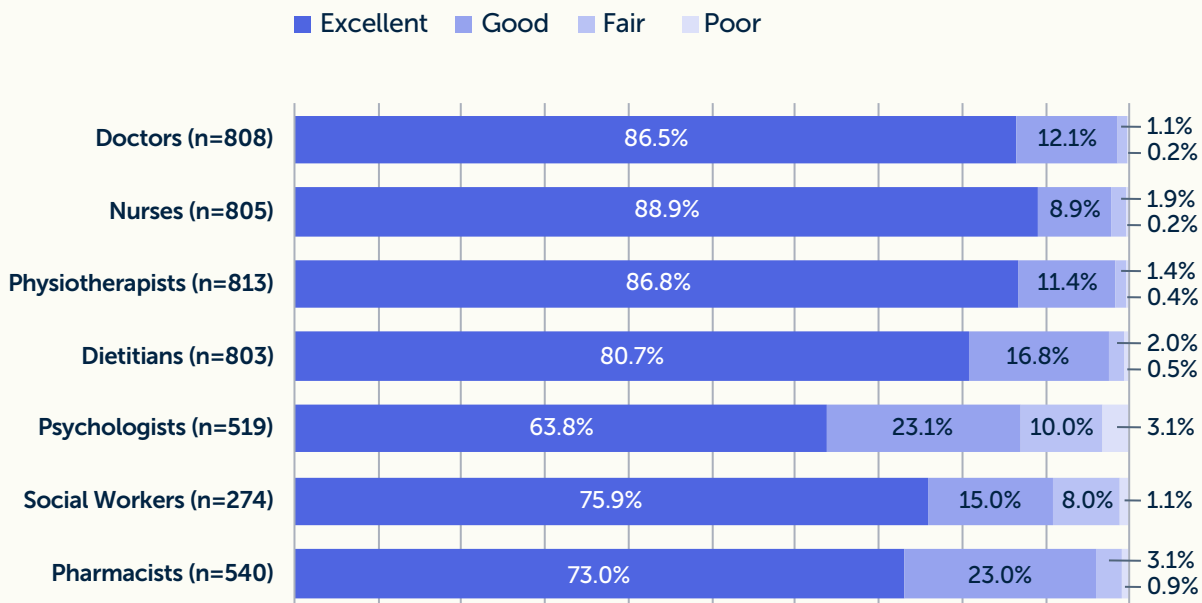
Note: Centres with fewer than 10 responses were excluded (7 centres totalling n=37 responses)



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

Figure 2: Ratings of support received from each CF specialist group

Note: number of valid survey responses included is stated for each staff group



All those who had accessed specialist CF doctors, nurses, physiotherapists, dietitians and pharmacists rated support from these groups particularly highly, with 98.6%, 97.9%, 98.3%, 97.5%, 95.9% 'good' and 'excellent' responses, respectively. This aligns with findings from the 2019/20 survey, in which these groups had been rated similarly highly, although pharmacists saw a slight improvement in the proportion of positive ratings between survey cycles (91% positive in 2019/20).

"Both consultants are brilliant, I couldn't ask for better care for my [child]."

"The nursing team are amazing. They respond so quickly and support us well as a family."

"Dietitian is excellent and supports [child] on a vegan diet. Physio very friendly and realistic in expectations of a toddler."

While satisfaction with support from psychologists and social workers was a little lower overall, these groups were still rated highly by most who had accessed them, with 86.9% and 90.9% 'good' or 'excellent' ratings, respectively. Again, this aligns with findings from the 2019/20 survey.

"Friendly team who know my [child] well. Excellent psychology services."

"Social worker provided support, which was excellent."



96.1% of ratings for members of the CF MDT seen in the last 12 months were excellent or good.

Section 2

Experiences of support with managing CF

CF MDTs are designed to provide holistic, person-centred care to all children with CF, supporting them and their families with all aspects of managing cystic fibrosis, including physical and mental health, as well as general wellbeing.

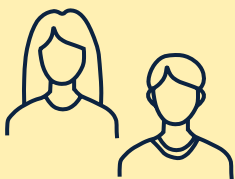
Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.1: Aims and Objectives of Service: The service aims to improve both life expectancy and quality of life for children with Cystic Fibrosis.

Objectives: The service will deliver the aims [...] by:

- Making timely diagnosis (including in response to newborn screening) with appropriate counselling and psychological support to the child and their family.
- Providing high quality proactive and preventative treatment and care to optimise lung function and nutritional status.
- Ensuring a safe, cost effective, high quality service for the recipients of the services commissioned.
- Ensuring equity of access to services for the CF population.
- Facilitating autonomy and transition from children's care to adult care and encouraging independent care.
- Supporting parents and families of children with CF, as well as the child.
- Supporting the child in helping them to manage their CF independently in order that they can aspire to a life less hindered by their condition and providing support to their families where appropriate.
- Ensuring effective communication between patients, families and the service providers.
- Providing a personal service, sensitive to the physical, psychological and emotional needs of the patients and their families

The patient experience survey explored respondents' satisfaction with the support they had received from their CF team over the last 12 months at key times and with important issues, from first diagnosis, managing treatments and inpatient care, to benefit applications, emotional health and starting nursery, school or work.



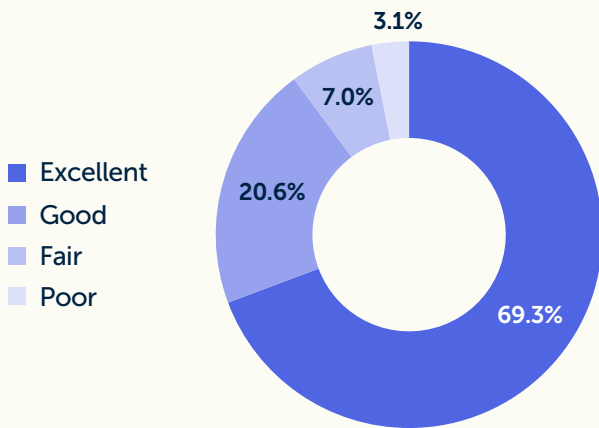
89.9% of ratings for support received from CF teams at key times and with key issues were excellent or good.

94.9% of ratings given for support with physical health and hospital care were excellent or good. In contrast, only **81.1%** of ratings for support with social and wellbeing issues were excellent or good.

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

Figure 3: Overall ratings of support at key times and with key issues

Note: Based on 3,848 ratings provided by 828 respondents across all key areas listed



Overall, the vast majority of respondents (89.9%) who had needed support in key areas or with key issues that were covered by the survey said that their experiences had been 'excellent' or 'good'. Only 3% of ratings given fell in the 'poor' category.

"They are amazing. From the diagnosis, they have been there every step of the way."

"Advice and support available at all times. They are part of our family."

When looking at ratings of support with physical health and hospital care, including initial CF diagnosis, managing treatments, hospital stays and intravenous antibiotics, these were very positive, with 94.9% of ratings given for support in these areas being 'excellent' or 'good'. But, overall ratings for support with social and wellbeing issues, including benefits, education, emotional health and relationships, were slightly less positive, with 81.1% being 'excellent' or 'good'.

There was only minor 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 and wellbeing issues.

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

Note: Centres with fewer than 10 respondents were excluded (7 centres totalling n=37 responses)



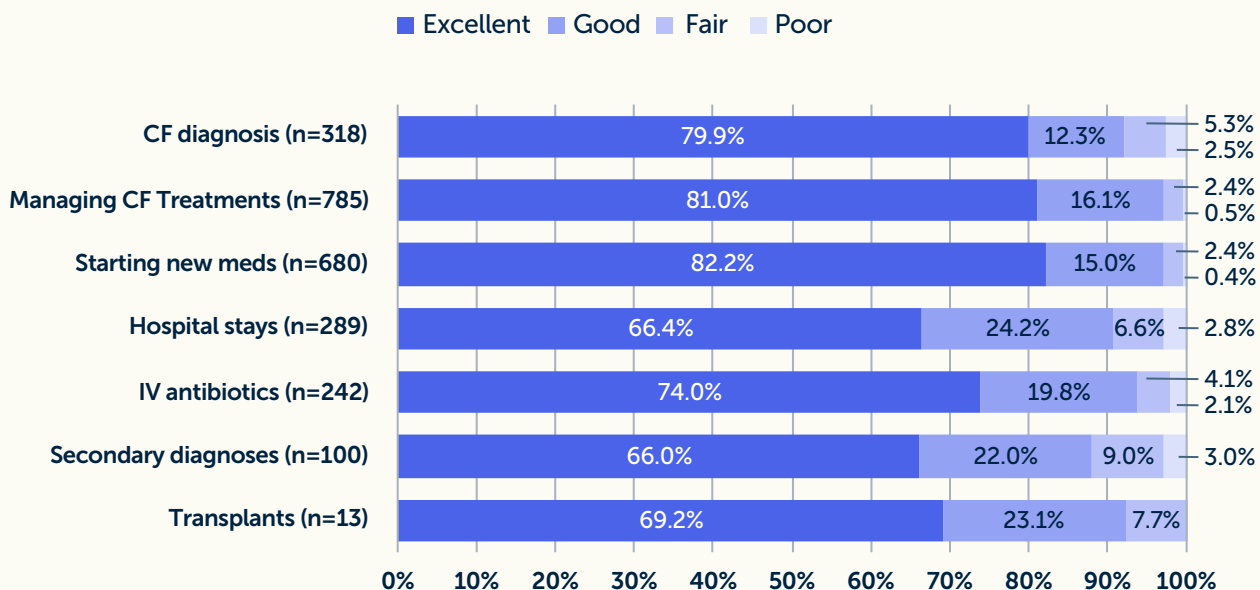
Experiences of support also varied depending on the specific area or issue that respondents had required support with (Figures 4a and b).

Support with physical health and hospital care

Support with starting new treatments, managing treatments, IV antibiotics, and first CF diagnosis were all rated highly by those who had needed support with these. 97.2%, 97.1%, 93.8% and 92.1% of respondents, respectively, said their CF team did an 'excellent' or 'good' job supporting them in these areas. Ratings for other key aspects of managing physical health were similarly positive.

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

Note: number of valid survey responses included is stated for each key areas / issue



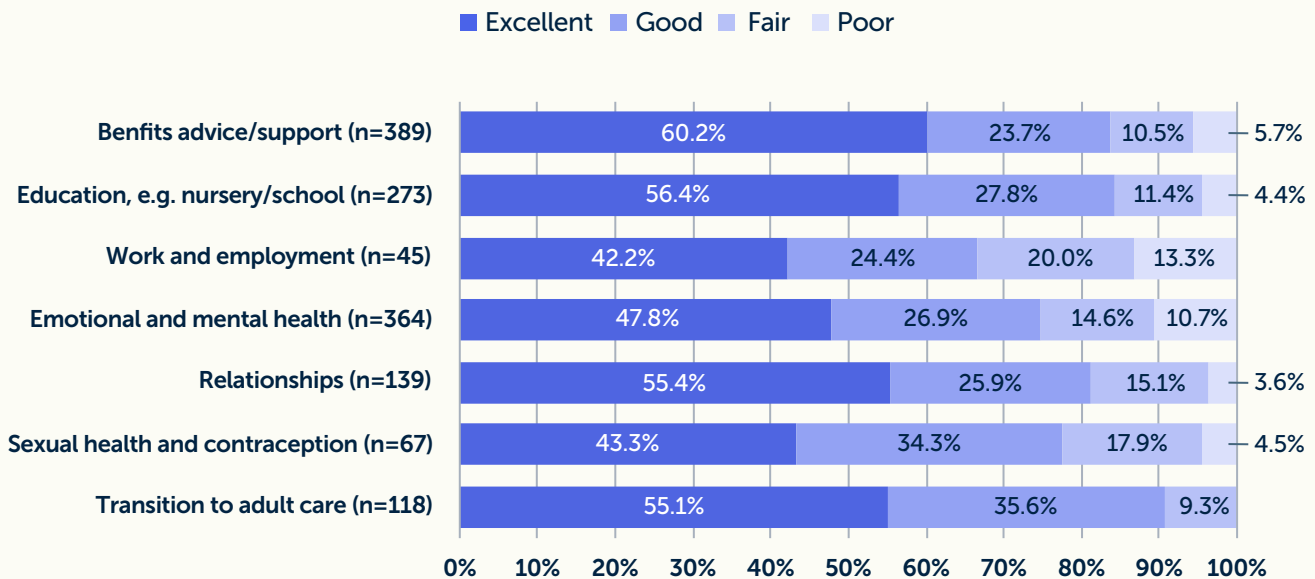
Not all these aspects of physical health and hospital care were explored in the 2019/20 survey, but where comparisons can be made, the findings are very similar between the two survey cycles. For all four aspects that can be compared (first CF diagnosis, secondary diagnoses, hospital stays and IV antibiotics), there were slight increases in the proportion of 'excellent' responses between 2019/20 and 2022/23, which is encouraging.

Support with social issues, wellbeing and mental health

In contrast to ratings for support with physical health, experiences of support with emotional wellbeing, relationships, benefits, and education were rated less positively, with just 74.7%, 81.3%, 83.8%, 84.2% 'excellent' and 'good' ratings, respectively. Over 10% of 364 respondents (n=39) who had needed support with emotional health rated their experiences as 'poor'.

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

Note: number of valid survey responses included is stated for each key area/issue



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

Not all these social and wellbeing issues were explored in the 2019/20 survey. However, where questions were included in both surveys, a comparison of the two shows a mixed picture. Support with benefits was rated similarly between the two survey cycles, whereas the proportion of 'excellent' ratings was lower for support with education, employment and sexual health in the 2022/23 survey. The proportion of 'excellent' ratings for support with relationships and transition to adult care, in contrast, increased between 2019/20 and 2022/23. However, it should be noted that the number of respondents for these questions was lower in the 2019/20 survey.

Section 3

Communicating with and seeing the CF team

Contacting the CF team

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

Cystic Fibrosis Service Specification - Children (NHS England):

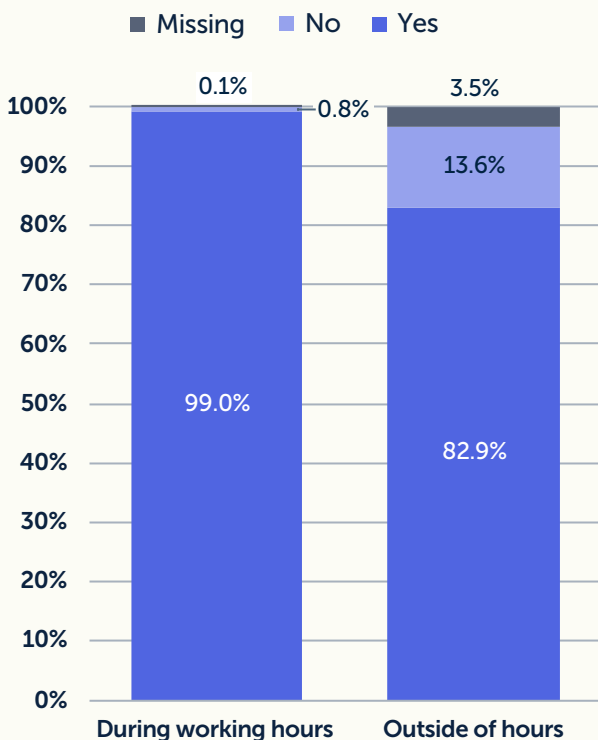
Section 3.2: Service description/care pathway: patients and their families will be made aware how to contact their clinical teams and cystic fibrosis support groups

Section 3.2: Specialist Care Responsibilities: Clear contact numbers should be given to patients to enable them to obtain advice from the specialist team at any time. During out of hours contact, a process must be in place to ensure a clear line of communication with a CF specialist. The specialist centre will agree arrangements for 24 hour services with network clinics to ensure equity of access across a network service.

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

Figure 5: Awareness of how to contact the CF team

Note: Based on 828 survey respondents, incl. those who skipped this question (missing)



Awareness of who to contact was excellent during working hours. However, 13.6% of respondents to the survey were unsure how to contact their CF team outside of their usual working hours. These findings are slightly better than in the 2019/20 survey, where 16.3% of respondents said they did not know how to contact their CF team out of hours.

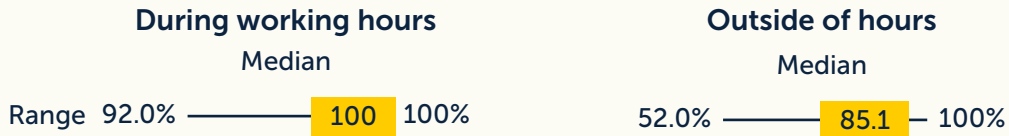


99.0% of respondents knew how to contact their CF team during working hours, falling to 82.9% out of hours.

This varied by centre, particularly for awareness of out-of-hours contact information.

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

Note: Centres with fewer than 10 respondents were excluded (7 centres totalling n=37 responses)



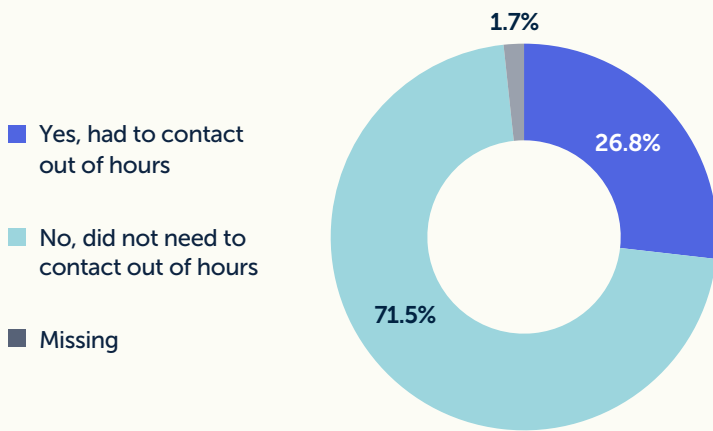
To understand the importance of having up-to-date contact details for CF specialists, the 2022/23 survey also explored whether families had needed to access the CF team outside of their usual working hours in the last 12 months.

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

Around a quarter (26.8%) of survey respondents confirmed they had needed to contact their CF team outside of usual working hours

Figure 6: Need to access CF team out of hours in the last 12 months

Note: Based on 828 survey respondents, incl. 14 who skipped this question (missing)



Communicating with and seeing the CF team

Since the COVID pandemic, many CF services have diversified the ways in which they communicate and meet with children and families affected by CF, making increased use of remote methods, such as telephone consultations, video conferencing and email, as well as increasing the use of home visits.

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.1: Aims and Objectives of Service: The service aims to improve both life expectancy and quality of life for children with Cystic Fibrosis.

The service will deliver the aims by:

- ensuring effective communication between patients, families and the service providers

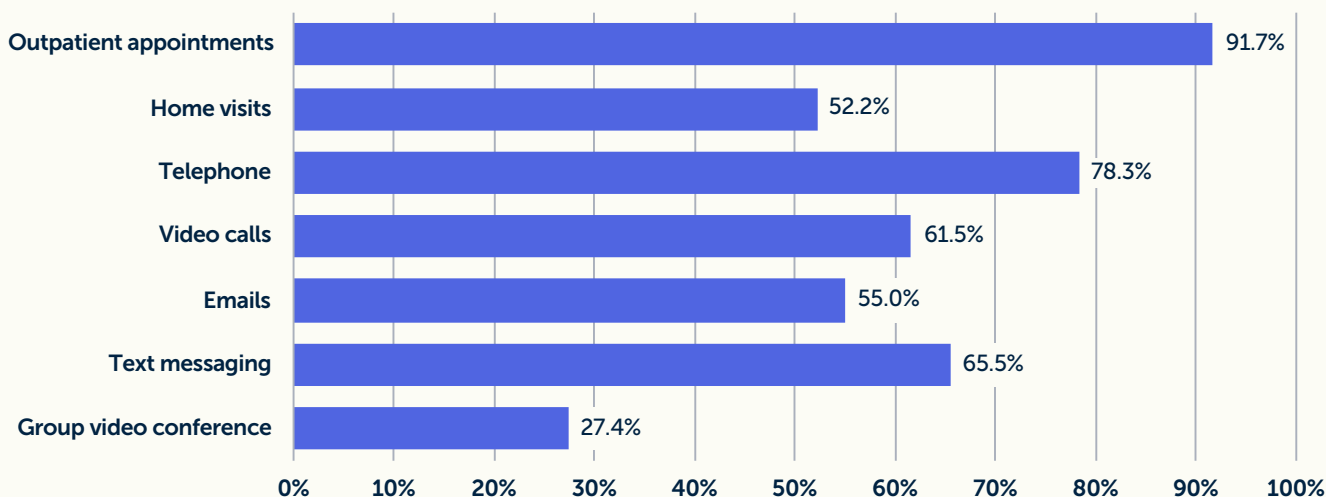
Section 3.2: Service description/care pathway: As a minimum [...] patients and their families will be afforded the right to be fully informed of their condition, and to ensure that information is communicated in an understandable, sympathetic and age-appropriate manner

The 2022/23 survey explored which communication methods and appointment formats had been offered in the last 12 months and asked respondents to rate their experience of each.

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

Figure 7: Communication methods and appointment formats

Note: Based on 803 respondents (excl. 25 who skipped this question); each respondent could select multiple communication methods

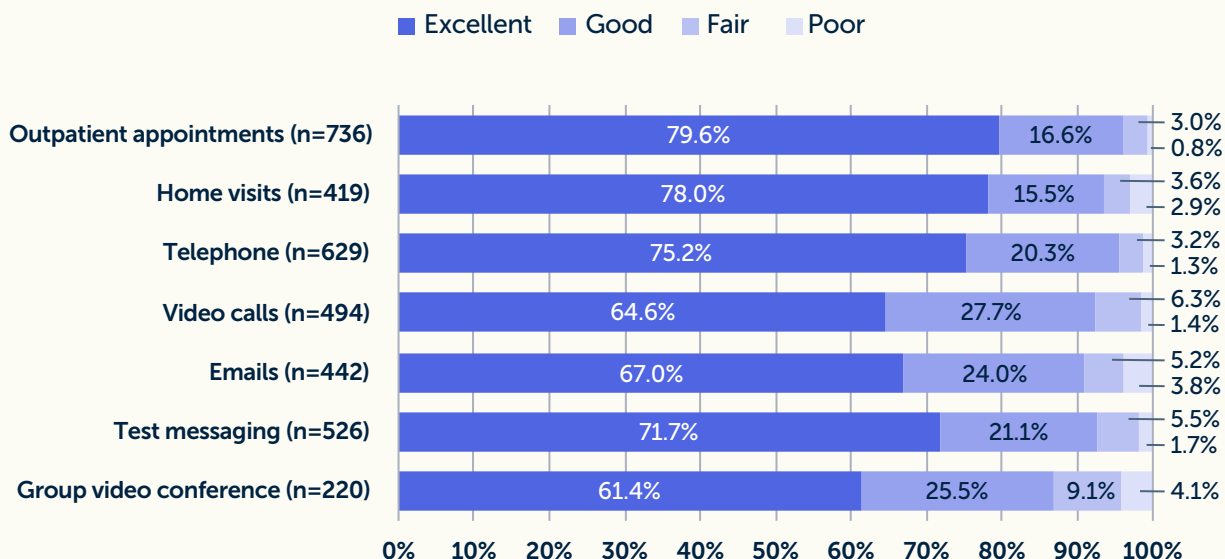


The vast majority of respondents (91.7%) confirmed they had had face-to-face contact with their CF team in outpatient clinic settings in the last year. Most respondents also said that they had used remote communication methods, such as phones (78.3%), text messaging (65.5%) and video conferencing (61.5%) to communicate with their CF team in the last 12 months. Only half of respondents (52.2%) confirmed that they had had a home visit.

Satisfaction with the different ways to see and communicate with the CF team varied. Figure 8 outlines the ratings given by children with CF and their parents for the different methods.

Figure 8: Ratings of communication methods and appointment formats

Note: Based on 803 respondents (excl. 25 who skipped this question); each respondent could rate each communication method they had used



Outpatient appointments were the highest-rated communication method, with 96.2% rating their experiences as 'excellent' or 'good'. However, all other methods were also rated positively by more than 9 of 10 respondents, including remote options, such as phone and video, as well as home visits. Group video conferences were the lowest-rated communication method, though 86.8% of respondents in the survey who had had a group video call still felt their experience had been 'excellent' or 'good'.



91.7% of respondents had had outpatient contacts with their CF team in the last year, with **96.2%** rating their experiences of such consultations as excellent or good.

47.6% of respondents said they would prefer to be seen in hospital clinics, while **40.3%** preferred a combination of virtual and hospital appointments in future.

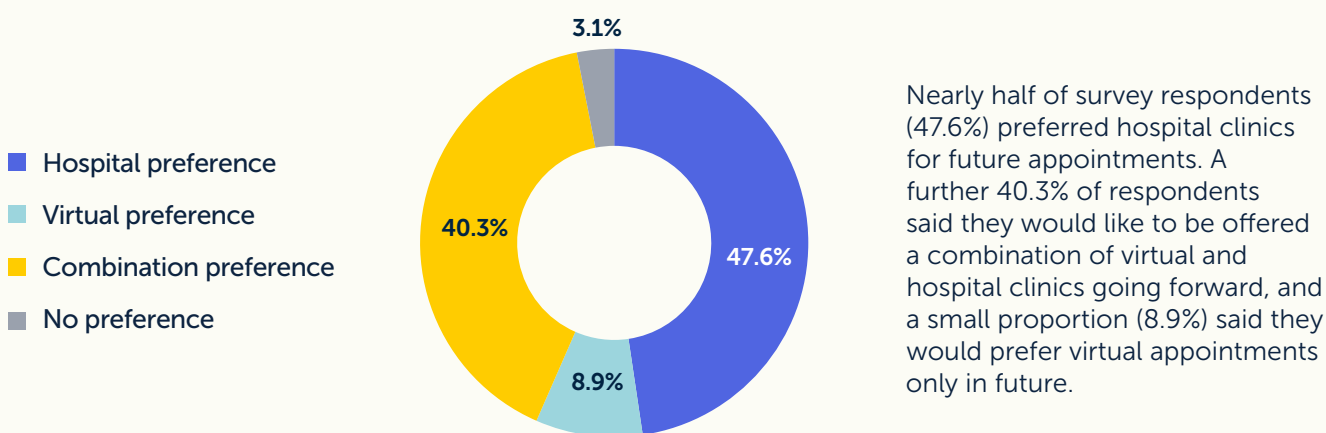
Future appointment preferences

In the 2022/23 survey, respondents were also asked about their future preferences for how they see their CF team.

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

Figure 9 Future appointment preferences

Note: Based on 808 respondents (excl. 20 who skipped this question)

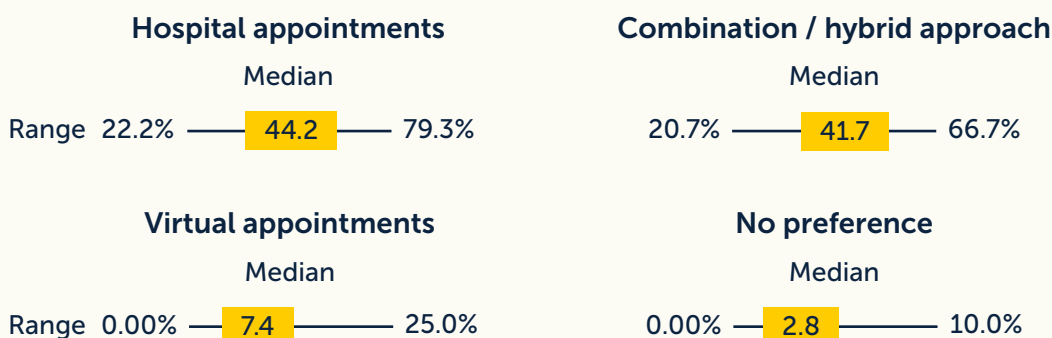


These findings differ from what we saw in our adult survey⁷, where 23.3% of adults with CF had a preference for virtual clinics and only 20.3% preferred hospital clinics, although a similar proportion (42.6%) said they would like a combination of both formats. Results from both the paediatric and adult surveys strongly indicate that continued access to face-to-face appointments should be available, particularly in paediatric CF care, and that CF teams should have the capacity to offer these.

There was some variation at centre-level in the proportions of respondents who preferred each appointment method.

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 were excluded (7 centres totalling n=37 responses)



⁷ Cystic Fibrosis Trust, Adult Patient-Reported Experience Survey 2020/21; UK Patient Reported Experience Measures survey (PREMs) - Adult Report May 2022 (cysticfibrosis.org.uk)

Many of the responses provided for future appointment preferences in the 2022/23 paediatric survey show that parents of children with CF value hospital clinics, as they provide reassurance and opportunity for physical examination by CF professionals.

“Having face-to-face physical appointments is much more thorough and reassuring. We as parents are not specialists and virtual clinics leave a lot of openness to self-diagnosis.”

“Can’t discuss much over a virtual clinic. Appointments need to be hands on, because patients need to be seen. Cannot diagnose over a screen.”

Other reasons given for hospital clinic preference included the ability to communicate more easily with the CF team and to get more engagement from children during appointments, particularly for younger children with CF.

“Easier to communicate and hold conversations, less risk of interruptions and easier to keep child involved in the appointment.”

“Virtual are good, but it doesn’t feel the same and child doesn’t always engage as effectively.”

Some respondents also flagged technical problems during virtual calls that could affect their experience and ability to communicate effectively with the CF team.

“Connection issues can sometimes be a problem, child can be shy on camera.”

“CF teams and medics [are] not techy - not necessarily using tech/virtual properly.”

Several parents also felt that visiting the hospital for clinic appointments helped their child get used to the CF team and the hospital environment, which they thought was beneficial.

Those who preferred to be offered a combination of hospital and virtual appointments in future provided similar reasons as those with a hospital preference for wanting to be seen face-to-face. However, these respondents also felt that virtual appointments had benefits, particularly if the child was well, including avoiding the need for travel and requiring less time off school and work.

“When well and no concerns, virtual clinics work better financially and around work and school.”

“I appreciate better consultations can be made in person, however children in school, especially in vital years, will be conscious of missing days of school.”

“It is not always necessary for a face-to-face appointment. This also cuts down on our travelling time/interruption of home life. However, I feel it is important to still see the team.”

Some respondents also felt that virtual clinics worked well for certain situations but said they would also like to be seen in hospital depending on what was needed.

“Combination of clinic and virtual would be ideal, depending on situation. Example lung function in hospital only and consultation with a doctor specialist, psychologist, dietetics etc could be online.”

“I feel virtual clinics are good for ‘nurse led clinic’ appointments. However, I sometimes feel they are a bit more disjointed and don’t flow as well, conversation can feel awkward compared to face-to-face appts.”

Others were concerned about the risk of infection and keen to avoid too many visits to hospital.

“The risk for children to travel in terms of getting germs is high, plus I feel there’s never enough separation between CF patients in communal areas, so there is a risk of them picking up each other’s infections.”

Similarly to reasons provided by those preferring a combination of virtual and hospital appointments, those who preferred virtual clinics often cited less disruption, avoiding travel and fewer days off school or work as reasons for their preference. Some also explained that their child would feel more comfortable with virtual clinics as hospital visits were stressful for them.

“[Child] gets a bit stressed out going into the hospital. So would be quite happy with virtual clinics.”

“[Child] gets anxious when going to hospital settings and parking can be a big issue.”

Responses provided for appointment format preferences indicate that there is a wide range of reasons and differing needs influencing preference, and that these should, ideally, be considered when planning appointments. Patient and parent choice, as well as clinical needs, should be taken into account, and an effort should be made to offer the most appropriate appointment format.

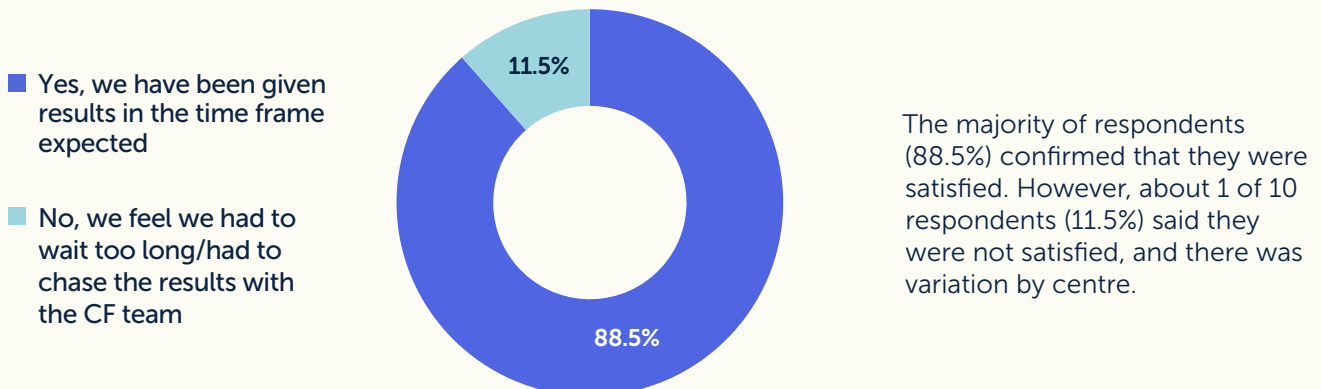
Communication of test results

In the 2019/20 survey, communication of test results was often mentioned as an area for improvement, with survey respondents feeding 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. The 2022/23 survey again asked about respondents’ satisfaction with the communication of test results.

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

Figure 10: Satisfaction with time taken to communicate test results

Note: Based on 754 respondents (excl. 74 who skipped this question)



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 responses to this question were excluded (8 centres totalling n=47 responses)



Comments left by some survey respondents illustrate issues experienced and the preference for CF teams to contact parents with test results as soon as possible, even if nothing untoward is found.

“Call when swab result in, even if clear, otherwise we are left wondering and then have to call anyway.”

“Results of swabs/bloods are never told to us unless I pester for them.”

“Communication to get sputum results back quicker rather than chasing them up or waiting for the next clinic. I have seen other centres have results emailed/texted to them or can check on them via an app.”



88.5% of respondents overall were satisfied with the time taken to communicate test results in general.

Section 4

Annual reviews

Current guidance recommends that all children 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, as well as conversations with different specialists in the CF MDT. Feedback from annual reviews should be provided in a timely manner to ensure that children with CF and their parents have a record of discussions and the healthcare plan going forward.

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.2: Service description/care pathway (Provision of Care), Annual Review: A full review must be undertaken by the specialist centre once a year, in line with the standards defined in The CF Trust document "Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK" (2011). A personal care plan must be produced by a consultant and agreed with the patient as a result of every annual review undertaken.

Quality Standards Domain 2: Enhancing the quality of life of people with long-term conditions: All children should have an annual review and management plan discussed with the family.

Quality Standard Cystic Fibrosis QS168 (NICE):

Quality Statement 1 Annual Reviews: People with cystic fibrosis have the results of all assessments they have had during the past year reviewed annually by a specialist MDT.

Quality measures (Process): Proportion of people with cystic fibrosis who have the results of all assessments they have had during the past year reviewed by a specialist MDT.

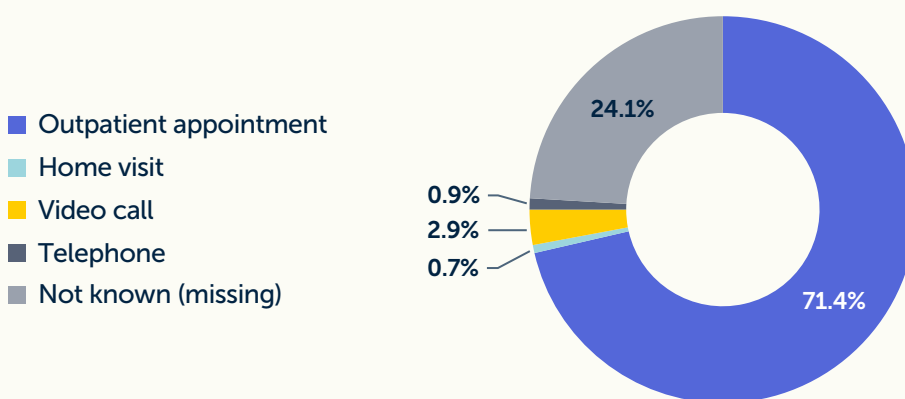
The survey explored how annual reviews were conducted in the previous 12 months, as well as asking about the tests and assessments carried out and the staff seen.

Survey question: If you/your child had an annual review in the last 12 months, please tell us how this was done.

Around 9 of 10 respondents (90.3%) confirmed that they had had an annual review in the previous year. It is unclear why nearly 1 in 10 respondents would not have had an annual review. However, it is possible that there is a delay to some reviews due to a backlog following the COVID pandemic or that some respondents had not been explicitly informed that they had an annual review and had deemed it just a usual clinic appointment. The remainder of this section focuses on those who had confirmed they had an annual review in the last 12 months and excludes 80 survey respondents who did not confirm this.

Figure 11: Format of annual reviews

Note: Based on 748 respondents (including 180 where AR format was unknown = missing)



Most had this as an outpatient appointment (71.4%), with 2.9% reporting they had their review via video call. There was also a large proportion of respondents (24.1%) who did not answer this question.



90.3% of respondents had an annual review in the last 12 months and most had this as an outpatient appointment.

Tests and assessments for annual review

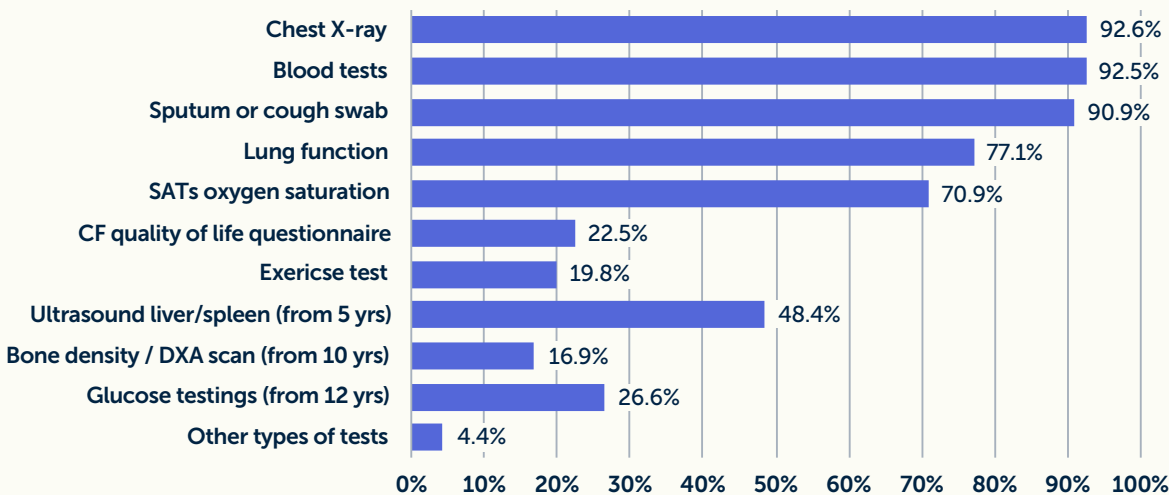
Respondents with an annual review were asked to select the tests and assessments they had from a list, with the option to add further tests in a free text box if needed.

Survey question: Did you/your child have any tests/assessments done for their annual review? If yes, please tick which ones from the list below.

This question relies on respondents accurately recalling which tests and assessments had been carried out and reviewed at their annual review, which is a limitation. However, many parents and children with CF will be familiar with the standard tests and likely be able to recall these correctly.

Figure 12: Tests and assessments for annual review

Note: Based on 733 respondents (excludes 15 who skipped this question); some tests and assessments are only recommended from certain ages, and we would not expect these to have been completed for all respondents



Chest X-rays and blood tests were the most common types of assessments respondents recalled having, with 92.6% and 92.5% recalling having these tests, respectively. Sputum or cough swabs had been completed for 90.9% of respondents. Lung function assessments and SATs oxygen saturation were also frequently completed and discussed at annual review, with 77.1% and 70.9% of respondents recalling having these tests. However, the proportions of respondents who recalled having completed an exercise test or quality of life questionnaire were much lower at 19.8% and 22.5%, respectively. This indicates that there may be variation in the types of tests and assessments completed for and discussed at annual review, though some of this variation may be entirely appropriate given the need to tailor care to individual patients.

Other tests, including liver/spleen ultrasounds, bone density scans and glucose testing, are only recommended once children reach a certain age, and hence we would not expect all respondents to necessarily have had these types of tests. 4.4% of respondents recalled having other tests at annual review, not listed in the survey, which included sweat tests, eye and hearing assessments, stool and urine samples, as well as other types of ultrasound scans.

Over 90% of respondents had chest x-rays, blood tests and sputum/cough swabs done or discussed at their annual review, but there was variation in other types of tests carried out.



Staff seen at annual review

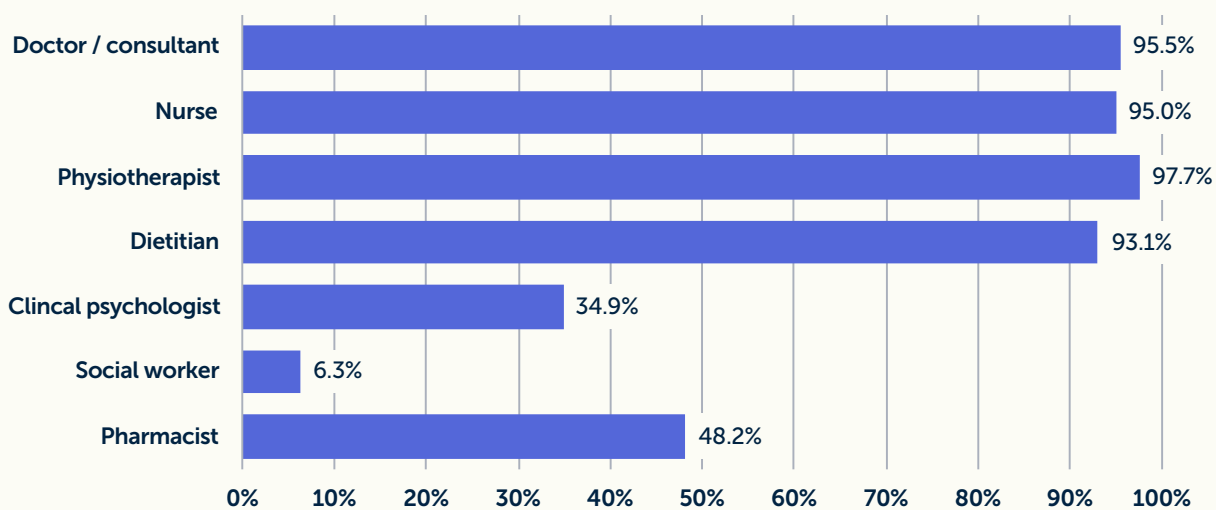
The survey also explored which members of the CF team children and their families had seen at their last annual review.

Survey question: Which team members did you/your child see for their 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 13: CF MDT staff seen at annual review

Note: Based on 734 respondents (excludes 16 who skipped this question)



More than 9 of 10 respondents confirmed they had seen a CF doctor, nurse, physiotherapist and dietitian for their annual review. 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 children and parents needed them.

The proportions of respondents who recalled seeing CF clinical psychologists, social workers and pharmacists at annual review were much lower, with 34.9%, 6.3% and 48.2%, respectively. Again, this finding aligns with survey responses on the accessibility of these staff groups. From the CF staffing tool, we also know that such roles do not exist in all paediatric CF centres or networks.

There was some variation by centre in the proportions of respondents who confirmed they had seen CF psychological and social staff and pharmacists at annual review.



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

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 were excluded (7 centres totalling n=37 responses)



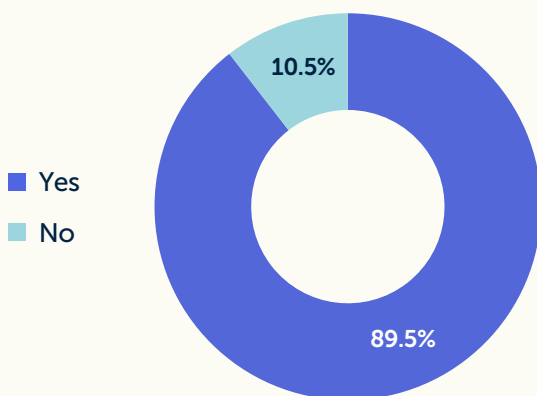
Feedback from annual review

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.

Survey question: Did you/your child receive written feedback from your annual review (please only answer if annual review was more than one month ago)?

Figure 14: Written feedback from annual review

Note: Based on 647 respondents (excludes 101 who skipped this question – their AR may have been <1 month ago and hence feedback would not yet be expected)



Among those who answered this question (n=647), nearly 9 in 10 respondents (89.5%) confirmed that they had received written feedback from their last annual review. However, about 1 in 10 (10.5%) said that no written feedback had yet been shared with them. This is a slightly lower proportion than in the 2019/20 survey, in which 12.9% said they did not recall having had feedback from their annual review.

Proportions of survey respondents who had received feedback varied by centre.

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

Note: Centres with fewer than 10 responses to this question were excluded (8 centres totalling n=47 responses)



89.5% of respondents confirmed they had received written feedback from their last annual review, but 10.5% could not recall having had feedback.

Section 5

Infection control and prevention

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

Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK (2011):

Section 4.1: Infection Control

- There must be local policies and clear operating procedures that involve segregating patients so that all CF patients are isolated from each other.
- Patients should not share rooms including bathrooms and toilets whilst inpatients in hospital.
- Hospital facilities must maintain a high standard of cleanliness.
- Patients should not be in contact with each other in waiting areas, e.g. CF clinics, wards, pharmacy, radiology etc.
- A high standard of hygiene should be practised by staff

Cystic Fibrosis Service Specification - Children (NHS England):

Quality Standards Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm: Adherence to standards of care to prevent cross infection. Centres should aim to reduce their prevalence of chronic pseudomonas infection. [Domain threshold: >14%]

In the 2022/23 survey, we asked about satisfaction with infection control in a variety of settings, including respondents' main CF centre or clinic, but also families' homes, inpatient wards and other hospital areas.

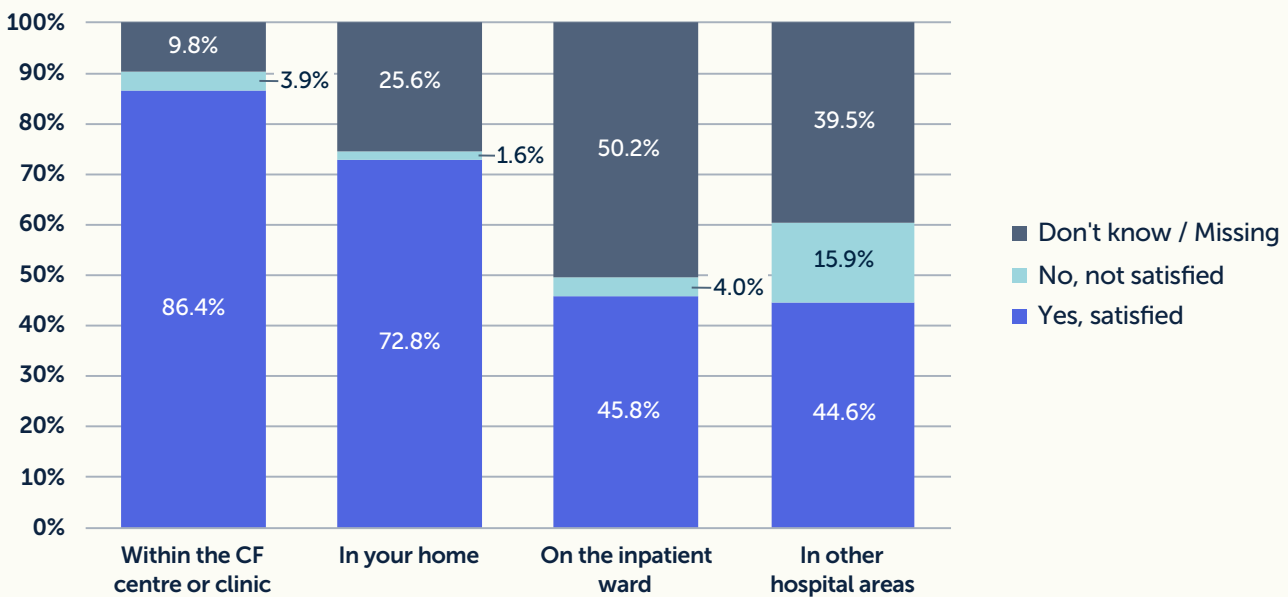


86.4% of respondents felt infection prevention measures were sufficient at their CF centre or clinic, but some raised concerns about infection control, particularly in other areas of hospitals, including x-ray and pharmacy departments.

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

Figure 15: Are infection control measures sufficient?

Note: Based on full sample of 828 responses; incl. those who responded 'don't know' and those who skipped the question (missing)



Overall, most respondents (86.4%) were satisfied with infection control measures in place within their CF centre or clinic. Only 3.9% of respondents said they did not feel infection prevention and control measures were sufficient. This is lower than the proportion of respondents saying they were dissatisfied with infection control measures in the 2019/20 survey (17.8%), which is encouraging.

Of the 3.9% (n=32) who said they were not satisfied with infection control in their CF centre or clinic, several flagged issues around arrival for clinic appointments and having to wait in waiting areas.

"We never receive any advice on where to go in the reception area in outpatients on clinic days. We could therefore be mixing with and [be] in close proximity to other people with CF. It would be better if we were given a specific area/room to go to when we arrive."

"There have been several occasions where I have been in the queue waiting for a room in outpatients with my [child] for [their] clinic appointment and there has been a CF patient in the same queue only a couple of meters away. Several children are booked in at the same time for clinic - these could be staggered by just 15 minutes or so to avoid crossing paths."

"Arriving at the hospital for clinic appointments at the same time as other CF patients is a concern, for example travelling to and leaving the ward. Once at clinic, it feels safe and well run."

Within homes, for example, during home visits, survey respondents usually felt infection control was well managed, with only 1.6% (n=13) saying they were dissatisfied. Some of these respondents felt they had not been provided with sufficient information about infection control in the home.

"No special measures have been put in place at home by the CF team."

"I've not had any guidance 'in the home' for bug prevention. But have read up on CF Trust website."

Many respondents did not comment on infection control in inpatient wards, possibly because they had not received care in this setting or because they were unsure what infection control protocols they could expect. Of those who provided feedback about this setting, the majority were satisfied, although 4% of survey respondents (n=33) were not.

“Doors to other CF children’s rooms were left open on the ward, even while children doing airway clearance. Children were allowed to play in the corridor. Nursing ward staff didn’t seem to understand the risk of cross infection or take it as seriously as the CF team.”

“There appeared to be another child with CF spending a lot of time out of his room in the ward where the CF children stay.”

Concerningly, 15.9% of respondents (n=132) said they were not satisfied with infection control in other areas of the hospital, particularly specifying issues within x-ray, ultrasound and pharmacy departments in their free text comments. Some were also worried about hospital staff awareness of the need for segregation in waiting areas and A&E.

“There are no measures in place after you leave the ward. We could be sitting next to someone with CF and have zero idea.”

“The pharmacy has always been an issue for me. It’s jam packed or you’re stood waiting around the busy corridors with scores of other people bustling past. On clinic days, I don’t know who to keep my [child] away from.”

“Going to A&E is always awkward, as the nurses usually don’t have knowledge on CF and think you are after special treatment when you ask if there is a separate room to wait in due to child having CF and cross infections.”

A few respondents suggested that a wristband or other item that would enable them to identify other CF patients in hospitals could help alleviate some concerns, although, in centres that have implemented such systems, respondents flagged these also had limitations.

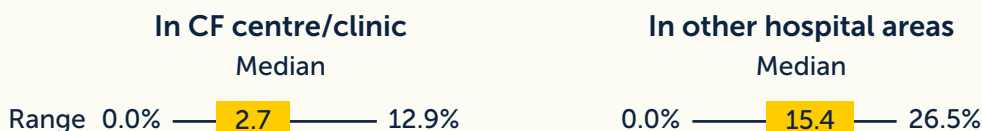
“I feel we should all be given something to show we [are] CF families, so we can be aware around the hospital - such as a CFT bag or band to wear.”

“We are encouraged to wear yellow bands, but [these] can difficult to see, especially with coats on.”

While survey respondents generally felt that infection control was well managed, there was some variation between centres in the proportions that felt dissatisfied with infection control measures.

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: Centres with fewer than 10 respondents were excluded (7 centres totalling n=37 responses)



Section 6

Hospital care

Outpatient clinic experiences

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.2: Service description/care pathway (Outpatient and Day Case Facilities): The facilities must take the need for infection control into consideration and demonstrate compliance with section 4.1 of the Cystic Fibrosis Trust "Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK" (2011) when providing facilities for annual reviews, treatment, day case etc. This will include ensuring that CF patients are not kept waiting in communal waiting areas and that they remain segregated from each other at all times, so as to minimise the risk of cross infection.

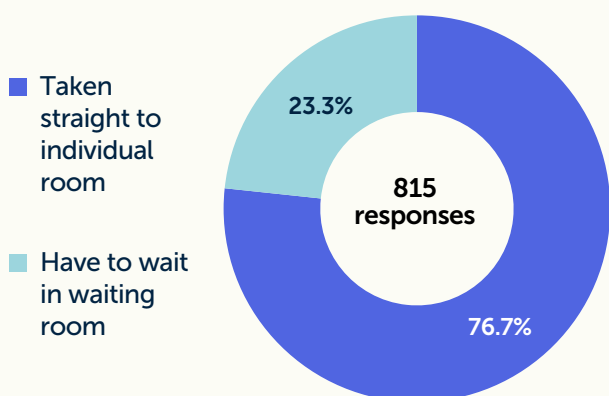
To more fully understand the experiences of children with CF and their parents when they attend outpatient appointments in their CF centre or clinic, we asked them to describe what happens on arrival, when being seen by the team, and when having lung function, height and weight measured.

Survey question: Please tick the boxes that best describe your/your child's experience in the last 12 months.

Note: Figures 16-19 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 16: "In CF outpatient clinic, what happens on arrival?"

Note: Based on 815 responses provided by n=779 survey respondents (excludes 49 respondents who skipped this question); 36 had experienced both scenarios; graph is out of total responses



In most instances, and in line with guidelines, children 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. The distribution of responses to this question was similar to findings from the 2019/20 survey.

However, 190 of 779 respondents who answered this question (24.4%) reported waiting in a waiting room on at least one occasion when they arrived at their CF clinic. Thirty-six of whom had also (on other occasions) been taken straight to a room, while 154 said they had only experienced having to wait in a waiting room.

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

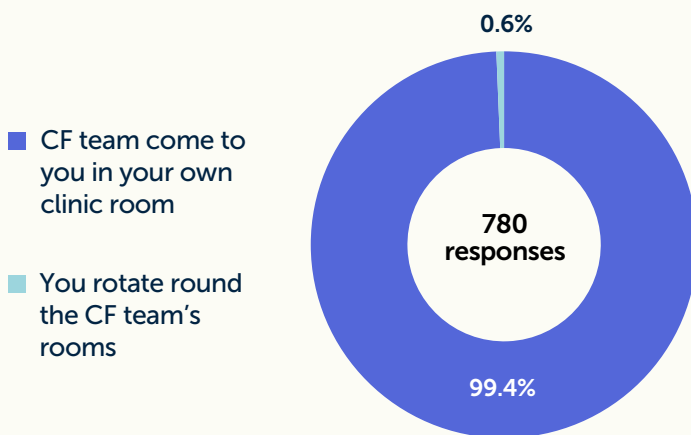
Centre-level insight: Proportion of responses indicating children with CF went straight to an individual room upon arrival

Note: Centres with fewer than 10 respondents were excluded (7 centres totalling n=37 responses)



Figure 17: “In CF outpatient clinic, how is care delivered?”

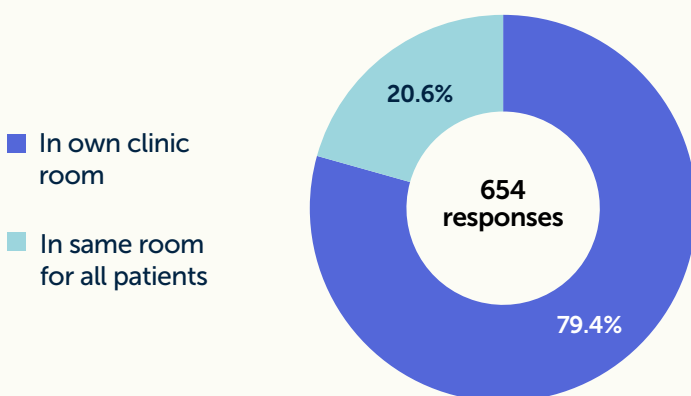
Note: Based on 780 responses provided by n=778 survey respondents (excludes 50 respondents who skipped this question); 2 had experienced both scenarios; graph is out of total responses



In line with current guidelines, the vast majority of children with CF are seen in their own clinic room every time they attend outpatient clinics, with MDT members rotating around patients' rooms. This finding is the same as in the 2019/20 survey. Only five respondents from five different centres reported ever rotating around their CF teams' rooms.

Figure 18: “In clinic, where is lung function measured?”

Note: Based on 654 responses provided by n=629 survey respondents (excludes 199 respondents who skipped this question); 25 had experienced both scenarios; graph is out of total responses



Not all respondents to the survey had lung function tests in outpatient clinics, but 629 answered this question. Of these, 135 (21.5%) had had lung function measured in the same room for all patients on at least one occasion, though 25 respondents from this group also said lung function had been measured in their individual room on other occasions. Overall responses show that lung function was mostly measured in patients' own clinic rooms (79.4%), which is similar to the response distribution in the 2019/20 survey. However, there was variation by centre in the proportion of responses confirming lung function was measured in patients' own rooms.

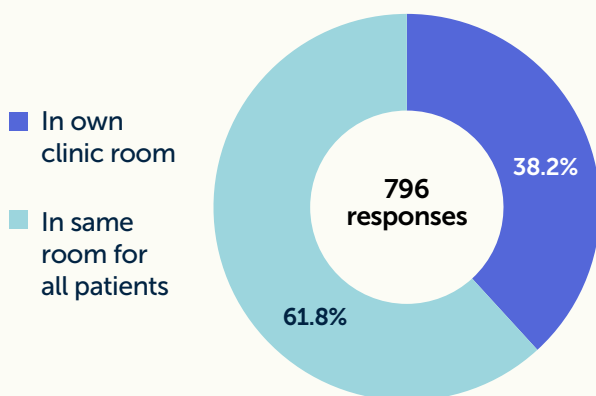
Centre-level insight: Proportion of responses indicating that lung function was measured in patients' own clinic rooms

Note: Centres with fewer than 10 respondents were excluded (7 centres totalling n=37 responses)



Figure 19: "In clinic, where are height and weight measured?"

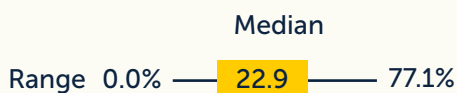
Note: Based on 796 responses provided by n=771 survey respondents (excludes 57 respondents who skipped this question); 25 had experienced both scenarios; graph is out of total responses/instances



In contrast to lung function, responses to the survey show that, in most instances, height and weight were measured in the same room for all patients, which aligns with findings from the previous survey. Overall, 492 of 771 respondents who answered this question (63.8%) said they had height and weight measured in the same room as others. Twenty-five of these respondents also said that height and weight had been measured in their own room on other occasions. There was variation by centre in the proportion of responses confirming that these measures were taken in patients' own 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 were excluded (7 centres totalling n=37 responses)



24.4% of children with CF and parents said they had waited in a waiting room on at least one occasion when they visited their outpatient clinic.

63.8% of children with CF and parents said that they had experienced height and weight being measured in a shared room for all patients on at least one occasion, whereas for lung function, this was just **21.5%**.

Inpatient facilities

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

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.2: Service description/care pathway (Inpatient Care): Beds in a ward suitable for cystic fibrosis care will be available within 24 hours for an emergency admission, as well as capacity to ensure elective and urgent admissions can be managed appropriately.

Inpatient facilities will meet the standards defined in the Cystic Fibrosis Trust “Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK” (2011).

Every CF patient will be in their own room, with en-suite facilities to minimise the risk of cross infection and to enable them to continue life as normally as possible.

Nurses on the inpatient wards require specific expertise, and will be committed to the CF service, with regular input and training from the specialist CF nurses. Patients will be admitted to a ward staffed by CF specialists or to wards that are familiar with the care and management of individuals with this condition and have developed the required expertise.

Quality Standards Domain 4: Ensuring that people have a positive experience of care: All children requiring inpatient care should be admitted to a ward staffed by CF specialist staff (as defined by national specialist service specification) [Domain target: $\geq 95\%$]

Quality Standard Cystic Fibrosis QS168 (NICE):

Quality Statement 2 Preventing cross-infection: People with cystic fibrosis have individual rooms with en-suite facilities when admitted to hospital as inpatients.

Quality measures (Structure): a) Evidence of local infection control strategies that cover inpatient settings for people with cystic fibrosis. b) Evidence of inpatient wards containing individual rooms with en-suite facilities.

Quality measures (Process): Proportion of inpatient admissions for people with cystic fibrosis where admission was to an individual room with en-suite facilities.

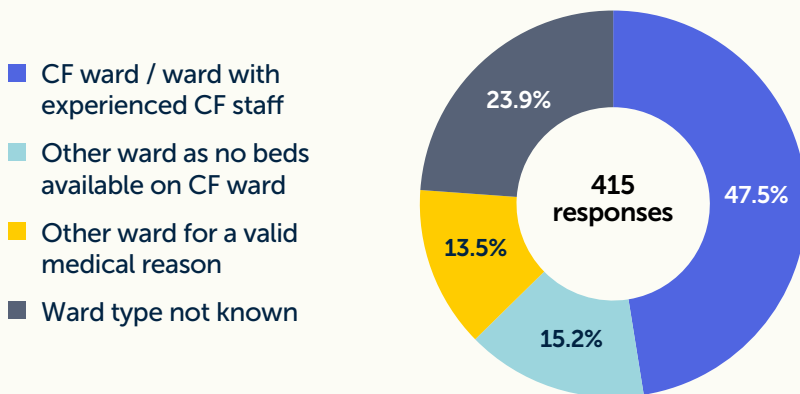
To understand the experiences of children with CF and parents when they had to stay in hospital for inpatient treatment, we asked respondents to describe the type of ward and room they had stayed in. Many survey respondents skipped these questions, likely because they had not had an inpatient stay in the last 12 months (number of respondents included in analysis is provided in graphs below).

Survey question: Please tick the boxes that best describe your/your child's experience in the last 12 months.

Note: Figures 20 and 21 are showing 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 episode, therefore providing more than one response to the below questions

Figure 20: "What type of ward did you/your child stay on?"

Note: Based on 415 responses provided by n=392 survey respondents (excludes 436 respondents who skipped this question); 23 had experienced both scenarios; graph is out of total responses

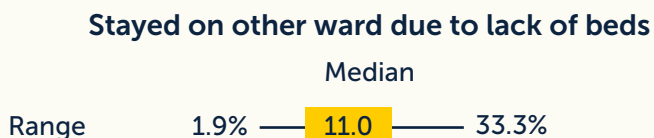


Just under half of responses (47.5%) confirmed children with CF had stayed on a ward with experienced CF staff, which is lower than the proportion in the 2019/20 survey, where 69.8% of responses indicated a stay on a ward staffed with CF specialists.

Sixty-three of 392 respondents who answered this question (16.1%) said that there had been at least one occasion where they had to stay in a different ward due to a lack of beds in the CF ward, although 11 of these said they had also had a stay on the CF ward on another occasion. Overall, 56 respondents said they had received care on a different ward due to a valid medical reason, and several were unsure of the type of ward they had stayed on. There was some variation in response distribution between centres.

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

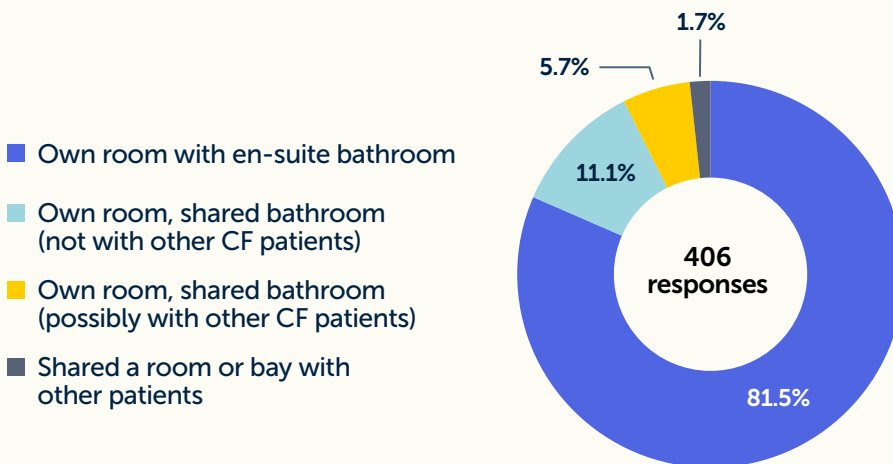
Note: Centres with fewer than 10 responses to this question were excluded (12 centres)



16.1% of 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.

Figure 21: "What type of room did you/your child have?"

Note: Based on 406 responses provided by n=383 survey respondents (excludes 445 respondents who skipped this question); 23 had experienced several scenarios; graph is out of total responses

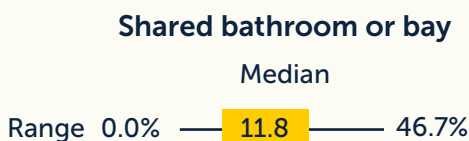


In line with guidelines, 81.5% of responses indicate that children with CF were given their own room with an en-suite bathroom, although several respondents also noted that they had stayed in a different type of room on other occasions. The distribution of responses to this question was very similar to the findings in the 2019/20 survey.

Twenty-three of 383 respondents (6.0%) said they had shared a bathroom with others on at least one occasion, which could have included CF patients. Seven of 383 respondents (1.8%) noted occasions when they had shared a bay with others. There was some variation in responses between centres.

Centre-level insight: Proportion of responses confirming that children with CF had shared a bathroom or bay with others during an inpatient stay

Note: Centres with fewer than 10 responses to this question were excluded (13 centres)



6.0% of respondents said they had shared a bathroom potentially with other CF patients on at least one occasion, and **1.8%** said they had shared a bay with others.

Inpatient care experiences

During inpatient stays, children with CF should have access to additional food, toys and equipment, as well as hospital education if required. Furthermore, other aspects of care, including the timing of intravenous (IV) antibiotics and receipt of drugs to take home, should be well organised.

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.2: Inpatient facilities will meet the standards defined in the Cystic Fibrosis Trust "Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK" (2011). [...]

In particular, inpatients will:

- have access to education facilities and support for school/college and examinations as appropriate
- have access to appropriate play and recreational facilities 7 days a week

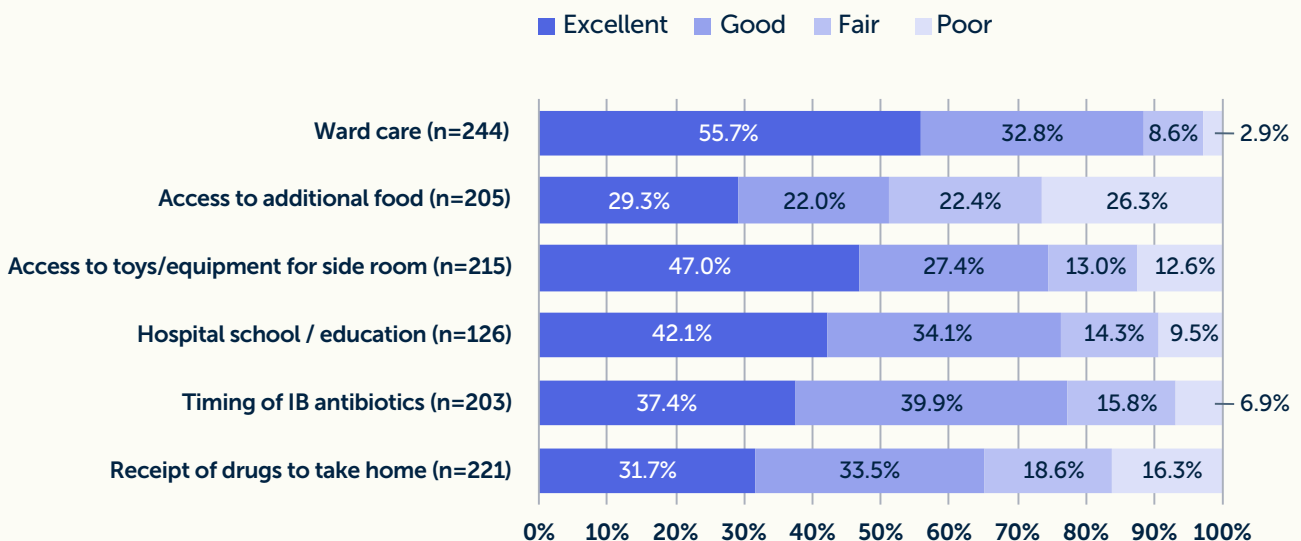
Provision will be made for inpatients to have a choice of food including high energy options and access to high energy mid-meal snacks and drinks. This shall include evenings and weekends.

The 2022/23 survey explored children's and parents' experiences of inpatient stays. Overall, 257 of 828 respondents (31.3%) provided one or more ratings for aspects of inpatient care.

Survey question: Thinking about when you/your child had to stay in hospital in the last 12 months, how good were the care aspects listed below?

Figure 22: Experiences of inpatient care

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



Many aspects of inpatient care were rated positively by survey respondents, with 88.5% of those responding to this question confirming that ward care had been 'excellent' or 'good'. Around three-quarters of respondents rated the timing of IV antibiotics, hospital education and access to toys/equipment highly, with 77.3%, 76.2% and 74.4% 'excellent' or 'good' responses, respectively. Access to additional food was the least positively rated aspect of inpatient care, with 26.3% of those who had required this type of support rating it as 'poor' and a further 22.4% saying it was merely 'fair'.



88.5% of respondents rated ward care generally as excellent or good, but respondents rated other aspects of inpatient care less positively, with **26.3%** saying that access to additional food during inpatient stays had been 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 children with CF.

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.2: Service description/care pathway (Intravenous (IV) Antibiotics): The service must have the ability to commence IV antibiotics on any day of the week. An urgent course of treatment will be implemented within a maximum of 24 hours of the clinical decision being made. There must not be a delay of longer than one week of the proposed admission date for a routine/elective/planned course of treatment.

Where appropriate, IV antibiotics may be provided at home, following receipt of the initial dose at the specialist CF centre.

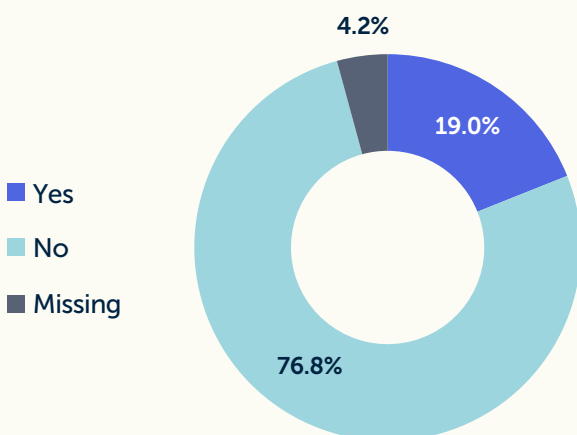
Quality Standards Domain 3: Helping people to recover from episodes of ill-health or following injury: There should be no delay in initiating IV antibiotic therapy for pulmonary exacerbation (as defined by national service specification)

To explore experiences with IV antibiotic therapy, the survey asked about access, timeliness, as well as preferences for hospital versus home IVs.

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

Figure 23: Intravenous antibiotic therapy in the last 12 months

Note: All survey respondents included (n=828)



Just under 1 of 5 children with CF in the survey (19.0%) had received IV antibiotic therapy in the last year. This is a smaller proportion than in the 2019/20 survey, in which 32.7% reported having had IVs. Part of the reason for a decline in survey respondents who had needed IV antibiotics in the last year may be due to the increased availability of CFTR modulators and better health for those children able to benefit from these drugs. Data from the UK CF Registry also show an overall decline in IV days⁸.

The proportion of children in the survey who had had IVs in the last 12 months varied by centre. Two centres had no respondents who had had IV antibiotics.

8 Cystic Fibrosis Trust, Annual UK CF Registry Report, 2022: UK Cystic Fibrosis Registry 2021

Centre-level insight: Proportion of respondents at each centre who received IV antibiotic therapy

Centres with fewer than 10 respondents were excluded (7 centres totalling n=37 responses)

IV antibiotics in the last 12 months

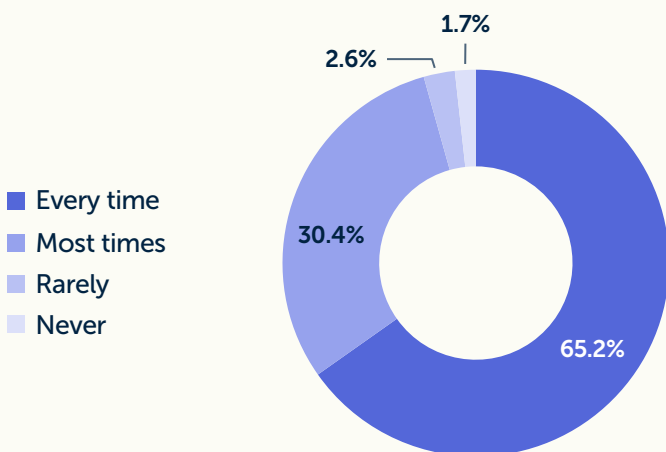


Respondents with IV antibiotic experiences (n=157) were shown several follow-up questions to further explore the timeliness and location of antibiotic therapy. The remainder of this section focuses on these respondents only.

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

Figure 24: Urgent IV antibiotic therapy started within 24 hours

Note: Based on n=115 respondents who had received urgent IV antibiotics, excl. 42 N/A and missing responses (did not need to start antibiotics within 24 hrs)



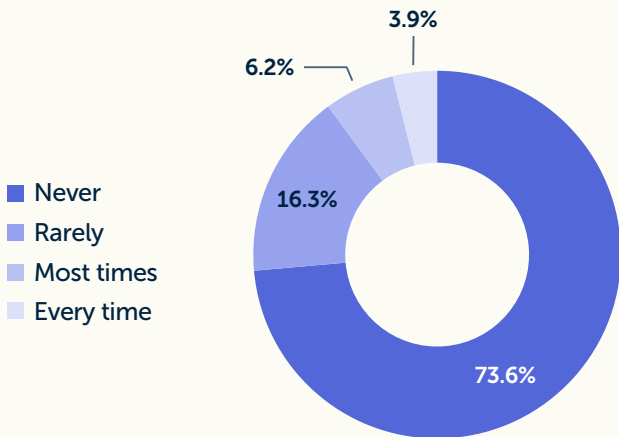
The vast majority of respondents (95.7%) confirmed that, where indicated, urgent IV antibiotics were started within 24 hours, 'every time' or 'most times'. This is a slight increase from the 2019/20 survey (92.2%), although the proportion confirming urgent IVs were started on time 'every time' reduced slightly from 69.5% to 65.2% in 2022/23, with a marginally larger proportion saying they started urgent IVs within 24 hours 'most times' in the 2022/23 survey.

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/planned IV antibiotic therapies about delays to their scheduled admission to better understand when and how delays occurred in this context.

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

Figure 25: Planned IV antibiotics delayed more than 7 working days

Note: Based on n=129 respondents who had received routine IV antibiotics, excl. 28 N/A and missing responses (did not require planned/routine antibiotics)

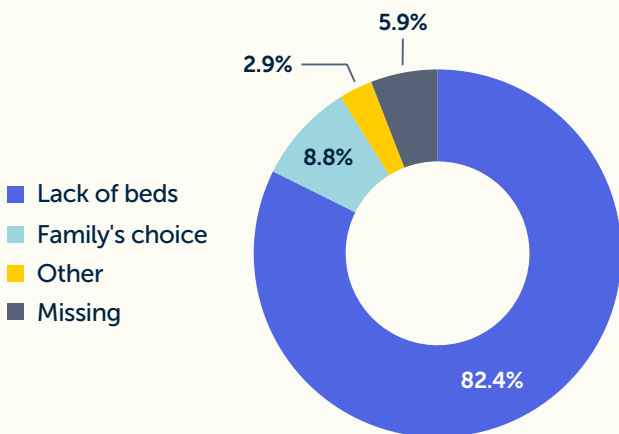


The majority of respondents (73.6%) confirmed that their routine/planned antibiotics were never delayed more than seven days from the originally scheduled admission date. This is a slight decrease from 2019/20 (78.3%). Thirteen people in the 2022/23 survey (10.1%) said they had started routine IV antibiotic therapy with more than seven working days' delay 'every time' or 'most times'.

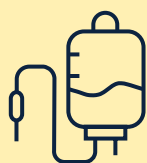
Survey question: If you/your child had a delay of longer than 7 working days to planned/routine antibiotics, what was this due to?

Figure 26: Reasons for delay to planned IV antibiotics

Note: Based on n=34 respondents who had experienced a delay of more than 7 working days; incl. 2 missing responses



Of the 34 respondents in the survey who had experienced a delay of more than seven days for routine IV antibiotics at some point in the last 12 months, the majority (n=28; 82.4%) said that a 'lack of suitable beds' had caused the delays to their scheduled admission date(s). Three others (8.8%) said that the delay had been due to the family's own choice.



65.2% of respondents had always started urgent IV antibiotics within 24 hours.

73.6% of respondents had never experienced a significant delay (>7 days) for an admission for planned/routine IV antibiotics.

Home IV antibiotic therapy

While IV antibiotics are usually started in hospital, 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.

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.2: Service description/care pathway (All Services): As a minimum, the model of care must be governed by assurances of standards of care, access with care at home or close to home (where appropriate), and consistency and equity of access including the provision of home antibiotic services.

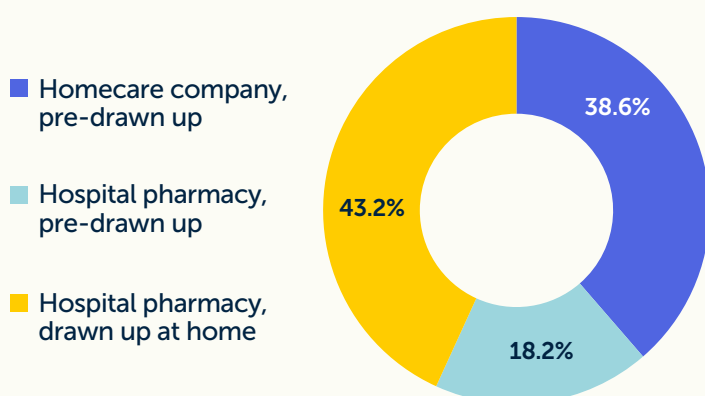
Section 3.2: Service description/care pathway (Homecare): Patients undertaking home IV antibiotic therapy will have a formal assessment of suitability. This will include formal training and an assessment of competency of the patient and their carers in administering the IVs as well as the suitability of the home environment. There will also be planned review and assessment by the prescribing physician to ensure efficacy of each course of home IV antibiotics.

Of 157 survey respondents who said they had had IV antibiotic therapy in the last 12 months, 44 (28.0%) confirmed that this had included home IVs. These respondents were asked to share information on how their home IVs had been delivered, as well as their experience with home IVs.

Survey question: In the last 12 months, have you/your child had home IVs, and if so, how were these delivered?

Figure 27: Access arrangements for home IV antibiotics

Note: Based on n=44 respondents who received home IV antibiotics; excl. 110 'not applicable' (did not have home IVs) and 3 missing



Most respondents who had received home IVs said these were either accessed from the hospital pharmacy but still required drawing up at home (n=19, 43.2%) or were delivered in pre-made-up form by a homecare company (n=17, 38.6%). Eight respondents (18.2%) reported receiving pre-made-up IVs from their hospital pharmacy.

Survey question: What was your/your child's experience of home IVs?

The survey then asked respondents to describe their experiences with home IVs in the last year. An analysis of 39 free text comments revealed that experiences with home IVs were overwhelmingly positive. Respondents said their experiences had been 'good', 'great', 'excellent' or 'efficient' and that they had felt supported by their CF team.

"We had our first course of home IVs and it was easier/less stressful than expected. The team trained me how to administer the drugs and timings, so I felt confident to do it at home when we were discharged."

"I was happy with the training provided and I felt confident doing the home IVs."

"We have few problems, if anything we are not sure of, we just ring CF team who help us with the best course of action."

Many respondents specifically mentioned that they felt home IVs were preferable to a prolonged hospital stay. Some provided reasons for this, including access to home comforts and the ability to keep up routines, although some parents noted that it put pressure on them as administration of home IVs became their responsibility.

"Much better than being an inpatient. Life more normal at home with siblings and TV, no beeping, and food [child] likes."

"Much better, as regular family routines can continue. Also can continue school, seeing friends, sleep in own bed. A bit tiring for me after 2 weeks."

"Hard work as a single parent, but valuable option to have available."

Some parents also reported issues with managing home IVs with regard to obtaining or storing the necessary products.

"Good [experience], once delivered - initially not ordered by hospital pharmacy and then struggled to get EpiPen. Difficult to take delivery too, as in hospital!"

"All positive - it seems necessary to order in one week blocks, so have to stay in for full 1st week even if not otherwise needed."

"Home IVs are much better, only downside is medication needs picking up every few days due to shelf life and lack of fridge space due to storing them."

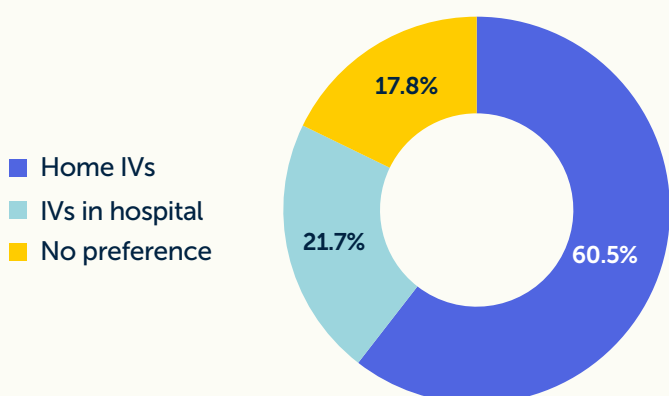
Future IV preferences

Given experiences with home IVs can vary, the survey asked children with CF and their parents 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/your child prefer and why?

Figure 28: Future preferences for location of IVs

Note: Based on n=152 respondents who received IV antibiotics in the last 12 months; excl. 5 missing



Around 3 of 5 respondents (60.5%) preferred home IVs, with 1 of 5 (21.7%) recording a preference for hospital IVs and 17.8% stating that they had 'no preference'. In the 2019/20 survey, 4 of 5 respondents (79.1%) had expressed a preference for home IVs, which means there was a reduction in the proportion preferring home IVs. This corresponded mostly with an increase in the proportion expressing 'no preference', which rose from 4.9% in 2019/20 to 17.8% in 2022/23.

Seventy-nine respondents gave further details as to their preference. Reasons provided by those with a preference for home IVs often referenced creature comforts, less disruption to routines, and the ability to look after other children.

"Staying at the hospital isn't great for maintaining routine and general wellbeing."

"Staying in hospital is so disruptive and the constant intervention means my [child] doesn't sleep properly, which has to be an important aspect of recovery."

"No worry if cross contamination in hospital, food readily available, no expense for parking/buying food, fits around school and work much better."

"I have 3 [children]. Would be easier for home IVs, as older kid needs me just as much as younger two."

Other respondents also cited avoidance of travel as a reason for a home IV preference.

"As we live far away from the hospital, it would be more efficient for us to complete them at home."

"We live 1 hour from hospital, so [it] is really draining on myself and my husband rotating, so someone is always at hospital with our [child]. We both work full time [...] so much less stressful doing home IVs."

In contrast, those who preferred hospital settings mentioned the reassurance they gained from knowing that health professionals were administering the IVs and reduced pressure and disruption for them as parents.

“We feel more secure under the supervision of the doctors.”

“Because less stress on parents as they’re supervised 24/7 so parents can go to work.”

“So I know everything is done correctly as my [child] has a port fitted I would be worried. I prefer being in hospital.”

Some respondents with a hospital preference noted that they may change their view as their child gets older.

“Because my child is only young but when older, it would be something I would like to learn for home myself.”

“At [child’s current] age in hospital, but as [child] gets older possibly at home.”

Given that many respondents expressed a preference for home IVs, CF teams should endeavour to allow families to administer IV antibiotics at home where this is appropriate and where adequate training and support can be provided. However, some children and parents still prefer to have IVs in the hospital; therefore, family preference should be taken into account when making decisions about where IV antibiotics will be administered.



60.5% of respondents said they preferred home IVs to hospital IVs.

Section 8

Care at home and in the community

Airway clearance at home

Many families affected by CF have a variety of airway clearance equipment at home to help manage cystic fibrosis.

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.1: Aims and objectives of service (Equipment): Individual patients will have access to a range of clinically appropriate airway clearance devices.

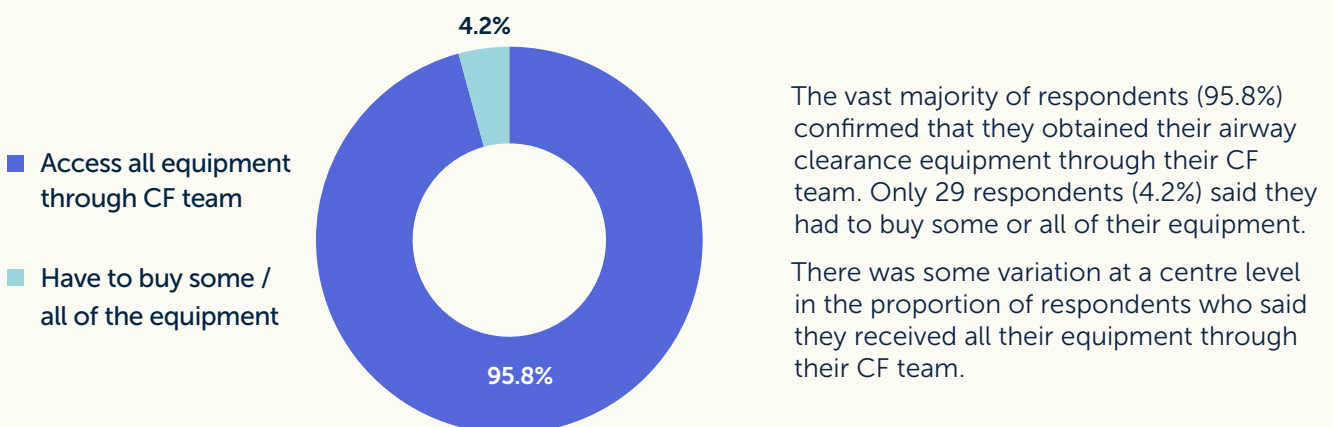
There will be a comprehensive nebuliser service, which aims to provide devices that deliver drugs in a fast and efficient manner. The service will also be able to provide a range of mechanical devices required to provide intermittent positive pressure breathing and non-invasive ventilation where needed.

The 2022/23 survey explored access to airway clearance equipment, as well as types of equipment in use. Of 828 survey respondents, 693 (83.7%) confirmed that they used airway clearance equipment at home.

Survey question: Were you/your child able to access all of the airway clearance and nebuliser equipment that you need and what type of equipment do you/your child use?

Figure 29: Access to airway clearance equipment

Note: Based on n=685 respondents; excl. 8 missing



Centre-level insight: Proportion of respondents who received their airway clearance equipment through their CF team

Centres with fewer than 10 respondents to this question were excluded (8 centres totalling n=47 responses)

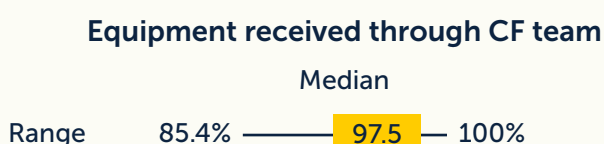
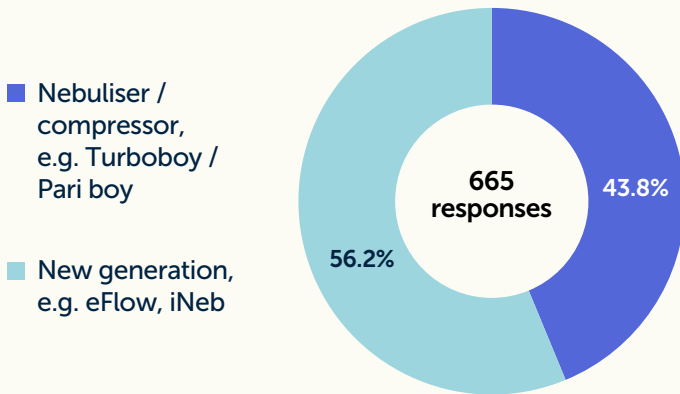


Figure 30: Types of airway clearance equipment

Note: Based on 665 responses provided by n=593 respondents, as some respondents used both types of equipment (more than one answer allowed); excl. 100 who skipped this question



There was a relatively even split in terms of the types of equipment in use, with 219 respondents noting that they used nebulisers/compressors, such as Turboboy and Pari boy, and 302 saying that they used new generation devices, such as eFlow and iNeb. A further 72 respondents confirmed that they used both types of equipment.

Apart from airway clearance equipment, families may have access to other treatments to help manage CF at home, including specialised medicines such as modulators and antibiotics. The 2022/23 survey enquired about respondents’ experiences with such medications, including delivery arrangements.

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

Of 828 respondents, 441 (53.3%) provided a response to this question. Overall feedback on specialised medications at home was positive, with survey respondents describing their experiences as ‘good’, ‘great’, ‘excellent’, and ‘brilliant’.

“Excellent, prompt delivery and if we were short, this was quickly addressed.”

“Able to collect from hospital pharmacy at short notice for use at home, good service.”

“Excellent service. Always delivered with a couple of weeks to spare and always in the delivery window. Very polite and pleasant team.”

“Modulators get delivered to the house and always have good correspondence from the company delivering them.”

However, other respondents reported issues with delivery arrangements, including specific concerns about deliveries managed by private healthcare companies. Many of these respondents found it difficult to ensure they were home to receive the medications and/or shared concerns around running low on occasion and having to chase deliveries.

“Hard to get medication. Using healthcare at home, have to chase, nearly run out a few times. Have to be home to receive delivery.”

“Generally good, although the private company using NHS funds, Sciensus, missed a delivery appointment and we nearly ran out of Kalydeco; we were down to our final sachet. This facility must be in-house rather than sub-contracted.”

“My [child] takes Kaftrio. It is hard work getting these, as they’re prescribed through Lloyds pharmacy homecare and only a one-month supply is given at a time. Having to rely on them calling you within enough time of the medication running out can cause anxiety, as I am not in control of it. If I were able to get a repeat prescription myself or get it directly from my CF team, this would be better.”

Some of those who had no home delivery arrangements in place also reported problems or concerns collecting medications or equipment replacements from hospital or local pharmacies.

“Brilliant service, but a pain I have to collect from hospital pharmacy when we don’t live near the hospital.”

“Long waits at hospital pharmacy, which is not great when waiting with a CF patient because of germs. Times to deliver to local Boots pharmacy can be too long.”

“We should be given spare parts to nebulisers and pep mask. Every time it breaks, we have to go to [hospital] to get another part - very frustrating.”

These responses indicate that, despite many positive experiences with accessing specialised medications for use at home, there is some variation in how these are accessed and the satisfaction with these arrangements. Many respondents confirmed their home deliveries were working well for them, but there were also several respondents who reported issues with requesting or having to chase repeat deliveries, or with receiving medications from homecare companies, including some missed deliveries. Some also noted that such companies were difficult to contact. On the other hand, those collecting medications from hospital or community pharmacies occasionally also reported issues, including long wait times and the need to travel to collect items.

Community care

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.

Cystic Fibrosis Service Specification - Children (NHS England):

Section 3.2: Service description/care pathway (Specialist Care Responsibilities): Clearly defined links should be in place with community services and hospitals. Centres serving more rural areas should be able to demonstrate an ability to provide either network care or outreach care for children where appropriate.

Section 3.2: Service description/care pathway (Homecare): Many patients and families require regular and consistent outreach from community services to support them.

This will include:

- support in the community by the specialist CF multi-disciplinary team,
- open access to nursing care in the community. This may be a CF nurse specialist from the CF service, or local Community nurses including children’s nurses who have specific training, experience and supervision in CF

The patient experience survey explored if children with CF and their parents had had access to community support and care in their homes.



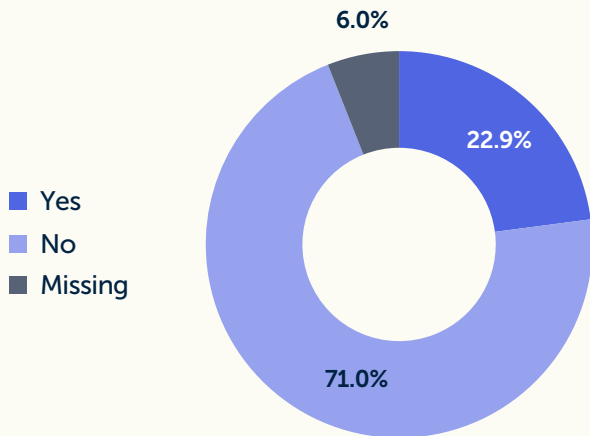
83.7% of respondents confirmed they used airway clearance equipment at home, with most receiving this through their CF team.

22.9% of respondents confirmed they had access to care at home and/or in the community.

Survey question: In the last 12 months, do you/your child have access to any community support/care delivered in your home such as physio, port flushes etc?

Figure 31: Access to community support and care at home

Note: All survey respondents included (n=828), incl. 50 who skipped this question (missing)



Just under a quarter of survey respondents (22.9%) confirmed they had had access to care at home in the last year, either through their specialist CF team or community staff. There may be some respondents among the other two groups who did not access this type of support but could have had it available if needed.

The proportion of respondents reporting access to this type of service varied by centre. This does not necessarily indicate such services were not available, as not everyone would have needed them and because not all individuals under a centre’s care responded to the survey.

Centre-level insight: Proportion of respondents who confirmed that they had access to care at home/community care in the last year

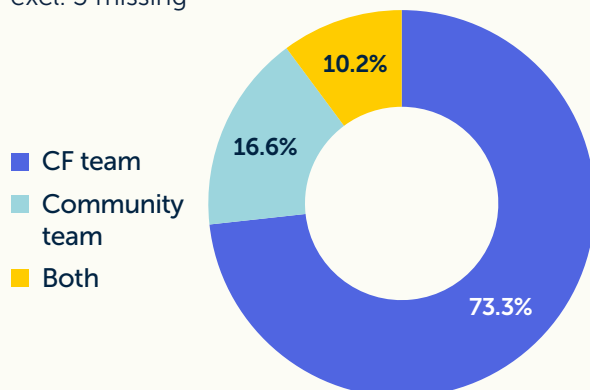
Centres with fewer than 10 respondents were excluded (7 centres totalling n=37 responses)



Survey question: If you/your child have access to community support/care delivered at your home, who provides it?

Figure 32: Community care or support provider

Note: Based on 187 respondents who reported having access to care/support at home or in the community, excl. 3 missing



Most respondents confirmed that care in the community was provided through their specialist CF team (73.3%), with 16.6% saying they received care through a community team and 10.2% reporting that community support was delivered by both.

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

To better understand the kind of services offered in the community, children with CF and their parents were asked to give details about the home care services they could access. From an analysis of free text comments (n=71), the most common services provided at home were port flushes, physio visits, blood tests and cough swabs.

“Port flush, access port prior to IVs at home or as inpatient, take bloods, manage button feed.”

“The community nursing team provide support to flush port. They also provide respite for a few hours and any other support I may need.”

“Physio came out a few times just to support us in transitioning to the next step in my [child’s] physio regime.”

Respondents were also asked to share any further comments or concerns about care at home or community care they had received.

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

Forty-five respondents shared further comments, with many praising the services they accessed in the last 12 months.

“CF nurses and physios always offer to come out if we have issues, even offer to visit the school to explain or help with physio. We really appreciate it.”

“My nurse, she is amazing. Everything we need, salt test, sorting meds, lung function, delivering equipment, blood test finger prick – you name it, she will do it.”

“Physio home visits have been good and local CF team taking bloods have been amazing.”

However, a few respondents expressed concerns about the services they could access or reported having limited access to care at home or in the community.

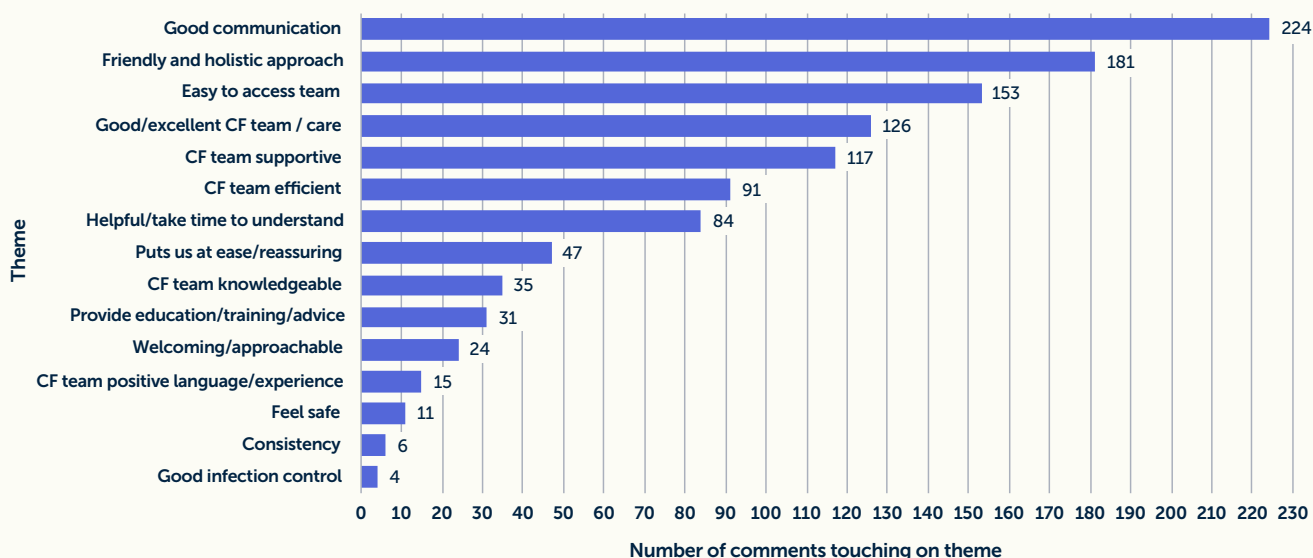
“We are very unhappy with [local CF team], so we travel [to main CF centre] to have [child’s] port flushed, and we haven’t seen the local physio for many months.”

“Community team busy - visits cancelled and rearranged.”

“Little support from local Child’s Health. Only for occasional needles, syringes and nebuliser parts.”

Figure 34: Thematic analysis of comments on best aspects of CF care

Note: Based on n=651 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 651



By far, the aspect of care most often mentioned in positive comments was ‘communication’. This is unsurprising, given that communication plays an important role before, during and after appointments, as well as during emergencies. Many survey respondents felt that their CF team were easy to contact, approachable and responsive when they had questions or concerns or needed advice. This also linked in with the theme of accessibility.

“Our home clinic and specialist centre are excellent at communication and are very approachable, no matter how silly our questions feel! An excellent team who are very supportive.”

“Access to the team via the CF nurse was excellent. The CF nurse is outstanding in communication - dealing with concerns. CF consultant also excellent in dealing with concerns and gets back quickly.”

“They are easy to contact for advice. Always very helpful and friendly. Give brilliant care, to my [child]. Never had any issues or complaints.”

Another aspect of communication often praised by survey respondents was the CF staff’s communication style, particularly when speaking to children with CF. Many respondents felt that team members communicated in ways that allowed smaller children to understand and were friendly, caring and empathetic.

“All staff have a lovely manner with my child. They talk to [them] directly and explain clearly what [child] needs to know. Support for the whole family - on hand when needed.”

“Clear and direct approach to discussing [child’s] needs with an empathetic approach and doing their best to accommodate [child’s] other disabilities.”

“Listen and communicate. Talk through options openly. They talk directly to my [child], not just to me. [...] They give very thorough explanations.”

Several respondents also mentioned that they felt listened to and that staff took time to understand them as a family, which are critical aspects of good communication, building trust, and delivering person-centred care.

"Whilst doing all the expected CF stuff, they take time to talk about family life etc. They genuinely care about my child and [their] wellbeing and are able to see past the CF. We feel listened to, there is no judgement, and I wholeheartedly feel that our CF journey would be a lot worse without them as individuals in it!"

"The CF team are amazing, we feel so lucky our little [child] has this incredible hospital [...]. The team are so supportive, listen to your concerns and always air on the side of caution (which as a parent is so comforting in the scary world of CF)."

"Compassionate, knowledgeable, they take time to listen to parental concerns (which in my opinion is paramount to do), they think outside the box for ways of managing my child, they work with me in thinking of ways to make life a bit easier [...], they humour my tangents."

Some respondents also valued timely and honest communication from their CF team about the results of tests and investigations.

"Keeps us updated with everything including tests and health."

"The best thing is that I can always ask our CF nurse, who answers all of my concerns, she lets me know if all the tests are good."

"They know my child well and always treat us in a friendly professional way. The team use positive language but are not shy about raising difficult topics e.g. where results are declining/showing cause for concern."

Many respondents also praised their CF team's approach to care more generally, describing teams as 'excellent', 'fantastic' or 'amazing' and as taking a caring and holistic approach to care delivery.

"Excellent communication, holistic care, feel very well supported. Amazing team!"

"Meets all needs holistically and will always see us promptly if required. Seamless care always."

"The CF team and play team are absolutely fantastic - friendly and very very caring. We've known them all for years and the relationship is very strong. My [child's] experience of hospital is always positive, which is down to the team."

"Support, communication, knowledge, reassurance, being there when needed. [CF service] are excellent. We feel they genuinely care and move mountains to look after their patients."

Respondents also felt their teams were 'supportive', 'reassuring' and 'compassionate', putting children with CF and parents at ease and helping them more easily deal with difficult situations and challenges.

"Treating my child as an individual and tailoring [their] care. My child is always reassured and supported during [their] treatments and at times of anxiety/worry."

"They always give me the reassurance that I'm never being a nuisance when I contact the team. They always support me psychologically with my worries and reassure me that I'm doing everything I can possibly do [...]."

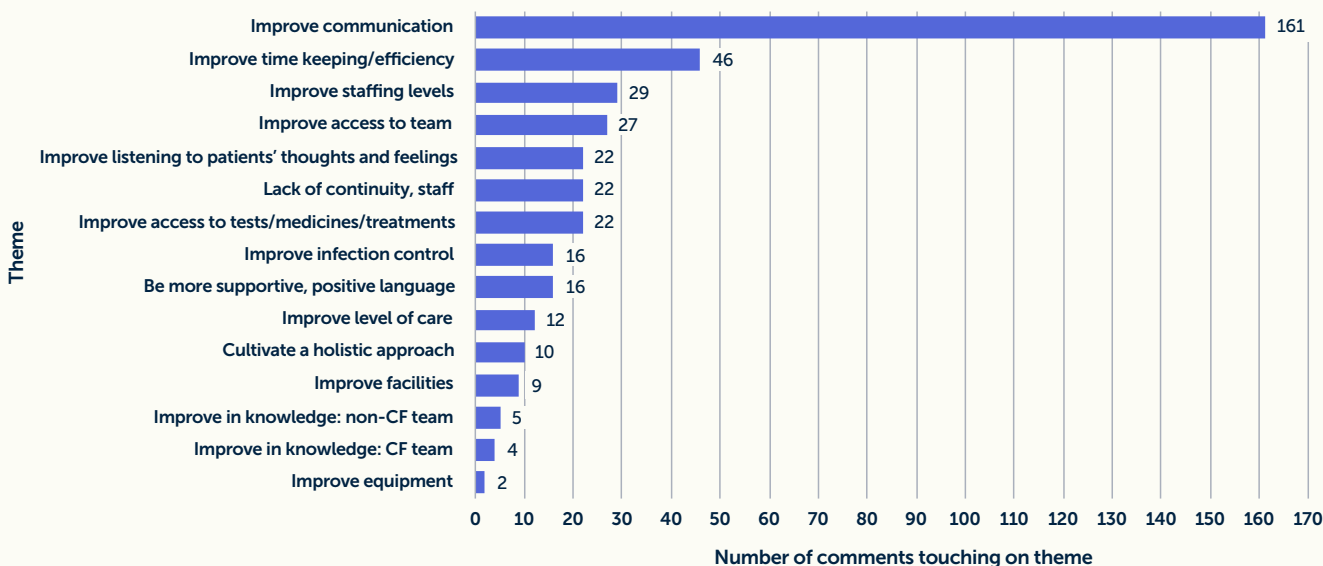
"They are accessible, friendly, helpful and professional. We never wait for them to deal with our queries. They show compassion. They are experts and great with young children as well as parents."

Several respondents also specifically fed back that their CF team was knowledgeable and provided useful advice and support to them when needed.

"Makes us feel at ease. Explains everything in easy to understand detail. Easy to reach and responds quickly to any concerns. Provides quality care for our child."

Figure 36: Thematic analysis of comments on areas to improve

Note: Based on n=282 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 282



Interestingly, the most common areas for improvement mentioned by respondents in the survey were linked to the theme of 'communication'. This indicates that there is variation in experiences with communication, as this was also the main theme identified in positive comments (see previous chapter). Improvement suggestions under the communication theme could be further broken down into various sub-categories, such as the ability to contact the team when needed, responsiveness, listening to parents and children, communication about appointments and test results, as well as communication between CF team members.

Responsiveness was a key area for improvement highlighted in the feedback. While this was also an area of praise, not all survey respondents had the same experiences. Some said they struggled to get through to their CF teams and made suggestions, such as having clear contact details, to help resolve this issue.

"Be available during the hours they claim to be available. Sometimes there is a delayed response."

"Make it clearer who to contact about what and when and how."

"Designated nurses for contact, phone number given – at least 2 for when 1 off – or have an answerphone stating who to contact. Currently left not knowing who can ask for help."

While some respondents had confirmed that they felt listened to by their CF teams within the positive feedback, others noted that there was room for improvement in terms of staff listening to families, making shared decisions, and being transparent.

"Listen. Make treatments more patient centred, one size does not fit all."

"A particular nurse speaks over us when we are talking."

"Senior/lead consultant doesn't always discuss treatments and plans for treatment/care, which is a curveball to what we experience with rest of team. Need to be more transparent and open."

Communication about appointments was another area of concern, with several respondents expressing a preference for email communications over letters.

"When we receive letters with a link to join an online consultation these links always have an error in them, so we can't join the meeting immediately. We also receive appointment letters very far in advance, with no follow-up reminders. Moving to an email system would work better, as it would be easier to refer back to appointment emails rather than trying to find the paper copy months later."

"Greater use of email for communication, e.g. send appointment letters as attachments to email messages rather than hard copies in the post."

Feedback from appointments and annual reviews, as well as timely communication of test results, including when all tests were fine, were also highlighted by many respondents as areas for improvement linked to the communication theme.

"Written notes from clinic take many months to be issued."

"Annual review in February, written information received September despite two requests at clinic visits."

"Maybe have an online system where parents can check results of cough swabs/blood results etc by ourselves, rather than having to chase team."

"I think CF nurse could phone with cough swab results even if ok, as I have had to phone for results [...]. Improve communication, saves me worrying."

Others noted that they would like to be kept more up-to-date with information about the CF team, new medications and treatments, as well as research.

"Inform when staff change/leave on Facebook page, with contact details for new staff, days worked / hours etc."

"More wider communications on CF news and department news."

"We always wait to be kept informed on new trials the team are involved in and what new opportunities are coming down the line e.g. new medications. There's very little updates or information on this."

Another area of communication that was touched upon in suggestions for improvements was internal communication between CF team members.

"Communication between team members could be a bit better."

"Communication better with each other (including pharmacy) and with parents. Rely less on parents' records and more on their own records."

"Consultants could be more consistent, so I don't have to continuously recap at each appointment and clarify what other consultants have said."

The efficiency of and wait times for clinic appointments was another area mentioned within several improvement suggestions.

"Waiting times in between patients could be reduced. Some clinics are quite lengthy due to waiting for the next clinician."

"Sometimes clinics can be long, as we have to wait for each member of the team. There is also a lot of repetition as each member of the team asks similar questions."

"Timing in clinic, wait a very long time for doctor and individual session with other HCPs."

Staffing levels and access to the CF team were two other themes commonly found within suggestions for improvements made by survey respondents. Several of these comments aligned with the gaps in access to CF psychologists, social workers, and pharmacists already highlighted in other parts of the survey.

"Ensure we have access to the full MDT at appointments."

"The psychological support on offer to both parents and children could be significantly strengthened."

"No psychologist [has] been available when needed."

"The social worker issue needs resolving. Since [name] left, there's barely any involvement. People seem to come and go. They'll pop up one day and introduce themselves, then disappear, only for someone else to pop up. I have no idea who the current one is, let alone how to get in contact. The lack of pharmacist - in over a decade, I've only ever seen one as an inpatient."

"We need a CF gastroenterologist who sits within the team. Paid privately for a GI appointment for my [child] recently."

Some respondents highlighted improvements that could be made to enhance infection control and prevention.

"Carry out height and weight tests in the private room rather than the general room. Cut down waiting times to prevent having to wait in a waiting room. However, these are always segregated, so not a major issue."

"Better segregation when arriving at outpatients on clinic days."

A few respondents suggested that improvements in knowledge around cystic fibrosis for non-CF staff at the hospital were needed to enhance understanding of the needs of children with CF. Conversely, others suggested that CF staff could improve their understanding of non-CF topics families wanted to discuss, such as fertility.

"Provide basic training of CF to all staff making and handling calls to avoid insensitive comments/questions."

"I feel they could better assist us in fertility to ensure our subsequent children do not have CF. The team is not very informed how to access fertility (specialised in CF) here and we do not know where to find the information."

Finally, some respondents also commented on other aspects of CF care, for example, expressing concerns about facilities such as inpatient wards and parking at hospitals, which may be difficult for CF teams to improve directly.

"Inpatient care is isolating and boring, poor Wi-Fi, poor signal, no play specialists, food on weekends hard to get hold of for patients, drugs given at wrong times that keep you up all night for next dose, hourly IVs on first nights is awful, boring grey rooms [...] and other staff don't understand CF, so can cause cross infection risk. Parking is bad."

"Parking at hospital a nightmare - so it's more hospital issue than CF dept issue."

Recommendations and next steps

Recommendations

Overwhelmingly, children with CF and their parents who responded to the survey perceived that they were well looked after by their CF teams. However, similar to the 2019/20 survey, insights from this survey highlight some variation in experiences with regard to the availability of certain specialists, approaches to communication, processes at annual review, 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.

Several general recommendations can be made from the patient experience insights presented in this report. These recommendations are generalised and based on feedback from children with CF and their parents who attend different CF centres across the UK. Many of the recommendations below align with the Service Specification and Standards of Care, re-emphasising the importance of implementing such guidelines consistently.

Recommendations for CF services from patients' experiences and feedback:

Access to CF team members and support:

- Ensure all families 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 children with CF and parents are aware of how they can access support from clinical psychologists and social workers, should they need it.⁹
- 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, e.g. Cystic Fibrosis Trust.¹⁰
- Ensure all families 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.
- Endeavour to offer continuity of care, ideally with a named consultant or nurse contact for each patient and clear cover arrangements for when the member of staff is on leave or unavailable.

Contacting and seeing the CF team:

- 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 and notifying families of any changes in CF team contact details in a timely way.
- Continue to offer face-to-face as well as remote appointment options, ensuring that all children with CF are seen in person at least once per year.
- Elicit families' preferred way to hear from and see the team and involve them in decisions about how they are seen and communicated with, if possible.

9 Cystic Fibrosis Trust is interested to hear from services that are struggling to secure staff or resourcing for psycho-social support (QI@cysticfibrosis.org.uk)

10 www.cysticfibrosis.org.uk/the-work-we-do/information-resources/publications

- Where remote appointments are used, CF teams should have the right equipment and support to ensure that connectivity is adequate to have an effective conversation with families (e.g. headsets and quality cameras for video calls, good Wi-Fi reception, IT support when required).
- Consider using emails rather than letters for appointments and send out reminders to ensure families are aware of when they are due to be seen and have the necessary details, e.g. login links to virtual calls.

Communication:

- Ensure effective communication among members of the CF team and a shared understanding of each family's needs.
- Ensure staff changes in the CF team are communicated to families in a timely way, for example via email or social media (e.g. Facebook group), and any changes in contact details for key staff are relayed to families if required.
- Endeavour to have processes in place to highlight developments in CF care and treatments, e.g. new medications and clinical trials or research opportunities to families.

Annual reviews:

- Endeavour to provide a full review by all specialties in the CF team at annual review, including pharmacy, psychology and social work.
- Ensure families have a clear agenda of the day and know what to expect.
- Ensure there are processes in place to share test results and written feedback from annual reviews with families in a timely manner.
- Ensure all required tests are performed for annual review. Where certain tests or assessments are not necessary for a child's annual review, provide an explanation to families as to why these are not needed.
- Schedule and run annual review clinics in a way that minimises wait times for children with CF and their parents, including waits at X-ray and pharmacy departments and for onward referrals.

Hospital care:

- Ensure infection control protocols are up to date and followed at all times.
- Ensure all staff, including at reception, are aware of CF patient segregation rules, and wherever possible avoid any waits in waiting rooms for children with CF, in line with best practice; if any wait in a waiting room (e.g. in pharmacy) is necessary, call ahead to check that there are no other CF patients present.
- Ensure non-CF staff in the hospital who come into contact with or care for children with CF, e.g. on wards, know about the risks of cross-infection and are aware of infection control and segregation protocols.
- Consider implementing a system to help children with CF and parents identify other families with CF when they are in the hospital; for example, this could be achieved through offering brightly coloured wristbands/bracelets.
- Endeavour to measure children's lung function as well as their 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.

- Where bathrooms are shared on other wards, consider protocols to ensure no other children with CF access the same facilities and endeavour to reassure children and parents that this is being checked regularly.

Care at home:

- Endeavour to support children with CF and their families to receive services in the community, including, where appropriate, remote monitoring (such as home spirometry).
- Ensure there is equity of access to home care and medications at home, including new generation nebulisers that deliver drugs faster and more efficiently.
- Where specialised medications are delivered by external companies, consider regular reviews of families' experiences of these services and ensure there are processes in place to support families with delivery issues.
- Endeavour to offer home IVs where possible and appropriate, with full training and ongoing support for parents, ensuring they feel confident to administer home IVs and know who to contact if there are any issues, including outside of normal working hours.

Many CF centres will already be working to meet most or all the above recommendations, and the survey findings show that experiences of CF care are overwhelmingly positive. However, guided by the insights from feedback given by children with CF and parents under their care, services should consider targeted quality improvement projects to address any outstanding challenges that may have been highlighted.

CF centre-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 within their local survey responses. All CF centres that took part in the PREMs work have received a bespoke data summary with the feedback from children with CF and parents 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 the PREMs 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 within a centre, a service could, for example:

- Undertake a QI project to ensure all families under its care are aware of contact details for out of hours emergencies.
- Consider how the team provides advice on benefits, emotional wellbeing, and education, and identify opportunities to make children and parents aware of the support it can offer in these areas.
- Develop a business case to apply for funding for a dedicated CF social worker or clinical psychologist role to provide support to children with CF and their families.
- Map out its process for relaying test results to identify opportunities to communicate these to families sooner, e.g. by implementing an electronic system such as an app that parents can access.

- Review its process for annual review clinics in hospital to explore opportunities to reduce waiting times for children with CF attending their review.
- Implement a training session delivered by CF team members to non-CF ward staff that may care for children with CF to ensure they are fully aware of infection control protocols.
- Assess its community and homecare offer and seek opportunities to strengthen this.

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 paediatric 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 children and parents with requests for feedback via surveys. The Quality Improvement team at Cystic Fibrosis Trust will re-run the survey again in 2025/26 and publish an updated report on experiences of paediatric CF care in the autumn of 2026.

In the meantime, we welcome any feedback on this report, as we are keen to continuously improve how we feed back 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.

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 e.g. segregation, cleaning, 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 made up of each discipline i.e. nurse, physio, social worker, 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	Children 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

© Cystic Fibrosis Trust 2023. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 2nd Floor, One Aldgate, London EC3N 1RE.

Uniting for a life *unlimited*