

UK Patient Reported Experience Measures survey (PREMs)

Adult Services Report

Data collection period

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UK Patient Reported Experience Measures survey (PREMs)

Paediatric Report

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Summary and key data

Participation and feedback

We would like to thank all people with CF, and clinical teams, for promoting and completing the PREM survey. Overall, 842 responses were received from people with cystic fibrosis attending 26 of 28 UK Adult CF centres, representing approximately 14% of the CF population in adult care in the UK. All CF centres that took part received tailored feedback.

Key UK-wide data insights

Access to and support from MDT



92% of respondents rated all members of MDT they had seen since mid-March 2020 as excellent or good.

11% of respondents said they could not see a social worker since mid-March 2020, as one was not available, and for psychologists this was 3.7%.

99% of respondents knew how to contact their CF team during working hours, falling to 74% out of hours.

86% of respondents rated support received from their CF team at key times as excellent or good.

91% of respondents had had a telephone consultation since mid-March 2020, with 93% rating their experience of such consultations as excellent or good.

Infection Control



70% of respondents felt infection measures were sufficient at their CF centre or clinic, but...

16.4% waited in outpatient waiting rooms

24.9% had their height and weight measured in the same room as other patients

14.2% were admitted to a non-CF ward, as a bed on the CF ward was not available

6.5% shared a room, bay or toilet, potentially with other CF patients

Annual Reviews



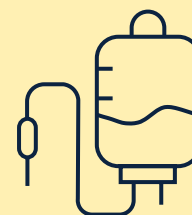
60% of respondents who had had an annual review since mid-March 2020 had this in a remote format, e.g. telephone or video call.

87% of respondents were satisfied with the time taken to communicate test results.

34% of respondents had not received written feedback from their annual review.

43% of respondents said they would prefer to be offered a combination of hospital and virtual appointments in future, while 23% preferred virtual and 20% preferred hospital appointments.

IV antibiotics



60% of respondents had experienced a delay in starting emergency IV antibiotics.

30% of respondents had experienced a delay in an admission for planned IV antibiotics.

68% of respondents said they prefer home IVs to hospital IVs.

Care at home and in the community



33.5% of respondents reported access to community care.

24.5% of respondents said they had received home IVs since mid-March 2020, many reporting positive experiences with this approach.

Next steps

All CF centres that took part in the PREMs work have been provided with tailored feedback to help them highlight existing good practice and identify local priority areas for quality improvement.

There are also several broader recommendations that can be made from the experiences and feedback shared, which are detailed in the final section of this report. Common themes where further action may be needed include:

- Access to members of the CF team, particularly psychosocial support
- Communication, particularly when using virtual formats and sharing test results
- Care in hospital, particularly around managing infection control
- Care in the community, particularly ensuring high quality provision and equitable access

The Cystic Fibrosis Trust will re-run the Adult PREMs project in 2023 to understand how experiences of people with CF change over time.

Introduction

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

We hope this report will help CF centres and other stakeholders to better understand experiences of adult CF care during the first year of the COVID pandemic and to highlight best practice, understand what patients and their families value from their care, and identify areas for quality improvement. In the longer term, these findings will also provide important baseline information to help us understand how experiences change over time, for example, as restrictions brought in during the pandemic ease, as highly effective modulator therapies become widely available and as the digitisation of NHS services continues.

Thank you for reading

Becca, Jana, Sophie and Fiona (The Quality Improvement team)

About the survey

The PREMs questions were developed with input from the Cystic Fibrosis Trust's Clinical Advisory Group (CAG) as well as our Quality Improvement (QI) working group, which is made up of people with CF, family members and CF health professionals.

From December 2020 to March 2021, people with cystic fibrosis under the care of participating centres were invited to complete the first adult services PREMs. This asked them to reflect on the care they had received in the months since the COVID pandemic and first lockdown began in mid-March 2020. Other questions explored preferences for the future and asked for suggestions for improvements people with CF wanted to see, based on their experiences.

All centres that supported the project were provided with a tailored report summarising their local insights and feedback, thus allowing them to evidence good practice and identify potential areas for quality improvement. In 2023, the Adult PREMs project will be repeated to help explore how experiences of people with CF change over 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

The first Adult PREMs UK report shows overall survey findings based on 842 responses from people with CF cared for at 26 participating adult CF centres (of 28 centres in the UK). 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). The number of responses that were included in the analysis, and responses that were excluded, are provided for reference alongside each figure within this report. Where respondents had provided free text comments, these were analysed and grouped into themes. The report contains anonymised quotes from free text responses to illustrate findings, where relevant. It also summarises general written feedback and suggestions for improvements provided by respondents.

Throughout this document you will see references to quality standards, aims or objectives drawn from the adult Cystic Fibrosis Service Specification¹, as well as occasional reference to the Standards of Care². These specifications are important to clearly define the standards expected from organisations that provide specialised CF care. References to service specifications are also provided to facilitate understanding of where quality improvement efforts could focus. For further explanation, please go to our website where you will find full details: cysticfibrosis.org.uk/laysummaries

1 NHS England, 2018: www.england.nhs.uk/wp-content/uploads/2018/08/Cystic-fibrosis-adult.pdf

2 Cystic Fibrosis Trust, 2011: www.cysticfibrosis.org.uk/sites/default/files/2020-12/Cystic%20Fibrosis%20Trust%20Standards%20of%20care.pdf

Who completed the survey?

Between December 2020 and March 2021, 902 people started the survey. Before analysing the data, 60 instances where individuals had started page one of the survey but had not responded to any of the questions, beyond stating their gender and age, were excluded.

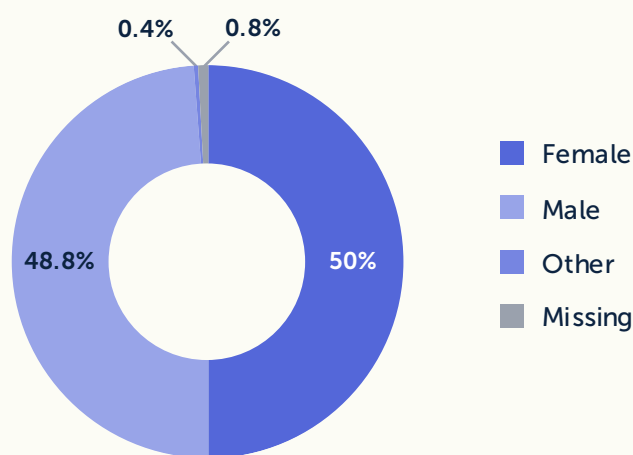
In total, 842 responses from people receiving care at 26 participating adult CF centres and some of their network clinics across the UK were included in the analysis. This represents insights from approximately 14% of the CF population in adult care in the UK³. An overview of the demographic characteristics of those who took part in the survey is provided below.

There were similar numbers of responses from women and men in our survey (50.0% and 48.8%, respectively), with 0.4% of respondents defining their gender as 'other'. For comparison, the CF Registry reported that 46.2% of the adult CF population in the UK were female and 53.8% were male in 2020⁵.

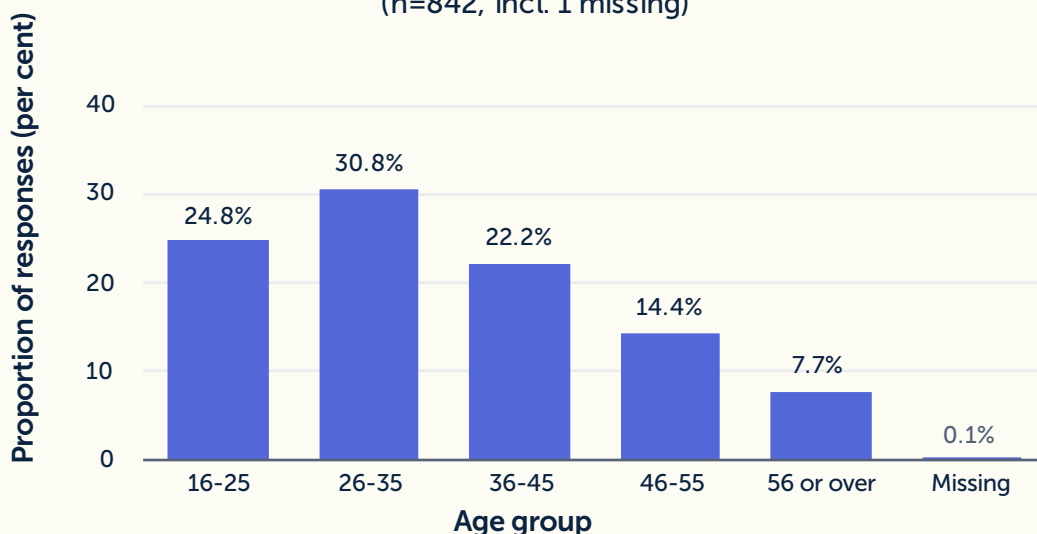
Most respondents were aged between 26 and 45 years (53.0%). Around a quarter of responses (24.8%) came from young adults aged 16-25, while just under a quarter of responses (22.1%) came from people aged over 45.

More than half of respondents (53.4%; n=450) defined their ethnicity as 'White British (English, Scottish, Welsh, Northern Irish)', with small numbers (n=36) from other backgrounds, including other white, Black, Asian and mixed backgrounds. 356 respondents (42.3%) chose not to provide ethnicity information.

Gender
(n=842, incl. 7 missing)



Age
(n=842, incl. 1 missing)



³ Cystic Fibrosis Trust 2020 Annual data report: <https://www.cysticfibrosis.org.uk/sites/default/files/2022-03/2020%20Annual%20data%20report%20-%20Version%203.pdf>

Section 1

Access

CF Multidisciplinary Team (MDT)

Adult Cystic Fibrosis Service Specification (NHS England):

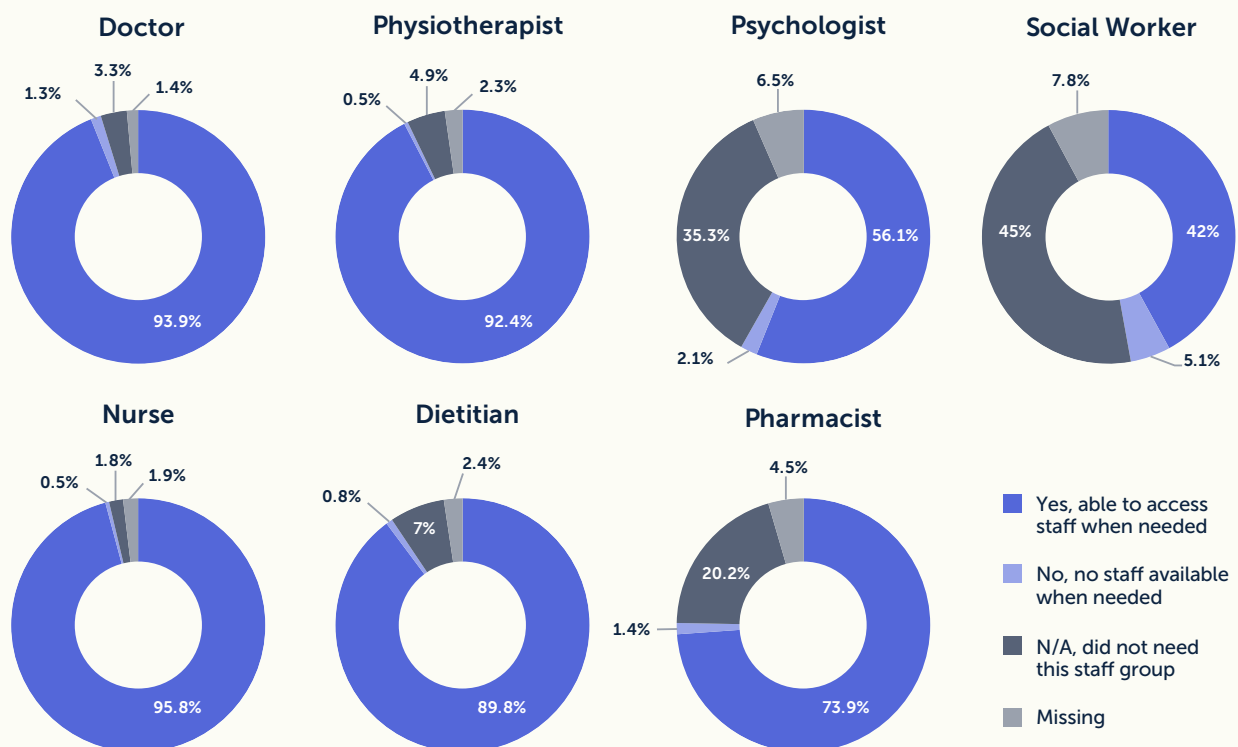
Section 3.1: Aims and objectives of service: Ensuring equity of access to services for the CF population

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 adults should have access to psychological support at annual review. [Domain threshold: $\geq 85\%$]

Question: Have you had access to each member of the CF multidisciplinary team (MDT) when you needed them, since mid-March 2020?

Figure 1: Access to members of the MDT since mid-March 2020 (n=842)



Most respondents confirmed that they had been able to access MDT members when they had needed to. There were differences in the proportions of respondents who had needed to access certain staff groups. Nearly all respondents said they had needed support from CF specialist doctors, nurses and physiotherapists at some point since mid-March 2020, but 20.2%, 35.3% and 45.0% of respondents said that they had not needed to access CF specialist pharmacists, psychologists and social workers, respectively.

More than 9 in 10 respondents (92.3%), who were able to access members of the MDT when they had needed them since mid-March 2020, rated support from staff they had seen as 'good' or 'excellent' (based on 4,580 responses across all staff groups from 824 individuals). However, there was variation by centre.

Proportion of respondents at each centre who rated support from any members of the MDT they had seen as either excellent or good

NB: Centres with fewer than 10 responses were excluded (4 centres; n=22 responses)

Median

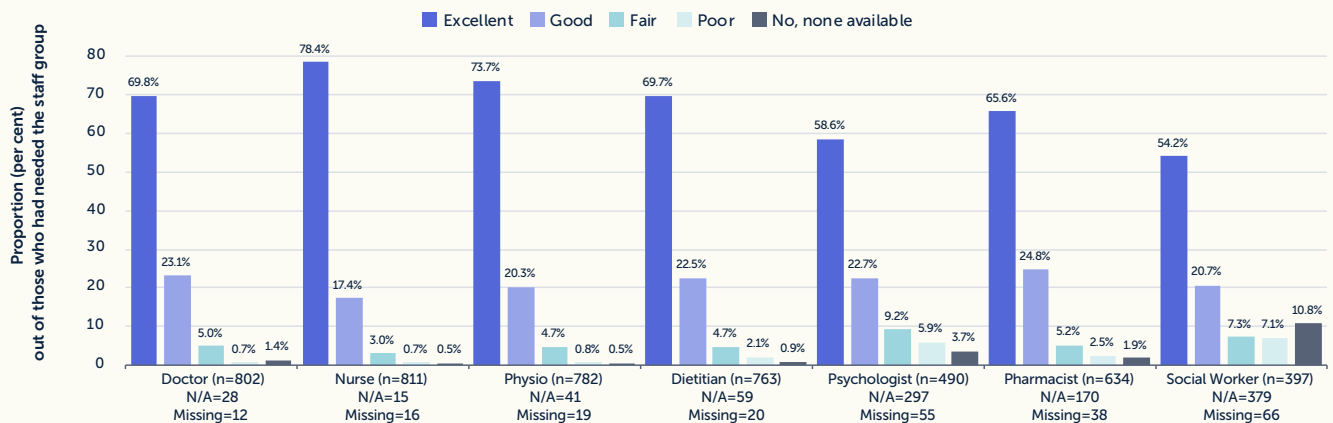
Range 82% — **92.1** — 98.6%

The proportion of staff rated as 'excellent' or 'good' also varied by staff group. And in some cases, respondents said that they had been unable to access support from certain MDT members when they had needed it, due to none being available.

Figure 2 shows proportions of responses and ratings for each staff group from those who said that they had needed to access the respective MDT member at some point since mid-March 2020. It excludes those who said they hadn't needed support and any missing responses.

Figure 2: Support from specialist CF staff when needed since mid-March 2020

NB: Based on data from 826 respondents (excludes 6 who had not needed support from any MDT members; 10 skipped question)



CF specialist staff group and number (n) of responses included in analysis for each group

Excluded responses: Not applicable (N/A – did not need support from staff group)

Excluded responses: Missing (did not respond to question for this staff group)

92% of respondents rated all members of MDT they had seen since mid-March 2020 as excellent or good.



11% of respondents said they could not see a social worker since mid-March 2020, as one was not available, and for psychologists this was 3.7%.

Of those who had needed support from members of the MDT, more than 9 in 10 respondents said they were able to access staff, and that those staff had been 'excellent' or 'good' for all staff groups, except psychologists and social workers. Those who had needed access to specialist CF doctors, nurses, physiotherapists and dietitians rated these groups particularly highly, with 92.9%, 95.8%, 94.0% and 92.3% 'good' or 'excellent' responses, respectively. However, satisfaction with access to and support from other staff groups was lower.

While fewer people overall said they had needed support from a social worker (397 of 842), responses from those who did, show that access to this staff group remains problematic for some. 10.8% of respondents who had needed a social worker reported being unable to see one, as no one was available, and 7.1% gave 'poor' responses for this staff group. In addition, 3.7% of respondents said they had been unable to access specialist psychologist support when needed, as none was available, and 5.9% gave 'poor' responses for this staff group. However, it should also be noted that social worker support was rated as 'good' or 'excellent' by 74.8% of those who had needed it, while specialist psychologist support was rated 'good' or 'excellent' by 81.2%, indicating that the majority of those seeking support from these MDT members still rate them highly when they are able to be seen. This was also reflected in free text comments left by some respondents.

"Great social worker who does everything she can to help me have my needs catered for."

"I have a really nice and supportive social worker."

"A really fantastic psychology service who has kept in touch via email and keeps reminding us of their availability if we need be."

Psychologist, pharmacist and social worker access levels displayed high levels of variation across centres and likely depend on the complexity of needs in the local population.

Proportion of respondents at each centre who saw a psychologist, pharmacist, or social worker in last 12 months

NB: n=820; Centres with fewer than 10 respondents were excluded (4 centres; n=22 respondents)



While these access figures are lower than for other staff groups, the figures for psychology consultation suggest higher engagement with psychology among people with CF, as Eurostat figures from 2014 on self-reported consultations⁴ placed the proportion of the general UK population accessing psychology support at just over 3.6%.

Some respondents also made suggestions of how services could improve access to psychosocial support.

"Offer appointments for psychology sessions and other support services later than 3pm."

"More access via email would be good."

⁴ EuroStat, 2020: Healthcare activities statistics - Consultations - Statistics Explained (europa.eu)

Contacting the CF team

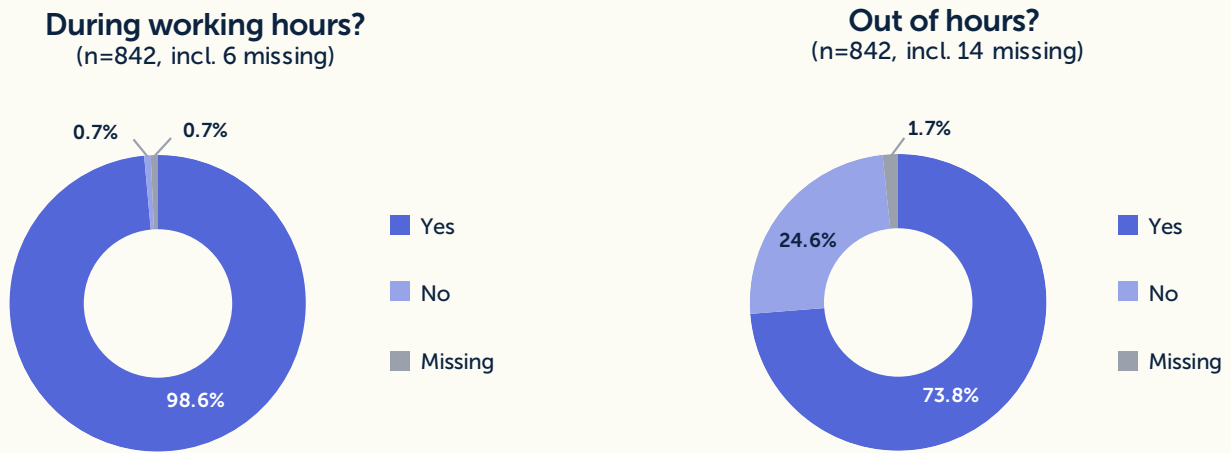
Adult Cystic Fibrosis Service Specification (NHS England):

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 Centre 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.

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

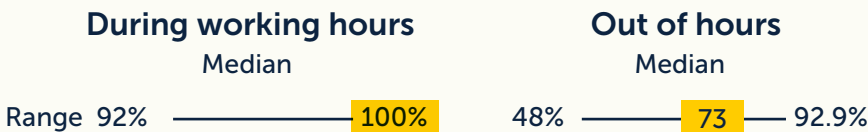
Figure 3: Awareness of who to contact



Awareness of who to contact was excellent during working hours, however nearly a quarter of respondents (24.6%) were unsure how to contact their CF team outside of their usual working hours. This varied by centre. Ten of 26 centres (38.5%) had a third or more of their respondents saying that they were not aware how to contact their CF team outside of working hours.

Proportion of respondents at each centre who said they know how to contact their CF team

NB: Centres with fewer than 10 responses were excluded (4 centres; n=22 respondents)



99% of respondents knew how to contact their CF team during working hours, falling to 74% out of hours.

Section 2

Experiences of care

Support at key times

Adult Cystic Fibrosis Service Specification (NHS England):

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

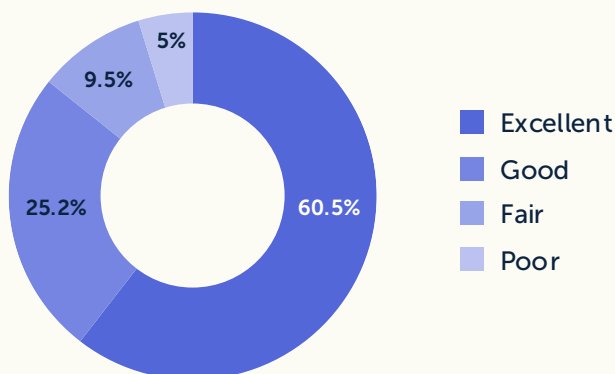
The service will deliver the aims by:

- making timely diagnosis with appropriate counselling and psychological support to the patient and their family,
- supporting the patient in helping them to manage their CF independently in order that they can aspire to a life less hindered by their condition and provide support to their families where appropriate.

Question: Please rate the support you have received from your CF MDT in these key areas since mid-March 2020. (List was provided)

Figure 4: Overall experience of support at key times

NB: Based on 3,206 ratings provided by 750 respondents across all key areas (excludes 20 who said none of the listed events applied to them ('not applicable'); 72 skipped question)



Overall, most respondents who had needed support at key times covered by the survey said that their experiences had been 'excellent' or 'good' (85.7%). Only 5% reported poor experiences of support provided through their CF team in some of the key areas listed.

"I couldn't ask for more of my CF team, they are amazing."

"Absolutely faultless support"

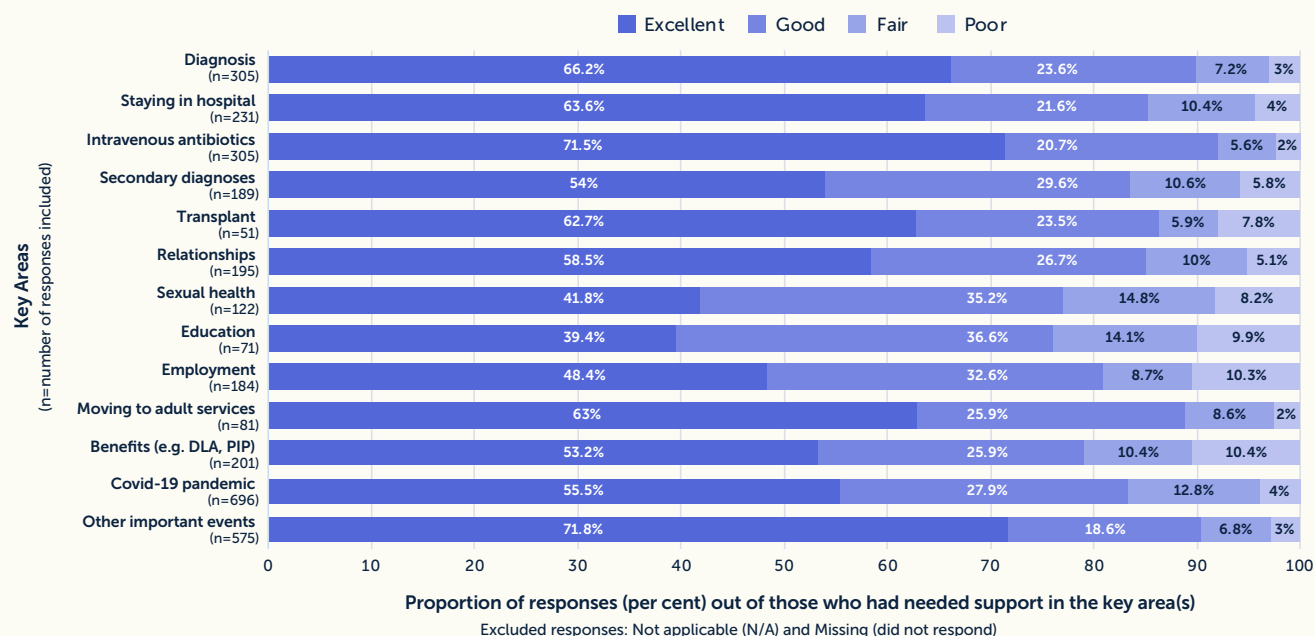
However, experiences of support varied depending on the situation or event (Figure 5). Support with diagnoses, intravenous antibiotics and transition to adult services were rated highly by those who had needed support with these, with 89.8%, 92.1% and 88.9% of respondents, respectively, saying their CF team did an 'excellent' or 'good' job.

In contrast, experiences of support with benefits, sexual health and education were rated less positively, with just 79.1%, 77.0% and 76.1% 'excellent' and 'good' responses, respectively, and over 20% of respondents stating their experiences of support at these times had only been 'fair' or 'poor'. More than 1 in 10 people with CF who provided a rating for benefit and/or employment support said that they had had poor experiences when seeking help in these key areas (10.4% and 10.3%, respectively).

Figure 5: Experience of support provided by CF team by topic

NB: Based on data from 750 respondents (excl. 20 not applicable and 72 skipped question)

NB: Proportions have been rounded to the nearest full number where they were <5%



Many respondents (575 of 842) provided a rating for support during 'other important events', such as access to new medicines. While not all of these individuals shared details about the 'other' area in which they had needed support, several (n=99) specified that they were referring to starting new treatments, many with Kaftrio, which was licensed in August 2020. Of these, 94 respondents (94.9%) felt that support received from their CF team to start new medicines had been 'excellent' or 'good'.

"I've been overwhelmingly excited about the new Kaftrio drug. I received the drug straight away and have had plenty of support from the CF team. Couldn't have asked for a better experience."

"I have recently started Kaftrio and the process was fairly speedy, everything was issued to me as prompt as possible."

"Access to Trikafta (Kaftrio) was arranged swiftly and efficiently."

"Access to new medicines has been excellent."

However, a few respondents felt that the support they had received to access new drugs had been lacking.

"Have not had any good support in regards to getting on modulator drugs. I have had to personally chase this up. Still waiting."

"Pretty late notice on all things Kaftrio."

Some respondents also provided ratings for other key areas in which they had received support from their CF team. These included port flushes, exercise programmes, and contact with genetics and family planning services. Generally, experiences of support in these areas were rated 'excellent' or 'good'.

Due to the challenging circumstances following the introduction of lockdown and shielding in mid-March 2020, many respondents (696 of 842) also reflected on support they had received during the pandemic, with 83.3% rating this support as either 'excellent' or 'good'.

“The team are always putting us first, and the care and extra infection control during COVID has been fantastic.”

“Regular updates regarding COVID guidelines, and help getting physio treatments and port flushing.”

However, experiences with support during the pandemic varied by centre, and a few people with CF reported poor experiences, often due to a lack of contact with their CF team.

“Not seen any of my team since lockdown”

“Had arranged telephone check up with CF Consultant. Never received the phone call.”

Proportion of respondents at each centre who rated experiences with support during the COVID pandemic as either excellent or good

NB: n=820; Centres with fewer than 10 responses were excluded (4 centres; n=22 responses)



Communication

Adult Cystic Fibrosis Service Specification (NHS England):

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

The service will deliver the aims by:

- ensuring effective communication between patients, and the service providers

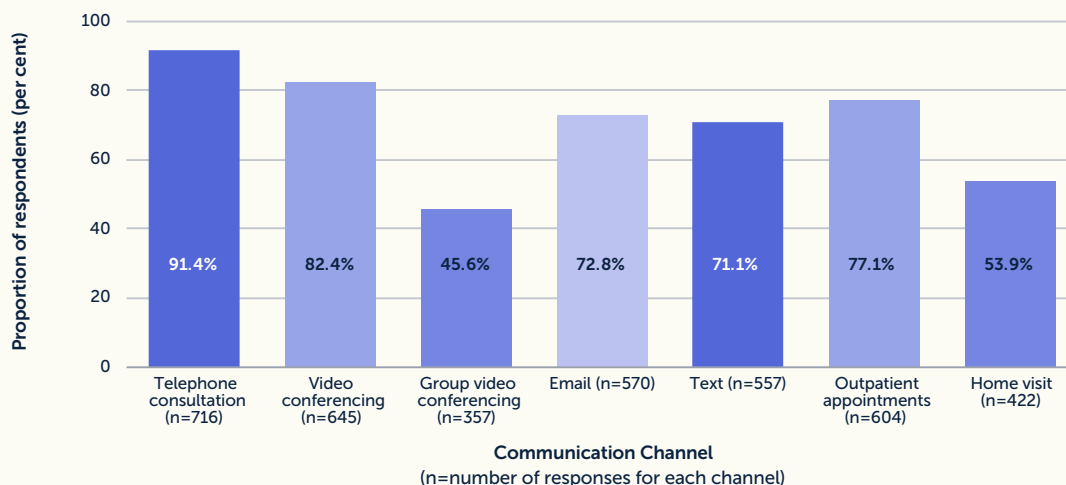
Section 3.2: Service description/care pathway: As a minimum [...] patients and their families will be afforded the right to be fully informed of their condition, and to ensure that information is communicated in an understandable, sympathetic and age-appropriate manner

Due to the COVID pandemic, services had to adapt the ways in which they communicated with people affected by CF, making increased use of remote channels, such as telephone consultations, video conferencing and email. The survey explored which communication channels had been used since mid-March 2020, and asked respondents to rate their experience of each communication method.

Question: Since mid-March 2020, please indicate how you have communicated with your CF MDT?

Figure 6: Communication channels used since mid-March 2020

NB: Based on 783 respondents (excl. 59 skipped question); respondents could select multiple channels, hence overall proportions add up to >100%



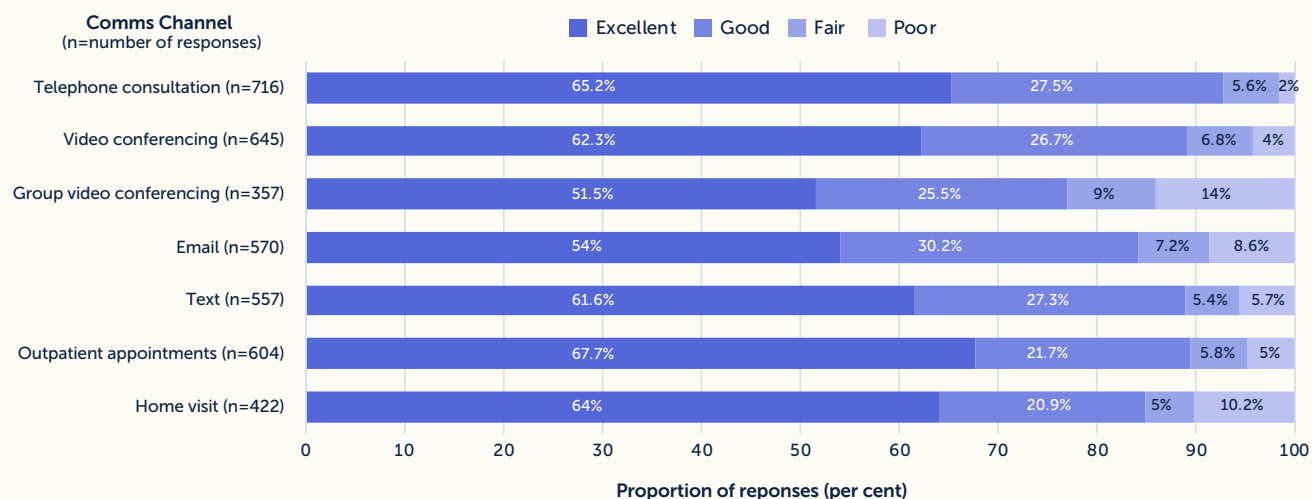
Most respondents said that they had used remote communication channels, such as telephone consultations (91.4%), video conferencing (82.4%) and email (72.8%) since mid-March 2020. However, more than three quarters also confirmed that they continued to have outpatient appointments and just over half said they had had a home visit.

Experiences of different communication channels varied. Figure 7 outlines the ratings given by people with CF for various communication channels they had used to communicate with their CF team since mid-March 2020.

Figure 7: Experience with communication channels since mid-March 2020

NB: Based on 3,871 ratings provided by 783 respondents (59 skipped question)

NB: Proportions have been rounded to the nearest full number where they were <5%



The telephone was the highest rated communication channel since mid-March 2020, with more than 9 of 10 respondents (92.7%) rating their experience with telephone consultations as ‘excellent’ or ‘good’. However, all other channels were also rated positively by more than three quarters of respondents. ‘Group video conferencing’ was the lowest rated channel, though 77.0% of people with CF in the survey who had had a group video call still felt their experience with this channel had been ‘excellent’ or ‘good’.

Virtual formats, particularly virtual clinics but also email correspondence, were often mentioned in free text comments, with accessibility and responsiveness driving positive experiences.

“Brilliant at getting back to you when you send emails or have a query. Always on time with virtual appointments.”

“The specialist nurses respond quickly to emails and are helpful in their response. Everyone keeps you informed if you need any changes in medication and communicate everything clearly at virtual clinics.”

“They are really attentive with communication and getting back to [you] when you have called about something.”

“Communication has been good with virtual clinics and home visits. Physios set up a mobile phone for non-urgent text queries, and the whole team are available on the phone when needed.”

Some respondents also commented on innovative uses of virtual channels that had been introduced by their service, for example to deliver virtual exercise classes.

“Our exercise physiologist has started virtual exercise classes 5 days a week and it has helped me immensely. It’s nice to move my body and also virtually interact with other CF patients.”

“I particularly enjoy the virtual leisure centre they have set up since March and hope it continues!”

Annual Review

Adult Cystic Fibrosis Service Specification (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.

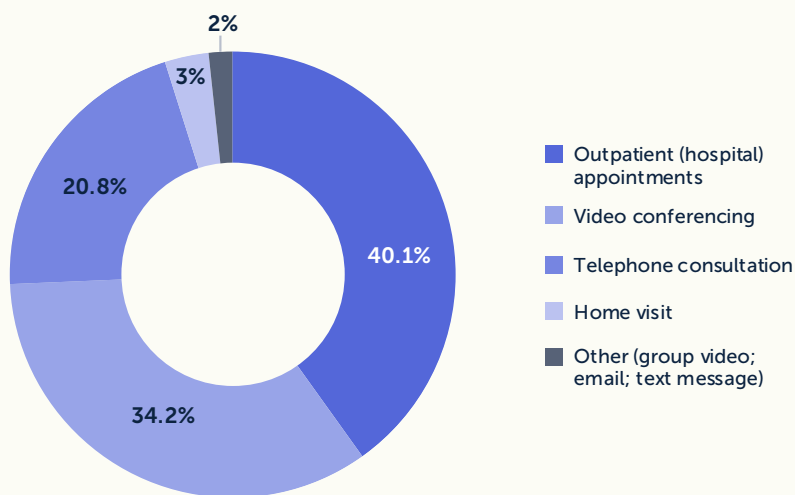
Quality Standards Domain 2: Enhancing the quality of life of people with long-term conditions: All adults should have an annual review and management plan discussed with patient. [Domain threshold: $\geq 85\%$]

Question: Since mid-March 2020 have you received an annual review, if yes please indicate how this was done?

About half of respondents (n=409) confirmed that they had had an annual review since mid-March 2020 and provided information about the format of their review. Despite the pandemic, 2 in 5 (40.1%) respondents confirmed that their annual review had taken place as an outpatient hospital appointment, while 55% said their review had been done via video conferencing (34.2%) or telephone (20.8%); however, this varied by centre. Only a small number of people with CF reported use of other annual review formats, such as home visits, group video calls or email.

Figure 8: How were annual reviews carried out since mid-March 2020?

NB: Based on 409 respondents (433 skipped question)



Proportion of respondents at each centre who had an outpatient (hospital) appointment for their annual review

NB: n=393; Centres with fewer than 10 responses were excluded (6 centres; n=16 responses)



60% of respondents who had had an annual review since mid-March 2020 had this in a remote format, e.g. telephone or video call.

34% of respondents had not received written feedback from their annual review.



Question: Did you receive written feedback from your annual review (only answer if annual review was more than one month ago)?

Among those who answered this question (n=433), 2 in 3 respondents (66%) confirmed that they had received written feedback from their last annual review. However, about 1 in 3 (34%) said that no written feedback had yet been shared with them. Proportions of those who had received feedback varied by centre.

Proportion of respondents at each centre who had received written feedback

NB: n=423; Centres with fewer than 10 responses were excluded (5 centres; n=10 responses)

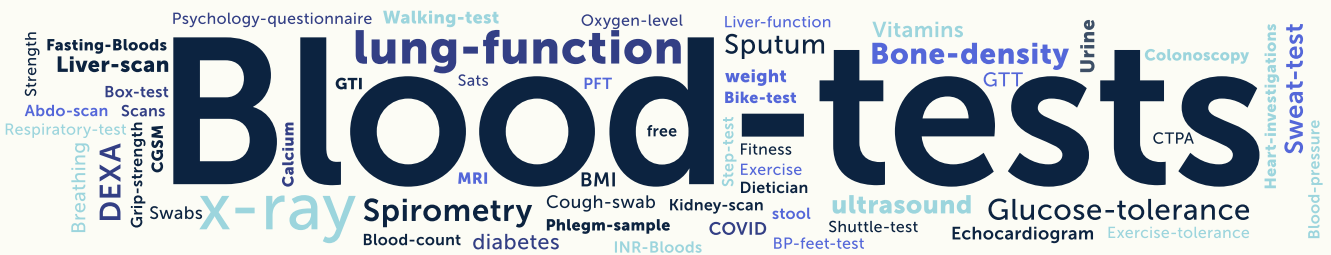


Question: Have you had any tests done for your annual review?

Respondents were asked to list any tests carried out for their annual review, to better understand availability and use of investigations during the pandemic. Among those who said they had had an annual review since mid-March 2020 (n=409), the majority (n=240; 58.7%) confirmed they had had one or several types of tests for their annual review. Only thirteen respondents (3.2%) stated that they had not had any tests as part of this process (156 skipped the question on types of tests).

Figure 9: Tests for annual review since mid-March 2020

NB: Based on 240 respondents (excludes 13 who said they had no tests in answer; 156 who skipped question on types of tests, and 433 who did not report an annual review since mid-March 2020); word size increases with number of respondents who said they had had the specific type of test



Blood tests were by far the most common type of test respondents had had, with a variety of different tests falling under this umbrella. Lung function assessments and imaging, including x-rays, CT scans and ultrasounds, were also reported frequently. This indicates that many services continued to offer tests and investigations for annual reviews during the pandemic.

Most people with CF who reported that they had had a remote annual review (e.g. by telephone call, video conference), confirmed that tests had been arranged for this. Only twelve respondents who had had a remote annual review said that no tests had been done.

Some respondents left comments about the care and tests they had received for their annual review, confirming that many services had adapted to carry out blood tests at home, while others continued to offer tests in clinic.

“Home visits for blood tests in 2020 made me feel safe as I didn’t need to go to a GP or hospital”

“During the pandemic a nurse has visited my home to take my bloods and keep me safe.”

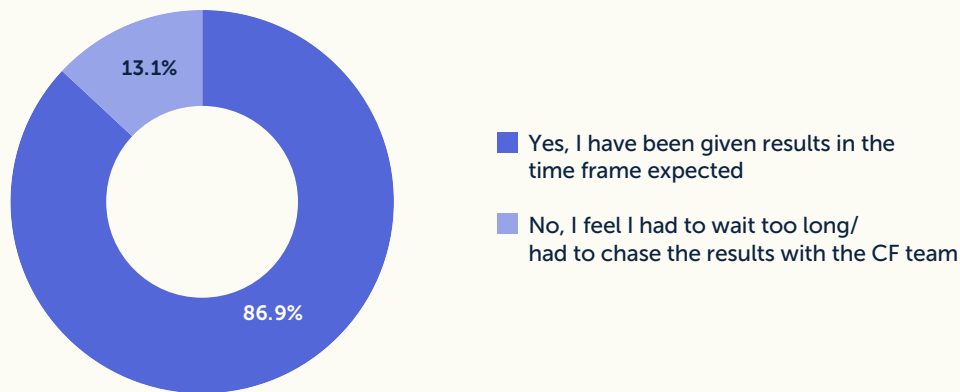
“I needed several blood tests and I was able to have these in clinic all through lockdown.”

Question: Are you satisfied with the time taken to communicate your test results?

When asked about satisfaction with turn-around times of tests and communication of results generally, the vast majority of people with CF in the survey confirmed that they were satisfied. However, there was variation by centre.

Figure 10: Satisfaction with time taken to communicate test results

NB: Based on 444 responses (excl. 168 'not applicable' and 230 who skipped question)



Proportion of respondents at each centre who were satisfied with the time taken to communicate test results

NB: n=424; Centres with fewer than 10 valid responses were excluded (6 centres; n=20 responses)



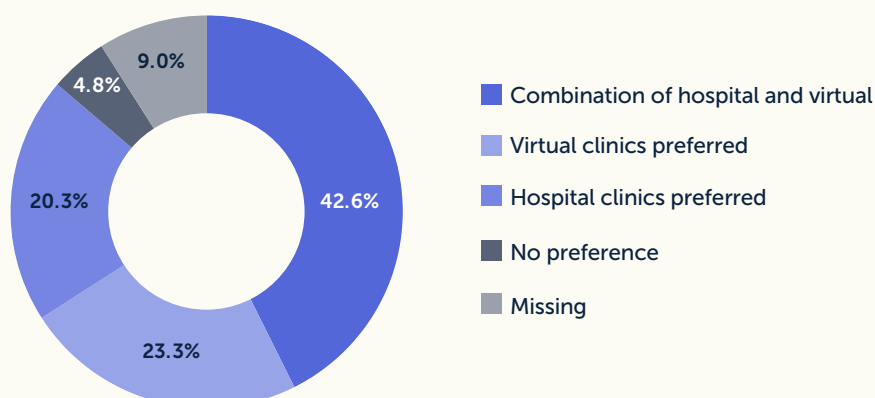
Future appointment preferences

The COVID pandemic resulted in rapid changes to services, including the widespread use of remote consultation approaches, such as telephone and video conferencing. While face-to-face appointments are expected to return, remote consultation formats will likely remain available as part of the digitisation of the NHS. It is therefore important to understand the preferences of people with CF, so that services can adjust their offer.

Question: If given the choice of continuing with virtual clinics versus hospital clinics for routine appointments, which would you prefer and why?

Figure 11: Preferences for the format of future appointments

NB: Based on 842 responses (incl. 76 missing responses, who skipped the question)



Most respondents (42.6%) said that they would prefer to be offered a combination of both appointment formats going forward. Many of these respondents felt virtual clinics were more convenient but valued the personal contact and access to tests during hospital visits (see Figure 12).

“Sometimes it’s good to see people, but sometimes it’s easier to do it virtually.”

“Sometimes it would be more convenient to discuss things over the telephone, however there are definitely times I’d rather speak to someone in person. Also tests or port flushes etc would be required.”

“The virtual clinics are very good especially with the pandemic. They save time, with travel, and it feels like it is easier to have access to various team members. However, it is still nice to have the face-to-face contact sometimes.”

“Balance of reduced visits and infection risk reduction, and being able to do in person lung function, tests etc.”

Similar proportions of respondents said they would prefer primarily virtual or primarily hospital appointments in future (23.3% and 20.3%, respectively). An analysis of reasons given by these respondents showed that a wish to reduce the amount of time and/or money required (e.g. for travel) to attend hospital appointments was a key driver for wanting to continue with virtual clinics in some form. Many also wanted to reduce infection risk by avoiding travel and spending time in hospital waiting areas. Similarly, respondents with a preference for virtual clinics more often referenced a reduction in anxiety.

“Quicker, takes less time than outpatient visit, also cheaper as no petrol/parking costs.”

“Easier to attend trying to work full time and I feel, less likely to catch anything I may pick up whilst at hospital in general.”

“It’s nice not having to travel to the hospital, because I get anxious when I go to the hospital.”

In contrast, those with a clear preference for hospital appointments referenced reasons such as the ability to communicate more easily, have face-to-face contact with MDT members, as well as access to tests and a thorough examination.

“Increased depth of conversation and discussion. Plus, opportunity for physical examination and PFTs. Better to build relationship/rapport with team.”

“Prefer to see my team, as more personal and they can judge better [how] I feel face-to-face.”

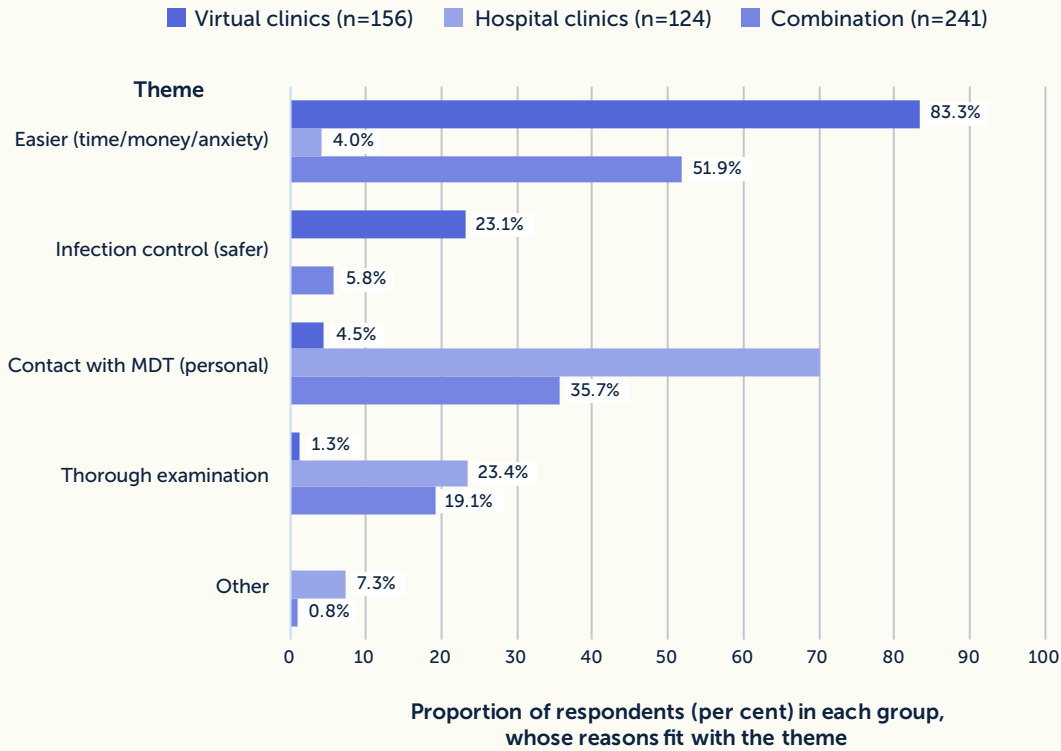
43% of respondents said they would prefer to be offered a combination of hospital and virtual appointments in future, while 23% preferred virtual and 20% preferred hospital appointments.



Figure 12: Reasons provided for preference of appointment format

NB: Based on 521 free text responses left by those with a preference for virtual or hospital appointments, or a combination; similar responses were grouped into 'themes'; themes with <5 responses have been grouped into 'other', which includes topics such as privacy

NB: Some respondents left comments that fit with more than one theme; these have been counted in each relevant theme, which is why proportions shown below may add up to >100%



Care at home and in the community

Adult Cystic Fibrosis Service Specification (NHS England):

Section 3.2: Service description/care pathway (Specialist Centre 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 an outreach service for adult services where appropriate.

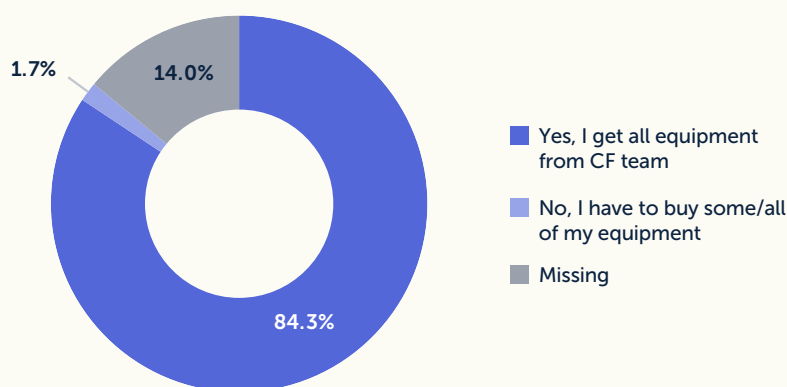
Section 3.2: Service description/care pathway (Homecare): Many patients and families require regular and consistent outreach from the multi-disciplinary team in this care.

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 who have specific training, experience and supervision in CF

Question: Since mid-March 2020, were you able to access all of the airway clearance and nebuliser equipment that you need?

Figure 13: Proportion of respondents who had access to airway clearance and nebuliser equipment (n=842, incl. 118 who skipped question)



Most respondents confirmed that they had been able to access all of the airway clearance and nebuliser equipment they needed since mid-March 2020.

“[My CF team] showed me some airway clearance techniques and help improve productivity.”

“When I need new nebuliser items, the hospital sends them out.”

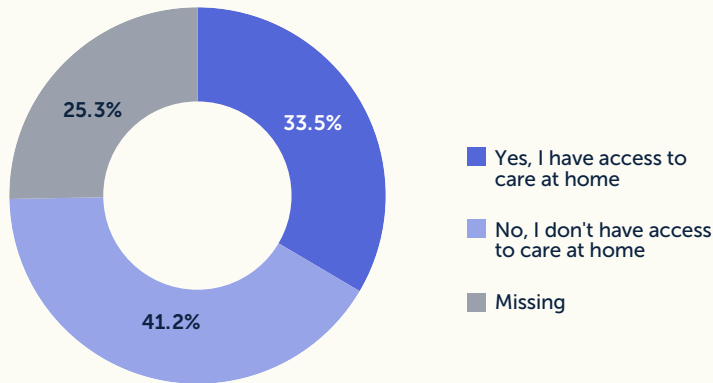
Only fourteen respondents (1.7%) said that they had had to buy some, or all, of their equipment.

In addition to being able to access airway and nebuliser equipment, availability of support delivered in a home setting, such as physio care and port flushes, could further reduce infection risk, particularly during the COVID pandemic, by avoiding travel and hospital visits. The survey therefore also explored if people with CF had access to community support and care in their home. However, it should be noted that some CF centres had to suspend home care services in the early phase of the pandemic until protocols were in place to ensure home visits could be carried out safely, which may have affected our findings.

Question: Since mid-March 2020, do you have access to any community support/care delivered in your home such as physio, port flushes etc?

Figure 14: Proportion of respondents who had access to community support/care

NB: n=842, incl. 213 who skipped question

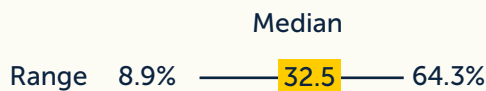


About 1 in 3 people with CF in the survey confirmed that they had had access to care at home since mid-March 2020, either through their specialist CF team or community staff. However, access to care at home varied by centre, and more than 40% of respondents overall reported that they did not have access to this kind of support.

Proportion of respondents at each centre who had access to community support

NB: Based on 820 respondents, incl. 206 who skipped question

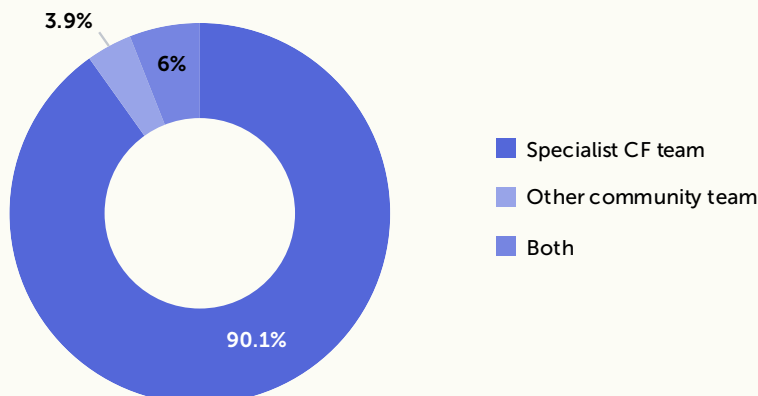
NB: Centres with fewer than 10 responses were excluded (4 centres; n=22 respondents)



Question: If you have accessed community support/care delivered at your home, who provided it?

Figure 15: Community care/support provider

NB: Based on 284 respondents who reported having access to care/support at home



Most respondents confirmed that care in the community was provided through their specialist CF team, with just 1 in 10 saying community support was also, or solely, delivered by other community staff.

Question: What do [the team delivering community care] do? Do you have any comments/ concerns about the service?

To better understand the kind of services offered in the community, people with CF were asked to give details about the home care services they can access. From an analysis of free text comments (n=99), the most common services provided at home were port flushes, IVs and blood tests. These could be provided by either CF specialist or other community staff, such as primary care nurses.

“I have had port flushes from the CF specialist nurses which went very well and were given at convenient times.”

“My CF nurse regularly visits my home to flush out my port and take bloods. I am able to discuss any concerns or thoughts about my health and medication, and she is able to assess my health and any needs/concerns.”

“Nurse at local GP practice does my port flush/blood tests.”

Other services offered at home included physio sessions, either virtual or in-person, as well as medication reviews, changes or delivery.

“I had a weekly physio appointment over video call in lockdown (brilliant).”

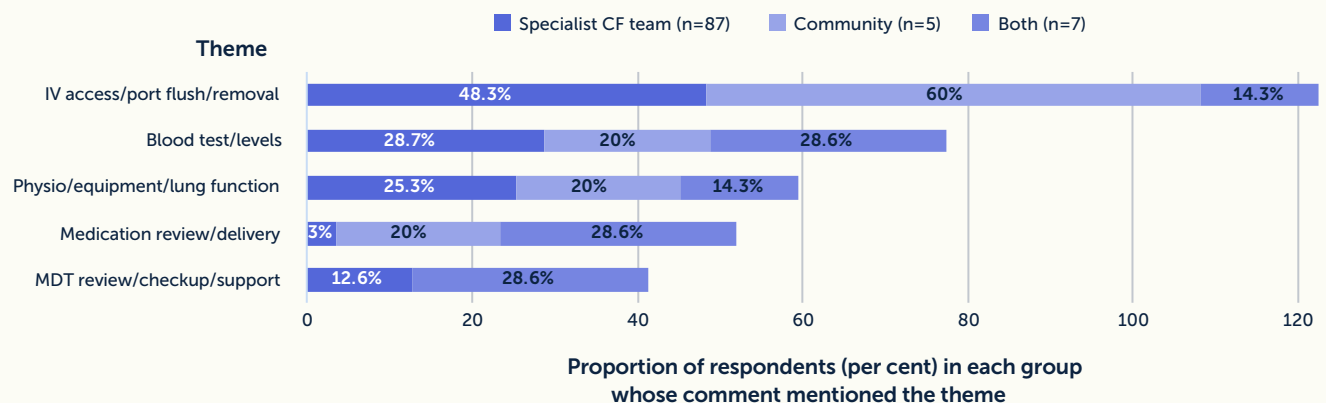
“Physio came to home to check how my physio is going and helping me with my daily therapy.”

“Had a visit for blood tests with specialist nurses so I can start Kaftrio which was quick, easy and well done.”

Figure 16: Types of services provided in community

NB: Based on 99 free text responses left by those with access to community care; graph shows findings of thematic analysis, which grouped similar responses into ‘themes’; themes mentioned by fewer than two respondents are not shown, these included ‘nurse review’ and ‘gastrostomy support’

NB: Some respondents left comments that fit with more than one theme; these comments have been counted in each theme, hence percentages can add up to >100%



Section 3

Infection prevention and control

General precautions

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

Adult Cystic Fibrosis Service Specification (NHS England):

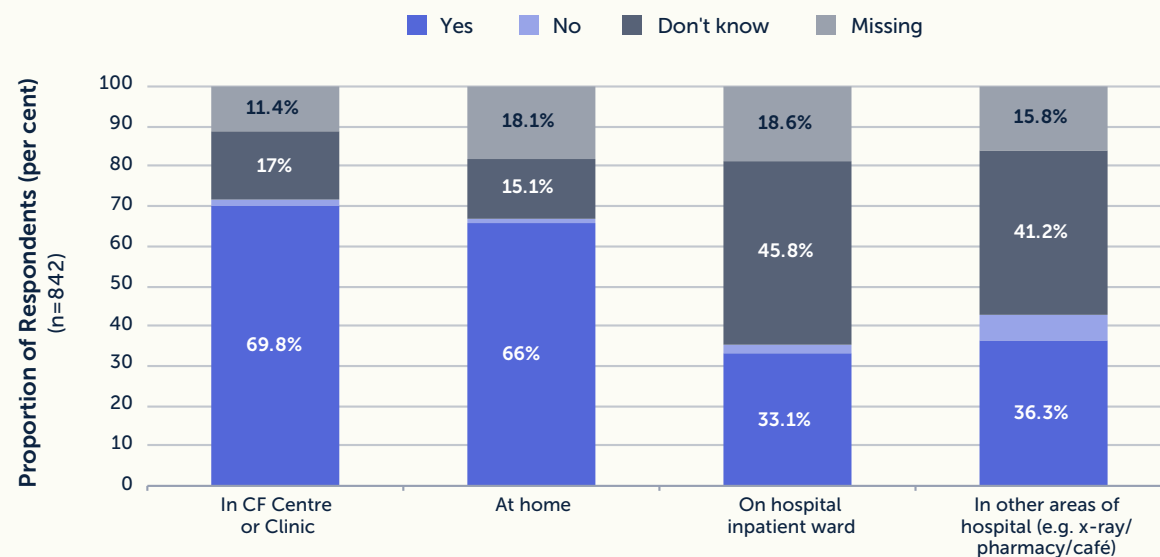
Quality Standards Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm: Adherence to standards of care to prevent cross infection. Centres should aim to reduce their prevalence of chronic pseudomonas infection. [Domain threshold: $\leq 65\%$]

During the COVID pandemic, infection control and prevention became even more important than usual. Therefore, the survey asked people with CF whether they felt that measures taken to help stop the spread of infections since the start of the pandemic – in various settings – were sufficient.

Question: Since mid-March 2020, do you feel that the measures put in place are sufficient to help stop the spread of infection?

Figure 17: Are infection control measures sufficient?

NB: Based on full sample of 842 responses; incl. those who skipped question (missing)



In CF centres/clinics and at home, around 2 of 3 respondents said that infection control measures were adequate, with many reporting that they felt 'safe' and well looked after by their teams.

"Services provided by my CF team have been of the highest standard. I feel safe when attending clinics and inpatient stays."

"The CF team do a great job of keeping you feeling very safe in the clinic surroundings and take great care to make you feel comfortable with all the safety precautions in place."

"All COVID secure and I felt safe when in hospital."

Respondents who felt that infection control measures were adequate often specifically mentioned segregation policies and procedures, including ways to identify other CF patients in clinic or hospital settings. Some of these policies had already been in place before mid-March 2020, as part of standard infection control in CF care, though additional steps to ensure segregation might have been introduced as a response to the pandemic.

"Patient numbers limited. Separate entrance to main hospital provided."

"Masks throughout hospital, temp screening and questionnaire for COVID exposure for all attendees, segregated waiting areas, minimal people in all areas."

"No mixing indoors, not allowed to leave room as an inpatient, regular COVID tests. No visitors allowed."

"Armbands for adults or yellow lanyards."

Use of personal protective equipment (PPE), other infection control measures, such as handwashing, as well as cleaning protocols and additional hygiene measures, were also mentioned by several respondents.

"PPE worn, windows open, surfaces wiped, hands washed, 2-metre distance observed as far as possible."

"I have had early appointments, separate room when attending hospital. Social distancing, PPE, alcohol gel etc."

"I feel that the CF clinic rooms, and ward, are very well cleaned between patients because of the risks."

"Clinics split by bug with time between appointment arrival and also UV cleaning between patients."

"Reassured by PPE used by nurses in home visits for blood tests."

"[Staff] always wear required PPE during home [visits], only do what [I'm] happy with, i.e. home treatment in garden if patient preferred, video clinic etc."

Only a small minority of respondents felt that infection control measures had not been sufficient in certain settings. This was attributed either to measures not being in place, or measures not being observed properly.

"X-ray Department: no segregation. Chairs were separated out, but other patients (not CF) were far too close."

"Some people are not wearing masks and keeping distance (staff and patients)."

"I had to wait in a small waiting room with patients not wearing masks and coughing. I was not given a COVID test and the porters etc did not have masks on and hygiene appeared poor."

"Not all staff knew the protocols for entering my room, some knew, but forgot or thought 'just popping in' did not need protocols to apply."

Many respondents felt unable to provide a response, because they had not accessed certain settings since mid-March 2020. This was particularly true for inpatient wards and other hospital areas, where more than half of respondents selected 'don't know' as a response or skipped the question, with some leaving comments such as 'Not been to hospital'.

While people with CF generally felt that infection control was well managed at their CF centre/clinic, there was some variation. At twelve centres, all respondents who provided an answer ('yes' or 'no' response) felt measures to reduce the risk of infection were sufficient. At nine other centres, at least one respondent felt infection control had not been well managed in their experience.

Proportion of respondents at each centre who felt that infection control measures were sufficient in their centre/clinic

NB: n=584; excludes 143 'Don't know' and 96 missing responses

NB: Centres with fewer than 10 responses were excluded (5 centres; n=19 responses)



Infection control in CF outpatients' clinic

Adult Cystic Fibrosis Service Specification (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.

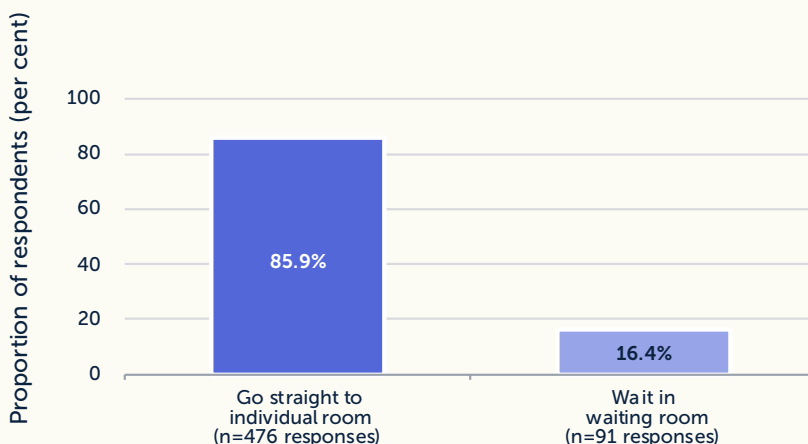
To understand the experiences of people with CF when they attend outpatient appointments in their CF centre or clinic, we asked them to describe what happens on arrival, when being seen by the team, and when having height, weight and lung function measured.

Question: Tick the boxes that best describe your experience since mid-March 2020

NB: All proportions below are provided out of respondents who answered the question; some respondents may have had multiple outpatient appointments and had different experiences at each, therefore providing more than one response to the below questions, hence percentages may add up to >100% where respondents selected >1 answer option

Figure 18: "Where do you wait?"

NB: Based on 567 responses provided by n=554 survey respondents; excl. missing=288



In most instances, and in line with the service specification, people with CF were taken straight to an individual room upon arrival and did not have to remain in communal waiting areas. Ninety-one respondents reported waiting in the waiting room when they arrived at their CF outpatients' clinic, which was identified by several respondents in comments as a cause of worry, as they were unsure if there were other CF patients present.

"Most of the time I'm in a waiting room, however they now make sure I'm in a quieter area or get a time slot."

"Some receptions don't inform you of other CF patients around, you have to ask those around you to stay safe."

There was variation by centre in the proportion of people with CF in the survey who said they were taken straight to an individual room when they arrive.

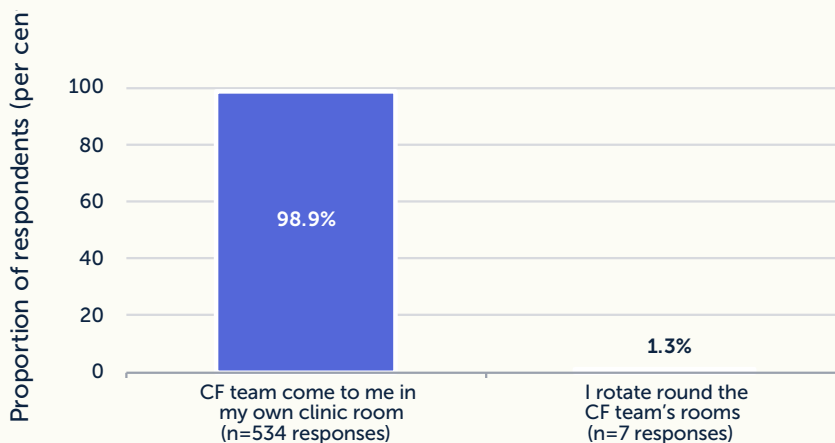
Proportion of respondents at each centre who said they went straight to an individual room upon arrival

NB: Based on 544 responses provided by n=531 survey respondents (missing: 288); Centres with fewer than ten respondents to this question were excluded (6 centres, n=23 respondents)



Figure 19: "How do you see the CF team?"

NB: Based on 541 responses provided by n=540 survey respondents; excl. missing=302



In line with the service specification, the vast majority of people with CF are seen in their own clinic room, with MDT members rotating around patients' rooms. Only seven respondents from four centres reported ever rotating round their CF team's rooms.

"At hospital you are in one room and don't move around, everyone comes to you, which works great."

Figure 20: “Where are height and weight measured?”

NB: Based on 520 responses provided by n=515 survey respondents; excl. missing=327

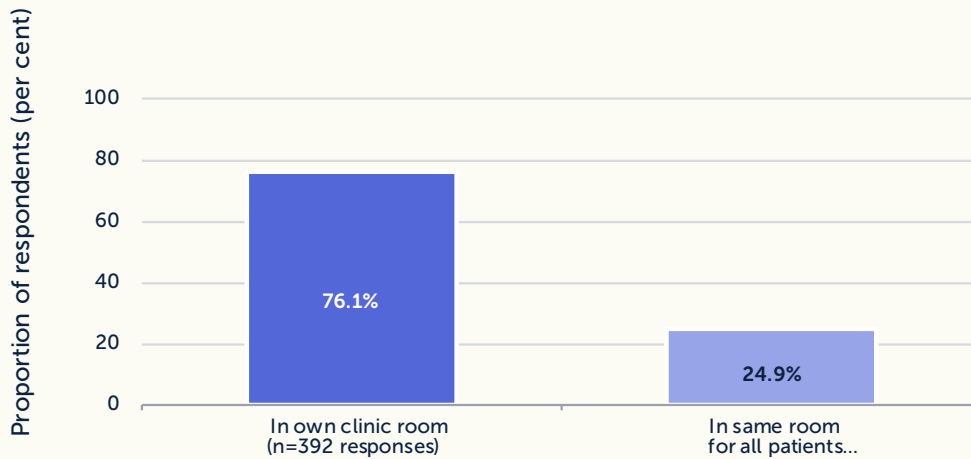
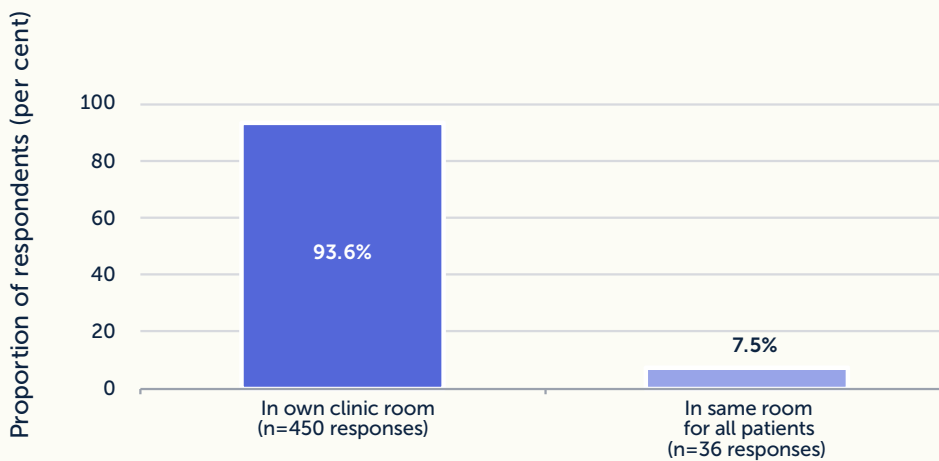


Figure 21: “Where is lung function measured?”

NB: Based on 486 responses provided by n=481 survey respondents; excl. missing=361

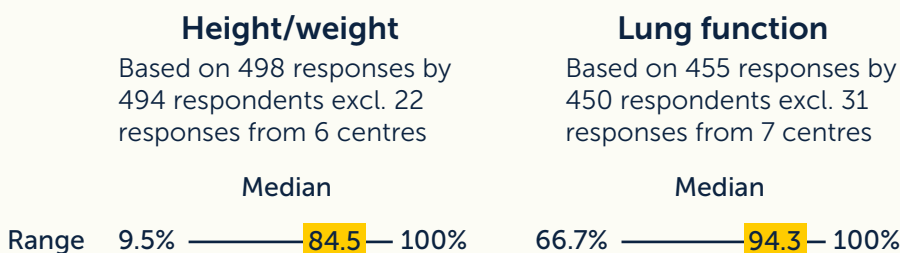


Around 1 in 4 respondents (24.9%) reported having their height and weight measured in the same room as all other patients, whereas for lung function, only 7.5% of patients reported being measured in the same room as other patients.

There was variation by centre in the proportion of people with CF in the survey who said that they had their height, weight and lung function measured in their own clinic room. At three centres, all respondents confirmed their height and weight were measured in their own clinic room, and at five centres, all survey respondents said lung function was measured in their own room.

Proportion of respondents at each centre who had their height and weight, or lung function, measured in their own clinic room

NB: Centres with fewer than 10 respondents to the question were excluded from this calculation



Infection control when staying in hospital

Adult Cystic Fibrosis Service Specification (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 adults requiring inpatient care should be admitted to a ward staffed by CF specialist staff (as defined by national specialist service specification) [Domain target: $\geq 95\%$]

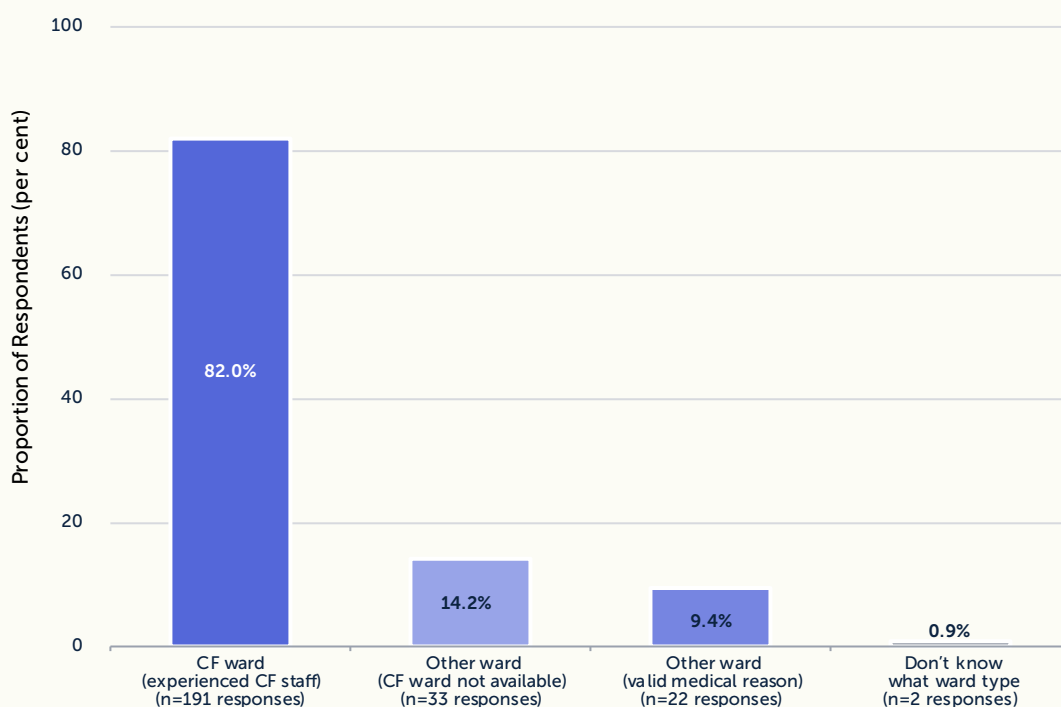
To understand experiences of people with CF when in hospital during the pandemic, we asked respondents to describe the type of ward and room they had stayed in. Many survey respondents skipped these questions, likely because they had not been an inpatient since mid-March 2020 (number of respondents included in analysis is provided in graphs below).

Question: Tick the boxes that best describe your experience since mid-March 2020

NB: All proportions below are provided out of respondents who answered the question; some respondents may have had multiple inpatient stays and had different experiences during each stay, therefore providing more than one response to the below questions, hence percentages may add up to $>100\%$ where a respondent selected >1 answer option

Figure 22: “What type of ward did you stay on?”

NB: Based on 248 responses provided by n=233 survey respondents; excl. N/A=321, missing=288



82% of people with CF in the survey who had had an inpatient stay since mid-March 2020, confirmed that they had been admitted to a specialist CF ward with experienced CF staff (Figure 23). A few respondents also commented on the efficiency with which wards and procedures had been adapted in light of COVID, and how they felt safe during their ward stay.

“The unit feels well run with good ward rooms. They are attentive to infection control and quick to resolve any issues.”

“I was incredibly impressed by the response to ensure patients could access inpatient treatment safely by adapting the existing CF ward.”

Twenty-two respondents (9.4%) said they had stayed on a non-CF ward for valid medical reasons, with most confirming that they were given their own room with en-suite bathroom on such wards.

“I spent a lot of time at maternity and they had everything distanced. Post-delivery, because of my vulnerable status, I was isolated from others on the ward.”

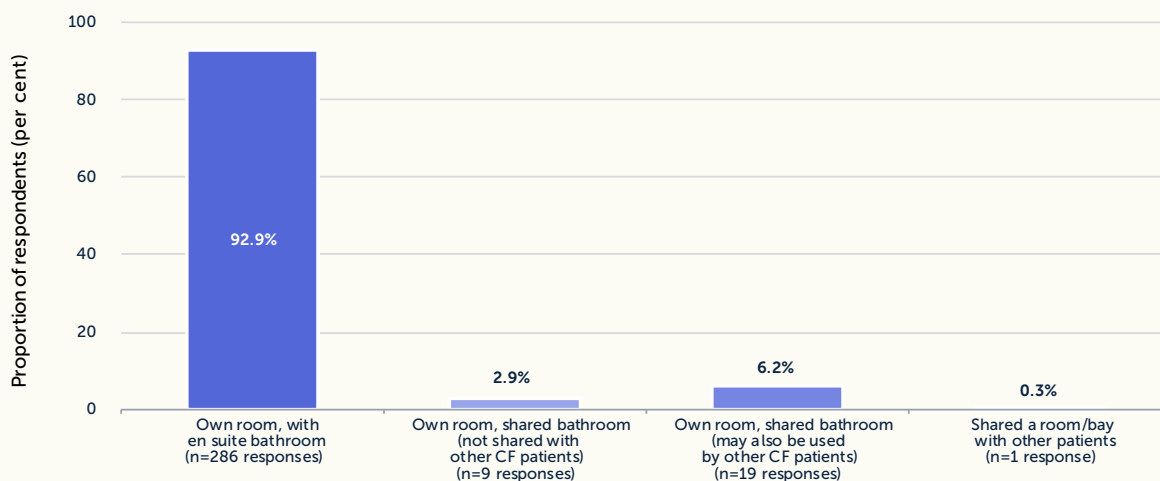
Only 33 people (14.2%) reported being admitted to another ward due to their CF ward not being available. Of these, 29 said they were given their own room, with en-suite bathroom, for their stay. However, several still had concerns and did not feel as safe as they would have on their usual CF ward.

“Our inpatient [ward] is being upgraded, so I had to go to another ward, which wasn’t as good.”

“From going from a one-bug ward to mixed, I don’t feel safe and protected.”

Figure 23: “What type of bed- and bathroom did you have?”

NB: Based on 315 responses provided by n=308 survey respondents; excl. missing=534



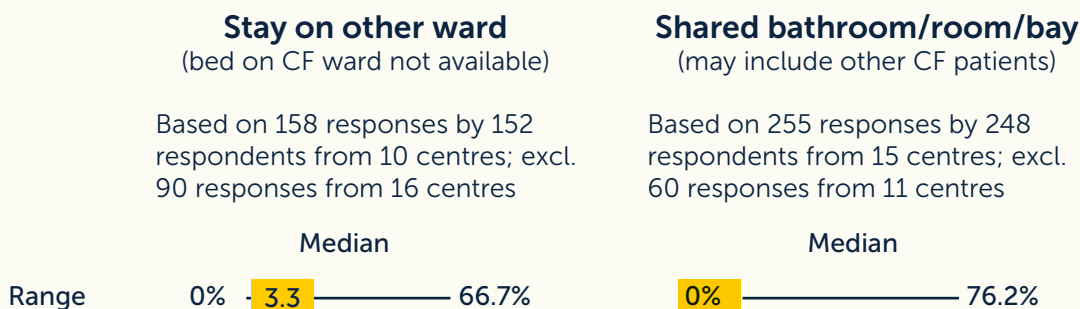
In line with the recommendations in the Standards of Care and Service Specification, almost all respondents (92.9%) who had had a hospital stay on any ward type said they were given their own room with en suite bathroom (Figure 23). Twenty-eight respondents reported sharing a bathroom with other patients, with 19 of these saying that this could have included others with CF. Only one person said they had shared a room/ bay.

“Could be better on ward, i.e. shared toilets when different patients have different bugs on the same ward.”

For most centres, there were no, or very few, respondents who reported staying on non-CF wards or sharing a bathroom or room/bay with others, potentially including other CF patients. However, the proportion of respondents reporting this varied by centre and there were some outliers. Participating centres have received tailored reports summarising responses from people under their care so they can explore how they compare.

Proportion of respondents at each centre who stayed on a non-CF ward and/or who shared a bathroom, room or bay with others

NB: Centres with fewer than 10 respondents to the question were excluded from this calculation



The survey did not specifically ask about experiences of visiting diagnostic services, such as x-ray or pharmacies, in other parts of the hospital. However, several respondents shared comments regarding their experiences, and voiced concerns about being able to identify and keep themselves apart from other people with CF.

“There are no measures in place outside of the ward or outpatients. From what I have ever seen, I could be sat next to someone with CF in X-ray, lung function etc and would never know.”

“Twice I have been sent to x ray and sat opposite other CF patients [...]. A massive lack of understanding in other departments. They thought I was upset due to COVID, not other’s bacteria.”

“I have come into contact with other CF patients in the outpatient’s reception in the past twelve months, and in pharmacy two weeks ago, where I was sat in the same room as two other patients with CF.”

14.2% were admitted to a non-CF ward, as a bed on the CF ward was not available

6.5% shared a room, bay or toilet, potentially with other CF patients



Section 4: Intravenous Antibiotic Therapy

Access to IV antibiotic therapy

Adult Cystic Fibrosis Service Specification (NHS England):

Section 3.2: Service description/care pathway (Intravenous (IV) Antibiotics): The service will 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 will 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.

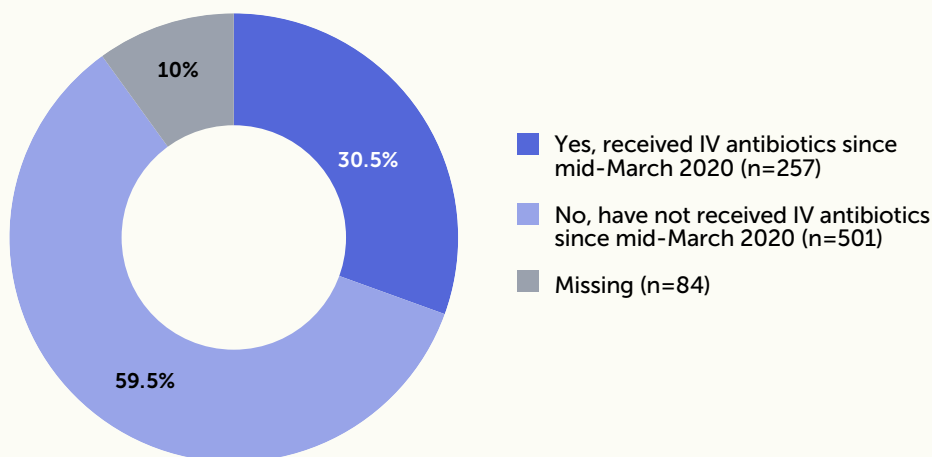
Quality Standards Domain 4: Helping people to recover from episodes of ill-health or following injury: There should be no delay in initiating IV antibiotic therapy for pulmonary exacerbation (as defined by national service specification) [Breach percentage >10%]

Timely access to intravenous (IV) antibiotic therapy is crucial to manage infection and exacerbations in people with CF. To explore experiences with IV antibiotic therapy during the pandemic, the survey asked about access, timeliness, as well as preferences for hospital versus home IVs.

Question: Since mid-March 2020, have you received IV antibiotic therapy?

Figure 24: Intravenous antibiotic therapy since mid-March 2020

NB: n=842, incl. 84 missing responses



Just under 1 in 3 people with CF in the survey (30.5%) confirmed they had received IV antibiotic therapy since mid-March 2020. These respondents were shown several follow-up questions to further explore their experiences with timeliness and location of antibiotic therapy, as well as care received while in hospital.

Proportion of respondents at each centre who received IV antibiotic therapy

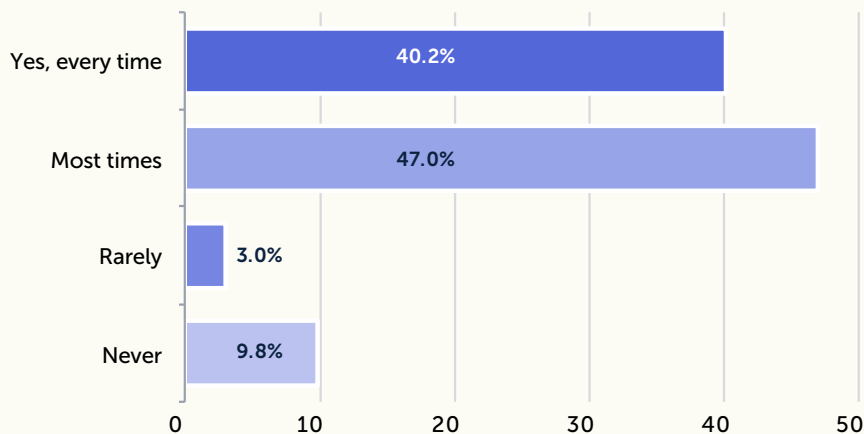
NB: Based on 820 responses; excl. centres with fewer than 10 responses (4 centres; 22 responses)



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

Figure 25: Urgent IV antibiotic therapy started within 24 hours

NB: Based on n=132 respondents who had received IV antibiotics since mid-March 2020, excl. 123 N/A responses (did not need to start antibiotics within 24 hrs) and 2 missing responses



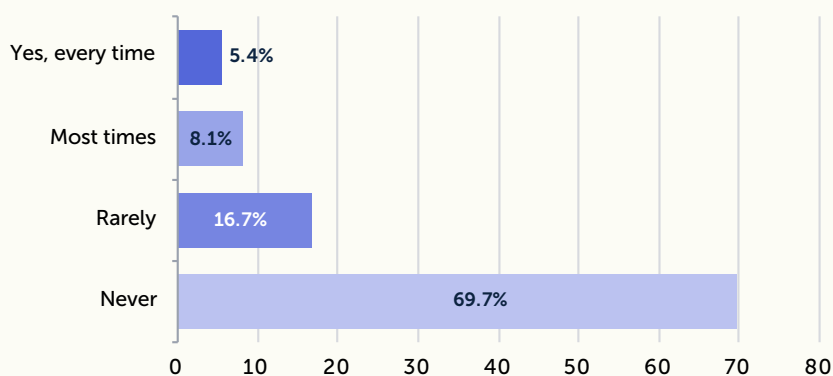
Most respondents (87.2%) confirmed that, where indicated, IV antibiotics were started within 24 hours 'every time' or 'most times' since mid-March 2020. However, nearly 1 in 10 respondents (9.8%) said that they had never started urgent IV antibiotics within 24 hours.

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 setting during the pandemic.

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

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

NB: Based on n=221 respondents who had received IV antibiotics since mid-March 2020, excl. 33 N/A responses (did not have routine/planned antibiotics) and 3 missing responses

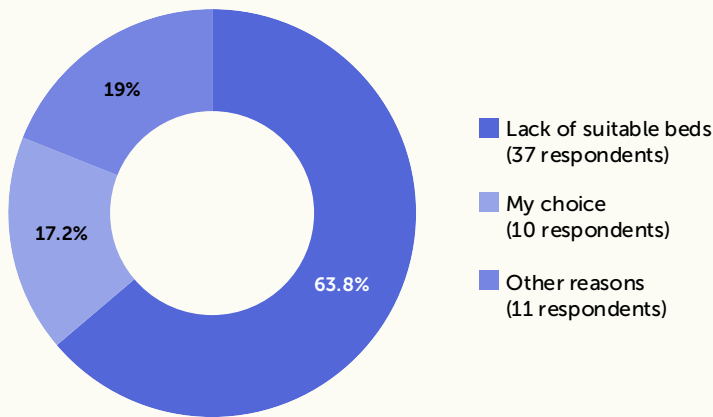


The majority of respondents (69.7%) confirmed that their routine/planned antibiotics were never delayed more than seven days from the originally scheduled admission date. Only thirty people (13.5%) said that they had started routine IV antibiotic therapy with more than seven working days' delay 'every time' or 'most times', with another 37 people reporting that such long delays happened occasionally but were 'rare'.

Question: If you had a delay of longer than 7 working days from your proposed admission date for IV planned/routine antibiotics, what was this due to?

Figure 27: Reasons for delay to start of planned antibiotics

NB: Based on n=58 respondents who had experienced a delay of more than 7 working days and provided a reason for this; excl. 9 respondents who skipped the question about reasons for delay

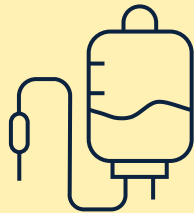


Of the 67 individuals in the survey who had experienced a delay of more than seven days to planned IV antibiotic therapy at some point since mid-March 2020, 58 people shared a reason for the delay. Nearly 2 of 3 respondents said that a 'lack of suitable beds' had caused the delays to their scheduled admission date(s) for routine IV antibiotics.

Eleven respondents provided 'other' reasons for delays, which included miscommunication between teams and patients, as well as instances where respondents felt there was not one single reason, but where delays were caused by a mixture of different circumstances, including lack of beds, personal choice, and others.

60% of respondents had experienced a delay in starting emergency IV antibiotics.

30% of respondents had experienced a delay in an admission for planned IV antibiotics.



Hospital care experiences

Adult Cystic Fibrosis Service Specification (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). [...]

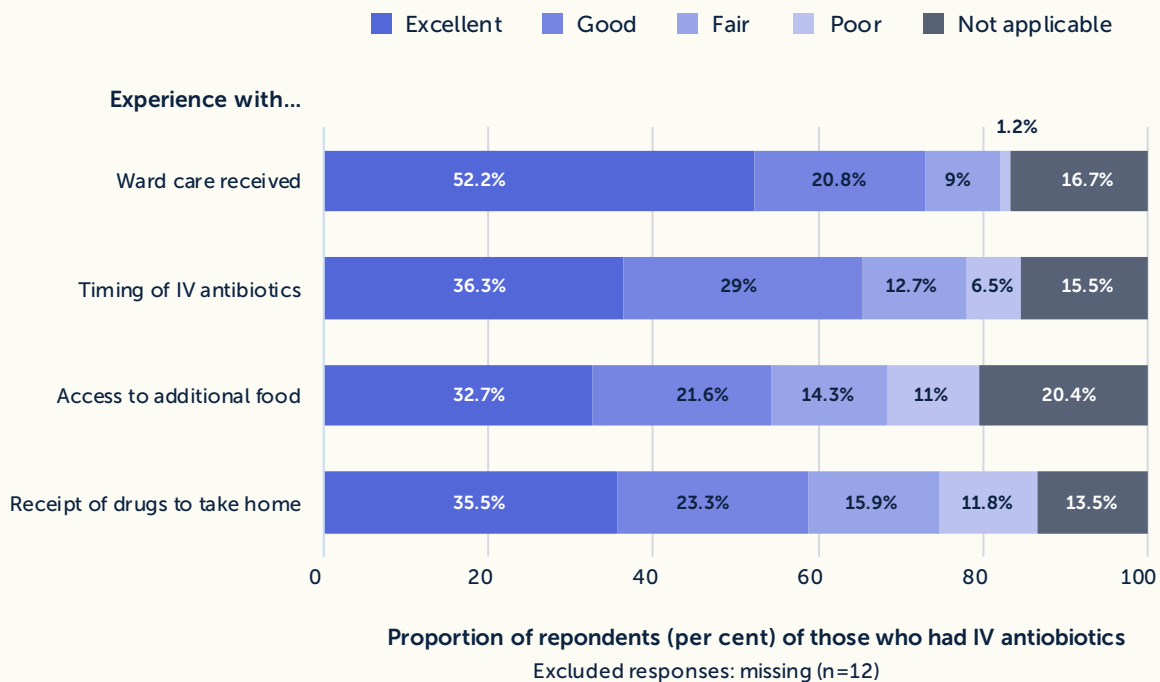
Provision will be made for inpatients to have a choice of food including high energy options and access to high energy mid-meal snacks and drinks. This shall include evenings and weekends.

Those who had attended hospital for urgent or planned IV antibiotic therapy were asked about experiences during their hospital stay, including ward care, timing of IVs and access to food and prescription drugs.

Question: Thinking about when you had to stay in hospital, how good were the following things?

Figure 28: Experiences of care when receiving hospital IV antibiotics

NB: Based on n=245 respondents who received IV antibiotics since mid-March 2020; excl. missing=12



More than half of respondents who had received IV antibiotic therapy in hospital rated all aspects of care explored in the survey as ‘excellent’ or ‘good’. Around 1 in 4 respondents said that access to additional food or arrangements for drugs to take home had only been ‘fair’ or had, in fact, been ‘poor’, indicating that there is scope to improve particularly on those aspects of care.

Home IV antibiotic therapy

Adult Cystic Fibrosis Service Specification (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.

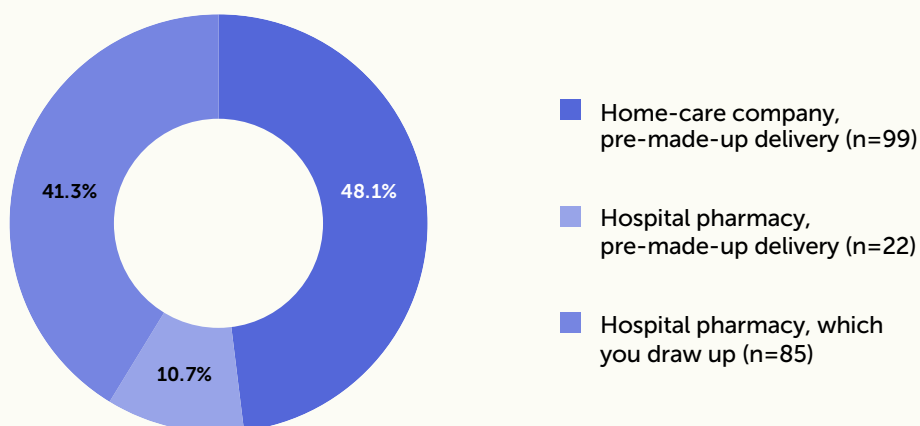
Section 3.2: Service description/care pathway (Homecare): Patients undertaking home IV antibiotic therapy will have a formal assessment of suitability. This will include formal training and an assessment of competency of the patient and/or their carers in administering the IVs as well as the suitability 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.

Throughout the pandemic, access to IV antibiotic therapies had to be maintained for people with CF and many respondents had received home IVs since mid-March 2020. Completion of IVs at home can reduce time spent in hospital for antibiotic therapy. 80.2% of survey respondents who had received IV antibiotics (206 of 257) provided information on how their home IVs had been delivered, as well as their experience with home IVs. This indicates that home IVs were available to many respondents during the pandemic.

Question: If given the option of home IVs, how are these delivered?

Figure 29: How are home IVs delivered?

NB: Based on n=206 respondents who received IV antibiotics since mid-March 2020; excl. 36 'not applicable' (did not have home IVs) and 15 missing



Most respondents who had received home IVs said these were either delivered in pre-made-up format by a home-care company (48.1%), or they came from the hospital pharmacy but still required drawing up at home (41.3%). Only 1 in 10 respondents (10.7%) reported receiving pre-made-up deliveries from their hospital pharmacy.

The survey then asked people with CF to describe their experiences with home IVs since mid-March 2020. An analysis of 125 free text comments revealed that experiences with home IVs were overwhelmingly positive. Most respondents (81%, n=101) said they had not run into any problems or issues, that their experiences had been good or very good, 'smooth' and 'well-organised', and that they had felt supported.

"Absolutely fine, no issues, had everything I needed."

“Delivery on time and smooth”

“I’ve done them a few times now and it’s very easy to do, as it’s already pre-made, and the delivery is fast.”

“Easier than staying in hospital. Always get advice and usually trained on home IVs before I leave.”

“Fabulous! The team are helpful and always only a phone call away, no matter what time of day or night/weekday or weekend. I feel so supported by them!”

“I found it very manageable and so much better, as I had access to my own bed and food, also made it easier to put weight on.”

While several respondents felt that administering IV antibiotics at home could be tiring and time-consuming, most of these respondents still said they preferred home to hospital.

“Brilliant. It’s tiring, but you can be comfortable and in your own home (and I often continue with work, especially now work from home is an option!).”

“Easy enough. Just time consuming and tiring while on the medication. Prefer home IVs generally, unless I’m too unwell to complete the course at home.”

Some respondents did, however, touch on challenges they had experienced. These included problems with deliveries and storing or drawing up of home IVs.

“Different companies have different arrangements, some better than others. Very difficult to contact [...]. Sometimes not enough items sent or incorrect.”

“Only problem was short shelf life of made-up drugs, so needed a bit of planning to ensure they didn’t go out of date / always had a supply.”

“I would prefer to have them [antibiotics] to mix at home, because then we don’t have to keep them in the fridge.”

Others mentioned a lack of support, particularly outside of normal working hours.

“[Home IVs] preferred. But there is a feeling of being left alone, because there are no routine calls. On the positive side, I could always get the support during weekdays when I call. The difficulty is during weekends and overnight when the line stops working – causing a delay/gap in treatment.”

“I had problems with my line at the weekend, the ward that were supposed to be able to help me didn’t want to know and just told me to go to A&E during a pandemic. I felt that I had no support over the weekend at all.”

“Good [experience], but more support when removing IV line would be useful.”

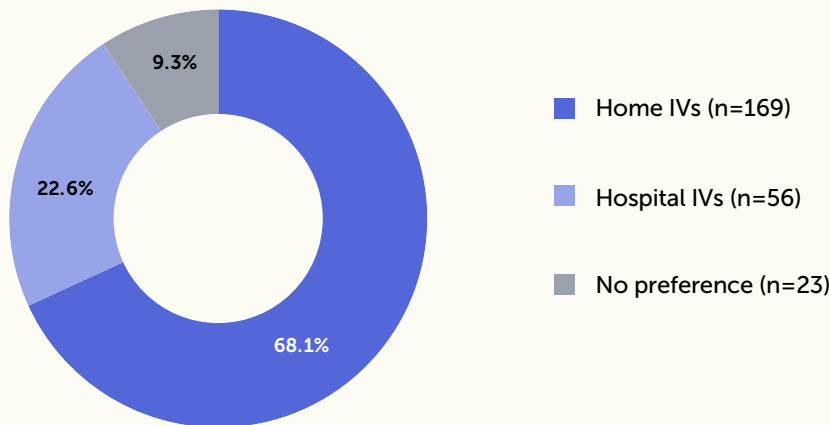
Among respondents who had received home IVs since mid-March 2020, these appear to be preferred by many. However, some people with CF will need more support to be able to confidently use home IVs, and others are likely to prefer hospital treatment, therefore both options should be offered, where possible.

Given experiences with home IVs can vary, the survey asked people with CF 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.

Question: If given the choice of completing IVs in hospital or at home, which would you prefer and why?

Figure 30: Preferences for home versus hospital IVs

NB: Based on n=248 respondents who received IV antibiotics since mid-March 2020; excl. missing=9



More than 2 in 3 respondents (68.1%) preferred home IVs, with just 22.6% recording a preference for hospital IVs and others stating that they had 'no preference' as it depended on the situation.

An analysis of comments about reason for preference for home versus hospital IVs showed that many of those who prefer completing their IV antibiotics at home referenced 'creature comforts', valued reduced disruption to their normal lives and access to support from family and friends.

"I like doing them at home as I'm in my own space and can sleep in my own bed with good food."

"I can fit work and the kids around home IVs."

"More comfortable, continue to look after my son myself. Can exercise and rest at my own pace."

"I like to be in my own surroundings, with my husband for support. Hospital is a long way from my home and I feel very lonely and isolated when I am in there."

Several respondents who preferred home IVs also felt there was less risk of cross-infection.

"Less chance of infection. Cleaner and more comfortable."

"Easier and less exposure to hospital bugs."

In contrast, those who preferred hospital settings often mentioned direct access to and reassurance from health professionals as driving reasons for their preference. These respondents also more often referenced poor general health, complexity of their CF, as well as side effects and allergic reactions⁵.

"Just in case something was to happen, there is always a nurse there."

"Due to suffering from side effects and allergic reactions, I prefer to be kept in hospital, as this makes me feel safe."

"Kidney function needs monitoring and only certain IV antibiotics work."

"It's preferable as, if I were to run into any issues, I would be in an environment to receive help immediately."

⁵ The Cystic Fibrosis Trust is part of the CF Anti-Microbial Resistance (AMR) Syndicate, which is looking to develop new medications to combat AMR, also offering the potential for alternative treatment options for those with allergies to existing antibiotics

Others with a preference for hospital IVs valued the time as an opportunity to rest and be looked after by others, with some noting that administering home IVs is 'stressful' and 'tiring'.

"I prefer being an in-patient, so I have a complete break from day to day stuff and a good rest."

"I like being cared for in hospital, as it gives me a break."

Table 1: Common reasons provided for home or hospital IV preference

NB: Based on n=140 respondents who gave a reason for their stated preference in a free text comment; excl. 23 with no preference and 85 who did not provide a reason

NB: Some respondents mentioned more than one reason for their preference and are counted more than once in the table below, hence percentages may add up to >100%; reasons given by fewer than 5 respondents are not shown

Preference for	Reason(s) given for stated preference	Proportion of respondents who mentioned reason
Home IVs (n=169; 100 free text comments)	Comfort: Be in home environment, usual surroundings & routine, own bed, food etc.	48.0% (48 of 100)
	Convenience: Easier, avoid travel, prefer to self-manage than be dependent	31.0% (31 of 100)
	Less disruption: Continue with usual activities (e.g. childcare, work etc.)	24.0% (24 of 100)
	Family support: Be with and access support from family and friends	14.0% (14 of 100)
	Infection risk: Reduced risk of cross-infection, feel safer at home	14.0% (14 of 100)
Hospital IVs (n=56; 40 free text comments)	Reassurance: Looked after by professionals, require monitoring due to complexity (e.g. allergic reactions to antibiotics), feel safer	52.5% (21 of 40)
	Rest: Opportunity to rest and take a break	30.0% (12 of 40)
	MDT support: Access to CF MDT members, incl. physios	15.0% (6 of 40)
	Ease: Less hassle than self-managing IVs at home	12.5% (5 of 40)

Section 5: Transplant care

Experiences of transplant care

Adult Cystic Fibrosis Service Specification (NHS England):

Section 3.2: Service description/care pathway (Transplantation): When the possibility of transplantation is appropriate, it will be discussed with the patient and family (where appropriate) as early as possible. Access to information will be readily available to patients.

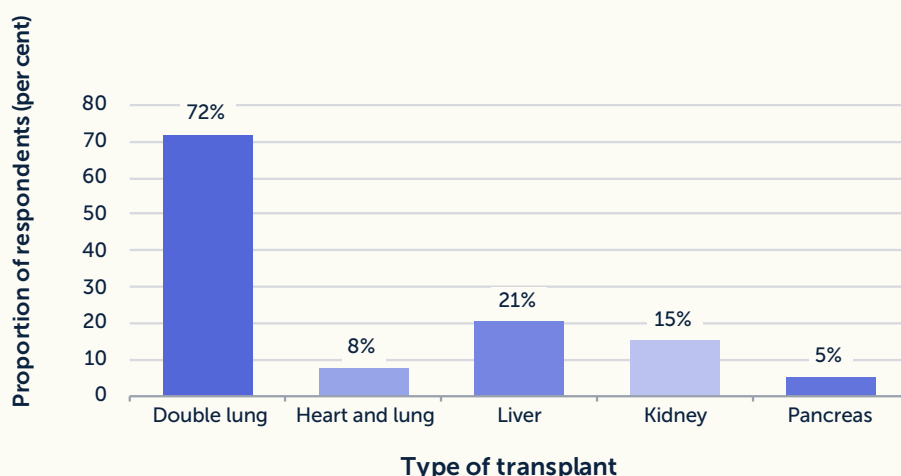
Referral to the transplant centre for further assessment, if appropriate, will be made as soon as potential candidacy has been assessed. Work up for transplantation will be undertaken in line with the guidance, processes and pathways defined by the transplant centre.

Question: Have you had a transplant? What type of transplant have you had?

Thirty-nine people with CF in the survey (5%) confirmed that they had had a transplant, with eight of these respondents having received multiple transplants.

Figure 31: Types of transplants

NB: Based on n=39 respondents who had received a transplant, incl. 8 with multiple transplants



To better understand how transplant patients are looked after following their transplant, the survey explored the care and services they receive from CF teams and transplant teams. Thirty individuals provided comments.

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

The majority of transplant recipients in the survey (70%) continue to be supported by their CF team with CF related issues, including airway clearance, nutrition and diabetes. Many also said that they continued to receive emotional support through their CF team.

"Mainly care around my diabetes and other CF related complications."

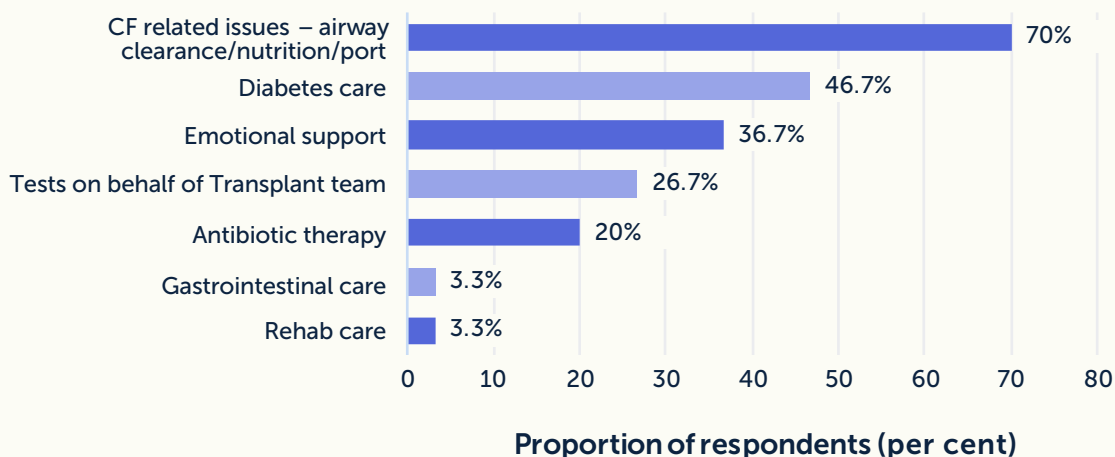
"Airway clearance, diabetes care and emotional support."

Others confirmed their CF team also help them to get tests done for their transplant team.

"They ensure I keep regular appointments with the liver clinic to monitor bloods."

Figure 32: Care from CF Team after transplant

NB: Based on n=30 respondents who had had a transplant and provided a response



Question: What sort of things does your transplant team do to help care for you after your transplant?

Several transplant recipients in the survey said that they did not have regular appointments with their transplant team but knew they could access them if required.

“My CF Centre does most of my day-to-day care, but Transplant Centre are always available if I need anything.”

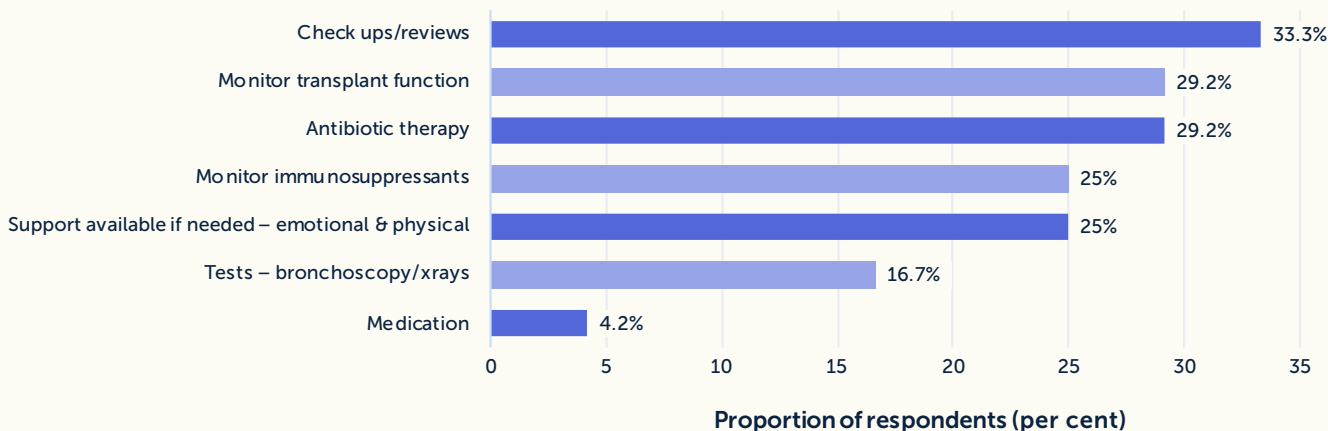
Among respondents who reported receiving specific care from their transplant team, services provided mainly focused on transplant check-ups, monitoring and antibiotic therapy.

“Just a 6-month review of all areas.”

“Look after rejection issues and drugs.”

Figure 33: Care from Transplant Team after transplant

NB: Based on n=30 respondents who had had a transplant and provided a response



Section 6: Good practice and areas for improvement

Excellence in care provided by CF teams

Throughout the pandemic, CF teams across the UK continued to provide care for people with CF under difficult circumstances. To explore areas where respondents felt their teams had excelled, the survey asked:

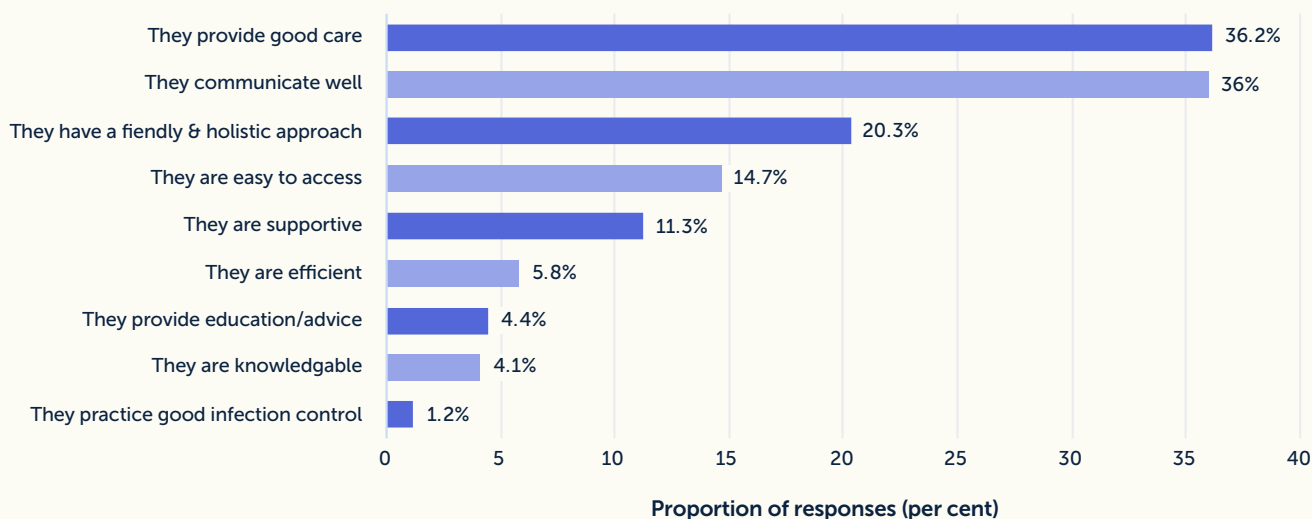
Question: What does your CF team do best?

Over 580 comments were received outlining things CF teams did particularly well according to people with CF under their care. Figure 34 shows a breakdown of common themes found in these free text comments.

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

NB: Based on n=586 free text responses

NB: Some respondents' comments fit with more than one theme and were categorised more than once, hence overall percentages may add up to >100%; themes mentioned by <5 respondents are not shown.



The quality of care CF teams provided was frequently praised by respondents, many of whom said their team, or aspects of care, were 'exceptional' and 'fantastic'.

"They are great all round, always very friendly and look after me exceptionally well. Highest praise and recommendation."

"They are fantastic at supporting patients in their lives and circumstances. Care is excellent and they are very patient and kind."

A large proportion of respondents felt their teams communicated particularly well and effectively, including when providing advice and education.

"Fantastic team with great communication and always available support via phoning the ward team. Whole team approachable and explain everything very clearly."

Many also valued that their teams listened to them and took into account their opinions and wishes.

"They know me well. They listen and where possible take on board my opinion. The whole team care, [I am] treated as an individual."

"They are always accessible if or when I need them! They are excellent at letting me control my own experience and make my own choices, while also guiding me."

Other aspects of care at which CF teams excelled, according to survey respondents, included taking a friendly and holistic approach to care, being easy to access, supportive, efficient and knowledgeable.

“Personalised and holistic care, going the extra mile, being kind.”

“Really great at keeping in touch and supporting with all aspects of my health. Doctors and nurses are all really friendly and knowledgeable, and I highly respect all of their opinions and trust the advice they give me.”

Figure 35: Best aspects of care

NB: Based on 586 responses; to produce word cloud, some similar terms were grouped (e.g. ‘communicating’ and ‘communication’, ‘need’ and ‘needs’)



Areas for improvement

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

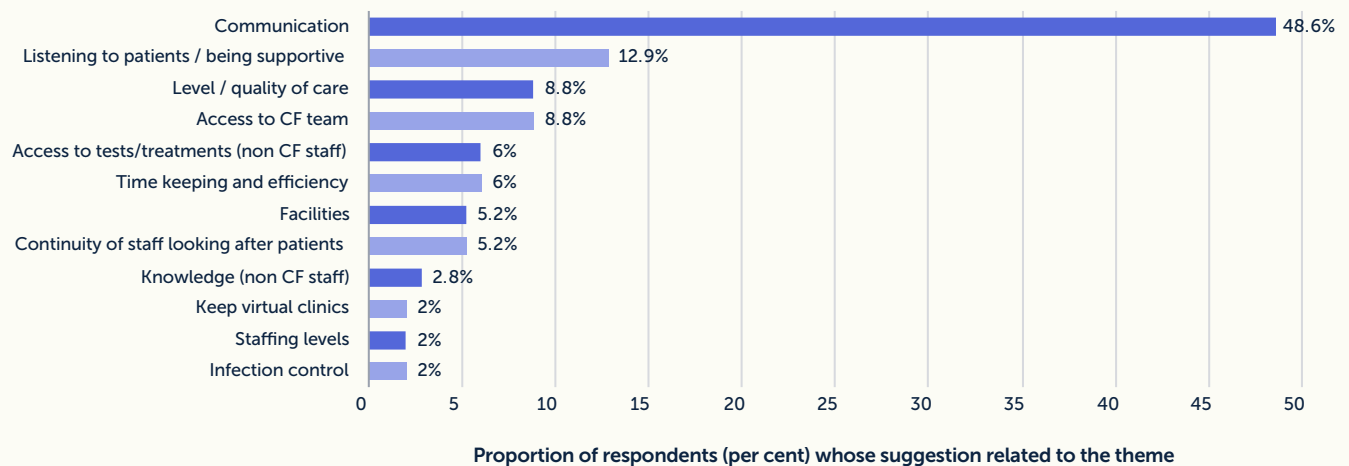
Question: What could your CF team do better?

Survey respondents provided 249 comments on aspects of care that could be improved. Figure 36 shows a breakdown of common themes found in these free text comments.

Figure 36: Thematic analysis of comments on areas to improve

NB: Based on n=249 free text responses

NB: Some respondents' comments fit with more than one theme and were categorised more than once, hence percentages may add up to more than 100%; themes mentioned by <5 respondents are not shown.



By far the most common area for improvement mentioned by respondents in the survey was 'communication'. Suggestions under this general theme could be further broken down into various sub-categories, such as communication about appointments and medical information, relaying of test results, communication between staff, as well as communication methods and timeliness.

Several patients felt that communication between them and their CF team could be improved, particularly with regards to appointment scheduling, staff changes, as well as relaying medical/treatment information and details about services available.

"The appointment system is not working properly and am getting repeat calls and appointments, and sometimes I am not sure what they are for."

"I'd like to know when team members are leaving or joining."

"Make us aware of the staff changes when they happen, as it can be a little overwhelming when you're in for an admission and don't know the team."

"Just communication, I'm not always aware of what's happening with my treatment as it's not always discussed."

"Explain some complicated medical issues better."

"Communicate better all of the services that are available to us."

Timely and routine communication of test results, even if tests were negative, was also flagged by several respondents as an area where their service could improve. Several specifically mentioned the importance of providing reassurance about negative test results.

"If [there is] anything the CF team could improve on [it] is ringing patients to inform them [of] the results of blood tests, sputum test etc. If the bloods and sputum results are okay, they do not ring me. Them not phoning to inform me increases anxiety."

"They could do better communicating over test results. A quick call or letter would be nice reassurance that everything is fine."

Many respondents in the survey also mentioned timeliness and responsiveness of communication and felt these were areas in which their CF team could improve. For some, this was particularly with regards to more timely sharing of test results, but others also mentioned general responsiveness to queries and concerns raised by people with CF.

"Give results quicker – avoid chasing and worrying."

"Communicate test results quicker, and better communication around big issues."

"Get back to you quicker about ongoing enquires from appointments."

Interestingly, several respondents suggested that an increased use of email communication could improve their experience.

"Could use email rather than letter for some generic things, like news or generic medication announcements."

"Emails instead of letters?"

"Provide an email address for any queries which is monitored 7 days a week (in the daytime)."

"Sometimes if you just need a standard prescription and don't need to talk to anybody, an email address would be easier than calling. Would also allow the doctors to address it when they have spare time."

In line with the finding that 65.9% of respondents either preferred virtual appointments, or wanted to be offered a combination of virtual and hospital appointments in future, several survey respondents also mentioned remote consultation formats in their responses, with many saying that they would like virtual formats to remain an option in future.

"Keep virtual appointment available in the future."

"Video calling has made it a lot easier and quicker. I'd be happy to carry on with it."

However, some respondents also made suggestions of how to improve virtual appointments, including requests for better equipment and the option to have video on the call.

"Use better quality audio equipment when on a video call; simple headsets with a microphone would help a lot. The current audio quality is low enough to impair discussion."

"Provide better standard of virtual care, with video calls instead of phone calls, and ensuring that everyone has a similar level of testing."

Aside from communication with patients, another area for improvement mentioned by some respondents was communication and collaboration among CF team members, as well as with other clinical teams.

"Communicate better within team. Sometimes [there is] miscommunication or stuff [is] not passed on correctly or effectively."

"The team members don't communicate with each other in clinic, so I find myself repeating large chunks [of] information to several different people/getting my observations done multiple times."

"Better cooperation with kidney team."

"Communication in the pharmacy department could be better to better facilitate new and repeat prescriptions."

Linked to the communication theme, several respondents also felt their CF team could listen more closely to their views and concerns, and some said their team could be more supportive towards them.

"Listen and have a better perspective of a situation. Approaches can be very rigid and not transparent."

"Listening to the patient, we aren't doctors ourselves but we know how we feel."

"Spend a little more time with you when you need support, clinic goes too quick before you speak to everyone, before you have to leave."

Continuity of care was also seen as important by many, who felt this area could be improved, with some saying they would value a named nurse contact.

"All the nurses are really helpful, but it would be helpful to have one individual as a dedicated point of contact, I never know who I will be speaking to."

"I never know who I'm going to end up talking to. It's frustrating, as you feel like you have to explain your situation from scratch every time you talk to a new person. I think it would be so much easier and more personal if patients were assigned to a main nurse to have their care dealt with."

Some respondents felt that there was room for improvements in the level and quality of care. These types of comments touched on different aspects of CF care, from general support to physiotherapy and dietetics, staff cover and access.

"Dieticians need some further training."

"Support mental health, not just refer to someone to talk to."

"Some members of the team could show more presence."

"Recruit additional CF trained staff."

Several respondents mentioned waiting times in clinics, in pharmacy and for referrals, suggesting that efficiency could be improved.

"Time spent in clinic appointment. Always seem to spend a lot of time sitting in a room on my own waiting for a member of staff."

"Waiting a long time for new referrals could be speeded up which would help with my motivation."

Other suggestions made by five or more respondents included improving access to treatments, including new modulator drugs, increasing knowledge about CF among non-CF staff and improving infection control.

Recommendations and next steps

From the insights presented in this report, there are a number of quality improvement activities that could be considered by services, depending on local challenges and priorities.

All CF centres that took part in the PREMs work have received a tailored feedback report summarising feedback from people with CF under the centre's care. Reviewing their centre report against the UK-wide findings and recommendations will help services to highlight good practice, and to identify local challenges and priority areas to target with quality improvement efforts.

CF centres that do not have their own, tailored PREMs report could use locally gathered patient feedback and the insights presented in the UK-wide report as a starting point to reflect on how care is delivered in their service and where QI work could have the most impact.

We can make several general recommendations from the patient-reported experience data presented in this report. These recommendations are generalised and based on feedback from people with CF who attend different CF centres across the UK. Many of the recommendations 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 patients see a psychosocial professional at least once per year for screening at annual review, and ideally have access to psychosocial support year-round, should they need it⁶
- Ensure staff can provide information and advice on benefits, education, employment and other areas, with appropriate signposting or referral to external services and resources as necessary, e.g. resources from the Cystic Fibrosis Trust⁷
- Endeavour to inform people with CF about new treatment options, such as Kaftrio, as soon as possible, supporting them to access such treatments in a timely way, where they are eligible and this is appropriate
- Endeavour to offer continuity of care, ideally with a named nurse contact for each patient and clear cover arrangements for when the member of staff is on leave or unavailable
- Ensure all patients know how to access support outside of working hours

■ Care in hospital

- Endeavour to schedule and run annual review clinics in a way that minimises waiting times for people with CF, including waits for pharmacy and onward referrals
- Ensure infection control protocols are up to date and followed at all times
- Ensure CF patients do not wait in waiting rooms, in line with best practice, wherever possible; if any wait in a waiting room, e.g. in pharmacy, is necessary, check that there are no other CF patients present
- Endeavour to measure patients' height, weight and lung function in individual clinic rooms, rather than a shared space
- Ensure patients with CF have their own room, with en-suite bathroom when staying on the CF ward
- Where bathrooms are shared on other wards, consider protocols to ensure no other people with CF access the same facilities and endeavour to reassure the patient that this is being checked regularly
- Ensure non-CF staff in the hospital who come into contact with people with CF know about the risks of cross-infection and are aware of infection control and segregation protocols

⁶ The 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)

⁷ <https://www.cysticfibrosis.org.uk/the-work-we-do/information-resources/publications>

■ Care at home

- Endeavour to support people with CF to receive services in the community, including arranging access to nursing care in the community
- Endeavour to offer home IVs where this is possible and appropriate
- Ensure patients feel confident to administer home IVs and know who to contact if there are any issues, including outside of normal working hours

■ Communication

- Ensure test results, including negative test results, and written feedback from annual reviews are shared with patients in a timely manner
- Endeavour to continue to offer hospital as well as virtual appointment options, including video calls, where possible and appropriate
- Where virtual appointments are offered, ensure that audio equipment and quality are adequate to have an effective conversation with the patient (consider using headsets and video)
- Ensure staff changes in the CF team are communicated to patients in a timely way
- Ensure effective communication among members of the CF MDT and across other teams and departments

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 people with CF under their care, services should consider targeted quality improvement projects to address any outstanding challenges that may have been highlighted.

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

- undertake a QI project to ensure all its patients are aware of contact details for out of hours services
- consider how it provides advice on benefits, education, employment and sexual health, and identify opportunities to make patients aware of and improve its offer
- map out its process for relaying test results to patients to identify opportunities to communicate these to patients sooner
- review its process for annual review clinics in hospital to explore opportunities to reduce waiting times for people with CF attending their review
- implement a training session delivered by CF team members to non-CF ward staff that come into contact with people who have CF
- assess its community offer and seek opportunities to strengthen this

The Cystic Fibrosis Trust's QI team and Quality Improvement Working Group are available to advise services during this work. Contact us at QI@cysticfibrosis.org.uk

Glossary

Word/phrase	Meaning
Annual review (AR)	A full health review undertaken by the specialist CF centre once a year.
CAG	Clinical Advisory Group for the Cystic Fibrosis Trust
Centre	Hospital providing expert care and specialised disease management to 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.
Infection control	Special measures to keep patients safe from infection e.g. segregation, cleaning, disinfecting.
In-hospital IVs	Intravenous antibiotic therapy given in a hospital ward.
IVs	Intravenous antibiotic therapy – a course of antibiotics through the vein to treat an infection.
Median	The middle value (number) when all values in a series are arranged from smallest to largest.
MDT	Multi-Disciplinary Team; your CF team made up of each discipline i.e. nurse, physio, social worker, dietitian.
NICE	National Institute of Clinical Excellence – provides guidance, advice and information services for health professionals.
PREMs	Patient-reported experience measures
Pulmonary exacerbation (acute infection)	Worsening of respiratory symptoms i.e. coughing with more mucus and shortness of breath.
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.
Range	Smallest to largest value.
Respondents	People living with cystic fibrosis who responded to the PREMs survey

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.

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