

UK Patient Reported Experience Measures survey (PREMs)

Paediatric Report

Data collection period

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UK Patient Reported Experience Measures survey (PREMs) Paediatric Report

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Introduction

The paediatric Patient Reported Experience Measures survey started in 2019 and aims to systematically capture patient and carer experience and satisfaction with their cystic fibrosis (CF) care. This first report gives an overview of paediatric CF care in the immediate pre-pandemic period. It will also provide vital foundational data to help us understand how patient and carer experience changes over time in response to introduction of highly effective modulator therapy, digitisation of NHS services, and the COVID-19 pandemic.

Graphs will show results split into two groups. The 'UK Network' cohort includes all responses (full and shared care), while the 'UK Centre' cohort focuses on those in full care only. Results are shown for 0-12 and 13+ age categories from the 25 CF centres that participated in the survey.

Unless otherwise specified, the questions ask about the 12-month period before the respondent completed the survey. This means data shown in this report cover care experiences between September 2018 and March 2020, depending on when respondents completed the survey.

Throughout this report you will see references to quality standards and aims or objectives from the paediatric Cystic Fibrosis Service Specification. These measures show the standards of care expected from organisations funded by NHS England to provide specialised care. For further explanation please go to our website:

cysticfibrosis.org.uk/laysummaries

The information contained in this report and sent to CF centres around the UK makes sure the voice of people with cystic fibrosis shapes the way that services evolve over time. We want to thank people with cystic fibrosis and their families for taking the time to complete these surveys. We are also incredibly grateful to CF clinical teams for supporting this work by sending out surveys and using the results locally.

If you have any feedback on this report please get in touch on social media, or by emailing the team at **QI@cysticfibrosis.org.uk**

Sophie Lewis

Clinical Quality Improvement Advisor

Summary and key data

673 responses were received from 25 paediatric CF centres, representing approximately 15% of the CF population in paediatric care across the UK.

0-12 years – 517 (417 full-care and 100 shared-care responses)

13+ years – 156* (133 full-care and 23 shared care responses)

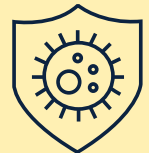
* 71 responses from patients, 55 responses from parent/carers and 30 responses unknown if patient or parent/carer

- There does not appear to be a significant difference in quality-of-care experience between full-care and shared-care respondents.
- There was variation between centres in the proportion of respondents who had
 - seen a psychologist, social worker or pharmacist;
 - overall rating of MDT;
 - access to community support;
 - infection control measures;
 - whether IV antibiotics were received in last 12 months;
 - experiencing a delay in receiving IV therapy, particularly planned IV therapy.
- More work is needed to understand delays in starting IV antibiotics for pulmonary exacerbation.

88.3% of respondents rated all members of MDT seen in the last 12 months as excellent or good.



71% of respondents felt infection was well-managed at their centre but...



18% waited in outpatient waiting room

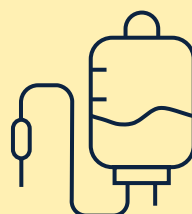
8% were admitted to a non-CF ward as CF ward not available

6% shared a room, bay or toilet, potentially with other CF patients



22% of respondents did not see a social worker when they had needed to in the last year, as one was not available, and **19%** did not see a pharmacist.

15% of respondents had not received written feedback from their annual review.



21% of respondents had a delay in starting urgent IV antibiotics.



51% of respondents reported access to community care.

Section 1

CF multidisciplinary team

Paediatric Cystic Fibrosis Service Specification: Section 3.1: Aims and objectives of service

Ensuring equity of access to services for the CF population

Paediatric CF Service Specification: Domain 2 – Enhancing quality of life for people with long term conditions.

Access to psychologist at annual review

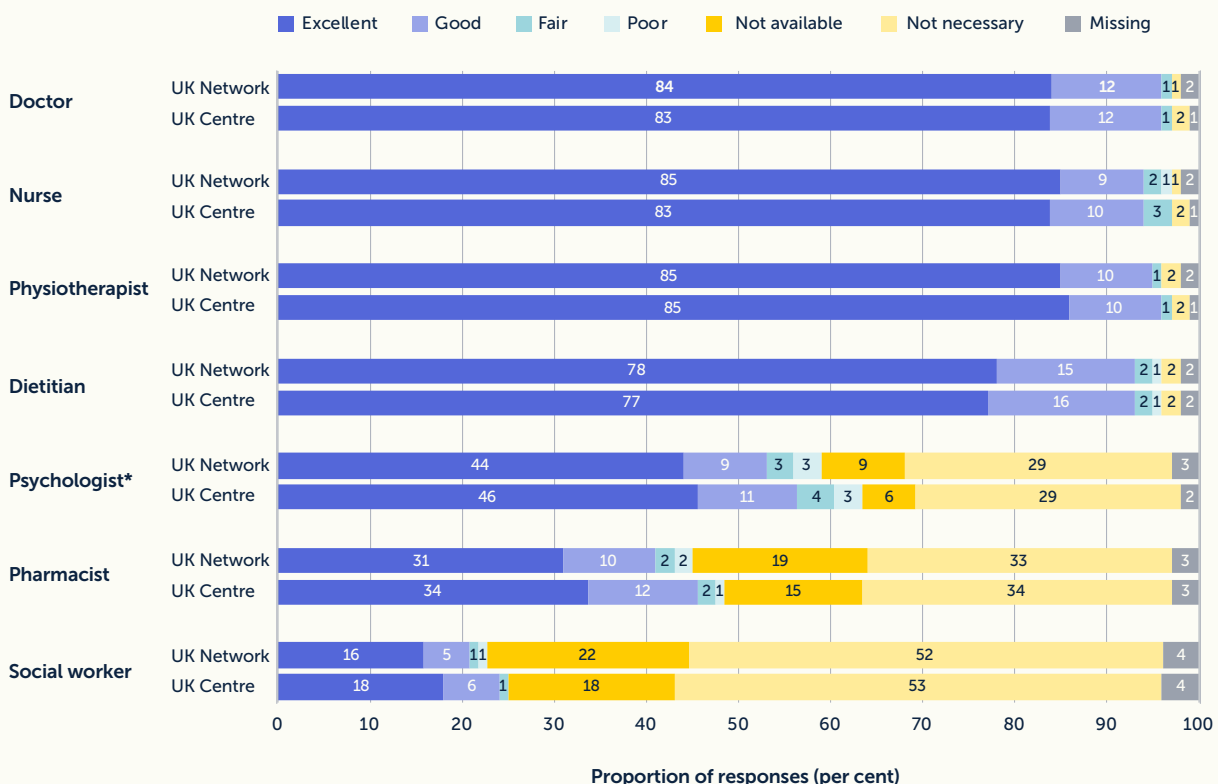
Figures have been rounded to the nearest whole number and results <0.5 have been dropped to make graphs easier to read. The number of responses varies between each section as some respondents did not answer all the questions.

Question: Did you/your child have access and support from each member of the CF multidisciplinary team (MDT) when you needed them over the last 12 months? (Response options: "Yes", "No, none available", "No, not necessary". If 'Yes', please rate your experience.)

The majority of respondents said they could access doctors, nurses, physiotherapists and dietitians when they needed to. And more than 90% rated support from these groups as either excellent or good. However 22% of 0-12 and 13+ respondents were unable to see a social worker as one was not available in the 12 months before the survey was completed. Findings were similar for pharmacists, with 19% of 0–12-year-olds and 17% of 13+ respondents saying they could not access a pharmacist when needed. If we exclude those who skipped the question and those who said access/support had not been necessary for them, then nearly half (47%) of respondents across the two age groups said that they had been unable to access a social worker when they needed to, as one was not available. For pharmacists, this figure was 28% and for psychologists it was 12%.

Figure 1: Respondents' experience with each staff group, 0-12 years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

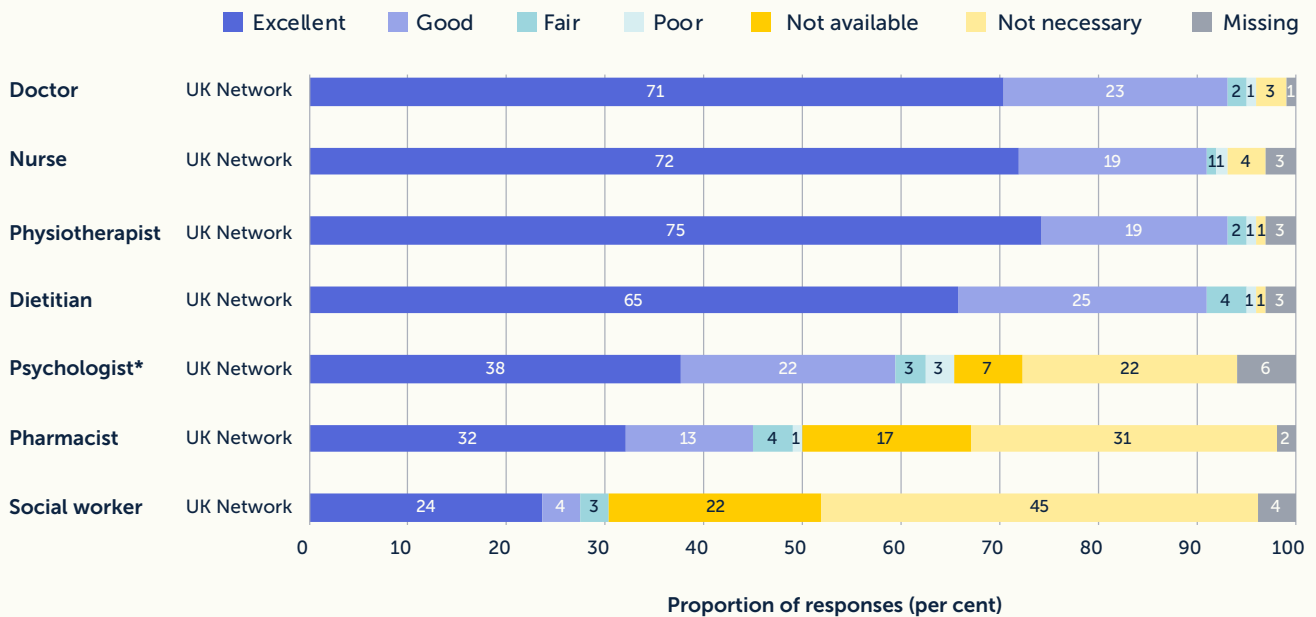


*85% is the minimum proportion of paediatric patients that should be offered access to a psychologist at annual review.

Figure 2: Respondents' experience with each staff group, 13+ years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received

*85% is the minimum proportion of paediatric patients that should be offered access to a psychologist at annual review



59% of the 0-12 respondents and 66% of 13+ respondents reported seeing a psychologist in the 12 months before the survey.

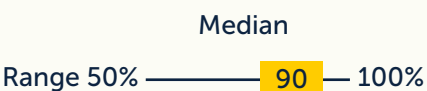
Proportion of respondents at each centre who saw a psychologist, pharmacist, or social worker in last 12 months.

Centres with less than 10 responses were excluded.



Proportion of respondents at each centre who rated CF care team members they had seen as either excellent or good.

Centres with less than 10 responses were excluded.



88.3% of respondents rated all members of MDT seen in the last 12 months as excellent or good.



22% of respondents did not see a social worker when they had needed to in the last year, as one was not available, and **19%** did not see a pharmacist.



Contact

Paediatric CF Service Specification: Section 3:2: Service description/care pathway.

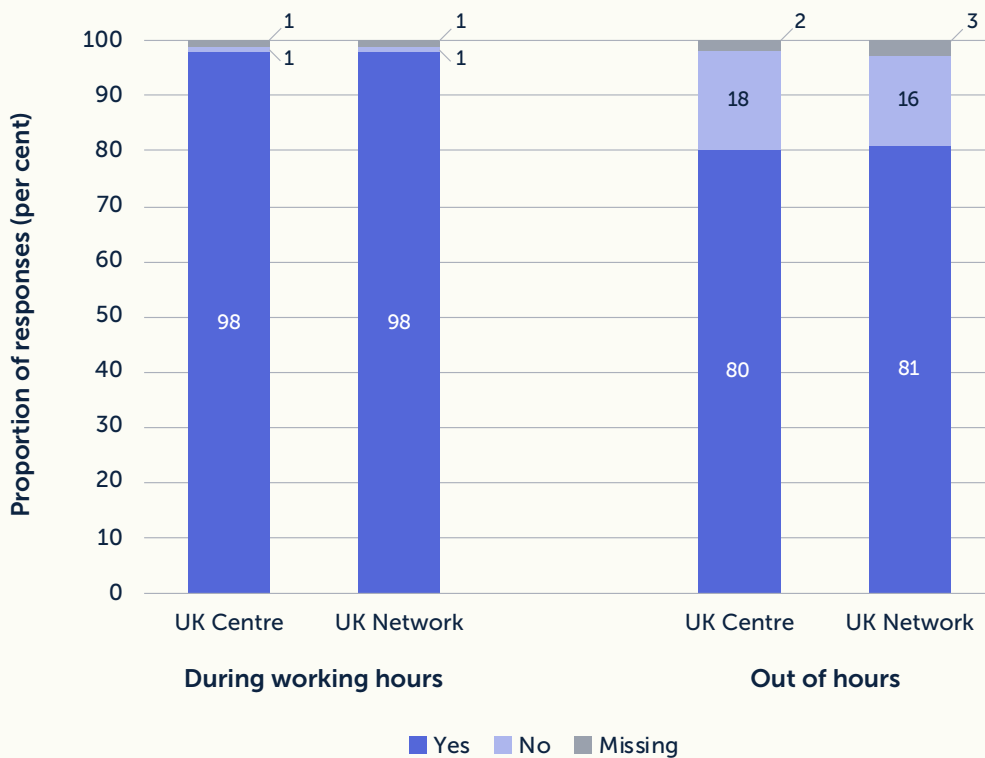
Patients and their families will be made aware how to contact their clinical teams and CF support groups

Question: Are you clear who to contact if you have concerns about your cystic fibrosis?

There was good awareness of how to contact the CF MDT during working hours, however 16% of respondents were unsure how to contact their CF team out of hours.

Figure 3: Awareness of who to contact, combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received



Proportion of respondents at each centre who know how to contact CF MDT outside of working hours.



16% of respondents did not know how to contact their CF team out of hours.



Referrals

Paediatric CF Service Specification: Section 3.5: Interdependencies with other services/providers

The service will provide access or referral to specialists.

Question: If needed, were you/your child able to see one of the professionals listed below in the last 12 months?

In the 13+ age group referrals to the specialist diabetes team are higher than in the younger age group – 29% had received a referral in the 12 months before completing the survey compared to 9% of 0–12-year-olds. More 13+ year olds had received a referral to a hepatologist (15% compared to 7% of 0–12 respondents) whereas there was little difference in levels of referral to a gastroenterologist between the age groups.

Figure 4: Proportion of respondents who have been referred, 0-12 years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received

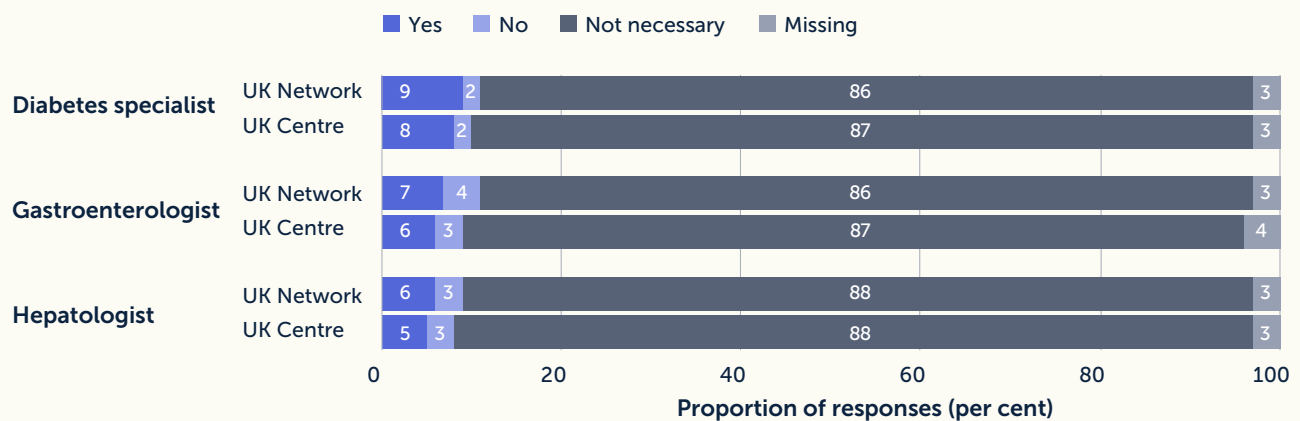
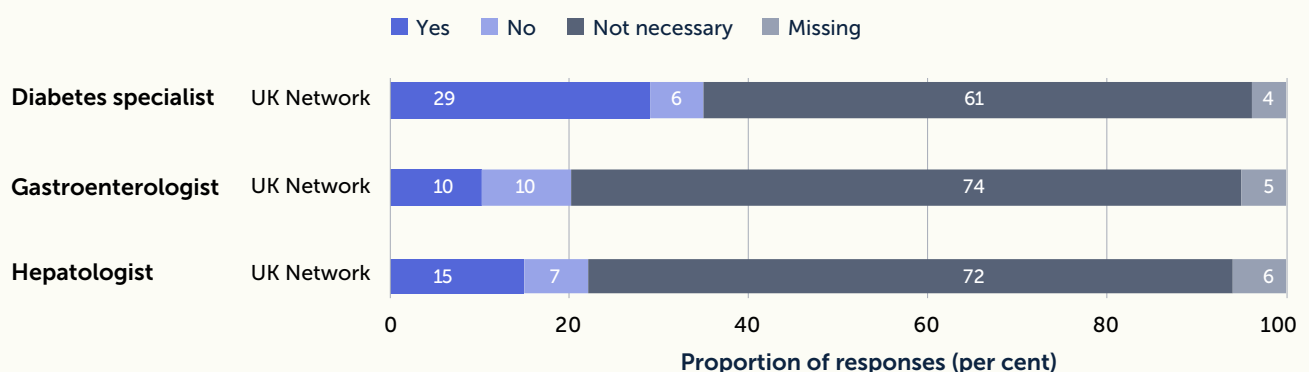


Figure 5: Proportion of respondents who have been referred, 13+ years



Proportion of respondents at each centre who had received a referral



Section 2

Experiences of care

Figures have been rounded to the nearest whole number and figures <0.5 have been dropped to improve graph readability.

The number of responses varies between each section as some respondents did not answer all the questions.

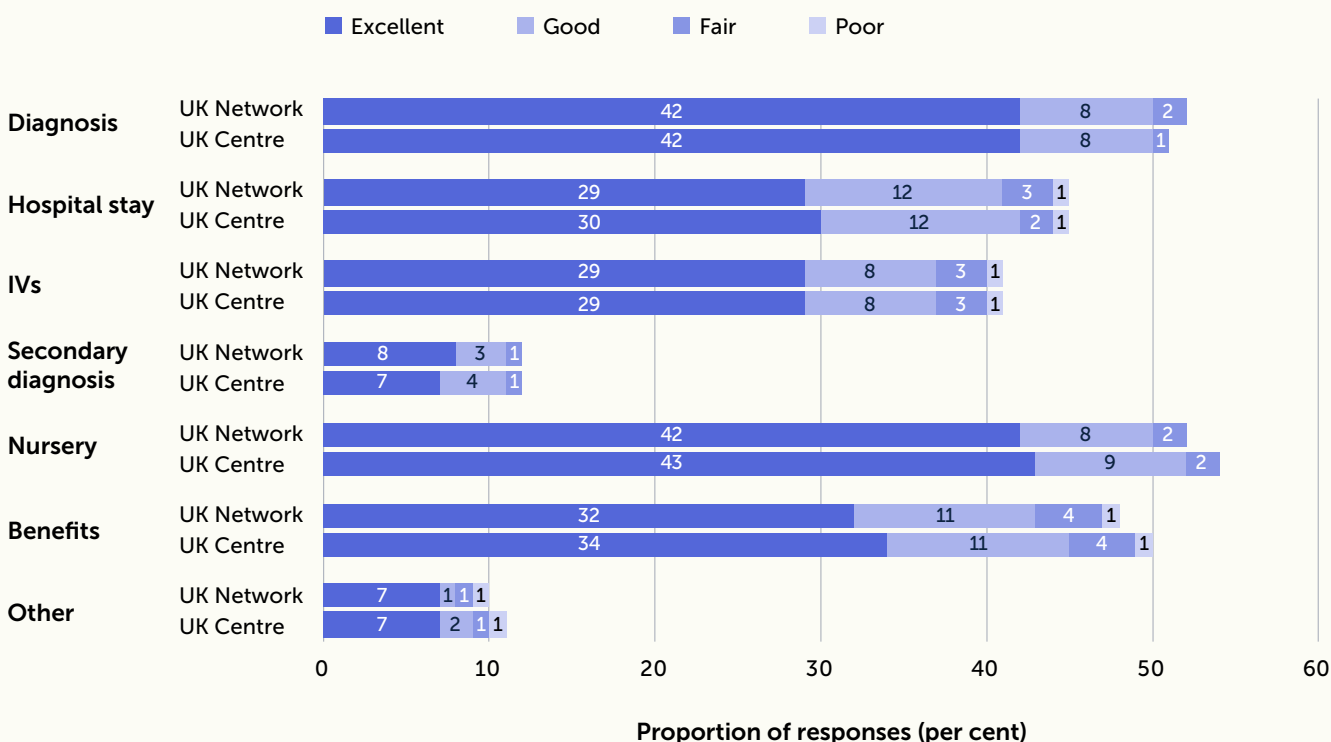
Support during key events

Question: Using the list below, please rate the support you/your child have received during the following important life events over the last 12 months.

92% of 0-12 respondents and 86% of 13+ respondents marked their care experience during significant life events as excellent or good. In the 13+ age group 8% of respondents marking their experience of transition and hospital stay as fair or poor. 9% of respondents marking their support for accessing benefits as fair or poor.

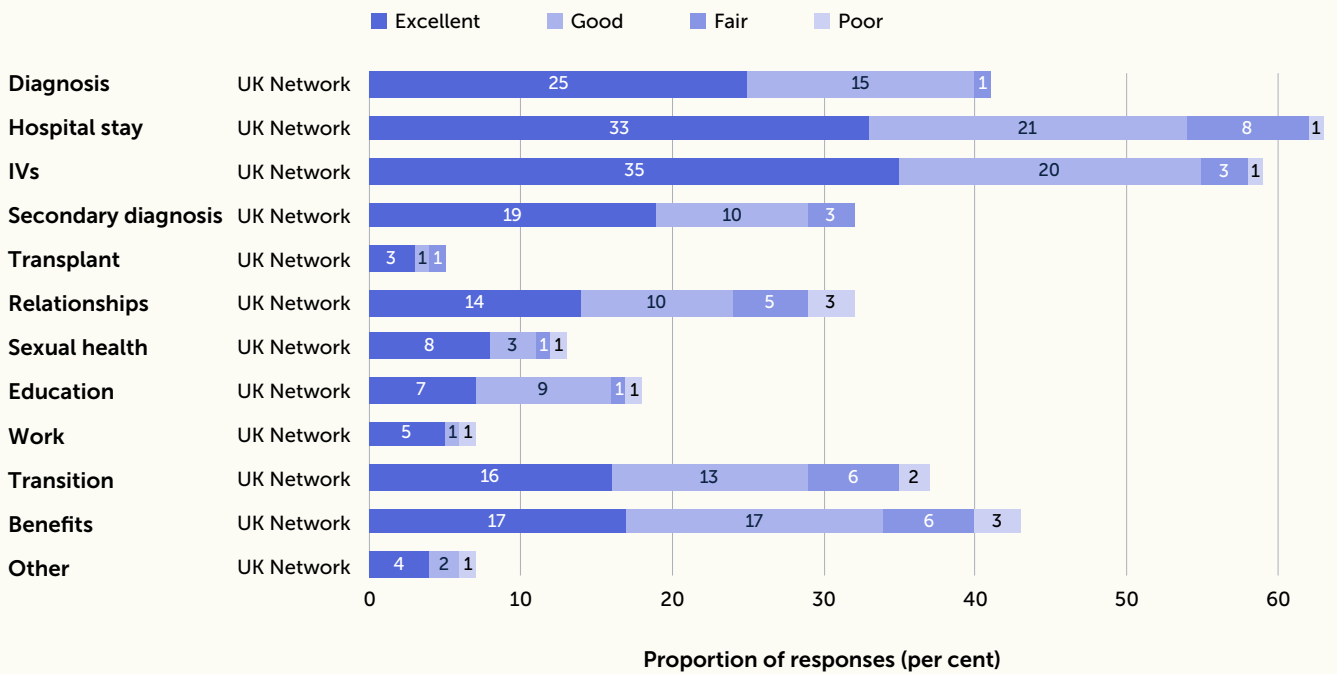
Figure 6: Experience of support during important event(s), 0-12 years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



Responses shown focus on those who said they had experienced support during specified events; where respondents said an event was not applicable to them or did not complete the question, data are not shown here, which is why the proportion does not add up to 100%

Figure 7: Experience of support during important event(s), 13+ years



Responses shown focus on those who said they had experienced support during specified events; where respondents said an event was not applicable to them or did not complete the question, data are not shown here, which is why the proportion does not add up to 100%

Annual review

Paediatric CF Service Specification: Domain 2: Enhancing quality of life for people with long term conditions.

All children should have an annual review and management plan discussed with the family.

Question: Have you and your child had a face-to-face annual review in the last 12 months?

Question: Were all the appropriate tests completed and available to discuss at annual review?

Question: Have you been given written feedback after your annual review?

According to the paediatric CF service specification, at least 85% of children should have an annual review and management plan discussed. 90.5% of paediatric respondents had a face-to-face annual review over the last 12 months, however further exploration is needed to identify whether those who did not have a face-to-face appointment had a virtual annual review or did not have an annual review at all. Some respondents' commented that they had not yet received written feedback as they were completing the survey at their annual review appointment. However 15% of 0-12 respondents and 13% of 13+ respondents marked they had not received written feedback following their last annual review.

Figure 8: Annual review (AR) experience, 0-12 years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

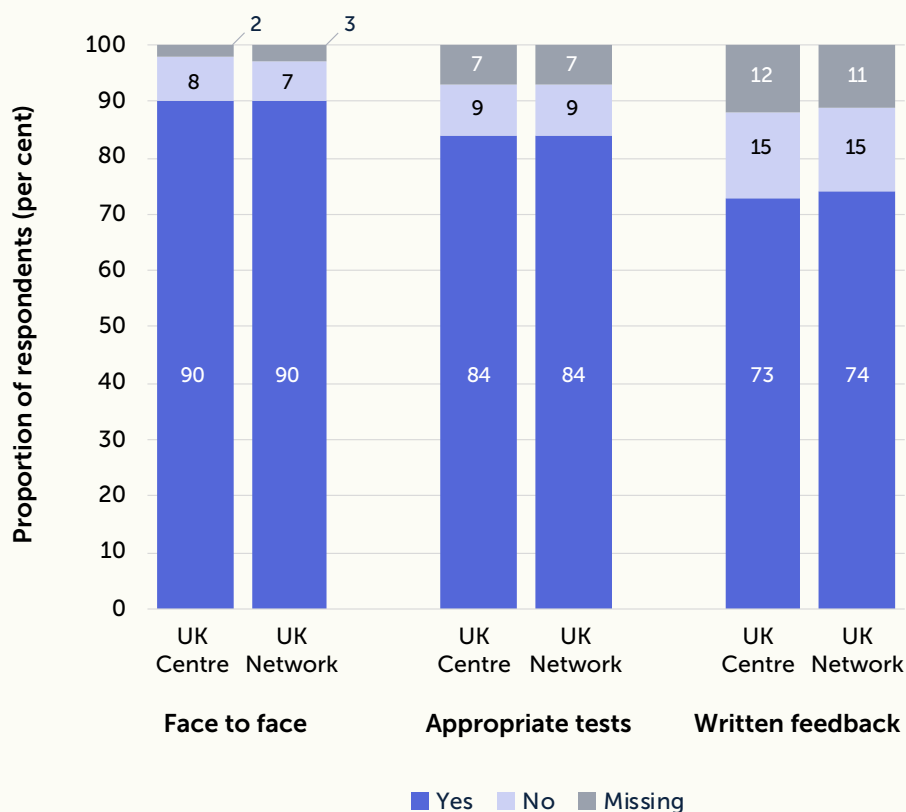
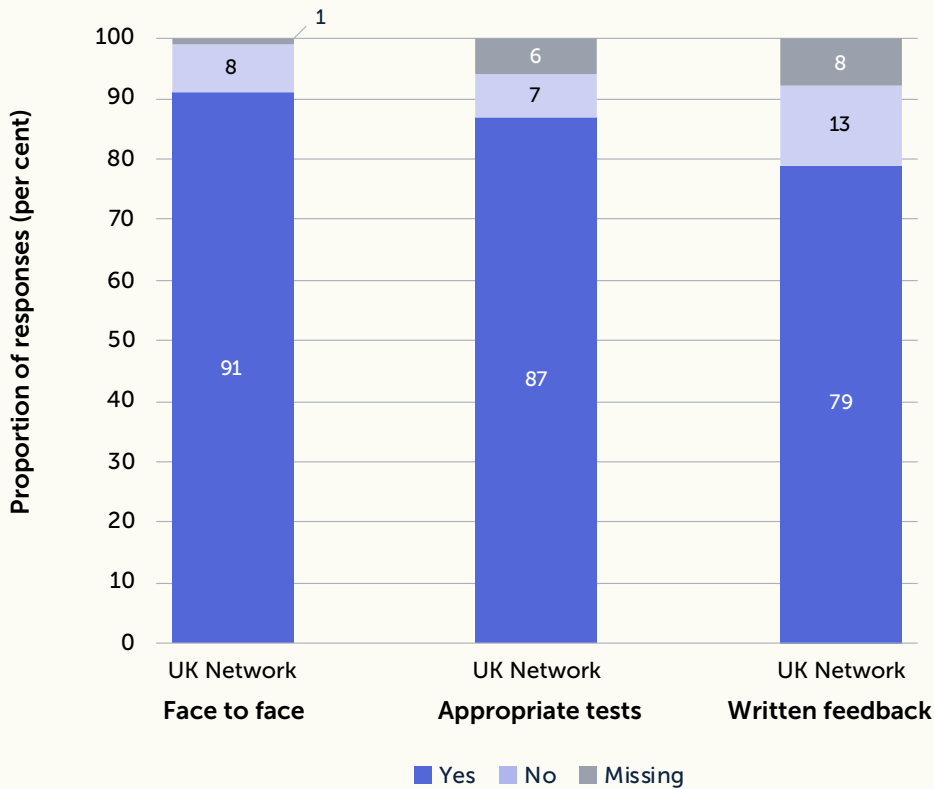


Figure 9: Annual review (AR) experience, 13+ years



Proportion of respondents at each centre who didn't receive:



15% of respondents had not received written feedback from their annual review.



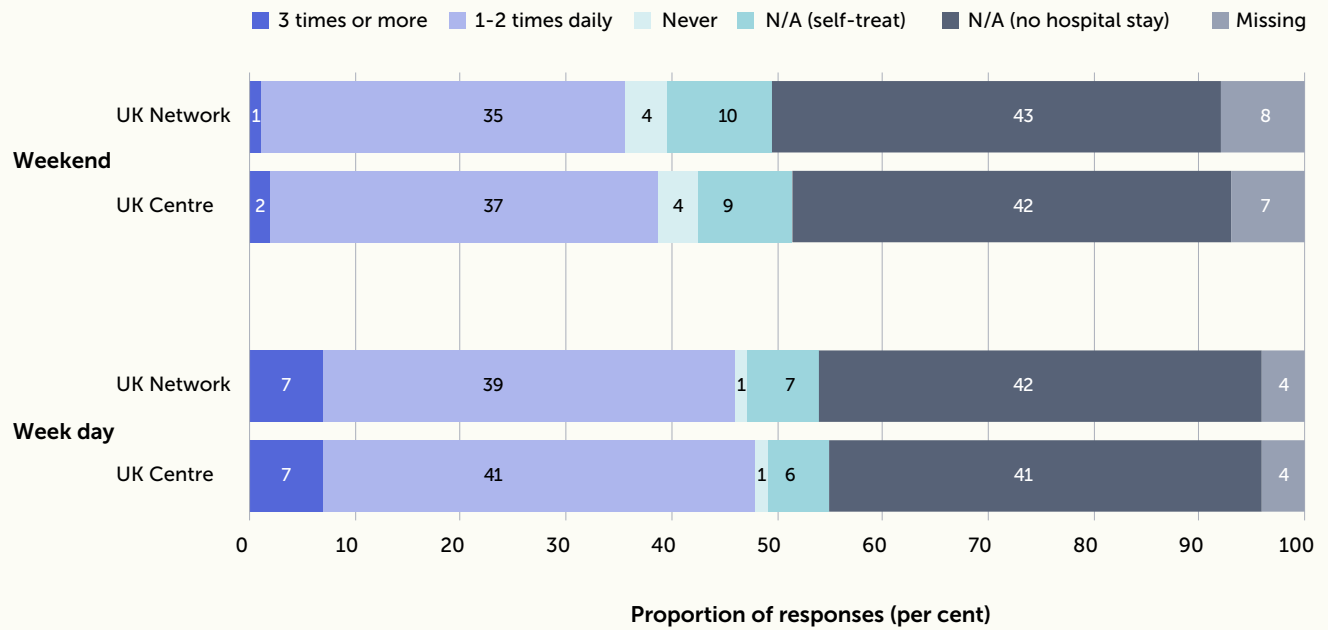
Access to inpatient physiotherapy

Paediatric CF Service Specification: Objective 3.2: Service description/care pathway
 Inpatients will be entitled to and receive physiotherapy treatment seven days a week if appropriate.

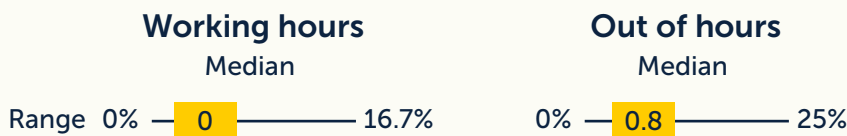
Question: How often are you offered help with physiotherapy when staying in hospital?

Figure 10: Respondents' experience of inpatient physiotherapy, combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey;
 UK Centre group only includes full care responses received.



Proportion of respondents at each centre who didn't receive inpatient physio



Community support

Paediatric CF Service Specification: Objective 3.2: Service description/care pathway.

Community support should include:

- Support in the community by the specialist CF multi-disciplinary team.
- Open access to nursing care in the community. This may be a CF nurse specialist from the CF service, or local community nurses including children’s nurses who have specific training, experience and supervision in cystic fibrosis.
- Support for patients receiving overnight enteral feeding.
- Care of indwelling vascular access devices, gastrostomies and other stoma.
- Physiotherapy input where appropriate.
- Liaison with nursery, school, or college for patients still in education.

Question: Does your child have access to any community support/care delivered at your home, such as physio and cough swabs?

Figure 11: Proportion of respondents who had access to community support/care, 0-12 years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

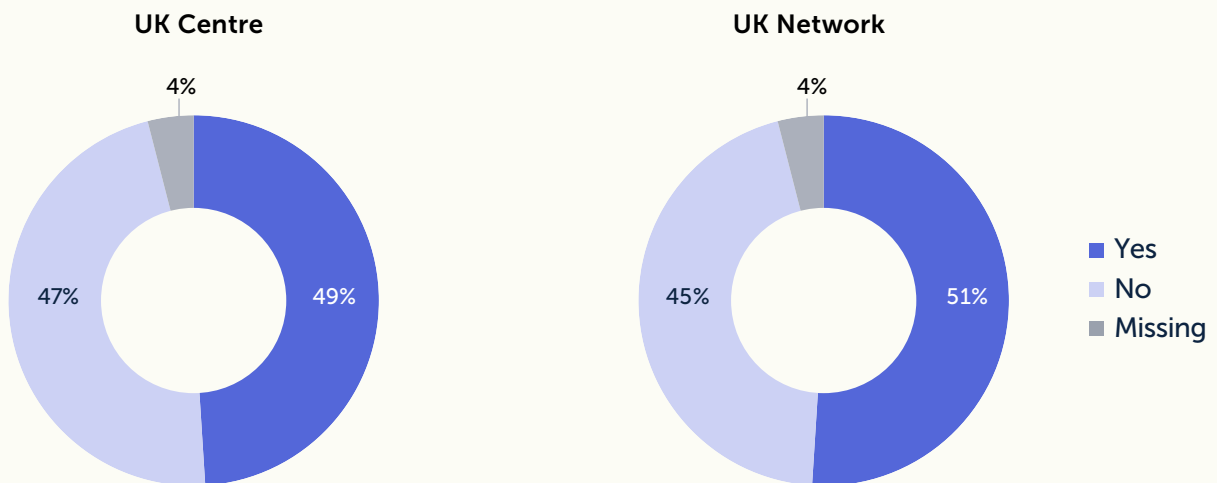
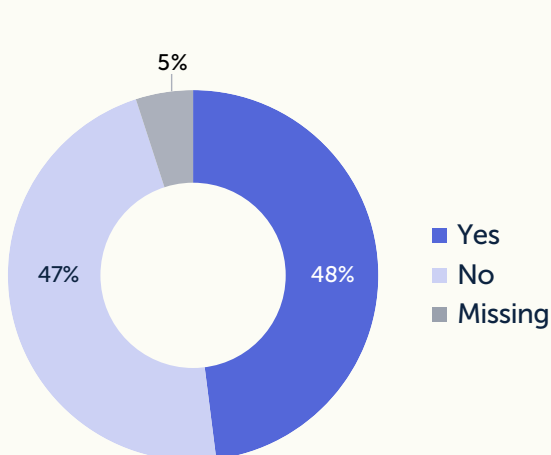


Figure 12: Proportion of respondents who had access to community support/care, 13+ years



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



51% of respondents reported access to community care.

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

Figures 13 and 14 show responses from the people who reported having access to community support (266 for 0-12 year olds and 75 for those aged 13+).

Figure 13: Respondents' community support provider, 0-12 years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

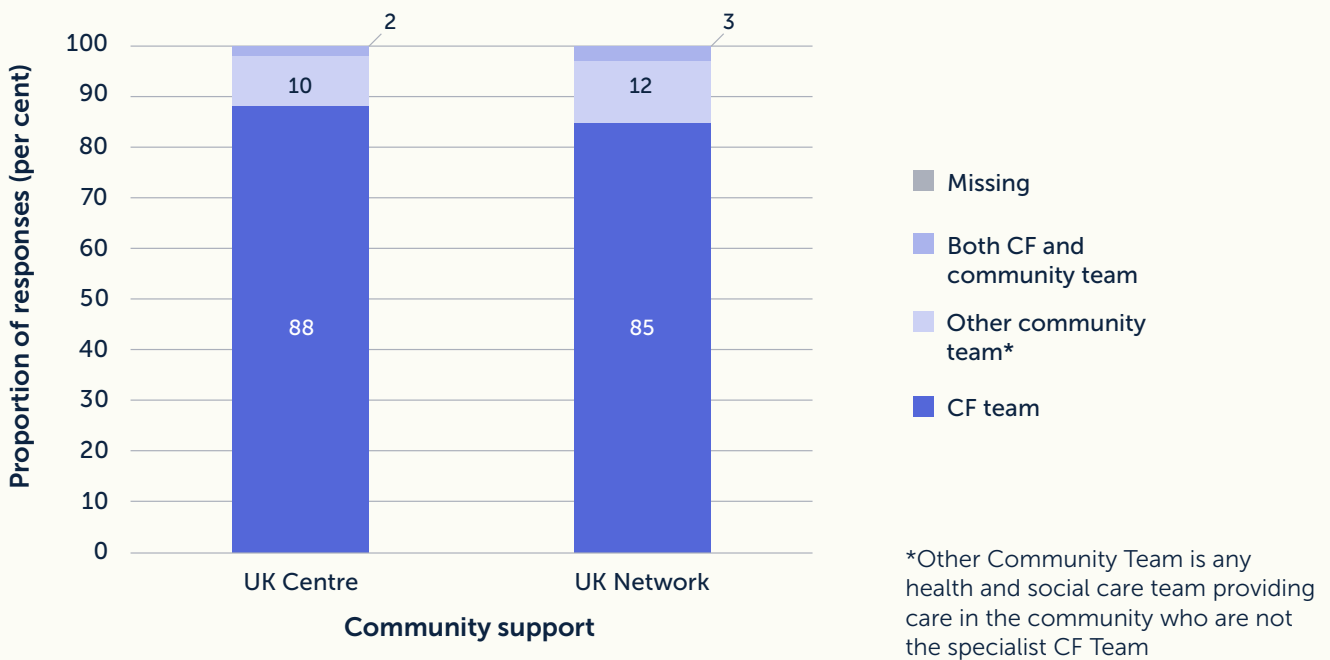
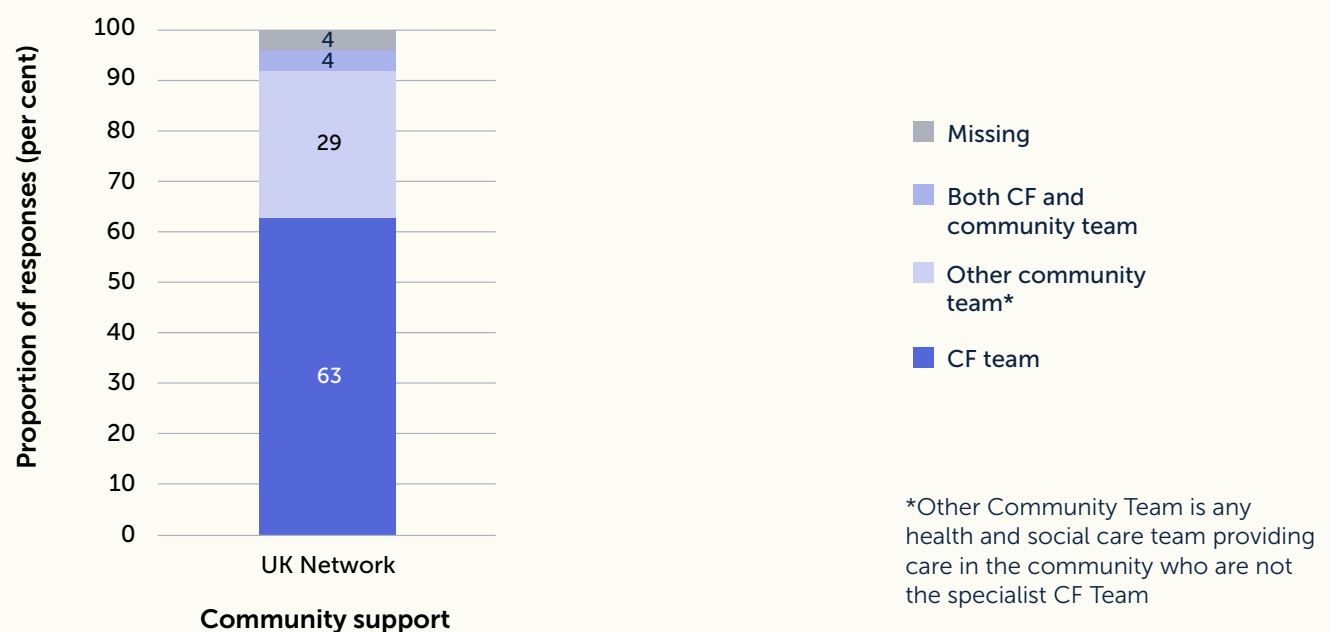


Figure 14: Network respondents' community support provider, 13+ years



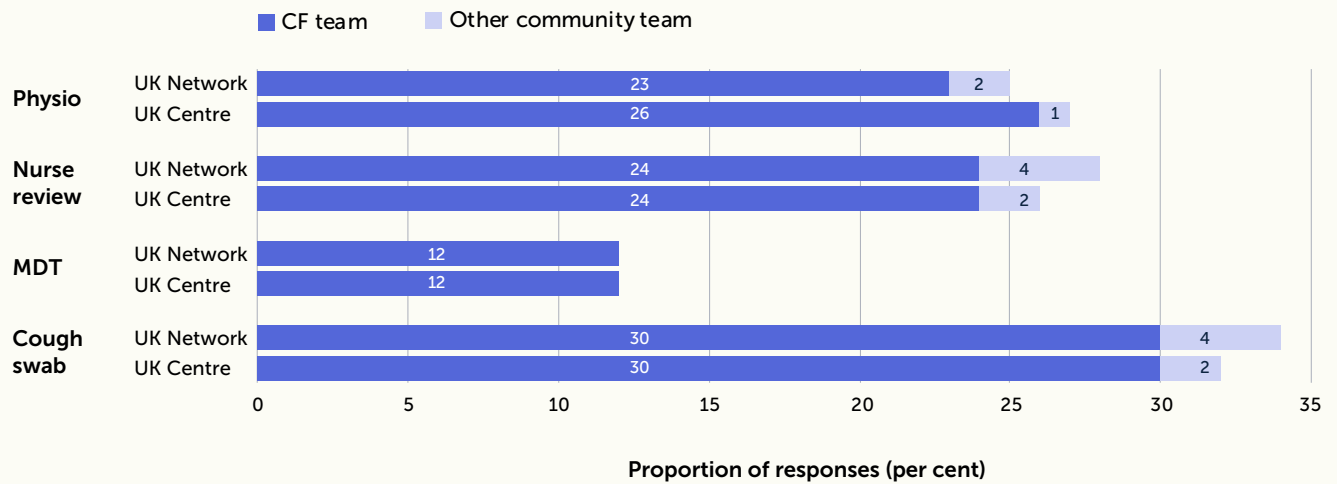
Question: What do the people who provide community support do?

Fewer than 10 respondents reported receiving support in the community from social workers, dietitians, gastrostomy, and medication including IVs.

No dietetics support was indicated by the 13+ respondents, whereas community support to take blood samples was indicated in 10% of 13+ respondents, compared to 0% of 0-12 respondents.

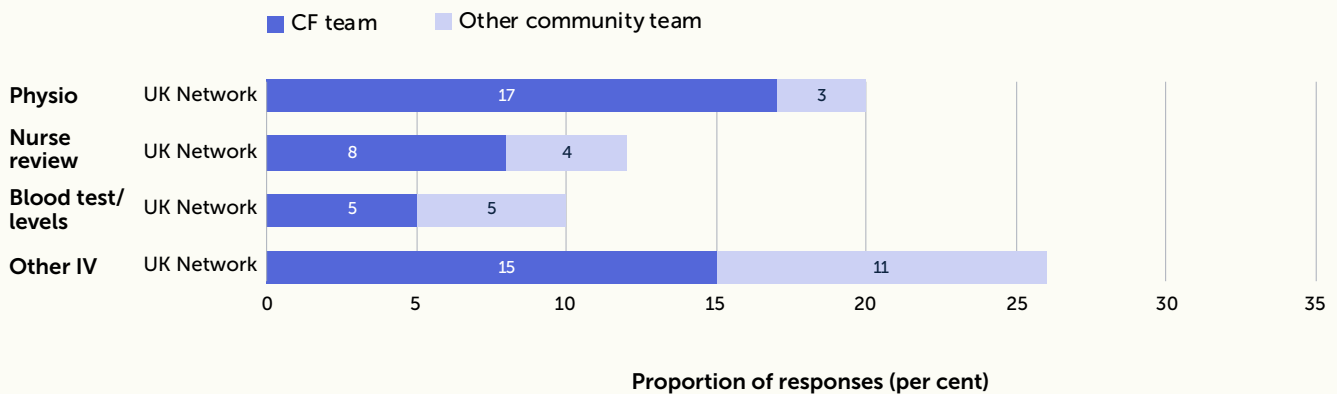
Figure 15: Types of support provided in the community, 0-12 years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



Responses shown focus on those who said they had access to support in the community; where respondents said access was not needed/applicable or did not complete the question, data are not shown here; types of support that <10% of respondents had access to are also not included in this figure.

Figure 16: Types of support provided in the community, 13+ years



Responses shown focus on those who said they had access to support in the community; where respondents said access was not needed/applicable or did not complete the question, data are not shown here; types of support that <10% of respondents had access to are also not included in this figure.

Section 3

Infection prevention and control

Paediatric CF Service Specification: Objective 3.2: Service description/care pathway

All children will be admitted to a facility which provides specialist CF care in single rooms with en-suite facilities.

Figures have been rounded to the nearest whole number and figures <0.5 have been dropped to improve graph readability.

NB: Figures can exceed 100% as respondents can tick more than one option.

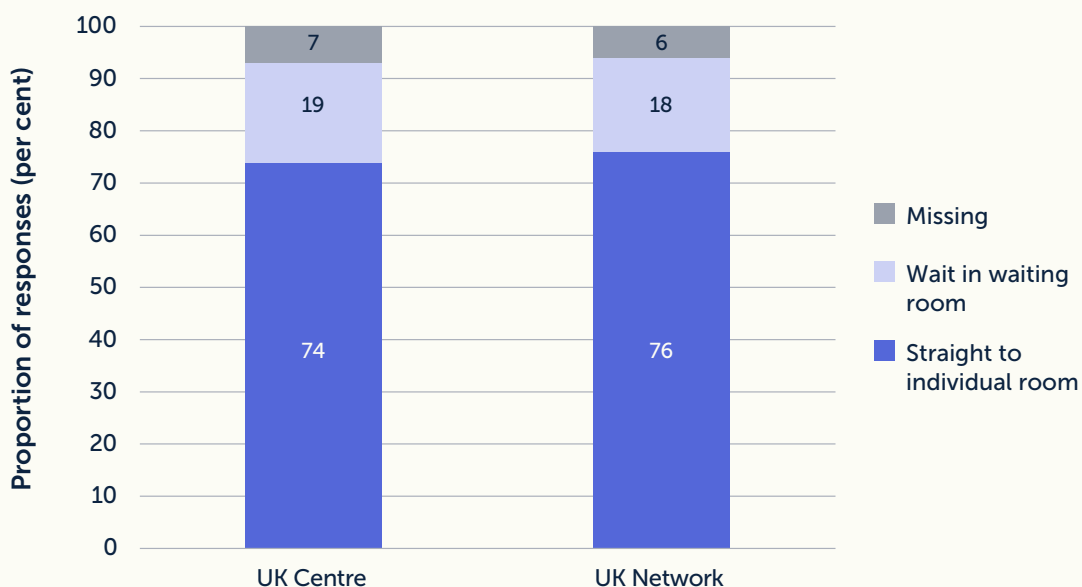
Outpatients

The person with CF or their carer ticked the categories that best described their experience of hospital care over the last 12 months.

18% of UK respondents reported using a waiting room when they arrived at their CF outpatients' clinic, which was identified by several respondents in later comments as a cause of anxiety as they were unsure if there were other CF patients present. Only 1% of respondents rotated round their CF team's rooms. 68% of respondents have their height and weight measured in the same room as all other patients. For lung function, 11% of patients reported being measured in the same room as other patients.

Figure 17: Experience in CF outpatients' clinic, "Where do you wait?", combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received



18% waited in outpatient waiting room.

Figure 18: Experience in CF outpatients' clinic, "How do you see the CF team?", combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

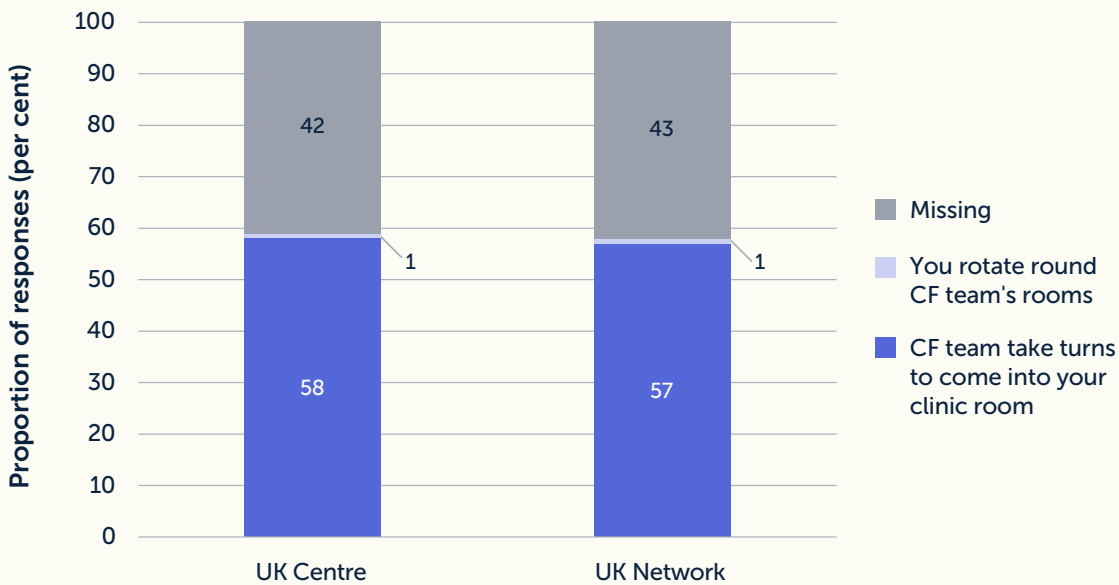


Figure 19: Experience in CF outpatients' clinic, "Where are height and weight measured?", combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

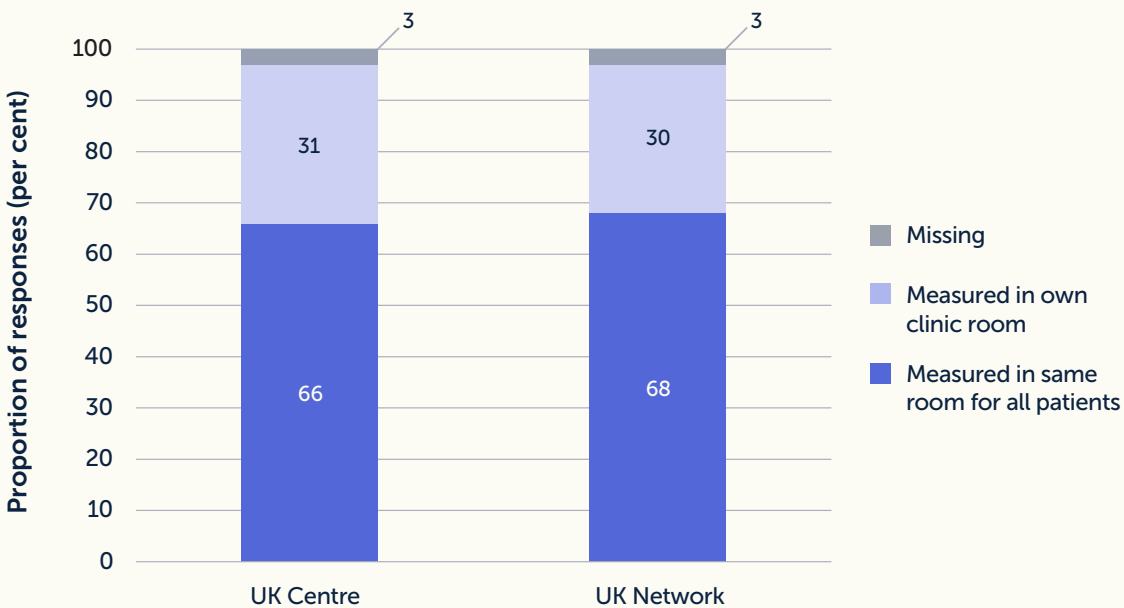
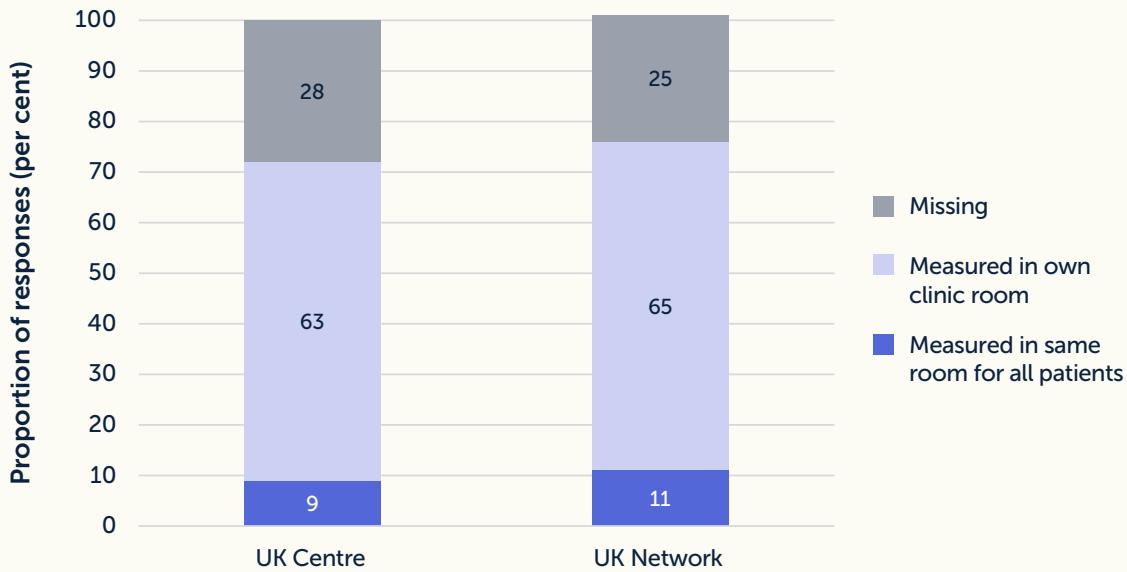
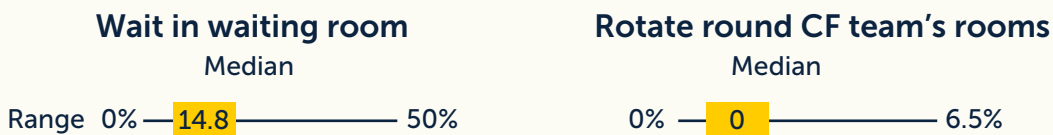


Figure 20: Experience in CF outpatients' clinic, "Where is lung function measured?", combined ages

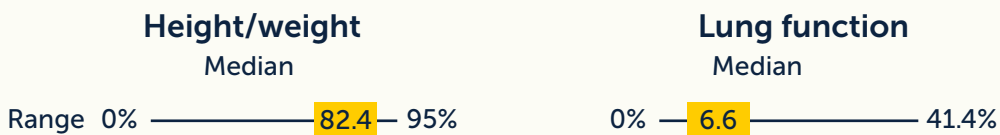
Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



Proportion of respondents at each centre who



Proportion of respondents at each centre who are measured in same room as all patients



When staying in hospital

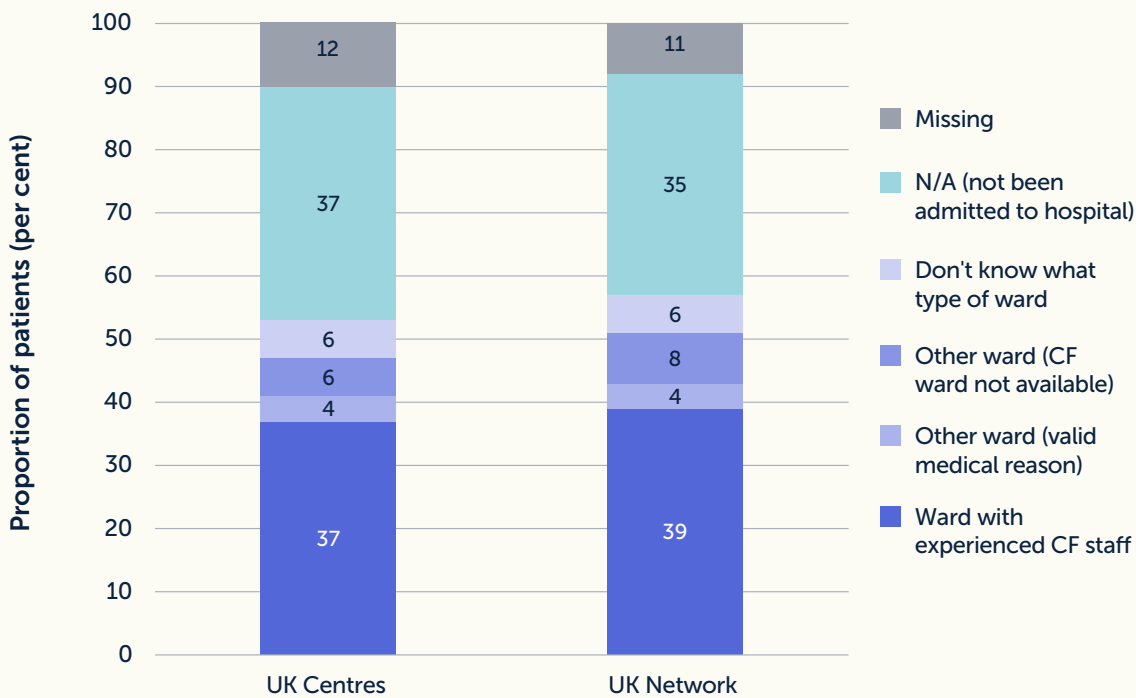
Paediatric CF Service Specification: Domain 4: Ensuring people have a positive experience of care.
 All children requiring inpatient care should be admitted to a ward staffed by CF specialist staff (as defined by national specialist service specification).

The person living with CF or their carer ticked the categories that best described their experience when staying in hospital.

8% of respondents reported they had been admitted to a non-CF ward as the CF ward was not available. NICE guidelines highlight that all patients admitted to hospital should have their own room with en-suite facilities.

Figure 21: Inpatient experience, "What type of ward did you stay on?", combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

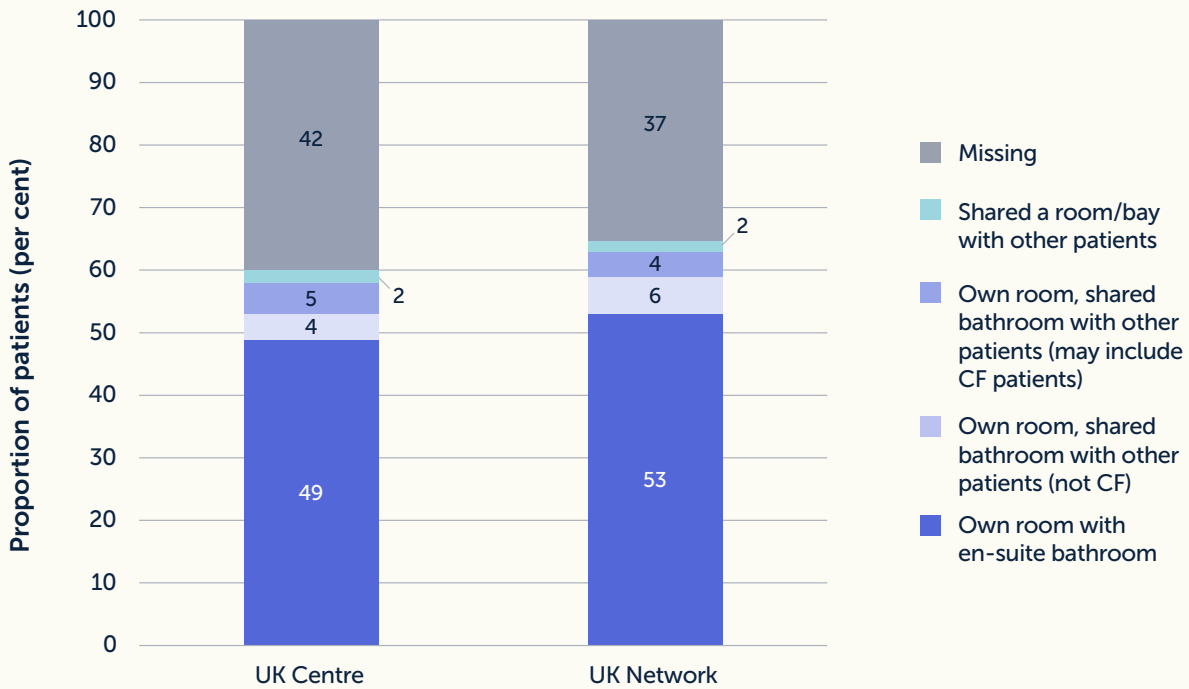


8% were admitted to a non-CF ward as CF ward not available.



Figure 22: Inpatient experience, "Type of bed and bathroom", combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



Proportion of respondents at each centre who

Shared a room/bay/toilet*

*Potentially with other CF patients.

Median

Range 0% — **4.1** — 34.3%

Stayed on a non-CF ward

(CF ward not available)

Median

3.2% — **8.2** — 20.7%



6% shared a room, bay or toilet, potentially with other CF patients.

X-ray and pharmacy departments

The person with CF or their carer ticked the categories that best described their experience of having an X-ray or visiting the pharmacy.

44% of UK respondents marked they had waited in an X-ray waiting room with other patients (potentially including CF patients) while 55% reported waiting in pharmacy with other patients (potentially including CF patients). 12% reported their CF team collected their prescription. Some respondents wrote comments stating that another practice was followed e.g., their prescription was sent to their local pharmacy.

Figure 23: Experience in X-ray department, combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

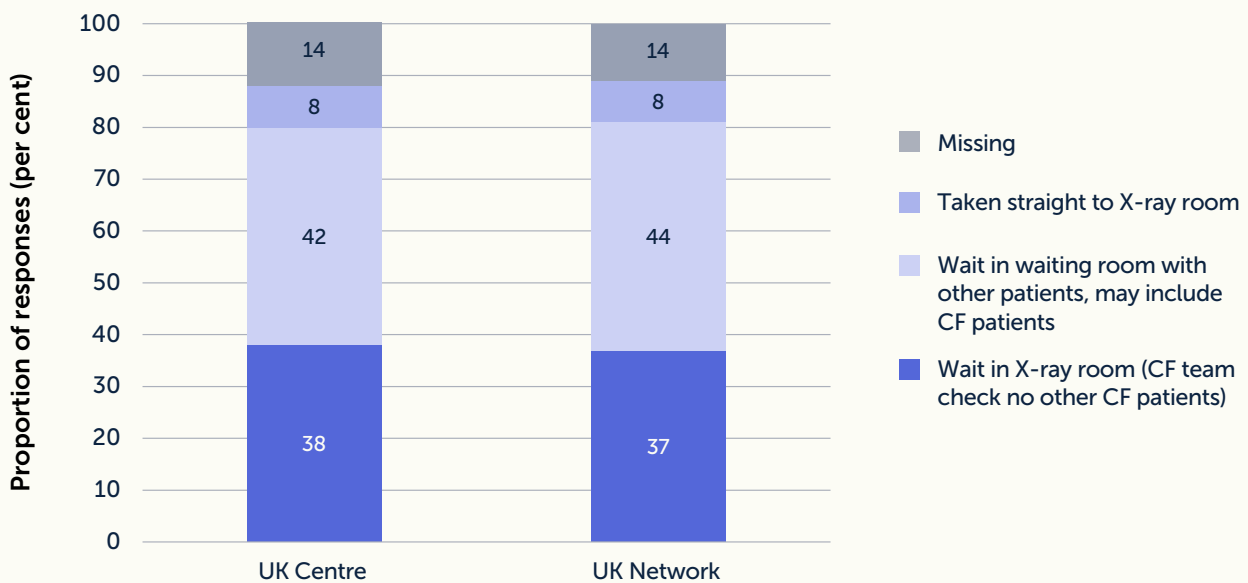
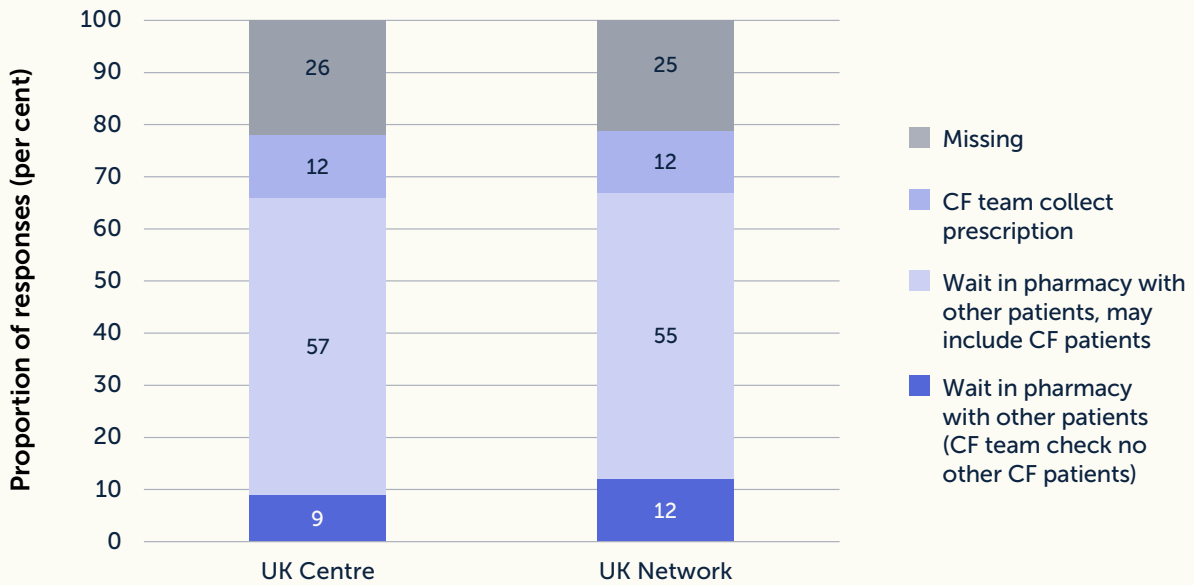
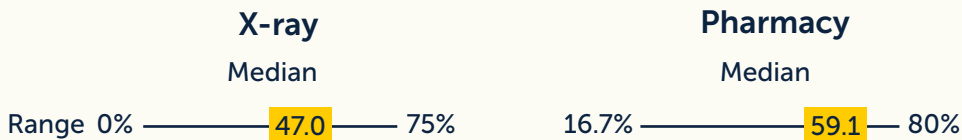



Figure 24: Experience in pharmacy department, combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



Proportion of respondents at each centre who used a waiting room

44% waited in a waiting room, potentially with other CF patients, while at x-ray, increasing to **55%** at pharmacy.

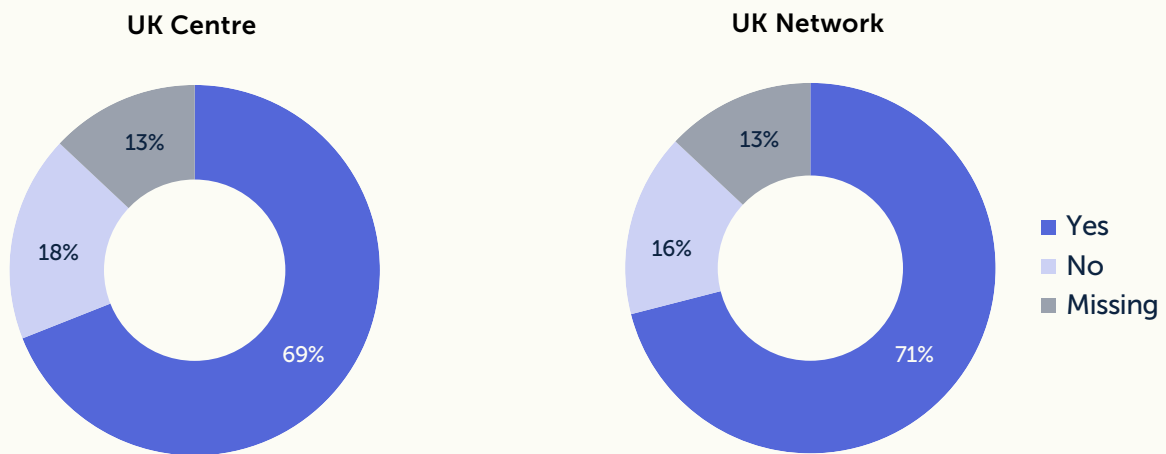
Infection control

The person with CF or their carer were asked about their view of infection control within their CF centre/clinic.

Question: Do you feel that everything that could be done, is done, to help stop the spread of infection in your/your child's CF centre/clinic (i.e. staff hand washing)?

Figure 25: Proportion of respondents who agree infection control is well-managed, combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



Proportion of respondents at each centre who felt infection-control was not well managed



71% of respondents felt infection was well-managed at their centre.

Section 4

Intravenous (IV) antibiotic therapy

Paediatric CF Service Specification: Objective 3.2: Service description/care pathway

- The service must have the ability to commence IV antibiotics on any day of the week.
- An urgent course of treatment will be implemented within a maximum of 24 hours of the clinical decision being made.
- There must not be a delay of longer than one week of the proposed admission date for a routine/elective/ planned course of treatment.
- Where appropriate, IV antibiotics may be provided at home, following receipt of the initial dose at the specialist CF centre or network care hospital.

Figures have been rounded to the nearest whole number and figures <0.5 have been dropped to improve graph readability.

The number of responses varies between each section as some respondents did not answer all the questions.

220 UK respondents said they had received IVs in last year. 28% of 0–12-year-olds and 52% of 13+ respondents marked they had received IVs in the last year.

Question: In the last 12 months have you received IV antibiotic therapy?

Figure 26: Proportion of respondents that received antibiotic therapy, 0-12 years

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.

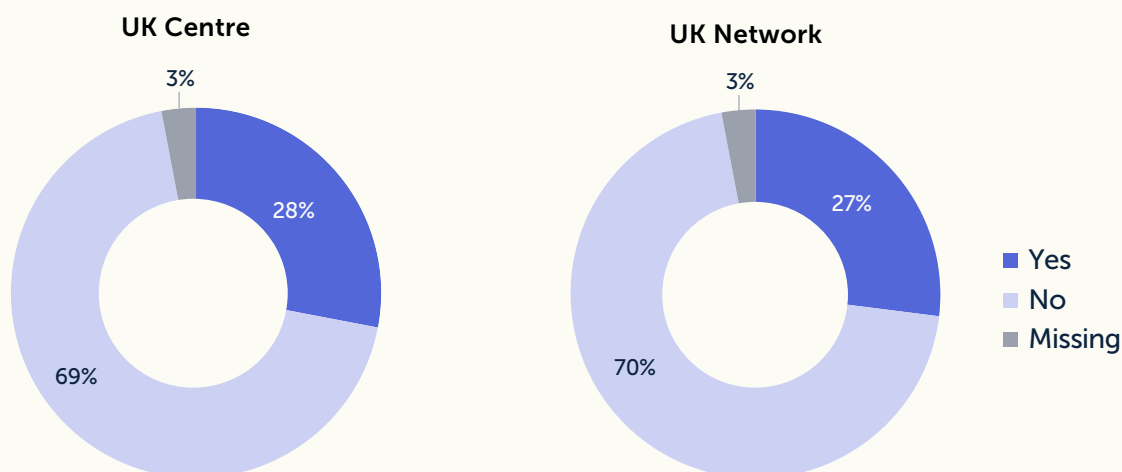
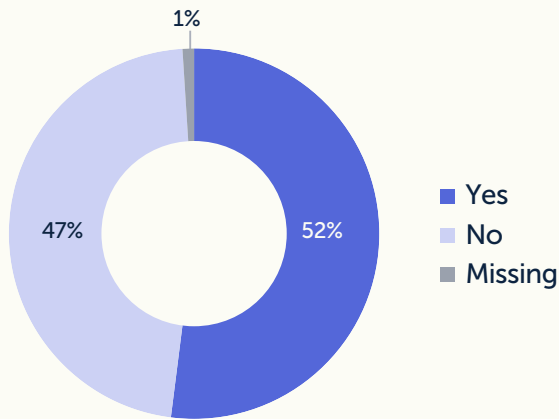


Figure 27: Proportion of respondents that received antibiotic therapy, 13+ years



Proportion of respondents at each centre who received IV antibiotics in last year



Question: Does your CF team start IV antibiotic treatment within 24 hours of identifying an acute infection?

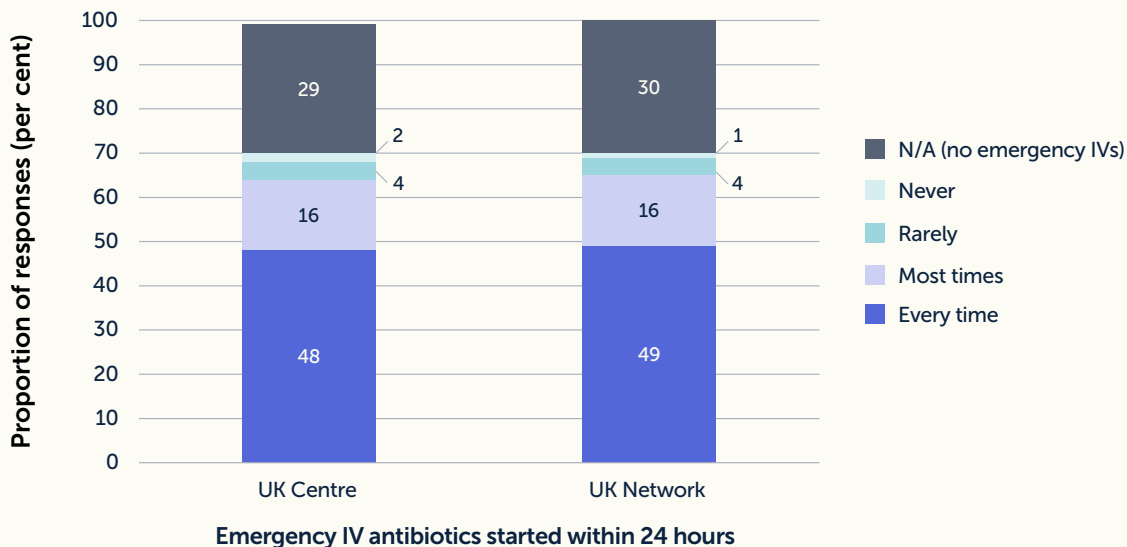
Paediatric CF Service Specification: Domain 3: Helping people to recover from episodes of ill-health or following injury.

There should be no delay (as defined by national service specification) in initiating IV antibiotic therapy for pulmonary exacerbation.

21.4% of paediatric respondents had a delay in starting IV antibiotic therapy for pulmonary exacerbation over the last 12 months.

Figure 28: Proportion of respondents' who started emergency treatment within 24 hours, combined ages

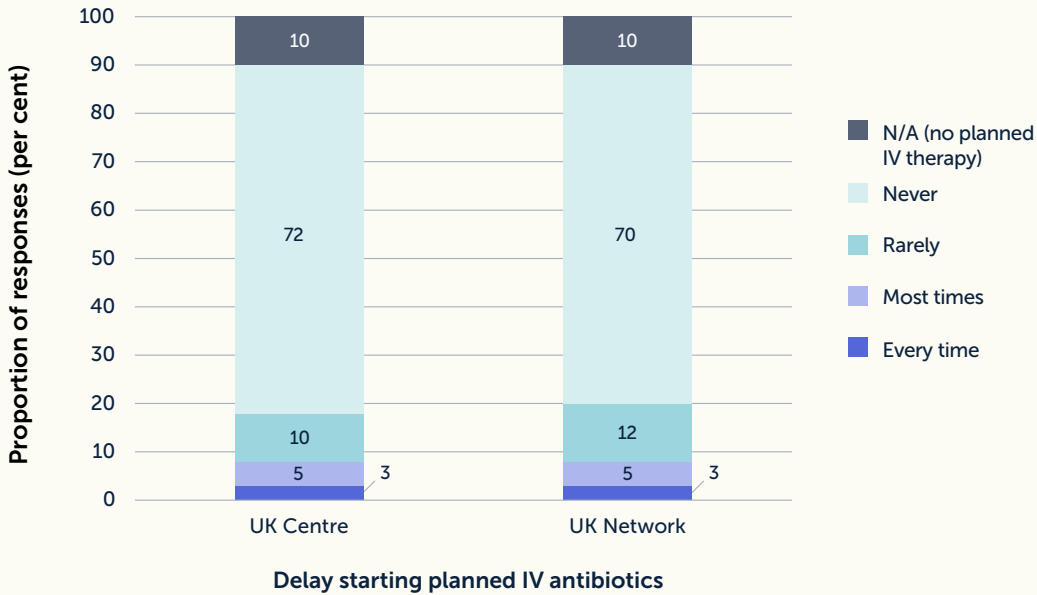
Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



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

Figure 29: Proportion of respondents who experienced a delay in starting planned therapy, combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



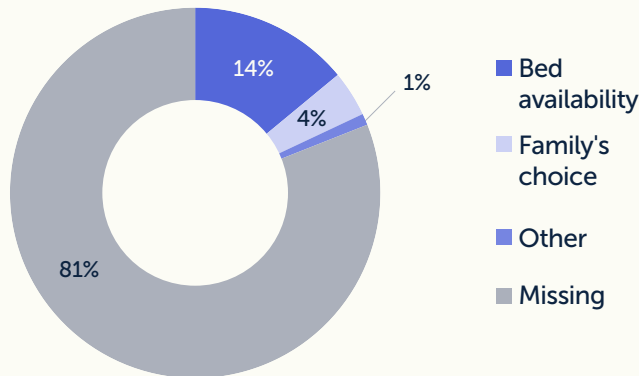
70% of respondents stated they had never had a delay in starting planned therapy (later than 7 days from their proposed admission date), however 8% stated they started more than 7 days later every time or most times.

Proportion of respondents at each centre who had a delay in starting



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

Figure 30: UK respondents' reasons for delayed start to IV antibiotics, combined ages



Most respondents who provided a reason for their delay in starting planned IV antibiotics stated it was due to lack of beds, while 4% said it was due to family preference.

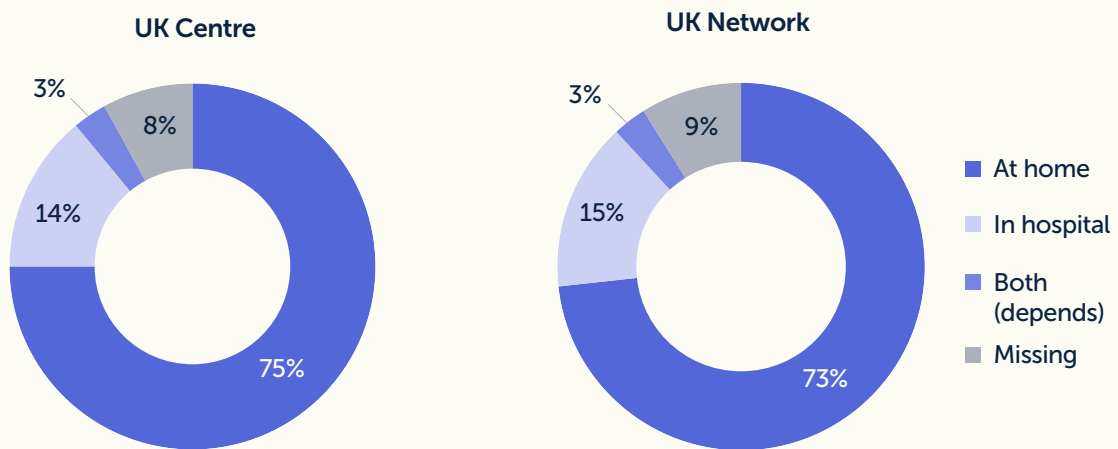
Proportion of respondents at each centre who said bed shortage was reason for delay in starting planned therapy



Question: If given the choice of in-hospital or home IVs, which do you/your child prefer and why?

Figure 31: Proportion of respondents' preferring in-hospital, home IVs or both, combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



73% of UK respondents preferred home IVs, with 15% stating a preference for hospital IVs and some respondents stating it depended on the situation.

Table 1: UK respondents' reasons for choosing home or hospital IVs, categorised into themes, combined ages.

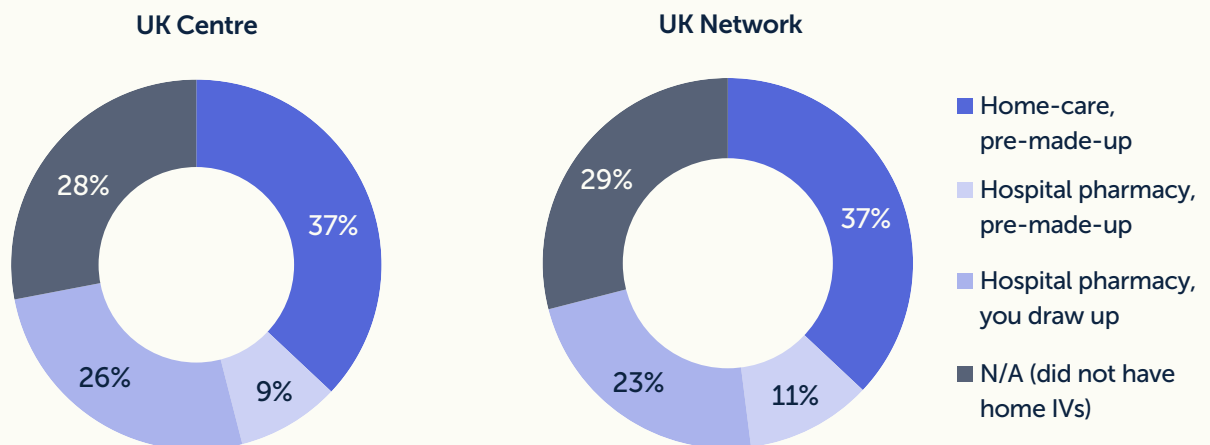
And why did you choose home or hospital IVs?		%
Home	Environment, bed, food, and so on	69
	Continue with life	38
	Lower infection risk	9
	See family and friends	6
Hospital	Feel reassured	36
	Help with IV/portacath	21
	Access to CF MDT	18

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

172 respondents who had received IV antibiotics in the last year completed this question.

Figure 32: How home IVs were provided for respondents, combined ages

Note: The UK Network group covers all responses received in the paediatric PREMs survey; UK Centre group only includes full care responses received.



Section 5

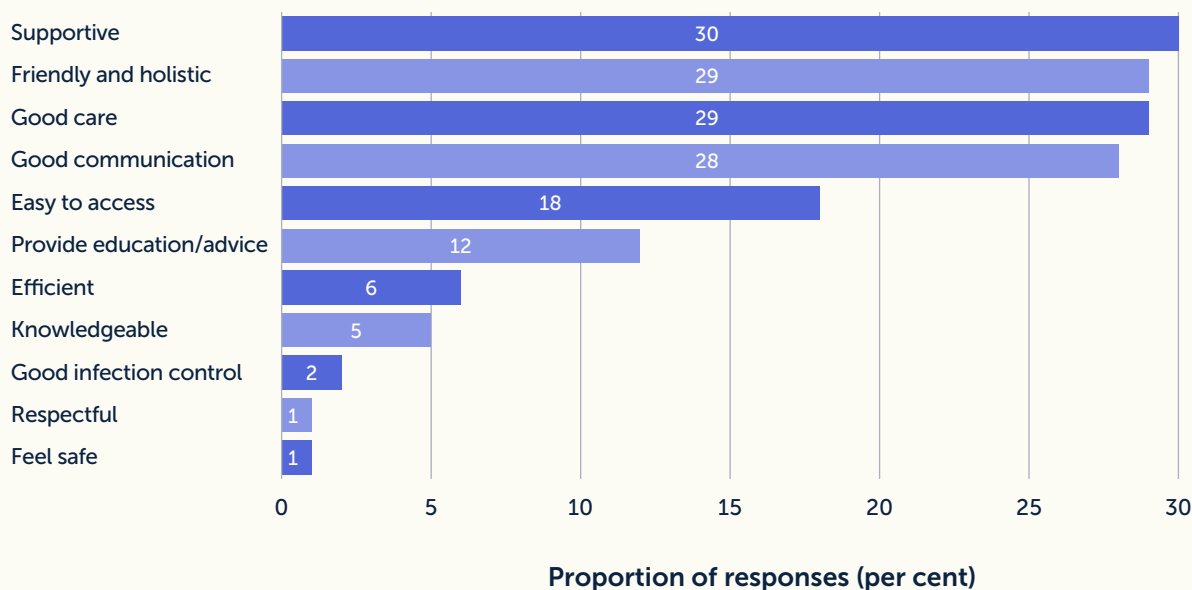
Summary of your CF care

Paediatric CF Service Specification: Section 3.1: Aims and objectives of service
Supporting parents and families of children with CF, as well as the child.

Question: What does your/your child's CF team do best?

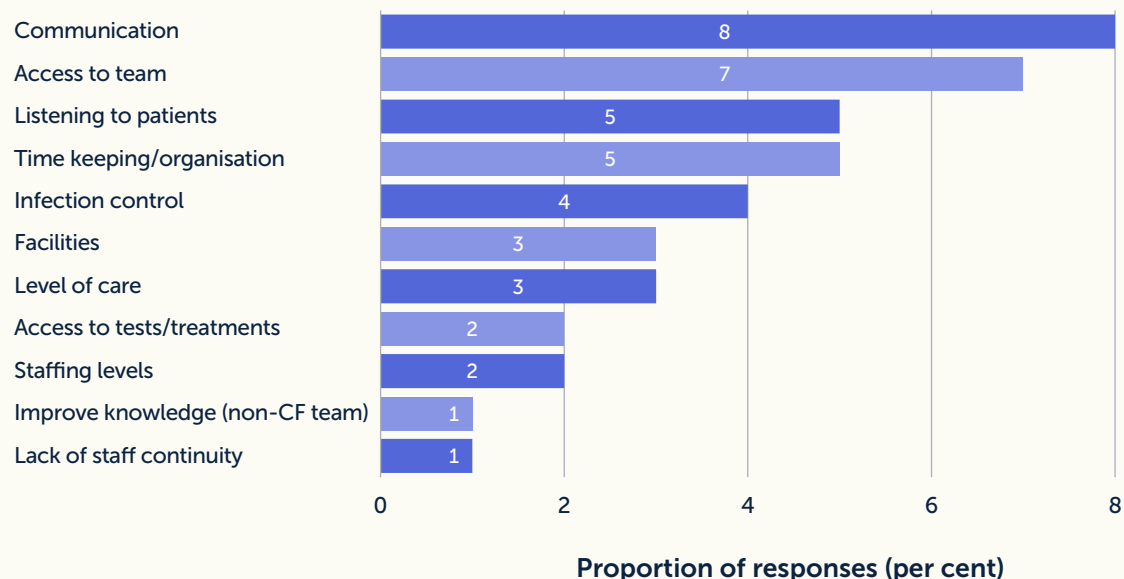
More comments were received on what CF teams do well (n=161) than what can be improved (n=42).

Figure 33: All respondents' comments on best aspects of CF care, categorised into themes, combined ages



Question: What could they do better?

Figure 34: All respondents' comments on aspects of CF care that could be improved, categorised into themes, combined ages



Section 6

Next steps

The paediatric Patient Reported Experience Measures survey allows people with cystic fibrosis to share feedback on their experiences of care and thereby shape the way that services evolve over time. Participating centres receive tailored feedback summarising responses from their patients and are encouraged to review this alongside the UK-wide findings in this report to better understand and evidence what their service does well, and to potentially identify areas for quality improvement.

This report is the first to provide a UK-wide perspective on experiences of CF care based on paediatric PREM data. It covers care provided in the immediate pre-pandemic period and offers a useful baseline to understand change over time, as services adapt to and come out of the pandemic. The next cycle of data collection for paediatric PREMs is planned for late 2022 to early 2023, and will enable us to gain further insights into experiences of CF care. All paediatric CF centres and networks are invited to take part, with registration beginning in the summer of 2022.

In the meantime, Cystic Fibrosis Trust's QI team is looking to improve and develop this data collection and report in future, and welcomes feedback on this publication, as well as on centre-level reports from those centres that participated in this work.

You can send feedback, comments and questions to the team directly at:

QI@cysticfibrosis.org.uk

Glossary

Word/phrase	Meaning
Annual review (AR)	A full health review undertaken by the specialist centre once a year.
Centre	Hospital department providing expert care and specialised disease management to people living with cystic fibrosis.
CF	Cystic fibrosis
Community support	Care given locally to the patient outside a hospital environment.
Cystic Fibrosis Service Specification	Standard of care you should expect from adult or paediatric CF centres in England.
Full-care	CF care that is wholly provided by the centre.
Gastroenterologist	Gastrointestinal specialist (digestive disorders)
Hepatologist	Liver specialist
Home IVs	Intravenous antibiotic therapy done 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 antibiotics/ IV Abx	Intravenous antibiotic therapy – a course of antibiotics through the vein to treat an infection.
Median	The middle number when all numbers are arranged from smallest to largest.
MDT	Multi-Disciplinary Team, your CF team made up of each discipline i.e. physio, social worker, dietitian.
Network	The provision of care across an area for both centre and shared care* patients (*looked after by a local hospital but overseen by centre).
NICE	National Institute for Health and Care Excellence – provides guidance, advice, and information services for health professionals.
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 support improvement in care.
Range	Smallest to largest number.
Respondents	People living with cystic fibrosis or a family member on their behalf.
Shared-care	CF care that is shared between a centre and local hospital.

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

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

cysticfibrosis.org.uk

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