

Cystic

**Fibrosis strength
in numbers**

Thank you

A huge thank-you to everyone who took the time to complete the UK CF Registry survey. Your input is invaluable, and we have learnt a lot from it. We hope you find the following report interesting. You can get in touch with the UK CF Registry by emailing PortCF@cysticfibrosis.org.uk.

Short of time?

You can access a summary version of this report [online](#).

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What is the UK CF Registry?

The UK Cystic Fibrosis (CF) Registry is a research project that has been hosted by the Cystic Fibrosis Trust since 2007. It securely collects information about people with CF in the UK who consent to this. Data is submitted by NHS employees at CF centres and clinics. We collect information on demographics (such as date of birth and gender), treatments and medications, and medical outcomes. Anonymous versions of the data are used to write annual Registry reports, for clinical research, to inform NHS commissioning, and to monitor the safety and effectiveness of new treatments.

Why did we do this survey?

The needs of the CF community, and technology, have changed a lot since the UK CF Registry moved to the Cystic Fibrosis Trust in 2007. Many enhancements have been made to the Registry since then, to allow us to monitor new treatments and use Registry data to inform the commissioning of CF services. We now want to build upon the success of the Registry by harnessing new technology to develop it further.

We know what is technically possible, and have an idea of what might be needed based on previous experience, what the CF community has told us in the past, and by looking at what similar Registries are doing in the UK and internationally.

We want to be sure that the direction we are taking meets the needs of people with CF, their families, healthcare teams, researchers and the wider NHS. We rely on the trust of people with CF, who consent to their data being collected by the Registry. It is vital that we maintain this trust as we move forward, by consulting and communicating with the people who are at the heart of the Registry. This survey is part of that process, in steering the Registry to an even brighter future and keeping excellent communication across the CF community as the key driving force.

How did we do this survey?

The questions for this survey were co-designed with a person with CF, the Cystic Fibrosis Trust's Head of Patient and Public Involvement, and the UK CF Registry team. Leading or loaded questions were avoided by keeping questions general and open-ended, allowing the opportunity for participants to qualify their answers using free text.

The survey was designed using www.surveymonkey.com. This survey builder allows users to define question types as well as page, question and skip logic. Branding can be added, and the survey can be sent out through mobile, web and social media. The design was intended to be easy and quick to complete to minimise effort from those taking the time to respond, and maximise the completeness and accuracy of answers to each question.

Only the first question, which checked that the person was eligible to complete the survey, was made mandatory. Although this meant that a small number of questions were 'skipped', it is hoped that this avoided people abandoning the survey altogether if they did not wish to respond to a particular question. Logic was built into questions to ensure that only relevant questions were displayed, and that only valid answers could be given (eg you can't answer both 'yes' and 'no' to the same question).

Explanations about the UK CF Registry were provided within the survey, to avoid only those with existing knowledge of the Registry being able to respond.

The survey was open to people who consent to data being collected on the Registry; people with CF and their parents/guardians. People were given two weeks to complete the survey, which was sent out using the Cystic Fibrosis Trust's Customer Relationship Management system, Facebook, and Twitter. Two reminders were sent via all of these channels half way through data collection, and then through social media the day before the deadline.

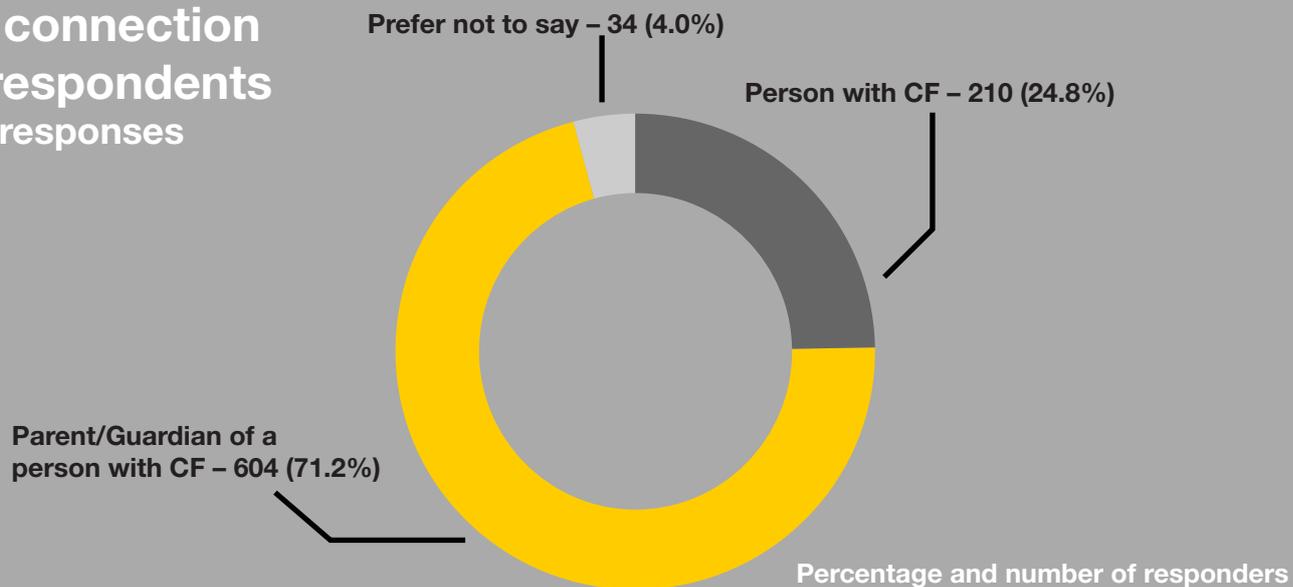
After the deadline, the survey was closed and data was exported in Excel to be analysed for this report.

Results

848 individual responses were received to the questionnaire.

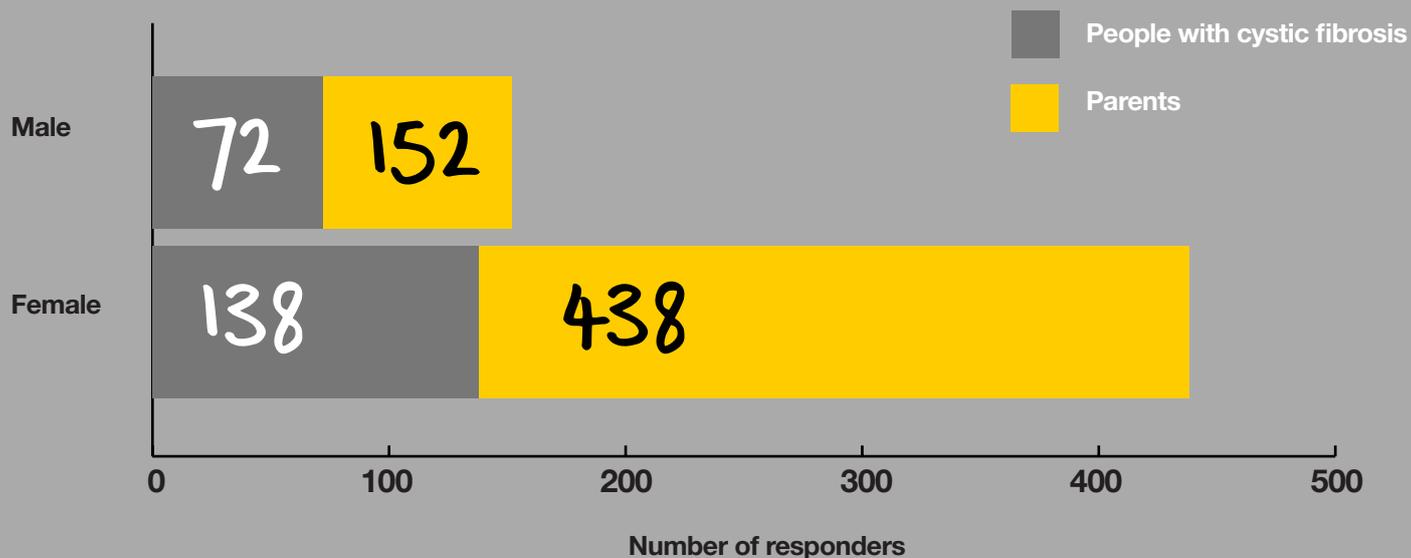
Respondents

CF connection of respondents 848 responses



Responses from people with CF represent approximately 2% of the total CF population¹

Gender of respondents 800 responses

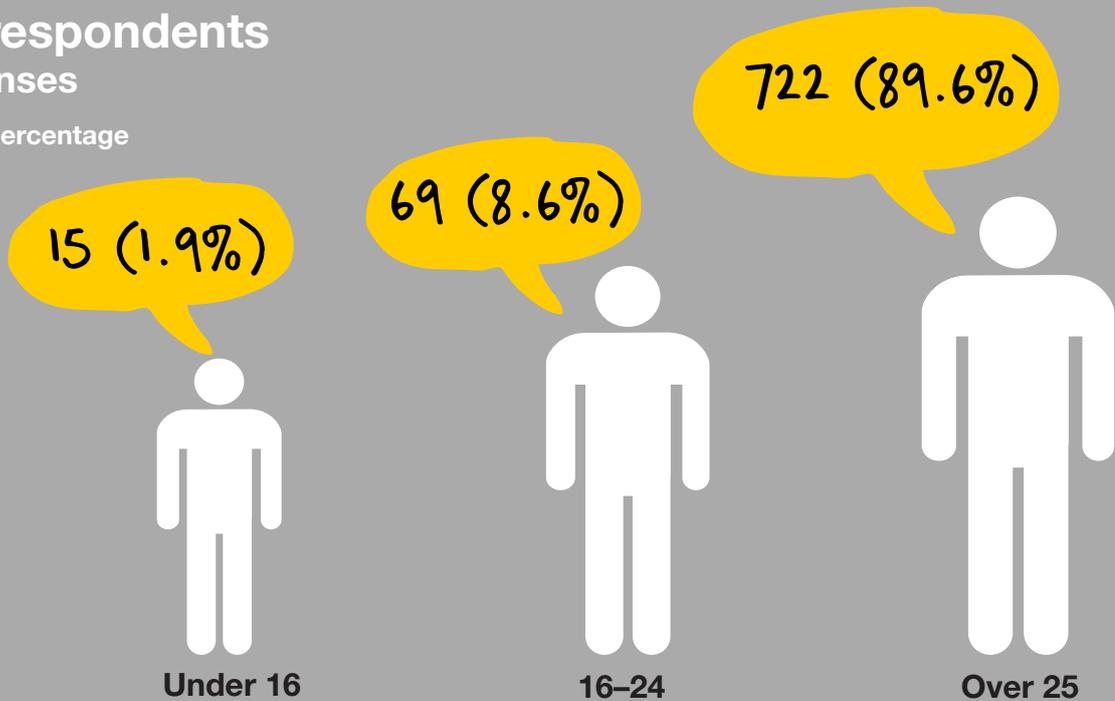


¹UK CF Registry Annual Data Report 2013

Age of respondents

806 responses

Number and percentage of responses



Access to UK CF Registry data

771 responses

We asked respondents whether they would like to be able to view the clinical data held about them, or their child, on the UK CF Registry.

	Response percent	Response count
Yes, all of it	74.2%	572
Yes, some of it	7.1%	55
No	5.7%	44
Don't know	13.0%	100

Some respondents took the opportunity to leave a free text comment to help us understand their answer. These answers were sorted into the categories shown below.

Reasons for wanting to access UK CF Registry data



To help understand and manage CF:
189 (47%)

To check the data are accurate:
28 (7%)

Because clinics don't always provide all the information:
9 (2%)

Curiosity about what the Registry collects and/or what is held about me or my child:
72 (18%)

To access information about my or my child's CF between clinic appointments:
10 (2%)

Because it's my right:
98 (24%)

Reasons for not wanting to access UK CF Registry data

54 free text responses

Concerns about data security/privacy:

8 (15%)

Need more information about the process and consequences of access:

20 (37%)

Data needs clinical input so that it can be understood:

11 (20%)

I already see my data through my CF clinic:

13 (24%)

I would be scared about what I might see:

2 (4%)

We explained that it may be possible for people with CF, or their carers on their behalf, to submit self-reported information direct to the UK CF Registry. Respondents were asked what type of information they would want to submit to the UK CF Registry. Each person could select more than one answer.

Self-reporting

723 responses

Information about my/my child's health

597 responses

Information about my/my child's experience of care

597 responses

None of the above

42 responses

Information about my/my child's quality of life

549 responses

Information about my/my child's opinion of my CF centre

597 responses

Access to self-reported data

668 responses

It would be technically possible to make self-reported information securely available to the clinical team responsible for delivering CF care to that person. For those respondents who said that they would like to self-report one or more types of information, we asked whether they would be happy for their clinical team to view their self-reported information.

	Response percent	Response count
No	4.0%	27
Some information/it depends	40.3%	269
All of the information	55.7%	372

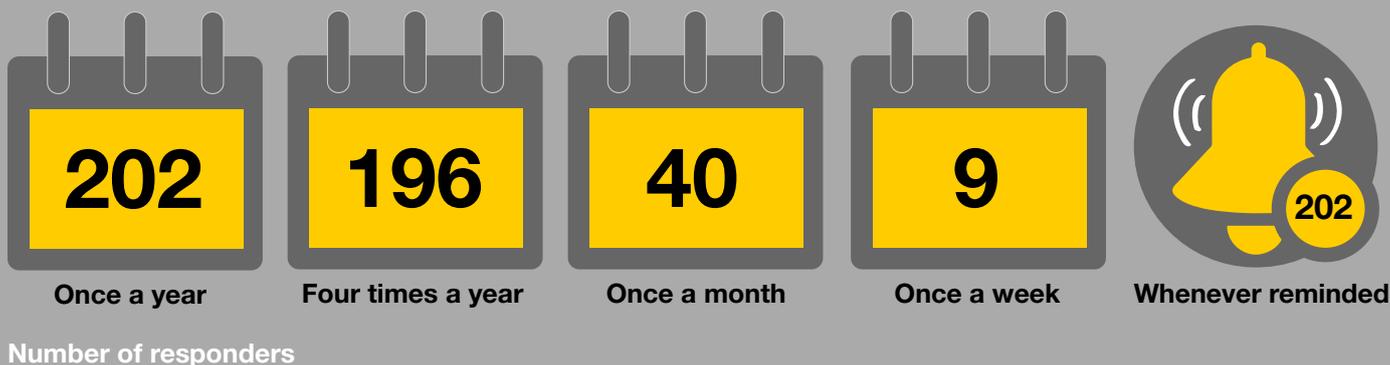
People who wanted to share their self-reported information with their clinical team felt that it is important to share information, good or bad, and work as a team to improve CF care.

Those who were unsure about sharing some or all of their self-reported information were concerned that saying something negative might negatively affect the care that they received from their clinical team. Some people felt that information should stay private or anonymous.

Of those people who said they were happy to self-report data, we asked how often they would be prepared to submit self-reported information to the UK CF Registry.

Frequency of self-reporting

649 responses



Results from the UK CF Registry

Data stored on the UK CF Registry is analysed by experts to find out what CF care and health outcomes are like, how they have changed over time, and how they compare to set standards and benchmarks.

Reporting frequency

685 responses

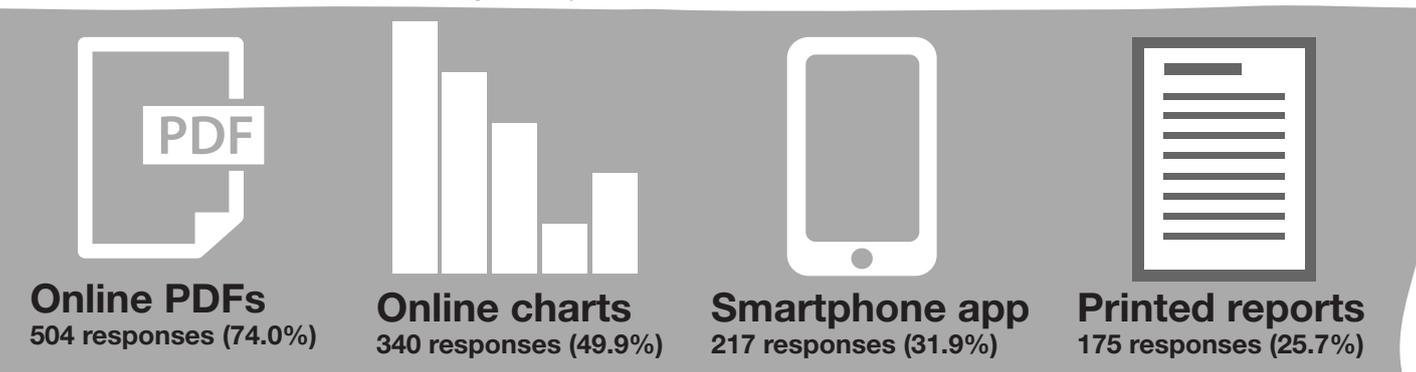
We asked respondents how often they would be interested in seeing the results from the UK CF Registry.

	Response percent	Response count
Once a year	50.1%	343
Four times a year	38.1%	261
Once a month	11.1%	76
Never	0.7%	5

Reporting method

681 responses

We asked respondents how they would like results from the UK CF Registry to be shared with them. More than one answer could be chosen by each person.

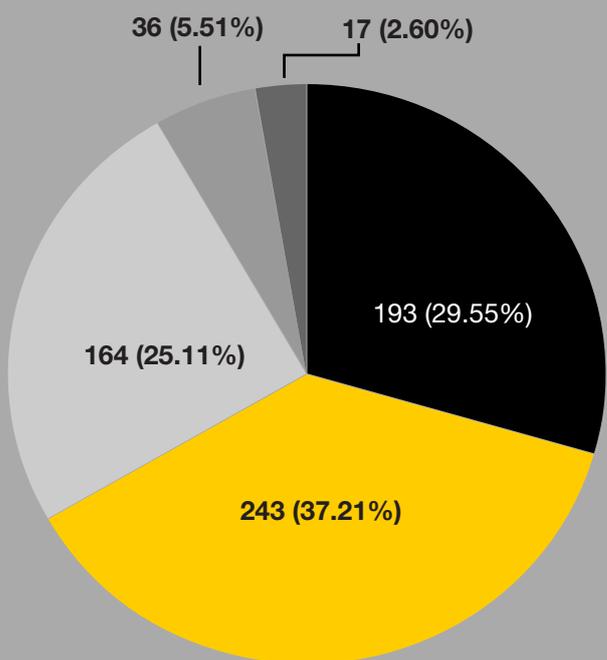
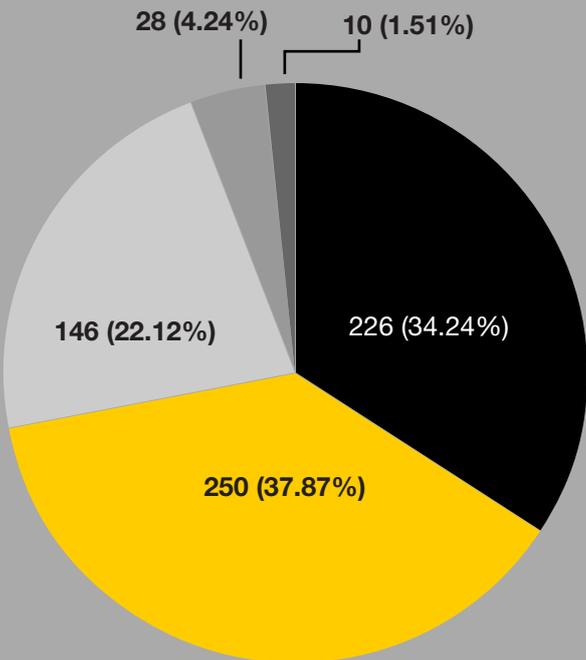


	Response percent	Response count
I'm not interested in seeing the results of analysis	0.9%	6
Email	0.7%	5
Large print	0.6%	4
Other	0.6%	4
Downloadable spreadsheet (eg Excel or CSV)	0.4%	3
Audio	0.1%	1
Braille	0.1%	1
Newsletter	0.1%	1
Online portal	0.1%	1
Regional meetings	0.1%	1
Through my clinic	0.1%	1
Video summary	0.1%	1

We asked people to rank the importance of different levels of detail that can be covered in reports from the UK CF Registry. Rankings ranged from 1 'extremely important' to 5 'not at all important'

Reporting detail 668 responses

Number of responders



Information about people with CF for the whole UK

Information about people with CF in my country (England, Scotland, Wales or Northern Ireland)

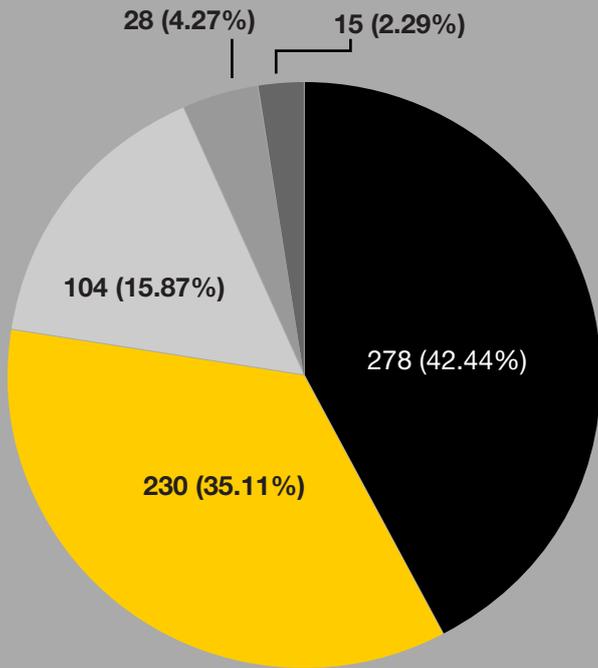
Rating average – 2.01
Response count – 660

Rating average – 2.14
Response count – 653

Key:
 Extremely important
 Very important
 Moderately important
 Slightly important
 Not at all important

Reporting detail continued

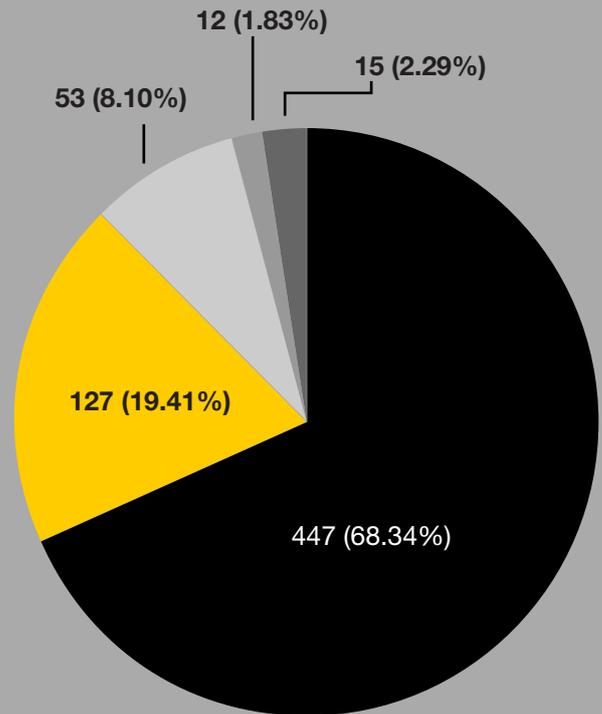
668 responses



Information about people with CF in my CF centre

Rating average – 1.89
Response count – 655

Number of responders



Information about me/my child

Rating average – 1.50
Response count – 654

Key:

- Extremely important
- Very important
- Moderately important
- Slightly important
- Not at all important

Reporting focus

653 responses

We asked people to rank the importance of different focusses of UK CF Registry analysis. Rankings ranged from 1 'extremely important' to 5 'not at all important'.

	Rating average
Whether NHS treatment guidelines are being followed by medical staff	1.45
Health outcomes of people with CF now	1.41
Health outcomes for people with CF over time	1.53
Quality of life reported by people with CF	1.54

Reporting uses

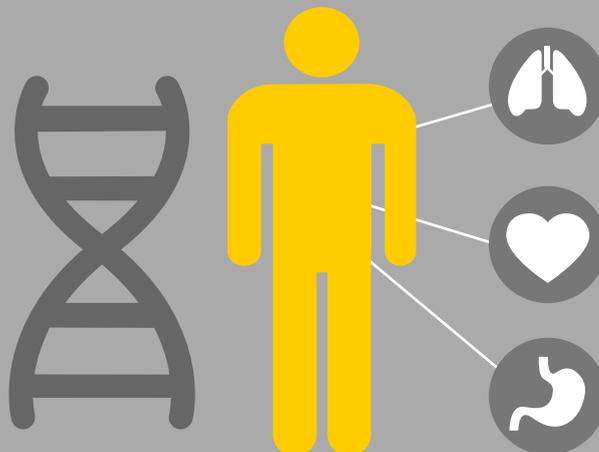
653 responses

We asked people what they would find results from the UK CF Registry useful for. More than one answer could be chosen by each person.

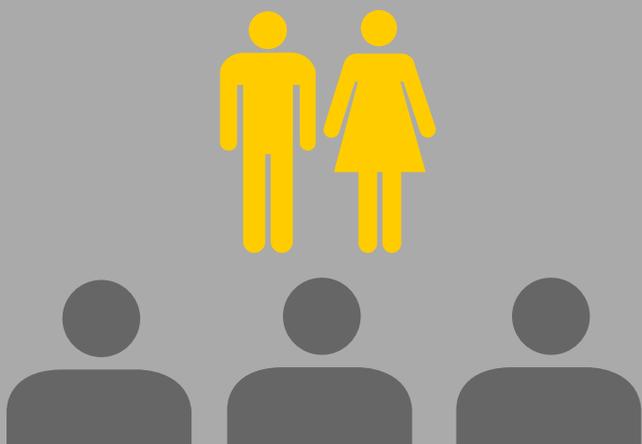
To choose treatments that are best for me
502 (76.9%)



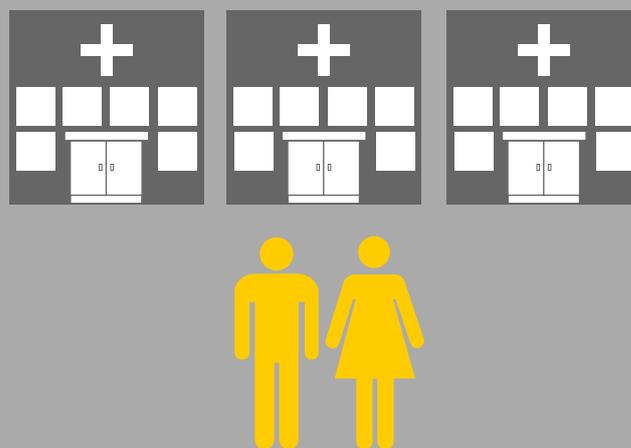
To understand CF
445 (68.1%)



To have a discussion with my CF team
375 (57.4%)



To choose a CF centre
163 (25.0%)



	Response percent	Response count
Other	8.3%	54
General interest	1.4%	9
To manage my care	1.2%	8
Compare CF centres	1.2%	8
Research	0.8%	5
Keep up to date	0.6%	4
Monitor standards of care for CF	0.5%	3
Analysis	0.3%	2
To discuss with my family	0.3%	2
Improve care for CF in general	0.3%	2
Explain CF to others	0.2%	1

Data sharing

654 responses

We asked respondents what they think anonymous data (that cannot identify individuals) should be shared for outside of the UK CF Registry team.

	Response percent	Response count
Developing treatments	91.3%	597
Researching the best care	88.2%	577
Improving the quality of care	88.1%	576
Monitoring the safety and effectiveness of treatments	79.8%	522
Informing the development of NHS services	74.0%	484
Informing people with CF about their condition	68.0%	445
Other	1.1%	7
Promote understanding of CF/fundraising	1.1%	7
Patient/parent involvement in care	0.3%	2
Global collaboration	0.2%	1

Clinical trials

643 responses

UK CF Registry data could be used to identify people with CF who could take part in a particular clinical trial for CF treatment. Clinical trials may be run by hospitals, universities, or pharmaceutical companies. All clinical trials are approved by an independent regulator.

We asked respondents if they would be happy to be identified and contacted about clinical trials they might be eligible for.

	Response percent	Response count
Yes, directly by the clinical trial researcher	28.9%	186
Yes, through my CF clinical team	56.8%	365
No	7.2%	46
Don't know	7.2%	46

11 people who said 'No' or 'Don't know' left free text comments to help us understand their answer. 100% of them said that they didn't feel the question was applicable to them because they are a parent of someone with CF, rather than having CF themselves.

18 people who selected 'Yes, through my clinical team' left a free text comment to help us understand their answer. 15 (83%) of these felt that this would maintain their privacy and ensure that they receive trusted clinical advice. The remaining three comments were more general comments in support of clinical trials.

Contact details

641 responses

At the moment the UK CF Registry does not hold full postal addresses or email addresses for people with cystic fibrosis. We asked people taking part in the questionnaire whether they would be happy for contact details to be stored so they could be kept up to date about Registry news. This could include a notification when new reports are available.

	Response Percent	Response Count
Yes	94.4%	605
No	5.6%	36

Linking data

620 responses

Electronically linking UK CF Registry data with other information could help inform research and care for people with cystic fibrosis. Linked data would only be shared in a format that does not identify individuals. We asked people what other types of information they would be happy for their UK CF Registry data to be linked with.

	Response percent	Response count
Education data	67.6%	419
Other health data	67.7%	420
Social care data	50.0%	310
Social media data	26.8%	166
Professional data	53.9%	334
None of the above	16.0%	99

How could we improve?

129 responses

54 responses stated that the person didn't know/had nothing to add, and one response was not applicable to the UK CF Registry.

The remaining 75 responses have been sorted into categories below. Some people left responses that fell into more than one category.

	No.	%
Better communication about what the Registry is, and what it does	14	19%
Make the results easier to understand	11	15%
Make more information available, about different areas and in more detail	9	12%
Give people with CF access to their own data	7	9%
It's good as it is	6	8%
Update results more regularly	6	8%
Involve people with CF and parents more	5	7%
Put in place suggestions from this survey	4	5%
Data protection should be a priority	3	4%
Introduce smartphone apps and better software	2	3%
Tell us more about clinical trials	2	3%
Make comparisons with other countries	2	3%
Improve the survey itself	2	3%
Make comparisons between CF centres and clinics	1	1%
Link Registry data with other sources	1	1%
Put out a magazine	1	1%
Move the Registry from the Cystic Fibrosis Trust	1	1%

Your questions answered

110 responses

We asked people if there is anything they would like to know about the UK CF Registry that they don't at the moment.

70 people who provided a free text comment stated that there isn't anything more they would like to know at present. Four people left a comment that could not be understood/categorised.

This left 36 responses asking for more information about the UK CF Registry. These have been organised into categories, with responses from the UK CF Registry team provided alongside them. Some people left responses that fell into more than one category.

1. Where can I access information published the UK CF Registry?

Three responses

- Our most recent Annual Report relates to 2013 data. You can download this and previous reports at cysticfibrosis.org.uk/registry. Our 2014 data report is due for publication in July 2015.

2. Can I access information specific to my CF centre?

Four responses

- Yes, this is included in our most recent Annual Report. Analysis at this level of detail is quite new to CF, and there is currently a research project running to explore how we can use centre-specific analysis to improve care and outcomes in cystic fibrosis. The results from this project are due in 2016. At the same time, we are learning from other Registries to continually improve the results we publish.

3. Can the Registry publish the results of clinical trials?

One response

- The results of clinical trials are first published by the organisation responsible for carrying out the trial. This could be a pharmaceutical or academic group. The Cystic Fibrosis Trust uses its website, blogs, and social media to bring these results to the attention of the CF community and help to interpret them.

4. How is the Registry funded?

One response

- Since 2012, the majority of the costs associated with the UK CF Registry are funded by contracts

held between the Registry and the NHS, and our work with industry to make medicines safer. This includes providing grants to CF centres to support them to enter data.

5. Is the Registry compliant with data protection?

Three responses

- Yes, the Registry is compliant with the Data Protection Act 1998. Data that can identify individuals is not given to third parties and only data for people who have given explicit consent is recorded on the Registry. The UK CF Registry has Research Ethics Committee (REC) approval. RECs safeguards the rights, safety, dignity and wellbeing of research participants, independently of research sponsors.

6. What is UK CF Registry data used for at the moment?

Seven responses

Clinical research

- Researchers can submit a data request to the UK CF Registry Steering Committee. If approved, pseudonymised data is securely transferred to the requesting party under a data sharing agreement. Data requests are only approved if they are of scientific/clinical merit, and satisfy data protection legislation.

Annual reports

- Data is analysed for the purposes of the public Registry Annual Report.

NHS commissioning

- The UK CF Registry provides country-specific reports to NHS England and NHS Scotland. The Registry also acts as the evidence base for tariff payments to CF centres in England.

Working with industry to make medicines safer

- The UK CF Registry monitors the safety and effectiveness of newly licensed treatments for cystic fibrosis. Reports are provided to companies responsible for manufacturing the drug, which they in turn share with the European Medicines Association. Patient-level data is not provided to industry as part of this process, and individuals cannot be identified from the reports. [Read more about our work with industry.](#)

7. What data is held in the UK CF Registry?

Seven responses

- The UK CF Registry team is currently working on an easy-to-read document showing what we

collect and why we collect it. In the meantime, as a result of the responses in this survey, we have made available [a PDF form version](#) of what we collect on our website.

8. What are the plans for the future of the UK CF Registry?

Five responses

- The UK CF Registry is going through a period of development, which includes updating the technology that supports it. Improving the IT support for the Registry means that, in future, it will be able to adapt more quickly to the needs of the CF community. This questionnaire is part of the development process for the UK CF Registry, so that we can better understand what people at the heart of the Registry; people with CF and their parents/guardians, want from it. We will use this information to steer the Registry in future, and will keep the CF community informed through the Cystic Fibrosis Trust website, social media, and our annual reports. Enhancements to the Registry could include securely giving people with CF access to their own Registry data, enabling people with CF to self-report data, and improved public reporting.

9. Tell me more about rare genes, and gene-specific outcomes

Four responses

- The UK CF Registry Annual Report includes the number of people in the UK with the more common genetic mutations. In 2015 we will also publish an appendix on the Cystic Fibrosis Trust website that gives a complete list of mutations for people with CF in the UK.
- In 2015 the Trust is running a 'Know your Genotype' campaign. It is designed to encourage people with CF to find out their genotype, and understand how this could affect their symptoms and treatment options. Find out more at www.genotypematters.org.

10. How are people with CF and parents involved in the UK CF Registry?

One response

- A CF parent and a person with CF are included in the UK CF Registry Steering Committee, which is responsible for the strategic direction of the Registry, and uses of the data. We are looking for ways to improve the way we involve the CF community, and this questionnaire is a first step towards this. The Cystic Fibrosis Trust will launch a new Involvement web page by the end of May

2015, where you will be able to get involved, and download our Involvement Strategy.

11. What happens if you want to opt out of the UK CF Registry?

One response

- People with CF, or their parents on their behalf when they are children, must explicitly opt in to their data being held on the UK CF Registry by signing a consent form provided by their CF clinical team. On moving to adult care a person must re-consent to their data being entered onto the Registry for it to be recorded by their new, adult centre.
- You can choose to opt out of the UK CF Registry at any time. You can either have no further data recorded, or have all of your previously recorded data deleted from the UK CF Registry.

12. Who is on the UK CF Registry team?

Two responses

- The UK CF Registry team is employed by the Cystic Fibrosis Trust, but no one else within the Trust has access to the UK CF Registry. Anyone within the Trust or on the Registry Steering Committee must go through the same data request process as anyone else wishing to access the data. The Registry Team includes:
 - Rebecca Cosgriff, Registry Lead
 - Elaine Gunn, Registry Data Manager
 - Niruja Balaskandan, Registry Coordinator

To contact the UK CF Registry team please email: PortCF@cysticfibrosis.org.uk.

13. Can you feed back the results of this survey?

One response

- The results of the survey are available in detail in this report. A [summary report](#) is also available.

14. Could you use Registry data to prevent cross-infection in schools?

One response

- We don't collect which school people with CF attend on the UK CF Registry, and passing information such as this on to schools would breach the confidentiality of the people we hold data about. To protect against cross-infection people with CF should tell their school that they have cystic fibrosis. People with CF, their families and schools can contact the Cystic Fibrosis Trust helpline for guidance on cross-infection: 0300 373 1000.

Conclusions

Response rate

The high response rate overall and for each question individually shows that people with CF and their parents are interested in the UK CF Registry and prepared to spend their time to give their views. The majority of our responses were from mothers of people with CF, which tells us that this is a particularly engaged group. Although the number of responses from fathers and people with CF themselves was good, we should do more to engage with these people about the UK CF Registry.

Access to UK CF Registry data

The majority of people responding to the survey wanted to access information about themselves or their child on the UK CF Registry. We understand from the responses that we need to be proactive about telling people how this would work, and providing more assurance in terms of data security and inaccessibility by others. We also learnt that not everyone wants to view all or indeed any of their data, so any access would need to be 'opt in', with the ability to show/hide data as desired.

Self-reporting

As lots of people felt that they would like to self-report information to the UK CF Registry, we should make this option available on a voluntary basis. How often people would like to submit information varied, so we will need to investigate further how often it is appropriate to collect self-reported data, and learn from others who are already doing this. A balance needs to be found between getting lots of information that might be less complete, and getting less information that is of better quality.

While a lot of people were happy for their CF teams to see their self-reported data, there were understandably some concerns around privacy, especially when it might concern their opinion of their centre. We need to make sure CF centres can use self-reported data to improve care, without making people with CF worried that it will affect their relationship with their centre. This may mean that centres can view their overall patient-reported results, but not results for individual patients.

Results from the UK CF Registry

People wanted to see results from the Registry with roughly the same frequency that they would be happy to submit self-reported data. This means that reports should continue to come out at least once

per year, whilst we might work towards reporting every three months.

Whilst most people wanted to access reports online, whether through a downloadable PDF document or a website, a significant number wished to access data through SmartPhone apps, and printed reports.

We asked some questions about what level of detail and which areas of focus people from the CF community are most interested in. The response we got was that for the most part people want as much information from the Registry as possible. We should be providing accessible reports that provide people with as much detail as possible, rather than focusing on producing only summary reports aimed at people with cystic fibrosis.

People with CF felt that they would use results from the CF Registry to manage their own care, understand their condition, and have a discussion with their clinical team. 25% of people responding to the survey would consider using Registry data to choose where they receive care. This is lower than the 75% reported in a [King's Fund study](#), and perhaps reflects that people with a chronic inherited disease might wish to stay at a centre close to them, where they have developed a relationship with their care team. That said, 25% is still a high proportion, and the desire to be able to compare CF centres and option to use this to make choices must be acted upon by the UK CF Registry.

Data sharing

The UK CF Registry can share anonymous extracts of data to third parties such as doctors and researchers. We asked what people with CF and their parents think we should be sharing data for.

People could select more than one answer, and whilst developing CF treatments was the most popular reason for sharing data, all of the reasons we currently share data for received high numbers of responses.

Clinical trials

UK CF Registry data could be used to identify people with CF who might be eligible to take part in a particular clinical trial. Most respondents were happy for the data to be used in this way, and expressed a desire to be involved in clinical trials both for their personal benefit and that of the wider CF community. The majority of those people who would be happy to be identified as eligible indicated that they would prefer contact to be made through their clinical team, so that they could gain well-informed advice and support independent of the study organisers.

Contact details

Almost all respondents were happy for the UK CF Registry to store contact information such as email addresses to keep them informed of matters relating to the UK CF Registry. These details would be supplied by individual patients and parents, so only those wishing to do so would be contacted by the UK CF Registry.

Linking information

Whilst over half of respondents were happy for their data to be linked with at least one of the other information sources we named, some stated that they were not. We should be proactive about explaining exactly what this process involves, and its benefits to the CF community. If linkage is to occur that isn't covered by the existing consent process, we should consider giving individuals the option to opt in or out of linkage analysis.

How could we improve?

In addition to the results already discussed in this section, the free text responses on how we can improve the UK CF Registry were extremely useful. Coupled with the questions we were asked about the Registry as part of the survey, the message has come through loud and clear that we need to be more proactive and clear about explaining what the UK CF Registry is, what it does and doesn't do, and how you can access understandable results. We will be working hard to meet this need over the coming weeks and months. So you can expect to hear more from the UK CF Registry very soon.

Get in touch

Why wait for another survey? We would really like to hear any questions or comments you have, about this report or the UK CF Registry in general. Get in touch by emailing PortCF@cysticfibrosis.org.uk.

cysticfibrosis.org.uk