

<b>Report:</b>	Cystic Fibrosis Team Patient Experience Survey Summary Report
<b>Report Collated By:</b>	NHSGGC Patient Experience Public Involvement Team. Contact: Lisa Martin, Project Manager: <a href="mailto:Lisa.Martin5@ggc.scot.nhs.uk">Lisa.Martin5@ggc.scot.nhs.uk</a>
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## Cystic Fibrosis Team Patient Experience Survey Summary Report

### Purpose of Report

This report summarises the key responses to a patient experience survey carried out by the Cystic Fibrosis Team. It presents the findings and where appropriate highlights emerging themes for further consideration and action.

### Background

The survey was developed by the Cystic Fibrosis Team with support from the NHSGGC Patient Experience Public Involvement Team (PEPI Team). It gathered feedback about peoples' experience of, and contact with the team during Covid, aiming to listen and learn from their feedback and use it to review, inform and improve the service going forward.

The aim was to understand the impact of changes to the delivery of the service as a result of Covid had on peoples' overall experience. The key change during Covid was that previously routine face to face appointments with patients were switched to telephone or virtual appointments, including annual reviews. The team wanted to understand how people felt about this change and what aspect, if any, of virtual appointments worked well and what could have been better. Patient feedback will be used to review and inform improvements to the service.

The survey was offered to an identified recipient group via a secure link to an online form, sent by letter and/or email, along with accompanying information about the purpose of the survey. Alternative formats were available on request. (X) People were invited to complete it. All recipients were aged 16+ years old.

Anonymity was identified as an important factor and this was made explicit in both the introduction to the survey and accompanying information, along with the right to withdraw if they chose to do so. The survey was available for completion between 22/03/2022 and 30/04/2022.

The PEPI Team led on collating and analysing the responses and on reporting. A total of 58 responses were received, representing a (X) % return rate. This is within the accepted range to meet the criteria of a credible sample size. All surveys were completed in full.

The standard NHSGGC Equalities Monitoring Form was attached to the survey and completed by 18 people. The equalities monitoring data is available here:

<https://forms.office.com/Pages/DesignPageV2.aspx?subpage=design&FormId=veDvEDCgykuAnLXmdF5Jmo62zbSzosNlpQmFIYurRrZUMjIMSUdHTVFCUjU0TTRINFIUVVc4VDE2TS4u&Token=d9fc2722e0ee457ba51fda10cb00cf64>

## Summary of Key Responses by Question (including a cross-section of comments)

### 1. Who is completing the survey today? (survey question 1)

57 people told us they completed the survey themselves and 1 person indicated they completed it with the assistance of a caregiver/trusted individual.

### 2. Please tell us your age (survey question 2)

Responses ranged from 17 years to 64 years old, with 16 people giving an answer of 45 years old or above. This could possibly indicate that a higher number of caregivers/trusted individuals were involved in completing the survey than is outlined at question 1, mistakenly giving their own age rather than that of the person they were supporting.

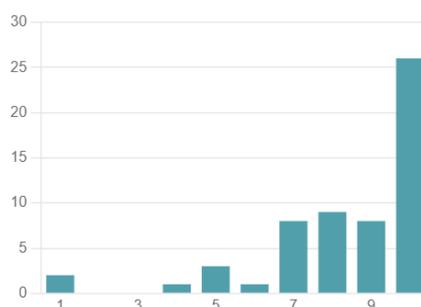
### 3. Please tell us the name of the health board area where you live (survey question 3)

Health board area	No.	Health board area	No.
NHS Greater Glasgow and Clyde	38	NHS Highland	4
Ayrshire and Arran	5	NHS Lanarkshire	7
NHS Forth Valley	1	NHS Lothian	1

2 people did not specify a health board area but listed West of Scotland Adult Cystic Fibrosis Centre instead.

### 4. How would you rate your *overall* experience with the Cystic Fibrosis team over the last 12 months, where 1 is lowest rating and 10 is highest rating? (survey question 4)

8.40  
Average Rating



**Additional comment about overall experience:**

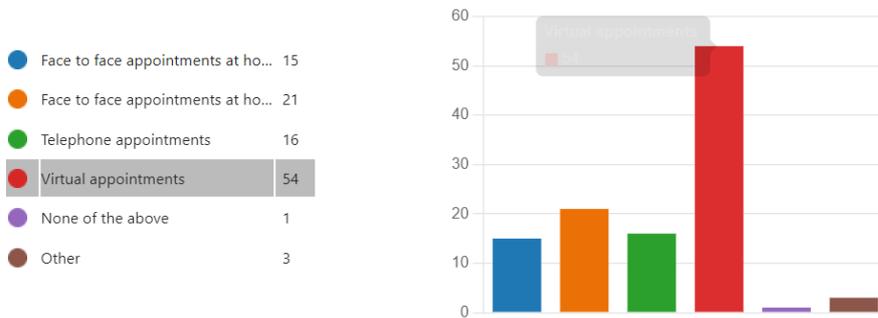
*The team have been very supportive over the period and when I needed a face to face consult it was ready available. The provision of bloods taken at home during the pandemic extremely useful. Pre-pandemic I use to attend a gym 3 to 4 times a week but having the Beam sessions with the physiotherapists has kept we fit, focused and motivated.*

*Excellent access to a wide ranging MDT and able to access team members rapidly both in person when needed, and virtually too. Have been able to benefit from outpatient IVs commenced by team as a day case. Opportunity to maintain/improve health through excellent CF physio exercise program. Chance to be in a clinical trial thanks to CF team trial base. Overall great for keeping me well through this even more challenging period.*

*I have had good care at home and the team have always been flexible with times to fit around me which I really appreciate. I would have liked to have an annual review in the last 2 years but understand this may have been difficult with restriction and staff shortages.*

*I feel that we have an excellent team but that on occasion communication between the team members could be better.*

**5. What type of appointments have you had with the team in the last 12 months? (survey question 6)**



People were asked to select all that apply, with the vast majority (54 out of 58) indicating they had a virtual appointment at some point in the last 12 months. Of those, 31 indicated they had only had either virtual or telephone appointments, with no face to face appointments at all either at hospital or home. The ‘other’ category was selected by 3 people who all said they had bloods taken at home. ‘None of the above’ was selected once however every completed survey had at least one other option selected, so we can assume this was a mistake or is captured as one of the responses in the ‘other’ category.

**6. We would like to know more about your experience of accessing virtual appointments. Please read the statements below and choose one option for each that best describes your experience. (survey question 7)**

	Fully agree %	Somewhat agree %	Somewhat disagree %	Fully disagree %	Not sure %
I am given the information I need in advance to be able to participate fully in the appointment	86	12	-	-	2

It would help if I was reminded in advance of the virtual appointment that I need access to my spirometry equipment	19	48	10	16	7
I have access to the right technology and equipment to be able to participate fully in virtual appointments	81	17	-	-	2
I am confident in my ability to use equipment and technology to participate fully in virtual appointments	83	10	2	2	3
My virtual appointments have happened without any technical hitches or problems	40	41	14	3	2

Overall there was an extremely positive response to the question about peoples' ability to access virtual appointments. Responses indicate that, in the vast majority of cases people were able to participate confidently and without any technical hitches. 67% people felt it would be helpful to be reminded in advance of the appointment to have spirometry equipment to hand.

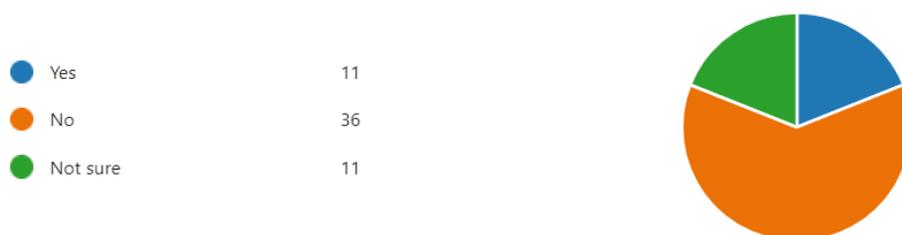
**7. Please tell us how you *felt* about the virtual appointment experience. (survey question 8)**

	Fully agree %	Somewhat agree %	Somewhat disagree %	Fully disagree %	Not sure %
I felt confident I was speaking to the right members of the team	78	17	3	-	2
I feel I had enough time to ask questions, including sensitive or detailed questions about my treatment or care	72	17	7	2	2
I felt I was being listened to	78	14	3	3	2
I was comfortable with the fact that a physical examination wouldn't be carried out at this particular appointment	55	19	16	7	3
I was comfortable with the fact that lung function wouldn't be recorded in the usual way	50	26	14	10	-
I was comfortable that objective measurements such as weight, height and/or chest x-ray would not be carried out at this particular appointment	53	19	19	7	2
Any queries or concerns I had were fully addressed	70	22	3	3	2
I felt my treatment and care was being well co-ordinated and managed	66	22	9	3	-
I was treated with compassion and understanding	78	17	2	3	-
I was able to involve people that matter to me in discussions about my treatment and care	62	19	2	2	15
I was able to participate in virtual appointments at home in a way that respects my privacy	82	16	2	-	-

Overall, the responses to questions about how people *felt* about the virtual appointment experience indicated a high degree of confidence, comfort with and understanding of the process. Questions about

person-centred approaches such as feeling listened to and being treated with compassion and understanding score particularly highly. Scores for statements on how people felt about the lack of physical examinations due to virtual appointments were scored lower. This might indicate that, for some people having a regular physical examination carried out by a clinician is viewed an integral part of their treatment and care plan and not being able to do this affected their levels of confidence, comfort and security. This was further explored in survey question 9. 15% of people indicated that they were not sure about being able to involve people that matter to them in discussions about treatment and care as part of the virtual appointment experience. This is a higher % of 'not sure' responses than for other statement, indicating that there may be a more general lack of awareness about the ability to do this, and not just during virtual appointments.

**8. Do you have any concerns about certain investigations not being carried out in the usual way? (E.g. diabetes screening, liver ultrasound, bone (dxa) screening? (survey questions 9 and 10)**



*As previously mentioned, getting sputum tested regularly I feel is very important as new bacteria or old can show up again in sputum but you would not know if your sputum has not been tested. Also the lung function carried out at home is inaccurate which means the wrong results would be documented in your file which can affect other things.*

*Have had no tests since the beginning of the pandemic. It would be helpful to understand the effect Kaftrio is having on my body*

*I don't feel the home spirometer is as accurate and would like to have my lung function checked with the hospital equipment every so often as well as having my chest listened to.*

**9. What do you think of the length of virtual appointments? (survey question 11)**

The scheduled time was agreed to be the right length by 54 of the 58 people who responded.

**10. General feedback about the experience of virtual appointments: (survey question 12)**

*I'm torn between the anxiety of not being seen in person to have proper check-ups / physical examinations, and my anxiety about Covid and my desire to avoid going to hospital. I've continued to shield and so I'm grateful for the virtual appointments, but I'd be lying if I said I wasn't also concerned about not having proper check-ups. For the time being, I'd rather continue with online appointments though.*

*The timing works much better, they are quicker as I do not have to get to the hospital. I feel the staff are quicker at getting to my appointment too. I am able to do other things while I wait to be seen by all staff members.*

*I totally agree with virtual appointments and would be disappointed if we went back to all face to face. However I do see a need for face to face for an annual review and if you are unwell and need your chest sounded. I would like a device to monitor my sats, I have bought 2 and they don't work accurately.*

*I'd like a hybrid model. Of every second clinic meeting being virtual. In person is better, but more time consuming.*

*If I'm honest I just want back in clinic once every 2 months like normal I also can't get on some medication till I'm back at hospital too so that's affecting me too.*

### 11. Face to face appointments (survey questions 13-15)

People were asked if they had any face to face appointments either at home, hospital or both over the last 12 months. 27 people indicated they had a face to face appointment, broken down as follows:

	Home	Hospital	Both	Not specific
1 appointment	1	6	2	1
2-3 appointments		4	6	1
4+ appointments		2	4	

Reasons given for last face to face appointment:

Annual review	22
Urgent appointment for an unforeseen issue or problem	15
Other (not indicated)	21

### 12. Annual review (survey questions 16-17)

People were asked about their experience of having an annual review. The question did not specify a face to face annual review.

	Fully agree %	Somewhat agree %	Somewhat disagree %	Fully disagree %	Not sure %
I felt confident I was speaking to the right members of the team	62	16	-	3	19
I felt I had enough time to ask questions, including sensitive or detailed questions about my treatment	62	17	2	3	16
I felt I was being listened to	65	14	2	3	16
Any queries or concerns I had were fully addressed	67	-	12	4	17
I felt my treatment and care was well co-ordinated and managed	71	10	2	2	15
I was treated with compassion and understanding	69	12	-	3	16
I was able to involve people that matter to me in decisions about treatment and care	64	14	-	3	19
I felt comfortable travelling to the hospital/clinic for my annual review	55	13	5	5	22

I felt safe in the hospital/clinic setting before/during/after my annual review	53	16	2	3	26
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22 people gave 'annual review' as the reason for their last face to face appointment with the team, however this will reflect some appointments that will have taken place before Covid. A significant number of people (17) indicated they had not had an annual review since pre-Covid. From some of their responses it's clear they were specifically referring to a face to face review. It is possible to speculate that some of those particular individuals may have had a virtual annual review but not recognised it as such. The term 'annual review' may be intrinsically linked to with a visit to a hospital or clinic setting, or seen to involve a range of physical or other examinations that could only be carried out in person. Only 7 people indicated in their answers that they had a face to face annual review in a hospital or clinic setting in the past 12 months. Others mention virtual appointments or 'partial annual reviews' where some but not all questions were asked.

It's possible that the term 'annual review' has different meanings to different people and therefore has resulted in a degree of inconsistency and a significantly higher level of 'not sure' responses to this particular set of questions.

*I haven't had a face to face annual review since the pandemic began*

*I don't think I've had a review identified as annual review but have had lots of discussions and tests for lung transplant so I'm not sure if this was seen as that*

*The clinic have been neglectful of annual reviews since my arrival, I don't feel that - even before the pandemic - that the reviews were well planned or thought over*

*My annual review was done virtually, I haven't been into the hospital for 18 months*

### 13. Which of these appointment arrangements would you prefer in the future? (survey question 18)

Virtual appointments wherever possible and practical	13
Face to face appointments wherever possible and practical	4
Face to face appointments only	3
Alternating between virtual and face to face appointments	34
Other (not specified)	4

### 14. What matters most to you in relation to appointments with the team? (survey question 19)

*Continuity. Being treated as an individual*

*Not taking too much of my time, especially when I feel well and nothing in my care is changing*

*Having time to talk openly, ask questions and having things explained fully so I completely understand everything*

*I think it's just that I prefer the routine of face to face appointments as I was able to get away from work, see you all, catch up formally and informally and feel looked after, it also gave me a kick up the bum for getting back onto lapsed treatments. However virtual apps are good when we feel well so could offer this to save time on both sides, unless bloods or samples required or for annual review*

*Getting to see all of the appropriate members quickly, being able to get all of the tests needed done at the same time*

*Ability to raise issues with health and feel actions taken. Seeing team members who know my case and knowing with an MDT that all specialist areas are being covered*

**15. Do you feel the Cystic Fibrosis Team works well together to support you, your treatment and care? (survey question 20)**

14 people scored:



11 people scored:



7 people scored:



3 people scored:



**16. General comments about experience with Cystic Fibrosis Team (survey question 23)**

*I think they are the best and if I could give all of them awards, I would. They're the only reason I'm able to live the way I do! I love them like a second family*

*The CF team have managed extremely well during the trying times of the pandemic and I have not once felt like I was forgotten about. My treatment has continued and I am so grateful that they have continued to look after my care with the same professional manner they have always done*

*I feel included in the team patient relationship. I take part weekly in exercise classes on zoom through Beam which are delivered despite shortages in staff sometimes. A sensitive team in all disciplines*

*I work in the NHS as a band 7 nurse so have a good understanding of the processes we need to follow I can only praise the team at the QE and feel they provide excellent care and have always addressed my needs . I am definitely an advocate of virtual appointments as it's so hard to get 1/2 day off work, which is what I need to travel to appointments. I am also happy to have face to face appointments when they are needed. I would like face to face for annual review and virtual for all other appointments, unless face to face was needed due to clinical need. I am happy to speak to anyone about my experience. I also really value the psychology service, come from a mental health background and have used the service, in hospital and at home*

*I suppose overall it's how we want the service to be in the future. We are managing the disease differently but still beset with smaller issues that need attention rather than quarterly appointments. I do think communication is a bad point, been sometimes hard to get nurses to get back to you, they never leave a message which can result in telephone tennis - we are adults and messages can be left, or use texts. There's different websites to get info from, none of them I really use so maybe a YouTube channel with videos from each team member showing equipment use, cleaning, Neb/inhaler taking. We can then subscribe and not miss anything of importance*

*I feel there could be more information provided to adults with CF regarding adult life, fertility and new research. Also check in with how we are mentally and not just physically as getting older with CF is daunting and there's not much information online regarding adult life with CF*

## 17. Patient Experience Focus Group (survey question 21)

People were asked if they would be interested in providing further feedback about their experience via participation in a patient focus group. 10 people indicated they would be interested and subsequently contacted the Patient Experience Public Involvement (PEPI) Team with their details. 10 further individuals indicated they may be interested, however only 4 of those subsequently contacted the team. A focus group session is scheduled for November 2022 and will be facilitated by the PEPI Team.



## Summary of Emerging Themes for Consideration and Further Discussion

### 1. Access to and experience of virtual appointments

Overall there were very few issues highlighted in relation to virtual appointments. Several people mentioned that they were not always clear about who was in attendance. This is a straightforward communication issue that can easily be addressed. Whilst still the minority a slightly increased % of people indicated they were less comfortable with the fact there was no physical examination taking place as a result of virtual appointments. Given the overwhelming majority of people also said they would prefer a blended model of virtual and face to face appointments it's likely that any anxiety on this issue would be addressed in the future.

67% of people felt it would be helpful to be reminded beforehand to have spirometry equipment accessible; this is something the team could build into their pre-appointment communication.

The length of virtual appointments was felt to appropriate, with 89% of people saying they had enough time to ask and have questions answered. This is a far higher % positive response than for annual reviews, where more people said they did not feel they had enough time for questions.

### 2. Face to face appointments

Of the 27 people who said they had a face to face appointment in the last 12 months 22 of those said it was for an annual review. This same number isn't reflected in the free text responses or the specific question about annual reviews, where only 7 people specifically mention having their annual review face to face in a hospital or clinic setting. It's possible that people may have conflated 'face to face' as also meaning virtual i.e. a video appointment with a team member. This is an area that needs further exploration and understanding.

### **3. Annual review appointments**

As already indicated there was some inconsistency across the responses in relation to whether people had an annual review in the last 12 months, as highlighted at point 12 above. Fewer people said they were confident they were seeing the right person/people or felt they had time to ask questions. There was a higher proportion of not sure answers to this set of questions, reflecting the fact that people were generally unclear about whether they had an annual review, or not. Several people wondered if questions asked at other appointments were classed as an annual review, but not labelled as such. There is scope to review the language used to describe different types of appointments, and to provide information to people about what an annual review consists of and where, how and when it might be carried out. This is an area where participation from people who use the service to design any patient facing information would be beneficial.

What was clearer from the feedback is that, even with the introduction of routine virtual appointments, people want to have their annual review as a face to face appointment wherever possible and practical.

### **4. Future appointments**

People indicated that choice and flexibility were key factors for any new appointment model going forward. The overwhelming majority of people wanted to retain a blended approach between virtual appointments and face to face appointments, with only 3 people stating a return to face to face appointments was their preferred choice. Convenience, time management and managing risk of infection were all given as reasons for preferring virtual appointments. Several people said that whilst virtual appointments work very well when their health is good, they might be less effective at other times, as direct contact with the team can provide reassurance, boost confidence and also compliance with physio routines etc. Some people also highlighted the close emotional connection they feel to the staff team, and the comfort and reassurance offered by the familiar routine of going into the hospital/clinic to see them. Engaging with people using the service and involving them in designing and delivering a new model could help mitigate some of these concerns.

### **5. Other issues**

Throughout the survey people took the opportunity to highlight the extremely high standard of treatment, care and support provided by the team, including the wider multi-disciplinary team, and to thank them for the work they do. This is reflected in the survey responses by the consistently high level of satisfaction experienced.

One person reported that they didn't feel they had received the level of service expected, after a move to Scotland from another part of the UK. There was a perception that there was a lack of communication between current and former care teams. Whilst this was a singular and specific case the team may wish to review processes and protocols to determine if there are any changes or improvements required, or if there is any learning from this persons' feedback for the team.

One person felt that there was a general lack of information about living with Cystic Fibrosis as an adult, and given relatively recent changes to treatment for many people whether this is something that can be addressed. It may not be directly within the gift of the team to provide this but they may be able to share this feedback with partners/other stakeholders.

Another person suggested a Youtube channel with videos on various issues, including practical demos for using different equipment. NHSGGC does make use of Youtube, and other services regularly post case studies and patient stories. This is something the team may wish to consider.

**REPORT ENDS**

