

# Experiences of Post Covid 19 Syndrome (Long Covid)

Summary of Feedback on Care Opinion Platform

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## **1.0 PURPOSE**

The purpose of this briefing paper is to demonstrate how the current Care Opinion database can be used to inform the Health and Social Care system on the experiences of service users/patients living with Post-Covid-19 syndrome (PCS) which is referred to as Long Covid across Northern Ireland. The following information reflects on stories published via Care Opinion from 01 January 2022 to 31 May 2023.

## **2.0 BACKGROUND**

At the request of the Department of Health (DoH), Strategic Planning and Performance Group (SPPG); (formerly Health and Social Care Board) and the Public Health Agency (PHA) have worked with all 5 Health and Social Care (HSC) Trusts to establish services to support people who continue to experience longer term physical, mental health and cognitive effects following coronavirus infection.

One-stop-shop Multi-disciplinary Team (MDT) assessment services have been established in each Trust and patients will be referred to the MDT assessment clinic from both primary and secondary care. Referrers will be asked to screen patients using a standard tool. The majority of diagnostic tests are expected to have been completed prior to referral in order to rule out other causes for the patient's symptoms.

The MDT clinics are not expected to provide an automatic medical assessment or examination but will deliver triage and assessment where appropriate from the MDT team, onward referral, diagnostics access and outcomes recorded.

The following services to support and assist people who are living with Post-Covid-19 syndrome have been established in all 5 HSC Trusts.

Strand 1 - Post-COVID-19 syndrome (PCS) patients referred by primary or secondary care to a one-stop-shop MDT assessment service.

Patients can be referred to the MDT assessment clinic from primary and secondary care. Patients receive a holistic assessment to include:

- identifying patients with breathlessness who may benefit from pulmonary rehabilitation;

- those who may need onward referral to secondary or community services and/or signposting to self-management resources.

Strand 2 - Bespoke pulmonary rehabilitation / dysfunctional breathing service for patients with significant respiratory symptoms Post-Covid-19 syndrome.

The purpose of this strand is to put in place timely, effective arrangements for outpatient rehabilitation following COVID-19 resulting in significant respiratory symptoms.

Strand 3 - Patients discharged from critical care (both COVID-19 and non-COVID-19).

The purpose of this strand is to put in place timely, effective arrangements for the follow-up and assessment of people discharged from critical care (both COVID-19 and non-COVID-19), reflecting the known risk of long-term sequelae following a long stay in critical care.

Strand 4 - Strengthening psychology support to all Trusts.

The psychological impact of COVID-19 (depression, anxiety disorders, post traumatic stress disorder (PTSD), traumatic bereavement, psychosis, risk to self and/or others) is recognised in extant national guidance. Each Trust has been supported to recruit an additional senior psychologist, with their main role supporting Strand 3, but also providing advice to staff working in strands 1 and 2.

Strand 5 - Regional MDT clinical physiology, SLT and dietetic support.

Selected patients may need diagnostic tests by respiratory clinical physiologists, onward referral for dietetic and speech and language therapy (SLT) from the one-stop-shop MDT assessment service, the critical care follow-up and pulmonary rehabilitation strands.

Strand 6 - Signposting and access to self-management resources.

Patients in Northern Ireland (NI) can access self-management resources which include the National Health Service (NHS) App 'Your Covid Recovery' (Managing the Effects | Your COVID Recovery).

The Online User Feedback Service (OUFS), Care Opinion was launched in Northern Ireland on 03 August 2020 providing opportunity for service users, families and carers to share feedback on their experiences of any service within Health and Social Care in Northern Ireland (HSCNI). Commissioned by the Department of Health the OUFS enables feedback which is open and transparent supporting services to engage with service users,

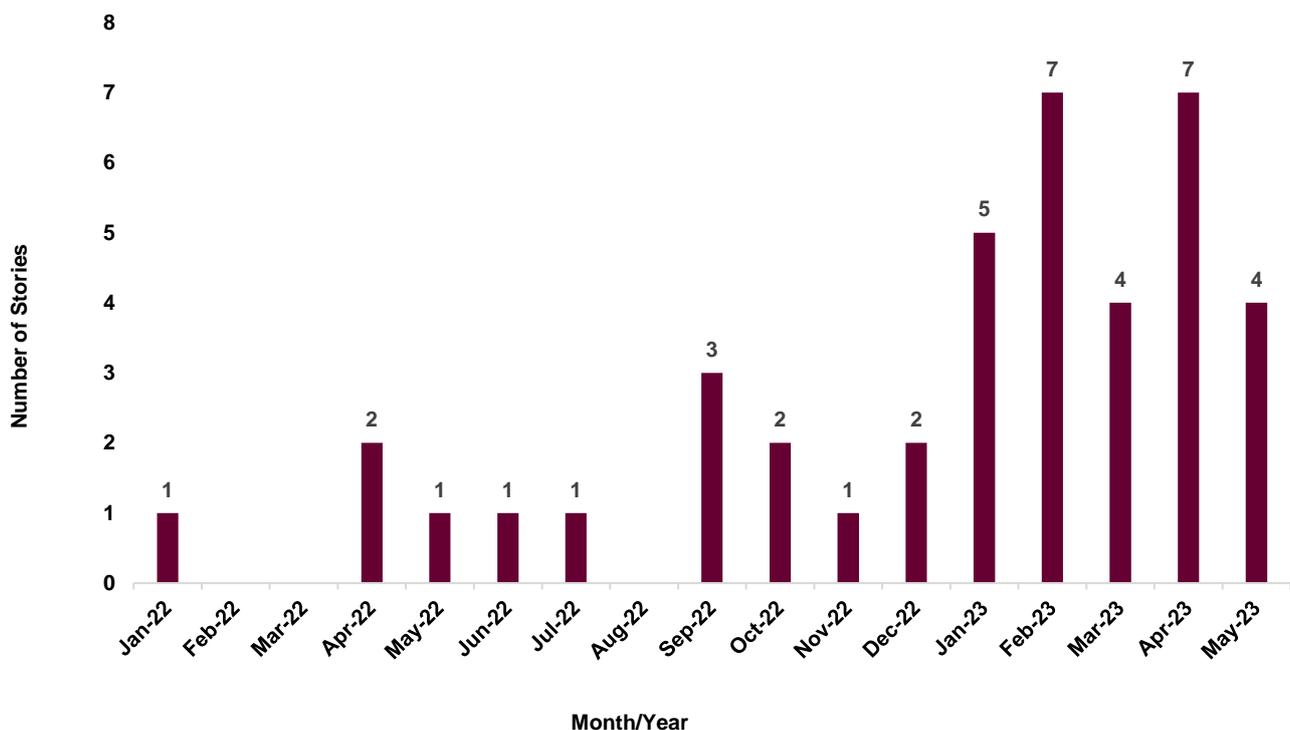
families and carers through a two-way feedback mechanism. The Care Opinion platform supports feedback to be shared safely as all stories are independently moderated prior to publication on the website [www.careopinion.org.uk](http://www.careopinion.org.uk)

### 3.0 CONTEXT

In total **41** stories have been shared on Care Opinion which relate to Long COVID. Figure 1 displays the number of stories published per month up until 31 May 2023. It is recognised there was focused campaigning through post Covid syndrome services within Health and Social Care Trusts from September 2022, supported by the Patient Client Experience Facilitators within each organisation. The methods used to submit these stories on Care Opinion were:

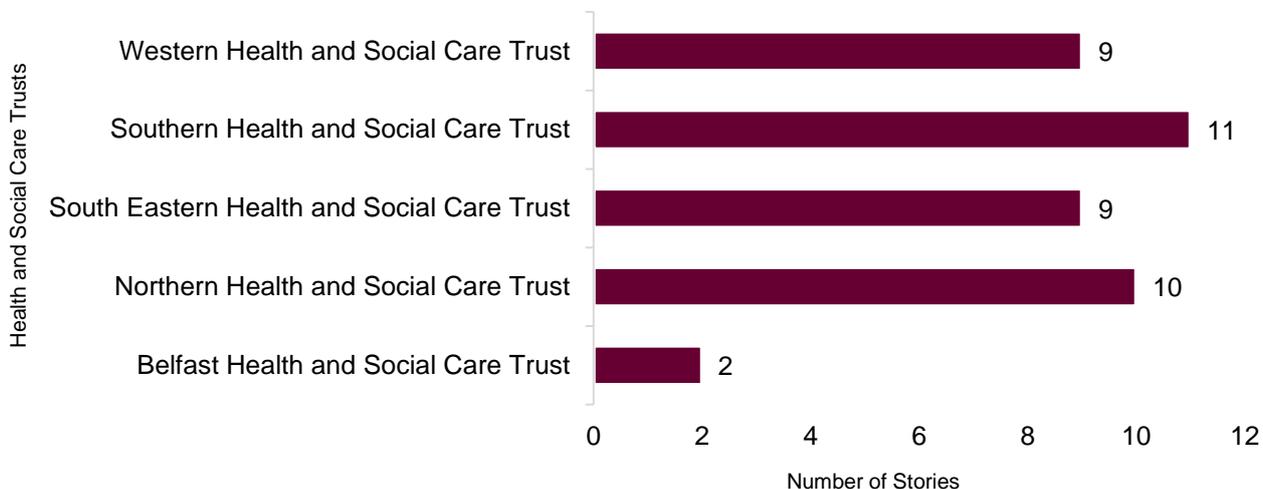
- Website - 76% (n=31)
- Kiosk - 12% (n=5)
- Leaflet - 10% (n=4)
- Telephone - 2% (n=1)

**Figure 1: Number of stories submitted each month on Care Opinion**



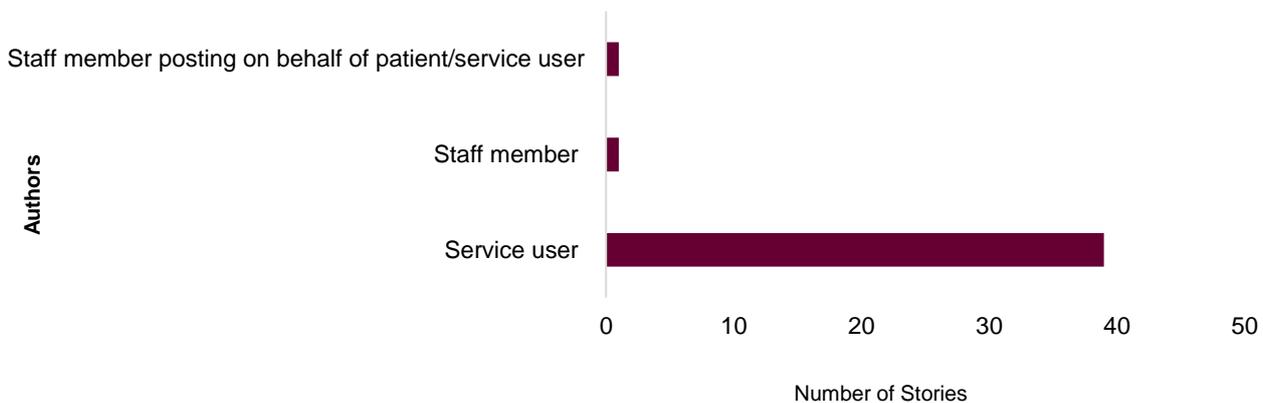
Stories have been submitted from across all Health and Social Care Trusts in Northern Ireland as outlined in Figure 2, although only two stories were generated from Belfast Trust.

**Figure 2. Number of stories per organisation**



Authors are asked to identify if they are a patient/service user, relative or carer etc. The responses are shown in Figure 3. The majority of stories have been submitted from the perspective of the patient/service user (n=39, 96%).

**Figure 3. Which term best describes you?**



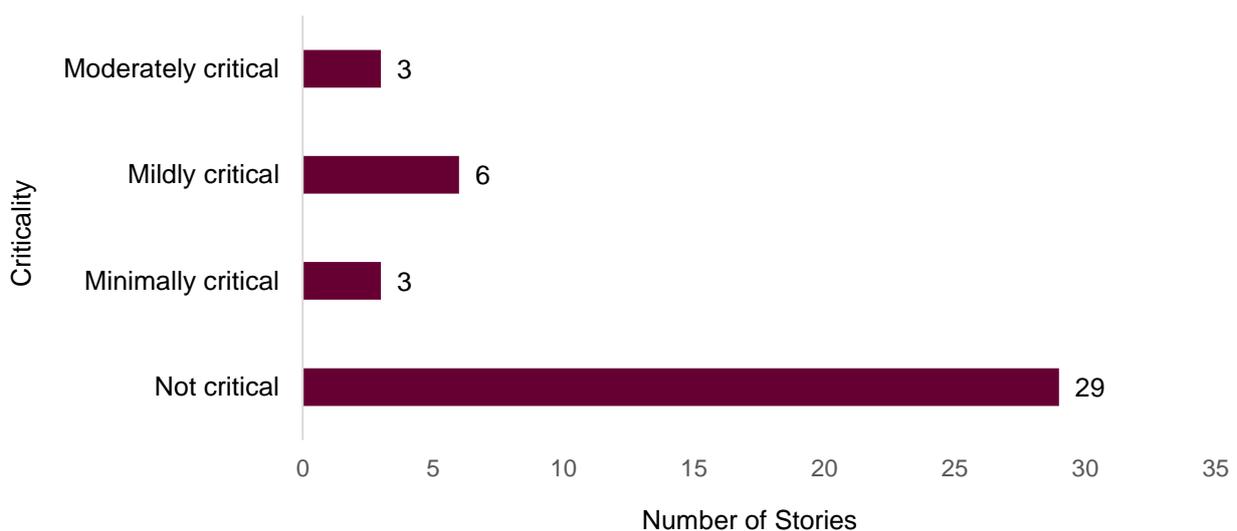
A unique function of Care Opinion is the two way feedback mechanism to ensure authors receive a response from the service and where necessary demonstrate the changes made. In line with research, responses should be within 7 days from publication of the story which demonstrates to the author that services have engaged with the feedback and learning has been shared. 100% (n=41) of stories shared have been responded to within the 7 day timeframe by the services, reflecting the commitment of services to engage service user experience through the stories shared.

## 4.0 SUMMARY OF STORIES

### 4.1 Criticality Scores

Care Opinion is built upon the concept of “what’s your story” and supports the author to highlight what matters most to them using their own words. As part of the analysis through Care Opinion each story is assigned a criticality score by an independent moderator to highlight the level of critique included in the story. The definition of criticality scores is summarised in Appendix 1 and supports an overview of the main content of the stories. Figure 5 illustrates the scores for the 41 stories submitted relating to PCS. The majority of stories (n=29, 71%) have been assigned a “not critical” score which indicates a wholly positive experience. Learning from the critical stories is included in Section 4.3.

**Figure 5. Criticality rating of stories submitted on Care Opinion relating to Long Covid**



NB: criticality scores are assigned by moderators (not the public) to stories to support our alerting service. They are assigned *per story* not *per service*, so may reflect criticism of services other than your own. We provide them here purely for information, with these caveats in mind.

### 4.2 Summary Questions

The stories are also summarised through three supporting questions included on the platform: -

1. What was good about your experience?
2. What could have improved your experience?
3. What are your feelings and emotions relating to your story?

Responses relating to PCS are summarised in Table 1 and further illustrated in the word clouds within Appendix 3.

**Table 1. Top 5 Author tags for stories relating to Long Covid**

What's Good?		What could be improved?		Feelings & Emotions Tags	
Helpful	12	Follow up	2	Supported	10
Staff	12	Information	2	Listened to	7
Friendly	7	Multi-disciplinary care	2	Grateful	5
Advice	6	Appointment wait	1	Encouraged	4
Professional	6	Communication	1	Informed	4

Areas for improvement are included in the thematic analysis of the stories.

### 4.3 Thematic Analysis

Framing each story with the lens of “what matters to you” the following themes have been identified in the narrative. Each theme is illustrated using quotes directly from the story to ensure the voices of the stories are heard. Names have been removed from each quote and replaced with a letter to support anonymity. The quotes encompass both the positive experiences where this was part of the experience and also the negative impact when the theme was not part of the experience. It is also important to highlight that the themes are not mutually exclusive and a number of themes can be identified within the quotes.

#### (a) Recognition of the impact of post Covid syndrome upon the individual

Within the stories authors give insight into the impact of PCS upon their daily lives and some of the challenges they have faced, reinforcing the importance of the services provided from the perspective of the service user.

*“...Long COVID was indeed taking its toll on me both physically and mentally and as the months rolled on I was really finding it hard coming to terms with this condition. Throughout my journey I was supported by my Work and the Multi Professionals within the Health Service... Working through the program with L has helped me progress physically...has helped me fight this long COVID, as best I can. With support I was able to progress to building up my physical health, by walking every day, which helped to build my strength...”*

*“... I developed long covid following an initial mild covid infection in May 2020. When my long covid symptoms developed 5 weeks after initial exposure, I was very anxious and frightened due to the SOB and chest tightness. I have suffered multisystem impact from Covid 19, with all of 2020 getting strange health issues, which resolved and then came back. In Nov 2020 I had a complete crash*

*which I'm still dealing with. As a result of chronic fatigue, dysautonomia, insomnia, pain, mobility issues, cognitive/ communication problems, I have been put forward for ill health retirement from my job. I was struggling mentally and physically with long covid before getting a referral to the post covid service... I learnt how to manage fatigue and the need to be aware of prewarning indicators because I was constantly crashing. Plan, prioritise and rest has become a vital component of my life...So in conclusion the South Eastern post covid service has been vital to me managing my condition and its complexities... Forever grateful..."*

*"...Now I have developed Long COVID, with lots of heart palpitations and shortness of breath which has culminated in my blood pressure rocketing and my GP prescribing me medication for this issue. I've been very low because I'm having difficulty in accepting that this is now the person that I have evolved into..."*

*"...Everyday long covid affects me, from toilet issues to periods all over place to fatigue, forgetting loads, no interests in listening as you feel your head is heavy and your brain's asleep. At present I'm trying new meds to help my lungs. I am still on the respiratory waiting list. Everyday I still have no smell or taste. Nearly 2 yrs later and Northern Ireland have offered no help apart from a 6 week rehab course. My hands are in a lot of pain. I feel so useless I really do. Yes, I'm doing classes but I'm tired now, so tired. It's a lonely journey and people look at you and say you are looking well but I feel awful and have no appetite. Apparently my obs are good, my hearts beating and I'm grand- but in reality I feel like crumbling. I wish I could go back to before covid. I need me back again..."*

## **(b) The importance of peer support**

Within the stories authors expressed the value in meeting with others who were experiencing PCS, supporting them with feelings of loneliness and isolation.

*"...My saving grace has been my acceptance into the Long Covid Clinic where we share our individual stories about how the illness has impacted upon each of us. In doing this it had been so good to know that you are not on your own..."*

*"...I learned quite a bit and also realised that there were patients whose experience was worse than mine. I am grateful for the opportunity to attend the course and would like to express my thanks to the presenters. If I can help others on their journey through or out of this pandemic I would be very willing to do so..."*

*"... I caught Covid in October 2021 and from then on been almost 6 months out of work with extreme fatigue, no energy whatsoever and no sleep. I was advised to apply for the CMP, was accepted, and had several zoom sessions with L and L and several other Long Covid 'patients' - Just to be able to speak to people who suffer from the same as you, and to have professionals who 100% know what everybody is going through..."*

*"...There was 12 or so of us, we discussed things with Sarah and Fiona and they set aside a time for us to talk as a group during the course in each session, it was so helpful to hear others experiences - for example, most of us thought we were having a problem with Alzheimer's, after our discussions, we realised we were in a similar place, and after discussing it we all felt relief, that we weren't losing our memory – it was just part of long covid. The group discussions were probably the most helpful part, and we learnt a lot of stuff about long covid, we had various people coming in, we learnt lots about all the different aspects of the issues that come with long covid, e.g about BMI, weight etc. we had maybe 4 different professionals come in and help, things like learning how to sleep properly. It was super educational..."*

## **(c) Empathetic approach of staff**

Authors of stories highlighted the importance of how staff provided an empathetic and listening ear – helping them to make sense of the symptoms they were experiencing.

*“...I had a Zoom appointment with T to assess my symptoms. She was so helpful. The assessment went at my pace to allow me to think and take everything in. It was so good to get answers to a lot of concerns I had. T was extremely patient and so knowledgeable and understanding. I came away at the end of the appointment with a plan in place and so much information...”*

*“...It’s such a lonely world when you feel so awful and have to navigate it alone. To have someone give time not only to listen, but to be heard and understood, was the most help I’ve received so far...”*

*“...I was very glad to have support from the Condition Management Programme staff during my 'long covid' illness; I was treated with respect, understanding and empathy at a time when little was/is known about 'long covid'; I felt less alone in my struggle and was offered advice on how to best manage my symptoms...”*

*“...I feel not alone in my condition, and that others are suffering similarly. It was very reassuring to be listened to and taken seriously. I really appreciate the care and concern the girls showed and the follow up care has been lovely. Makes you feel more than statistic...”*

*“...To be able to speak to professionals who had an understanding of the issues I was experiencing, was such a relief because I was extremely distraught. I personally felt that I was not being believed and I got the impression that I was becoming an issue. I went from rarely going to the practice to having a significant presence at the health centre...”*

#### **(d) Individualised plans/Importance of Multidisciplinary Input**

Authors reflected experiences which were person centred and consider the person’s individualised needs in relation to managing PCS symptoms. These reflections included face to face appointments, telephone consultations or education sessions. Reference was also made to appropriate referrals to meet the individual’s needs and the importance of pathways to engage with multiple professions.

*“...They [Post COVID clinic] went above and beyond in their duties and it was such a beneficial experience for me to have their expertise, together with other medical experts and Consultants, to outline the best way forward for me in what has been such a traumatic time since the onset of my illness...”*

*“... I felt that I was in the hands of people who knew their job and who wanted to do their job to the best of their ability and knew what I needed.... For me this was the NHS at its best...”*

*“...I attended the Post Covid Respiratory Service within the Southern Trust and I must say I was well looked after, they made the appropriate referrals for me....”*

*“...No one explained why I was feeling this way or discussed it with me until I spoke with T in the Post Covid Syndrome Service. It was great for someone to finally listen to all my symptoms and reassure me that it was long covid and that she would be able to provide me with some tools to manage my symptoms as well as make some referrals to other areas such as Speech & Language Therapy & respiratory...”*

One author highlighted concern their assessment was limited to respiratory with limited multidisciplinary approach. This refers to experience in November 2021 when the clinics were being established.

*“...With my own research I found out about covid rehab now in NI November 2021. Contacted GP to get a referral. If GP knew I had long covid why could they not have automatically referred me . Again I have to advocate for myself. Assessment over telephone December 2021. Referred to respiratory clinic . NI really needs a multisystem clinic for long covid patients to assess all the symptoms they are dealing with...”*

### **(e) Content of the programme**

The majority of stories shared a positive experience of engaging with PCS programmes and would recommend the service to other service users experiencing PCS. There were a number of suggestions to improve the programme reflecting upon the content of the education sessions. There was also an element of discontent in understanding the symptoms, with questions remaining unanswered and limited knowledge on why they are experiencing symptoms.

*“... I'm not sure that some of the education sessions which were conducted separately worked very well for example the sessions on sleep and diet or when the presenter read straight from slides! However, I'm glad that I did the course...”*

*“...I would have liked more dietary education...”*

*“...After 2 years suffering from multiple symptoms ,I had pinned my hopes on learning something that would help improve my health. But I am no better after the sessions, I am no wiser as to why I have the symptoms that I do. I have to wonder, is that it? 2 years later, is that all the help that is available? I found the exercise sessions difficult. Long covid is more than just deconditioning, people like me have post exertional malaise and exercise can cause a crash. I feel like more consideration needs to be given to those that suffer PEM and the impact that moderate exercise can have on the individual. The information sessions could have been held over zoom and a booklet or handout would be beneficial especially for those with cognitive difficulties caused by Long Covid...”*

*“...I got some useful tips on coping with my symptoms, but I would have liked more medical information as to why I have the symptoms I have, so I left with a lot of unanswered questions...”*

*“...May 2022 completed 6 weeks of rehab. This consisted of doing exercise 2 mornings for 6 weeks. A psychologist for an hour and the council did a morning of healthy eating...We were monitoring heart rate while completing a walk test and after exercise. No feedback given about the results of recordings. Telling patients that it's self resolving ,wait and see you will better isn't the answer and comparing to other viral illnesses in the past doesn't help give me peace of mind no one has an answers from research...”*

*“...The programme material was very informative and I found it very helpful to have the printouts and written info to review later on and keep as a reference to share with my husband was great. The skills learnt in condition management are useful tips that I can still do at home myself. The referrals to other clinics and treatments has been very helpful. I feel the length of the programme was about right...”*

### **(f) Duration of the Programme**

Within the feedback there were a number of reflections on the benefits of the programmes and a desire to see the clinic extended.

*“...I would increase the clinics from 6 weeks to 12 weeks as I found around the 6 week mark you were only really starting to get into the feel of the clinic, while attending the clinic any exercises that were shown from that week and previous weeks you continued to do as you wanted to show the staff at the clinic you were doing your exercising at home but after the 6 weeks those home exercise routines become less and less and you revert back to previous ways as you have nothing to keep you encouraged!...”*

*“...It was so gratifying to be told by S and C, my Nurse and Physio, that mine was a real condition. Their invaluable advice and help for the duration of 12 weeks and if I'm honest I would have liked the course to last much longer than the 12 weeks...”*

### **(g) Waiting Times/Delays**

A small number of authors highlighted discontent with lack of communication within the referral process and a need to invest in resources or to develop a process to inform service users of the likely timeframe to be seen. Also, linked to multidisciplinary working there was a need to enable referrals from the PCS service as opposed to returning to GP.

*“...After being critically ill with Covid for the first 6 months of 2021, and feeling continually fatigued with Covid, I requested my GP to refer me to Long Covid Clinic. That request was made at the start of December but to date I have heard nothing. I feel let down, especially when I read about our Executive making statements about setting these Clinics up, and reading of how many patients have been referred...I would appreciate being told something of how many clinics have been set up and how many patients are being actually treated, not just referred. When might I expect to hear about my own referral?...”*

*“...I am so grateful for this service, It has really helped me. It took 6 months to get the appointment but with more staff in place it would cut down the waiting time...”*

*“...I feel the Respiratory Physio running the clinic-they were exceptional- but red tape needs removed so they can refer patients onto other disciplines such as cardiology, dietetics, community physio, occupation therapy, ENT or can refer patients for further physio, scans, X-rays, bloods. This process would speed up a patients recovery from long covid and reduce the whole debacle of having to be referred back to your GP or referring consultant, waiting weeks/months on appointments, just cut out the middle man and get things moving faster!!...”*

*“...Fairly rapid initial contact followed by weeks of silence and no communication. No information fed back to GP- I had to phone round multiple departments in a search for individuals as there's no clinic number to ask for results to be forwarded. No clear remit or scope communicated to GP either- we waited months expecting onward referral to be told that wasn't their job. No central telephone number as a POC, at least not one that anyone ever answers... I got lost in the system and investigations took 15+ weeks longer than I was advised. I'm over a year down the line and haven't been referred to anyone medical yet because of delays...”*

### **(h) Recognition support for mental health is part of Long COVID management**

Authors highlighted the impact of PCS upon their mental health and the importance of the PCS clinics to engage with mental health services/sessions

*“...The last thing I would like to comment on is what we would call “the elephant in the room”. I wasn't acknowledging the fact that my mental health was suffering and again thanks to L, where she subtly brought this to the fore. This was hard for me to recognise and address as my instinctive*

*nature was “this doesn’t happen to people like me”. Again L was a fantastic help and guide for me...”*

*“...The team offered support with the one to one interactions and group programmes. I required CBT for a number of weeks to deal with anxiety and I'm using the techniques I learnt, to deal with the loss of my health and function, the loss of my career and the need to sell my home of over 20 years...”*

#### **(i) Support following engagement with PCS services/follow up**

There were a number of concerns raised in relation to support following treatment through PCS clinics. This includes lack of support in relation to returning to work and moving forward in managing PCS.

*“...Detailed slow phased return to work over extended period was recommended, which was realistic & reflected my needs. Extremely disappointed when the same Trust OH & HR teams failed to follow this return to work plan despite the fact that Same OH team had made my initial referral. Seems to be a serious lack of joined up thinking when advice of Post COVID practitioner is disregarded & traditional phased return to work enforced...”*

*“...The rehab only lasted 6 weeks but they put me through the 6 weeks a 2nd time. It was great, I miss it, it gave me a purpose in life, something to get up and do, to get going... I really think I still need support, although when I finished the sessions with E and H I thought I was OK. My experience of the rehab clinic was excellent, they couldn’t have done any more for me...Rehab twice a week gave me motivation, now days any outing for me is to a hospital appointment. Covid has changed my life a lot...”*

*“...I also feel there should be a call back service to the clinics after 3 months, 6 months and a year to see and document your progress and then leave it up to the staff who have brought you this far to make a decision about discharging you. 6 weeks is definitely not long enough to make a decision about anyone with long covid and their recovery, the 6 week clinic/program should be the initial tester to see where your at and to test your exercise tolerance, concentration and to set up a plan to continue with your after care, then the next 6 weeks should be focussed on getting you moving and pushing you so you know what your limitations are!...”*

#### **4.4 Changes Recorded**

As Care Opinion supports a two way feedback mechanism between authors of stories and responders in a service it is possible for a responder to highlight changes made. There has been **1 change made** (as recorded by responders) by services as a direct result of engaging with an individual story as detailed in the link below. It is recognised learning and change is a continual process and not always captured on the platform.

[My experience with the Long COVID clinic | Care Opinion](#)

*“...Dear Nurse To Patient, I am the Post Covid Clinical Coordinator. Thank you for your patience for our response. Firstly, I would like to apologise for the experience you had with the Post Covid Service. Due to the difficulties with contacting our team that you have highlighted, and as we are a part time service, we have introduced a new service line number that is now manned daily with a voicemail service. We have also contacted switchboard and are working with them to ensure*

*patients are directed to the appropriate service. As we are a one stop shop we can only give guidance on how long Pulmonary Investigations may take to contact you for an appointment, unfortunately their waiting times are out of our control and I can only apologise for your wait...”*

## **5.0 NEXT STEPS**

The analysis presented in this paper is based upon the stories shared from 01 January 2022 to 31 May 2023. It is anticipated the following actions will support PCS services within Health and Social Care Trusts to continue to demonstrate their commitment to listen and learn from the experience of service users, families and carers through Care Opinion:

- 1- Consider the themes identified within the briefing paper and learning and potential actions which will support a better lived experience for people engaging with Long COVID services.
  
- 2- Embed the concept of Care Opinion into PCS services through training led by Trust Patient Client Experience (PCE) Facilitator and opportunities through Care Opinion - this includes Care Opinion awareness training, framing the ask and responder training.
  
- 3- Learning presented from stories shared on Care Opinion can provide insight into current experiences of PCS services – This information should support service development or inform Quality Improvement initiatives relating to PCS services alongside other sources of learning such as complaints, research and groups for people living with PCS.

## Appendix 1:

### Definition of Criticality Scores assigned by Care Opinion Moderators

Score	Definition	n=41
0	<b>Not Critical:</b> Entirely positive or neutral postings with no hint of criticality.	29
1	<b>Minimally Critical:</b> Mention of dissatisfaction with non-clinical non-personal aspects of care, typically “facilities” issues such as food, parking, or waiting.	3
2	<b>Mildly Critical:</b> More specific but still mild criticism, which may also include non-clinical but interpersonal issues such as attitude of staff, compassion, politeness. This might include the timely nature of the service whether in hospital or in the community where it has caused distress, e.g. carers not turning up on time	6
3	<b>Moderately Critical:</b> Criticism which may include alleged shortcomings in clinical or non-clinical aspects of care, the Author may not say what the effect of these are. Also includes serious comments about facilities: ‘never cleaned’; and where people’s essential basic care needs are not being met, e.g. inadequate nutrition and hydration, development of bedsores	3
4	<b>Strongly Critical:</b> Serious criticisms of specific unnamed staff or groups of staff, or of clinical or other care or facilities. This might have had very serious consequences for physical or emotional health. These will be described by the Author. There might also have been social consequences that have increased the risk or vulnerability of an individual	0
5	<b>Severely Critical:</b> Posting alleges or describes actions or events which may be illegal, grossly negligent, or allege serious misconduct by named members of staff or organisations	0





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