

# Long Covid/Post Covid Assessment Clinics

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## 1. Executive Summary

In response to the Covid-19 pandemic, NHS England and Improvement provided funding for 2020/21 to the Nottingham and Nottinghamshire Clinical Commissioning Group to facilitate the implementation of the Long Covid/Post-Covid Syndrome assessment clinics for patients with multiple and on-going symptoms 12 weeks after having the Covid infection. The Nottingham and Nottinghamshire Clinic was launched in March 2021.

The Nottingham and Nottinghamshire Clinical Commissioning Group and Integrated Care system engaged with individuals who have accessed the Long Covid/Post Covid Syndrome assessment clinics to understand their views and experiences. Collated feedback will inform the Long Covid/ Post Covid syndrome treatment pathway moving forwards.

A variety of approaches were used to offer opportunities for citizens to engage via telephone interviews, an online Survey and online focus groups. The engagement ran from the 20<sup>th</sup> of September 2021 until 17<sup>th</sup> of December 2021. A total of 4 online surveys were completed and two telephone interviews conducted.

Findings included:

- Carers could benefit from understanding more about Long Covid symptoms and how best to support loved ones.
- To increase the range of services included in the treatment pathway.
- To include questions within the assessment clinics questionnaire that reflect both physical and mental health symptoms, not only anxiety and depression.

Additional findings and recommendations can be found further on in this report.

Thank you to all participants who took the time to provide feedback and share experiences via the online survey and telephone interviews.

## 2. Background

Post Covid Syndrome is defined as “signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.” (NICE Guidance NG188). Long Covid is the

collective term used to describe both the ongoing signs and symptoms of Covid 19 at 4 to 12 weeks after infection AND Post Covid Syndrome.

Prior to this engagement commissioners undertook workshop discussions to understand the views of professionals. These workshops also included citizens who had experienced Long Covid. The feedback gathered from the workshops, initially informed the design of the wider Long Covid/ treatment pathway. The engagement activities in this report will contribute to the ongoing development of the Long Covid treatment pathway moving forwards.

In addition, Healthwatch Nottingham and Nottinghamshire produced a report representing the experiences of people with Long COVID. These experiences were shared during the above-mentioned workshops.

Once GPs have exhausted other options for care including self-management, they have been able to make an e-referral into the assessment clinic for patients with multiple new and ongoing symptoms 12 weeks after the covid infection that require a full assessment and specialist MDT approach. The e-referral is received by Nottinghamshire Healthcare Trust's (NHT) Call for Care service or CityCare's hub and triaged. Clinical assessors have arranged a virtual assessment wherever possible with the patient using a screening tool. At this point they may be referred directly into appropriate existing services to meet their needs, or an MDT discussion is facilitated. Medical input and oversight is provided to the MDT by a consultant. A care plan and referral into appropriate community health, mental health and secondary care services will be made and care co-ordination will be undertaken.

The assessment clinics have complemented existing community, mental health and secondary care services and pathways by offering comprehensive physical, cognitive and psychological assessments and specialist Multi-Disciplinary Team (MDT) assessment. Existing mental, community and secondary care services have continued to provide treatment for individual symptoms, the clinics and MDT have offered a more coordinated approach where there are multiple symptoms.

## **2.1 Aim and Objectives**

The aim of the engagement was to understand the views and experiences of those who have accessed the Long covid/Post Covid Assessment Clinics to help shape the clinics and treatment pathway going forwards.

The key objectives the communications and engagement activities aimed to meet were:

- To understand experiences and views from patients around what works well and what they would like to see improved for the clinic and treatment pathway in future.
- To understand experiences and views from carers around what works well, what they would like to see improved and what their needs may be as carers.

### 3. Engagement Methodology

Online engagement opportunities were offered via a survey and focus group sessions. Telephone interviews were also offered for those who found it more accessible.

This was a targeted piece of engagement and promoted through channels directly linked to individuals who had been referred to the Long Covid/Post Covid Syndrome assessment clinics.

The engagement opportunities were shared with CityCare, Nottinghamshire Healthcare Trust, specific GP practices that had referred to the clinics and Healthwatch -who had identified individuals that had attended the clinics following their own Long Covid piece of engagement (please see appendices).

Engagement originally ran from the 20<sup>th</sup> of September until the 15<sup>th</sup> October with focus groups on the 6<sup>th</sup> 9<sup>th</sup> and 12<sup>th</sup> of October, evening, weekend and daytime sessions were available. Telephone interviews were offered at times to suit the convenience of citizens and the survey was open online.

Due to lack of uptake and to allow the best opportunity for citizens to participate, the engagement period was extended until the 17<sup>th</sup> of December. The focus groups were to be arranged based on participant availability, however, did not run due to lack of registrations for the sessions. The survey and telephone interviews continued to be open which yielded further responses.

### 4. Findings

The online survey was completed by 4 respondents and 2 telephone interviews were carried out which provided in-dept insight into the experiences of accessing the clinics. All views obtained were shared by those who had direct experience of and interaction with the clinics. Though we welcomed views from carers, feedback directly from carers was not received. However, those who participated with engagement shared what they believe would help carers with loved ones who are experiencing Long Covid symptoms. The response from the survey and telephone interviews have been grouped into key themes and trends.

#### 4.1.1 Survey findings

### **Experience of getting help from the GP**

- 75% strongly agreed/agreed that they felt listened to by their GP and their symptoms were understood, 25% disagreed.
- 50% strongly agreed/agreed that the GP explained which tests they needed to have, 25% neither agreed nor disagreed and 25% disagreed.
- 50% of respondents agreed that the GP discussed options with them, 25% neither agreed nor disagreed and 25% disagreed.
- 25% were signposted to the Your COVID Recovery Website, 75% neither agreed nor disagreed.
- The feedback on being signposted to information about Long COVID was mixed, 50% agreed/strongly agreed and 50% neither agreed nor disagreed.
- A more in-depth discussion with the GP regarding symptoms and what could improve them would be helpful.

### **Additional support**

- 50% accessed the Your Covid Recovery Website for information and guidance and found it somewhat helpful, 50% did not access the Your Covid Recovery Website.
- 50% tried the self-management tools from the Your Covid Recovery Website and found them somewhat helpful.
- Further support was obtained from, Facebook self-help groups, newspaper articles, medical journal articles, research on the internet, counselling via a workplace scheme and via private healthcare.

### **Experiences at the clinics**

- All respondents either strongly agreed or agreed that they were invited quickly for an assessment, felt their clinician understood their symptoms, were listened to, were signposted to information about Long Covid and understood which services they were being referred to and what would happen next.
- 50% felt that their care was coordinated well, 25% disagreed.
- There was a fair split of opinion from agree through to disagree on the clinician discussing the options with the patient.
- 25% were signposted to the Your COVID recovery website via the assessment clinic.

### **Additional comments**

- More attention to physical symptoms, breathlessness, heart palpitations would be beneficial during assessment at the clinic.
- Shorter wait times from the date of referral by a GP to an assessment by the clinic would be helpful.

- A more proactive approach to contacting patients with Long Covid. This is a very lonely and not understood condition which affects physical and mental health.

### **Found helpful about the Long COVID/post COVID assessment clinics**

When asked about what was found helpful about the assessment clinics, patients tended to refer to the treatment that they were referred into rather than the assessment clinic.

- Attending Teams meetings with other sufferers in the same situation was helpful.
- Knowledgeable staff.
- It was a structured programme over a 12 week period that was flexible enough to allow each participant to engage at their own ability and target levels.

### **Satisfaction rating on the experience of the assessment clinics**

75% were satisfied/very satisfied, 25% neither satisfied nor dissatisfied.

### **Accessing treatment support following assessment**

- 25% accessed treatment support following assessment, 75% did not access treatment following an assessment.

### **Experience of treatment rating following assessment**

- 25% were neither satisfied nor dissatisfied

## **4.1.2 Telephone interview findings**

### **Telephone interview feedback**

- Accessing online information is difficult for those without access to a computer.
- The Your Covid Recovery website was found to be slightly helpful.
- More services should be available to refer into to.
- More diagnostic tests should be available.
- Changes are needed in the pathway to better reflect the nature of the illness.
- Long Covid should not be treated as anxiety.
- The majority of the Long Covid/post Covid syndrome assessment clinics questionnaire has a heavy focus upon depression, anxiety and mental health, which is not helpful for people experiencing physical symptoms. It would be helpful to include questions about the following:  
Fatigue levels, shortness of breath, post exertion malaise, breathing difficulties, pain, temperature regulation issues, blood pressure issues, dizziness, light

headedness, blurred vision, changes in eating, gastro-intestinal difficulties, heart rate / function abnormalities, panic attacks, sleep disturbances, numbness, tingling, pins and needles, whether or not the patient is vaccinated and whether or not this has helped or hindered their recovery.

- Commonly occurring symptoms reported were: Intense fatigue, almost falling to the floor, cough, dry throat, hoarse voice, very bad headaches, feelings of vertigo, feelings of blacking out and half fainting with nausea.
- Referrals to more appropriate services and shorter waiting times to access services.
- It would be helpful if the clinics worked more closely with the patients GP for context.
- The treatment pathway was not able to improve my situation.
- Waiting times to access treatment can be long with some waiting roughly 6 months.
- Revise the current questionnaire to reflect all the symptoms of Long Covid.
- Communication from the clinics was irregular.
- Carers could be supported to understand the illness and the importance of pacing and how fatigue can impact individuals.
- Financial compensation to carers to ease the burden of having to work part time.
- Providing carers with an information pack with advancements in the illness could help. It's vital that carers are kept up to date.
- Support with transport could be helpful.
- It is important that healthcare professionals do not treat Long Covid as a psychological condition.

## 6. Recommendations based on data and feedback collected

- A guidance document for carers to support their understanding of Long Covid symptoms. To provide guidance around how to support individuals with fatigue and how to pace activities.
- For carers to receive updates as more knowledge is gained about Long Covid.
- To provide information about Long Covid in hard copies in addition to online resources.
- To ensure services to treat the full range of symptoms are included in the treatment pathway.
- To ensure the assessment clinics prioritise both physical and mental health symptoms equally at assessment.

## **7. Conclusion and next steps**

The information gathered from this engagement will inform the Long Covid/Post Covid Syndrome treatment pathway moving forwards. Following this a “You Said We did” report will be produced to reflect how the patient and carers voice has developed the treatment pathway moving forwards.

## 8. Appendices



Key Stakeholders.pdf

Appendix 1 - List of stakeholders



Long COVID leaflet  
updated.pdf

Appendix 2 – Leaflet



Focus group  
presentation and inter

Appendix 3 – Focus group presentation and telephone interview questions



Long Covid  
patient.carer survey.p

Appendix 4 – Patient/carers online survey



Long covid post  
covid syndrome asses

Appendix 5 – Patient/carers online survey full results



Equality and diversity  
survey.pdf

Appendix 6- Patient/carers online survey equality and diversity results



Message to send via  
SMS.pdf

Appendix 6 – Text message

Appendix 7- Healthwatch Report - Health and Social Care needs of people with Long  
COVID -August 2021



Long-Covid-Report-F  
INAL.pdf