

HSI21/084

GOVERNING BODY

Title of paper	Patient Story		
Agenda item	6	Date of meeting	8 December 2021
Executive lead	Helen Ives, Executive Director of Workforce		
Author	Karen West, Long Covid Allied Health Professions Lead, SE Hampshire		

Purpose	For decision	<input type="checkbox"/>
	To ratify	<input type="checkbox"/>
	To discuss	<input type="checkbox"/>
	To note	<input checked="" type="checkbox"/>

Link to strategic objective	<p>This paper has links to Objectives:</p> <ul style="list-style-type: none"> • 1 – Operational Delivery • 3 – Service Transformation
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Executive Summary	
<p>This presentation introduces Roger's story and provides information on his patient experience of being referred to the long Covid service, his journey through the service, and how it has supported him through recovery.</p> <p>The video that will be shared at the meeting sets out Roger's experience in his own words.</p>	
Recommendations	The Governing Body is asked to receive and note the patient story
Publication	Include on public website ✓

Please provide details on the impact of following aspects	
Equality and quality impact assessment	There are no equality and quality impacts to note
Patient and stakeholder engagement	The report will be of interest to patients and stakeholders across the CCG
Financial impact, legal implications and risk	No impact
Data protection impact assessment	None to note

Long Covid Case Study

Karen West

Lead AHP Long Covid SE Hampshire

08/12/21

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Respect

Roger's Story

Assessment 26/01/21

- Suspected Covid May 2020. Complaining of fatigue, breathlessness, pain in his lungs and a burning pain centred over his right collar bone which he rated < 8/10
- Pain helped by analgesia and when a fan was blowing on it. Worse with heat
- Pre-assessment questionnaires also indicated low mood and anxiety
- Unable to work repairing starter motors (self-employed)

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Initial Plan

- Enrolment onto the Living With App
- Signposting to fatigue information on the App
- Sent additional information on fatigue management

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Living With App

- Designed for people with long covid
- In use across the ICS
- Features include
 - Patient Reported Outcome Measures (PROMS)
 - Symptom reporting and tracking
 - Sources of reliable information
 - Messaging feature



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09/02/21

- Tried to do too much, needed a few days in bed to recover
- Talked about fatigue management strategies to avoid cycles of boom and bust
 - Prioritising
 - Pacing
 - Chunking activity
- Suggested using fatigue diary to look for patterns in activity and rest

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16/02/21

T/C in response to messages via App

- Overdid things last week, crashed
- Very anxious about feeling unwell and going for his Covid vaccine
- Supported planning for vaccination with rest, mindfulness and relaxation before and after
- Talked about trying not to get disheartened by setbacks

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16/03/21

- Generally better, still having difficulty pacing himself
- Great improvements in questionnaire scores for fatigue and anxiety
- Discussed sleep habits as sleeping a lot during the day and not at night
- Introduced walking as an exercise, starting at 5 minutes/day
- To continue with pacing and mindful rest

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Respect

01/06/21

- Generally feeling better, scores remain the same but is more active - doing exercises from the app and walking for 5-6 minutes a day without ill effect
- Relapse after his second jab but is now 47 days since his last relapse
- Daughter is getting married in August, unsure if he will be able to go to the wedding, pressure from family to attend

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Message Exchange

- 🌀 06/07/21 “I walked 5 times 41 minutes in total, did my washing , had a shower and exercise I also been doing 1 and 2 kilo weights I’m just so unfit now but I think it’s safe to say I’m over the long covid 😊”
- 🌀 12/07/21 “I am walking about 8 miles a day. The main problem is my head ... still I can’t concentrate so I just keep going for walks. I am on antidepressants, hopefully that will sort it or maybe it will just slowly get better”
- 🌀 02/08/21 “I was self employed but I decided to get a job ...I start next Monday 9th ... things are looking up”

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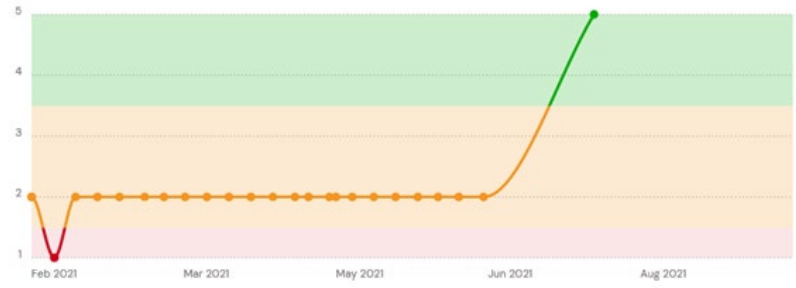
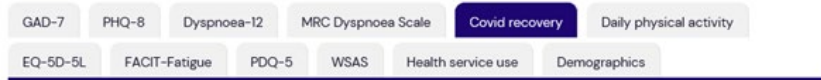
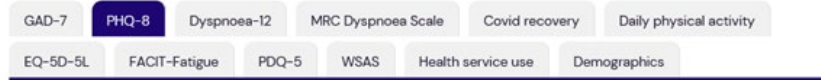
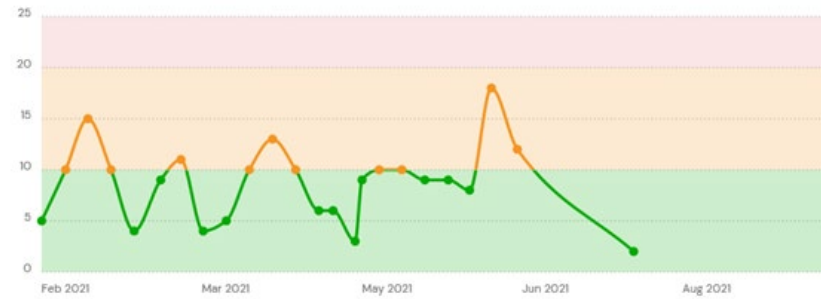
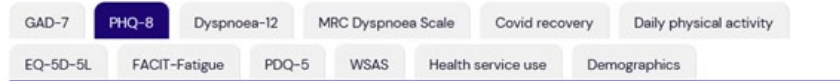
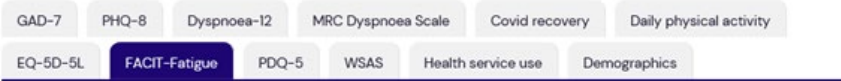
Final Assessment

- Feeling really good, walking 10 miles a day, using rowing machine, started gentle running
- Looking forward to starting work, daughter is getting married tomorrow, may dance at the wedding
- Head is in a much better place
- Feels able to be spontaneous again, out enjoying doing the things he used to do - dancing starts in September

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PROMS



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In his own words...

With thanks to
Roger for allowing
me to share his
story

<https://vimeo.com/650361274/686f8823e4>



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