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2023

Constrained Candidacy: Exploring different barriers to attaining healthcare access and treatment for Long COVID illness by NHS workers in Scotland

Dr Nick Adams

Nicholas Norman Adams, Emma MacIver, Catriona Kennedy, Flora Douglas, Diane Skåtun, Virginia Hernandez Santiago, Nicola Torrance*, Aileen Grant*

*** Joint principle investigators**

LoCH
Long Covid in Health Workers

SCHOOL OF NURSING, MIDWIFERY AND PARAMEDIC PRACTICE

CHIEF SCIENTIST OFFICE

ROBERT GORDON UNIVERSITY ABERDEEN

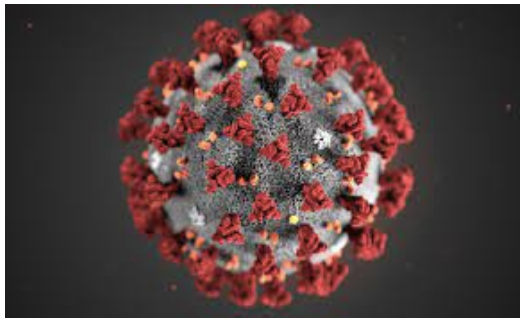
1495 UNIVERSITY OF ABERDEEN

University of St Andrews

Background: *The LoCH Study*

Aims and Objectives:

- Long COVID (LC) effects 1.2 million people in the UK, including 120,000 NHS workers.
- LC remains poorly understood, comprising manifold symptoms ranging in severity, disrupting quality of life and work abilities: *Harrowing, life-changing, devastating, mourning a 'former life' and 'former self'.*
- This study aims to explore the experiences of NHS workers with LC to understand their illness experiences, conceptualisations of healthcare eligibility, and barriers to attaining healthcare.
- Candidacy theory is applied to understand, barriers faced re perceived eligibility for healthcare and healthcare access



LOCH

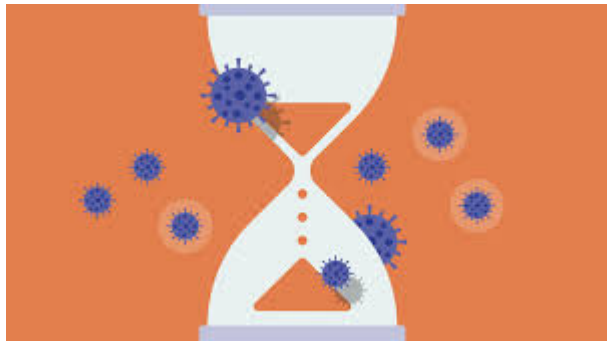
Long Covid in Health Workers

Methods: LoCH - *A Longitudinal, Mixed-Methods Approach*

Two time points / Six-months apart.

Methods Timeline: Quantitative

- Online questionnaire at two time points: Initial Q June 2021 – Oct 2021, Follow-up Q Feb 2022 – June 2022.
- Shared via social media, email advertisement from NHS boards circulated by internal NHS communications teams. Range of roles and occupations.
- Eligibility - Employed in an NHS healthcare setting in Scotland, 18+, self-identified as having prolonged Covid-related symptoms; including both ongoing C19 symptoms (from four to twelve weeks) and post-C19 LC (twelve weeks or more) (NHS, 2023). Positive C19 test not required.
- Questions: Long COVID symptoms, health and experiences around working in the NHS, HRQL (SF-12), EQ-5D-5L EQ-VAS, PHQ4, Promis SF-V1-4A.
- Q1 (n=471 completions) Q2 (n=302 completions). 11 NHS-S health boards.



NHS (2023) Long-term effects of COVID-19 (long COVID) *What is long COVID?* Accessed 10th April 2023 from: https://www.nhs.uk/conditions/covid-19/long-term-effects-of-covid-19-long-covid/#:~:text=What%20is%20long%20COVID%3F,which%20is%20still%20being%20studied.

Methods: LoCH - *A Longitudinal, Mixed-Methods Approach*

Methods Timeline: Qualitative

- Purposefully sampled at two time points: 1: September 2021 and January 2022, 2: March 2022 – June 2022.
- Semi-structured with interview guide, in-depth, online-based
- First interviews n=50
- Second Interviews n=44
- Over a hour, harrowing, participant wellbeing. Focus on being believed, barriers to healthcare access and treatment.
- Qualitative Analysis – Braun and Clarke, Mixed - Inductive, Deductive. NVivo used as an analysis aid.
- **A focus on these interviews for this remainder of this presentation.**

Applying a theoretical framework:

- ***Candidacy theory***

- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., ... & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC medical research methodology*, *6*, 1-13.

- Tookey, S., Renzi, C., Waller, J., Von Wagner, C., & Whitaker, K. L. (2018). Using the candidacy framework to understand how doctor-patient interactions influence perceived eligibility to seek help for cancer alarm symptoms: a qualitative interview study. *BMC health services research*, *18*, 1-8.

1. ***Identification*** – the process by which individuals recognise themselves as in need of a service.

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6. ***Offers of -and resistance to- services*** – an individual may refuse services, such as appointments, referrals and treatment at any stage in their journey.

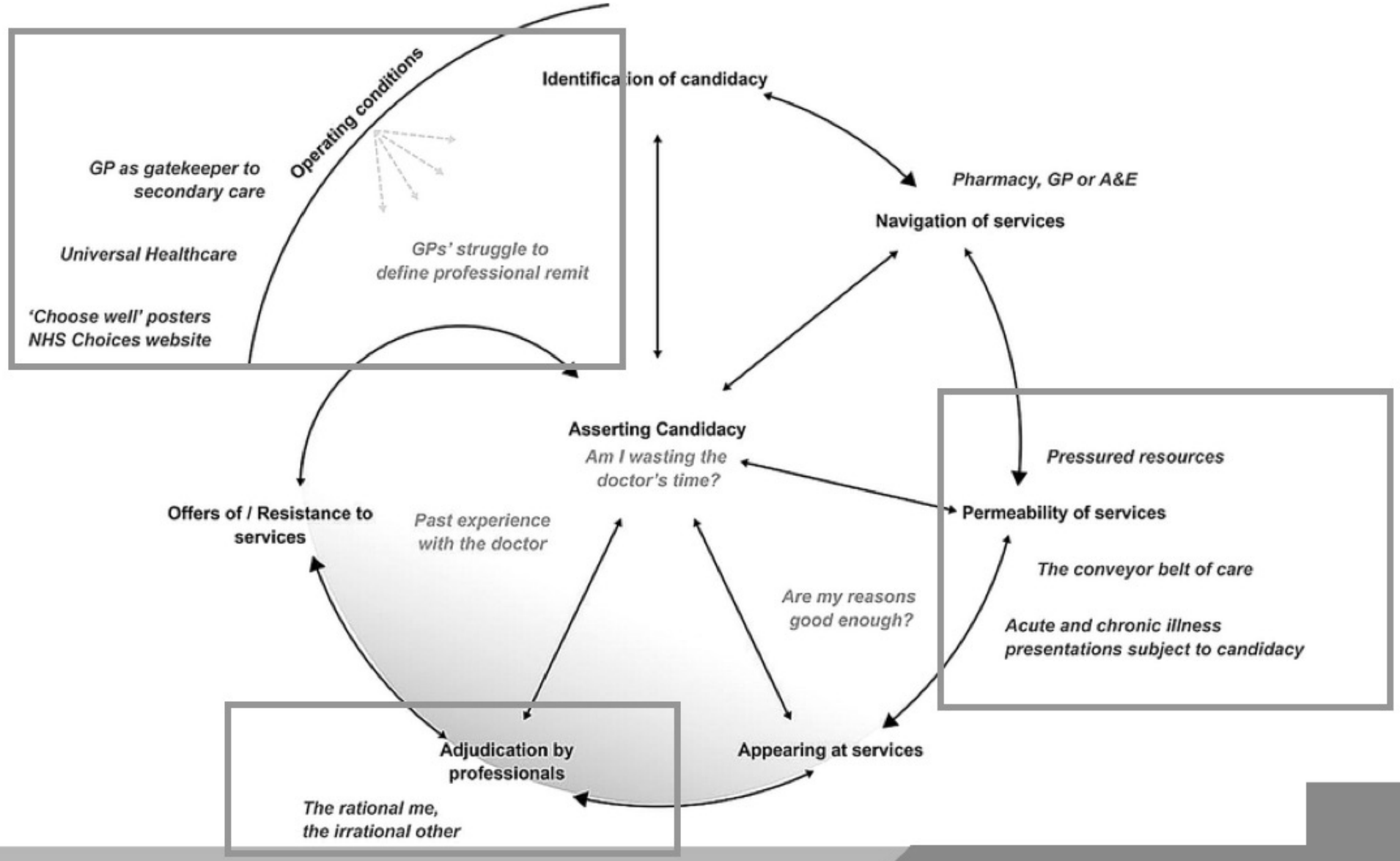
7. ***Operating conditions*** – wider macro-local influencers over the above dimensions. Candidacy is subject to influence from multiple factors in the wider social sphere such as environmental, political, social and economic contexts that overlap with the above domains (e.g. news coverage, social concerns, public opinion, healthcare trends).

The candidacy cycle – Llanwarne et al. (2017).

Applying the **candidacy framework** to make sense of findings:

- **Adams, N. N., MacIver, E., Kennedy, C., Douglas, F., Hernandez Santiago, V., Kydd, A., ... & Grant, A. (2022). The GP can't help me, there's no point bothering them: exploring the complex healthcare journeys of NHS workers in Scotland suffering from long COVID: a longitudinal study**.

- Llanwarne, Nadia, et al. "Wasting the doctor's time? A video-elicitation interview study with patients in primary care." *Social science & medicine* 176 (2017): 113-122.



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Combined findings: *A case for Constrained Candidacy at the 'Illness Identification Stage'*

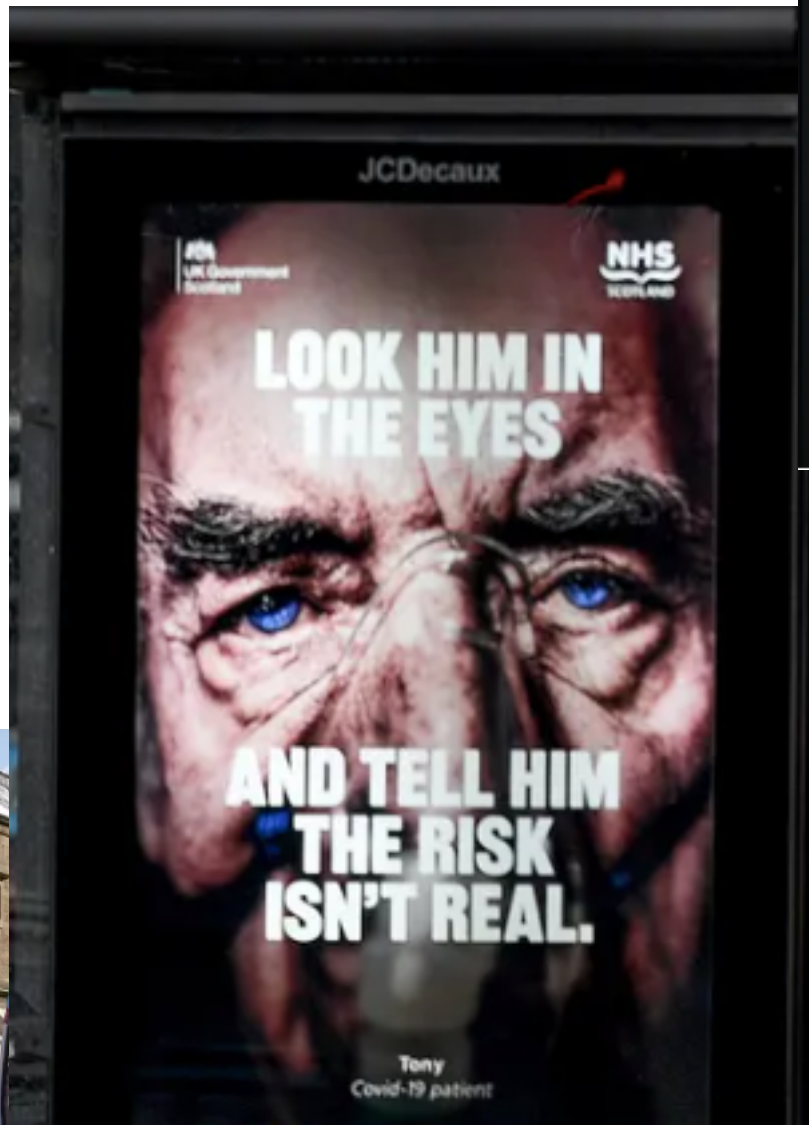
Breakdown of Key Thematic Findings: A focus on 'Individual' candidacy

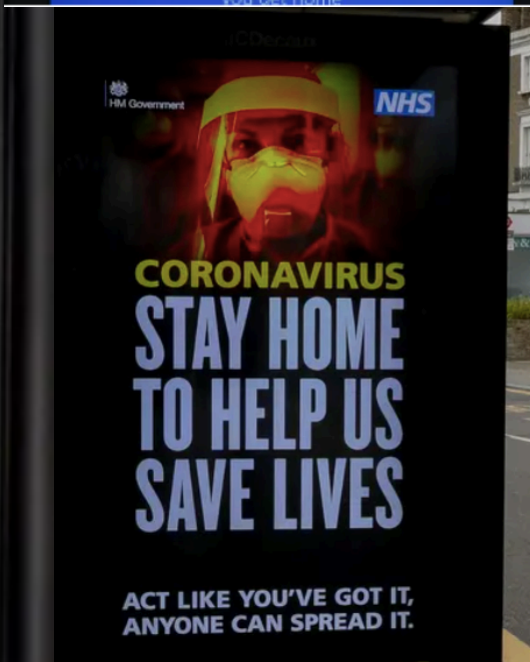
'Real-world' effect Dimension	*Impacted Candidacy Domain*
Context: • Is it Really Long Covid? • Healthcare Access: Do I deserve Healthcare? • Personal Pressures and 'guilt' over initial help-seeking for Long Covid symptoms.	• *'Operating Conditions'* • *'Presentation (Appearance at Services)'*
Illness Climate: • Striving to be believed and a downturn in effort, leading to withdrawal of help-seeking.	• *''Navigation'* • *'Permeability'* • *'Adjudication by professionals'*
Sense-making of Long Covid Illness: • **Nurses – Questioning own medical expertise and self-diagnosis: withdrawal, coping by being back at work** • **Doctors - Utilisation of individual 'skills' and 'capital' -BUT- disillusionment at lack of resources /** • **clash with own professional experience 'giving healthcare' with experience of 'receiving healthcare'.** • **Doctors - Frustrations with level of care received – withdrawal from seeking m**ore care "it's pointless" • **Doctors – in need of a service, but not the services that are available.** • **Doctors - 'Indirect treatments' work : further questioning of LC illness.**	• *'Offer of and Resistance to Services'*

Combined findings: *A case for Constrained Candidacy*

1) Context: the restrictive pandemic healthcare context.

- Wider Operating Conditions as Context
- Climate of anxiety
- Participant voices ”the NHS was closed”
- Telephone triage at GP practices / no face-to-face appointments
- Initial message of ‘no contact, unless emergency’ and ‘if it can wait…’
- **Constructed ‘guilt for help-seeking’ – amplified for NHS workers.**
- **Severity motifs - ”It might not be Long Covid”.**





Combined findings: *A case for Constrained Candidacy*

2) *Illness Climate*: low GP knowledge surrounding LC and how LC could be treated - trends for ascribing symptoms to other factors, and reluctance to diagnose LC.

"At the beginning, my GP was lovely, but I don't think she knew what to do with me. Not because she's not very knowledgeable, but because the knowledge wasn't there. […] She knows me as well, out with it, because unfortunately, it's a small world in [this city]. But, but I don't think she really knew what was causing all my symptoms, but nobody does still […] I think she did the best she could in the situation. It probably took me a while to go to her because I felt like I was wasting people's time, and thought I would just get better. So, that's partially my fault for not seeking help earlier. […] I worry that they miss things, because they didn't take me seriously when I went to see the respiratory consultant. I had severe chest pain, which was pleuritic, in my back. I was worried I might [have] had a PE [Pulmonary Embolism] because the clotting nature of things. And he didn't, he basically just said, oh, I don't really know why you're here […] I'm not altogether happy about how I was managed from that point of view. Again, I'm not blaming anyone, but I think that I feel like I've been slightly ignored. The renal consultant offered investigations, but […] by the time I saw him, my renal function had started to get slightly better. I didn't really want to waste people's time if it's something that will naturally get better with time. […] I feel slightly abandoned by colleagues that I have worked with but not because they are, I do understand the strains on the NHS and I don't want to be waste resources at the moment. But I think had I been not medical perhaps they would have taken me more seriously, cause if it'd been anybody else they would probably have shouted louder, but I don't like to do that"

- Medic (GP) Interview 1

Combined findings: *A case for Constrained Candidacy*

2) *Illness Climate*: low GP knowledge surrounding LC and how LC could be treated - trends for ascribing symptoms to other factors, and reluctance to diagnose LC.

"I went […] to my GP about [LC symptoms] before Christmas [and they] would say, nah, that's in your head kind of thing like - I was like, but what about this chest pain, like I know that my heart rates through the roof, I know my blood pressure's through the roof. So, that surely is a reason why I'm getting this chest pain. And they were like, no, no, that's just, like that's just a mental thing. And if I mentioned about my blood pressure and stuff it was immediately, oh, you're overweight. So, that'll be that. Like, essentially, they said I was fat and depressed and to get over it"

- Nurse, Secondary Care, Interview 1

"I felt really daft, like I would be going to my GP for [Long COVID symptoms like] my hair falling out, or I've constantly got issues with my bowels - or I feel sick all the time or my heart rate seems like it's racing all the time. And they were like, oh, you're just anxious, or it's, maybe it's because you're slightly overweight or maybe it's because you're depressed and all this type of stuff. Like there's never the, only person who said, who diagnosed me with long COVID was a consultant at the hospital when I went"

- Nurse, Secondary Care, Interview 1

Combined findings: *A case for Constrained Candidacy*

3) *Sense-making* of LC, healthcare availability and access, linked to some occupational group's role-identity.

"I developed POTS and it meant that kind of for mental clarity, I was better lying down. Like I really struggled to think when I was upright. And so I'd be in my bed and I'd like trying, you know [to] read the latest sort of scientific papers and things to try and get an idea as to what the hell was going wrong with me. And, eventually, [I] was convinced enough that it was sort of micro clots and platelets, and in December, I managed to persuade my GP to prescribe for that"*

- Medic (GP), Interview Two.

"I think I've lost most of what I used to be really because I'm not working […] I've always been a doctor, you know, it's a big sort of job that takes a lot of your, your time. And I can't do my sort of sports and hobbies that I used to do. I can't go traveling. So, I think I've lost most of what I had before, to be honest"

- Speciality Doctor, Secondary Care, Interview One.

*Postural orthostatic tachycardia syndrome (POTS) is one of a group of disorders that have orthostatic intolerance (OI)

Combined findings: *A case for Constrained Candidacy*

3) *Sense-making* of LC, healthcare availability and access, linked to some occupational group's role-identity.

- **It's definitely Long COVID - *but* - No relevant care available for me. I have to develop 'trial and error' care for myself.**
- **It's not the medical care I would give, or would expect to receive.**
- **Disillusionment, and eventual stagnation of support-seeking. 'Failed' by the system.**

"There is no push to do any investigations to find out why so many people, who should be healthy are not, and who should be functioning are not functioning. […] normally as a doctor, if you can find the reason you want to look closer because there may be something treatable, but I feel with long COVID is all just sort of under the long COVID umbrella. You have long COVID, so it's okay for you to not be able to breathe, for you to have chest pains, for you to not be able to do as much work as you normally would or exercise and, and you get [pet] answers and you get sometimes ridiculous reasons for things….[…] how much can someone rest? You have a life to live".

- Medic (GP), Interview Two.

Applying a theoretical framework:

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Combined findings: *A case for Constrained Candidacy*

Context

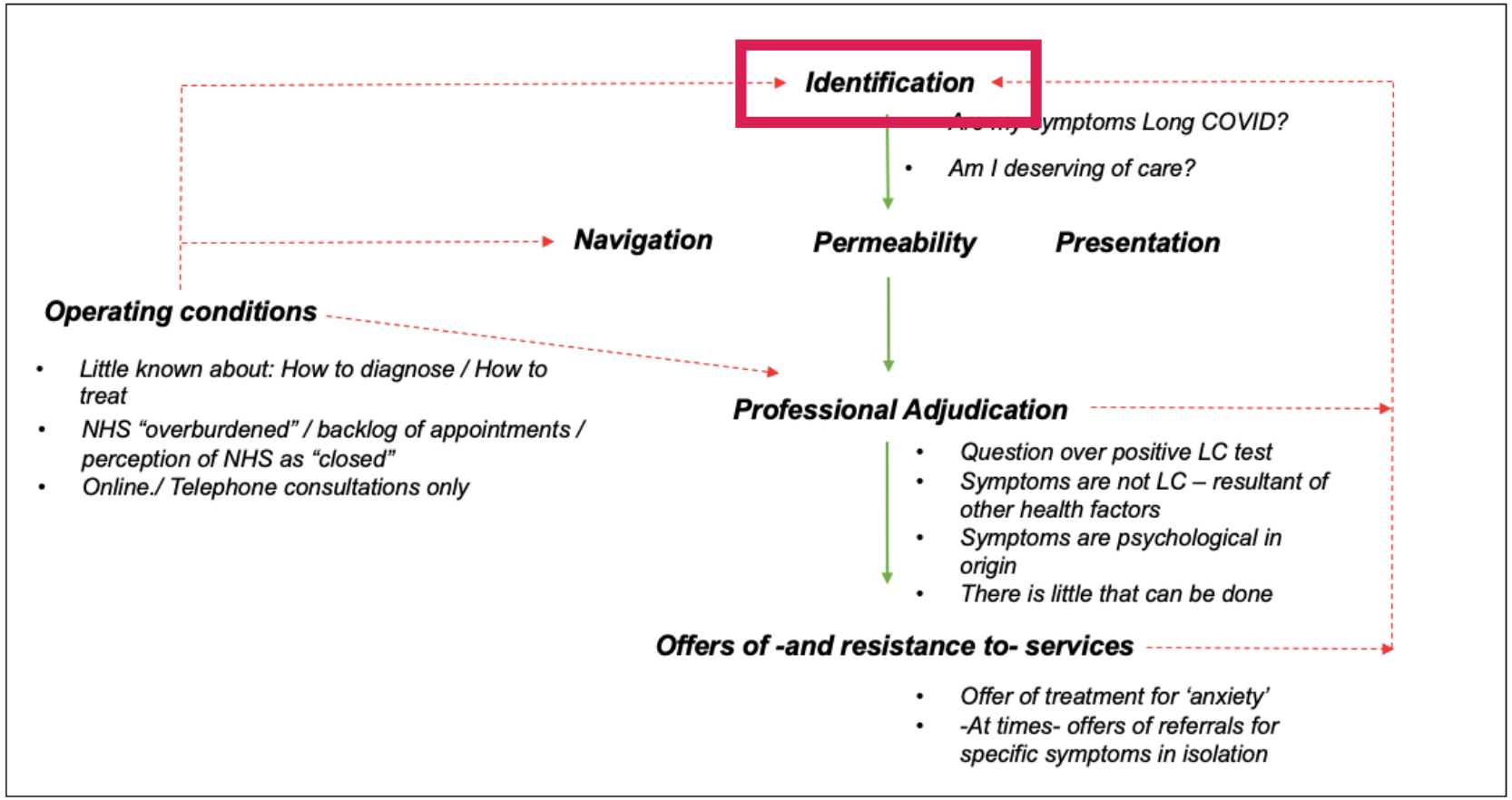
- *Operating Conditions*
- *Presentation*

Illness Climate

- *Navigation*
- *Permeability*
- *Adjudication by professionals*

Sense Making

- *Offer of and resistance to services*



Conclusion

- **Candidacy Theory** typically presents as a **staged model of progress** with barriers to be overcome, the first step on the healthcare journey is developing **Illness Candidacy.**

- Rather that progressing through the framework, individuals **longitudinally have their individual Long Covid Illness candidacy *constrained*; NHS workers move through the candidacy domains in reverse-fashion; returning, and becoming 'stuck' at the 'first' 'illness identification' stage.**

- Thus, **NHS workers' complex journeys represent *Disrupted -Constrained- Candidacy*:** workers faced intersecting challenges across multiple candidacy domains that actively restricted their ability to seek and receive healthcare for their LC symptoms.

Conclusion / Take home

- Long Covid is a unique illness; difficult to diagnose, manage and develop coping and recovery strategies for. Developing candidacy for Long Covid is a process unlike other illnesses.

- Individuals are their own experts with regards to their illness experience. Being believed and listening to patients, identifying symptoms as long Covid and providing a pathway for diagnosis and support are the most identifiable predictors of positive healthcare access journeys and the subsequent development of coping strategies.

Thanks, Questions:

Forthcoming paper – writing in progress…