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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.

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Experiences of Health and Illness:

“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.

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Project Overview: (The LoCH Study)

**NHS Workers in Scotland:
Have you experienced symptoms of
Covid for longer than four weeks?
We want to hear from you**



Please visit:
www.rgu.ac.uk/LoCH
for more information, Scan the
QR Code to the right,
or email: loch@rgu.ac.uk



- Data drawn from **Phase 1** of ‘The LoCH Study’: an investigation of NHS workers experiences of Long Covid illness
- Recruited for completion of a questionnaire: 471 Responses
- Qualitative Measure: Semi-structured Interviews. Purposeful sample - drawn from those who completed the questionnaire
- 50 participants interviewed; drawing from a range of workers; Ancillary, Medics, AHP, Nurses, other – range of genders and ages.
- **Long Covid – Symptoms of Covid-19 lasting longer than four weeks:**
NICE. Common symptoms of ongoing symptomatic COVID-19 and post-COVID-19 syndrome | COVID-19 rapid guideline: managing the long-term effects of COVID-19 | guidance.
Available: <https://www.nice.org.uk/guidance/ng188/chapter/Common-symptoms-of-ongoing-symptomatic-COVID-19-and-post-COVID-19-syndrome>
- What is Long Covid?

Project Overview: (The LoCH Study)

Interviews key points:

- All conducted remotely, via Teams; reflective of the distanced climate of Covid-19.
- Interview guide. (approx. 24 questions).
- But – focus on encouraging the participant to talk about their own journey and lived experience.
- Incredibly rich qualitative data set, many interviews ran longer than an hour.
- Often difficult and challenging interviews. Made more difficult -at times- by the distanced nature of interview (MS Teams).
- **Interviewees: often first time they had ‘talked out’ their LC experience or felt ‘listened to’; ‘legitimised’.**



Qualitative Analysis: Interview Content

Inductive, thematic analysis. Braun and Clarke -

- Clarke, V., Braun, V., & Hayfield, N. (2015). Thematic analysis. *Qualitative psychology: A practical guide to research methods*, 222(2015), 248.

One of the major theme topics: Participant's complex, fragmented and challenging journey of negotiating access to health care for their Long Covid symptoms.

This included:

- Feeling dismissed-stuck-treading water-forgotten-in limbo in the healthcare journey
- Absence of clear, specific Covid19/Long Covid supports -or- lack of awareness of such supports
- This was interlinked with how participants viewed Long Covid illness:
- **Doubting the legitimacy of Long Covid ("is this real?") – impacts illness candidacy.**

How can we make sense of this?



Applying the candidacy framework to make sense of findings:

- **The Candidacy Framework** describes how individuals conceptualise their eligibility for accessing healthcare services and legitimise service engagement (Dixon-Woods et al., 2006).
- **Anticipation** of poor communication with healthcare professionals, and poor expectations of knowledge and advice deter healthcare engagement.
- Conversely, **positive beliefs** regarding accessing clear illness information facilitate healthcare interactions.



Applying the candidacy framework to make sense of findings:

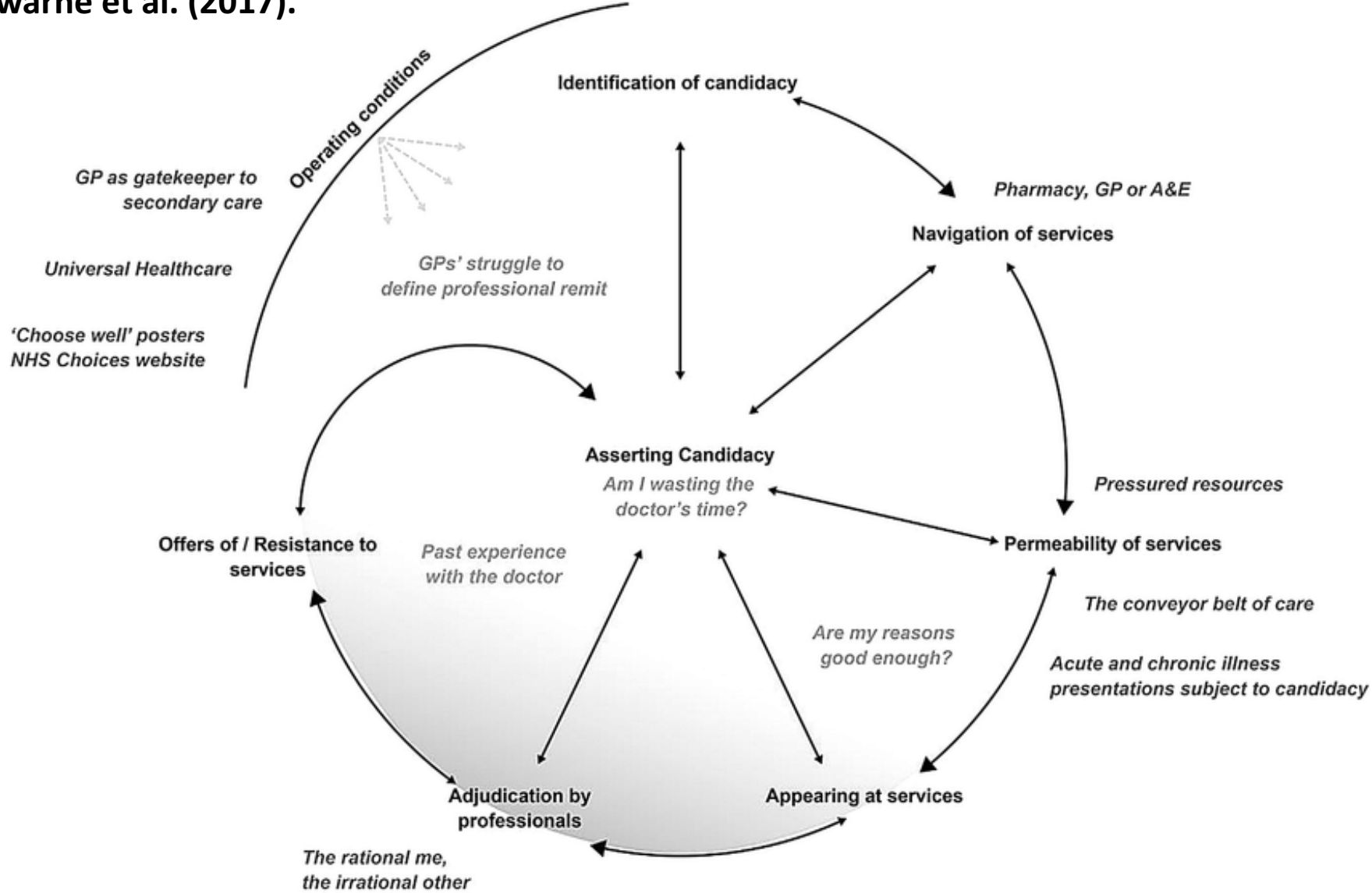
Adapted description of the stages of the Candidacy Framework
 – **Tookey et al. (2018).**

Stages	Description
1. Identification of candidacy	Process in which a person comes to appraise their issue as needing medical help which legitimises them as a candidate for particular health services.
2. Navigation of services	Knowledge of services provided and appraisal of the practicalities involved in making contact with and accessing services. Includes barriers to accessing services such as needing transport, convenience of appointment times and accumulated costs of attending services.
3. Permeability of services	The ease with which a person can use health services. Includes levels of gate-keeping within a service, the complexity of its referral processes, and the 'cultural alignment' of services with the person's needs and values.
4. Appearance at services	The person's ability to assert their candidacy by presenting at services, articulating their issue and articulating their 'need' for care.
5. Adjudication by healthcare professionals	A person's candidacy is judged by healthcare professionals, subsequently influencing the person's progression through services and access to care. Adjudication may disadvantage certain people by perceiving them as either 'deserving' or 'undeserving'.
6. Offers of, resistance to services	A person may refuse offers at multiple stages in their journey to treatment including resisting offers for appointments, referral, and treatment.
7. Operating conditions and local production of candidacy	Incorporates factors at societal and macro levels which influence candidacy, such as the availability of local resources for addressing candidacy, and relational aspects which develop between the healthcare provider and patient over multiple visits.

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), 1-8.

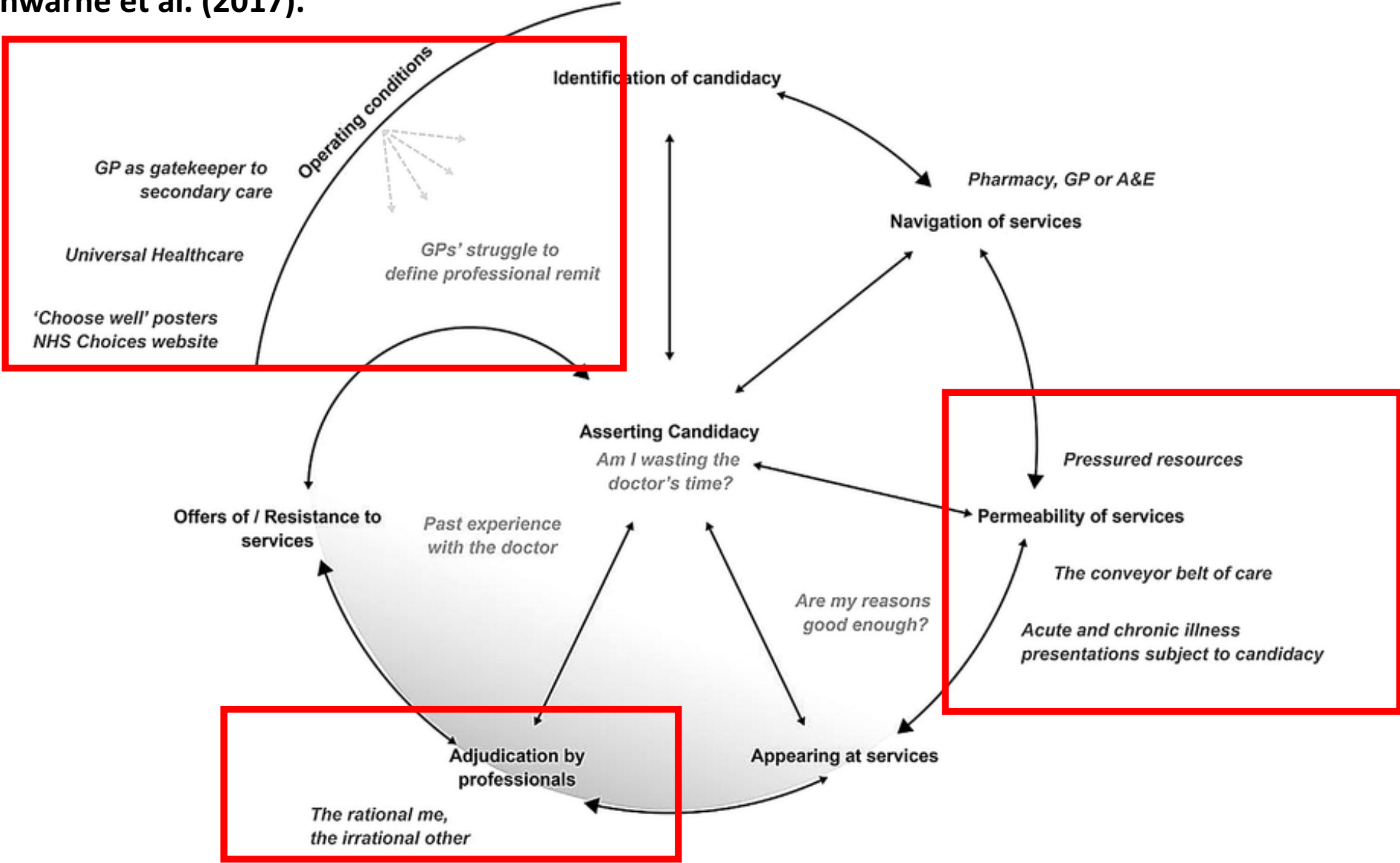
Applying the candidacy framework to make sense of findings:

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



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Applying the **candidacy framework** to make sense of findings: Exploring the complex healthcare journeys of NHS workers in Scotland suffering from Long-Covid

Operating Conditions:

'Wider societal, macro; local, influencers' – that shape sense-making regarding illness and legitimacy of accessing healthcare for illness.

Social Barriers

Two levels in Covid-19 Climate – as explored in the research findings:

Information that affects - healthcare access perceptions:

- **Perception of -unprecedented- 'closing down' of GP access and a move to distanced diagnostic methods – even if participant believes healthcare access is required, it is not possible...**
- **Working in the 'overburdened' NHS: If I seek help, I'm part of the problem – Includes GPs / Nurses / Medical Doctors / AHP / Ancillary / Others**

Information that affects – illness perception:

- **If you're young; you'll 'bounce back' quickly. If you've vaccinated, you'll be 'alright'. I just need to 'give it time'.**

Things [healthcare access], [...] they're slowly just opening up again

-Nurse

Even though I've worked in a hospital, I still feel as if those things were, you weren't welcome to access them, unless you were acutely unwell. (32.22) the GP [...] so they closed their doors and I mean, to be fair, my GP has been seeing patients the whole time, but, you just didn't know what you were going with, maybe that was unwise, but it just didn't feel like we had the right to bother them without it's being serious, if you know what I mean?

-Ancillary Worker

My GP was very much like, you're young, you've got your health, you've got no medical history, you're not going to be affected like this.

-Nurse

Applying the candidacy framework to make sense of findings: Exploring the complex healthcare journeys of NHS workers in Scotland suffering from Long-Covid

Permeability of services:

Individual beliefs and norms regarding 'access -and- alignment of services with a person's needs and values'

Practical Barriers

Cultural alignment:

Doubt surrounding total absence of resources:

- Even if I secure GP access, they won't be able to help me...
- They...
 - Won't know what to 'do with me' – Long Covid is a complex combination of -often different and changing- symptoms.
 - Where to refer me to
 - How to make me better

I know what they're doing in the hospital, the GP can't help me, there's no point bothering [them], which kind of was supported when I went to the GP and he didn't necessarily fully understand how I was feeling, how I was doing. And then on top of that was like, are you depressed? I was like, no, I'm not.

-Dietician

A few of my friends who have caught COVID cause we all work in the same sector, and some of them are fine now, they're not experiencing any ongoing symptoms. And then one friend, she doesn't experience much but very breathless and very tired a lot of the time. And then some friends, who've never caught COVID, don't believe I'm actually unwell. They're like, it's not real...

-Nurse

Applying the candidacy framework to make sense of findings: Exploring the complex healthcare journeys of NHS workers in Scotland suffering from Long-Covid

Adjudication by healthcare professionals:

*'Experiences of (and beliefs regarding) assessment/Judgement by healthcare professionals
The designation of legitimate/non-legitimate?'*

Psychological Barriers

**Adjudication: Judgement of -
already fragile- and
perpetually 'threatened' illness
candidacy:**

- **Dismissed.**
- **I'm scared of being 'invalidated': i.e. told, 'it's all in my head' or 'you are well'**

I went back into hospital in March, two days prior to that, I'd been to my GP saying I feel really, I don't feel well. Like, I'm not right. I felt really shaky, my temperature remained, which wasn't usual, so usually I would have a temperature and it would go down on its own, but this time it remained the whole time for three days above 39. My chest started getting that tight way, and I was like, something's not right? And they were, they refused to do my bloods, they were, they're like no, they said at this point [...] it's getting silly, you can't keep coming back and then two days later I got taken into hospital and, what you're experiencing is real, it's just we don't have a lot of information about it. You should never be told that isn't your experience because, because we don't know about it doesn't mean that isn't a real thing

-Nurse

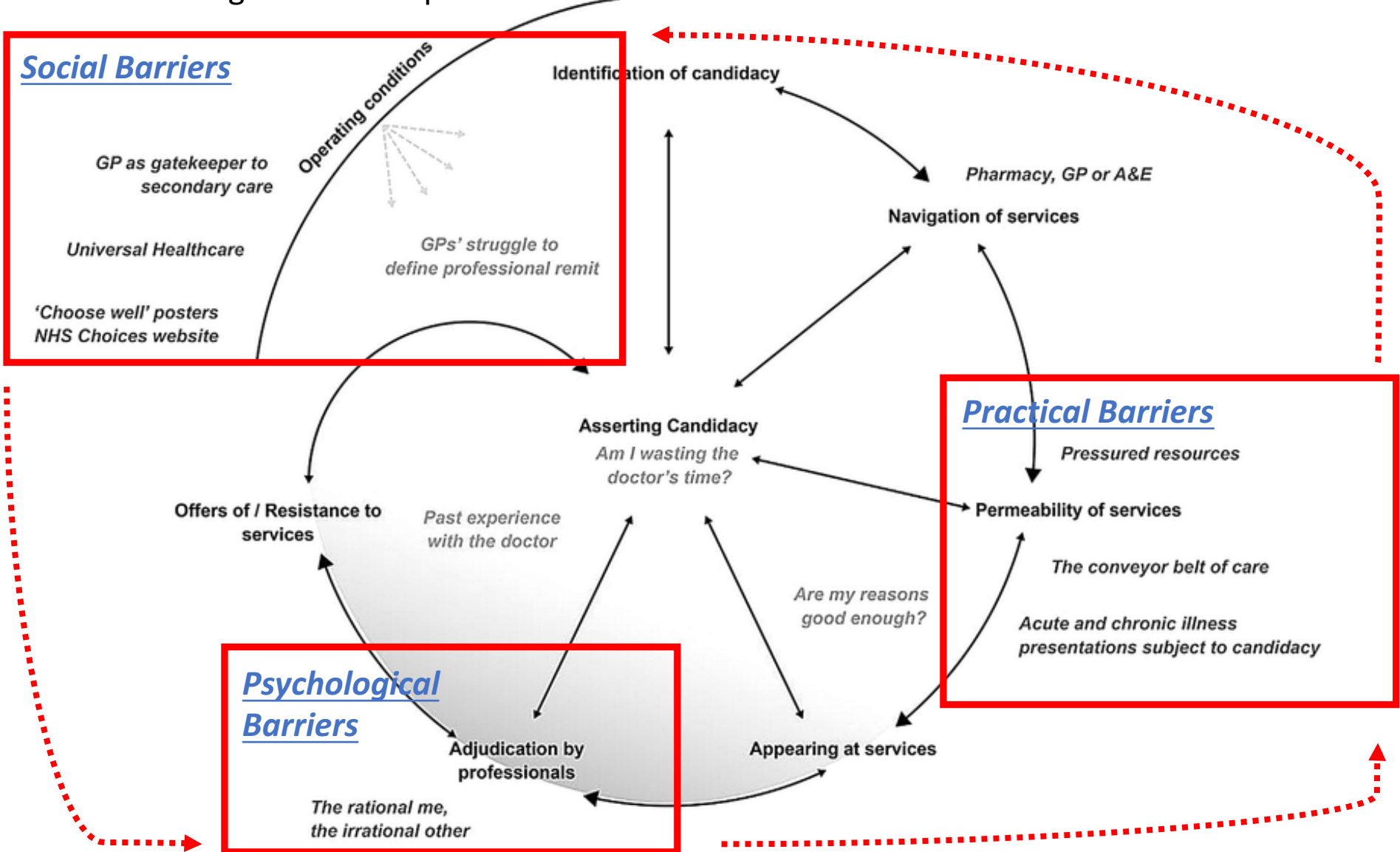
I felt really daft, like I would be going to my GP for my hair falling out, or I've constantly got issues with my bowels. Or I feel sick all the time or my heart rate seems like it's racing all the time. And they were like, oh, you're just anxious, or it's, maybe it's because you're slightly overweight 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

Applying the candidacy framework to make sense of findings:

The candidacy cycle – Experiences of Long Covid – Adapted

- Ability to develop illness candidacy is constantly 'under threat'.
- Together, factors actively constrain individuals from seeking healthcare for Long Covid Illness



Long Covid healthcare navigation: Snakes and Ladders!?:



“[Healthcare] limbo”



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