Variation in Long COVID experiences in the population

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In our population study of 133,526 people with COVID-19(1):

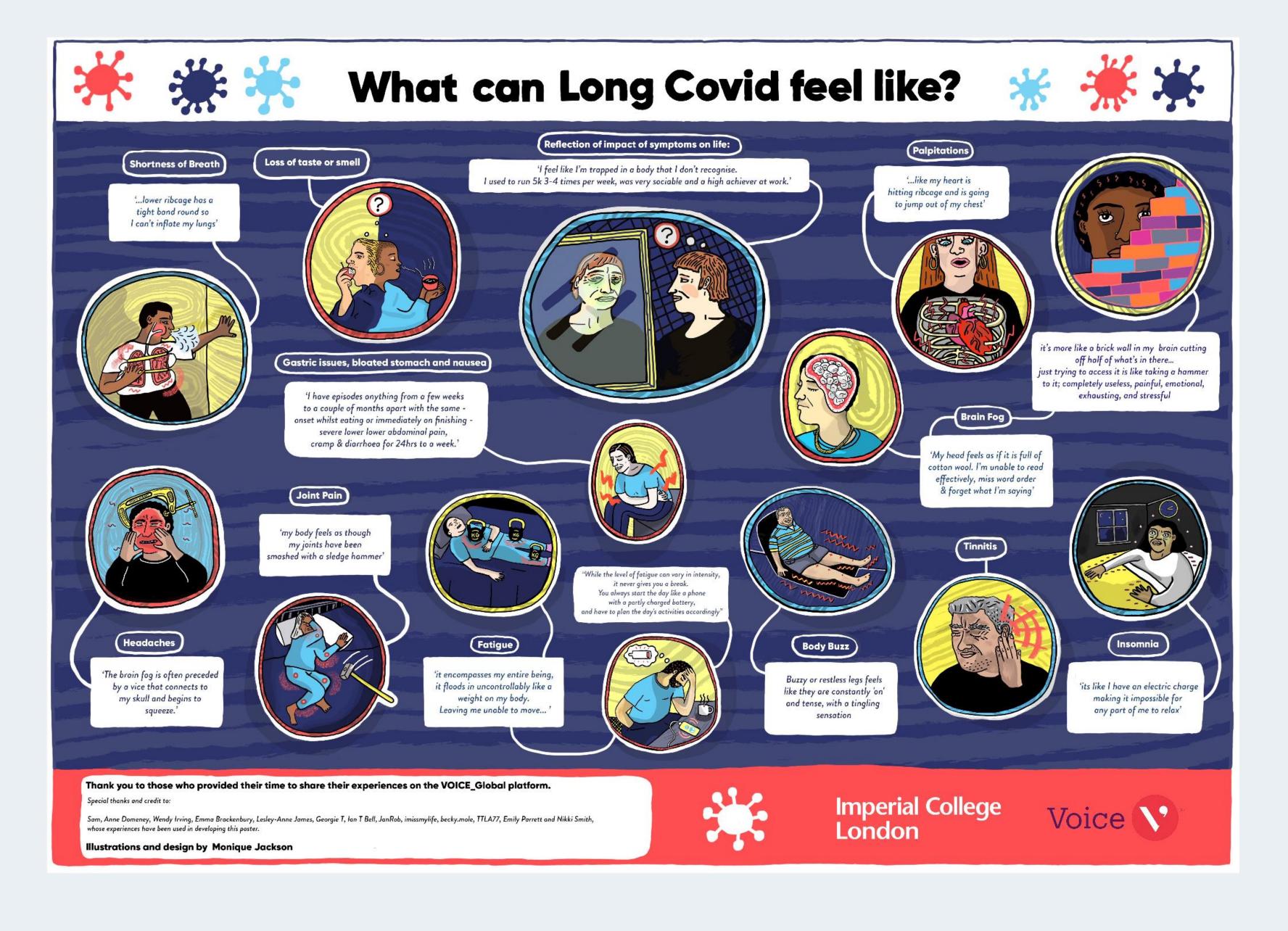
- 1 in 13 reported symptoms for 12 or more weeks
- 1 in 20 for more than a year
- 31% with symptoms for ≥12 weeks recovered within a year
- Long COVID was 88% less likely with Omicron compared to Wild-type

1.00 — Wild type — Alpha — Delta — Omicron — Overall — O

chison C et al. Nat Comms 2023

Interviews with 60 people with persistent symptoms >12 weeks:

- Two thirds used the term Long COVID about their condition
- They described a wide variation in symptoms which were often fluctuating & unpredictable
- Most had not accessed clinical care or patient support groups
- They did not seek treatment or support because their symptoms were not severe enough, there was a lack of knowledge, and 'there is nothing anyone can do'
- · Participants from ethnic minority groups indicated structural barriers to accessing care



Experience of Long COVID

never had COVID-19

- Common persistent symptoms were mild fatigue (67%), difficulty thinking or concentrating (55%), joint pain (55%), difficulty sleeping (50%), headaches (49%), breathlessness (33%)
- 52% reported their health status as "good", 36% as fair and 12% reported their health status as bad, compared to 76%, 20% and 4% respectively for people who had
- Illustrator Monique Jackson used the words of participants to visualise their experience of symptoms

Study Rationale and Methods

While existing studies with samples drawn from Long Covid support groups have made key contributions, there is a need to understand the perspectives of a more diverse group of participants. The REACT programme is one of the world's largest coronavirus monitoring studies (methods in refs 2,3) and is based on a random sample of adults in England.

We use data from a follow-up survey of REACT participants (n=276,840, ref 1); and interviews with a sample of those participants reporting persistent symptoms for 12 or more weeks (n=60).

Interviews were purposively sampled for, to ensure diversity by oversampling under-represented groups and were informed by a pilot study (4). We used descriptive statistics to describe the profile and duration of COVID-19 symptoms from survey responses. Interviews were analysed using thematic analysis.

Conclusion

- Our findings suggest a wide range of experiences of prolonged symptoms following COVID-19.
- The majority of those affected had not sought help through healthcare or Long COVID support groups.
- Their experiences may be missed in much research, and their needs may not be considered in the development of approaches to treatment and care.

Acknowledgements

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Study web page