

To: PS(I)

From:

NR

Clearance:

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Date:

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## LONG COVID – WEEKLY UPDATE

### PARLIAMENTARY DEBATE ON LONG COVID

- Parliamentary interest in Long COVID has significantly increased in recent weeks, with an evidence session focused on Long COVID by the APPG on Coronavirus on 12 January, a Backbench business debate on 14 January and a higher volume of PQs in general. The main issues raised in the APPG session and the debate were:
  1. Data and publication of statistics on Long COVID;
  2. Whether Long COVID is an occupational disease (and what this might mean for health and social care workforce as well as other occupations such as teachers);
  3. Long COVID and children (and policy implications re schools);
  4. Mental health; and
  5. Parallels with other diseases such as chronic fatigue syndrome.
- Social media activity suggests the APPG will continue to be active on Long COVID and will call for three things:
  1. Better reporting of Long COVID data/statistics
  2. More money for research into Long COVID
  3. recognition by employers and the welfare system of the impact of Long COVID
- The campaigning organization 'March for Change' is also leading a petition calling on the Government to recognise Long COVID as an occupational disease and set up a Long COVID compensation scheme. It has so far received just over 9000 signatures.
- At the end of the backbench debate, Layla Moran MP requested a meeting with her and other members of the APPG to discuss issues not covered by MS(PSM)'s closing speech , including the creation of a patient register, giving Long COVID the status of an occupational disease, and increased financial support.

*"I thank the Front Bench spokespeople, and particularly the Minister for her response and for listening so diligently to the debate. I thank her for the update on the research and the NHS response. It is clear that we are finally getting going, but I hope that she also recognises that we need to*

*continue to finesse and change as our understanding evolves. I hope she will take a personal interest in that. Finally, it would be wonderful if she would consider a meeting with me and others in the all-party group, to talk about the areas that she did not cover, in particular publishing the register, if that is possible, and a recognition by employers that Long COVID could be an occupational disease, and the support that would be needed by those who suffer from it."*

- The issues highlighted for further discussion are complex and need further policy work. **Our overall recommendation would be to offer a meeting but to widen the focus to listening to the APPG's concerns and meeting the challenges of Long COVID more broadly.**

## **UPDATES FROM NHSEI**

- NHSEI has provided a further update on progress against the Five Point Plan (Annex 1).
- Cathy Hassell has requested a pre-briefing with her and Ian Dodge before the roundtable on 29 January. This meeting is currently scheduled for 4.30pm on Tuesday 26 January and will be a chance for you to discuss NHSEI's progress and raise any issues or concerns with them in a more private setting, ahead of the roundtable.

## **ROUNDTABLE PLANNING**

- The next roundtable will have a focus on effective use of data in treating and understanding Long COVID.
  - ONS has agreed to discuss their new Public Health Data Asset and new research on the epidemiology of post-COVID syndrome following hospitalisation with coronavirus
  - Dr Ben Goldacre has agreed to speak about forthcoming research on Long COVID
  - We are expecting to hear updates on the NIHR research commission (although announcements will not be until February)
  - There will be an update from the surveillance team within DHSC
  - We will also have the usual update from NHSEI, with a particular focus on data
- It would be helpful to agree whether you would like the February roundtable to have a specific theme again, or to be a general update session. Initial suggestions for a theme could include: a deeper dive into inequality issues, mental health, links to other chronic conditions such as chronic fatigue syndrome, children and young people.

## **DASHBOARD AND DEVELOPMENT OF DIGITAL SUPPORT FOR SELF-CARE**

- We have been progressing discussions around the dashboard internally. Following these discussions, we are putting together an overview of the sorts of indicators we might want to collect and working on how to mitigate the potential challenges in data collection and availability.

- On your commission for a digital solution to support self-care, we have had exploratory conversations with NHSX and NHSEI. NHSEI confirmed that the rollout of Phase 2 of the Your COVID Recovery website, which provides tailored rehabilitation modules for patients and the ability to set and track progress goals with their clinicians, was in progress. NHSEI is tentatively considering future developments, including rollout across each of the DAs and providing a more comprehensive bespoke service, but stated that further funding and resource would be required to deliver these. We would welcome the chance to discuss the possibilities with you in more detail.

## TOPICAL ISSUES

- **CMO briefing on Long COVID:** CMO and GCSA have been commissioned to do a note for no.10 on 'what we know' about Long COVID. The taskforce strategy team (Cabinet Office) have also been developing some thinking around the long term impact of Long COVID on public health, and what considerations (if any) should be taken into account in terms of our strategic thinking around the easing of NPIs as the vaccine is rolled out. The priority for the team this week has been preparing the briefing for the CMO (the briefing will be CC'd to you for information). We have arranged a meeting with officials in Cabinet Office to understand more about their role and work.
- **Quad meeting:** Long COVID will be on the agenda for the upcoming Quad meeting with Simon Stevens on Monday 25 January 2021. We have suggested that SoS may wish to ask Simon Stevens for an update on NHSEI's 5 Point Plan, data on referrals to and use of the new Long COVID assessment services, and an view on his main concerns for the future impact of Long COVID on the Health and Care system.
- **Cross-UK engagement:** Following your letter to the Devolved Administrations, Jeane Freeman, Cabinet Secretary for Health and Sport in Scotland has accepted the offer of a meeting. We are yet to hear from Northern Ireland and Wales. We held another useful working-level meeting on 20 January 2011 with officials from the Scottish Government and have now made contact with officials in Northern Ireland and have a meeting scheduled. We are also aware that a meeting across the Devolved Administrations has been arranged for public health officials to discuss Long COVID next week, which we have requested to attend.
- **Parliamentary business and media inquiries:** There has been a noticeable uplift in the number of media inquiries and PQs linked to Long COVID and in particular, activity linked to children and young people.
- **ONS data update:** On 20 January 2020, we received an update from the ONS which has now been published publicly. The ONS estimated that during the week commencing 27 December 2020, 301,000 people in England had symptoms that had persisted for between 5 and 12 weeks (95% confidence interval: 274,000 to 329,000). This is higher than the 186,000 figure that was provided for the week commencing 22 November 2020.