Witness Name: Edward Scully

Statement No.: 1

Exhibits: ES/1 – ES/178

Dated: 15 September 2023

UK COVID-19 INQUIRY

WITNESS STATEMENT OF EDWARD SCULLY

I, Edward Scully, of the Department of Health and Social Care, 39 Victoria Street, London SW1H 0EU, will say as follows: -

- 1. I am employed by the Department of Health and Social Care (the Department) as Director of Primary and Community Health Care, a post I have held since April 2020.
- Before this post, I have been Deputy Director for General Practice in DHSC, from 2017 to 2020; Programme Director for NHS England Operating Model, in NHS England from 2016 to 2017; and Deputy Director for the Integration of Health and Social Care from 2013 to 2016 in the Department of Health (predecessor to DHSC).
- 3. I make this statement in response to the request from the UK COVID-19 Public Inquiry (the Inquiry) dated 18 August 2023, under Rule 9 of The Inquiry Rules 2006 (SI 2006/1838), requiring the Department to provide an overview of the Department's work on Long COVID, the role of the Long COVID Policy Team and the Long COVID Oversight Board, including the work undertaken and their role in core political and administrative decision making.
- 4. As this is a corporate statement on behalf of the Department, it necessarily covers matters that are not within my personal knowledge or recollection. This statement is to the best of my knowledge and belief accurate and complete at the time of signing. Notwithstanding this, it is the case that the Department continues to prepare for its involvement in the Inquiry. As part of these preparations, it is possible that additional material will be discovered. In this eventuality the additional material will of course be provided to the Inquiry and a supplementary statement will be made if need be.

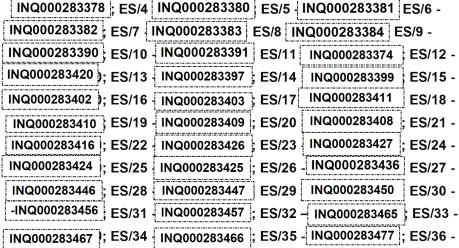
5. In Section 1 I describe the work of the Department's Long COVID Policy Team (the Team), from its formation in October 2020, and the role of the Long COVID Oversight Board (the Oversight Board) established in June 2021. In Section 2, I describe key events in the development of our understanding and response to Long COVID, with reference to different periods of the pandemic, to provide additional context to this work. These include decisions or actions taken by others which are relevant to or impacted upon Long COVID policy, but which did not directly involve input from the Long COVID Policy Team. I cannot comment on the processes by which these decisions were reached.

Section 1

Long COVID Policy Team

- In October 2020, the Department began to assign resources to further develop its policy response to Long COVID, against an overarching ambition for the UK to lead the world in developing and implementing a swift, evidence-based, patient-focused response to Long COVID.
- 7. By January 2021, a permanent and dedicated team had been established to work on Long COVID. The Team's role was to work with stakeholders, government bodies and research organisations to stimulate and co-ordinate action to understand and manage Long COVID, and to share that knowledge across the system. At all times, the Team kept their approach under review, and have been open to changing approach as new evidence emerges.
- 8. The Team's initial aims included:
 - a. Building relationships and proactively engaging with Long COVID stakeholders;
 - b. Ensuring alignment between the Department's policy response and that of other government departments;
 - c. Ensuring alignment between the Department and NHS England (NHSE) service delivery plans, monitoring progress and escalating issues as required through the Department's COVID-19 governance arrangements;

- d. Providing timely lines and briefings on Long COVID, as required;
- e. Supporting National Institute for Health Research (NIHR) and UK Research and Innovation (UKRI) on the development of targeted research calls as outlined above, promoting the need for robust research into Long COVID which informs policy and improves Long COVID services.
- f. Working with National Institute for Health and Care Excellence (NICE) and others to develop and refine clinical case definitions of Long COVID;
- g. Using available data to understand as far as possible the prevalence and impacts of Long COVID;
- h. Supporting the development and communication of appropriate information of Long COVID and where to seek support, aligning messaging with wider pandemic communications; and
- Engaging with devolved governments to share information and align approaches to Long COVID as practicable within the devolution arrangements.
- 9. The Team had a limited direct role in core political and administrative decision-making. The Department's ministers have been key decision makers for many of the events detailed in this document. The Team acted in an advisory capacity, for example advising on their understanding, at the time, of Long COVID as a clinical condition and providing other information as requested. As with all policy teams in the Department, they provided written advice to ministers in the form of submissions or briefings. Key submissions for this period are at ES/1 INQ000112675; ES/2 INQ000283377 ES/3



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INQ000283480 ; ES/37 - INQ000067500; ES/38 - INQ000067499; ES/39 - INQ000067643; ES/40 - INQ000067642; ES/41 - INQ000283481 ); ES/42 - INQ000112153; ES/43 - INQ000112152; ES/44 - INQ000112233; ES/45 - INQ000112232; ES/46 - INQ000112234; ES/47 - INQ000112317; ES/48 - INQ000112318; ES/49 - INQ000193812; ES/50 - INQ000193811.
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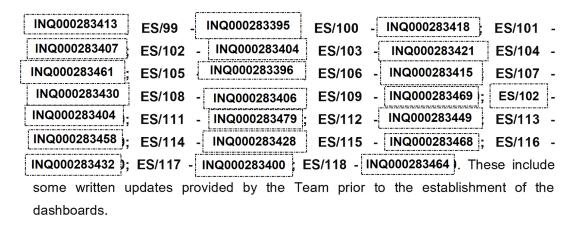
10. The Team periodically received commissions from senior officials, and from central government for summaries of the latest understanding of Long COVID. While factual information was provided (correct at the time of submission), I cannot comment here on how the information may have been used in relation to any particular decision subsequently reached by those parties. Those commissions are at ES/51 -

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INQ000283483 ; ES/52 INQ000283485 ; ES/53 INQ000283484 ; ES/54 - INQ000283488 ; ES/55 INQ000283486 ; ES/56 - INQ000112181; ES/57 - INQ000193761; ES/58 - INQ000112195; ES/59 INQ000283487 ES/60 - INQ000193770; ES/61 INQ000283490 ; ES/62 INQ000283491 ; ES/63 - INQ000283489 ; ES/64 INQ000283493 ).
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11. At the request of Parliamentary Under-Secretary of State for Innovation (PS(I)), in February 2021 the Team began to provide the responsible minister with regular written updates on Long COVID, together with a separate dashboard. The dashboard provided a snapshot of prevalence and activity data, media and social media commentary, and a summary of NIHR-funded research studies and their progress. The dashboards were discontinued in July 2022. All written updates and accompanying dashboards are exhibited at ES/38 - INQ000067499; ES/37 - INQ000067500; ES/40 - INQ000067642;

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ES/39 - INQ000067643; ES/42 - INQ000112153; ES/43 - INQ000112152; ES/45 -
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12. The Team remains in operation, although there have been periodic changes in personnel.

Long COVID Oversight Board

- 13. Whilst Long COVID was initially seen as primarily a health issue, as time went on potential impacts on other government departments (OGDs) were recognised, such as the impact on children's education and on people's ability to work.
- 14. Whilst the Department was engaging separately and routinely with OGDs, it established a Long COVID Oversight Board to discuss and co-ordinate whole of government activity and policy development. The Oversight Board had no role in political or administrative decision-making. Any decisions that followed discussions were the responsibility of the relevant organisation or government department concerned. The Team provided a secretariat function to the Oversight Board.
- 15. The Oversight Board ran from June to November 2021. Although the Long COVID Oversight Board was of some use as a means of connecting a broader group, it was found that the discussions replicated member-to-member engagement and as such the Oversight Board was discontinued in November 2021. The Oversight Board was not a formal governance arrangement and so had no programme of work to deliver. Minutes ES/119 INQ000283423 ; ES/120 INQ000283433 ; ES/121 INQ000061266; ES/122 INQ000061267; ES/123 INQ000066583; ES/124 INQ000066584; ES/125 INQ000066585; ES/126 INQ000067093; ES/127 INQ000067094; ES/128 INQ000067095; ES/129 INQ000111897; ES/130 INQ000111898; ES/131 INQ000067416; ES/132 INQ000067417 were distributed to members for awareness only.

Section 2 - chronology of events

March 2020 to June 2020: the first wave

16. In the early stages of the pandemic, the focus of the Department and the NHS was on

preparing for and managing acute pressures arising from COVID-19 infections. Long

COVID was only beginning to emerge as an issue requiring either a policy or health

response.

17. It was during this period that Long COVID began to be recognised by patients and by

clinicians. The term emerged on social media in May 2020 as people began to share

anecdotal experience about their failure to recover or the onset of new and unexplained

symptoms. The term was gradually adopted more widely in print media and by patient

representative groups established on Facebook and other social media platforms. Initial

descriptions of patients reporting persistent symptoms after discharge from hospital

appeared in the scientific literature from Summer 2020 (ES/133 - INQ000283371

18. By the end of this period the term had gained wider recognition, and it was becoming

clearer that the NHS would need to provide support for people with persistent or new

symptoms following COVID-19 infection. NHSE began to plan and prepare a range of

initial support interventions for people with Long COVID.

Guidance on long-term needs of COVID-19 patients

19. On 5 June 2020, NHSE set out in guidance their understanding at the time of the long-

term healthcare needs of COVID-19 patients and actions for providers to meet these

ES/134 - INQ000050846.

20. The guidance outlined the most significant issues that patients recovering from COVID-

19 may present with on discharge from hospital and how these issues should inform the

patient's new or amended personalised care and support plan. This included what they

would be able to do for themselves to manage their needs and what wider support they

would need from services including social care and the voluntary sector.

21. The guidance was subsequently withdrawn and replaced by commissioning guidance

(ES/135 | INQ000283496

July 2020 to September 2020: preparing for potential further waves

Your COVID Recovery

- 22. On 5 July 2020, NHSE announced the launch of its *Your COVID Recovery* online ondemand rehabilitation and advice service (ES/136 INQ000283370 ES/137 INQ000283497). *Your COVID Recovery* is a website designed to help individuals recover from COVID-19 and manage the effects both on their body and mind effectively, reducing the impact it has on their day-to-day life.
- 23. The website contains a personalised and tailored package of modules covering topics such as fatigue and breathlessness management and nutritional advice for use by patients following a clinical consultation, under the supervision of a clinician. Individuals are encouraged to set goals and choose the resources that may help them achieve their targets.

Clinical guidelines

24. On 30 September 2020, NHSE commissioned NICE and the Scottish Intercollegiate Guidelines Network (SIGN) to co-produce a clinical case definition and clinical guidelines for healthcare providers and clinicians to help them identify and provide treatment for those affected by Long COVID.

Research study into long-term health impacts of COVID-19

- 25. On 5 July 2020, the Secretary of State Matt Hancock announced a major new UK study into the long-term physical and mental health implications of COVID-19 (ES/138 INQ000283372
- 26. It was announced that the study the Post-hospitalisation COVID-19 study (PHOSP-COVID) which was backed by £8.4 million of funding, would be led by the National Institute for Health and Care Research (NIHR) Leicester Biomedical Research Centre, a partnership between the University of Leicester and the University Hospitals of Leicester NHS Trust.

September 2020 to December 2020: the second wave

Stakeholder engagement

- 27. By around October 2020, the Department began to develop its policy response to Long COVID, within existing resources. Key activity included mapping Long COVID activity and interest across the healthcare system and establishing working relationships, particularly within NHSE. The PS(I) Lord Bethell was active in this process, meeting key NHSE clinicians and commencing the series of Long COVID roundtables in October 2020 that continued throughout the pandemic. The last roundtable was held on 10 March 2022 (ES/139 INQ000058536; ES/140 INQ000058981; ES/141 INQ000112676; ES/142 INQ000059730; ES/143 INQ000060080; ES/144 INQ000193410; ES/145 INQ000111202; ES/146 INQ000061094; ES/147 INQ000061418; ES/148 INQ000067049; ES/149 INQ000067606; ES/150 INQ000193796).
- 28. Each roundtable brought together clinicians, patient representatives, academics and other stakeholders to discuss challenges, emerging issues and data. The roundtables enabled ministers and department officials to hear directly about what patients were experiencing, on-going research studies and to hear a variety of views that helped to shape the overall approach to Long COVID.

Research

- 29. On 15 October 2020, NIHR published a rapid review of the evidence around ongoing COVID-19 symptoms (ES/151 INQ000058418). Amongst the key conclusions of the review was that a set of diagnostic criteria for ongoing COVID-19 were necessary, which should be recognised by healthcare services, employers and government agencies.
- 30. In November 2020, NIHR and UKRI launched a UK-wide targeted research call of up to £20 million to fund ambitious and comprehensive research into the longer term physical and mental effects of COVID-19 in non-hospitalised individuals (ES/152 INQ000283379). The call specification was developed with advice from a specially convened group of experts, including department officials, and people with lived experience of Long COVID. Proposals were required to consider the lived experiences of those suffering with the effects of COVID-19 and include plans for patient and public involvement in the co-production of research questions and their delivery.
- 31. At the national level, the discussions of the Scientific Advisory Group for Emergencies (SAGE) noted the challenges around estimating Long COVID given the lack of a clear clinical case definition and the importance of phenotyping to aid a clearer understanding of the condition (ES/153 INQ000120560 ES/154 INQ000120569

32. On 16 December 2020, the Office for National Statistics (ONS) announced plans for estimating the prevalence of, and risk factors for, Long COVID symptoms and health complications following COVID-19 infection (ES/155 INQ000283393). An initial set of early experimental results was also released.

Long COVID services

- 33. On 7 October 2020, NHSE announced £10 million investment in a five-point plan to designate specialist Long COVID clinics in every area across England, to complement existing community and rehabilitation services (ES/156 INQ000283373
- 34. On 6 November 2020, NHSE published national guidance for commissioning these clinics, providing information on referral routes, patient pathways, clinic design and service outcomes (ES/135 INQ000283496).
- 35. On 15 November 2020, NHSE announced that a network of 40 Long COVID specialist clinics were due to launch within weeks across England (ES/157 INQ000283385]. It was stated that the clinics would bring together doctors, nurses, therapists, and other NHS staff to undertake physical and psychological assessments of those experiencing enduring symptoms. In the same announcement, NHSE confirmed the establishment of a new Long COVID taskforce, which included patients, researchers, charities, and clinicians, to help manage the approach to Long COVID services and produce information and support materials to develop wider understanding of the condition.
- 36. On 18 December 2020, NICE published a set of clinical guidelines on the identification, assessment, and management of Long COVID (ES/158 INQ000283459). The guidelines recommended distinguishing between three clinical case definitions to identify and diagnose the long-term effects of COVID-19:
 - a. Acute COVID-19: where there are signs and symptoms of COVID-19 for up to 4 weeks.
 - b. Ongoing symptomatic COVID-19: where there are signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.
 - c. Post-COVID-19 syndrome: where signs and symptoms that develop during or after an infection consistent with COVID-19 continue for more than 12 weeks and are not explained by an alternative diagnosis.

- 37. The guidelines noted that the term 'Long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19 and that it includes both ongoing symptomatic COVID-19 and post-COVID-19 syndrome.
- 38. The guidelines were produced in a highly collaborative manner by NICE, in consultation with a wide range of patient groups, clinicians and other stakeholders and considering the evidence available at the time. The guidelines have since been held up as an exemplar internationally and adopted as a model in other countries. The guidelines were produced as a living review and are updated periodically to take account of newly available evidence.

Communications

39. On 21 October 2020, the Department launched a film featuring a number of people discussing their experience of Long COVID as a means of underlining the importance of adopting the key recommended public health behaviors (ES/159 - INQ000283375

January 2021 to March 2021: responding to peaks

Research

- 40. On 18 February 2021, the Department announced the outcomes of the targeted research call described in paragraph 29, awarding £18.5 million to 4 new research studies aimed at better understanding the longer-term effects of COVID-19 on physical and mental health (ES/160 INQ000283412
- 41. On 16 March 2021, NIHR published a second review of evidence around people's experiences of Long COVID (ES/161 INQ000283422 It was noted that there was enormous variation in the estimated prevalence of Long COVID due to different measurement criteria, making comparing studies impossible. It further noted that whilst there was a growing list of symptoms associated with Long COVID, little was known about different clusters and patterns of symptoms (described as phenotypes, syndromes or clusters). The report concluded that, amongst other things, more research was needed on the incidence of Long COVID and its causes.
- 42. On 25 March 2021, the NIHR launched a second call for research proposals on helping and supporting people with Long COVID (ES/162 INQ000283429). The call would fund

up to £20 million of research on treatment, healthcare services and diagnostics for adults and children with Long COVID who had not been unwell enough to be admitted to hospital. The new funding call was focused on four research areas:

- a. Pharmaceutical treatments, including the effectiveness of drugs already being used as treatments, and non-pharmaceutical therapies;
- Treatment pathways and service management approaches, including healthcare, community and social care services;
- c. Diagnostics, including what tests are appropriate;
- d. Other topics to help and support individuals with Long COVID.
- 43. At the national level, the Government's COVID-19 Response Spring 2021 Guidance was published on 22 February 2021 (ES/163 INQ000234766). The Guidance noted that whilst for many people COVID-19 is a mild illness, for some, regardless of age, the effects can linger into the long-term. The Guidance referenced the NIHR and UKRI funding for ambitious studies that will help the Government learn more about the long-term effects of the virus.
- 44. SAGE discussions between January and March 2021 noted early analysis from the ONS on estimated prevalence of Long COVID and the need to link Long COVID research with national core studies underway (ES/164 INQ000075792 ES/165 INQ000092855 ES/166 INQ000120602 ; ES/167 INQ0000221772

April 2021 to May 2022: moving to business as usual and preparing for future waves

Long COVID services

45. In April 2021, NHSE published national guidance for post-COVID syndrome assessment clinics (ES/168 INQ000283438). Within this guidance, NHSE noted that in March 2021 it had provided a further contribution of £24 million for post-COVID assessment clinics to support the anticipated demand for these services in 2021/22. A further £100 million was committed for 2021/22 in June 2021 (ES/169 - INQ000283498) and a further £90 million for 2022/23 (ES/170 - INQ000257303).

- 46. In June 2021, NHSE published 'Long COVID: the NHS plan for 2021/22' (ES/169 INQ000283498). The plan involved 10 key steps:
 - £70 million to expand Long COVID services to add to the £24 million already spent on Post-COVID Assessment Clinics.
 - b. £30 million for the rollout of an enhanced service for general practice to support patients to be managed in primary care, where appropriate, and enable more consistent referrals to clinics for specialist assessment and treatment.
 - c. Care coordination: care coordinators will support the running of Post-COVID Assessment Clinics.
 - d. Establishing 15 Post-COVID assessment children and young people's hubs across England in order to coordinate care across a range of services.
 - e. Developing standard rehabilitation pathway packages to treat the commonest symptoms of Long COVID.
 - f. Extend the use of the Your COVID Recovery online rehabilitation platform.
 - g. Collect and publish data to support operational performance, and clinical and research activities.
 - h. Focus on equity of access, outcomes and experience.
 - Promote good clinical practice through the national learning network on Long COVID for healthcare professionals.
 - j. Support NHS staff suffering from Long COVID.
- 47. In July 2022, NHSE published a further plan for improving Long COVID services (ES/171 INQ000238590). The plan provided an update on progress made on the actions set out in the plan for 2021/22 and set out a framework for deploying the £90 million committed by the NHS for Long COVID services during the 2022/23 financial year.
- 48. As a result of these investments, 100 Long COVID clinics and 13 specialist pediatric Long COVID hubs are now in operation, the latter providing clinical advice and support

to general paediatric services. NHSE began to publish activity data from the 100 clinics from September 2021, which is updated monthly and provides information on referrals, waiting times and follow up appointments. This does not include data from the specialist pediatric hubs.

Research

- 49. The ONS began to regularly publish estimates of population prevalence of Long COVID in the UK from April 2021. These were updated monthly until March 2023 and have helped to shape our understanding of how Long COVID cases are affecting different demographic groups and different parts of the country.
- 50. In July 2021, the ONS added questions on Long COVID to the 2021/2022 Schools Infection Survey, to provide a more granular understanding of how Long COVID was affecting school-aged children.
- 51. In July 2021, the Department, in collaboration with NIHR and UKRI, announced the outcome of the second targeted Long COVID research call described in paragraph 39, confirming funding for an additional 15 research studies to improve our understanding of Long COVID and how to treat it (ES/172 √ INQ000283460). It was announced that the projects would focus on:
 - a. Better understanding the condition and identifying it;
 - b. Evaluating the effectiveness of different care services;
 - c. Better integrating specialist, hospital and community services for those suffering with Long COVID;
 - d. Identifying effective treatments, such as drugs, rehabilitation and recovery, to treat people suffering from chronic symptoms;
 - e. Improving home monitoring and self-management of symptoms, including looking at the impact of diet; and
 - f. Identifying and understanding the effect of particular symptoms of Long COVID, such as breathlessness, reduced ability to exercise and 'brain fog'.
- 52. Since the announcement of the outcome of the second research call, stakeholders have continued to lobby for increased investment in research. NIHR and other research funders continue to welcome applications for further research into Long COVID.

- 53. In October 2021, the World Health Organisation (WHO) published its clinical case definition of Post COVID-19 condition, to help bring some global consistency to definitions and terminology (ES/173 INQ000283474). The WHO definition broadly aligns with that produced by NICE. At the point at which the WHO published its definition, NICE were in parallel consulting on potential changes to their clinical case definition and guidelines. Their refreshed guidelines were published in November 2021 (ES/174 INQ000283394). Whilst no changes were made to the clinical case definition, some amendments were made to the guidelines for healthcare professionals around identification, management, multidisciplinary rehabilitation and follow up. The list of common symptoms was updated to underline how these may be different for children and young people.
- 54. During this period, SAGE discussions noted Long COVID as one of four major risks arising from high infection rates (ES/175 INQ000215655) and discussed ONS analysis, setting out some of the knowledge gaps around the condition (ES/176 INQ000092856
- 55. In May 2022, NIHR published a new themed evidence review summarising the portfolio of research underway to improve our understanding of, and find treatments for, Long COVID (ES/177 INQ000283495].

Communications

- 56. In December 2021 the Long COVID Policy Team worked with the Department's communications team to publish new guidance highlighting the range of non-health support available to people with Long COVID (ES/178 INQ000283482 Although GOV.UK content on COVID-19 has changed since publication in February 2022 of the Government's COVID-19 Response: Living with COVID-19 (ES/179 INQ000257327), this page remains available on GOV.UK.
- 57. Broader public health messaging was largely the responsibility of Public Health England (PHE) (now the UK Health Security Agency (UKHSA)) and I therefore do not comment further here on this aspect of the pandemic response.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: P	ersonal Data
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Dated:15.09.23