Witness Name: Michael Wordingham

Statement No.:

Exhibits:

Dated:

UK COVID 19 INQUIRY	

WITNESS STATEMENT OF MICHAEL WORDINGHAM

I, MICHAEL WORDINGHAM, of Grimaldi Building, 154a Pentonville Road, London N1 9EH will say as follows:

Introduction

- I am Policy Manager at the Royal National Institute of Blind People ("RNIB") a post I
 have held since June 2022. Prior to this, and at the time of the pandemic, I was a
 Policy Officer with responsibility for accessibility. I am duly authorised by RNIB to
 make this statement.
- 2. I make this statement to provide information to the Inquiry on the experience of people with sight loss in relation to the test, trace and isolate systems deployed by the UK Government.

Summary

3. In November 2022, the Office for National Statistics published data which showed that people with a vision impairment were forty per cent (40%) more likely to die from Covid-19 than a comparison group without sight loss. That was even when adjusted for things like age, socio-demographic status, and overall health.

- 4. Blind and partially sighted people experienced a range of additional challenges during the pandemic particularly around the provision of accessible communications in all their forms and including the test, trace and isolate systems as we detail below.
- 5. Throughout the pandemic, RNIB experienced a dramatic increase in the use of our services driven by people with sight loss reaching out for support. In response, we immediately scaled up our services where they were needed most and lobbied the Government at every opportunity to consider people with sight loss in their thinking and decision making, with variable levels of success.
- 6. We have set out the experiences of blind and partially sighted people in relation to covid testing below together with the steps that RNIB took to address this situation. In RNIB's view, the Government must put in place a robust system for capturing the lessons learned through the testing trials outlined below for the benefit of future public health interventions such as other at home screening tests and other at home devices. There should also a review of all home screening kits in relation to their accessibility with concrete steps taken to address the issues raised. It is also essential that consideration of accessibility is built into the design and procurement process of any medical devices and alternative processes such as in person testing put in place where necessary.
- 7. More widely we consider that the Government must urgently improve its understanding not only of the effects of sensory loss but its understanding and implementation of the law. It must ensure that this is taken into account in policymaking across the board not only, but perhaps most importantly, in relation to pandemic planning and response, given the devastating impact these decisions may have.

About RNIB

8. RNIB is the UK's leading sight loss charity and the largest community of blind and partially sighted people in the UK. We provide a wealth of services including practical and emotional support through our RNIB Connect community and our Sight Loss Advice Service, guide business and public services on accessibility, campaign for change, and have a library of over 60,000 accessible reading materials, including daily newspapers.

- 9. Every day 250 people begin to lose their sight. We want society, communities and individuals to see differently about sight loss. In our 150th year, RNIB renewed our focus on creating a world where there are no barriers to people with sight loss. As a campaigning organisation of blind and partially sighted people, RNIB promotes the rights of people with sight loss in each of the UK's countries.
- 10. Our priorities include creating a society that is inclusive of blind and partially sighted people's interests and needs. One of our particular campaigning priorities is the provision of accessible information in all its various forms, from accessible health information to ensuring that account is taken of the relatively high levels of digital exclusion amongst blind and partially sighted people in the provision of public services.
- 11. RNIB also provides expert knowledge to business and the public sector through consultancy on improving the accessibility of products and services. We also have an extensive transcription service.

About sight loss in the UK

- 12. Almost two million people in the UK are living with sight loss that has a serious impact on their daily lives and activities. This equates to almost one person in thirty, whose ability to access written information, services and the built environment (amongst other things) is potentially limited or compromised by their visual impairment. It is predicted that by 2050 the number of people with sight loss in the UK will double to nearly four million.
- 13. Although sight loss affects people of all ages, as we get older we are increasingly likely to experience sight loss and in the UK one in five people aged 75 and over are living with sight loss. This rises to one in two people over the age of 90.
- 14. People from certain ethnic communities are also at greater risk of some of the leading causes of sight loss. Black African and Caribbean people are four to eight times more at risk of developing certain forms of glaucoma compared to white people. The risk of diabetic eye disease is around three times greater in South Asian people compared to white people. Black African and Caribbean people are also at a higher risk of diabetic eye disease.

- 15. There are 3.5 million people in the UK who have been diagnosed with diabetes, and a further 500,000 people living with undiagnosed diabetes. People with diabetes are at increased risk of diabetic eye disease as well as glaucoma and cataracts. Within 20 years of being diagnosed, nearly all people with type 1 diabetes and almost two thirds of people with type 2 diabetes will have developed some form of diabetic retinopathy.
- 16. There are estimated to be more than one million adults in the UK with a learning disability. Adults with learning disabilities are 10 times more likely to experience sight loss than the general population.
- 17. We understand that all the above groups have proved to be at more risk to Covid 19 than the general population. In addition, and as referred to above, more recent data from ONS for the period between 4 January 2020 and 20 July 2022 showed that the risk of death involving COVID-19 was 8 times greater for people with a visual impairment aged between 30 and 69 (12 times for those with both a hearing and visual impairment).
- 18. Around 320,000 people are registered as severely sight impaired (blind) or sight impaired (partially sighted) in the UK.

Digital by Default

- 19. RNIB is increasingly concerned about the assumption, by various Government departments and more widely, that everyone is online and so it is acceptable to rely on online provision and not make alternative arrangement for those who are not. This was particularly an issue during the pandemic and in relation to test, trace and isolate in particular.
- 20. The Labour Force Survey for the first quarter of 2020 included an additional question about internet usage. It found that 91% of people aged 16 and over in the UK had used the internet in the last three months. For people who were blind or partially sighted the figure was 60% and 23% of blind and partially sighted people said they never use the internet.
- 21. Age is a key factor in internet usage, with older people in the general population less likely to use the internet than younger people. People with sight loss are less likely still to use the internet if we compare specific age groups. Data on internet access

from the Office for National Statistics (ONS, 2015) showed that usage of the internet amongst blind and partially sighted people was lower than that amongst the general population: 96 per cent of people aged 16–64 in the general population had used the internet, compared to 78 per cent of blind and partially sighted people. The proportion of people of pension age in the general population who had used the internet was 56 per cent, compared to 30 per cent of blind and partially sighted people

- 22. It is undoubtedly the case that older people are more at risk of Covid and yet they were likely to have the least access to online information/provision. In RNIB's view, the above issues need to be tackled before the Government can confidently rely on online methods for its public health and other messaging/processes.
- 23. Given the level of digital exclusion amongst blind and partially sighted and olds people it was important that test, trace and isolate did not solely rely on online systems for its operation.

The legislative/regulatory context

- 24. In 2010 the Government enacted the Equality Act. There are nine protected characteristics under the Act including age, race, sex and disability. Individuals who have been certified by an ophthalmologist as being sight impaired (partially sighted) or severely sight impaired (blind) are automatically considered to be disabled for the purposes of the Act.
- 25. The Act makes it unlawful for a service provider or those exercising public functions to treat a disabled person less favourably on the basis of their disability. In addition, and most importantly from a sight loss perspective, service providers and those exercising a public function are required to make reasonable adjustments. This includes the provision of information in alternative formats.
- 26. The duty to make reasonable adjustments is anticipatory. This means an organisation cannot wait until a disabled person wants to use its services, but must think in advance (and on an ongoing basis) about what disabled people with a range of impairments might reasonably need (in order to access a service), such as people who have a visual impairment, a hearing impairment, a mobility impairment or a learning disability.
- 27. In addition to the substantive provisions of the Equality Act. Those exercising public functions are also subject to the Public Sector Equality Duty. This requires them to

have "due regard" to the need to eliminate discrimination, advance equality of opportunity and foster good relations (between persons who share a relevant protected characteristic and persons who do not share it). In order to comply with the duty, organisations are expected to impact assess policies and practices before implementing them and on an ongoing basis in order to understand the impact and to identify potential mitigating steps to reduce or remove adverse impacts.

- 28. Although the Equality Act was introduced in 2010, the duties outlined above in respect of disability are much more longstanding and were previously contained in other legislation. The Disability Discrimination Act (DDA) was introduced in 1995. The reasonable adjustments provisions came into force in 1999. The DDA is still in force in Northern Ireland. The Disability Equality Duty (the forerunner of the PSED in respect of disability) was introduced in 2006.
- 29. Despite the longstanding nature of these obligations, and an expectation that they would, by this time, have been firmly embedded in decision making, the experience of blind and partially sighted people during the pandemic was that little, if any regard, was given to the impact that measures were likely to have on disabled people or the need to make any necessary adjustments. The response frequently given when a discriminatory impact was raised was that decisions were being made at speed and there was simply not time to give consideration to equality issues. However, this simply shows that equality obligations/considerations had long been neglected and were not embedded in decision making. This meant decision makers were therefore going from a standing start. In addition, decision makers often didn't understand that building equality considerations into the decision-making process was vital in order to keep people safe and would potentially save time in the future. And even when RNIB had specifically alerted decision makers to equality considerations, the same mistakes were made time and again.
- 30. The Public Sector Web Accessibility Regulations 2018 also requires all public sector websites to meet international standards of accessibility. This came into force in September 1919 for new websites, 2020 for existing websites and 2021 for mobile apps.
- 31. In addition to the requirements of the Equality Act and the Web Accessibility Regulations, the Department for Health and Social Care and the NHS in England are also subject to the NHS Accessible Information Standard DCB1605 ("the Standard").

The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss. It has been in force since August 2016. As with requirements of the Equality Act, little if any regard was given to the need to ensure that health communications, including communications in relation to test, trace and isolate, were accessible. It was not apparent that NHS England and the Department understood that the Standard also applied to them and not just hospitals and GPs.

Covid Testing

- 32. From the introduction of Covid-19 testing, blind and partially sighted and other disabled people were unable take the test independently. The system was rolled out with two main ways to get a test at a drive-in centre or through a home testing kit neither were accessible to blind and partially sighted people and was a clear example of how accessibility considerations were not built into Government programmes.
- 33. RNIB first raised the inaccessibility of the testing programme on 4 May 2020 MW/01 [INQ000535957] asking for a meeting to discuss the specific challenges faced by blind and partially sighted people and offering support. We raised: 1) The accessibility of the test booking website for people using assistive tech like screen readers. 2) Alternative ways to book for people who are not online and how well they are publicised. 3) Access to drive through testing centres and mobile testing units for people who do not have access to a car. 4) The accessibility of home testing kits to people with moderate and severe sight loss. We also asked for a meeting to discuss the issues.
- 34. We received a reply on 7 May from DHSC **MW/02** [INQ000535958] explaining that they were working on improving access to the COVID-19 test programme, including trialling screenreaders and assistive technology. They provided a telephone number for people not able to use the self-referral portal and explained that they were considering instructions in Brialle and offering home testing administered by health worker. They asked for our views on these options and other possible solutions. We responded on 9 May 2020. **MW/03** [INQ000535959]

- 35. We subsequently met with a member of the Covid-19 Essential Worker Testing Programme Team at DHSC on Friday 15 May 2020 to discuss how to improve the accessibility of the testing process. We discussed the provision of alternative formats for Home Testing Kit instructions including audio led instruction videos. We also discussed the roll out of city centre walk-in test centres. We provided feedback on the accessibility of two .pdf instructions for Self-Test Kits and Test Centres and Home Test Kits. On May 29 we sent DHSC "Ten tips to help you communicate with a people with sight loss who come for a Coronavirus Test MW/04 [INQ000535960].
- 36. On 2 June we met with a member of the COVID-19 National Testing Programme team. We discussed the provision of alternative formats for test kit instructions. On June 2 we received an email to say that they were "currently exploring whether the Home Test Kit is suitable for blind individuals to self-administer." MW/05 [INQ000535961] We met with the National Testing Programme team and Deloitte on 5 June to discuss what changes could be made to the testing process to support people with varying degrease of sight loss. We spoke again about providing alternative formats of test instructions and using the sight loss registers to communicate with blind and partially sighted people in their required format. We also shared figures from RNIB's Sight Loss Data Tool.
- 37. On 10 June we met with the National Testing Team and Deloitte to discuss codesigning a trial with blind and partially sighted people to understand the barriers they face to taking a home text PCR test and how to improve the accessibility of the testing programme. Over the next three weeks RNIB worked with DHSC to co-design the trial and recruit participants.
- 38. The trial started on 30 June with 43 blind and partially sighted participants with varying levels of sight loss, years living with sight loss and confidence with technology. It was an end-to-end trial and participants were asked to order a test kit online or over the phone. They were then observed over Zoom taking the test using the kit and text only alternative format instructions that had been sent to them. They were then asked to pack the test kit into the box and bags provided and send it off by post or courier to the lab to get the result. Each participant was then interviewed asking about the end-to-end experience of the process.
- 39. The trial confirmed that many elements of the home test kit programme were not accessible to blind and partially sighted people **MW/06** [INQ000535962]. Two of the

key findings of the trial were that finding and reading barcode numbers for registration and courier pickup was almost impossible for trial participants to complete without assistance. Elements of the packaging of the kit, particularly assembling the box, was almost impossible for blind and partially sighted people to complete. The trial highlighted that there was no way to register and receive your test result unless you have an email address. Some other recommendations from the trial report were 1) To explore options for assisted testing at home, either over the phone or in person. 2) Make text only instructions available through the gov.uk platform use more detailed and haptic descriptors where possible.

- 40. Following the trial DHSC asked us to support with a second trial to gather more evidence from a larger group of blind and partially sighted participants to test changes to the testing programme to make is more accessible. Work on the second trial started on 8 October 2020 and included contributions from the Macular Society, Visionary and the Thomas Pocklington Trust as well as RNIB.
- 41. The scope of the second trial included: 1) a trial of a live video assistance service with trained support specialists from the 119-call agent population, using the Be My Eyes smartphone app which supported participants to carry out the end-to-end home testing process via a free, live one-way video call. 2) a trial of improvements to the packaging design of the returns box with participants either receiving an easier to assemble flatpack design or a preassembled box. 3) an online portal providing alternative formats of home testing instructions including HTML text only, Easy Read and accessible PDF formats. 4) improved instructions with enhanced descriptions for a sample of participants who were testing the redesigned flatpack returns box. 5) improvements to general accessibility and usability of online services.
- 42. The trial was carried out in January and February 2021 with 98 blind and partially sighted participants. 72% of participants classed themselves as being severely sight impaired or blind 43% stated their eye condition had been present from birth and a further 24% had been affected for most of their lives. **MW/07** [INQ000535968]
- 43. The trials led to some minor changes to the testing programme in February 2021 to make it more accessible, some ten months after we had first raised our concerns. These included 1) home test kits could be ordered over the phone by calling 119, without needing an email address or access to the internet. 2) easier to assemble boxes 3) test instructions being made available in large print, audio and braille. 4) live

video assistance being provided via the BeMyEyes App, an app which connected blind and partially sighted people with sighted trained 119 staff through a live call to take the PCR tests at home. The provision of live video assistance was only able to support blind and partially sighted people who had a smart phone and were familiar with using the BeMyEyes app. Despite RNIB calling for in person support with test kits and that being a recommendation from the first trial, this was never provided.

- 44. RNIB started working on another trial with UKHSA later in 2021 to improve the accessibility of the LFD tests. MW/08 [INQ000535969] Blind and partially sighted people were telling us that they were not able to take the test as they could not see the line to tell them the result. The small-scale trial was carried out in November 2021. The findings demonstrated that there were major barriers to blind and partially sighted people completing and LFD test, particularly removing the foil lid to the vile and squeezing the liquid into the test cassette. BeMyEyes was trialled to support with taking the LFD test.
- 45. Blind and partially sighted people participants and BeMyEyes agents described three main areas of difficulty using the test kit, identifying kit components, removing the foil seal from the extraction tube and ensuring the correct sample volume was added in the appropriate fashion to the sample well. Some of these difficulties were in part the result of the BeMyEyes agent being unable to adequately view the activities of the participant during particular steps. Blind and partially sighted people participants experienced challenges in conducting the tests while holding their smartphone as some parts of the process required them to use both hands. This required them to prop up their cameras up by other means in unsuitable positions which limited the ability of the agent to observe and provide assistance. Even though agents had the benefit of having a kit in front of them to assist them in providing descriptive and directional language to participants throughout the testing process, the lack of colour contrast of some components sometimes proved problematic for users as well as agents.
- 46. In six out of the seven completed tests, BeMyEyes agents could not confidently witness whether the correct number of drops had been squeezed into the LFD specimen collection well, nor whether contamination of this well or its contents had occurred via touch by the blind and partially sighted people participants. This step was the strongest pain point for blind and partially sighted people participants and BeMyEyes agents and was a particular example where the users' difficulty was

- compounded by the difficulties for agents to direct suitable positioning of the blind and partially sighted people participants' cameras.
- 47. Although there were clearly some real challenges to providing support over video, as a result of the trial live video assistance was put in place to for LFD tests. Again, this service could only help blind and partially sighted people who were digitally included and comfortable using a smartphone.
- 48. Alternative format instructions were also developed but this took a very long time to be put in place due to the different LFD kits available and there being no way of knowing which kits would be sent out to people when they ordered them. Eventually RNIB were commissioned to provide test kit instructions in alternative formats and send them out in partnership with the test a trace programme at the same time as the test kits.
- 49. For both PCR and LFD tests all this "retrofitting" meant that the tests could only be made partially accessible. No in person provision was provided to support people to take the tests and no changes were made to the design of test kits themselves, only to the packaging, ordering, and registering process, and the provision of instructions and auxiliary aids.
- 50. During ongoing monthly meetings as part of the UKHSA 'Steering Group Blind & Partially Sighted Users' following the LFD trial, RNIB and partners organisations repeatedly requested the establishment of a DHSC-wide working group to look at the accessibility of at-home medical tests. It is unclear if the Government has put in place a system for capturing the lessons learned through the trials for future public health interventions such as other at home screening tests although RNIB has recently worked with NHS England to successfully trial a more accessible home bowel screening kit.

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:	Personal Data	Michael	Wordingham
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Dated: 19/05/2025