Dated: 24 November2023

Exhibits: 47

UK COVID-19 INQUIRY

WITNESS STATEMENT OF MATTHEW REED

I, Matthew Reed, will say as follows: -

1. I am the Chief Executive Officer (CEO) for the end-of-life care charity Marie Curie. I am preparing this statement pursuant to a Rule 9 request dated 24 February 2023. I took up office as CEO in February 2019 and led Marie Curie through the pandemic period and the relevant period for this Inquiry. Prior to joining Marie Curie, I was for seven years Chief Executive Officer of The Children's Society delivering, with Local Authorities care for young people experiencing exploitation and multiple disadvantage. I was also previously Chief Executive Officer of The Cystic Fibrosis Trust.
2. Palliative and end-of-life care is an essential service. There is barely a family anywhere in the UK who does not have a painful story of poor end-of-life care of a much-loved relative, whether through lack of care available when it is needed, inappropriate care, or poor care coordination. There is no second chance to get this right for individuals. The opportunity is lost for ever for both the person dying, and their loved ones and survivors. Poor, or absent, end-of-life care has real and lasting impact on people's lives, such as complicated grief. In children this can in turn create lasting problems in adulthood. Badly handled end-of-life care can therefore have consequences that last for decades.
3. The statement is intended as an organisational response by Marie Curie and has been prepared with input from a number of individuals employed by Marie Curie. This statement has also been through a verification exercise within Marie Curie to check the accuracy of the information contained herein. In providing this statement, I have received assurances from the key contributors and via the verification exercise that where information is not in my direct knowledge, it is accurate to the best of the

knowledge and belief of Marie Curie, and in signing the statement of truth at the end of this statement I reasonably rely on those assurances.

4. As an organisation, Marie Curie is committed to assisting the Inquiry and in doing so I have tried to include as much information as is reasonably and proportionately possible in these circumstances.

Marie Curie's function and role in relation to healthcare systems in England, Wales, Scotland and Northern Ireland

5. Marie Curie is the UK's largest charitable provider of palliative and end-of-life care services. The charity delivers expert care through its nine hospices (located in Hampstead; Solihull; Bradford; Liverpool; Newcastle; Cardiff & the Vale; Belfast; Edinburgh; and Glasgow), in people's own homes via our Community Nursing Service in all four parts of the UK, and via our free Information and Support Service, which includes online resources and a free telephone support line available to anybody affected by dying, death and bereavement. In the year 2022/23, we provided care to around 44,000 people.
6. NHS commissioning bodies provide around a third of Marie Curie's total income, covering 45% of the cost of running our hospices and Community Nursing Service, including the necessary but indirect costs such as IT, estates, administration, human resources, quality assurance etc. all of which are essential to safe service delivery. This funding from the NHS commissioning bodies is provided as payment for services we provide to the NHS on a commissioned basis in each of the UK nations.
7. The remainder of Marie Curie's income, including all of the funding for our Information and Support Service, HR, IT, finance, quality and safeguarding, and our research and policy activities, comes from donations to the charity from retail, the public and corporate sponsors. The fundraised income is therefore fundamental to Marie Curie's ability to operate its services with the NHS; the services we provide to the NHS cannot be run without our fundraised income.
8. As of 1 April 2020, Marie Curie was contracted by the NHS to provide services in England to 77 of the 135 Clinical Commissioning Groups (CCGs) in existence at that time; in Wales, to six out of the seven Health Boards; in Scotland, to all of the Health and Social Care Partnerships except Shetland; and in Northern Ireland, to all of the Health and Social Care Boards. In England, Marie Curie also provided (as at 1 April 2020) a small number of services directly to local NHS Foundation Trusts. All of Marie

Curie's nursing and hospice service provision is registered with the appropriate regulator for health and social care services depending on its geographical location in the four nations of the UK.

Marie Curie's strategic response to the pandemic

9. The approaching pandemic in March 2020 presented two substantial strategic questions for Marie Curie:
    a. The ability or otherwise to protect Marie Curie staff, versus the mission to serve the public and the nation in the substantial end-of-life crisis.
    b. The balance of protecting the organisation's finances and potentially its viability, versus the need to serve the public.
10. Marie Curie's Trustees and I as CEO took the decision on 24 March 2020 to be mission-focused in our pandemic response and therefore to do everything the charity could to serve people at the end-of-life. The challenge was to fulfil this mission whilst protecting Marie Curie staff, and trying to protect the solvency of Marie Curie. Balancing all these factors required considerable effort and commitment by all Marie Curie staff throughout the pandemic period.
11. This decision was communicated to staff by MS Teams at an all-staff meeting, and the organisation mobilised on an emergency footing to serve the nation and ensure we did all we could to ensure good end-of-life care for as many people as possible throughout the pandemic period. Marie Curie cared for 49,553 patients between 1 April 2020 and 31 March 2021, as compared to 44,780 in the previous 12 months.
12. It became apparent within days of the pandemic starting that the key role Marie Curie could play was twofold: ensuring that people had the best end-of-life care they could, and keeping patients away from the acute sector as part of the UK strategic response to alleviate pressure on the NHS. If we had been unable to fulfil this, many more people would have been exposed to acute hospital admissions. Marie Curie is proud of the role it played in preventing that happening, despite the considerable challenges. On 16 March 2020 we had set out in a position statement what Marie Curie could do to assist the National Response and what we could do with the right resource, including (1) increasing NHS community capacity; (2) increase bed capacity in our hospices for NHS priorities other than Covid-19; (3) offer specialist end of life care through digital technology; (4) lead bereavement and psychological support; and (5) co-ordinate volunteers ***[MR/01 - INQ000348977]***.

13. It should be noted that there was, not unsurprisingly, a high level of fear amongst Marie Curie clinical staff as to whether they or their relatives would survive the pandemic because of their exposure to Covid-19 at work. The bravery of all Marie Curie staff working on the frontline is to be commended.
14. Marie Curie's daily operations depend on the generous donations of Marie Curie supporters and shoppers, creating £118.7m in financial year 2019/20. At the start of the pandemic Marie Curie held reserves of £54.5m, equivalent to about four months' expenditure.
15. The impact of the UK going into lockdown and having sustained periods of lockdowns on the voluntary income that sustains Marie Curie was existential. Marie Curie saw this crucial income plummet, threatening both the solvency of the charity and more importantly our ability to undertake the critical Covid-19 work and objectives detailed above. To govern this risk, Marie Curie started operating on a weekly cash flow basis as a measure of whether we could undertake planned operations. Governance of this and Marie Curie's finances was overseen by the Finance & Resources Committee, a committee of Marie Curie's Board of Trustees, who met fortnightly starting from 8 April 2020. This enabled the organisation to move with agility.
16. To achieve the core strategic decision of continuing to support patients and their loved ones at the end-of-life, and supporting the NHS, Marie Curie had to take measures to mitigate the serious financial risk to the short and long-term sustainability of the charity. This required Marie Curie to stop all but essential expenditure. Measures taken included Morrisons supermarket agreeing on 20 March 2020 to second Marie Curie's retail staff, and then subsequently furloughing all retail and many other staff from the fundraising and enabling functions on rotation such as finance, HR, and IT. Senior staff agreed to take voluntary salary cuts, non-clinical staff had planned pay rises cancelled. All non-time critical or non-essential projects or infrastructure investments were put on hold, and building rents were renegotiated with landlords, including Marie Curie's London office. There was a freeze on all non-clinical recruitment.
17. At the same time as taking measures to reduce expenditure, every effort was made to increase income.
18. In March 2020, I wrote to all Clinical Commissioning Groups and Health and Care Boards across the four UK nations to try to renegotiate contracts in respect of NHS commissioned work ***[MR/02 - INQ000348978] [MR/03 - INQ000348979]***. This represented writing to more than 100 organisations, making it clear that in order to be

able to continue to support people at the most vulnerable times in their lives on behalf of the NHS, Marie Curie needed to secure funds to cover the gap in our income caused by the pandemic. We asked these organisations to fund the current services that we provide on their behalf on a full cost recovery basis through the period of the pandemic and the social isolation measures. Marie Curie was clear that providing this additional support fell squarely into the message being given by the Prime Minister that everything would be done, and funding made available to do so, to make sure that health services continued to support the people they need to support. We received some positive responses, particularly in areas where commissioners were aware of the role that Marie Curie was playing in the local Covid-19 response and the pressures on fundraising. However, many commissioners did not offer to renegotiate our contracts, and instead directed us to the subsequently arranged government grant scheme, detailed in paragraph 35. Some of the agreed increases in funding were time-limited, for example, for three to six months, but this provided crucial financial support pending financial input from central government. Marie Curie's Chair, Vindi Banga also emailed HM Treasury on 30 March 2020 to press the need for urgent financial support to support the continued operations of Marie Curie ***[MR/04 - INQ000348980]***.

19. Marie Curie launched an emergency fundraising appeal on 20 March 2020 to supporters and the wider public. This included a number of broadcast media interviews by me and other Marie Curie staff to appeal directly to the public to support Marie Curie financially, as we were in turn supporting the nation and dying individuals. The generous support of our volunteers, donors and corporate partners resulted in Marie Curie raising an unplanned and much needed £7.145 million between March 2020 and November 2020.
20. Marie Curie also worked with Sue Ryder, Together for Short Lives and Hospice UK to secure additional funding from the UK government and devolved governments in order to ensure the continued provision and expansion of our clinical services, as detailed in paragraph 29 below. These organisations worked well together before the pandemic and it was natural to continue to work collectively during the pandemic given the shared challenges that we were facing.
21. Marie Curie recognised that the individual and collective high levels of bereavement though the period would create a psychological shock, individually and collectively. The effect of previous bereavement shocks, such as following the 1939-1945 war, had long-lasting effects. This was being exacerbated by the inability of families to be with

loved ones before their death, at their death, or to attend funerals and other rites of passage that are important facilitators of normal grief reactions. Our actions on this were twofold.

a. We scaled up our Information and Support service dramatically in several ways, (i) launching two new telephone-based support services (one specifically to deliver bereavement support in March 2020, the other to provide more general emotional support in April 2020), (ii) creating a new online information hub, explicitly for dealing with bereavement and end-of-life during the pandemic, to help the public to navigate the plethora of Covid-related restrictions, (iii) extending the opening hours of our existing telephone support line, from six days per week to seven, (iv) creating two new printed booklets and updating the existing online "palliative care knowledge zone" aimed at clinical professionals who are not specialists in end-of-life care. The new online hub had at its peak 25,000 users per week in April 2020. In total the number of users of our Covid-related information webpages was over 541,000 over the pandemic period. Demand for our telephone support services soared, and remains at those same high levels today, evidencing the long-lasting effect of the pandemic on levels of grief and bereavement in the UK. I wrote to the Secretary of State for the Department of Work and Pensions on 27 March 2020 urging the Government take steps to make the Bereavement Support Payment available to unmarried couples as soon as possible ***[MR/05 - INQ000348981]***.
b. We planned for and delivered a UK-wide National Day of Reflection on 23 March 2021 marking the first anniversary of the UK lockdown. I had written to the Secretary of State for Digital, Culture, Media & Sport on 21 April 2020 calling for a discussion on a national day of grief and healing once the Covid-19 crisis has passed ***[MR/06 - INQ000348982]***. Over 850 businesses, not-for-profit and grassroots organisations as well as members of the Royal family, politicians, and celebrities supported the day across the UK. It was Marie Curie's furthest-reaching campaign ever, generating more than 6,000 pieces of media coverage compared to an average of 1,195 for the whole of March 2020, and our digital communications reached 8 million people. Marie Curie trended on Twitter throughout the day, and we saw almost 20,000 comments in a single day. Our website traffic was up 500% and our support line enquiries up 219% compared to the previous year.

Marie Curie's operational functions during the course of the pandemic

22. Over the course of the Covid-19 pandemic, Marie Curie employed around 2000 frontline health and care staff (data correct as of 1 April 2021), which represents approximately 50% of Marie Curie's pre-pandemic total workforce, providing care for hundreds of dying patients every day, some who were Covid-19 positive, in their own homes and in our hospices. We provided vital support to the NHS by keeping these patients out of hospital and reducing pressure on acute and critical care capacity. This included providing remote Advance Care Planning into care homes. In our community services, our clinical workforce is made up of approximately 80% healthcare assistants (HCAs) and 20% registered nurses (RNs). In our hospices, our nursing staff work as part of a wider multidisciplinary team including medical staff and allied health professionals such as physiotherapists, occupational therapists, social workers, chaplaincy staff and pharmacists. Some medical staff are directly employed by Marie Curie, while others work under NHS honorary contracts (working to Marie Curie policies and procedures).
23. At the outset of the Covid-19 pandemic, Marie Curie's Board of Trustees and Executive Leadership Team met regularly to lead and manage the charity strategically and operationally in a responsive and agile manner. The Executive Leadership Team met daily from before the first lockdown, and throughout the early months of the pandemic. The Board's Finance & Resources Committee met fortnightly during this period to provide a necessary oversight of Marie Curie's financial position and financial governance, as detailed at paragraph 15 of this statement. The meetings had a flexible agenda and structure, to accommodate the rapidly changing landscape.
24. Marie Curie also established a cross-organisational operational business continuity group called the Coronavirus Response Team (CRT) that sat below the Executive Leadership Team. The CRT was established on my direction on 10 February 2020 as the scale of the pandemic as an end-of-life crisis in the UK and existential threat to Marie Curie came into sharp focus. The CRT was active until June 2022. The CRT had operational oversight over all functions including staffing, changing biosecurity and travel rules across different parts of the UK, wellbeing, health and safety, fundraising, and internal communication and dissemination and sharing of information. Due to the rapidly developing nature of the pandemic, Marie Curie was required to

respond at pace to changes, and as a result not all meetings were minuted due to pressures on staff time.

25. For direct clinical services, a clinical operational pandemic group commenced daily meetings from 12 March 2020, where the following topics were discussed daily: the status of PPE levels across all of our services, and availability of new PPE supplies, how many cases of Covid-19 were present in our patient population, levels of staff sickness and staff shortages. Membership of the group consisted of senior leadership from Marie Curie's Caring Services directorate, along with representatives from the Health and Safety, Internal Communications, and People teams. The group covered all four nations. One task of the pandemic group was to review guidance across the four UK nations from the Department of Health and Social Care, the Welsh government, the Scottish government, the Department of Health in Northern Ireland, NHS England, NHS Wales, NHS Scotland, Public Health England, Public Health Scotland, Public Health Wales, Public Health Agency (Northern Ireland), the Care Quality Commission, and any local guidance issued by local authorities in relation to specific local outbreaks. This represented a significant challenge, as guidance across the four nations often differed, and the volume of guidance the group was required to review and communicate internally was very large. The passage of time makes it difficult to give specific examples, but these were wide-ranging, covering things such as testing, visiting and self-isolation affecting staff. The pandemic group would determine the need to implement, update, replace and then ratify internal policy and training. Information would also be shared in terms of updates and 'sitreps' (situational reports) of the situation across our nine hospices and in our Community Nursing Service (as required to be submitted to the Strategic Data Collection Service). Sitreps for Marie Curie Nursing Services and hospices were reported on by area: Central, Eastern, London, North East, North West, Northern Ireland, Scotland North, Scotland South, South East, South West and Wales. Sitreps for hospices were reported on by location: Belfast, Bradford, Edinburgh, Glasgow, Hampstead, Cardiff & the Vale, Liverpool, Newcastle and West Midlands. These covered patient status, service status, staff sickness and absence, supply / stock levels, and the impact on service delivery, as set out in the examples from Nursing Services (eastern) and Hospices (Glasgow) ***[MR/07 - INQ000348983]***. Over time and once the situation had stabilised, the pandemic group met less frequently, switching to weekly meetings in May 2021.

26. Marie Curie kept its own staff updated on changes to national guidance, guidance specific to each of the four UK nations, and the implementation of (or changes to) internal policies and procedures via email communication, all staff MS Teams meetings, and newsletters. This was made more challenging by changes to restrictions and guidance typically being communicated as a daily email from a central email address (email@notifications.service.gov.uk) at 17:30-18:00, just before our community nurses' evening shifts began and outside of office hours. Often the detailed guidance was not published until the following day. It was the responsibility of the Marie Curie Quality team to review incoming information. This is central function which trains, advises and monitors the quality of delivery of our clinical services, and has responsibility for ensuring that the care Marie Curie provides is compliant with legal and regulatory requirements. Following receipt of new information or guidance there were then discussions about that information over email between colleagues, or verbally at the next daily pandemic group call. Email communications relaying new guidance or changes to procedure were sent to relevant clinical staff by email by the Quality team. Marie Curie's clinical teams based in each geographical place where the charity provides its services were then responsible for actual implementation. The particular issue with new guidance being published around 17:30 was that staff working in Marie Curie's central Quality team and in managerial roles theoretically stop work for the day at around that time. Instant implementation of the guidance was required (that is, new guidance needed to be implemented for the night shift immediately following publication) but the timing meant it could be challenging for clinical teams responsible for delivering our services to receive any advice they required about implementation.
27. During the pandemic, Marie Curie changed the ways its services were delivered in line with restrictions in place and staffing availability. Face-to-face outpatient care based at our hospices ceased as soon as the first lockdown was announced. In-patient care in our hospices, care delivered in person in people's homes, and care and support delivered over the telephone (or by other methods which did not involve face-to-face contact), were prioritised. Hospice care delivered virtually (via telephone, email or video conferencing) increased 90% in the period April 2020-July 2020, compared to the same period in 2019. Marie Curie saw a significant increase in its activities in the community, seeing a 20% increase in home visits overall (in April-July 2020, compared to April-July 2019), with some services seeing 35% more patients. The number of

inpatients in Marie Curie's hospices fell, driven principally by staffing shortages due to Covid-19-related absences in Marie Curie's staff body. There were 1,379 inpatient admissions in the period 1 March 2019 and 31 July 2019, compared to 1,098 inpatient admissions in the period 1 March 2020 and 31 July 2020, which is a 20.4% decrease in inpatient admissions. This is very similar to 2019 and 2020 full year comparison where there was a 20.7% decrease in admissions. There was an initial reduction in admissions from Jan 2020 but then there was an increase in admissions over May and July 2020 and then the general decline continued until Jan 2022. The reasons for staff absence is not a simple figure to breakdown, as it involves analysis of several different data sets. However, staff absence was driven by sickness, self-isolation, shielding, caring for a family member, furlough (staff were furloughed on rotation). I deal with the reasons for these operational changes in more detail later in this statement.

Communication, engagement, and collaboration with external organisations

28. From the onset of the pandemic, I regularly met virtually with CEOs from other organisations delivering and representing palliative and end-of-life care, namely Hospice UK, Sue Ryder, and Together for Short Lives. At such a challenging time for voluntary sector organisations working alongside the NHS, but outside of the protective umbrella, it was vital for us to work together to ensure we could optimise our collective efficacy in the national interest. We shared the same challenges of funding, staffing, access to PPE, testing and bed capacity which it was felt were best addressed with officials from the DHSC and NHSE together. Collectively we met virtually with officials from the DHSC and NHSE to discuss and optimise these strategic and operational matters, and to try to elevate our activities to a footing similar to those being directly delivered by our colleagues across the NHS, and to gain the support and protection that our staff deserved.
29. On 19 March 2020, Marie Curie was a co-signatory with Hospice UK, Sue Ryder and Together for Short Lives, of a letter to Mr Hancock MP, the then Secretary of State for Health. In that letter we collectively sought help in securing funding for the viability of the hospice and end-of-life sector at such a challenging time ***[MR/08 - INQ000348984]***. We asked the Government for urgent help to sustain these critical services, and to ensure that we could continue to play our part in the wider health and care system. Our collective and specific requests were that Government (i) provide £200 million during the crisis so that charitable hospice and end-of-life care services could continue

to care for 225,000 people per year; (ii) guarantee that funding for any additional services required of these organisations to take pressure off the NHS would be fully funded and paid in advance; (iii) ensure the same access for charitable hospice and end-of-life staff to PPE as existed for NHS staff; (iv) to make Covid-19 testing available for staff working in charitable hospice and end-of-life care services who display symptoms, and for the patients and families that they support; (v) clarify the status of charitable hospice and end-of-life care staff as 'essential workers', and provide them with the same support to be able to continue working as was being afforded to the NHS; and (vi) ensure that hospice and end-of-life care services were involved in local and regional emergency planning arrangements.

30. This letter and subsequent pressing of the DHSC, resulted in numerous meetings being held, organised and managed by the DHSC. I attended these meetings, along with colleagues from Hospice UK, Sue Ryder and Together for Short Lives. Ms Helen Whately MP attended meetings in her capacity at the time as Minister of State for Care. The meetings were also attended by various civil servants, Ms Emma Dean (special advisor to Mr Hancock), and senior personnel from NHSE, including Ms Sue Bottomley and Mr James Sanderson. The first meeting was held virtually on 23 April 2020. I do not hold minutes for these meetings, but the agenda subjects covered those concerns raised in the letter to Mr Hancock dated 19 March 2020, with funding, PPE and workforce matters being the early considerations. As funding issues were resolved, bed capacity became more of a focus, along with vaccinations, and the risk of the system becoming overwhelmed again over the winter of 2020/21. Collectively, we were asking for the things that we needed in order to continue to deliver our services in a way that was safe for patients and our workforce and supported the national strategic focus of the NHS. I address later in this statement the solutions that were put in place in relation to funding, PPE and workforce matters.

31. Alongside the meetings with the DHSC, we collectively met with NHSE. These meetings were held virtually, approximately monthly. These meetings were more fluid and practical matters and possible solutions were discussed, but the themes and objectives were the same as those detailed in the paragraph above. I do not hold minutes in relation to these meetings. I address later in this statement the solutions that were put in place in relation to funding, PPE and workforce matters.

32. The meetings referred to at paragraphs 30 and 31 themselves did not necessarily provide instantly confirmed outcomes, but they were the forum in which we were able

to collectively put forward our position and set out what was needed for consideration by the DHSC and NHSE. As a general observation the response of the DHSC and NHSE was engaged, in due course contributing to solutions, although potentially constrained in its urgency by the wider systems failings and inertia.

33. The challenges around staff safety were focused on access to testing and the supply of PPE. During the pandemic there were many more PPE requirements and particular specification requirements dictating what type of items needed to be procured. These requirements were different to before the pandemic. Some items had to be procured by Marie Curie for the first time, for example FFP2 face masks. Marie Curie was also finding it needed to procure PPE in significantly greater quantities than before the pandemic, due to the requirements of the guidance. Prior to the pandemic, Mare Curie clinical staff working in the community ordered items such as nitrile gloves, aprons and hand sanitiser products directly from a company called Lyreco. Lyreco fulfilled the orders and delivered direct to nurses' homes and to Marie Curie offices. Prior to the pandemic, Marie Curie staff working in our hospices ordered gloves, aprons and hand sanitiser through NHS Supply Chain, for delivery to the hospices. From the outset of the pandemic, in the case of both Lyreco and NHS Supply Chain, most items were out of stock and unable to be ordered. Stock replenishment dates were unavailable. Items were withdrawn from the catalogue and listed as Unavailable to Order. This was particularly the case for the main brands of hand sanitiser. In the early days the Executive Leadership Team met several times a day to decide whether there was sufficient PPE for the next shift to be deployed. We do not hold statistical data on the deployment of any shift or part of any shift due to PPE shortages but the ELT were concerned about sufficiency of PPE supplies. On 24 March 2020, I escalated concerns to NHSE ***[MR/09 - INQ000348985]***. I brought to the attention just one example from that week of a member of staff doing a 12 hour shift with no PPE. On 9 April 2020, Marie Curie's Chief Nurse (Julie Pearce) emailed NHSE regarding PPE and that email refers to visits in patients own homes being cancelled ***[MR/10 - INQ000348986]***. On 15 April 2020, Marie Curie's Chief Nurse (Julie Pearce) emailed Steve Oldfield at the DHSC and Emily Lawson at NHSE in which they highlight the PPE challenges, that nursing teams are working "hand to mouth" and that community nursing visits were being cancelled ***[MR/11 - INQ000348987]***. The challenges around this, and securing testing and PPE from NHS suppliers, are expanded on below. Up until mid-April 2020 we experienced the supply of PPE as being chaotic with multiple assurances from

NHS bodies unfulfilled and agreed orders subsequently being inexplicably cancelled by NHS suppliers up until 15 April 2020. Our concerns were escalated to the Chair of NHS Improvement on 30 March 2020 ***[MR/12 - INQ000348988]*** and 10 April 2020 ***[MR/13 - INQ000348989]***. We also asked supporters and staff to raise concerns around the supply of PPE with their own MPs and raised the issue in broadcast interviews. We contacted Steve Oldfield, Chief Commercial Officer at DHSC by email on 15 April 2020 to reiterate our concerns (as detailed above). He passed that email to Dr Sara Felix (Deputy Director at the National Supply Disruption Response at DHSC) and she replied on 16 April 2020 to confirm that NHS Supply Chain were now working to include Marie Curie on their future push deliveries ***[MR/14 - INQ000348990]***. An agreement was finally confirmed on 19 April 2020 that Marie Curie would receive a weekly push delivery of PPE from NHS Supply Chain to be delivered to our West Midlands hospice to cover all Marie Curie staff across the UK ***[MR/14 - INQ000348990]***. Over one hundred Marie Curie staff and volunteers and corporate partners then established a national PPE distribution network at pace to supply Marie Curie clinical staff across the UK, including daily shipments from Birkenhead to Belfast to supply our teams in Northern Ireland. Further operational detail regarding the challenges we faced in sourcing PPE are detailed in paragraphs 52-57 below.

34. On 11 November 2020, prompted by the DHSC's confirmation that asymptomatic testing was due to begin for all patient-facing NHS staff, Marie Curie and Sue Ryder were joint signatories of a letter to Prof. Whitty (then Chief Medical Officer and DHSC Chief Scientific Officer) and Prof. Stephen Powis (then National Medical Director of NHS England & Improvement) copied to Ms Helen Whately MP (then Minister of State for Care, DHSC) and Jeremy Hunt MP (then Chair of the Health & Social Care Committee) ***[MR/15 - INQ000348991] [MR/16 - INQ000348992] [MR/17 - INQ000348993]***. In that letter, we expressed our grave concern that rising transmission of the virus was impacting upon our ability to operate fully and safely over the winter despite rigorous infection control measures being in place and urged that regular asymptomatic testing be extended to patient-facing staff of independent healthcare providers and the wider hospice sector, with appropriate prioritisation alongside NHS staff. Likewise, we also requested confirmation that, as and when a vaccine became available, the same approach would be taken.
35. On 20 April 2020 the group secured a commitment from the DHSC and NHSE to financially support Hospice UK's members, Marie Curie, Sue Ryder and Together for

Short Lives ***[MR/18 - INQ000348994]***. This support was provided from the Covid-19 emergency fund on the basis of bed capacity, which included care provided where a patient remained at home. This funding was parallel to similar schemes used to procure beds in private hospitals or Nightingale hospitals where funding was calculated by reference to the number of beds and the projected fundraising losses in the hospice and palliative care sector as a direct result of the pandemic. In the case of the hospice and palliative care sector however, beds (in hospices and in the community i.e., in patients' own homes), were fully staffed and actively protected the acute sector by keeping patients out of hospital. The level of funding that Marie Curie received is detailed in paragraph 75 below. It is important to stress that funding did not per se allow Marie Curie to increase care provision. The funding replaced funds which we had projected to fundraise as part of our "business as usual" activities to raise voluntary donations. As a result of the lockdown, we were not able fundraise using methods we had previously used (face-to-face collections and social events for example). The result was a dramatic and sudden drop in income, which threatened the organisation's status as a going concern, as detailed in paragraph 15. The funding from government ensured the organisation's future financial stability by replacing lost voluntary income.

36. In return for funding, Marie Curie was required to submit bed vacancy data on a national capacity tracker twice a day and submit monthly financial returns. It was not entirely clear why this information was required, and it felt bureaucratic and confusing, taking individuals away from important operational patient-facing work.
37. Marie Curie representatives also attended a number of external meetings organised by various organisations during the course of the pandemic. This was at both a national and local level, and included those bodies identified in paragraph 8 of this statement. Communication was variable but included attending (remotely) meetings and email communications. The approach that was generally taken within Marie Curie was for individuals from our Nursing and Quality team to lead internally on specific matters and attend meetings held in relation to those matters, and then feedback to Marie Curie's internal pandemic group. Marie Curie were not the organisers of these meetings and did not therefore keep minutes. From my knowledge of these meetings, they were largely the fora in which Marie Curie staff asked questions, sought clarification and raised concerns, rather than through formal communications and submissions. In Northern Ireland, Marie Curie already worked as part of an integrated

health and social care sector and had robust avenues of communication across the health, social care and voluntary sectors. The Department of Health in Northern Ireland allocated additional funding to support both hospices and hospice community services with Covid-19 pressures at the outset of the pandemic. This enabled Marie Curie in Northern Ireland to have access to improved IT, which facilitated working from home and included access to Microsoft Teams on tablets, so that Marie Curie staff in Northern Ireland could attend regular meetings with partner organisations across health and social care, including being able to link in the services with which Marie Curie were working closely such as those delivering district nursing care. New lines of communication were also opened up for Marie Curie, an example being that staff joined a team focused on care homes which allowed them to provide support in care homes, something that they had not done to any significant degree prior to the pandemic. Colleagues in Northern Ireland report that these meetings provided fora in which Marie Curie, along with all health, social care and voluntary sector organisations could receive and share information, ask questions and raise concerns.

38. At a local level Marie Curie staff and teams worked collaboratively with other organisations during the pandemic, demonstrating the vital contribution that colleagues from within Marie Curie Caring Services (Hospices and Community Nursing Services) were making in addition to their more recognised services. A few examples of these initiatives are detailed below.

39. Marie Curie made an offer on 27 March 2020 to NHS Improvement to support the establishment of the Nightingale Hospitals via an email from our Chair to Baroness Harding ***[MR/19 - INQ000348995]***. Colleagues from Marie Curie Caring Services subsequently supported their colleagues in the NHS who had been tasked in preparing the Nightingale hospitals. Whilst Marie Curie had no formal role, Marie Curie staff supported NHS colleagues in London, Cardiff and the West Midlands in providing information about palliative care and about support (if required) for discharging people home for end-of-life care ***[MR/20 - INQ000348996]***. In Birmingham, the Medical Director and Head of Operations at our Solihull hospice volunteered to be involved in the development of the Nightingale hospital there, and to provide palliative care advice and support to the staff who would be working with the patients. This is just one example of how Marie Curie staff went over and above to support their NHS colleagues.

40. A further example of how Marie Curie staff supported local NHS services was in Liverpool where colleagues worked with Liverpool University Hospitals NHS Foundation Trust (which incorporates two acute and one non-acute hospitals) and Woodlands Hospice to establish a 'Pan-Liverpool' consultant on call rota to cover palliative care services in specialist inpatient units, hospitals and the community across the city. The on-call rota was to provide in-person care, in the form of planned hospital and hospice ward rounds at weekends and bank holidays, and also telephone advice between 5pm and 9am, seven days a week. This ensured that the service was sustainable in the face of possible sick leave due to Covid-19 and allowed the redeployment of resources or staff to support areas which were struggling due to shortages or sickness. Also in Liverpool, Marie Curie medical consultants worked on the specialist palliative care inpatient ward in a local NHS hospital to support the hospital consultants to deliver care to Covid-19 positive patients that hospital staff had assessed as being not appropriate to receive, or likely to benefit from the interventions that might be available on the Intensive Care Unit such as invasive ventilation. Marie Curie staff report that this was a stressful environment to work in; the patient throughput was very high with many dying after only a few hours on the unit, with the bed immediately being filled with another patient. Due to visiting restrictions the medical staff were required to have many difficult and distressing conversations about patients over the telephone.
41. Similarly, the Hospices of Birmingham and Solihull (HoBS) project brought hospices in the area together (Marie Curie's Solihull hospice, Birmingham Hospice Selly Park and Birmingham Hospice Erdington) to develop a responsive call centre manned by palliative care clinical nurse specialists and allied health professionals. Patients, carers and all healthcare professionals could call the centre for advice. In addition to telephone advice, we provided a visiting service. Together, these hospices set up new rota systems to work collaboratively and moved their base so they worked out of one of the hospices and served the wider Birmingham and Solihull (BSOL) area. The clinical teams were supported by a 24/7 palliative care consultant and pharmacist on call rota for out of hours advice enabling the four local hospitals, the community and three hospices to call for medical consultant or pharmacy advice 24 hours a day 7 days a week. This is still in place today.
42. In Northern Ireland, there was collaborative working prior to the pandemic. In three of the five NHS Trusts, Marie Curie's rapid response team sits within the out of hours GP

service, and in the other two NHS Trusts, in the District Nursing team. In all areas, the work is coordinated by the NHS who refer patients to the Marie Curie rapid response team and support the delivery of care. Marie Curie nurses can access electronic GP records in the areas where they sit within those teams and can read and add to paper records held by the District Nursing team. During the pandemic, Marie Curie nurses supported district nursing colleagues during periods when their staffing was reduced covering palliative and end-of-life care patients. This was made possible by increased funding from the Northern Ireland Department of Health of over £1 million which allowed an expansion of the rapid response team and an increase from one to two nurses per shift.

43. Prior to the pandemic, Marie Curie in Northern Ireland had not been significantly involved in care delivered in care homes. However, through the setting up of specialist groups across health and social care early in the pandemic, we were able to increase our presence in care homes, and support care homes with the delivery of palliative care in the ways they do elsewhere in the community.
44. Early in the pandemic, Marie Curie in Northern Ireland were able to provide specialist support around the verification of expected death. Marie Curie staff had been trained in this area, whereas many staff working in the community were not. This was recognised as a problem, particularly where GP services had been reconfigured leading to fewer home visits. Marie Curie staff initially undertook a significant amount of this verification work, before providing training materials to other health providers for them to adapt and use to train their own staff ***[MR/21 - INQ000348997]***.

Marie Curie's evaluation of the impact of the Covid-19 pandemic on the delivery of palliative care

45. Marie Curie is the UK's leading charitable funder of palliative and end-of-life care research. It is recommended that this statement is read alongside the following reports commissioned by or produced by Marie Curie in collaboration with others, which provide greater detail than the summary which follows:
    a. Better End-of-life. Dying, death and bereavement during Covid-19 (2021):
        - Research report ***[MR/22 - INQ000348998]***
        - Marie Curie policy briefing ***[MR/23 - INQ000348999]***
    b. Fairer Care at Home. The Covid-19 pandemic: a stress test for palliative and end-of-life care:

- England report ***[MR/24 – INQ000349000]***
- Scotland report ***[MR/25 - INQ000349001]***
- Wales report ***[MR/26 - INQ000349002]***
- Northern Ireland report ***[MR/27 - INQ000349003]***

46. As outlined in Marie Curie's *Better End-of-life - Dying, death and bereavement during Covid-19* report (2021) (produced by an expert group of clinical and non-clinical academics from King's College London Cicely Institute, Hull York Medical School, the University of Hull and the University of Cambridge, along with patients and carers), palliative and end-of-life care services, both those provided by Marie Curie and by other providers in the UK across all settings saw increased activity during the pandemic (page 23 of 2021 report). Services from all parts of the UK and across the English regions reported being busier than before the pandemic (page 23 of 2021 report), this being reflected in the results of a joint survey of palliative care professionals conducted by the Association for Palliative Medicine of Great Britain and Ireland and Marie Curie in December 2020 and January 2022 ***[MR/28 - INQ000349004] [MR/29 - INQ000349005]***. The feeling was that there was a sharp increase in activity which led to services being significantly stretched, by reason of Marie Curie providing end of life care, and more people were dying, therefore more care was required. Marie Curie were not aware of any particular differences in death rates or activity levels from nation to nation as we have not undertaken the research to compare data sets. The experience of Marie Curie was that the concentration of covid cases varied from place to place at a more local level, and there were local waves at different times, so Marie Curie could be busier in one geographical area than another at any one time. This experience of an increase in activity required teams to make rapid innovations, adapting their services in response to restrictions and working to educate and upskill wider health and social care professionals on issues such as symptom and pain control (pages 13 and 14 of 2021 report).
47. At the time of preparing this statement, Marie Curie has undertaken research into inequalities in access to palliative care, and research on the impact of the pandemic on palliative care (as referenced in paragraph 44 of this statement). Research has not however been undertaken by Marie Curie seeking to investigate the impact of inequalities and the provision of palliative care specifically during the pandemic.
48. Marie Curie's experience is that the following matters presented a particular challenge to the delivery of palliative care in our services:

a. Recognising the role of palliative and end-of-life care as essential healthcare
b. Access to PPE as non-NHS frontline services
c. Restrictions on visiting
d. Staffing
e. Testing
f. Funding

Recognising the role of palliative and end-of-life care as essential healthcare

49. Whilst there was a recognition from the early stages of the pandemic that many people would likely die as a consequence of Covid-19, there appeared to be little focus from the UK's healthcare system on the need for palliative and end-of-life care, or recognition of palliative care as an essential part of the Covid-19 response. This was reflected by the lack of guidance produced which specifically addressed the settings in which Marie Curie services operate, namely hospices and in the homes of our patients. Most guidance was written predominantly for hospitals and care homes, despite organisations such as Marie Curie providing established and essential healthcare. Marie Curie therefore had the challenge of reviewing and interpreting this guidance, often different in each of the four parts of the UK, to provide its staff with the clarity needed in our operating environments. Establishing the applicability of this guidance to our practice and communicating this to staff was a burden and persisted throughout the pandemic.
50. This is reinforced by our research findings. For example, one respondent in the first report from the *Better End-of-life* programme reported difficulties in accessing PPE as a result of not being treated as a "frontline NHS" service (page 27 of 2021 report).
51. Colleagues in Northern Ireland report that many Marie Curie staff were bank staff or staff working under contracts with more than one organisation at the outset of the pandemic. Within the care sector, Northern Ireland staff were advised not to move between multiple organisations, and within the NHS there were attempts to restrict spread through staff movements. This, together with a well-publicised drive to encourage people to shore up the NHS, which was supported by many of our staff, created a workforce issue for Marie Curie in Northern Ireland where staff opted to work exclusively in either care homes or the NHS. Marie Curie cannot provide accurate data on the number of staff lost due to the restrictions on movement as its data will also include staff who were lost due to other reasons. Colleagues in Northern Ireland

reported this as a factor in having a reduced workforce to meet the demands and we know that in terms of overall figures, we had a turnover of staff of approximately 10%.

Access to PPE

52. The failure of the DHSC and organisations working on the supply of PPE in England to recognise the role of palliative and end-of-life care services as 'frontline services' with the NHS throughout the initial stages of the pandemic, led to resources being hard to secure in many areas, regardless of the availability of funds (see paragraph 33). In Northern Ireland, colleagues reported that initial issues were quickly overcome. In Scotland and Wales, local NHS commissioning bodies were broadly supportive of Marie Curie and supplied Marie Curie with PPE. In Scotland, Marie Curie experienced some initial difficulties with supply, but these were swiftly resolved. In Wales, the local NHS commissioners (Health Boards) were supportive of Marie Curie and supplied Marie Curie with PPE. It also appeared that there was a lack of clarity in decision-making which led to confusion about who should be supplying PPE to non-NHS frontline services. The DHSC (Director of PPE) wrote to Hospices, including Marie Curie, by letter dated 15 April 2020 ***[MR/30 - INQ000349006]***. In that letter the advice given by the DHSC was that hospices were *"to explore their usual routes for sourcing PPE, including through the NHS Supply Chain or wholesalers. However, we [DHSC] understand that in some cases hospices have experienced disruption via their usual NHS Supply Chain. In response to this, alternative arrangements have been put in place by Department of Health and Social Care (DHSC). This includes a one-off issue of 300 free fluid repellent facemasks in March to every CQC registered hospice in order to meet the immediate PPE demand."* That letter went on to advise that after that short-term plan *"arrangements have been made to ensure that hospices can request PPE from 7 major wholesalers which ordinarily provide PPE to adult social care."* We were told that DHSC were working to provide stock of PPE equipment to these wholesalers to ensure they could support our needs, however they recognised that these wholesalers do not routinely stock FFP3 masks. Hospices were told that if they were unable to obtain PPE through this route and there remained an urgent need for additional stock, including for FFP3 masks, they can approach their Local Resilience Forum (LRF) who had received a short-term supply of critical PPE to help them respond to urgent local spikes in need across the adult social care system and other front-line services, including hospices. If hospices were unable to obtain PPE through the above routes, we were told to escalate requests to the National Supply Disruption

Response. These were the routes that Marie Curie had pursued prior to 15 April 2020, and Marie Curie found that: (i) all of its usual suppliers of PPE were out of stock (as explained in paragraph 33), including existing or pending orders we had placed with the NHS Supply Chain being cancelled by them; (ii) the one-off issue of 300 masks barely had any effect on our overall stock shortage, as we required around 8000 face masks per day across the whole of Marie Curie's operations; (iii) Marie Curie requested stock from the seven major wholesalers and found they consistently had no stock; (iv) our staff subsequently sought to engage with many LRFs across England, but found a variety of different barriers to obtaining stock: lack of clarity over which local organisation was responsible for making decisions regarding the distribution of PPE by the LRFs (our staff found themselves being passed from one local organisation to another), very low stock levels such that the amount the LRFs were able to provide was wholly inadequate to meet our needs, refusal of the LRFs to supply Marie Curie because they had not been told by National Supply Disruption Response or DHSC that they were permitted to supply PPE to us; (v) when we escalated our requests to the National Supply Disruption Response, we were told by them to go back to the LRFs, and our orders with NSDR were cancelled. These routes did not result in Marie Curie receiving adequate PPE to support the delivery of our service. It was only from 19 April 2020, when it was confirmed that Marie Curie would be part of the weekly push delivery of PPE from NHS Supply Chain, as described in paragraph 33, that the situation improved.

53. Marie Curie services experienced significant challenges obtaining suitable stocks of Personal Protective Equipment (PPE) from 1 March 2020 until around 31 July 2020 (the different experience in Northern Ireland is discussed below), including hand sanitiser, masks, aprons, and face shields, as well as shortages of other equipment (such as syringe pumps) and essential medications. For example, on 30 March 2020, one week into the first nationwide lockdown, four of our nine hospices reported less than one week's supply of surgical face masks, while five had less than a day's supply of FFP3 masks and only one had a sufficient (more than one week) supply of goggles or visors.

54. In March 2020, Marie Curie's usual supplier of PPE (through NHS Supply Chain) became unable to continue provision of essential items as they were no longer in stock. Following advice from government [DHSE] (see paragraphs 33 and 52 for the detail of communications and advice) Marie Curie placed emergency orders for PPE

through the National Supplies Distribution Resource Team (NSDR). We were referred on to Local Resilience Forums (LRFs) to access emergency supplies; however, the response from LRFs at this time was poor, with some supplying only small amounts of PPE and others referring back to the NSDR until the changes detailed at paragraph 52 were implemented. For the PPE Marie Curie did receive through these channels, there was a heavy reliance on our own internal structures, utilising our volunteer workforce, to support the onward distribution to our frontline staff across the whole of the UK. While these issues were being resolved, Marie Curie made efforts to buy necessary PPE from alternative sources, however prices in the market for PPE had increased significantly. Some hospices were given donated items from local businesses, however items donated did not always comply with standards published in government guidance, so could not be used.

55. In Northern Ireland the position was different. Early in the pandemic, Marie Curie in Northern Ireland also faced challenges in sourcing PPE. During this time, supplies were provided from Marie Curie's internal UK-wide national distribution stream. This problem was however only short term in Northern Ireland and resolved within a couple of weeks following discussions with the Department of Health, Health Boards and NHS Trusts, with the agreement that Marie Curie would submit a weekly order to Trusts who would in turn fulfil those orders. The problem in Northern Ireland was resolved through discussions over the telephone and video-calls between Marie Curie, the Department of Health, Health Boards and Trusts.
56. Despite continuing to raise access to PPE with NHSE and DHSC, PPE shortages had a direct impact upon the ability to care for patients. In line with Marie Curie internal guidance, home visits could not be undertaken if staff did not have the required PPE. Marie Curie nurses visit hundreds of patients in their own homes across the UK every day and the shortages faced in the early stages of the pandemic had a direct impact upon patient care through the cancellation of appointments. Our staff reported being distressed by these shortages and cancellations, conscious that there were patients whose care needs at the end-of-life were not being met as a result. Some of our staff also expressed their anxiety to me about their personal safety, given the challenges we faced in obtaining appropriate PPE in a timely manner. Whilst Marie Curie has formal processes for the raising of concerns such as Freedom to Speak Up, due to the fast pace with which things were changing and the challenges being faced, concerns were often raised through face-to-face conversations. Marie Curie also set up a

pandemic internal inbox for staff to submit questions or concerns which was checked daily, discussed as standing agenda item by the pandemic group, and content from this email inbox was used to developed FAQ content on the Marie Curie intranet. Senior members of staff at Marie Curie, including myself (see paragraph 33), addressed concerns raised directly with us (or communicated to us), and the FAQ page on the intranet also enabled a wider organisational response. In July 2020 we also undertook a staff survey to support our understanding.

57. While access to most PPE was resolved by the summer of 2020, Marie Curie services still faced ongoing challenges in particular in obtaining certain specialist PPE and accessing appropriate "fit testing" (an assessment by a trained practitioner of an individual's physical requirements and measurements, which aims to ensure that the PPE supplied fits the individual properly and so provides the intended level of protection), as required for certain types of PPE. The problem with fit testing was that we did not have sufficient access to appropriate practitioners to undertake the testing. Marie Curie did not employ staff qualified to conduct fit-testing in-house, and did not routinely require or conduct fit-testing on its own sites prior to the pandemic. As a result we did not have in every location in which we operate an established agreement with a local provider of fit-testing services, so it was necessary to source the service externally. We experienced difficulties in establishing agreements with hospital trusts, as only some of our hospice staff were also NHS / Trust employees.

58. The *Better End-of-life* report found that experiences of PPE shortages were common amongst hospice and palliative care services, with between 33% and 61% of services in all parts of the UK experiencing PPE shortages (most commonly in the North West of England and West Midlands) (page 27 of report). Concerns were raised (as noted in paragraph 52) that this related to Marie Curie not being treated as a frontline NHS service.

Restrictions on visiting

59. The restrictions on visiting had a significant impact on patients, their loved ones and Marie Curie staff. As highlighted in Marie Curie's *Compromised connections* report ***[MR/31 - INQ000349007]***, which examines the impact of Covid-19 on hospice care, across the hospice sector visiting restrictions were often unclear to patients and their families and caused significant distress in many cases where some family members could not be with their loved one at the end of life, and where patients were isolated and deprived of social contact at the end of life. Sometimes, restrictions drove

decisions about preferred place of care, with patients choosing to stay at home rather than be admitted to hospices and be unable to see their families (pages of 12 and 13 of the above report).

60. In line with guidance, Marie Curie introduced visiting restrictions in all of our hospices in March 2020, and these remained in effect to differing degrees depending on local restrictions, tier restrictions and in response to local outbreaks throughout 2020 and 2021. Restrictions included facilitating limited hospice visiting from a limited number of people (sometimes one, or in carefully assessed circumstances, two) during the last hours and days of life and virtual visiting. This had a significant impact on patients and their families, who were in many cases faced with the prospect of having to choose which visitors were permitted to visit or be present in the final days of a patient's life. The requirement to limit visitors led to significant emotional distress, both for patients and their families, and also for staff, who were required to have difficult discussions and provide emotional support to those facing these hard decisions. Significant staff time was also spent having these discussions, sometimes at the expense of providing other forms of patient care. Conversations were often highly emotionally charged, and the regularity of these conversations took a significant toll on staff wellbeing. Due to legal visiting restrictions being different in all four parts of the UK (and regionally), producing local guidance for visiting rules (and screening visitors) was challenging. Some hospices in the early days of visits also had to redeploy clinical staff to screen and test visitors for Covid-19 symptoms. This activity diverted clinical staff from their usual duties providing care to patients. Over time, and with the relaxation of testing requirements, this screening role was taken on by volunteers or reception staff.
61. Virtual visiting was established within a week of the first lockdown being introduced and required minimal training for hospice staff so that virtual meetings could be arranged quickly and simply. Patients who were well enough were therefore able to virtually see and speak with their loved ones at this critical time, but virtual visiting could not replace a visitor's physical presence for all patients, including those who were unconscious or unable to communicate in their last hours or days of life.
62. Outside of the pandemic period, in-person visitors can help provide a constant observational presence, which can be of assistance to clinical staff. The requirement to put on full PPE before entering a patient's room impacted how responsive staff were able to be, both in terms of speed of entry into a patient's room in an emergency situation and in terms of reducing the available time for staff to deliver face-to-face

care. Full PPE also created a physical barrier which impacted on the ability of staff to physically and emotionally engage with patients.

63. The experience of some of Marie Curie's medical staff, supported by the survey undertaken by the Association for Palliative Medicine and Marie Curie (referenced at paragraph 46 of this statement), was that in some cases, patients declined the offer of a hospice bed and ultimately died in another setting, such as their home rather than in a hospice with limited time with their loved ones. Some patients who died in Marie Curie hospices during this period did so with only a single loved one present.
64. The survey undertaken by the Association for Palliative Medicine and Marie Curie (referenced at paragraph 46 of this statement), showed that those working across specialist palliative care felt that Covid-19 also had an impact on some patients' willingness to engage with health services, with some patients delaying seeking care until they reached a crisis. Marie Curie staff working in our Community Nursing Service reported that in some cases early in the pandemic, patients under their care had had limited or no other interaction with any other health or social care provider since the government's call to "protect the NHS". Marie Curie's Community Nursing Service delivered fewer planned visits during 2020 and conversely saw a rise in rapid response visits, though overall community patient numbers increased. Our hospices had 20% fewer in-patient admissions during 2020 than in 2019, which, anecdotally, may have been partly caused by patient unwillingness to be admitted to an inpatient unit and be cut off from their loved ones due to social distancing and visiting restrictions.
65. Along with inpatient services, our hospices provide a range of day services, allowing patients to receive sessions of care and support before returning home the same day, and outpatient appointments. These services and appointments were curtailed as soon as the first lockdown was announced in March 2020, with only urgent cases being seen on an outpatient basis, and consultations being undertaken by phone or video where appropriate. Where patients did come into hospices for outpatient appointments, strict measures were put in place.
66. The restrictions in place in our hospices necessitated a vital shift of more of our palliative care services into community settings, supporting people in their homes and in care homes. In 2020 and 2021 the ONS data (2021 ***[MR/32 - INQ000349008]***: Tables 11a and 11b, field E6 / 2020 ***[MR/33 - INQ000349009]***: Table 11, field E11 / 2019 ***[MR/34 – INQ000349010]***: Table 10, fields E21 and F21 / 2018 ***[MR/35 - INQ000349011]***: Table 10, fields E9 and F9 / 2017 ***[MR/36 – INQ000349012]***: Table

9, fields F12 and F13 / 2016 ***[MR/37 – INQ000349013]***: Table 9, fields F12 and F13 / 2015 ***[MR/38 - INQ000349014]***: Table 9, fields F12 and F13) shows that more people died at home and in the community than compared to the previous five-year average. As already discussed, this shift to more community-based services was however impacted in the early stages of the pandemic by the availability of PPE (and throughout the pandemic by the staffing resource, as detailed below).

67. The restrictions on families visiting their dying relatives in their own homes meant that Marie Curie nursing staff were at times also providing essential nonclinical services such as shopping and psychosocial support. Our view was that this service was not only clearly beneficial to and valued by patients, but also protected the acute sector from the alternative, namely more hospital admissions. The social isolation experienced by many of our community patients was evident to many of our nursing staff, with some reporting that in some individual cases, Marie Curie staff were the only people those patients had seen since the first lockdown began.

Staffing

68. Marie Curie saw significant disruption due to staff shortages throughout the pandemic. These shortages were as a result of staff sickness, in addition to staff having to shield or self-isolate in line with government guidance, including those who had come into contact with someone who had tested positive (variable depending upon the guidelines in place at the time). In the relevant period, Marie Curie lost 17,124 days to sickness due to Covid-19, being an occurrence count (the number of absence periods, i.e. the number of incidences of covid) of 1,729. As we did not measure the percentage of working time lost, we cannot accurately say how the occurrence count reflects sickness absence as a percentage of working time lost. It should also be acknowledged that staff who were approaching the end of their careers were also lost during the pandemic due to a decision to cease working, with some staff reporting that delivering palliative and end-of-life care in full PPE was not how they wanted to deliver care, and others having concerns for their own health.

69. The 2021 Better End-of-life report (page 31) similarly found that across the UK hospice and palliative care services reported staff shortages during the pandemic – these were most common in Wales and London where 60% of responding services reported staff shortages. Shortages were associated with sickness, shielding, and self-isolation. In some instances staff were found to be redeployed from palliative care to other roles.

Within Marie Curie, any redeployment was within the organisation, for example to information and support services, rather than redeployment to the NHS.

70. In some cases, Marie Curie was able to innovate by re-deploying staff who were shielding, and use them to provide certain services using methods that did not require face-to-face contact. At the start of the pandemic, one of the London CCGs commissioned Marie Curie to provide an Advance Care Planning service to patients living in care homes. With many of the local workforce on sick leave due to Covid-19, Marie Curie provided this service virtually using staff situated in various locations all over the UK who were shielding in accordance with government guidance, but who were otherwise able to work, with some reporting a keen personal desire to work virtually, both in order to be part of the national response to Covid-19, and to combat the social isolation created by shielding. Some staff who were shielding were redeployed to our Information and Support service, to be part of the augmented clinical team contributing to this important component of Marie Curie's pandemic response.
71. In many cases Marie Curie's staff showed great bravery and commitment to our mission, putting our patients' interests first, at the expense of their own. Some staff who were routinely caring for patients in our hospices voluntarily chose to live apart from their own families in the early weeks of the pandemic, in the hope that this measure might reduce their chances of contracting Covid-19, which could then have spread to our patients.
72. Across the UK, the ONS data (ONS Deaths registered in England and Wales 2021, Table 1, fields B6 and B7 / NRS Weekly deaths, Scotland, 1974 to 2023, Table 2, fields AV4-AV56 and Aw4-AW56 / NISRA Monthly Deaths, Table 1, fields P16 and Q16) shows that over 1.36 million people died during 2020-2021 ***[MR/32 - INQ000349008]***. This left an estimated 6.8 million people bereaved; an additional 750,000 compared to what would have been expected based on the five-year average from 2015-2019 (ONS data (ONS Deaths registered in England and Wales, 2021, Table B8-B12 / NRS Weekly deaths, Scotland, 1974 to 2023, Table 2, fields AQ4-AQ56, AR4-AR56, AS4-AS56, AT4-AT56, AU4-AU56 / NISRA Monthly Deaths, Table 1, fields K16, L16, M16, N16, O16) ***[MR/33 - INQ000349009]***. Marie Curie found themselves providing more bereavement support than before, with Marie Curie launching a dedicated telephone Bereavement Support Service in 2020. Our bereavement services found themselves stretched beyond capacity due to additional demand, which was not met with additional resource from Government. Marie Curie's

work with the UK Commission on Bereavement, for example, found that 40% of bereaved people who wanted formal bereavement support did not receive any.

Testing

73. Staff absence was compounded by barriers in access to staff testing, caused by palliative and end-of-life care staff working for independent and charitable providers not being seen as 'frontline NHS' at the outset of the pandemic. Access to staff testing for Marie Curie staff varied from place to place. In areas where there were well-established relationships between Marie Curie staff and local NHS staff (for example such relationships were more common in geographical areas where Marie Curie's hospices are located), Marie Curie found it easier to access testing provided by the NHS. In areas where these relationships were less established, it was very challenging, and at times it was not possible for Marie Curie to access staff testing facilities run by the NHS. The individual in Marie Curie who led on testing reports that she struggled to identify the decision makers within the DHSC to escalate her concerns to regarding gaining access to testing. The geographical spread of our community services also impacted access to testing and resulted in staff attending testing sites a significant distance from their home location. This picture is in contrast to Northern Ireland where initial difficulties regarding staff access to testing were quickly resolved through communication with the Department of Health and following that as a general matter no difficulties were reported in staff being able to gain access to tests.

Funding

74. The pandemic had a significant impact on Marie Curie's fundraising. Whilst the NHS provides around a third of Marie Curie's total funding, as detailed at paragraph 6 above, the remainder of Marie Curie's funding, including all of the funding for our Information and Support Service and our research, policy and campaigning activities, comes from our retail shops and donations to the charity from the public and corporate sponsors. This fundraising was significantly curtailed by lockdowns and other public health restrictions. March is the month of our annual flagship 'Great Daffodil Appeal' fundraiser, which in previous years involved widespread face-to-face fundraising activity, and so had to be scaled back substantially in 2020, and then also in 2021, resulting in reduced fundraising income from the campaign.

75. As detailed in paragraph 35 above, in April 2020 HM Treasury allocated a package of £200 million in emergency support for the charitable hospice sector in England (with equivalent amounts made available in the devolved nations via the Barnett formula) to

ensure they remained open and continued providing services the NHS rely on them to supply, supporting the national response to the Covid-19 pandemic. A further £125 million of support for the sector in England was announced in November 2020 as part of the NHS Winter Plan. Marie Curie received £21.5 million in total across both of these schemes, covering all four nations. This funding was used by Marie Curie to sustain core services through the Covid-19 pandemic, as well as enabling us to increase the support provided to people in their own homes and provided much-needed stability throughout 2020 and into 2021. There had been a considerable collective effort by Hospice UK, Marie Curie, Sue Ryder and Together for Short Lives, to secure this funding which unlike the NHS had not been made automatically available despite the key roles we played in delivering crucial care and keeping patients out of NHS hospitals. The time required to secure this funding, and the monthly vulnerability of it, inevitably detracted from our ability to do even more to further support families and the UK strategic response. When I wrote to the Secretary of State for Health on 29 September 2020 to acknowledge the financial support provided to Marie Curie ***[MR/40 - INQ000349015]***, I raised the need to build stronger foundations for the future, including sustainability of critical services we deliver into integrated pathways, competing priorities when commissioning services, and how services should be commissioned. In a further letter dated 2 November 2020 ***[MR/41 – INQ000349016]***, I asked the Secretary of State for Health to to urgently investigate the provision of care for people dying at home during the pandemic, and to ensure that there is easy access to sufficient care to meet the needs of all those dying at home and their carers this winter, building on Marie Curie's briefing paper of June 2020 in which Marie Curie had made End of Life care recommendations for the winter ***[MR/42 - INQ000349017]***.

Palliative care provision within acute hospital settings

76. Marie Curie only delivered a limited amount of palliative care in acute hospital settings during the pandemic, for example in the form of our medical consultant team working extra shifts in hospitals in Liverpool, as described earlier in this statement. The transfer of patients between our hospices and acute hospital settings sometimes caused challenges for visitors, due to differences in visiting rules. As part of the emotional and practical support offered at end-of-life, Marie Curie staff were required to support patients and visitors to navigate these differing sets of rules, including offering

emotional support required in situations where patients and families became confused or distressed by the differences.

Areas of learning identified by Marie Curie in response to the pandemic, the impact on healthcare systems and how any lessons might apply in future

77. Marie Curie has made a number of formal submissions on the learning that it has identified from pandemic and the delivery of care. We made submissions to the Health and Social Care Committee Inquiry: Delivering Core NHS and Care Services during the Pandemic and Beyond in May 2020 ***[MR/43 - INQ000349018]***, provided a response to DCMS Committee inquiry: Impact of COVID-19 on charity sector in April 2020 ***[MR/44 – INQ000349019]***, and responded to House of Lords Select Committee Public Services Committee inquiry: Lessons from coronavirus in November 2020 ***[MR/45 - INQ000349020]***. We also contributed to the UK Commission on Bereavement Report: Bereavement is Everyone's Business (2022) ***[MR/46 - INQ000349021]***, and published Terminal illness and bereavement during the Covid-19 pandemic in Northern Ireland: Perspectives of those left behind and lessons for the future ***[MR/47 - INQ000349022]***. I draw on all five of those responses and publications, and the wider Marie Curie experience, as I have tried to share in this statement, in the following paragraphs when considering the question of learning in response to the pandemic.
78. Marie Curie encountered severe delays and difficulties in the following areas which impacted on our ability to deliver care and to respond to the challenges created by the pandemic. Better support in these areas would have significantly increased our capacity to care for more people, and allowed us to offer a greater level of support to the NHS. Without improvements in these areas, the issues we faced during the pandemic will be repeated in a future pandemic.

- Tardy recognition of hospice and palliative care services as "essential" or "front line"
- Not being given the same access as NHS bodies to government support at the outset of the pandemic in the following areas, despite delivering essential and NHS commissioned services throughout the pandemic period at increased scale:
    - Funding
    - PPE
    - Testing

- Vaccines

- Weak integration of systems of care between the NHS and charity sector service deliverers, with inadequate and at times confused communication channels to decision-makers within government agencies
- Fragile understanding in the pandemic of the immediate and lasting effects of poor end-of-life care, by which we mean that for people living with a terminal illness, experiencing poor end of life care can have significant impacts, from inadequate pain and symptom management to a loss of independence and a higher risk of unplanned and unnecessary admissions to hospital. For many, poor end of life care can mean that they do not die in the place of their choosing. This can cause significant distress to people at the end of life and mean that their death is unnecessarily stressful, painful or undignified. For family members and carers of people with a terminal illness, caring for somebody who is experiencing poor end of life care can also be distressing, from having to support a loved one who is in unnecessary pain or dealing with the impact of hospital admissions. Family and unpaid carers may also find they are providing more care themselves to make up for inadequate care from health and care services. Family members and carers of a person who has received poor end of life care may also be at a higher risk of complicated grief after their loved one dies; complicated grief refers to intense, long-lasting symptoms of grief, together with ongoing problems and difficulties in coping with life, which are either more severe than normal or last for a longer period of time.
- Inappropriate guidance and visiting restrictions for our hospice and community end-of-life settings
- Lack of recognition of the vital role played by volunteers.

79. The scale, and nature, of mortality experienced in 2020 should therefore not be understood as a one-off event, but as a 'window into the future' of what could become the 'new normal' in the coming decades. With this in mind, there are a number of key areas in which Marie Curie believes lessons must be learned to ensure that the highest quality care can be provided to all of those who need it in future.
80. Marie Curie's experience of the pandemic has highlighted both achievements and weaknesses in the UK's delivery of palliative and end-of-life care, and the need to prepare for greater demand for these services in future. As a result of the UK's ageing

population, by 2048 it is estimated that 147,000 more people will be dying with a palliative care need in the UK every year. The pandemic also saw care homes overtaking hospitals as the most common place to die in England & Wales, a shift that previously had not been projected to take place until 2040.

81. The pandemic has exposed systemic problems with the current model for delivering palliative and end-of-life care. During 2020 and 2021, palliative care and hospice services struggled to access essential supplies, including PPE, during the first months of the pandemic, and experienced similar challenges accessing vaccination and testing later on. Charitably funded services were particularly impacted as they are often considered outside of NHS supply chains, impacting upon the care received by patients. It is essential that palliative care services, whether predominantly within or outside of the NHS, are resourced appropriately to meet rising demand for these services in future.
82. There is a significant risk that the rising demand for services may see the current funding model for palliative care, which was put under considerable strain during the pandemic, unable to cope. Should this occur, it would be likely to increase existing inequalities in access to palliative care. Greater demand for care will also require a more sustainable and resilient funding model for the whole of the end-of-life sector, with a reduced reliance on voluntary income and a greater proportion of funding coming from statutory sources than at present.
83. Palliative and end-of-life care services played an essential front-line role during the Covid-19 pandemic, and palliative care must be considered an essential part of the response to future pandemics. End-of-life care services relieved distressing symptoms experienced by people with Covid-19, supported people with and without Covid-19 to remain in their homes, reduced pressures on acute hospital services, provided education and support to the wider health and social care sectors, and provided bereavement support to families. In many cases, these services rapidly innovated during the pandemic, shifting resources from inpatient to community settings to meet changing need. As I hope is clear from this statement, whilst the clinical care delivered to our patients was unchanged, there were some key important differences in the way that care was delivered during the pandemic, particularly when trying to deliver care in full PPE. PPE increased distance and created a barrier which hindered our delivery of a key element of our service, which is to provide emotional support and security at a frightening time, for people at their most vulnerable time of life. Human connection

was hampered by the use of PPE; emotional comfort not as effective, not being able to do some of the most basic things which underpin care, like holding the hands of our patients. It was also recognised that patients were experiencing increased isolation. For example, in our hospices, patients were often in a room on their own, were subject to restricted visiting (and sometimes no visits), and those patients who were Covid-positive were subject to an even more restrictive visiting regime. This physical isolation was significant to the wellbeing of our patients.

84. There was a sustained increase of deaths at home during the pandemic, and the proportion of home deaths has not yet fallen to the level it was at before the pandemic began. We know that home is the most commonly-expressed preference for place of death for people with a long-term illness, and it is possible that the experience of the pandemic may have permanently changed societal expectations around death and dying, including accelerating a shift towards more people dying at home. While the NHS Long Term Plan includes dying in the preferred place of death as a quality measure, without adequate care and support in the community dying at home may not be a positive experience. An integrated system-wide approach, including specialist palliative care, primary care and community nursing, and social care is required. Understanding workforce needs – and the education needs of this workforce – will be vital to delivering this approach, and collaborative models of care will be vital to enabling this collaborative approach to end-of-life care.
85. Deaths in care homes trebled during the first wave of the pandemic. In England, Scotland and Northern Ireland, care homes temporarily overtook hospitals as the most common place to die. While there has been significant attention paid to the experience in care homes during the pandemic, the focus has been predominantly on infection control. More attention should be given, and more research undertaken, on how to deliver palliative and end-of-life care in the future, both during future pandemics and outside of future pandemics as the UK's population ages.
86. The pandemic also saw more families and carers having to provide care, when professional care was unavailable in the community or at home. Carers and family members need to be supported so that they are equipped with the knowledge, information, skills and resources to care for those close to them, including knowing how to access health and social care services when needed.
87. The pandemic has had profound impacts on experiences of bereavement in the UK and the support needed by those who have been bereaved. People bereaved during

the pandemic are at greater risk of complicated grief, which can leave a long legacy of physical, psychological and economic consequences for individuals and for society. However, people are often unaware of bereavement support options, such services often lack capacity to meet the needs of everyone who may benefit from them, and where they exist they can be hard to access. Increased provision of bereavement services must be prioritised, and public information on bereavement support options improved.

88. Better data on dying, death and bereavement outcomes is essential to understanding and improving the quality of care provided across the UK. Too often, this data is either not collected or is limited in its scope; even basic comparable data on the place of death is not available in all UK nations. Integrated data systems that include information on palliative care delivered by both specialist and generalist providers in all settings, are essential.
89. There has not been any substantive and sustained improvement in the wider context in which Marie Curie operates since the pandemic. The issues I have identified above have not been rectified. In a future pandemic, these issues would arise again with no lesser negative impact.
90. Furthermore, with the number of people requiring palliative care set to increase significantly over the next 25-30 years, even without another pandemic, the UK will be faced with a significant shortage in end-of-life care, with the poorest in our society set to suffer the most. The government must take action to avert this impending and predictable crisis.

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

Dated: 24 November 2023