GSC0028

Written evidence submitted by Marie Curie

Marie Curie is the leader in end of life experience in the UK. We work hard to provide a better life for people living with a terminal illness and their families. We offer expert care across the UK in people's own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives.

Our free information and support services give expert care, guidance and support to families so they can have something that really matters to them – time to create special moments together.

We are the largest charitable funder of palliative and end of life care research in the UK and campaign inside and outside Parliament for the policy changes needed to deliver the best possible end of life experience for all.

Summary

1. The Covid-19 pandemic has had a devastating impact on fundraising both at Marie Curie and across the whole independent hospice sector. With 50% of the funding needed to deliver our community nursing services and 65% of our hospice funding coming from charitable donations, the pandemic had a significant impact on our income.

2. This reduction in income took place at the same time as an increase in demand for Marie Curie's palliative and end of life care services, due to the significant increase in deaths during Covid-19. Research published on 8 April from Marie Curie's Better End of Life programme demonstrates that this increased demand was experienced by palliative and end of life care services of all types and in all parts of the UK during Covid-19[1].
3. HM Treasury provided £200 million of emergency support for the hospice and end of life care sector in England in April 2020, with an additional £125 million made available in November as part of the NHS Winter Plan and proportionate sums made available in the devolved nations. This funding has allowed the sector to respond to the Covid-19 pandemic by increasing its services and provided much-needed stability throughout 2020-21.

[1] https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2021/better-end-of-life-research-report.pdf

4. The processes put in place to access funding, and reporting procedures, were however often complex and subject to change, with little clarity over why certain decisions were made. In addition, reporting requirements appear to have been designed without charities like Marie Curie, operating in all four nations of the UK, in mind. Nevertheless, Marie Curie was likely better placed to absorb the burden of these requirements than smaller providers and we are aware of some small charitable providers who experienced significant challenges accessing funding.

5. Funding has supported Marie Curie's caring services in our nine hospices across the UK and our community nursing services in all four nations. The emergency grant funding has been used to sustain core services as well as increase the support we are providing to people in their own homes, work in partnership to support other organisations and introduce a new national bereavement support service.

6. The emergency funding provided by the UK's governments has been very welcome as a short-term measure to address the impact of the crisis on the sector and has, in general, achieved its objective of supporting those charities providing frontline services to continue to support the NHS, patients and families during the pandemic.

7. However, it must be recognised that emergency grant funding to support the independent hospice and end of life care sector is not a long-term solution. Governments across the UK must review funding for palliative and end of life care services provided by the voluntary sector to ensure that support is both resilient and fit for the future.

8. In 20 years' time, there are expected to be 100,000 more people dying each year in the United Kingdom, and demand for palliative and end of life care is set to increase rapidly, as more people live for longer with multiple and complex conditions. New models for delivering palliative and end of life care in the community will be needed to reduce pressures on the NHS and ensure that people are supported to die at home if that is the place they have chosen. Larger numbers of family members and carers will require support through dying, death and bereavement.

9. There is a particular need for more focus on sustainable resourcing for the delivery of end of life care in community settings. An increased proportion of people are choosing to die at home – an ongoing trend which sharply increased during the pandemic, and it is crucial that people dying at home receive all of the care and support they need.

Impact of Covid-19 on Marie Curie services and fundraising

10. Marie Curie has been on the frontline of the Covid-19 pandemic. Our doctors, nurses and hospice staff have been providing care every day for hundreds of dying patients, some who are Covid-19 positive, in their own homes and in our hospices. We are providing vital support to the NHS by keeping these patients out of hospital and reducing pressure on acute and critical care capacity.

11. In the early stages of the pandemic our fundraising activity ground to a halt. For the first time, we were forced to cancel all public collections and events for our annual Great Daffodil Appeal – Marie Curie's flagship annual fundraising appeal – from 17 March. We estimate the impact of cancelling all events from this date was a lost £1 million in income. More widely, we were forced to close all our charity shops (over 160 shops throughout the UK), which generated c£1.5m per month in the prior financial year. We also had to stop all face-to-face donor recruitment activities and cancel fundraising events. We estimate that the gross impact (before taking account changes to plans and emergency support) of this disruption to our activity was to create an income shortfall of anywhere between 25-40%.

12. In the previous financial year before Covid-19 (2019-20) we invested £165.6 million in our core caring services, research into terminal illness, and campaigning for better end of life care. 50% of the funding needed to deliver our community nursing services and 65% of our hospice funding comes from charitable donations, while our research, campaigning and information and support services are entirely funded by charitable donations.

13. The significant drop in fundraising income necessitated a number of saving and efficiency measures including use of the Coronavirus Job Retention Scheme and taking measures to adjust other costs. At the same time, we were required to adapt many of our services over the course of the pandemic – for example, introducing visiting restrictions at our hospices and delivering some services remotely – while there were more demands on our services than before.

How well the Government's funding has been distributed

14. Working alongside independent hospices and Hospice UK, in the early stages of the pandemic Marie Curie called for the governments of the UK to step in and provide emergency funding for the sector, so we could continue to support dying people and their families and provide frontline care.

15. In April 2020 the Chancellor of the Exchequer announced a package of £200 million in emergency support for the independent hospice sector. A further £125 million of support was announced in November as part of the NHS Winter Plan. In total, Marie Curie's share of this support in England has been £12.2 million.

16. In the devolved nations, support was made available to the independent hospice sector via the devolved governments with funding provided via the UK Government in line with the Barnett formula. The total funding provided in each nation to date has been[2]:
    - Scotland: £27 million (Marie Curie share £3.8 million)
    - Wales: £9.3 million (Marie Curie share £1.5 million)

[2] NB: Marie Curie services in Scotland and Northern Ireland also accessed some additional funds through local Covid-19 funding pots in addition to the funding made available through the Barnett formula, which are included in the above totals.

- Northern Ireland: £8.4 million (Marie Curie share £3.2 million)

17. Overall, it has been difficult to accurately determine how effectively Government funding has been distributed as criteria for distribution were not clear and appear to have changed over time. However, the funding has provided much needed support to the independent hospice sector, which provided stability over the peaks of the pandemic.

18. Emergency funding has enabled the sector to respond to the Covid-19 pandemic by increasing capacity and service activity for the patients we care for at the end of life; in particular for people who are nearing the end of life in their own homes. In addition, the sector has been able to support other organisations through the Covid-19 pandemic and work in partnership with the care and community nursing sectors.

19. We consider that Government funding has represented value for money in the short term, both for the Government itself and for the independent hospice sector. However, this does not mean that the longer-term viability and financial stability of the sector has been assured. In 20 years' time, there are expected to be 100,000 more people dying each year in the United Kingdom, and demand for palliative and end of life care is set to increase rapidly, as more people live for longer with multiple and complex conditions. New models for delivering palliative and end of life care in the community will be needed to reduce pressures on the NHS and ensure that people are supported to die at home if that is the place they have chosen. Larger numbers of family members and carers will require support through dying, death and bereavement.

The experience of Marie Curie with accessing funding and application processes

20. As noted above, the processes put in place for accessing funding were often overly complicated and changed on several occasions. Administration was also initially burdensome with reporting required at times twice a day, seven days a week. This eventually dropped to once a day, seven days a week when the process was challenged.

21. It was not always clear how decisions around funding allocation had been taken or what the rationale for these decisions was. For example, there was initially a lack of clarity about how groups of patients were being defined and the weighting of funding applied to certain cohorts. Similarly, in the first funding round we received an initial assurance that funding would not be offset against additional fundraising, but this assurance subsequently changed – after Marie Curie had put significant effort into launching an Emergency Appeal.

22. These difficulties with process were particularly pronounced for Marie Curie as a national charity operating in all four nations of the UK. The grant rules were different in each nation, and the decision made by NHS England to align its capacity tracking with CQC registrations did not work effectively for Marie Curie as a national charity

operating in different parts of the country – this made the process overly complicated. It should be noted that NHS England did acknowledge this and did the best it could to accommodate when working with Marie Curie data and submissions, however the process was not optimal.

23. The process of capacity and activity reporting was reasonably straightforward in England using the NHS England capacity tracker – although as with the processes for accessing funding, did change over time. However, this process did not appear to be linked to the financial reporting required on a monthly basis and it was difficult to understand the relationship between the two sets of reporting.

24. The short-term nature of the funding mechanism also caused some issues. Determinations about how much funding individual providers should receive were made based upon income and expenditure over very short periods – monthly/quarterly – whereas our fundraising activity works over much longer-term horizons. Those who donated to Marie Curie's Emergency Appeal, or who donated through other mechanisms, do not expect their donations to be used in the same month/quarter it is donated, however these donations were netted off against our expenses for that period in order to determine our 'need' for grant funding.

25. It should be noted that Marie Curie's experience, as a large charity that operates across all four nations of the UK may not have been typical for either the charity sector or the independent hospice sector, where many providers are smaller charities.

What use Marie Curie has made of the funding we have received

26. Funding has supported Marie Curie's caring services in our nine hospices across the UK and our community nursing services in all four nations. The emergency grant funding has been used to sustain the core services we are commissioned to provide which, as outlined above, are normally reliant in part on fundraised income – both hospice and community-based services, including urgent rapid-response, planned multi-visit and overnight care, and fast-track pathway support out of hospital. A case study of this service adaptation is included below.

Case study: The Hospices of Birmingham and Solihull Service

Several hospices provide specialist palliative and end of life care to the diverse communities that populate the Birmingham and Solihull area, but prior to the pandemic each had different offers of support out of hours with no part of the area covered by a comprehensive out of hours specialist palliative care service. Each hospice also had its own referral pathway, creating confusion amongst professionals about how to make a referral.

Without a single point of access, patients struggled to know how to get support and often had to dial 999 to get help with distressing symptoms such as pain and breathlessness. This typically resulted in people being admitted to hospital because they could not obtain the care and support they needed in their home.

When in mid-March the number of cases began to peak, each individual hospice faced the prospect of being overwhelmed by the twin pressures of more patients coming their way at the same time as more of their staff were going off sick.

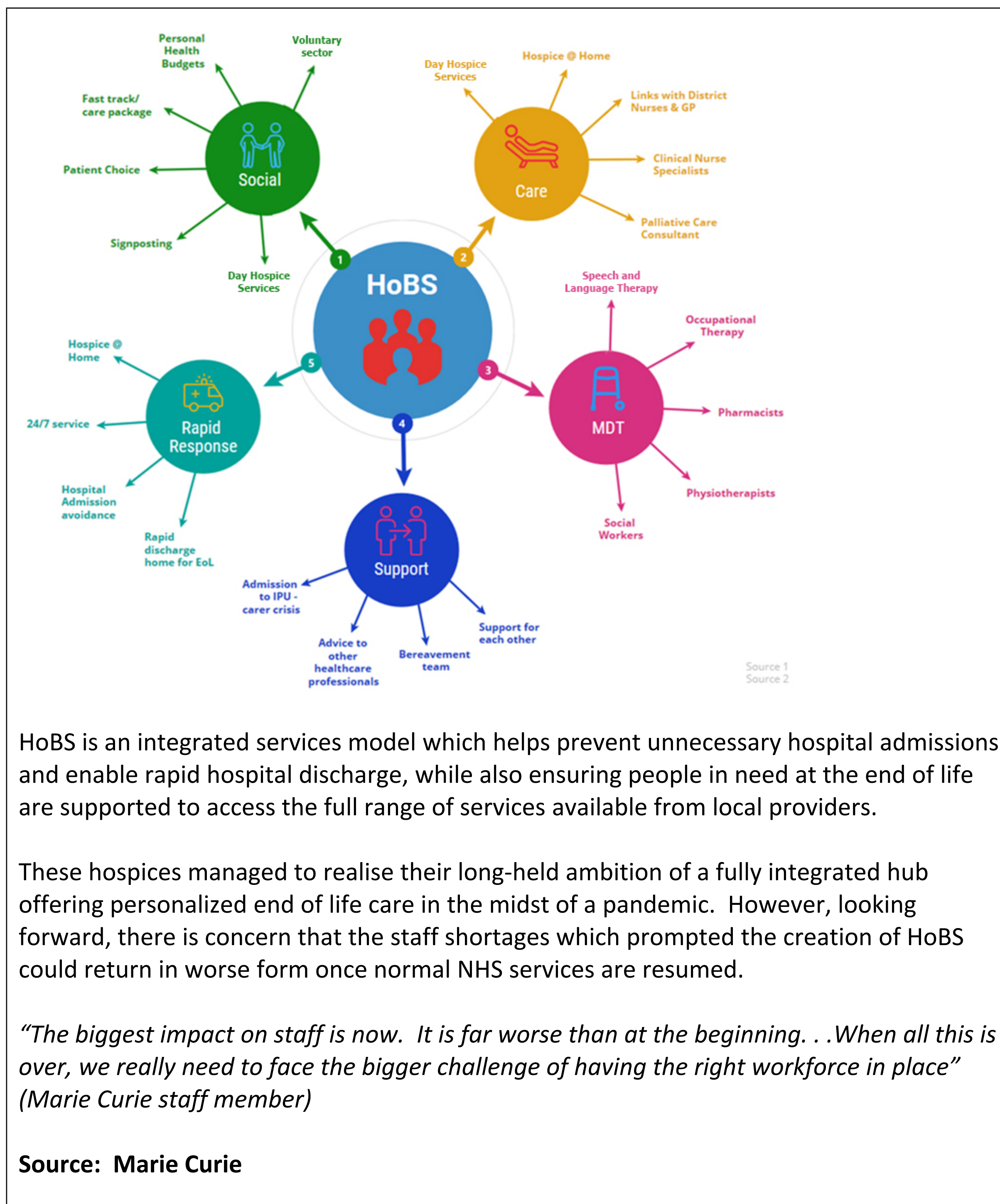
To respond to these challenges, a new model was developed out of informal conversations held during a leadership training course that took place the eve of the pandemic. These conversations built on long-standing and positive working relationships between local professionals.

Known as 'Hospices of Birmingham and Solihull' (HoBS) the new model amalgamated the staffing resources of the specialist palliative and end of life care sector in Birmingham and Solihull through the creation of a single point of access. Key partners included St Mary's Hospice, John Taylor Hospice, Marie Curie West Midlands, and Solihull Macmillan Team (University Hospital Birmingham Community).

Direct pathways were also set up to St Giles Hospice and Birmingham Community Healthcare Trust along with University Hospitals Birmingham, West Midlands Ambulance Service, Continuing Healthcare Team, District Nursing teams and other voluntary sector providers through Birmingham Voluntary Services Council.

Professionals wishing to make a referral for palliative and end of life care were provided with a single phone number to call, and they would then be connected immediately to the right service. Referrals could be made at any time of the day or night, with a specialist palliative care nurse always on hand to assist with emergency and complex cases.

The services available to a patient calling HoBS



HoBS is an integrated services model which helps prevent unnecessary hospital admissions and enable rapid hospital discharge, while also ensuring people in need at the end of life are supported to access the full range of services available from local providers.

These hospices managed to realise their long-held ambition of a fully integrated hub offering personalized end of life care in the midst of a pandemic. However, looking forward, there is concern that the staff shortages which prompted the creation of HoBS could return in worse form once normal NHS services are resumed.

"The biggest impact on staff is now. It is far worse than at the beginning. . .When all this is over, we really need to face the bigger challenge of having the right workforce in place" (Marie Curie staff member)

Source: Marie Curie

27. Funding has also enabled Marie Curie to provide additional support in people's homes and increase our capacity – in 2020-21 we provided 13% more activity supporting terminally ill people at home than in the previous financial year. This additional activity reflects the shift towards death at home during the pandemic; even outside pandemic peaks 40% more people died at home in Great Britain over the last year compared to the five-year average[3].

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[3] England and Wales data (ONS) and Scotland data (NR Scotland). Place data not available for NI. Figures based

28. Furthermore, financial support helped greatly with cash-flow in the early stages of the pandemic during the period of maximum disruption to Marie Curie's fundraising activity. In particular, this allowed us to meet the initially significant increased costs of PPE during the early stages of the pandemic – until mechanisms had been introduced for Marie Curie and other independent providers to obtain PPE in a coordinated way, we were having to pay inflated costs to obtain it from private sources.

Whether the Government has achieved its objective of supporting those charities most in need

29. The emergency funding provided by the UK's governments has been crucial as a short-term measure to address the impact of the crisis on the sector, allowing charities like us to continue supporting dying patients and their families throughout the pandemic. We believe that, in general, the grant funding made available by the Government did achieve its objective of supporting those charities providing frontline services to continue to support the NHS, patients and families during the pandemic.

30. The funding has helped to keep Marie Curie solvent and will continue to help us sustain our services into the 2021-22 financial year. However, Marie Curie's services remain highly dependent on charitable giving and we expect the fiscal environment will continue to be very challenging for at least the next 18-24 months.

31. The long-term impact of Covid-19 on Marie Curie and the independent hospice sector as a whole is not yet clear; fundraising income is not nearly back to the level it was pre-pandemic. Measures such as emergency funding and the Coronavirus Job Retention Scheme have helped stabilise the situation in the short-term, but these are temporary measures and over the long term they are not a substitute for a more sustainable funding model for delivering palliative and end of life care services.

32. Emergency grant funding to support the independent hospice and end of life care sector is not a long-term solution. Governments across the UK must review funding for palliative and end of life care services provided by the voluntary sector to ensure that support is both resilient and fit for the future.

33. With 100,000 more people expected to be dying each year by 2040, demand for palliative and end of life care will increase rapidly – this will require models for delivering palliative and end of life care in the community, and a more sustainable funding model for the sector, if everybody who needs palliative and end of life care in future is to have the best end of life experience.

34. There is a particular need for more focus on sustainable resourcing for the delivery of end of life care in community settings. An increased proportion of people are choosing to die at home – an ongoing trend which sharply increased during the pandemic – and it is crucial that people dying at home receive all of the care and support they need.

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on w/e 27 March 2020 to w/e 19 March 2021)

April 2021