

Written evidence submitted by the MS Society

Written submission to the Digital, Culture, Media and Sport Select Committee's call for evidence on impact of COVID-19 on DCMS sectors

- 1.1. Multiple Sclerosis (MS) is a chronic neurodegenerative condition for which there is currently no cure. In MS, the body's immune system attacks myelin, the protective cover around nerve fibres. Damage, which can occur anywhere in the central nervous system, interferes with messages travelling from the brain and spinal cord to other parts of the body. Symptoms are many and varies, but unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, fatigue and painful muscle spasms, among many other things. MS affects over 130,000 people in the UK, many of whom experience their first symptoms during the peak of their working lives, in their 20s and 30s.
- 1.2. The MS Society is the UK's largest charity for people living with MS. We're here for everyone living with MS – to provide practical help today, and the hope of a cure tomorrow. Our goal is to see a world free from the effects of MS and to reach this aim the MS Society is the largest charitable funder of MS research in the UK. We provide emotional wellbeing and financial support and information for people affected by MS, and campaign for positive changes to welfare, social care, access to medicines and health services, more generally. We want to be there for our community when they need us most, and cannot be if we do not get more support from the Government to make it through these times.
- 1.3. This submission sets out how the Government can act to provide specific support for medium sized charities like the MS Society so that we can continue to provide support to those living with MS across the UK and their families when they need it most. It also looks at the short and long term impact of coronavirus on charity funded medical research, including recommendations on how the Government can act now to safeguard essential research into treatments for conditions such as MS.

2. Impact of COVID-19 on medium sized UK charities

- 2.1. Disability and medical research charities like ours are facing significant and unprecedented challenges due to COVID-19, trying to meet the increasing needs of our communities and to ensure they aren't disproportionately affected for the long term.

- 2.2. The pandemic is affecting the mental and physical wellbeing of disabled people especially hard. The Office for National Statistics recently found that a higher proportion of disabled people than non-disabled people were worried about the effect of the coronavirus pandemic on their well-being (62.4% for disabled people compared with 49.6% of non-disabled people); their access to groceries, medication and essentials (44.9% compared with 21.9%); their access to health care and treatment for non-coronavirus-related issues (40.6% compared with 21.2%); and their health (20.2% compared with 7.3%) in May 2020.¹
- 2.3. This trend is borne out by our own research. The MS Society conducted a survey of 2,383 people with MS after the outbreak of COVID-19 in the UK (24 April – 11 May 2020)². When asked what information would be most helpful at the moment, 43% said they would like more information on how coronavirus relates to their MS, 26% said that they would like information on how to manage their health and MS during this period, and 21% said they would like information on how to stay physically active at home. In the same survey, only 36% of respondents felt supported, 35% said that they feel anxious and 10% feel scared as a result of the ongoing pandemic.
- 2.4. The figures show a clear need for additional support for our community. This will continue to be the case. While we are moving past the peak of the pandemic and lockdown restrictions are easing for lots of the country, many people with MS are still shielding and there is concern in the community that these groups will simply be “left behind”. We are working tirelessly and with less money and fewer staff to put in place a whole range of new digital service to replace those we can no longer deliver face-to-face and make sure no one feels alone. Reflecting this increased demand, between 12 March and 15 June 2020, our COVID-19 related webpages received on average 6,100 unique daily views.
- 2.5. The charity sector provides support across these areas that not only provide huge benefit to many vulnerable people but also alleviate pressure on public services. For example:
 - 2.5.1. Providing clear and detailed information on how people should interpret Government guidelines in specific circumstances. For example, we recently spoke with a nurse who estimated that clear information provided by the MS Society on the coronavirus risks of

¹ Office for National Statistics, Coronavirus and the social impacts on disabled people in Great Britain: May 2020, 11 June 2020, <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/may2020#changes-to-disabled-peoples-well-being-during-the-coronavirus-pandemic>

² The MS Society and the UK MS Register surveyed 2387 people with MS between 24/04/20 and 11/05/20. The survey was only able to be completed online on the UK MS Register. The study was promoted via MS Society social media and direct mail, UK MS register direct mail and via professional contacts. (unpublished)

different immunosuppressive drugs and on social distancing advice, combined with the operation of our helpline, reduced calls to the NHS by 50% amongst people with MS.

- 2.5.2. Using existing networks to identify and support vulnerable people. Many charities maintain a network of local support across the UK (the MS Society has 270 local groups) and therefore have much richer qualitative information about people who are struggling with staying at home and self-isolating. This is proving a vital lifeline, especially for people that have low digital access and so are less able to engage with official websites on support.
 - 2.5.3. New digital tools to support people and help maintain social contact. Having existing networks gives charities a huge head start in engaging people in new forms of interaction that help them maintain quality of life
 - 2.5.4. Providing intelligence to the Government. Through engagement with its communities (helpline calls, webinars, social media) the charity sector is generating a huge amount of intelligence about the lived experience of vulnerable people and is able to feed that back to Government. Since the start of the pandemic, the charity sector has been supporting the Department for Environment, Food and Rural Affairs to help ensure that vulnerable people are able to access deliveries of food and essential items. This includes providing advice to the Government on how best to reach and communicate with these groups, to communicating directly the options available to people in our communities.
- 2.6. What has been clear since the start of the pandemic is that our community needs our support now more than ever. However, as a result of COVID-19, the MS Society is facing a drop in income of close to a third (~£10 million) as hundreds of planned individual and major fundraising events, like the London and Berlin Marathons can no longer take place. This is being felt across the sector. A recent survey has found that 84% of charities report a decrease or significant decrease in their total income during lockdown, resulting in the sector facing a £12.4 billion loss of income as a result of the pandemic.³

Stuart, living with MS and a helpline volunteer, told us about the important service that the MS Society is providing throughout the pandemic:

"Being able to take a call where someone can be in bits at the start of a call, or not in a good place at all, and by the end of a call see that they are sometimes laughing, or you can just hear in their voice they are in a better place, that's what it's about. Just using my experience to talk to people."

³ Joint report carried out by the Institute of Fundraising, Charity Finance Group and the National Council for Voluntary Organisations (between 23 March – 12 May)

3. How effectively has the support provided by DCMS, other Government departments and arms-length bodies addressed the sector's needs?

- 3.1. Despite this predicted loss, the MS Society hasn't received any support from the Treasury's £750 million funding package for charities. This funding was largely made available for smaller and larger charities. Unfortunately, this has meant medium sized charities like the MS Society, particularly those supporting people with rarer conditions and disabilities, have not received support.
- 3.2. While we were pleased to see many important charities get a financial lifeline, the way it was allocated reflected an incomplete understanding of the charity sector and the value added by its different constituencies. Much of the important work in the sector comes from medium-sized charities focussed on a specific condition. These charities:
 - 3.2.1. Are the trusted source of information for people with a given condition, serving as a first port of call and answering a huge range of queries that would otherwise fall to the NHS and could not be dealt with by generic charities (it would not be realistic to expect Citizen's Advice to answer a question about how an MS drug interacts with COVID-19 infection, for example)
 - 3.2.2. Have deep links with some of the most vulnerable and hard to reach, groups in the country (some of whom will have low digital access). Charities are ideally positioned to support those who otherwise may not have heard what was available. These networks are the results of decades of community-level work and, through no fault of their own, simply cannot be replicated by monolithic public services.
 - 3.2.3. This same network allows condition-specific charities to put people in touch on a manageable scale that is united around a common cause (the condition), but large enough to create a critical mass where everyone can find something for them - a combination that may be less realistic with both very large charities and small grassroots organisations.
- 3.3. Smaller and larger charities have a vital role to play in the response to the pandemic and in civil society more broadly. However, the Government's existing funding package is not only inadequate overall, it has been allocated in an imbalanced way. There is a clear opportunity for a further tranche of funding focussed on medium-sized condition-specific charities that were not eligible for the first tranche, thereby redressing the imbalance and making the overall support to the sector more nearly proportionate to the huge losses it is seeing.
- 3.4. Without such support, difficult decisions need to be made in order to secure the future of the organisation. We have had to take advantage

of the Government's Job Retention Scheme but this has meant that our impact has suffered in key areas. Yet even after doing so, some of our highly valued services, such as financial support grants designed to help those living with MS, have had to be paused in favour of cheaper forms of indirect support.

- 3.5. In spite of doing everything possible to maintain our impact and balance our finances and in the face of such a massive drop in income we are likely to have to restructure the charity around a narrower scope. This will be very difficult not just for our staff and will have an inevitable impact for our community in terms of the services that give them help, the research that gives them hope and the campaigning that gives them a voice.

Recommendations:

To provide the vital support medium sized charities need to get through this crisis the Government should:

- Provide further funding for charities supporting people with a long-term conditions to provide some of the key services that will be required in a "long tail" pandemic, such as condition-specific information and digital services to keep active and keep in touch
- Allow charity staff who are on furlough leave to volunteer for the charity they work or to allow them to continue help meet the increased demand on our services

4. Impact of COVID-19 on medical research charities

- 4.1. Medical research charities are an essential part of the UK's world-leading life sciences sector but have been affected severely by COVID-19. According to the UK Research and Innovation Annual Report⁴, the collective spend of 149 members of the Association of Medical Research Charities (AMRC) in medical research in the UK in 2019 stood at £1.9 billion, representing over half of all public spend on medical research.
- 4.2. Between March and May 2020, AMRC charities reported a loss of 38% in fundraising income when compared to the same period last year. As a result, AMRC members are planning for an average 41% decrease in their research spend in FY 2020/2021, resulting in a projected reduction in UK medical research investment of between £252 and £368 million.⁵ More than two thirds of AMRC members are deferring upcoming grant rounds and withdrawing future funding.

⁴ UK Research and Innovation, Annual Report and Accounts, 2018,-2019

⁵Association of Medical Research Charities, COVID-19: The risk to AMRC Charities (10th June), <https://www.amrc.org.uk/covid-19-the-risk-to-amrc-charities>

- 4.3. The short-term economic impact of COVID-19 will have longer term consequences on research and development and the continuity of charity-funded medical research now and in the future.
- 4.4. As a medical research charity, we spend between £5 – 6 million of our annual income on MS research every year. As well as fundraising further for innovative ring-fenced research projects within our £100 million Stop MS Appeal. COVID-19 has meant we have had to make quick decisions about the research we fund, including cancelling our 2020 grant round and postponing other research in order for us to survive through this year and continue supporting our community.
- 4.5. Clinical trials and studies we fund have had to be paused or stopped with over 70% of our university research programmes reporting to us a significant disruption in their ability to continue with their vital research. People with MS now face significant delays to the pipeline of innovative new treatments reaching the NHS and for many this could mean an increase in disability progression while they wait.
- 4.6. The delay in treatments reaching people with MS will be due to the need for costed extensions to university research programmes; the costs attached to dismantling and restarting clinical trials and studies, and us having no choice but to postpone or cancel future research grant rounds and planned new programmes. As it stands, there's a real threat these will be unaffordable to restart once the crisis is over.
- 4.7. The gap in research funding we are faced with and delay to trials, studies and programmes, puts the MS research sector at risk. Every month essential research is put on hold is another month the treatment pipeline is delayed. If clinical trials are interrupted for so long they cannot continue as planned it could take us more time still to get back to where we started. Many people will sadly see their condition get worse and their disability advance as the development of new treatments are stopped or delayed. It leaves people with MS behind, and it will undoubtedly add pressure to already stretched social care services and the welfare system.

Recommendation:

- We desperately need the Government to provide emergency funding to ensure the continuity of charity-funded research now and in the future. This will allow research to restart and continue when the NHS and the country is ready, ensuring the UK research ecosystem is maintained and patients benefit from charity funded research.
- The Government should support AMRC calls for a [Life Sciences-Charity Partnership Fund](#). The proposal sets out a co-investment scheme that provides a level of match funding from Government for future charity research over the next three years. AMRC is asking for at least £310

million from Government in the financial year 2020/21 to bridge the sector's projected research spend gap. This would be matched by funding from charities to maintain consistent research investment.

5. How might the sector evolve after COVID-19, and how can DCMS support such innovation to deal with future challenges?

- 5.1. Digital-first approaches can overcome not just geographic barriers but also those between different silos of thinking or focus. We think there is a real opportunity for the Department to enable more partnerships between the charity, public and private sectors. For example, charity physical activity services could be integrated into an NHS pathway for care of that condition.
- 5.2. Crucially however, charities usually need to be commissioned to provide these services at a scale that allows them to plan and grow operations. Too often charity services are seen as a free and unlimited resource, or receive contracts short-term contracts that require major upfront investment to honour, but are then not renewed. A more strategic approach to planning and a dedicated fund to pilot new approaches would both be very helpful initiatives from DCMS.
- 5.3. There are also policies that the Government could implement that would make the fundraising environment easier for charities. One simple but effective idea would be an information campaign for the public on the role that charities have played in the pandemic and why it is so important to continue supporting them.
- 5.4. To give another example, many charities receive a significant portion of their income from generous legacies left to them when a person dies. Very often the majority of someone's estate is housing wealth and so a legacy cannot be passed on until the house is sold. Wider measures to stimulate the housing market (for example a stamp duty holiday) would therefore have a knock-on benefit for charity fundraising.
- 5.5. Finally, if social distancing measures continue to make face-to-face events impossible, the Department could support a digital infrastructure that makes large scale virtual fundraising events possible. It would not be possible for a single charity to coordinate a "virtual London marathon" on the scale of the traditional one. But if there was a core infrastructure for a virtual marathon then charities could fundraise on the back of it and personalise the content.