

## Written evidence submitted by MS Society

### Introduction/Summary

- 1.1. Multiple Sclerosis (MS) is a chronic neurodegenerative condition for which there is currently no cure. 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. The MS Society welcomes the important short term support provided by the Government through its Job Retention Scheme, which has given us the flexibility to think more strategically about the future of the organisations without incurring significant immediate job losses. While there was challenges with the way changes to the scheme was communicated, and we are left with concerns over our long term financial position as the scheme draws to a close, support afforded through the scheme has saved jobs and allowed us to plan more strategically for some of the difficult months ahead.
- 1.4. 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.<sup>1</sup>
- 1.5. This financial gap will exist for as long as some form of social distancing remains. With support from the Job Retention Scheme winding down, this submission sets out why it is essential that the

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<sup>1</sup> Joint report carried out by the Institute of Fundraising, Charity Finance Group and the National Council for Voluntary Organisations (between 23 March – 12 May)

Government acts now to provide additional financial support for the following groups:

- **Medium sized charities** – that support people with a long-term conditions. These organisations will provide essential key services that will be required a “long tail” pandemic, such as condition-specific information and digital services to keep active and keep in touch; and
- **Charity funding medical research charities** – If the Government is serious about retaining the UK’s standing as a global lead in the life sciences, it is essential that it recognises the importance of charity-funded research now and in the future. Emergency funding 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.

1.6. Furthermore, as lockdown measures are eased, restarting the economy in a fair way involves providing proper levels of support so that employees who are clinically extremely vulnerable to COVID-19 have the confidence to return to work safely. This should include:

- Ensuring that employers have the information and resources to make necessary adjustments to ensure workplaces are COVID-secure; and
- Fair remuneration to clinically vulnerable employees who are unable to safely return to their workplace, such as retaining ongoing access to the Job Retention Scheme, until they are no longer at high risk. This is essential to avoid the impossible choice between health risk and their financial security.

## **Job Protection Scheme and Self-employment Income Support Scheme**

### **2. How effective have these schemes been in maintaining employment and reducing job losses?**

- 2.1. The Job Retention Scheme has been very welcome, giving us the short term security needed to survive this period without incurring immediate job losses. However, even after taking advantage of the scheme, 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.
- 2.2. Despite lockdown being eased over recent weeks, as long as some form of social distancing exists we will continue to lose expected

income as fundraising events which depend on mass gatherings are delayed or cancelled. Unlike many other sectors, we are therefore expecting to lose income as long as COVID-19 remains in circulation or until a vaccine is found, and as a result are projecting for losses into the year 2022.

- 2.3. This long term uncertainty, coupled with the gradual winding down of the Job Retention Scheme, will only delay some of the more severe measures we'll have to take in the medium to long term. 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.
- 2.4. We therefore need the Government to address the significant medium and long term funding gap that the sector faces. Examples of specific support required is listed below.

### **3. Has the Government struck the right balance between targeting support and making it easy to access?**

- 3.1. The Job Retention Scheme is generous and allowed us the short term flexibility to furlough staff. However, there has been some practical challenges with its implementation, which made it more difficult for some employers to access than it needed to be. Information about the scheme were communicated disparately, with employers learning first of key changes through televised announcements and having to wait for a considerable amount of time for detailed guidance explaining those announcements. In many cases, guidance was contradictory and late, meaning that it was difficult to meet deadlines.
- 3.2. This was a challenge for a medium sized employer with a dedicated HR team in place. The scheme must have been even harder for small employers with little access to HR or legal counsel. In future, we would recommend that detailed operational guidance must be published at the same time as any announcements relating to changes to schemes such as this.

### **4. Where has Government support been too generous and where has it not been generous enough?**

- 4.1. The only significant support that we have been able to access is through the Job Retention Scheme. For the reasons outlined above, this is welcome, however does not mitigate against the long term challenges arising as a result of us not being able to fundraise.

Responses to the following questions identify where the Government needs to provide additional support.

## **5. Should the Government intervene more actively in terms of state-aid, bail-outs and its industrial strategy?**

- 5.1. 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. However, the Government's £750 million funding package for frontline charities has been inadequate and allocated in an imbalanced way, with many key charities like ours unable to access. There is a clear and pressing need for targeted investment for these groups.

### **Support for medical research charities**

- 5.2. 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. Medical research charities are a vital part of the UK's diverse research base. In 2019, Association of Medical Research Charities (AMRC) members funded half of publicly funded medical research nationally by collectively investing £1.9 billion in UK research and development. Furthermore, charities invest in the UK's skills pipeline and have made long term investments in research capacity and capability. In 2019, 17,000 researcher salaries were funded by AMRC members, including 1750 PhD students<sup>2</sup>.
- 5.3. The medical research sector has been severely affected by the pandemic. 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.<sup>3</sup> More than two thirds of AMRC members are deferring upcoming grant rounds and withdrawing future funding.
- 5.4. In first phase of the pandemic, 70% of clinical trials and studies funded by AMRC charities were stopped, paused or delayed. This meant thousands of patients were unable to participate in life-changing research. As lockdown restrictions lift, AMRC predict that we will start to see trials and studies resume but some may never restart, their progress stalled by research funding cuts.

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<sup>2</sup> AMRC, Life Sciences Charity Partnership Fund, A proposal from the Association of Medical Research Charities, 3 June, <https://www.amrc.org.uk/Handlers/Download.ashx?IDMF=95406ac4-721e-4f52-bba2-2953b6dc36e4>

<sup>3</sup>Association of Medical Research Charities, COVID-19: The risk to AMRC Charities (10<sup>th</sup> June), <https://www.amrc.org.uk/covid-19-the-risk-to-amrc-charities>

- 5.5. As a medical research charity, the MS Society spends 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. 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.
- 5.6. 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.
- 5.7. 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.
- 5.8. If the Government is serious about retaining the UK's standing as a global lead in the life sciences, it is essential that it recognises the importance of charity-funded research now and in the future. Emergency funding 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.

### **Recommendation**

- 5.9. 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.

### **Support for medium sized charities**

- 5.10. 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.<sup>4</sup>
- 5.11. 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)<sup>5</sup>. 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.
- 5.12. The figures show a clear need for additional support for our community. This will continue to be the case. As we move 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.
- 5.13. 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:
- Are the trusted source of information for people with a given condition, serving as a first port of call and answering a huge range

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<sup>4</sup> 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>

<sup>5</sup> 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)

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)

- 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.
- 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.

5.14. 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 £750 million 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, to redress the imbalance and making the overall support to the sector more proportionate to the huge losses it is seeing.

### **Recommendations:**

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

- 5.15. Provide further funding for medium sized 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; and
- 5.16. 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

## **6. How and when should the Government's support packages be wound up?**

- 6.1. For the reasons outlined above, the financial gap for charities will exist for as long as some form of social distancing exists. This means that we will need some form of long term support once the Job Retention Scheme is closed and as long as social distancing remains. Without long term support to fill this funding gap, we will struggle to provide

the essential support to our communities at a time when they need it most, and continue to fund future research and development into cures and treatments for MS.

## **7. What actions does the Government need to undertake to pursue to support a successful exit strategy?**

- 7.1. A successful exit strategy must carefully balance the reopening of the economy with the health needs of those deemed “clinically extremely vulnerable” to COVID-19. Steps must be taken to ensure proper levels of employment support to those groups to ensure that vulnerable people are not forced to choose between financial security over health and safety. This will include measures that ensure vulnerable people do not have to return to work if it is not safe for them to do so.
- 7.2. Many people in these groups are worried and are unsafe at work. This is due to a lack of awareness of the current employment guidance and inadequate workplace protections. The scale of concern among those in the clinically vulnerable group is significant and increasing as more are expected to return to work, particularly those in lower income jobs, without the necessary consideration and protections in place.
- 7.3. There is clear evidence that employers do not have adequate tools to assess and consider the risk to clinically vulnerable staff and what is an adequate level of risk to take. Many employers are not sharing assessments and engaging with vulnerable staff in these processes and communicating the results.
- 7.4. As part of any successful exit strategy, it is essential that protections are adequate for those in the clinically vulnerable group, ensuring their safety comes first. It must also ensure financial support remains for those people so that they are not forced to choose financial security over the health and safety.

### **Recommendations:**

- 7.5. Clinically extremely vulnerable employees who are unable to be safe in the workplace, either through socially distancing or being given alternative roles, should be fairly remunerated. As part of this the Government should consider allowing these individuals to retain ongoing access to the Job Retention Scheme until they are no longer at risk or their employers have made necessary changes to ensure their workplaces are COVID-secure. This is essential to avoid people choosing financial security over their health.
- 7.6. The Government must produce clearer employment guidance and risk assessment tools, based on up to date risk evidence, specifically dealing with the issues of clinically vulnerable staff. This should include enabling employers to understand and deliver on their legal obligations to offer reasonable adjustments to support disabled people to remain in work.



- 7.7. Extremely vulnerable employees must be supported to stop work immediately if safety guidelines are not followed by their employer. More must be done to help people assert their legal rights, quickly, easily and cheaply/without a negative financial impact.
- 7.8. In the event of increased COVID-19 transmission rates, vulnerable people should get prioritised access to financial support so that they are able to shield immediately.
- 7.9. Government should conduct a transport review to ensure that those individuals at a higher risk from COVID-19 are able to safely go to work.

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