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Update on Equality, Diversity & Inclusion

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Purpose/Summary
The Board is asked to **note** progress on improving equality, diversity and inclusion over 2018, as well as key plans to build on this over 2019. It is asked to **decide** whether it is content to publish a summary of progress on Board and leadership diversity and also **decide** whether it would support a Trustee sponsor for the EDI programme.

Previous Board discussions
The Board approved an Equality Diversity and Inclusion strategy for 2018-21 in December 2017 (BD.2017.12.07.11). The strategy included a set of specific actions for 2018 and committed to updating the board on progress against these.

Details
1 Vision for EDI
1.1 As part of the corporate strategy, the Board endorsed the following overall vision for equality, diversity & inclusion at the MS Society:

Our vision is to ensure that we have a fully integrated and embedded approach to equality, diversity and inclusion (EDI) in what we do; and that we demonstrate that we understand and value difference.

We will work together toward this by taking an ambitious approach and integrating EDI into a whole range of our activities.

We will highlight the contribution that EDI can make in meeting the needs of the people we support, through our staff, volunteers, partners, friends and contacts, based on common goals, behaviours and our values.

2 Progress over 2018 and plans going forward

2.1 Overall, we have completed most of our objectives for 2018 and this has led to good progress towards our vision for EDI. In some cases (such as evidence and information-gathering) we have completed the specific actions we set out to, but identified further work to fully realise the impact intended. In other areas (such as local support and staff inclusion and diversity) staffing shortages and a wide range of competing priorities have delayed progress on specific actions.

2.2 As part of our new governance arrangements, we established a Equality, Diversity and Inclusion Reference Group of staff and people affected by MS, to advise on strategy and increase our accountability. The Group has agreed a collective comment on 2018 progress as set out at **Appendix 1**.

2.3 As part of our 2019-21 business planning we agreed a cross-organisational EDI plan to build on progress to date. A full update against each 2018 action is included at **Appendix 2** and the 2019-21 business plan is available on request.

2.4 We have set out key milestones achieved in 2018 and key plans for 2019 in the below table, to show how we envision future plans building on progress to date.

	2018	**2019**
Internal-facing	We have established a **governance structure,** centred around a senior-level working group, to oversee progress on EDI and agreed a **detailed vision for EDI** with staff and people affected by MS (available on request). The Board agreed 2018 objectives for **Board, Council and senior leadership diversity** against which it will report. The Board has also agreed EDI-related expectations for the composition of the Board and Councils. We have trialled new staff **recruitment practices** to improve diversity. We have published our **gender pay gap** results and are working on staff development plans that will respond to the remaining gap. Expectations around EDI were reflected in 2019-21 **business plans** and in separate strategic segmentation work. Initial **integrated communications spike** in December around disability rights.	Putting in place a **more empowered structure** that involves junior staff more extensively in the programme Developing a new **training programme** focused on practical application of EDI principles for all staff (with specific leadership training). Putting in place a new **talent and succession planning strategy** to improve proportional representation of staff in senior roles. **Guaranteed interview scheme** for qualified candidates from under-represented backgrounds, as well as other changes to recruitment. Putting EDI at the heart of new **corporate strategy** and **Project Orange** programme. Further **integrated communications** to increase the profile of EDI, and comfort in engaging with EDI concepts, amongst internal staff, volunteers and the wider MS Community.

External-facing	An initial landscape **review of evidence** has been completed along with a MS Register analysis around EDI in the MS community. These findings have fed a further in-depth research project to report in early 2019.	Dedicated **outreach and support programme** to under-represented groups in the MS community, building on primary research on experiences of and barriers to engagement with external services and the MS Society.
	In June 2018 the Board approved a revised **policy development process** to better reflect EDI (BD.2018.06. 97.04), which is now operational.	Guidance and e-learning on **inclusive volunteer recruitment** rolled out and **new volunteer survey** to better capture EDI and potential for further improving recruitment.
	We have started collecting data to better **understand the reach of our local groups**, as well as providing **EDI good practice** for groups.	Continue to provide **guidance to local groups** on good practice and inclusive approaches that could be replicated.
	We have developed a **standardised data collection** for equalities information for staff and volunteers.	**Standardised monitoring of reach** to different communities of our website, information, events, and other activities.
	We undertook a range of **external engagement** to understand other organisations' approach to EDI.	Using new evidence to **explore opportunities for strategic collaboration** with other organisations (both on funding and improving impact).

3 Governance and next steps

3.1 One of our commitments in the EDI strategy was for the Board to publish an annual description of what it has done to address its own and senior leadership diversity and its performance against its own objectives. Subject to comments on progress, we propose to publish a short summary of this (see the first part of Appendix 2) – which has been agreed through the Governance Committee (see agenda item 23) within a general summary of overall progress (Appendix 6), as part of our 2018 Annual Report.

3.2 The Board may also wish to consider a formal sponsor for the EDI programme at Trustee level. The sponsor role could involve one or more of the following:
   a) taking a lead for the Board, beyond annual reviews, in providing assurance on progress against its own agreed plans;
   b) taking responsibility for ensuring that, in the Board's wider work, the EDI perspective is considered where appropriate; and
   c) providing visible leadership within the MS Community, for example through blogs or the occasional personal appearance, as an ambassador for our EDI focus.

3.3 Such an approach could have benefits in terms of increased assurance or visibility of the programme, but this should be balanced against the risk of implying that EDI is only the responsibility of the Sponsor, rather than of all Trustees and of the Board collectively. Were the Board to be supportive of the principle of a sponsor, which is a judgement for the Board to make, appointment could be further explored by the Chair or through the Governance Committee.

4   Conclusion and recommendations

4.1   The Board is asked to **note** progress on 2018 objectives and plans to build on this over 2019 and to **decide** whether it is content for a progress report to be published as part of our 2018 Annual Report.

4.2   The Board is asked to **decide** whether or not it supports a Trustee sponsor for EDI and, if so, on which potential elements described at 3.2 the role would be focused.

Appendix 1

EDI Reference Group statement on 2018 progress

Commenting on progress across the EDI programme over 2018 (including the detailed progress report at **Appendix 2**), the EDI Reference Group has agreed the following collective comment.

We recognise great progress throughout 2018, with positive steps taken in a number of important areas on our EDI journey. If we continue making improvements at this pace, we will be on a trajectory towards becoming a more inclusive and representative workplace. Whilst there is still distance to go in achieving our EDI vision, we believe work in 2018 has set a strong foundation for further progress in 2019 and beyond.

The Reference Group recognises that more staff time will need to be prioritised in order to ensure that momentum continues and builds from its current foundation, and to support the embedding of EDI into all that we do, so that it isn't considered an 'added extra'. Resolving current issues around staff and volunteer engagement and consultation will be vital to creating positive EDI outcomes, and there is a particular need to achieve more volunteer involvement in the development of EDI within the organisation and for the communities it serves. We also want to see the MS Society learning from other organisations who do EDI well and embedding this learning, so that we stay ahead of the curve in adapting positive EDI workplace policies and embedding EDI into our organisational culture.

The EDI Reference Group looks forward to supporting the Strategy Group and the wider organisation in 2019 in this important programme of work.

Appendix 2

Progress report against specific 2018 actions

Embed EDI into our leadership, policies, systems, processes and governance	
Take steps to ensure our Board, Councils and senior leadership is more diverse.	In the 2018 recruitment round for the Board we stated EDI as a priority for Board recruitment, carried out an assessment of the composition of Councils and used that to inform emphases within advertising and, for both Board and Councils, used a wide range of advertising to broaden those who were aware of this recruitment. In relation to the Board we prioritised improvement of BAME representation through targeted co-option at the start of 2018 and have also improved BAME representation within the England National Council. See "Increase the diversity of staff and volunteers" section below for further details on steps to ensure senior leadership is more diverse.
The board will agree specific diversity objectives.	The Board considered principles in June 2018 and was supportive of the idea that the correct population against which to identify ourselves for comparison purposes was (a) society as a whole (not the MS Society or the MS community) in relation to the Board but (b) for councils might be more about the MS community. The Board then agreed specific objectives for Board, council and senior leadership and the Board has also agreed specific targets around composition of Board and National Councils. It stated that the purpose should be linked to the concept of accessing the best individuals.
Publish an annual description of what it has done to address the diversity of the board and the charity's leadership and its performance against its diversity objectives.	We plan to publish a short summary of this, alongside a general summary of overall progress on EDI, as part of our 2018 Annual Report.

Increase the diversity of staff and volunteers at all levels in the organisation and ensure they have great learning and that we improve our culture (so that irrespective of diversity traits, our people feel valued and respected)	
Ensure that our employment policies and approaches reflect hidden disabilities.	Our review confirmed that our current policies and recruitment practices are based on best practice and compares well with the sector. This particular objective builds on those and is our longer term aim and will be reflected in the work we do to improve our recruitment practices.
Use diverse methods of recruitment to ensure that we target underrepresented groups effectively.	We have used a number of devices to ensure that we practice this in recruitment including co-option to the Board, targeting agencies to provide a broad range of candidates and targeting particular job sites and publications. However it is too early to comment on the success of these measures overall.
Establish a succession and talent planning approach, ensuring inclusivity & diversity	Due to changes in senior positons and staffing issues in the HR team, this is now in plan for 2019.

in progression opportunities.	
Develop a systematic way of collecting diversity information in relation to volunteers.	There is a data collection form being used on our volunteer online recruitment site. Beyond data gained when volunteers apply through our online system – though not all do – the main point of data capture for volunteers is our Volunteering Survey. In 2017 we captured data on age, gender and ethnicity. Additional questions will be added for the next survey in Spring 2019 matching our new standard data (see below).
Increase our EDI profile in volunteering to ensure that we target under-represented groups effectively.	We have been piloting the use of new approaches to and sources of volunteer recruitment to improve diversity, though with limited success to date. Helpline and Council volunteer recruitments have been analysed, though there are no clearly successful avenues. In particular, neither recruitment campaign was very successful in recruiting BME volunteers. Further research into different groups and their experiences of MS and engagement with the MS Society will help to think through next steps.
Externally report on gender pay and take action to improve if necessary.	We have published our gender pay gap, which is significantly below the sector average. The main reason a gap still exists is that men are in a relatively high proportion of senior positions (although we have more women than men at all levels of the organisation and our Executive Group is 60% female). Improvements to talent and succession planning are being designed to help with this over time.
Ensure the induction and leadership programme includes EDI training.	The induction programme includes a session on disability equality with an introduction to wider EDI concepts. The last leadership development programme started before our EDI strategy was agreed so there has not yet been an opportunity to incorporate EDI but this is now being incorporated into a wider review of the programme.
Encourage and support staff-led initiatives to promote, raise awareness, and prompt discussions related to equality, diversity, and inclusion	We had internal activity and blogs on mental health awareness week, London Pride, international women's week and other milestones. In addition 10 staff volunteered to run an integrated communications campaign for International Day of Persons with Disabilities in December. This included blogs from people with MS, a Facebook Live session with our Disability Law Service advisor, and announcing our ambition to become a "Leader" in the Disability Confident Employer scheme. The campaign had strong engagement from the community on social media and a positive reception overall, setting a template for similar EDI integrated activity spikes over 2019.
We will develop and promote research and evidence that highlights the inequality that different groups of people with MS experience and offer positive solutions to address the issues of discrimination and exclusion through policy, practice and public awareness	
Complete a landscape review of evidence of experiences of people with MS from different backgrounds and publish the findings.	Landscape review has been completed and shared internally. Its ability to draw conclusions was hampered by lack of data in several key areas and therefore led to further research activities (see below), after which we will publish the findings of all research to date.
Scope how other organisations approach EDI, with a	We have discussed approaches to EDI with organisations including Parkinson's UK, MND Association, Alzheimer's Society, Neurological Alliance, Nesta, Age UK, Cabinet Office and the Richmond Group. Most

particular emphasis on access to treatments and services.	organisations saw EDI primarily in terms of internal diversity, with a focus on recruitment and culture change rather than analysing impact in terms of EDI. It is therefore difficult to comment on external approaches to access to treatments and services as this was rarely a focus, although that does also indicate an opportunity for thought leadership.
Use the evidence gathered to further define and agree future research activities in this area and to build our research into ongoing activities	We have built on our landscape review (see above) with a much larger project conducting primary research into the experiences of people with MS from different backgrounds and their engagement with the MS Society. This was commissioned in November 2018 and will report in early 2019. The findings of both the initial review and the further research will be fully incorporated into planning for our My MS My Needs 3 survey to run from March 2019 and the EDI Strategy Group will consider wider implications of the research for the organisation.

We will continue to mobilise a diverse range of individuals and communities to speak up and out about the changes needed to improve their lives.

Review our campaigning strategy, policy development process and associated programmes of work to ensure we have appropriate processes in place to fully understand and assess the impact of our external affairs work on people with MS from different backgrounds	The Board approved a revised policy development process that takes greater account of EDI (BD.2018.06.07.04) and this is now operational. The primary research outlined above will include a wealth of qualitative information about perceptions and involvement with MS Society that will inform a full review of our approach to campaigning and influencing in 2019. As this broader review of our campaigning and influencing strategy was planned for 2019, it made sense to align our EDI review with that timetable.
Review our engagement with campaigners from diverse groups, establishing targeted improvement plans where issues are identified	As above, the new primary research will help us understand this further. We have also conducted a survey of the campaigns community to start to build further insight into this audience. This work is informing a review of our approach to campaigning and influencing, which will seek to better support campaigners to campaign on the issues that matter to them. This is likely to unlock a lot of new engagement opportunities, as well as improve our ability to develop targeted plans.

We will develop more accessible national services.

Embed effective measurement and insight to understand the accessibility, acceptability and usage of our national services amongst diverse groups, and to establish targeted improvement plans where issues are identified.	Retrospective national grants impact analysis captures EDI information, as does the grants application. We have agreed a standardised EDI data collection form that we will implement more widely in 2019 (see below). We have also established a reference group of staff and people with MS to advise on strategy and hold the working group to account for progress against agreed objectives. Separately we established the Experts by Experience Steering Group and Network to ensure services are co-designed and are accessible and reflective of community need / aspirations. 162 people currently participating in the Network. All the new pilot services we set up in 2018 will collect EDI data of service users. However, a key learning to date is that this must be

	proportionate and avoid overwhelming people who use our services with data collection.
We will develop more accessible and inclusive local networks and support groups.	
Pilot a range of different approaches in our local services, developing specific services aimed at targeted groups.	Our activity in this area has broadly focussed on improving our data on the reach of our services and on collating good practice. We have not been able to establish pilots but we have built significant resource into our plans for 2019 to respond to continued learning via other routes as below, with the potential for resourced improvement plans where relevant.
Learn from pilots and existing activity within our local networks before developing a resourced improvement plan for 2019 and beyond.	Improving data collection We don't currently have separate data on EDI for our local network volunteers, but they make up a very high proportion of all our volunteers so it is reasonable to assume responses to the volunteer survey are broadly representative. We estimate that we have about 10-15,000 service users in local networks. We do not systematically monitor who uses our services locally, however as part of evaluating local groups recently as part of our Reducing Loneliness study we captured demographic information for 867 people. This starts to help build up a picture of our reach that we will enhance over 2019 as set out below. We are just beginning to start to collect data on attendance numbers for each service and we will agree which services to start collating data from based on the new organisation-wide monitoring form (see below) in order to embed the approach over time. As part of our evaluation of our local newly diagnosed events we are collecting EDI data (however roll-out and completion has been slow). We will also collect EDI data from service users from our *Improving the quality of life* project funded by the Big Lottery Fund which will work with 500 people over two years in Manchester to improve their emotional and financial wellbeing. Improving local practice We are also looking at examples of good practice - to give local groups practical tips on how to widen their reach e.g. not have meetings in church halls. We have collected examples of good practice and will be sharing these in forthcoming issues of Teamspirit. We are also considering packaging up census data. Public Health England produced slides showing how the community looks in your area which could provide a baseline for local groups. However this would just cover England and not the rest of the UK. Experience shows that groups targeted at specific communities struggle to find a role locally and may best be supported in different ways, for example online, so it will be essential to develop further thinking in this area alongside plans for national level support (see above).
Systematically gather data which enables us to understand our current reach and improve our offer as a result of this evidence.	
Agree the data we need to collect to help us monitor and understand equality	It was agreed to approach embedding a more standardised data collection in two parts: i) Agree the data we need to collect - a draft EDI data form has been developed and currently undergoing final checks

and begin embedding across the organisation.	ii) Develop and roll out an implementation plan with guidance and support. This is to take into account that for some areas of our work where we have a "captive audience" it will be much easier to embed e.g. staff and volunteer recruitment, and more challenging in other areas e.g. Helpline, local services etc. For areas it is more challenging we will capture information where we can e.g. as part of evaluating our local newly diagnosed events, as part of a survey to our members etc. We have begun to embed a core dataset in some initial areas (Helpline, planning of Volunteer Survey)
Review and make changes to our planning and reporting processes to ensure consideration of EDI is embedded.	Guidance for detailed 2019-21 business planning included the need to consider EDI (at a minimum). We also agreed a specific three year EDI plan and budget, which allowed us to provide clear planning assumptions to the organisation as a whole and ensure clear reporting mechanism for priority areas. In 2019 we will develop tools to help staff assess impact/implications of planned work for different groups of individuals, and report EDI data (against improvement targets).
Embed EDI as part of developing organisational segments and adapt our marketing in response to new insights.	EDI is at the heart of work to develop organisational segments. We have set a key questions for strategic segmentation on how we can better meet the needs and engage a diverse MS community. We will use the newly founded Insights Group to draw together different forms of evidence across EDI and segments and ensure the insights generated are fed to teams across the MS Society.