

## Terms of reference

### Equity, Equality, Diversity and Inclusion (EEDI) Reference Group

Terms of Reference agreed by	EEDI Reference group
Last review date	Jul 2025
Next review date	Jul 2026
Accountable director	Vicky Annis - Executive lead for EEDI
MSS point of contact	Head of Equity, Equality, Diversity and Inclusion (EEDI)
Author	Liz Purbrick- Head of EEDI and the EEDI reference group members.

#### 1. Introduction

The EDI reference group was created in 2018 and the name was update in 2025 to the EEDI reference group to reflect a focus on equity as well as equality. Its initial purpose was to ensure that the MS Society fulfilled its intent and ambitions with regards to EDI.

The EDI reference group was a key partner in the development of our first EDI strategy in 2021. Our approach to EDI was centred on the experiences of people living with MS and their call to action to do more to address the inequality, marginalisation and discrimination experienced by the MS community.

After the launch of the EDI strategy, the group wanted to continue to contribute to the EDI strategy work and have supported several key initiatives. While the group is relatively small, it is diverse. We aim to have diversity across the protected characteristics and wider, but also in terms of stage of MS and connection to MS including representation from the devolved nations.

This group was an important stakeholder in the implementation of the previous EDI strategy. Moving into the next strategy cycle EEDI will be embedded within our wider organisation strategy. This group will remain a key stakeholder and the voices within it amplified across more of our

work. This document sets out the remit, approach and expectations of this group.

## **2. Purpose of the group**

- To support the development and delivery of equity, equality, diversity and inclusion within our organisational strategy.
- To provide constructive feedback and challenge to the MS Society on various aspects of EEDI. This group will provide their insight, feedback, lived and learned experiences to ensure that our approach continues to improve and that it reflects the needs of the diverse MS community.

## **3. Scope**

- Supporting the EEDI work within our organisational strategy, which covers the whole MS community – people living with and affected by MS, volunteers, staff, supporters, donors, researchers involved in our medical and care research
- Supporting individual team and function based EEDI action plans, objectives and impact goals.
- UK wide

## **4. Accountability**

The group report directly to the Head of EEDI and the EEDI activity group. Through these routes their views and voices are shared with leadership across the organisation and our executive group. Feedback can then also be shared with the board of Trustees.

However, the EEDI reference group is an independent group and critical friend to the MS Society. As such the views and contributions of this group and its individual members are also independent and should not be influenced by the MS Society.

Should the group be required to support any decision making, a quorum of 6 people will be required. If a quorum is not reached any decision making will be postponed or another meeting arranged as appropriate.

## **5. Membership**

Except for MS Society staff members, all members of this group are MS Society volunteers. The membership of the group includes the following people:

- Experts by experience (including people affected by MS and people from marginalised or under-represented groups)
- External EEDI experts

- Head of EEDI
- Public Involvement Manager

In line with our EEDI policy, we seek lived experience from the MS community who may experience marginalisation due to:

- age
- disability
- trans and non-binary identities.
- marriage and civil partnership status
- pregnancy and maternity status
- race (by race we mean colour, nationality, ethnic and national origin)
- religion or belief (including no religion or belief)
- sex or gender identity and expression
- sexual orientation
- socio-economic status or class
- geographic background
- caring responsibilities. This includes caring for a disabled person, older person or child and parental leave.
- mental health status
- menopause and periods

Individuals beyond this core membership are invited to meetings to discuss projects with the group as needed.

## **6. Expectations of members**

All members will respect each other and treat each other with kindness. Our meetings are an accountable space where members can share their honest opinions and views. We will listen to each other and be inclusive of people's individual views and experiences.

## **7. Roles and responsibilities of members**

### **Group members**

Group members can attend meetings to fit around their lives. It is not mandatory to attend every meeting. Members will attend meetings and be prepared to share their thoughts and feedback on various pieces of work. There may be materials to read or work on before or after the meetings.

To maintain an accountable space we ask that people try to keep their cameras on during the meeting but mute themselves unless they are talking. But members should do what is most comfortable for them.

### **Head of EEDI**

The Head of EEDI will take notes of conversations and will pass feedback on to the organisation in an anonymised way. They will also organise the meetings and keep group members up to date with progress. They will organise and chair the meetings and support members to feel safe and included. They will share the meeting notes with all group members after each meeting.

They will be the point of contact for other members of staff who wish to meet with the EEDI reference group. They will prepare the meeting agenda and ensure any documents for review are shared with the group at least 1 week before the meeting.

The Head of EEDI will meet with each new applicant to the group in an informal interview. They will detail the purpose of the group, find out more about the background of the applicant and ensure they are aware of the expectations of each group member.

The Head of EEDI will also be responsible for sharing other opportunities for group members to participate in the work of the organisation and ensure lived experience is included in strategic work across the organisation.

### **Public Involvement Manager**

Every other month the meeting will be dedicated to the research EDI action plan. The public involvement manager will bring together an agenda for these meetings and share with the Head of EEDI to send to the group. They will chair these meetings and take notes to feedback to the research EDI working group.

The public involvement manager will manage external visitors to the group and be an additional point of contact for group members.

### **EEDI Advisory Group volunteer**

This role will represent the EEDI reference group at the EEDI advisory group meetings. The advisory group is an internal group who support the implementation of EEDI within the organisational strategy.

This person will support the Head of EEDI by sharing information between the two groups. They will more closely link the EEDI reference group and advisory group and be an additional voice of lived experience in those spaces.

## **8. Ways of working**

- **Flexible** - Meetings are arranged between 5 – 6pm but the date is chosen based on the availability of group members. The times and frequency of meetings will be reviewed on an annual basis.
- **Supportive** – This group was established to ensure the voices of people affected by MS are the foundation of our EEDI work. This group supports the EEDI work, but members of the group also support each other. The members of the group are also welcome to challenge approaches and raise concerns.
- **Collaborative** – The members of the group will work together to develop ideas and their feedback. Staff members will ensure that feedback is carried back into the organisation and that updates are regularly provided. Outcomes as a direct result of the input of this group will be shared with the group members.

## **9. Meetings and information management**

- Meeting chair – Head of EEDI
- Frequency – Maximum 1 per month
- Format – All online
  
- Head of EEDI will:
  - Manage a forward agenda of topics to be discussed at each meeting
  - Liaise with members to prepare for meeting discussions
  - Log actions arising from each meeting and update against them in the following meeting.

## **10. Information management**

- All members will annually review this document and will be given the option to review their contact information and membership of the group.