DEBRA Member Involvement Policy

Summary

DEBRA exists to serve the EB community. People affected by EB are at the heart of everything we do. DEBRA values the experience, expertise, and views of the EB community and will engage and empower the members to have a voice in shaping DEBRA's strategy and charitable activities. By including their views across our work, we will ensure that the outcomes are more relevant and useful to the people we most want to help.

This policy outlines DEBRA's definition of involvement, and our approach to member involvement across the charity.

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Purpose

DEBRA is a member-centric organisation. To deliver relevant and impactful services, and change to the EB community, we need to put the views and voices of that community at the centre of our work across the charity.

To understand how we will engage and involve the EB community in our work, please see the Member Engagement Strategy.

This policy defines involvement, as opposed to volunteering activities, and details how DEBRA colleagues should be involving members in their work so that their contributions are coordinated and appropriately recognised, and the best results are achieved for both DEBRA and for our members.

This policy also contains the process for requesting input from our members in a piece of work.

Objectives of the member involvement policy

- To state that responsibility for involving members in planning, service delivery, development, and review of DEBRA's activities lies with all colleagues.
- To state our commitment to involve members and recognise their contribution consistently across the charity.
- To clarify the difference between member involvement and other types of member contributions.
- To clarify the process for involving members to ensure that (1) DEBRA best learns from, and values, member experience and expertise; and (2) members feel the impact that their contribution has made, and feel valued, respected, included, and empowered.

Definition of involvement

DEBRA is committed to the active involvement of people affected by EB to influence our work.

'Involvement' is used to describe an activity where people affected by EB can influence DEBRA's current work and its future direction. It is important to distinguish this from supporting or participating, where the EB community help us to deliver certain aspects of our work but are not drawing on their experience of EB to influence the direction of the work.

Types of member contributions:

Volunteering	Lived Experience Involvement	Participation / Supporting
May or may not be affected by EB	Must have a direct experience of EB, usually DEBRA members	May or may not require direct experience of EB
Expectation at the start that you are giving your time (as opposed to money) to charity	Expectations at the start are varied and project-dependent	Expectations at the start are varied and project-dependent
Part of a formal scheme (volunteering in shops/office) with agreements and a 'line manager'	Not always within a formal structure / reporting line	Not usually part of a formal structure/agreement
Does not normally involve sharing aspects of your personal life	Can be an emotional toll of sharing aspects of your personal life	Can be an emotional toll of sharing aspects of your personal life
Aim is to help deliver DEBRA's operational work	Aim is to influence the direction of DEBRA's work using EB experience	Aim is to help deliver DEBRA's operational work, and may or may not include sharing EB experience
e.g. A shop or office volunteer, part of the formal volunteering scheme	**e.g. Reviewing our research grant applications to help decide what research DEBRA will fund, joining a steering committee to direct a strategic project**	**e.g. talking about their personal experience of EB at a launch event, or giving feedback about a campaign**

DEBRA highly values all these different ways to contribute, and we couldn't deliver our work without them. But it is important to define lived experience involvement from the other activities:

(1) to ensure that DEBRA is actively involving the EB community to help shape and define what we do as a charity. By confusing other contributions as involvement, we risk not fulfilling our involvement aims and not allowing those affected by EB to shape what we do.

(2) because in many circumstances it is now best practise to pay lived experience contributors for their insights, so as DEBRA explores this area, we need to define exactly which contributors this could apply to.

(3) this policy does not cover volunteering, and there are other policies and processes to follow when working with volunteers.

Other definitions:

- Stakeholders: A group or individual who can affect or is affected by the achievement of DEBRA's objectives.
- DEBRA Members: Individuals who are signed up to the DEBRA membership scheme.
- EB Community: Anyone living with, affected by, or working with EB, or has a professional interest in EB, who may or may not be part of the DEBRA membership scheme.
- Member contributions: members who are giving their time and/or expertise to DEBRA in any way.
- Case study: an example of how DEBRA has supported a member.
- Member story: the personal experience of a member affected by EB.

Responsibilities

- It is the responsibility of each team at DEBRA to understand when and how to involve and include members in their work to strengthen their outcomes.
- It is the responsibility of all managers and colleagues to identify how their work could impact members and the EB Community and when they should be consulted or informed.
- Any colleague in contact with members must update CRM with their communications.
- It is the responsibility of all colleagues to consider the needs and any adjustments required to enable members to be involved and included, being mindful of the impact this involvement may have on them and how to access additional support if required.
- It is the responsibility of the manager requesting member involvement to ensure that they carry out an appropriate risk assessment for their activity/work.
- The Senior Leadership Team (SLT) has responsibility for leading the organisation on EB community involvement, ensuring it is embedded in the planning and review of DEBRA's strategy and services.
- The Member Services directorate is responsible for facilitating the conversations with colleagues to find involvement opportunities in their work and to understand the best way to deliver involvement activities.
- The Member Services team is responsible for understanding, reviewing, and reporting on the member involvement activities across DEBRA to grow our capacity in this area.

- The Charitable Purposes Committee (CPC) is responsible for reviewing and monitoring DEBRA's performance in relation to stakeholder involvement regularly.

Appendix A lists some examples of teams that have involved, or are planning to involve, members in their work.

Approach to involvement

Involving Member Services:

Given the responsibilities set out above, Member Services must maintain an overview of members' contributions across DEBRA and must therefore be informed of any activity that involves our members.

Before any colleague reaches out to members to take part in their work, they must liaise with the membership team first. Whether informing the membership team of specific members to involve, or asking for help in finding members to involve in a campaign or a project, the requesting colleague must use the "Member Request Form" on the DEBRA intranet.

By including Member Services in your plans, it will enable us to:

- Inform you of any changes in the health or welfare of members - information that will not be accessible for everyone on CRM.
- Offer our expertise and experience in working with members on similar projects and help ensure you have everything in place that is required to safeguard the members (appropriate risk assessments etc).
- Ensure that our processes for including members in our work are transparent and accessible to most of our membership, so that involvement opportunities are available to all our members.
- Ensure that we don't overburden a few individuals.
- Help you find the best people to help you with your work - new members regularly join the membership and the involvement network.
- Help make any links across our involvement and volunteering activities for members, to see how we can improve their experiences with DEBRA and ensure that we get the most out of the activities as well.
- Help to ensure that all types of EB are represented in our activities and communications, so that members can see that DEBRA is here for anyone with any type of EB.
- Apply consistency in how members are involved, thanked, and recognised for their contribution.

- Enable us to report more effectively on the number of members involved with activities across DEBRA, as we have targets for involvement and diversity.

It is the responsibility of the colleague requesting member involvement in an activity to ensure they have an appropriate risk assessments in place to safeguard the members taking part in their work.

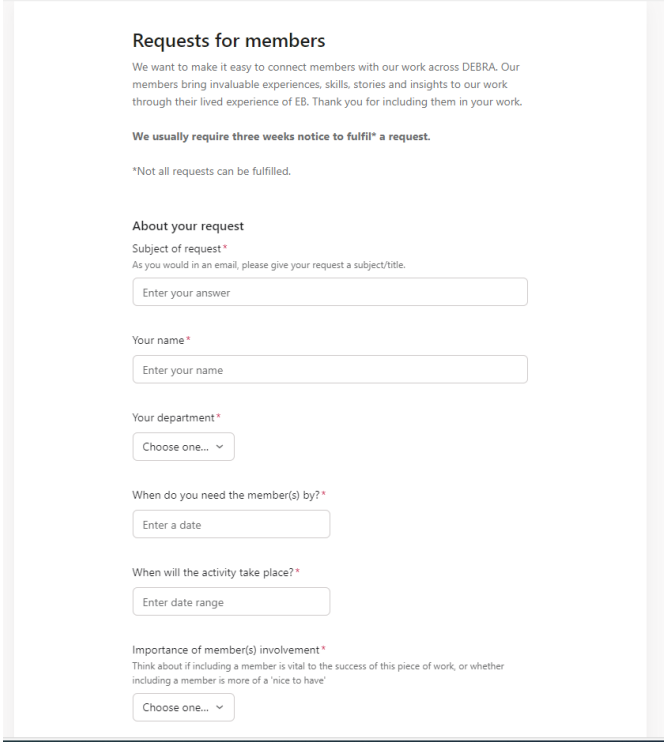
This approach of ensuring that all activities with members must come via the membership team is regularly reviewed to ensure that it works for all colleagues and for our members.

The process for requesting member contributions:

To request any member contribution in your work, you can use one easy link, which can be found on the DEBRA intranet in the "Member Services" tab. Whether you are requesting a case study, or a member to attend an event, give a speech, or to arrange a focus group, requests should be submitted via Asana:

Requests for members - Form by Asana

For example:



Once this has been submitted, the member engagement team will filter the request and forward to the appropriate person within Member Services. Member Services will then work with you to find the right member(s) for your work, advise on necessary risk assessments or adjustments needed, and agree how those members will be recognised for their contribution, and how and when they will be fed back to about the difference their contribution has made.

For detailed information about requesting and managing case studies, please see the "Requesting and Managing Case Studies policy".

Thanking, recognising and reimbursing:

DEBRA values the contributions that our members make and aims to ensure there are no barriers to being able to get involved. All out-of-pocket expenses will be reimbursed, including travel expenses, but must be pre-approved by the manager responsible for the work they are involved in. What we will and will not reimburse should be made clear to the member at the point of signing up. It is not obligatory to claim reimbursement as some members may prefer not to claim. This is in line with the Volunteer Policy, and please see the Expenses Policy for further details.

It is best practise in research, and increasingly across the charity sector, to offer payment for involvement activities. DEBRA is currently working on our own approach to payment for involvement, and has trialled some approaches to this in 2024/25. A formal lived experience payment policy will detail our approach in 2025. We are therefore not yet able to offer payment for involvement as a standard way of recognising a member's contribution. Colleagues should consider other appropriate ways to show appreciation of people's time. Lived experience acknowledgement payments may be appropriate in specific situations, and colleagues should consult the Head of Membership & Engagement if they feel this is appropriate for DEBRA members or healthcare professionals involved in their work.

Please note that Trustees can never be offered payment for their involvement.

DEBRA will never offer a payment to people who share their stories with the media, or who campaign politically, in order to protect their independence. We will never offer payment to those sharing their story with us, to ensure that they are taking part in this activity as a free and active choice, and not because they feel in any way coerced or pressured to do so. Colleagues involved in this activity have a responsibility to ensure that payment for this activity doesn't happen, and that gifts to thank members for their contribution in the public sharing of their story should be spontaneous (not agreed beforehand), and in proportion to the activity, so as not to risk "paying in kind" for their contribution.

The table below aims to give guidance to colleagues to assess the level of member contributions, and some corresponding ideas for thanking members appropriately. Please note this is over and above "out of pocket" expenses, as above.

Tier of member contribution	Corresponding ways to say "thank you"
Tier 1 – highly involved and disruptive to their routine Members have given up a large amount of time – either more than a whole day in one go or adding up to more than a day over the course of three months. And/or members have shared details of their life that are particularly painful or personal. Members have had to go out of their way to accommodate our requests with little or no benefit personally (they may have had to travel quite a long way, filming equipment been set up in their house), performed an activity outside their comfort zone.	• In these circumstances it might be clear that a particular interest or 'reward' would really appeal to an individual. This should be approved at SLT level and should be attributed to all members involved in the same activity. • A gift, e.g. a bunch of flowers, or a 'thank you' hamper. • If a group of members were involved, consider a gathering of some sort to say thank you. • A video message of thanks from the team involved. • A public thanks from a senior colleague. • Invitations to exclusive DEBRA events can be considered, but colleagues have a responsibility to check whether that member has already attended similar events in the last couple of years.
Tier 2 – minor disruptions to their routine Members have given up to a day of their time in one go or adding up to a day of their time over the course of six months. Members have shared their experience of EB, which may have included some personal information.	• Personal thanks from a senior colleague. • Thank you card, or Christmas card. • Small DEBRA branded goods (badge, bag, pen, and notebook). • Consider a certificate recognising the contribution if appropriate. • A video from DEBRA colleagues showing the impact they've made.

Members have had to shift things around in their routine to accommodate us.	
Tier 3 – activities that are relatively easy to fit into their lives Members have given up an hour or two of their time, either in one go or cumulatively over the course of six months. While the members have given up some of their time or shared their experience, they have also benefitted from the activity personally (gained new information, skills or connections). Members were not inconvenienced too much in taking part (e.g. online sessions at more manageable times)	• A heartfelt thank you from the colleagues involved (email or card/letter depending on situation). • Consider a certificate recognising their contribution if appropriate.

Health & Safety

Every day, people are injured; sometimes seriously, sometimes fatally, while doing paid or unpaid work. DEBRA takes its legal responsibilities seriously, and will ensure so far as is reasonably practicable the health safety and welfare of our volunteers and/or member contributors while they are at work and in relation to all activities or operations they are tasked with carrying out and to comply with all relevant legislation, including:

- Health and Safety at Work etc. Act 1974
- Management of Health and Safety at Work Regulations 1999

The health & safety of 'formal' volunteers is covered in the Volunteer Policy. For members involved in events or meetings organised by DEBRA, the team organising the activity will be responsible for ensuring that the risk assessment includes the activities carried out by members. Members will be provided with sufficient information, instruction and, where appropriate, training to undertake their activities safely. The organising team will be responsible for making any reasonable adjustments to enable members with additional needs to take part comfortably and safely.

Any accident, incident or near miss involving a member will be reported, investigated, and then preventative action taken. Accident reports will be reviewed regularly to identify trends and enable action plans to prevent reoccurrence.

Related documents

- DEBRA Membership Policy
- DEBRA EDI Policy
- Member engagement strategy
- Volunteering Policy
- Health & Safety Policy
- Expenses Policy

Appendix A – Examples of member involvement activities across DEBRA

Member Services

- Member Services involves the EB community in identifying needs, priorities, satisfaction levels, and activities that directly support people living with EB, for example in prioritising grants, "pathways" project for proactive and self-help support at key life stages, location of new holiday homes, and ways of enabling members to meet and share experiences online and in person.
- Members are involved in the design of Members' Weekends.
- Healthcare professional members are involved in developing services such as the EB podiatry training course, and online information / publications.

Governance and strategy

- As set out in the DEBRA Articles of Association, at least 50% of DEBRA Trustees are people with direct experience of EB.
- Members are informed of available roles on DEBRA's committees as well as Board of Trustees.
- The EB Insights study allows members to tell DEBRA where we can improve, what we should be focusing on as a charity to deliver more for the EB community, and what it means to live with EB today. This enables us to devise strategies and plans that address the areas of greatest need.

Research programme and Clinical Practice Guidelines

- DEBRA involves the EB Community in identifying priorities for research funding and for developing clinical practice guidelines.
- All Clinical Practice Guidelines (CPG) Panels are required to include at least one EB patient, as well as clinicians covering a range of expertise in each topic.
- Members are involved in deciding what research we fund at the research grant application stage, with their scores and comments being delivered to board alongside those of other clinical and research experts.
- Members are sign-posted to opportunities to get involved in research external to DEBRA where we are confident about the study and its relevance to our members.
- Members are forming lived experience groups or panels to inform research at the pre-application stage, to influence the design of EB research projects.

- Members submit their testimony of what it means to live with EB in order to influence and strengthen our official submissions to bodies such as NICE, Genetic Alliance and the AMRC.

Fundraising

- Traditionally DEBRA has included members and the EB community in fundraising activities through a variety of volunteering activities such as assisting with campaigns, sharing their stories, attending events, and raising funds should they wish to do so, however it is not an expectation.
- The fundraising team consider the needs and any adjustments required to enable members to be actively included.
- The fundraising team is now considering how to involve members in the design of certain fundraising activities, to see whether they enable more members to be able to take part.

Marketing and communication

- To date DEBRA has valued our members' lived experiences in bringing important information, messages and views to the EB community, and in helping the wider public understand the impact of EB. These stories whether in written words, images or video are actively used across the DEBRA teams and help us understand the needs of the EB community.
- DEBRA supports and empowers the EB community to tell their stories and help others better understand the condition.
- The EB Insights study allows members to tell us directly what they want to see and hear more or less of from DEBRA, and their views shape our plans.
- Members views were sought as part of the brand refresh in 2022.
- As work evolves, we would like to find more opportunities for members to influence what our communications look like - email, our website, campaigns or documents.

People

As part of a new colleague on-boarding process, members used to talk to new colleagues and volunteers about their lived experience of EB as part of an interactive session, enabling colleagues and volunteers to better understand how EB affects people differently, and where DEBRA can help.