

Welcome to the IMMDSR Patient Reference Group!

This document sets out the terms of membership of the group, explaining what you can expect from Traverse as a member, and what we ask of you.

Purpose of the Patient Reference Group

The purpose of this group is to assist in the development and implementation of the Government's response to the IMMDS Review.

This group will provide challenge, advice and scrutiny to the Government's response to the Review. Through this process, the group will:

- Share their passion for everyone's voices to be heard, including those from different communities
- Use their powerful desire for change to elicit positivity from the negative experiences discussed
- Seek more transparency at a system level, particularly around:
 - The role of regulators and conflicts of interest
 - Better understanding of risks associated with medicines and medical devices
 - A clearer complaints process that is easier for everyone to navigate
- Help to promote change so that this doesn't happen again, with patient voices at the heart of the change process

How the Patient Reference Group will work

At regular meetings, members of the group will share ideas recommendations and challenge the Government's plan to develop and deliver the IMMDS Review.

The group will be chaired by a member of the group who will be chosen by the group once the group is in place.

An experienced facilitator and team from Traverse (an independent public engagement organisation) will support the Chair and facilitate each meeting.

Group Membership

Group members have been identified through an open recruitment process.

We looked for 15 people in total. We have striven for the group to include a range of different people from across England, with different experiences of medicines and medical devices, including, being a patient, carer, family member or a representative on behalf of a group of



patients. DHSC values and promotes diversity. We encouraged applications from all sections of the community. We also welcome those who have already been involved in the review and those who have an interest in patient safety generally.

We invited people to express an interest in joining the group we then agreed the best group to reflect different areas, interests and experiences.

Individuals interested in joining the group, were able to apply by filling in this short online form or by recording and uploading a short video.

Timetable

The group will meet on:

- Thursday 25th February, 1-3.30pm - Initial group meeting, getting to know each other
- Tuesday 16th March, 5-8pm – Development session
- Thursday 25th March – Meeting 2 (time TBC)
- Thursday April 29th – Meeting 3 (time TBC)

We will agree the best time to meet based on the preference of the majority of group members.

Dates for meetings in May and June will be agreed with the group once it is set up.

Meetings will pause over the summer whilst government is in recess and group members take annual leave. The group will re-convene in the autumn with dates and frequency of meetings to be agreed with the group.

Meetings will be held virtually, and full support will be available to help you with this.

Thank you payments

All members of the group will be reimbursed reasonable expenses and recognised for your time with a thank you payment of £75 for each meeting attended.

Code of conduct

We ask that all group members treat each other, and the Traverse team, with respect and without discrimination. We want all members to feel comfortable sharing their views without judgement. Any behaviour that does not meet this standard may result in you being asked to leave the group.

Confidentiality and your data

Group members are not expected to sign a confidentiality agreement. However, there may be discussions, especially related to the development of policy that group members will be asked to treat as confidential and not share outside the group, this will be made clear prior to



discussion. Group members also cannot speak on behalf of the Department of Health and Social Care, and the Department of Health and Social Care expect that you refer any formal enquiries (such as from the press or formal stakeholder bodies) to pressofficeneedsdesk@dhsc.gov.uk.

We will hold your personal details on file in order to invite you to events and to administer thank you payments, but this will be separate from any data on the views you express in the group events. We will report all feedback you give to us anonymously. These anonymous reports will be shared with our colleagues in the Department of Health and Social Care, and a high-level summary will be made available to those who have expressed interest in the work of the group.

I agree to these terms of membership of the IMMDS Patient Reference Group.

Name:

Signed:

Date: