

Meeting 1 – 25/02/21

Group members

The first Patient Reference Group meeting started with members of the group introducing themselves. The membership collectively reflects a rich spectrum of experiences and perspectives which will enhance our work. Some members have been personally affected by the medical device/medicines considered by the Independent Medicines and Medical Devices Safety Review (IMMDS Review) and have experienced physical, mental and emotional, impacts. Some have been caregivers to those who have been directly affected and others have a strong interest in patient safety more broadly. There is geographical representation from across England and a diversity of experience in the group.

The professional background of members includes experience of working in patient safety, human resources, medical anthropology, law, palliative care, executive leadership and management, and mental health and ex-offender services. Some members of the group also have experience of previous work in related areas including working with the NHS and/or campaign groups.

Experience of all three medicines/devices which were explored in the IMMDS Review are represented within the group. There are 3 members who have experience of or interest in sodium valproate. A further 3 people have an experience of or interest in Primodos, and there are 2 people who have an experience of or interest in vaginal mesh.

Other members of the group have experience of various other medicines and medical devices, as well as an interest in general patient safety.

Several group members have previously given evidence to the IMMDS review.

Issues the group want to consider

Although the members bring a range of experiences to the group, there were four common themes that came through from their introductions.

1. A passion for everyone's voices to be heard, including those from different communities.
2. A powerful desire for change; for positivity to come out of the negative experiences discussed
3. More transparency at a system level, particularly around:
 - a. The role of regulators, and conflicts of interest
 - b. Better understanding of risks associated with medicines and medical devices
 - c. A clearer complaints process that is easier for everyone to navigate



4. Helping to promote change so that this doesn't happen again, with patient voices at the heart of the change process

These themes will be explored further in upcoming meetings, to help the group agree on their core purpose.

Terms of Reference

Members were given the opportunity to reflect upon and discuss the Terms of Reference. In particular, the notion of confidentiality was discussed in depth. It was agreed that the sharing of personal experiences within the group will always remain confidential and private. What is more, topics and ideas that are discussed during meetings will be attributed to the group as a whole and not as one individual's input.

It was also noted that members are present as individuals rather than as representatives of any organisation.

Finally, it was agreed that Traverse will capture the key themes and points of meetings and create summaries that will be uploaded to their website for the public to gain a sense of what the group is discussing.

There was not an expectation for members to sign the Terms of Reference as they were written, but instead members were given the chance to discuss and consider their position. Some questions arose from this discussion, as outlined below:

1. Is it okay to speak about being a member of the group?
 - o Yes. We do not expect membership to be kept secret.
2. Is it okay to share the meeting notes that are on the website with others?
 - o Yes. The key themes and summaries will be made appropriate to share and inform others of what the group is discussing.
3. Is there any scope to make findings published on the website accessible via multiple languages?
 - o Traverse will create a proposal for how that could work and get back to the group.
4. If a member shares their name publicly, but has a common name, how will they be identified?
 - o That is another issue Traverse will consider and respond to.
5. Some people had concerns regarding the environment of social media and external interest in this patient reference group. This may influence whether or not they would like their name to be public as a member of the group.
 - o The group discussed the importance of being transparent and showing confidence in the group, and that they would support each other. There was also an understanding that should any member be contacted regarding the group, they can send the correspondence on through the



appropriate channels and do not need to respond to it themselves. It was therefore agreed that names would be shared publicly.

The role of Department of Health and Social Care (DHSC) and Traverse

Two representatives from DHSC were in attendance at the meeting and will be attending future meetings. The intention is that there will not be lots of different DHSC staff presenting to the group, but that these two representatives will be available to work collaboratively with the group as the Government moves towards a full response and provide relevant information to the group throughout the meetings.

Traverse's role is to provide independent facilitation of the group meetings and ensure everyone's voices are heard including the co-chair once this person has been chosen by the group.

Traverse will manage the administration of the group: taking minutes of meetings; sharing these and agendas with the group; and managing thank you payments for the group.

Co-chair election process

Members interested in becoming the co-chair for the group were invited to (re)confirm their interest no later than the end of the day on 01/03/21. Referring to the recruitment pack for the group, potential co-chairs are required to outline what they would bring to the role. Responses can be submitted in writing, audio recording or video recording by the end of the day on 15/03/21.

All responses will be shared with all group members to watch and read ahead of the meeting on 25/03/21. At this meeting, each potential co-chair will have 5 minutes to answer any questions or clarifications the group may have. An anonymous vote will then take place to determine the co-chair. In the event of a tie, the group will be asked to re-cast their votes. If the tie is not resolved, the co-chair role will be shared between the two members with the most votes.

Next session – development session on 16/03/21

The group will next meet on 16/03/21 from 17:00 – 20:00 for a development session. The purpose of this session is to provide the group with a consistent understanding of the different aspects of the health system and government departments, so they know what areas their advice and recommendations may influence. This session will cover:

- Healthcare system and DHSC's role
- Key points of influence and decision making
- Prioritisation of IMMDS Review recommendations to discuss in the group

If the group have any topics / questions they would like to cover in the development session, please email IMMDSRPatientGroup@traverse.ltd