

Meeting 2 – 25/03/21

Matters Arising from Session 1 and Development Session

Core Purpose and Terms of Reference:

During Meeting 1 Traverse created a short paragraph to capture the themes from members' introductions to form a record of the core purpose of the group. It is proposed that this is included in the Terms of Reference and, if agreed by the group, that Traverse will upload the Terms of Reference to the website.

The key themes that formed this key purpose were as follows:

- A passion for everyone's voices to be heard.
- A powerful desire for change and something positive to come out of these negative experiences.
- A clear desire for more transparency at a system level. Around the role of regulators, understanding risks of medicines, and a clearer complaints process.
- Helping to promote change so this doesn't happen again, with patient voices at the heart of the change process.

If any member felt that was not an accurate portrayal of their purpose, they were asked to let Traverse know by the end of the day, otherwise it would be included in the terms of reference and uploaded [here](#).

Inclusivity and Accessibility:

The group discussed the accessibility of documents which are produced from patient reference group meetings. Traverse agreed to put a statement on the website outlining that if a person needs support to access the documents, including in different languages, that they can contact the project inbox for help. Traverse also agreed to make sure all documents produced would be in plain English and to explore producing 'easy read' documents.

One member asked if it would be possible to embed links to documents onto the Independent Medicine and Medical Devices Safety Review (IMMDS Review) website. The Department noted that the review website is no longer active, but that the First Do No Harm APPG website may be a natural place if further access was needed. The Department agreed to investigate this point.

Appropriate link between the group and the Department:

The group discussed the possibility of a representative attending DHSC weekly IMMDS Review working group meetings. The Department outlined that it would be more influential to have the relevant policy leads attend the patient reference group (PRG) meetings, as the internal working group is not a decision-making meeting, and topics of discussion will not always be relevant to the work of the PRG. It was



agreed that a standing agenda item would be added to each PRG meeting where the Department will give group members a readout from the working group meetings.

It was also agreed that the Minister of State will attend a PRG meeting in June, to listen to feedback from the group.

Recommendation 9:

In response to a query regarding recommendation 8, the Department noted that the PRG has been established in order to address this recommendation.

Election of Co-chair

Traverse's role in the group going forward will be to facilitate, the co-chair will work alongside the team to help coordinate and lead the patient reference group. 6 group members put themselves forward for the role and submitted written applications which all group members had the opportunity to read prior to the meeting. Candidates had five minutes each to answer questions from the group before a vote took place.

An anonymous vote took place via the online platform Mentimeter. All 12 group members in attendance at the meeting voted. There was a tie between two members, so a second vote was cast between these two candidates.

Marie was elected as co-chair.

Recommendation 8 Discussions

Policy leads from DSHC joined the meeting to discuss the first part of recommendation 8, *Transparency of payments made to clinicians needs to improve. The register of the General Medical Council (GMC) should be expanded to include a list of financial and non-pecuniary interests for all doctors, as well as doctors' particular clinical interests and their recognised and accredited specialisms.*

They gave a short presentation which was followed by a Q&A with members of the group. The group then went into two separate breakout rooms to discuss the recommendation. The key points which arose from the group were:

- Any registry of interests must be mandatory and must be regularly updated. It must apply to all clinical decision-making staff and capture non-permanent staff members such as locum and bank staff, as well as procurement / any individuals involved in the decision-making process. A number of group members indicated that they would not support the response to this recommendation if the registry of interests was not mandatory.
- Any registry should be a widely publicised, and easy for patients to understand and access. This also linked to discussions of whether there should be a centralised reporting system rather than clinicians reporting to their employing organisation.



- Patients should be made aware of, and understand, the importance of transparency, including the way in which payments are made to clinical staff and how this may affect the decision-making process.
- Any approach must have a clear and consistent message shared across the NHS and independent sectors.
- Other work that is being undertaken in response to similar recommendations, for example in the Paterson report and any other systems being implemented or set up should be aligned.
- The monitoring of any registry needs to be independent.
- Significantly, group members also raised concerns about the second part of recommendation 8, *In addition, there should be mandatory reporting for the pharmaceutical and medical device industries of payments made to teaching hospitals, research institutions and individual clinicians*. They wanted to know why this was not being discussed with the first part of the recommendation, and asked for an update at the next meeting.
- The Sunshine Payments Act in the United States and the Centers for Medicare and Medicaid Services open payments were suggested as models to explore for the recommendation.

The policy leads took away the key points from the discussion and will provide a written update at the next meeting. DHSC also committed to giving an update on the second part of recommendation 8 at the next meeting.

Wrap up and next meeting

The next meeting is 29th April where the group will discuss recommendation six. Following feedback, Traverse noted that they will work with DHSC to circulate any information provided by policy leads at least a week in advance of the next PRG meeting.

A group member asked about setting up a WhatsApp group. Traverse outlined that they won't facilitate a WhatsApp group but if anyone has any documents they wish to share, to send them to the project inbox and Traverse will disseminate them by email.