

## Meeting 6 – 24/06/21

### Welcome

The co-chair welcomes the group and outlines the agenda.

Traverse restated the group rules and the offer of the victim support service.

### Matters arising from session 5 and DHSC update

Traverse noted that there are materials being waited on from recommendation 3,4 and 7 teams. The department expects a response from the teams shortly and noted it has taken longer due to the volume of questions received.

The department update that they are continuing to draft the report and are working to ensure that feedback from the group is reflected in the government response to the IMMDS Review.

### Meeting with the Minister of State for Patient Safety, Suicide Prevention and Mental Health

The Minister of State for Patient Safety, Suicide Prevention and Mental Health, Nadine Dorries MP, introduced herself and her departmental responsibilities, which include being the lead Minister for the government response to the IMMDS Review. The Minister noted that the report made the pain and suffering of patients very clear, and that it highlighted that women were not being listened to or taken seriously. The Minister said that IMMDS Review has provided the momentum to launch new work on women's health, such as the Women's Health Strategy.

Group members then had 2 minutes each to introduce themselves to the Minister and relay the most important point they would like to voice. This could have been why they felt the group is important, or a point about the IMMDS review's recommendations. Traverse highlights that each individual brings their own experiences to this group and that's why it is so powerful. This was then followed by a roundtable discussion with the Minister

The key points which arose from the group were:

### **The Patient Reference Group**

- There is a real opportunity for action. This will only happen if the group is listened to. The issues discussed have been raised before and there needs to be acknowledgement and action to prevent this happening again.



- Many people are proud to be part of the group and to be making a difference. There is a general agreement that there is pride in how strong and honest the group is.
- However, members will assess if differences have been made based on the publication of the government response. Some group members expressed frustration at the expectation of taken that to date hasn't happened quick enough.
- **Redress:** There is huge disappointment and anger at lack of redress offered. The group are accepting of the apology from the government, but it is nothing without redress or action to follow it up. There is a desperate need because of sacrifices and harms caused in people's lives.
- Patients shouldn't have to wait years to access redress or receive responses. The time between apologies and actions isn't good enough. It's taken too long to receive an apology; it shouldn't be the same amount of time to see action. There should not be future occurrences of this happening.

#### **Cultural change and listening to patients:**

- The system is broken and doesn't listen to and learn from patients or failures. Patients have time again been dismissed despite their experience and knowledge. The MHRA and other areas should be listening, practicing humility and developing.
- There are inequalities in health because the voices that should be heard are not, including those from minority communities. Affected patients must be involved in consultations.
- How, in response to the report, will implementation within healthcare happen? How do the NHS, MHRA leadership know that that's happening on the ground? It is too simple to say all organisations need to have patient engagement, organisational leaders need to also be held accountable to responding to patients at a local level. How can you ensure that the commitment to listen to patients is happening? As its clear that this is not happening. Women are ignored every day, in particular women of colour and women from disadvantaged backgrounds. Group members noted that Ministers need to have mechanisms to ensure accountability for delivering change. The group were concerned that without clear accountability mechanisms, change wouldn't be achieved.
- Both organisational culture and societal norms need addressing around healthcare. There is a need to move away from expectations of paternalistic healthcare, and to educate people, beginning in schools, to have an expectation of knowledge and consent. The mention that a majority of people were happy with their NHS experience may not be a good thing if they only have an expectation of paternalistic care, this needs to be unpicked further.
- The mention of those happy with their experience highlights a lack of listening from the minister as there are many people who aren't. It's not just culture,



there is hard evidence of things that needs to change. Once the system has changed the culture will change. Once there is an organisation looking at what needs to change, then you will unlock all of these systems. Baroness Cumberlege was successful because she took time to listen and sit down with groups of harmed people. Not with unharmed people who don't know what we've been through.

**Specific actions needed:**

- Key examples of actions needed included: a database with patient capture, medical devices to be introduced in small numbers, adverse events to be reported to MHRA on a compulsory basis, for financial and non-financial gifts to be publicly logged, an American style sunshine payments act, amongst others.
- There needs to be an overhaul of the MHRA, which was first discussed in 2005 yet nothing has happened.
- Practical things that need to change. Particularly around conflict of interest and being able to trust your GP.
- Regarding the conflicts of interest, we need to track the money being siphoned into the system. In relation to recommendations 8a and 8b, finding where there are financial investments in medicines and medical devices will show why they are chosen. Have patients make informed choices and hold healthcare professionals accountable.
- It was acknowledged by one member that whilst complaints may be listened to, there is no duty to respond. They must be listened to in order to learn and avoid repeating mistakes. There was a lack of confidence from members that this would not occur again.

The Minister expressed credit to all the members for their impact and bravery, acknowledging the harrowing nature of their stories and the IMMDS Review. The Minister noted the department is working hard to implement recommendations and changes and commended the group for their influence in such a limited time frame. Finally, she noted that the department are also working on patient safety at large and seeking broad improvements.

**Recommendation 5**

The team from NHS England and Improvement gave a short presentation on their work in relation to recommendation 5, Networks of specialist centres should be set up to provide comprehensive treatment, care and advice for those affected by implanted mesh; and separately for those adversely affected by medications taken during pregnancy.

This was followed by a whole group Q&A, and then two breakout group discussions. This followed the format of previous meetings.

The key points which arose from the group were:



### **Specialist centres for mesh**

- The group asked about progress on the operationalisation of the specialist mesh services. It was noted that the centres are moving from focussing on mobilising, to consolidating how they operate, and how they work with other centres.
- It was noted that good progress was being made to establish a centre in the South West, and that NHS England and Improvement hope to be able to announce the name of the centre shortly.
- Group members asked what information patients were being given by specialist mesh services regarding treatment options for mesh complications. The group stressed the importance of real-time data collection, and of centres working together to share data on patient outcomes and experience.
- Group members also stated that it was critically important to gain feedback from patients to inform future actions. The specialist services need to put in place strong mechanisms for seeking feedback from patients. Patients also need to know where to go if they're not getting the information they need. That needs to be systematised.
- It was asked why the NHS has not committed to fund the development of a validated PROM (patient reported outcome measure) for mesh. One group member said that PROMs had previously been promised, but are not yet in place.
- The specialist mesh services became operational on 1st April this year, but there is not yet an approved outcome measure for mesh removal. How will data be gathered on mesh removals in order to track outcomes? and how will information be shared between specialist services if it is not gathered in a uniform fashion?
- An independent academic researcher is needed to help with developing both interim measures and future PROMs to capture patient outcomes. You cannot design an interim questionnaire without an independent academic. At the moment it is merely platitudes.
- Paternalistic health care has been an issue for mesh centres. Feedback is needed for how that can be worked on.

### **Specialist centres for medications in pregnancy**

- Group members described some of the challenges faced by families in accessing healthcare services. These included it being difficult to access services locally, and people having to spend many years and a large amount of money gaining multiple opinions from consultants in attempting to receive a diagnosis for conditions such as foetal valproate syndrome. There is a need to increase the pool of experts who are able to diagnose affected children, and to increase the pool of knowledge. There are a lot of families who are not



able to get a diagnosis, as there is no simple test (for foetal valproate syndrome).

- There is also a need to provide mental health support. All individuals adversely affected by medications such as valproate have experienced trauma, and access to mental health services particularly for children is practically non-existent. Physical medical care is important, but so is medical care.
- A group member noted that over the past 20 years they have observed matters go from bad to worse. We need to move forward but it needs to be recognised that there are 20,000 children in the UK alone who have experienced avoidable harm from valproate, who still cannot access healthcare or educational provision. Changes need to be made rapidly. Care for people affected needs to be prioritised, and there needs to be a sense of urgency.
- Group members stated that it was important to consider both future cases, e.g. better earlier identification of those at risk during pregnancy, and to consider children/ adults who have been affected by medications in pregnancy. This will ensure that no-one is missed in accessing support services.
- Patients felt strongly that regional access that must be the same throughout the country, for those affected by valproate as well as mesh. This should include access to clinical genetics, toxicology, paediatric care, and coordinate care and support for families using local services.
- Some group members felt that centres would be a place to coordinate this, but that there needs to be consistency across different regions. The cost of centres would not be too high because much of what is needed is already in existence, it's just not coordinated.
- The group agreed with the need for multi-disciplinary teams (MDTs) to coordinate care for those affected, and the need for better training for consultants, and for there to be professional leadership, for example by Royal Colleges.
- The group also felt that it was important for there to be authority and accountability to ensure that there are accessible services across the country.

The co-chair expressed to the policy team that they provided good information, but that it would be useful to capture where barriers are stopping them from accomplishing what they want to do.

### End of Project Report

Traverse acknowledged the feedback so far, which asked for bolder language expressing the strength of opinions and some queries to be clarified in the writing.

One group member asked if releasing the report at the same time as the government response will prevent the group having an opportunity to respond to it and was concerned input of the group would cease.



There was consensus in the group that the report should be released alongside the government response.

The group expressed a desire to continue to oversee the implementation of the policies and provide a patient voice. The Department agreed to take this request away for consideration.

### Group discussion of patient journey and patient engagement

Traverse acknowledged that the group have been heard when highlighting the importance of the recommendations fitting into the bigger picture on patient engagement. Traverse noted that there will be a specific section in the end of project report addressing those feelings of people being unheard or silenced. Members are invited to comment on the issue in the chat or in follow-up emails.

### Wrap up and close

An additional meeting to engage with the MHRA was set for late July, and it was noted that this will include a discussion on 'next steps', as many members have expressed a desire to continue involvement with this group and the influence on and accountability it holds over these policies.

The co-chair highlights the difficulty of these meetings but appreciates the genuine desire to change from some policy attendees. They note it has been a massive step and has made a difference. It is also highlighted that the co-chair has a joint responsibility for signing off on the report.