

HPRA Patient Forum Meeting Record

Tuesday 20 September 2022, Hybrid meeting (HPRA offices & Microsoft Teams)

Chair: Dr. Paula Kilbane

1 Welcome & Introductions

The Chair welcomed the members to the meeting.

2 Declarations of Interest (DoI)

There were no DoI's declared.

3 Adoption of the agenda

The agenda was adopted.

4 Record of the last meeting and matters arising

The record of the meeting held on 7 June was agreed.

5 Matters arising/issues of Interest

Matters arising from the last meeting were discussed, including the status of workplan actions. The Chair spoke to the recent coverage regarding the use of valproate during pregnancy. The commitment of patient organisations in raising awareness of the recommendations for use of valproate in people of childbearing potential and during pregnancy was acknowledged. It was noted that a public inquiry into the historical licensing and use of valproate is anticipated and that a terms of reference

is awaited. The members were assured that the HPRA will participate fully in the inquiry process and when complete, the outcome will be addressed with the members.

6 Workplan 2022, Adverse experiences associated with medicines/medical devices and reporting to the HPRA

Feedback from members was sought on a Questions and Answers (Q&A) document about the reporting of safety issues to the HPRA. The Q&A document is intended for use by patient organisations on their websites. It's purpose is to raise awareness of how to report and to signpost those interested to the relevant HPRA webpage. Members provided feedback on the proposed text including the importance of using plain English. The members highlighted that the Q&A document was a targeted intervention, as the audience is limited to those who would view a patient organisation website. Consideration of minority groups was needed. The HPRA highlighted that the Q&A document was a complementary method to those already in place to raise awareness. It was agreed that the feedback from members would be considered and text updated as appropriate. The updated text would be shared with the members for further comment.

7 Workplan 2022, Coordinating the management of shortages

A presentation was given on the HPRA's role in co-ordinating the management of shortages of medicines on the Irish market. The presentation described why medicines shortages can occur, the multistakeholder nature of HPRA's coordination role, as well as the information available on the HPRA website in relation to shortages.

8 Work plan 2023

A discussion was had on the work plan for 2023. It was highlighted that a number of work plan topics from 2022 would continue on into next year. The members provided their individual preferences for new topics to be included. It was explained that all topics would be reviewed to identify areas of mutual interest, taking into account the terms of reference for the forum. A proposal for the 2023 workplan would be made at the December meeting.

9 AOB

An update was given that the policy for considering potential conflicts of interests of members was now final and published on the HPRA website.