

## HPRA Patient Forum Meeting Record

Tuesday 26 March 2024, Hybrid meeting (HPRA offices and Microsoft Teams)

Chair: Dr Paula Kilbane

### **1 Welcome and introductions**

The Chair welcomed those present and the members introduced themselves. Members in attendance included Mary Casserly, Melody Buckley, Mandy Daly, Jacqui Browne, Karen Keely\*, Siobhan Freaney, Ann Twomey, Nuala Ryan\*, and John Dowling (\*attended for part of the meeting).

### **2 Declarations of interest**

No conflicts of interest were declared.

### **3 Adoption of the agenda**

The agenda was adopted.

### **4 Record of the last meeting**

The record of the meeting held on 12 December 2023 was agreed.

### **5 Matters arising/issues of interest**

Members endorsed the draft workplan for 2024, which will be published on the HPRA website. Members were updated on the development of the annual report for 2023, on the preparations being made for another

patient speaker event, as well as ongoing work on forum membership and the terms of reference.

## **6 Online Sales of Medicine**

A presentation was given by the Compliance department concerning the online sale and supply of falsified and illegal medicines. Members commented that the information was very useful and noted their interest in further information sessions on this topic.

## **7 Guide to Reporting Suspected Safety Issues**

An update was given on the guide co-created with the forum following its launch in September 2023. A good response to the guide on social media was noted, and the Epilepsy Ireland website was highlighted as an example of how the resource can be used. There was discussion on the usefulness of the guide and the importance of using multiple resources to target a wide variety of audiences was acknowledged. It was agreed that the HPRRA would again highlight the guide through social media channels. Members were asked to raise awareness through their own advocacy work, as appropriate.

## **8 AOB**

The HPRRA provided forum members with an overview of recent participation in a DIA Conference session focusing on National Competent Authorities (NCA) engagement with individual patients and patient organisations on a range of different regulatory activities.

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<sup>1</sup> [HPRRA Patient Forum Resources](#)

Outcomes of a EUPATI survey on interaction of NCAs across Europe with patients were shared with forum members.