

# HPRA Patient Forum Annual Report 2022

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## **1 BACKGROUND**

The HPRA Patient Forum is a platform for dialogue and exchange with patients on issues relevant to the regulation of medicines and medical devices and gives Irish patients a voice in the regulatory process. The terms of reference for the forum provides that an annual report is submitted to the Authority. This is the first annual report since establishment of the forum. The report describes the meetings and work activities of the forum over 2022 as well as the results of a survey of members.

## **2 MEETINGS**

There were four meetings of the forum held in 2022. Meetings were either virtual or hybrid. The number of forum members attending increased over the year, with eight members in March and June, 12 in September and 14 in December. For each meeting, an agenda was agreed with the members, which covered topics from an agreed workplan, as well as standing items and matters arising. A record of forum meetings was published on the HPRA website.<sup>1</sup>

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<sup>1</sup> HPRA Patient Forum meeting reports <https://www.hpra.ie/HOMEPAGE/about-us/patient-forum/meeting-reports>

### **3 WORKPLAN**

Forum members and the HPRA collaboratively developed a workplan for 2022 which reflected areas of common interest and was aligned with the purpose of the forum.<sup>2</sup>

As the inaugural year of the forum since establishment, the focus was to deepen the engagement between HPRA and members, as well as to explore topics identified as a priority. The forum agreed to focus on work related to HPRA culture and values and adverse event reporting as core topics. In addition, a number of information sessions were held to update members on areas of HPRA of work that were of particular interest. Further details on each of these topics is given below.

#### **3.1 HPRA culture and values**

The HPRA launched its strategic plan in 2021, including a refreshed mission statement and organisational values. A key value of the organisation remains 'putting the interests of those who use health products first'. The HPRA sought the perspectives of members on approaches the HPRA could take to deepen understanding within the organisation of the importance of this value and on how

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<sup>2</sup> <https://www.hpra.ie/docs/default-source/publications-forms/corporate-policy-documents/patient-forum-rolling-workplan-2022.pdf?sfvrsn=4>

best to foster a patient focused culture. The members agreed that strengthening this core value can reinforce a culture that will aid in the delivery of the organisation's mission. Input was sought from the members on the approach to employee corporate induction, from which a training module was developed on the importance and meaning of the 'patient focused' value. Members gave valuable input into the design of the module, and one member contributed by recording a video interview with key messages for HPRA staff. The training module was launched in May 2023 for all staff and will form part of the induction curriculum for new starters.

The HPRA also explored member perspectives on the value of a patient speaker program, through which patient representatives can be invited to speak to HPRA staff on a topic of interest. Members agreed that such a programme could give HPRA staff an opportunity to hear of the real experiences and challenges that face the patient community and that in working collaboratively in this way, it may enhance understanding and highlight the importance of the 'patient focused' value across all facets of the organisation.

It was agreed to run a pilot session with members participating in 2023. The pilot session was held on 1 June and explored patient public involvement in research through presentation and panel discussion with members and an academic speaker. The session was very well received by staff, in particular the inspiring stories of the journey of patient advocates and of the evolution of patient public involvement in research over time.

### **3.2 Adverse event reporting to the HPRA and involvement of patient organisations in raising awareness**

Members have emphasised in their feedback through the forum the importance of public awareness that a patient, carer or consumer of health products can report adverse experiences to the HPRA. The members expressed this is of fundamental importance to the patient community, recognising that patients, carers and members of the public can give valuable insight to the health products they use. Whilst recognising the benefits of health products, the members reflected how patients can inform of the difficulties and adverse events that can also be encountered. The importance of easy to use and accessible options to report, as well as the important role of healthcare professionals was also emphasised.

As part of the workplan, ways the forum could further contribute to efforts to increase public awareness of the role of the HPRA and to encourage reporting of adverse experiences with health products were agreed.

Firstly, the HPRA worked collaboratively with members in the annual WHO led social media campaign (#MedSafetyWeek) to raise awareness around reporting. Members were provided information about campaign ahead of its launch. This included key messages and themes for the campaign, along with links the content and where it would be posted online during #MedSafetyWeek. Members were invited to engage and share in the social posts from the HPRA. A number of our forum members actively participated in the campaign by liking the posts and

resharing content on their own channels. This assisted in creating more awareness and audience reach for the campaign overall.

Members also agreed to work with the HPRA in developing a notice that can be included on patient organisation websites to signpost to the HPRA reporting. Development of this notice was progressed with members in 2022, and it is anticipated that work will be finalised in 2023.

The 2023 workplan also foresees continued collaboration in this area, including feedback from members on the proposed new HPRA website.

### **3.3 Information sessions**

Information sessions were held on topics, such as, the readability and understandability of package leaflets for medicines, and on the HPRA's role in the management of medicines shortages. These sessions served to deepen mutual understanding of HPRA and member perspectives on these topics, with very useful insights shared. It was agreed to hold similar information sessions in 2023.

## **4 TRANSPARENCY**

Key information relating to membership and forum activities was published on the patient forum webpage.<sup>3</sup> In addition to general information, records published included the terms of reference, meeting summary reports, a list of members of the forum and a policy for managing potential conflicts of interest.

## **5 MEMBER SURVEY**

Members were surveyed on their views and perspectives on participation in the forum, including on topics covered during meetings, opportunities to comment and participate in discussions, logistical support around meetings, and whether the forum met overall expectations.

Six forum members completed the survey. In response to the questions asked between 80-100% either agreed or strongly agreed that a good range of topics were covered, that there was opportunity to comment and engage in discussions, that logistical support was good, and that the forum had met their overall expectations (Figures A to D).

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<sup>3</sup> HPRA Patient Forum information page <https://www.hpra.ie/homepage/about-us/patient-forum>



General feedback was also given, with overall trends in the responses positive. Members expressed a greater understanding and appreciation of the work of the HPRA, while the forum itself was seen as an important mechanism for patients to provide feedback on a range of issues and to stay up-to-date with latest developments in the regulation of medicines and medical devices.

Some members felt that participation was beneficial in informing their role, particularly when discussing matters related to the HPRA and the regulation of medicine. Moreover, forum members were encouraged by the level of support for the forum demonstrated by senior leaders within the organisation.

The key findings of the survey were presented to members at a meeting in March 2023. The members present expressed their support of the survey findings and feedback.

**Figures A to D: Forum member survey responses**



*Data presented as proportion of respondents who expressed support for statements pertaining to A) relevance and interest of topics covered, B) opportunities to comment and engage in discussions, C) logistical support around meetings, and D) overall expectations for the forum.*

## 6 CONCLUSION

The HPRA Patient Forum was established formally in 2022. The members worked collaboratively together with the HPRA to progress all items within an agreed workplan, with several outputs directly translating in the day-to-day operation of the HPRA. Valuable insights and feedback were given by members to the HPRA on a range of topics. The forum has demonstrated itself as a valid platform for patient engagement and has helped ensure the work of the HPRA continues to be patient focused. The forum has agreed to continue to progress within the framework of the current terms of reference. A workplan for 2023 has been adopted, through which the forum will continue its work. Members will take the opportunity to review membership criteria within the current terms of reference, to ensure it enables a diverse and inclusive representation of the patient community.

The HPRA is one of few EU member states to have a patient forum of this nature, and forum members have identified the importance of highlighting this work within the regulatory network. The HPRA remains absolute in its commitment to ensure the development and work of the forum are fully supported, and to share the challenges and learnings as we progress.

The HPRA wishes to take the opportunity to thank all forum members for their engagement, enthusiasm, and dedication to make this a success and looks forward to developing the approach further in 2023.