

HPRA Patient Forum Annual Report 2023



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1 BACKGROUND

The HPRA Patient Forum is a platform for dialogue and exchange with patients on issues relevant to regulating medicines and medical devices. It also gives patients in Ireland a voice in the regulatory process. The terms of reference for the forum provide that an annual report is submitted to the Authority. This is the second annual report since establishing the forum in 2022. The report describes the meetings and work activities of the forum throughout 2023 and the results of a survey of members.

2 MEETINGS

There were four hybrid meetings of the forum held in 2023. The number of forum members attending remained relatively constant throughout the year, with seven members attending in March, eight in June, five in September, and seven in December. The members agreed on an agenda for each meeting, covering topics from the forum's work plan, standing items, and matters arising. A [record](#) of all forum meetings held in 2023 was published on the HPRA website.

3 WORK PLAN

Forum members and the HPRA collaboratively developed a [work plan](#) for 2023 that reflected areas of common interest and was aligned with the forum's purpose.

The forum focused on deepening the engagement between the HPRA and members by developing a mutual understanding of perspectives concerning a range of regulatory topics. The forum also agreed to focus on work related to regulatory communications for the public, provide input on the HPRA's website redevelopment project, and engage in continued learning on the HPRA's role in the regulation of medicines and medical devices, coordination of medicines shortages, and the organisation's interaction with the broader healthcare system. Members also expressed an interest in exploring the Patient Forum's terms of reference, with specific consideration of matters relating to the diversity and inclusiveness of the membership.

3.1 Regulatory communications and website redevelopment

Raising awareness among patients and members of the public of the importance of reporting adverse experiences with health products to the HPRA was a particular area of focus for the forum. Work on developing a guide that aimed to raise awareness of the importance of reporting safety issues was initiated in 2022 and finalised in 2023.

Forum members contributed to developing this guide by helping to identify and draft key messages and providing valuable feedback on approaches to improve accessibility. The guide was developed to be a helpful resource for patient organisations to raise awareness of the importance of reporting to the HPRA, which they could post on their respective websites or include in any other relevant material.

Since its publication in September 2023, the guideline has achieved approximately 7,000 impressions across different social media platforms, including LinkedIn and X (formally Twitter). The HPRA and forum members agreed to continue highlighting this resource through various communication channels.

Developing accessible information resources and communication platforms are key components of the HPRA's current strategic plan. The HPRA initiated work in 2023 to completely redevelop the organisation's website to create an accessible digital experience for all users. Forum members participated in early-stage usability testing and provided valuable feedback on the initial design of the HPRA's new website.

3.2 Information sessions

Information sessions were held on topics related to the HPRA's role in regulating medicines and medical devices, coordination of medicines shortages, the organisation's interaction with the broader healthcare system, and work to redevelop the HPRA's website. These sessions deepened mutual understanding of HPRA and member perspectives on these topics. Forum members provided beneficial insights during subsequent discussions following presentations on each topic throughout the year. It was agreed to hold similar sessions in 2024.

3.3 Review of the Terms of Reference

The HPRA is dedicated to being an organisation that acknowledges and values diversity and inclusion, which is embedded in the organisation's values, culture, and activities. And this commitment to diversity and inclusion extends to the Patient Forum.

During focused discussions on the terms of reference, members expressed the need to consider underrepresented groups and ensure HPRA information is understandable and accessible to all. Members also expressed their support for opening the forum to new applicants. It was agreed that a review will be undertaken in 2024 to assess the forum's diversity and inclusiveness and develop a plan to ensure the forum, in so far as possible, incorporates the voices of underrepresented patient cohorts.

3.4 Patient Speaker Programme

The HPRA also sought members' views on the benefits of a patient speaker program, where patient representatives could be invited to speak to HPRA staff on topics of interest. Members agreed that this program could provide staff with valuable insights into the real experiences and challenges faced by the patient community. Collaborating in this manner could strengthen understanding and emphasise the importance of maintaining a 'patient-focused' approach throughout the organisation.

It was agreed to conduct a pilot session with members in 2023. This session took place on June 1 and focused on patient and public involvement in research, featuring a presentation and a panel discussion with members and an academic speaker. The staff highly appreciated the session, especially for the inspiring stories shared by patient advocates about their journeys and the development of patient and public involvement in research over time.

4 TRANSPARENCY

Key [information about membership and forum activities](#) continues to be published on the patient forum webpage. In addition to general information, records published included the terms of reference, meeting summary reports, an updated list of members of the forum and a policy for managing potential conflicts of interest. Forum members also agreed to include a list of attendees in each meeting record, which commenced in September.

5 MEMBER SURVEY

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

Four forum members completed the survey. Responding to the questions asked, all respondents either agreed or strongly agreed that a wide range of

topics was covered, that there was an opportunity to comment and engage in discussions, that logistical support was good, and that the forum had met their overall expectations (Figures 1 to 4).

As part of the survey, respondents also provided general feedback concerning their experience of the forum. Members view the forum as an important platform for learning more about the HPRA's remit and staying updated with the latest developments in regulating medicines and medical devices. Members also expressed satisfaction with the open, transparent, collegiate approach and the opportunities to engage in meaningful discussion. Finally, highlighting the forum's work within the European regulatory network was considered important, especially considering that the HPRA is one of a limited number of agencies across the EU that have established a patient forum. The survey's key findings were presented at a meeting in June 2024, in which members expressed their support of the outcomes and feedback.

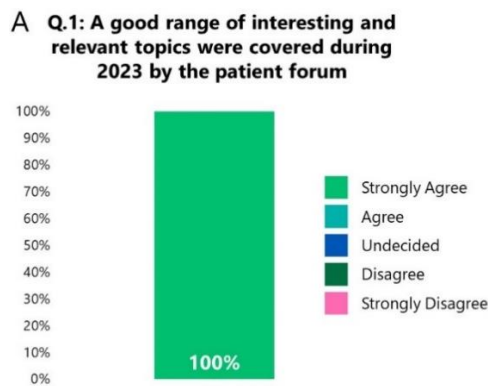


Figure 1: Response to forum member survey question 1. Data was presented as a proportion of respondents who expressed support for a statement about the relevance and interest of topics covered. 100% of respondents strongly agreed.

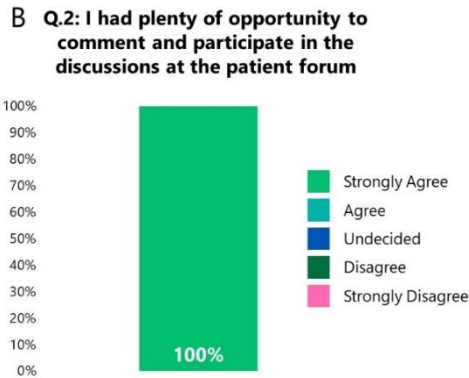


Figure 2: Response to forum member survey question 2. Data was presented as a proportion of respondents who expressed support for a statement about the opportunities to comment and engage in discussions. 100% of respondents strongly agreed.

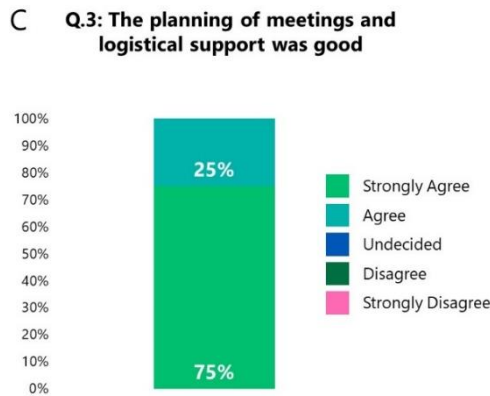


Figure 3: Response to forum member survey question 3. Data was presented as a proportion of respondents who expressed support for a statement that meeting planning and logistical support was good. 75% of respondents strongly agreed and 25% of respondents agreed.

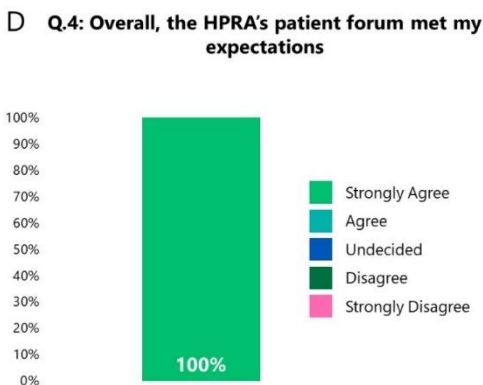


Figure 4: Response to forum member survey question 4. Data was presented as a proportion of respondents who expressed support for a statement about overall expectations for the forum being met. 100% of respondents strongly agreed.

6 CONCLUSION

The Patient Forum continues to represent an important engagement platform for dialogue and exchange on topics relevant to patients regarding the regulation of medicines and medical devices.

Valuable insights and feedback were provided by members across all topics included in the 2023 work plan. Direct benefits for the organisation include the development of a guide for patient organisations promoting the importance of reporting safety issues to the HPRA, in addition to receiving valuable feedback on the early design of the organisation's new website.

The forum has agreed to continue to operate within the framework of the current terms of reference while a review is completed, specifically focusing on the diversity and inclusiveness of the membership.

A work plan for 2024 has been adopted, through which the forum will continue its work.

The HPRA wishes to take this opportunity to thank all members for their engagement, enthusiasm, and dedication to making this patient forum a success and looks forward to continuing this important work.