

14 June 2023
EMA/89221/2023
Stakeholders and Communication Division

Patients and Consumers Working Party (PCWP) meeting 27 June 2023

Chairs: Juan Garcia Burgos (EMA)

Welcome and introduction

Juan Garcia Burgos (EMA) opened the meeting, welcoming all participants in person and online as well as the Working Party co-chairs.

1. PCWP operations

1.1. Feedback from satisfaction survey

Giulia Gabrielli, Patient Liaison, presented the results of the 2023 satisfaction survey of patient and consumer organisations. In a change from previous years where individuals who participated in EMA activities were surveyed, this time the survey involved all 42 eligible organisations.

Despite the low participation rate, results indicate a high level of satisfaction of the responding organisations with respect to representing the patient community, the variety of activities for participation and interactions with EMA. Some areas for improvement included a request for more systematic patient involvement in the evaluation of the benefits and risks of medicines, concerns around timelines and difficulties in finding patients for regulatory activities.

When asked about the value of being an eligible organisation, this was highly valued by responders, who consider that EMA eligibility brings legitimacy to their organisation; they also appreciated the regular communication, the Agency as a forum for EU representation and access to the PCWP.

Priority topics, rated by patients based on the [EMAN](#), varied a little to those selected by the HCPOs, which highlights the relevance of a multistakeholder approach and the importance of engaging with patients, consumers and healthcare professionals. It was agreed that future satisfaction surveys should involve members in their co-creation, with the aim of increasing impact and participation. For more details, see [presentation](#).

1.2. Follow up on suggestions for new mandate proposed by PCWP members

With the start of the new PCWP mandate and co-chair election in 2022, several member organisations sent a letter to EMA inviting an exchange on suggestions to improve collaboration and contributions to the work of the Agency. A follow up meeting was held in October 2022 and the discussion was brought to the whole working party in the first PCWP plenary.

Angela Bradshaw (PCWP member, Alzheimer Europe) presented elements from the letter that included the meeting format and organisation, member involvement in EMA initiatives and capacity building. In addition, the idea of reinstating working groups and topic leads was raised as well as how to better support the PCWP co-chair.

EMA presented some of the changes that have and will be implemented and then opened to the working party for more discussion and suggestions. See [presentation](#) for more details.

2. EMA communications

2.1. Working together to combat disinformation

Monika Benstetter (Head of Media and Public Relations) began her presentation by defining both misinformation and disinformation and the potential impact on both on society and public health, showing that it is critical that misleading or confusing information be addressed.

EMA's experience during pandemic was shared and will help shape the Agency's framework on mis/dis information. The framework consists of three pillars i) monitoring of the main issues and where they come from, more social listening and media monitoring, expanding expertise in data analytics; ii) actions needed include increased proactivity in 'pre-bunking' false information, reaching the 'public' by engaging in different ways, communicating the science (and people) behind the decisions, all of which will contribute to improving health media literacy and helping people to better understand what they are reading and iii) outreach by sharing insights and experience, co-creating and joint campaigning. For more information, please see [presentation](#).

2.2. EMA Perception survey to stakeholders

Christopher Gadd, Head of Online Communication, presented the results of the 2022 EMA communication perception survey. EMA runs this survey every two years, to gauge general perception of communication and engagement, identify communication challenges and opportunities, and support continuous improvement. Stakeholders and partners rather than the general public are targeted; the profile of respondents to the 2022 survey was presented.

Key highlights included high satisfaction with EMA communication and an awareness of the products and channels being used, which include digital platforms. Respondents said that they generally read and disseminate EMA communications, with fewer reproducing the material for their own websites and other communication channels. External communication was rated positively to very positively and regarding whether the level of engagement was sufficient the respondents mainly agreed or strongly agreed. Further, EMA's engagement was rated as better than or as good as other international institutions or regulatory agencies. Areas for improvement could include further tailoring of communication deliverables to meet the needs of partners, increasing awareness and use of some communication tools, further improving its websites and making more resources available in languages other than English.

Overall, the results show that respondents felt that the communication by EMA was of good quality and that the Agency was perceived to be open and transparent with good engagement with stakeholders. Following the presentation, the discussion focused on how to increase the reproduction of EMA's content, refine its communication deliverables to meet partners' needs more closely, and ensure the right support for these activities. For more details, see [the presentation](#). The full survey report is [available](#).