

Patient and public engagement (PPE) consultation – interim findings

Background

Earlier this year the Board and CET agreed a step-change was required in the Agency's delivery of PPE. To help inform the development of a longer-term PPE strategy, we ran a formal public consultation for 12 weeks (15 July to 7 October 2019) to seek views on how we should engage and involve patients and the public in our work.

We also held five engagement events across the UK to support the consultation: one in each devolved administration, one in London and one specifically for members of the Patient Group Consultative Forum.

The broad areas covered by the consultation were:

- public awareness and understanding of our work
- involving patients and the public in our work, including early in the regulatory decision-making process
- how patients and the public raise concerns with us

Responses and respondent profile

We received a total of 808 responses to the consultation, and 64 people attended the five engagement events.

61% of all respondents said they have had no previous interaction with the Agency.

Approx 67% of respondents identified as patients, 22% as healthcare professionals, 19% as carers, 19% as health/research charity representatives. (NB: respondents could select multiple descriptions as some identified with more than one grouping.)

Analysis and emerging findings

We have conducted initial analysis which has identified the following key emerging themes:

1. **Responsiveness** – Agency perceived as not responding quickly enough when patients raise matters of concern and there is typically a lack of communication to follow-up and maintain engagement once an issue has been raised.
2. **Transparency/accessibility** – existing information available from the Agency (e.g. Patient Information Leaflets, website) not easily understood by patients and does not explain clearly enough the Agency's role in keeping the public safe.
3. **Communicating through partners** – to help address some of the issues relating to profile and transparency, the Agency should make greater use of stakeholders such as healthcare professionals, health system organisations, fellow regulatory agencies, research charities and patient groups to provide information about its role and responsibilities.
4. **Patient involvement** – patients and carers would like their voice to be heard throughout the regulatory process and will require information, support and training in order to equip them to participate and to help manage expectations regarding the outcomes from their involvement.
5. **Public profile** – need for a wide-ranging general public information and awareness raising campaign to address a relatively low profile and lack of knowledge about the Agency's existence, role and responsibilities, and also about the Yellow Card reporting scheme.

We are conducting a more detailed qualitative analysis of the responses and drafting a formal Agency report of the consultation for CET and Board approval, that we will aim to publish in January 2020.

Longer-term PPE strategy to be developed for discussion at CET and the Board early in 2020. We envisage a further short consultation on the draft strategy in early 2020.