

The Patients Association: Feedback on their strategy

Questions

1. What do you think of our proposed purpose and scenario plan?

The Purpose was clearly written and focused. We welcome in particular the importance of collaborative working for achieving the Association's strategic purpose, which very much aligns with the intent of our own draft corporate strategy for 2021 – 2025. However, we believe that the strategy could benefit from highlighting more of the Patients Association's core work in the strategy to set out how this will inform the delivery of the Association's strategic purpose. For example, it could focus more prominently on the importance of identifying good patient experiences, speaking up, good complaints handling, awareness of professional standards and patient safety.

The scenario plan is a helpful approach and an effective way to show the balance of resource available and the approach to involving patients by providers. We would recommend that it could be improved with a more in-depth explanation on what the diagram is showing.

The strategy talks about access and benefits through equal partnerships. Some specific information around benefits and the Association's vision for effective equal partnerships (in the context of service design and delivery) would be helpful to assess how this aligns with our own guidance on Shared Decision Making, which will be published shortly.

We would also like to see a more explicit reference to the impact of telemedicine and other digital healthcare advances (including genomic and more personalised forms of medicine) within the scenarios and the impact that this might have on patient accessibility. It may also be worth considering the impact of climate change – as a driver of healthcare demand - to the list of contextual factors considered on page 3.

2. Do you like it? Yes/No

a. Is there any specific feedback you would like to give

The purpose and scenarios are set out clearly, but there could be more detail on how you will achieve the aims. Further detail on effective collaboration and what this looks like for a patient group would also be useful.

Although we recognise the strategy is based on uncertainty, you may wish to prioritise particular areas that patients can influence to promote a better patient experience, identifying what matters most to patients to help do so (and examples of this could include providing practical support to improve communication with health professionals as well as empowering and equipping patients to make better decisions about their care).

Patients are not a homogenous group and different cohorts face particular challenges – an issue that was central to the recent Independent Medicines and Medical Devices Safety Review. The strategy could focus more on understanding the challenges faced by different patient groups with actions delivered either separately or in partnership to help combat these. Furthermore, it may also be helpful to acknowledge that different healthcare systems exist across all four countries of the UK and therefore there may be some local variation in how the scenarios are applied, with local country specific challenges to effective patient engagement and collaboration in each case.

3. What's your reaction to our proposed purpose?

- a. **I like it and think it's achievable**
- b. **I like it but think it's too ambitious**
- c. **I like it but think it doesn't go far enough**
- d. **Other (please specify – free text)** We like it, and think it is achievable, but needs more detail

4. What is the role of patients as partners in health and services?

- a. **The patient as a partner is a critical part of a responsive and compassionate health service**
- b. **The patient as a partner can contribute but clinicians and managers should be the ultimate decision makers**
- c. **The patient as a partner can contribute but patients do not have the expertise to make decisions on multi-million-pound services**
- d. **Other (please specify – free text)**

5. What help do you need to work in partnership with patients?

We are working towards ensuring that our patient engagement is diverse, representative and accessible – to inform this, it would therefore be helpful to understand the Association's view on what 'good practice' looks and feels like when partnering with patients. It would also be helpful to understand how the Patients Association intend to engage patients on the content and focus of the strategy. We would also welcome:

- Guidance from the Patients Association on how the system can support better partnership working with patients
- Support from the Association to obtain a patient's perspective on proposed changes we are seeking to make to our policies and processes. This is particularly relevant when we need to access patient groups with different needs and priorities, for example young people, those with poor health literacy and hard to reach groups.

6. How do you think our strategic aims will affect the way you will work with the Patients Association in the future?

We are keen to increase our engagement and partnership working with the Patient's Association as we develop our corporate strategy and, as part of our aspiration to embed the patient's experience within our work, seek to improve the level and quality of patient and public involvement across all that we do.

We look forward to hearing more about how the Association intends to deliver its strategic purpose and from this, identifying those areas in which we might collaborate effectively to achieve our respective aims.

7. Would you engage with us on the agenda? Yes/No