General conclusions and recommendations

Imagine a healthcare system that is respectful of and builds on the broad cooperation of patient communities.

In a talk delivered at the IEEPO 2021 conference, Bogi Eliasen defined the following key factors for the transformation of healthcare:

- Building a 'global co-operative of health' that includes perspectives from the 'bottom-up' across all levels, priorities and groups/stakeholders
- 50/50 aspiration - investment in primary healthcare systems, disease prevention
- Personalised health is not just about precision medicine; it is also about screenings, early detection, and early intervention as well as related care including services, tools etc.
- Empowering patients to understand and take ownership of their own health and care and how they use their data, transparency, traceability
- Empowering patients to be the bridge builders across disease areas and countries and work together with companies and with public institutions.

The role of cooperation

As Bogi Eliasen and Mary Baker state in the Foreword to this Position Paper, we can only be successful if we work together.

In the past, there has been unnecessary and harmful competition between patient organisations and across disease areas, specifically competition for research attention and resources. However, humanised healthcare and universal health coverage are imperatives that call for multi-stakeholder cooperation and partnering to tackle competition. The work and nature of patient organisations do not fit traditional business logic, and they are based on sharing rather than accumulating resources (Bereczky 2019).

It's crucial to also raise the expertise and knowledge of patient organisations and patient leaders. The role of patients in the healthcare landscape is still largely ignored. Despite some good examples like the Innovative Medicines Initiative and Horizon Europe frameworks of the EU, there is a lot more to do if we want to include patients as the 4th P in public-private partnerships (PPP). However, this requires resources, people, money and technology.

Despite these challenges, if we put our hearts and minds together in true partnership, patient organisations around the world can become the force required to drive transformative change.

13. https://ec.europa.eu/info/research-and-innovation/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe_en

Prioritised calls to action

In conclusion, the IEEPO Position Paper defines the following calls to action as priorities:

- **Patient organisations should facilitate conversations with all stakeholders about the need and value of compassionate care.**
- **Develop strategies that address the current challenges in achieving health literacy by incorporating the specific needs of patient populations so that they are involved in the design, and delivery of solutions. Example challenges include, elderly patients may be socially isolated as a result of the**
- **pandemic, digital illiteracy and the 'digital divide' affects how people access health information and therefore manage their own health.**
- **Patient communities should be empowered to generate data and share insights with both public health authorities and industry, in order to 'have a seat at the table'. They can provide valuable data and patient insights to inform regulatory decisions, such as HTA processes, treatment reimbursement and work with industry to strengthen disease advocacy and medicines research and development.**
- **Governments should be held responsible for driving the synchronisation of care between primary and secondary services to humanise healthcare.**
- **All stakeholders should focus on the humanising of healthcare and how the person in need can become the point of gravity of their work.**

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