

EPF 5 Key Asks

EPF campaign on the European Parliament elections in 2019

The five key messages have been redrafted following feedback from the Leadership meeting in April 2018. The messages are structured as follows:

- Theme
- Key message.
- Supporting paragraph to add some explanation or elaboration of the key message.
- Internal notes to explain the rationale for some revisions.

We would like to avoid changes to the key message itself as it has been carefully drafted following reflection and feedback received. The wording of the supporting paragraph is still more in draft form and will be further refined, comments here are very welcome.

	Enabling the participation of patient organisations in health policy
Message	“Patients’ experience and expertise can make European health policy more effective, efficient and equitable. Patient organisations add real value to health policy and should be appropriately resourced.”
Supporting paragraph	The current EU Health Programme recognises the centrality of the patient perspective in health policy, stating that healthcare practices should be informed by feedback from and interaction with patients. Patient organisations are a vital part of civil society and contribute the unique perspective of patients, which is the most undervalued and underused resource in health systems. They should be represented in all health decision-making bodies at EU and national levels. No health policy decisions should be made without the participation of patient organisations. To enable them to play their legitimate role, patient organisations should be appropriately resourced through sustainable, ethical funding at EU and national levels.
Notes	<i>A slight reformulation of the message, adding “efficiency” to indicate that resources can be targeted in a better way with patient involvement, and with explicit mention of Patient organisations.</i>

Patients' access to care and non-discrimination	
Message	"For a prosperous, inclusive and fair Europe, everyone, everywhere must have affordable access to the healthcare and support/social care they need."
Supporting paragraph	Healthier people contribute to economic growth and wealth. Everyone is able to reach their individual potential for health and well-being when they have timely and affordable access to the full spectrum of care and services, based on need not means. Equitable access boosts growth and contributes to a society that is productive, cohesive and inclusive. Equitable access requires adequate investment, but it is also in itself an investment in the whole of society.
Notes	<i>The original statement focused on "healthy people" – but ignored the fact that patients are not healthy. We rephrased the message by focusing on inclusivity, equitable access and needs/means. "We are all patients" is not a statement EPF can make; we have therefore gone with "everyone, everywhere". Healthy people contribute to economic growth and wealth; this is addressed by the word "prosperous", but also inclusive, and fair (simpler word for equitable). Affordability was added as it is a key aspect of access.</i>

Patient empowerment	
Message	"Only patients know what matters to them most in the management of their health condition. All patients should have the right to define their own goals and participate as equal partners in care, supported by a European <i>bill of patients' rights/charter.</i>" *
Supporting paragraph	Differential access across the EU to empowering care practices and culture of partnership, including shared decision-making and self-care support, is a specific type of <i>inequality</i> in the quality of care. The EU must address this by actively promoting patient empowerment so that all patients everywhere have care that is person-centred and based on the same fundamental patients' rights. We want the EU to adopt a new, comprehensive and up-to-date European <i>bill/charter</i> of patients' rights to bring the currently fragmented rights together in one document, developed together with patient organisations.

Notes	<p><i>The original sentence included the word “normal” but given the comments received and the high potential for misunderstanding that word, we took it out instead using the phrase “what matters”.</i></p> <p><i>* The term “bill of rights” was suggested by a couple of participants; unfortunately it is a US term which we would rather not use, but to use “charter” could risk confusion with the current “European patients’ rights charter”, which was not developed by EPF. We would like your views on the term to be used, as well as for refining this message further. Possibly a reference to health professionals’ training here? Capturing the importance of PE in one sentence is tricky.</i></p>
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Patient-centred digital health	
Message	<p>“Europe’s digital health tools must be patient-driven to really empower people, make better research and build sustainable health systems.”</p>
Supporting paragraph	<p>The purpose of digitalising healthcare is to ensure better and sustainable health systems, but also to make care more person-centred. Patients are the “owners” of their health data, and should be able to freely and easily access all their information as well as decide who to share it with. Electronic health records must be shared and interactive, so that patients can also contribute their own experience and knowledge. Access to safe and high-quality digital tools must be ensured across the EU. Digital health literacy must be prioritised to really enable patients and citizens to get meaningfully involved in the digitisation process.</p>
Notes	<p><i>There were a number of comments on the original sentence. Because it is about more than ownership, we changed “patient-owned” to “patient-driven”. Someone said the messages sounded like advocacy for digital health rather than patient-centeredness in digital health, so we tried to address this also by the “patient-driven” concept. The transition to digital systems is already happening, so the word “future” was deleted.</i></p>

Patient involvement in research	
Message	“Patients’ priorities must drive EU-funded research, with patients as equal and fully-resourced partners.”
Supporting paragraph	To deliver high value and address sustainability concerns, healthcare systems must be driven by patients’ needs and priorities. Meaningful patient involvement in research is a moral imperative – because research directly impact patients’ lives – but also a practical imperative, because a meaningful definition of “value” or “added therapeutic value” is only possible with patients. More research needs to be directed towards non-pharmacological issues, such as patient-centred healthcare models, in order to inform policy and support implementation of good care in Member States. The EU should adopt a coherent framework for involving patients meaningfully, working with patient organisations and compensating their expertise in all EU research funding. Publicly funded research also needs to be fully transparent on its results and data to reduce duplication and waste in research and produce better quality results for patients.
Notes	<i>The message is based on the discussion on the day, emphasising the importance of research on priorities that matter to patients, as well as patients’ role as equal partners with the resources that go with it.</i>