

EPF's Response to the EU's Beating Cancer Plan Public Consultation

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This statement is the European Patients' Forum's response to the European Commission's public consultation on the Beating Cancer Plan. The European Patients' Forum is an umbrella organisation of patients' organisations across Europe and across disease-areas. Our 75 members include disease-specific patient groups active at EU level and national coalitions of patients, among which several large umbrella organisations.

EPF's response highlights several issues which are not addressed in the public consultation questionnaire, but which in our view warrant inclusion in the plan. Our statement has been developed in a consultative process together with our members. EPF welcomes the opportunity to provide input to the development of the EU's Beating Cancer Plan, an initiative which affects many of our members. We hope the Commission will consider our recommendations when defining its priorities for the plan.

Introduction

Cancer¹ is the second leading cause of death and disability in the EU and is recognised as one of the major contributors to premature deaths according to the State of Health in the EU reports, affecting patients, their families, their caregivers, but also the society at large.² Cancer carries with it a huge societal and personal burden due to premature deaths, loss of productivity and the costs associated with treatment and care.³ Access to accurate diagnosis, including diagnostic tests as well as referrals to specialists, has been identified as a major barrier to quality cancer care.⁴

Challenges faced by cancer patients and survivors include those related to their treatment pathway, navigating the health system, as well as quality of life and the ramifications of living with and after cancer. These challenges are often interconnected. Therefore, EPF urges that the beating cancer plan be co-designed with patients to ensure it meets their needs.

Cancer intersects with other chronic diseases in complex ways. Many chronic diseases share the same risk factors, so improving prevention across the board is vital. Moreover, some chronic diseases predispose patients to certain forms of cancer, and cancer patients often have comorbidities. Links between cancer and, for example, chronic liver disease and inflammatory bowel disease are well known, but others are not yet fully understood. A recent study identified chronic disease as "an overlooked risk factor for cancer, as important as five major lifestyle factors combined." Chronic diseases such as heart disease, diabetes, lung and kidney disease contributed to more than a fifth of cancer risk and more than a third of the risk of death from cancer.⁵

With 40% of cancer cases classified as preventable, there is an urgent need to ensure everyone in the Europe has access to a **continuum of services** including health promotion and disease prevention. Moreover, there is also potential to improve prevention of other chronic diseases if effective policy measures are adopted in the plan.

Synergies with existing initiatives will be vital to **avoid duplication and waste of resources**. Close alignment with research initiatives under Horizon Europe, especially its Cancer Mission, as well as the

¹ In this statement we refer to "cancer" as a catch-all term, although in reality there are as many as 200 different types of cancer, and patients with a specific cancers may have specific needs. Our feedback as a cross-disease umbrella patient organisation is based on the commonalities in the experience of patients. The EU cancer plan should address all types of cancers, including those that are less frequent/pediatric cancers and rare cancers in adults.

³ https://www.iccp-portal.org/sites/default/files/resources/ECL-vision-EU-Beating-Cancer-Plan_final.pdf

⁴ EPF [survey report](#) and [position](#) on quality of care, (2016- 2017)

⁵ Tu H et al. (2018) "Cancer risk associated with chronic diseases and disease markers: prospective cohort study", *BMJ* 2018;360:k134.

successor programme to the Innovative Medicines Initiative should be ensured. Moreover, the Beating Cancer Plan should ensure synergies with the EU's strategy on data and the Commission's forthcoming pharmaceutical strategy.

This will require a **well-coordinated transversal and multisectoral approach** (“**Health in All Policies**”) that recognises the role of non-health sectors in shaping the social, economic and commercial determinants of health. Involving cancer patients, patient representatives, health professionals and academia in evidence-based policy making with a focus on research, prevention, diagnosis, treatment, and overall survivorship will be vital. The cancer plan should finally also include a strategy for **evaluation**, with concrete benchmarks and timelines, to gauge its impact.

The ongoing **COVID 19 pandemic** is having an impact on cancer care. A study by UCL estimated that the COVID 19 emergency in England could result in at least 20% more deaths over the next year in patients newly diagnosed with cancer.⁶ The changes in diagnosis and treatment protocols, social distancing measures, change of behaviour in seeking medical attention, and the overall economic impact may have serious indirect consequences on patients. Accordingly, it is essential that the plan takes this into consideration.

EPF's recommendations for a successful Beating Cancer Plan

In EPF's view the EU's Beating Cancer Plan should aim to build on and complement existing actions to concretely improve the situation of cancer patients across the EU. An effective plan should also ultimately lead to **indirect benefits for all chronic diseases**, for example by raising the quality of chronic disease management, improving understanding on the links between diseases, and addressing survivorship issues and non-discrimination. We also see redressing health inequalities across the EU and within countries as an important goal of the plan. Below, we set out our core recommendations from a patient perspective.

1. Access to a holistic range of services

Implementing a true life-course approach implies affordable access to the whole continuum of services, from health promotion and prevention through rapid and accurate diagnosis to prompt, high-quality treatment, appropriate follow-up care and support. The right treatment, given at the right time, not only improves patients' health and quality of life, but can also save costs in the long term.

- **Early diagnosis**

Stark differences in cancer incidence exist across Europe. For example, there are big differences in incidence rates of certain preventable cancers such as cervical cancer. These variations in incidence rates partly reflect differences in national policies regarding prevention and screening.⁷ Patients have identified access to timely and accurate diagnosis as a major gap and a priority.⁸ Harmonised policies across EU member states are therefore needed, with the ultimate goal of ensuring better outcomes.

- Preventive screening should be provided for those cancers for which it exists. All types of cancers, including hereditary and rare cancers as well as rare diseases linked to tumours should be

⁶ <https://www.ucl.ac.uk/news/2020/apr/deaths-people-cancer-could-rise-least-20>

⁷ https://www.oecd-ilibrary.org/docserver/health_glance_eur-2018-en.pdf?expires=1588356727&id=id&accname=guest&checksum=DE1572E5562012999E3B32622D767D5B

⁸ EPF (2017) report of a survey on Patients' perceptions of quality in healthcare, available at <https://www.eu-patient.eu/whatwedo/Policy/quality-of-care/> EPF's findings are in line with the All-Can patient survey of 4,000 cancer patients and caregivers from over 10 countries: <https://www.all-can.org/what-we-do/research/patient-survey/>

included in screening programmes. European Reference Networks (ERNs) for rare diseases/cancers can help provide a list in their respective domain;

- Genetic tests should be available at an affordable price and reimbursed. Identifying patients at risk, irrespective of their age, can enable good surveillance and appropriate clinical management;
- Equal access to vaccines is crucial as evidence from the uptake of the HPV vaccine⁹ demonstrates;
- Access to expert pathologist is also crucial to ensure timely and accurate diagnosis and thus adequate treatment. Expert pathologists/centres should be identified in each member state for timely referrals;
- Access to a second expert opinion should also be an available option;
- For each type of cancer, optimal monitoring based on evidence-based recommendations should be accessible for all patients wherever they live in the EU;
- The cancer plan should engage with the EU strategy on data and Artificial Intelligence and include implementation of effective, safe and high-quality AI systems to support early diagnosis of cancer.

- **High-quality treatment and multi-disciplinary care**

Every patient has a right to treatment that is tailored to their individual needs and preferences. Shortcomings in care highlighted by patients include the lack of a comprehensive multi-disciplinary approach to cancer care, considering the psycho-social needs of patients, and quality of life through support, rehabilitation and palliative care.^{10,11}

A tailored approach to patient care includes also access to **personalised (precision) medicine** where the patient can benefit from this, and the necessary diagnostic tests to determine the best treatment options. Personalised medicine presents enormous promise, with insights from genomics and other -omics gradually leading to a more individualised approach to treatment; precision diagnostics will make it possible to detect and treat diseases at an early stage with higher effectiveness, better tolerability and fewer side effects; and personalised prevention based on an individual's risk profile will enable targeted prevention, so that ultimately many may never become "patients" at all. However, progress in translating personalised medicine into standard care is slow and patchy, and the real value of some new treatments has been sometimes called into question.¹² Thus while we call for better embedding of personalised / precision treatments into patient care and equal access for patients to these treatments, there is also a need for accompanying actions to improve health literacy and communication about the benefits and risks of precision therapies, and fully informed, shared decision-making. Aspects that need to be considered also include medicines shortages, off-label use of medicines, medication errors, and the risks of handling of cytostatic or chemotherapeutic agents for patients and their families.

Shared decision-making is a vital cornerstone of person-centred care and a fundamental patient's right and should be applied every time an important decision needs to be taken – whether to attend screening, have a genetic test, or choose between different treatment options. Regrettably, being fully

⁹ <https://www.epfweb.org/node/965>

¹⁰ https://www.oeci.eu/Attachments/Policy_Statement__Multidisciplinary_Cancer_Care_02-12.pdf

¹¹ 2008 council conclusions on reducing the burden of cancer

¹² <https://scienceblog.cancerresearchuk.org/2019/06/19/nhs-to-fast-track-new-personalised-cancer-medicines-but-its-not-ready-quite-yet/>; « The promise and the hype of 'personalised medicine' ». Tim Maughan, *The New Bioethics*, Vol. 23 No. 1, 2017, 13–20.

https://www.researchgate.net/publication/317083364_The_Promise_and_the_Hype_of_'Personalised_Medicine'

involved in decision-making regarding one's own health is still not a reality for many patients even in countries with highly-developed healthcare systems.¹³

A systematic assessment of **health-related quality of life**, including physical, mental and social health, nutritional status screening and optimal nutritional care for cancer patients have also been highlighted as important components. Improved attention to mental health aspects is recurrently cited by patients as a cornerstone of cancer care which is, for the most part, insufficiently attended to today.

The establishment of 24 European Reference Networks for rare diseases, including four ERNs relevant to rare cancers (EURACAN, PaedCan, EuroBloodNet and GENTURIS) has been a major step forward in bringing together **expertise from across the EU** to enable faster access to accurate diagnosis and high-quality treatment. The involvement of patient representatives in ERNs is a major asset to bring in the patients' experience and knowledge of diseases and establish partnerships with clinicians to further improve treatment and follow up care. EPF recommends that this model could be also applied to non-rare cancers and other chronic diseases with a significant disease burden in order to improve the standard and accessibility of treatment.

Greater attention should be paid to **collaboration between disease-specialists**, ensuring all patients benefit from multi-disciplinary care teams, and to improving the quality of care for cancer patients who also have other chronic health conditions – multimorbidity is a growing trend and requires well-coordinated care shaped around patients' holistic needs and preferences. Multi-disciplinary teamworking implies a need for changes in the education and training of healthcare professionals and the need for embedding patients in professional education.¹⁴

- **Follow-up care and survivorship issues**

Patients with cancer face many challenges whilst undergoing treatment and when the active phase of treatment is completed. These include having rehabilitation and psychological support, the necessary flexibilities to be able to return to work, protection from discrimination in the workplace, affordable access to insurance, and support for carers. These add to the burden of the diagnosis, the disease itself and the treatment, not only on an individual patient but on the whole family.

There is still no implementation across the board of **long-term follow-up care plans for cancer survivors**. The harmonisation of EU health systems and incentivising member states to implement the European Code against Cancer recommendations, applying CanCon best practice model of Comprehensive Cancer Care Networks (CCCNs),¹⁵ the integration of European Reference Networks (ERN) into national healthcare systems, and the adoption of the Joint Action on Rare Cancer (JA RC) recommendations¹⁶ are the cornerstones for moving forward.

Moreover, whilst advances in cancer treatment have led to longer survival of patients, they have also led to more long-term side effects, for example, an increase in cardiovascular disease in cancer

¹³ Richards T (2017) « The responses to the 'cancer drugs scandal' must fully involve patients", *BMJ* 2017;359:j4956.

European Patients' Forum (2017) Patient Empowerment Toolkit, <https://www.eu-patient.eu/globalassets/library/publications/patient-empowerment---toolkit.pdf>

¹⁴ "Patients as teachers – what can patients teach professionals?", Report of the EPF Congress, 2019. <https://www.eu-patient.eu/globalassets/events/epfcongressreport.pdf>

¹⁵ Comprehensive cancer care networks – Test driving the model in southern Czechia, March 2019, <https://cancerworld.net/spotlight-on/comprehensive-cancer-care-networks-test-driving-the-model-in-southern-czechia/>

¹⁶ Rare cancers' policy: A comparative analysis of the priorities and recommendations on rare and paediatric cancers based on National Cancer Control Programmes (NCCPs), Rare Diseases Plans, EU funded initiatives and priorities for patients' organisations, 2019, [link](#).

survivors.¹⁷ These relationships between cancer and comorbidities should be further studied and understood and incorporated into long-term treatment and monitoring.

2. Reduction of health inequalities

Tackling access barriers and redressing health inequalities should be, in our view, an explicit goal of the EU plan. The European Union and the EU Member States are committed to achieving the **UN Sustainable Development Goals**. One health target under Goal 3 “ensuring healthy lives and promote wellbeing for all at all ages” call for universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all by 2030.¹⁸

However, the 2018 State of Health in the EU country health profiles and the 2019 companion report¹⁹ show how **gaps in access to healthcare** are undermining universal health coverage across the European Union, in every country. Patient organisations have long been aware of these gaps. EPF’s work with its membership has found that many patients face access barriers, from getting a diagnosis to being able to consult a specialist. When starting treatment is delayed, patient’s quality of life and functioning is affected, and overall costs to the health and social system are likely to increase.²⁰ In 2017, European Union leaders in 2017 proclaimed the European Pillar of Social Rights. Principle 16 of the pillar states that “Everyone has the right to timely access to affordable, preventive and curative health care of good quality”.²¹ EPF recommends that this right be fully implemented, and that access to care²² be adopted as a key indicator when monitoring the European implementation of the 2030 Agenda.

Member States should implement **evidence-based policy measures to reduce access barriers**. Recent research by the WHO shows choices of coverage policy have a significant impact on access, especially policies on reductions, exemptions and caps on co-payments and eliminating user charges.²³

The adoption of a strong EU-level framework on **health technology assessment**, including uptake of joint clinical assessments by Member States, could significantly improve equal access to high-quality treatments. Mechanisms for meaningful patient involvement in HTA need to be improved both at national and European level to ensure decisions are fully informed by patients’ needs and preferences.²⁴

Better implementation of the **cross-border healthcare directive** can reduce inequalities in patients’ access to treatment in cases where treatment in their home country is either not available in a timely manner or of adequate quality. Equally important is more effective use of the **Regulation** on the

¹⁷ “Making cancer-related comorbidities an EU health priority”, https://www.escardio.org/static_file/Escardio/Advocacy/Documents/Joint-statement-Making-cancer-related-complications-comorbidities-EU-health-priority.pdf

¹⁸ <http://www.who.int/sdg/targets/en/>

¹⁹ https://ec.europa.eu/health/sites/health/files/state/docs/2019_companion_en.pdf

²⁰ https://www.eu-patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf and <https://www.eu-patient.eu/globalassets/policy/quality-of-care/quality-survey-report.pdf>

²¹ https://ec.europa.eu/commission/sites/beta-political/files/social-summit-european-pillar-social-rights-booklet_en.pdf

²² Access to care should be monitored using patients’ experiences and indicators co-developed by patients in order to capture the true accessibility of healthcare accurately.

²³ Can people afford to pay for health care? New evidence on financial protection in Europe, WHO, <http://www.euro.who.int/en/publications/abstracts/can-people-afford-to-pay-for-health-care-new-evidence-on-financial-protection-in-europe-2019>

²⁴ EPF’s position of the Commission’s proposal for a Regulation on health technology assessment, <https://www.eu-patient.eu/globalassets/policy/hta/epf-position-statement-on-hta.pdf>

coordination of social security systems²⁵ by member states. Patients do not generally want to travel for treatment, but for those who do need to, these options should be used to their maximum benefit.²⁶

Access to clinical trials across borders, which is outside the scope of the cross-border healthcare legislation, is often the only way some cancer patients can have a chance at treatment. This topic has been recently explored in a study²⁷ and the findings should be considered in the EU cancer plan to plug an important access gap.

Inequity in **access to medicines** is a major access barrier. Medicines form a key aspect of treatment for many cancers. New and better medicines hold the promise of significant improvements to health and quality of life, or even a cure. Due to these advances, many patients with cancer can now expect to live longer, though progress is faster in some cancers than in others.²⁸ However, unacceptable disparities in access persist; it can take years for patients to have access some medicines in some parts of Europe after the granting of marketing authorisation.²⁹ At the same time, there are concerns about the costs of new medicines.³⁰ Prices of cancer medicines are growing at a faster rate than others, putting health equity at risk.³¹ EPF will shortly publish its updated recommendations on the pricing and value of innovative medicines from a perspective across diseases, building on our 2016 proposals for a framework for fair and equitable access and calls for equitable and affordable access to medicines to be explicitly included in the development of the EU cancer plan.

- **Health literacy**

A **health literacy strategy** should form a fundamental building block of the EU cancer plan. Health literacy – the ability to make sound decisions about one’s health in everyday contexts – is a key aspect of patient empowerment, as well as a patient’s right and a determinant of health. Health literacy is also a fundamental strategy in redressing health inequalities and in effective prevention strategies.³² People with higher health literacy have healthier behaviours, report less chronic disease, are more adherent to treatment, feel healthier and live longer. Conversely, low health literacy associates with less use of preventive and chronic disease management services and greater mortality. The costs of low health literacy are thought to be substantial and have been estimated to account for 3-5% of total system costs.³³ It is, however, important to bear in mind that health literacy cannot be tackled only by addressing individuals with more education and information. It is a profound challenge for healthcare systems and organisations, for example to communicate better with users, to design more easily

²⁵ Regulation on the coordination of social security systems, <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A02004R0883-20140101>

²⁶ EPF Position on the cross-border healthcare directive, https://www.eu-patient.eu/globalassets/policy/cross-borderhealthcare/epf_position_statement_cbhc_220416.pdf

²⁷ <https://www.theparliamentmagazine.eu/articles/event-coverage/eu-cancer-group-calls-better-cross-border-access-clinical-trials>

²⁸ OECD (2018) Pharmaceutical Innovation and Access to Treatment, pp. 27-30 with many more examples. Available at <http://www.oecd.org/health/pharmaceutical-innovation-and-access-to-medicines-9789264307391-en.htm>

²⁹ Akehurst et alii: “Variation in Health Technology Assessment and Reimbursement Processes in Europe” in: Value In Health, 20, 2017

³⁰ WHO news release at the close of the Fair Pricing Forum, 18 April 2019. <https://www.who.int/news-room/detail/13-04-2019-at-who-forum-on-medicines-countries-and-civil-society-push-for-greater-transparency-and-fairer-prices>

³¹ WHO (2018) “Pricing of cancer medicines and its impacts”, Technical Report. Available at <https://apps.who.int/iris/bitstream/handle/10665/277190/9789241515115-eng.pdf?ua=1>

³² Roediger A et al. (2019) “Nothing about me without me: why an EU health literacy strategy embracing the role of citizens and patients is needed”, *Archives of Public Health* vol.77, no: 17. <https://archpublichealth.biomedcentral.com/articles/10.1186/s13690-019-0342-4>

³³ Consensus paper: Making health literacy a priority for in EU policy, https://www.eu-patient.eu/globalassets/policy/healthliteracy/health-literacy-consensus-paper_2016.pdf

navigable pathways, and to meet the needs of all people including those with low health literacy. Thus health literacy considerations should be embedded in all aspects of health systems.³⁴

3. Research and innovation for the benefit of patients

The EU should support **research focused on patients' unmet needs**, including groups that are under-represented in research such as women, older people, children, and patients with rare cancers. Adequate investment in epidemiological, biomedical and genetic research should be secured. The EU Beating Cancer Plan should ensure close synergies with the research programmes – Horizon 2020 and the successor programme of IMI – as well as the EU's strategy on data; the latter aims to improve possibilities for sharing data safely and to pool data across Europe for research, including the development of personalised medicine and supporting the repurposing of existing medicines.

The **involvement of patients** in research improves discovery, development and evaluation of effective medicines based mainly on the collaboration approach of identifying and understanding the needs, gaps, research priorities and other elements throughout a medicine lifecycle. The importance and added value of involving patients in research in the oncology field has already been demonstrated.³⁵ The IMI-funded project PARADIGM is currently driving good practice in patient engagement in pharmaceutical research and development; good practices derived inter alia from such projects urgently need to be mainstreamed.³⁶ In addition, the EPF-led European Patients' Academy on Therapeutic Innovation (EUPATI) has since 2012 focused on educating patient advocates and the wider public on medicines research and development.³⁷

Once treatments are approved for use, there is a lack of **real-world evidence** on how well they work for patients in real-life conditions. Further research is needed to fill the gap. Treatment optimisation refers to applied research studies that seek to provide answers to questions such as how to combine a new treatment with existing ones, comparative effectiveness of alternative treatments, optimal duration of treatment should be to maximise benefits and minimise side effects, and how treatments impact patients' quality of life and overall survival. This is becoming an important question as treatment advances have led to longer survival of patients with cancer, but also to more **long-term side effects and comorbidities**.³⁸ These relationships should be further studied and understood. Applied research is a necessary complement to the current clinical trials framework and usually done by academic/non-profit institutions or public-private partnerships.³⁹

Finally, as we have emphasised above, **patients' needs go beyond medicines** and include other therapeutic options, social and community services and peer support. Thus "innovation" should be supported in this wider sense, encompassing better ways of structuring and delivering integrated

³⁴ Kickbusch et al., eds. *Health Literacy. The Solid Facts*, World Health Organization 2013.

<https://apps.who.int/iris/bitstream/handle/10665/128703/e96854.pdf>

³⁵ Patients Involved – Collaboration in an oncology trial: <https://www.eupati.eu/clinical-development-and-trials/patients-involved-collaboration-in-an-oncology-trial/>

³⁶ PARADIGM (<https://imi-paradigm.eu>) goes beyond clinical research: its outputs will include guidance for HTA bodies to facilitate patient involvement in early dialogues; fair market contractual agreements; recommendations on capacities and capabilities to operationalise patient engagement activities and recommendations on how to identify the right match(es) for the right activity. Outcomes of PARADIGM will be published towards the end of 2020.

³⁷ <https://www.eupati.eu/>. The EUPATI public Toolbox has been used by 3.5 million users worldwide.

³⁸ "Making cancer-related comorbidities an EU health priority", https://www.escardio.org/static_file/Escardio/Advocacy/Documents/Joint-statement-Making-cancer-related-complications-comorbidities-EU-health-priority.pdf

³⁹ Treatment optimisation in drug development. Study for the European Parliament's Panel for the Future of Science and Technology. European Parliamentary Research Service, Scientific Foresight Unit (STOA) PE 641.511. March 2020.

health and social care; more efficiency and effectiveness; social innovation; and the development and effective use of new user-driven technologies.

The development of an appropriate frameworks, methodologies, and funding for applied clinical research and non-pharmacological health research to improve patient care should be addressed as part of the EU Beating Cancer Plan. **Co-production with patients** should be adopted as an explicit condition for obtaining EU research funding, and for good practice guidelines should be developed with patient organisations to avoid tokenism.

4. Better data to inform policy

The EU health statistics framework, while extensive, has several gaps and thus fails to capture many aspects of healthcare access and quality of care that matter to patients. The OECD countries' health ministers recognised in the 2017 statement that data generated by health systems focus too much on system inputs and activities, and not enough on the outcomes of care and patients' experiences of care. "Opportunities for cross-country comparative analysis of outcomes are also very limited, hampering the capacity of policy makers to gain new knowledge that would help them provide health services shaped around patients' needs. Such information is pivotal to delivering health services that are truly responsive to patients. This is a major gap in international health statistics requiring urgent attention."⁴⁰

Patient organisations have a wealth of knowledge gained over years of work with their grassroots communities. Their engagement in both quantitative and qualitative research is needed to understand the access barriers experienced by patients in a more granular way, in particular groups that are vulnerable to discrimination in healthcare. The co-production of new indicators for inclusion in the EU health statistics should then be considered to guide result-oriented policy solutions.⁴¹

On quality of care, **appropriate measures** for patient-reported (patient-prioritised) outcomes and experiences of care should be co-developed with patients to assess and benchmark the quality of care. Patient experience measures are needed to assess how well the healthcare process works for patients. These areas are starting to be addressed by the OECD PaRIS surveys, which currently include a specific survey on breast cancer, and should be further supported.⁴²

There is a need to sustain and develop disease-based **patient registries**, make them interoperable, and develop new ones where there are knowledge gaps. Patient organisations should play a central role in the architecture of such registries to ensure they capture outcomes that matter.

5. Meaningful patient involvement

As we have outlined above, meaningful patient involvement is needed at all levels of the health system in order for policymakers, regulators and industry to gain knowledge on what is important to patients. This is fully in line with the commitment of OECD – including EU – countries to include the patient perspective in assessing the performance of their health systems.⁴³ Investment is needed in **frameworks, structures and methodologies for meaningfully incorporating patients at all stages**,

⁴⁰ Recommendations to OECD ministers of health from the high level reflection group on the future of health statistics. Strengthening the international comparison of health system performance through patient-reported indicators. OECD, January 2017.

⁴¹ EPF's Roadmap towards achieving universal health coverage for all by 2030, <https://www.eu-patient.eu/globalassets/campaign-on-access/taking-action---a-roadmap-to-achieving-universal-health-coverage-for-all-by-2030.pdf>

⁴² <https://www.oecd.org/health/paris.htm>

⁴³ OEC 2017, as above.

from setting research priorities to clinical research, regulatory assessment, health technology assessments, pricing and reimbursement decisions, through to pharmacovigilance and patient safety more generally, and real-world evidence collection.

A common understanding is needed on the concepts of “innovation”, “value” and “added therapeutic value”. Patients’ views should be central to this understanding, including patients’ perceptions of quality of life and their ability to participate in society, patient-relevant clinical and quality-of-life endpoints, patients’ views on benefit/risk and standards of care. There should be a commitment to ensuring that patient-prioritised and co-developed outcome measures including PROMs and patient-prioritised endpoints are embedded in clinical and translational research, in order that new treatments meet patients’ needs better. Work undertaken by the OECD PaRIS project can provide guidance in this regard.

6. The essential role of patient organisations

Patient organisations have unique expertise, experience and outreach to their communities and play an invaluable role from prevention, early diagnosis and screening, to treatment and supporting quality of life after cancer. Good practices and initiatives developed by patient organisations include the ECPC’s Living Well During Cancer Treatment, Nutrition Patient Handbook;⁴⁴ the Men’s Health Forum’s guide to support men staying or returning to work after a cancer diagnosis;⁴⁵ ESMO-ECPC Survivorship Guide;⁴⁶ All CAN’s The ‘right to be forgotten’ for improving access to loans and insurance for cancer survivors;⁴⁷ and the network of informal leaders of cancer patient organisations WECAN.⁴⁸

EPF is in a unique position being the only European-level, non-disease specific umbrella patient organisation. Working in concert with our membership, we convey a coherent patient perspective and support the empowerment of patients as effective, credible civil society actors and partners in shaping participatory and inclusive health systems. Through our Youth Group and youth training programme, we nurture a future generation of patient leaders. EPF plays a leading role in defining what constitutes meaningful patient involvement in health policy, projects⁴⁹ and research, *inter alia* through our leadership of the PARADIGM project and EUPATI. Thus, EPF can support the implementation of good practices in healthcare policy and practice that work for patients and ensure synergies and learnings from the cancer plan can be applied across all chronic diseases, while existing best practices from the chronic disease field can inform the activities of the cancer plan.

⁴⁴ <https://ecpc.org/wp-content/uploads/2019/08/ecpc-nutrition-booklet-living-well-during-cancer-treatment-3.pdf>

⁴⁵ <https://www.menshealthforum.org.uk/news/men-work-cancer>

⁴⁶ <https://www.esmo.org/content/download/117593/2061518/1>

⁴⁷ <https://www.all-can.org/efficiency-hub/the-right-to-be-forgotten-improving-access-to-loans-and-insurance-for-cancer-survivors/>

⁴⁸ <https://wecanadvocate.eu/rapp/>

⁴⁹ Value+ policy recommendations: https://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_policyrec.pdf