

Europe's Beating Cancer Plan Consultation **an Overview**

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Other strands of consultation have been managed separately by the respective DGs and committees, with NIVEL carrying out a survey of EU Member States (MS) for the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases (SGPP) and SANTE.

List of abbreviations

CCCN	Comprehensive Cancer Control Networks	ePAG	European Patient Advocacy Group
CCJA	Cancer Control Joint Action	ERNs	European Reference Networks
DG RTD	Directorate General Research and Innovation	HiAP	Health in All Policies
DG SANTE	Directorate General Health and Food Safety	IARC	International Agency for Research on Cancer
EBCP	Europe's Beating Cancer Plan	iPAAC	Innovative Partnership for Action Against Cancer (iPAAC) Joint Action
ECAC	European Code Against Cancer	JA	Joint Action
ECCO	European Cancer Organisation	JRC	Joint Research Centre
ECIBC	European Commission Initiative on Breast Cancer	NCCP	National Cancer Control Programmes
ENCR	European Network of Cancer Registries	NCD	Non-Communicable Diseases
ENVI	European Parliament's Committee on Environment, Public Health and Food Safety	PA	Patient Association
EPAAC	European Partnership for Action Against Cancer	PREM	Patient-Reported Experience Measures
		PROM	Patient-Reported Outcome Measures
		SGPP	Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases

Key messages

1. **Europe, its citizens, the cancer community, public health professionals and other stakeholders have high expectations of the EBCP.** The EBCP has been enthusiastically received across the cancer community. Stakeholders appreciated being consulted by DG SANTE and actively sought to shape the plan. All groups stressed the importance of the EU dimension in tackling cancer; the value of a comprehensive approach; and the need to implement effectively.
2. **Addressing the whole cancer continuum is a particular strength.** One of the most highly rated aspects of the EBCP was that the plan covers all of cancer control: from prevention; early detection and diagnosis; treatment and care; to the quality of life of cancer patients, survivors and carers. This 'holistic' approach was widely seen as adding value and relevance.
3. **The convergence of synergies with other EC initiatives is a potential asset.** The fact that the EBCP intersects with other EC initiatives was seen to create huge scope for concerted action. Some of the examples highlighted were: the ENVI committee inputs; the recommendations of the Horizon Europe Cancer Mission Board; the consensus, deliverables and Roadmap arising from the iPAAC Joint Action; the Joint Research Centre's (JRC) initiatives; and the implementation and update of the European Code Against Cancer (ECAC).
4. **Addressing risk factors from a Health-in-All-Policies perspective is central to primary prevention and a unique opportunity within the EU.** The cancer community acknowledged that tackling risk factors in a cohesive way is a huge

challenge but hold that it is essential to the primary prevention pillar. They believe that the EU is a unique context in which comprehensive actions are possible across sectors and issues. Stakeholders hope the EU will leverage its ideal position to align the efforts of its various directorates and policies and support actions across the widest spectrum of actors in order to reduce risk factors and help prevent cancer.

5. **The benefits of addressing cancer prevention are expected to pay dividends in many other chronic non-communicable diseases (NCDs).** Respondents highlighted that many of the risk factors for cancer overlap with those for other NCDs. Facilitating the primary prevention of cancer will therefore have wider impacts and advantages for other chronic NCDs, including cardiovascular and respiratory diseases, as well as diabetes.
6. **There was support for an EU role in optimizing existing screening programmes while new programmes are under development.** The community was positive about the EU's part in the development of new, effective and efficient screening programmes. They also felt that the EU should use the inevitable 'waiting time' as new protocols are validated, to improve the existing programmes in Europe, strengthening organization, quality standards and controls.
7. **The EU has a very positive role to play in early detection.** Stakeholders believe that the EU makes a major contribution in promoting evidence-based best practices; in focusing on quality; in prioritizing equity of access to early detection; and in establishing a model of standardization to promote quality overall.
8. **The EU is well placed to identify best practices, treatment and patient pathways across a complex and heterogeneous field.** Stakeholders agree that the diversity of cancer types means there is a real added value in work at the EU level to promote common approaches. The EU is seen as being in a strong position to provide solutions by identifying best practice, as well as by defining treatment and patient pathways stratified by cancer variety. The EU added value goes beyond treatment to wider patient pathways, covering the entire trajectory, including survivorship and social experience.
9. **The European Reference Networks (ERNs) were valued by a wide mix of stakeholders as a**

pioneering and powerful tool for tackling the issues. Those consulted acknowledged that ERNs were designed to be drivers of research and test beds for innovation for rare diseases, not least paediatric and rare cancers. There was nonetheless widespread support for building on the model to go beyond rare cancers. ERNs, provided they were more adequately funded, were seen as a powerful way of sharing best practices, research and guidelines; of promoting collaboration; and of tackling difficult to treat malignant tumours.

10. **Instruments to support survivors were important, with respondents insisting that they be developed (and implemented) in ways that reflect patient experience.** Those consulted highlighted that the range of instruments, from survivorship follow-up, care plans and infrastructures to interoperable IT tools, must take into account the experience of patients. It was felt the EU should support this to help ensure that the capacity to implement and deliver was put in place across Europe and that best practices in care were rolled out equitably.
11. **Access and equity are uneven both within and between countries across Europe and stakeholders hope the EU will address this.** A range of those consulted, with a mix of perspectives, all voiced concerns about access to cancer services. They recognized the responsibility of national authorities for provision but felt strongly that the EU also has a key role to play in promoting equal access to comprehensive support across the four pillars. Most of those consulted agreed that the EU should be looking at equity issues, within countries and between EU MS, including equality of access across the population and for vulnerable groups, including cancer survivors. Paediatric cancers were specifically flagged as an area for concern, because of the importance attached to them by the public consultation, but also because survival rates are markedly uneven across the EU.
12. **The EU is believed to have a key role in cancer research.** Those consulted felt investing in research had always been an EU flagship and that support for cancer research was particularly important. Respondents felt coordinated European action (built around the recommendations of the Mission Board) will make it possible to find solutions to existing and emerging challenges more efficiently, effectively and rapidly.

Background

Objectives of the overview

This overview presents the outcome of consultations conducted by the European Commission during the development of the ‘Europe’s Beating Cancer Plan’ (EBCP).

The Commission organized three main strands of consultation to ensure open and inclusive discussion with a wide range of stakeholders (individuals, organizations, networks and critical informants) to share their view. It also carried out additional consultations with Member States. This overview aims to:

- Summarize the key findings of the three consultation strands:
- Consultation on the Roadmap
- Open public consultation
- Targeted stakeholder consultation;
- Capture the cross-cutting conclusions, highlighting main themes, perceptions and concerns;
- Flag the parallel work of other consultations including the ENVI committee; the SGPP consultation with MS; iPAAC; and DG RTD’s Mission Board amongst others;
- Draw out the implications of the consultation to inform the development of the Cancer Plan; and
- Inform the public about the outcome of the consultation.

Synthesis of consultation stages

This section brings together the main findings from all three strands of the consultation as well as the views of the MS and of MEPs as captured by DG SANTE discussions directly with them.

Summary 1: The Roadmap consultation

The consultation was carried out between 04/02/2020 and 03/03/2020 with respondents invited to contribute to the shaping of the Roadmap.¹ The questionnaire was designed by the DG SANTE Cancer Team, who also collected and analysed results. Full results are in the factual report.²

The respondents broadly endorsed the EBCP initiative. There was particularly strong support for the Prevention Pillar (tobacco legislation and workplace exposure to environmental risk factors) but also overall enthusiasm for each of the other pillars. A number of suggestions were made on strengthening the EBCP and some well supported 'themes' emerged where those consulted felt the EBCP might place more emphasis. These were:

- Paediatric cancers, including innovation in medicines, work on genetic mutations that play a role in cancer and survivorship strategies;
- Integration of Real-World Evidence data platforms and technological innovations (AI) for personalized care;

¹ European Commission (2020) Europe's Beating Cancer Plan Roadmap Ares(2020)693786. <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Plan>

² European Commission (2020) Europe's Beating Cancer Plan: factual report from the Roadmap consultation.

- Improving training standards for medical professionals;
 - Health literacy for patients, carers and citizens;
- Equal opportunities for EU citizens to access cancer prevention and care;
- Sound monitoring and surveillance systems at EU level to inform policies; and
 - Sharing of best practices by MS within the EU.

Summary 2: The public consultation

The consultation took place online between 04/02/2020 and 22/05/2020, and invited respondents to contribute to the shaping of cancer policies at the EU level. The questionnaire was designed by the DG SANTE Cancer Team, who also collected and extracted responses. The Observatory analysed online responses and looked at additional responses received after the closing date or offline (n=26). Results are presented in detail in the Public consultation factual report.³

Overall the public consultation attracted a wide mix of inputs with participation from citizens and organizations from all EU countries and beyond. There was some evidence of concerted responses by particular interest groups, but these were not of a scale to undermine the results. There was clear consensus in many areas and nearly all who replied stated the EU should do more to address cancer across all four pillars. There was also considerable support for additional focus on

- Paediatric cancer;
- More emphasis on tackling risk factors particularly alcohol;
- Tax and regulation of the alcohol industry;
- Setting care standards across MS; and
- Monitoring the implementation of EBCP.

Respondents wanted to see effective implementation with improvements reflected in population health and user experience outcomes, and in increased support for people affected by cancer.

Summary 3: The targeted stakeholder consultation

Key stakeholders were identified based on relevant expertise and their ability to represent a wide group of cancer stakeholders or a broad European perspective. The consultation meetings (focus groups, n=6) and supplementary interviews (n=4) were carried out between 20/07/2020 and 08/09/2020. Results are set out fully in the Targeted stakeholder consultation factual report.⁴

Focus groups were organized around stakeholder type: patient representatives, international agencies, the cancer community, public health, professional associations, and bio-med-tech industry. Participants took part in facilitated discussions and addressed questions that reflected on the EBCP Roadmap (see factual report). A record of the meetings in the form of key messages was sent to all invitees for further comment before consolidation and analysis.

Results were wide ranging and well represented in this overview and its key messages. They generated rich, in-depth and focused views as well as detailed thematic inputs and do not lend themselves to summary but key themes grouped by pillar were as follows:

- Prevention: a 'Health in All Policies' approach; comprehensive and multi-sectoral action on risk; promoting healthy behaviour; action on: alcohol, tobacco and food; environmental and occupational risk; commercial determinants of health; and protection for young people.
- Early detection and diagnosis: equitable early diagnosis; high quality diagnostics; guidelines, standard setting and regulation; improved screening; quality assurance; sharing of best practices; improved data collection; monitoring, research and analysis.
- Treatment and care: standards, guidelines and quality assurance; rare and paediatric cancers; multimorbid and geriatric patients; European Reference Networks; patient experience in pathway development; mental health; multidisciplinary care teams; communication; workforce education and shortages; investment in key areas; and research.
- Life after cancer: physical, medical, psychosocial, employment and wider needs of survivors; integrating survivorship into the cancer pathway; follow-up care; long-term side-effects and

3 European Observatory on Health Systems and Policies (2020) Europe's Beating Cancer Plan: factual report from the public consultation

4 European Observatory on Health Systems and Policies (2020) Europe's Beating Cancer Plan: factual report from the targeted stakeholder consultation

co-morbidities; stigma, discrimination and financial implications; and needs of younger patients, families and carers.

Additional and cross-cutting issues included fostering EU synergies; promoting best practices and quality; data and information exchange and interoperability; research coordination; encouraging innovation and health technology assessment. There was also shared support for the EU's role on equity and vulnerable groups (including the impact on them of socioeconomic determinants of risk); communication and health literacy.

Summary 4: The SANTE consultation with Member States

SANTE worked with NIVEL to develop a short survey for members of the SGPP, drawing on the previous rounds of consultation. The survey took place in July 2020 and aimed to understand how MS see priorities in cancer and to get an insight into the types of actions MS consider part of an EU level response. The report summarizing the survey results is based on the 19 MS responses received by 28 August 2020. Key findings were:

- The four main pillars of the EBCP were of high national priority; and
- Knowledge, data and scientific evidence were identified as an additional pillar and one where the EU-wide approach is particularly effective.

MS saw the particular added value of the EU in specific areas as being around:

- A generational approach to prevention;
- Environmental pollution and tobacco (for prevention);
- Quality and timeliness of screening (for early detection);
- Access to medicines and treatments (for treatment); and
- Quality of life of cancer survivors and social protection for survivorship.

Additional areas of concern mentioned were:

- Equity in access to treatment (particularly in relation to paediatric cancers);
- The impact of COVID-19; and

- Consistency (or lack of consistency) in EU regulations on alcohol, tobacco and unhealthy diet.

Pillar 1: Prevention

If there is one pillar that respondents across all forms of consultation think is an essential part of the Europe's Beating Cancer Plan, it is primary prevention. There is consensus that the EBCP should address all cancer risk factors and prevention interventions.

A 'Health-in-All-Policies' (HiAP) perspective is a considered a unique opportunity within the EU:

There was unanimity across the different stakeholders consulted that addressing prevention means going beyond the health system to all policies within society. This is an area where the EU is seen to have a very significant added value with its responsibilities in (amongst other areas) agriculture, climate action, education, employment and social affairs, environment and trade. Those consulted advocated structural action to foster an environment that facilitates healthy behaviours, as well as health promotion and education actions to allow people to make the healthiest choices. They wanted the EBCP to take up the HiAP opportunities and foster synergies with other EU initiatives.

The cancer community sees the EU (and an HiAP perspective) as having a key role in addressing risk factors:

Respondents typically felt that the EU has made a remarkable effort in **tobacco prevention and control** (although many flagged that there was still work to be done) but identified the **regulation of alcohol** as an area where the EU could do much more (on pricing, marketing and labelling). It was also agreed that urgently targeting **physical inactivity** and **obesity** through prevention efforts was a priority. There were repeated demands for EU action on unhealthy foods and for more environmental regulation. There were also references to the value of reducing air pollution, carbon emissions and the use of plastic – and of leveraging cross-cutting policies such as the Green Deal and Farm-to-Fork Policy.

In relation to the above, the **commercial determinants of health** were frequently identified as something the EBCP might address in a tangible way both by flagging the risks around vested interests and by encouraging and recognizing transparent, quality and patient-oriented practices. There were some calls to ensure more transparency and rigour in control of companies to minimize harmful practices and promote quality, socially beneficial models and approaches. Others expressed the

hope that the Green Deal would consider social justice dimensions and protect vulnerable populations. It was also suggested by some that the EU should promote better **regulation of cross-border marketing and (digital) advertising**, with regulatory instruments to help MS.

Many of those consulted emphasized the links to the risks for other non-communicable diseases (NCDs) and some advised that the EBCP should encourage MS to apply the WHO's 'best buys' on NCDs.

Stakeholders consistently cite the European Code Against Cancer (ECAC) as a useful tool: ECAC aims were seen to chime with the HiAP perspective. Some respondents felt its collaborative nature and the link to the International Agency for Research on Cancer (IARC) was a virtue. The public consultation also called for ECAC to be widely implemented (evaluated and updated) and for the next iteration to be developed synergistically and in the context of the EBCP, perhaps with tailored messages and pragmatic guidance for decision-makers and explicit EBCP support for the tools offered by the ECAC.

Respondents urge openness, learning and collaborative links: Those consulted agreed that the EBCP depended on the political will and consensus to carry it out. There were frequent references to the need for systematic and regular evaluation of the process and its impact but also to the value of transparency and self-criticism. In this context many felt that the existing synergies between agencies and programmes (iPAAC Joint Action, JRC (EC), Cancer Mission Board, IARC) could be strengthened, and external agencies involved in the consultation expressed a willingness to engage.

Additional issues 1: Prevention

There was a range of other issues flagged, including some lobbying by supporters of medicinal cannabis and vaping. The most EBCP-relevant points to emerge were:

- **The role of vaccines in prevention:** there was widespread feeling that effective vaccines should be harnessed, and their role reflected in the EBCP. Respondents emphasized the EU's part in increasing citizens' adherence to vaccination programmes and in developing European-level mechanisms to tackle anti-vaccine movements and fake news.
- **Occupational exposure to carcinogens:** this was flagged as a significant issue that could be addressed by EU-level action to better understand the existing

burden and to support compliance with health and safety legislation at the national level.

- **Artificial tanning devices for cosmetic purposes (sunbeds):** there was a suggestion that the EBCP initiate a more public health-driven approach to regulation.

Pillar 2: Early detection and diagnosis

Early detection and diagnosis were also and consistently identified as fundamental to the EBCP. Respondents were conscious that practice has been developed and promoted by the EU in line with sound principles. It was felt nonetheless that there was scope for strengthened action.

There were calls for the EBCP to build on existing EU screening practice, including by fostering systematic evaluation: Those consulted recognized that the EU focus on screening for breast, cervical and colorectal cancer has been valuable in meeting current scientific criteria on population-based screening programmes. There was widespread feeling that the choice of screening programmes was justified and useful but also that their implementation in MS could be improved. There were frequent calls for the EBCP to help optimize their organization; foster appropriate stratification; set quality standards; and support **monitoring and evaluation**. Various stakeholders flagged that the three programmes would benefit from a continuous systematic updating process. More widely there were hopes that the EBCP might encourage more efficient collection and review of data and indicators and more consistent **monitoring of standards** in early diagnosis and screening programmes.

Many sections of the community want the EBCP to resist screening where there is insufficient evidence and instead promote early diagnosis: The need for population-based cancer screening programmes to meet clear criteria before adoption was strongly articulated. The EBCP was seen as an opportunity to insist that screening only be rolled out when the cancer is common, sensitive to safe and uncomplicated detection, and more easily and effectively treated if diagnosed at an early stage. Respondents also acknowledged that current evidence on the balance between benefits and harm is still equivocal for screening of many cancers (prostate, stomach and lung) and suggested that when evidence does not yet support screening the EBCP should promote early diagnosis, particularly in lung cancer. It was felt that the EU could play a very positive role in promoting

standardization of effective models that promote evidence-based practice, quality and equity. EU-wide regulation (or other action) was also flagged as a possible tool for balancing academic and scientific perspectives with those of partners in biotechnology to help minimize commercial and market-driven bias. There were some suggestions that sound algorithms for early diagnosis based on rigorous science might be more effective for selected populations and certain types of cancer than population or broadly-based screening programmes and that these should be explored and promoted under the EBCP. There were also suggestions that the EBCP might have a useful role in new (and more) research on the effectiveness of screening for different types of cancer.

A wide range of stakeholders support ERNs and their role beyond research including in early detection for rare and paediatric cancers: Those consulted stressed that paediatric and rare (less frequent) cancers are particularly problematic in that they rely on early access to 'scarce' specialists/specialist centres and expertise. The special role of ERNs and the EBCP in promoting the sharing of expertise internationally was underlined.

Additional issues 2: Early diagnosis

Other (minority) views that emerged included:

- Standards for early detection: there was some support for the EC building on its screening role and setting standards for early detection, patient pathways and maximum waiting times;
- National Cancer Control Programmes: it was suggested NCCPs should include early detection;
- Research on biomarkers: a few respondents felt the EC should support new research based on large population cohorts to identify biomarkers for the early detection of cancer and encourage efficient interaction between academia, biotechnology and population cohorts;
- High-quality diagnostics: some felt the EU could support laboratory capacity, and improve guidelines, regulation and quality control and also perhaps play a role in development; and
- WHO essential guides for early diagnosis: WHO Europe flagged its short guides on screening (2020) and on early diagnosis (2017) and the scope for the EBCP to foster collaborative support to MS on setting priorities for early diagnosis and screening and on implementation.

Pillar 3: Treatment and care

All those consulted were clear about the limits to the role that the EC can play in treatment and care in line with the principle of subsidiarity. Nonetheless the consultation felt that its presence in the EBCP was important. EU-level attention was seen as critical in supporting the equitable, timely and appropriate care of cancer patients; offering information and support for cross-border care and reimbursement of care; and in fostering action to meet complex and wide-ranging needs.

Those consulted want the EBCP to improve outcomes and foster equity including by promoting consistent standards and quality: There was a widespread understanding that EU leadership in setting uniform standards of quality were important in securing the best outcomes and in addressing equity between population groups and between MS.

The EBCP was seen as an opportunity to build on existing foundations and improve standards equitably: It was considered well placed to foster the identification of best practice and the definition of treatment pathways stratified by cancer variety in a way that individual MS are not. Respondents suggested it might therefore support the development, approval and roll-out of guidelines for standards of care across all MS in all areas and particularly where the variability in clinical practice and outcomes is not easily justified. Stakeholders hoped the notion of integrated and patient-centred care would be incorporated into the understanding of quality and any standards set. The EBCP's potential role in quality assurance mechanisms to underpin the standards as above was clearly identified. There were suggestions that the EC could roll out accreditation mechanisms through a network of 'certified' Comprehensive Cancer Centres (CCCs) and their related networks (CCCNs), which would in turn further enable accreditation of national focal points.

The EBCP was often seen as a driver for linking (and closing the gaps between) different types of care: Stakeholders consistently pointed out the gap between different elements of provision and, in addition to widely supported calls for better integrated care, flagged specific areas for action.

Those consulted repeatedly highlighted that **psychological/mental health** is not often sufficiently addressed in practice and hoped it would be suitably emphasized in the EBCP. Many hoped the EBCP would encourage a wider view of treatment that included mental health elements and that it would recognize and promote

the importance of multidisciplinary teams. It was also suggested it could actively encourage patient experience and patient voices in shaping the entire cancer pathway.

Many groups also felt the EBCP could encourage clinical cancer care across Europe to become more appropriately **comprehensive care**. Respondents asked for greater emphasis and support for cancer surgery; radiotherapy; interventional oncology and nuclear medicine. In these areas, urgent issues to be addressed at EU level were flagged around: education and labour shortages, research, recognition of professional qualifications and investment in infrastructure. There were also concerns about pain management and suggestions that the EBCP could promote European standards.

There was widespread concern about the way different clinical specialties are articulated and communicated, and hopes were expressed that the EBCP could encourage **better linkages and good practice**. Areas that were flagged for EBCP attention were the ‘ties’ between radiotherapy and other cancer treatments; mental health care and psychosocial care; and the various aspects of geriatric oncology and treatment of elderly patients with co-morbidities. There were also some suggestions that the EBCP might encourage the planning of palliative care earlier and not at the very end of life.

There was seen to be scope to better align NCCPs with the EBCP to support improvement: Respondents felt that the EBCP could promote more comprehensive and uniform national cancer plans that would in turn better support implementation of the EBCP. Some referenced the European Guide developed by the iPAAC Joint Action to support streamlining and comprehensiveness of NCCPs.

The importance of ERNs in equitable access for rare and paediatric cancer patients was stressed repeatedly: Those consulted consistently stated that coordinated activity at the EU level was a major benefit for patients with rare cancers and that a European network of specialized centres could mitigate access issues. They valued ERN mechanisms and strongly advocated the EBCP making the approach more ‘operational’, including by promoting the Directive on European reference networks; cross-country molecular tumour boards; and standard platforms for exchanging patient data across Europe. There were also calls for a well-designed, regulated and financed process of cross-border care to address equity with the EBCP perhaps offering guidance on appropriate reimbursement procedures for patients and professionals. Stakeholders also clearly felt

that ERNs suffer from chronic underfunding and lack of administrative resources and hoped the EBCP would tackle financial and functional support. There were also calls for more systematic links to related national reference structures to maximize the benefits to patients (and their flexible, rapid and equitable access to treatment and care). In addition, and importantly, respondents wanted ERNs to consider **patients’ access to multi-centre and cross-border randomized controlled trials** (RCTs).

There was also considerable discussion of the important but under-recognized area of paediatric cancer. Many flagged that there are few incentives to develop new treatments for childhood cancer, and that this area is often not reflected in the NCCPs, and hoped the EBCP would address this. It was also hoped the EBCP could promote good practice to tackle the unacceptable inequality in outcomes in paediatric cancers across Europe (which was attributed largely to a failure to adhere to clinical guidelines). Some also asked that the EBCP promote better managed transitions between paediatric and adult cancer care to more systematically ‘bridge the gap’.

Respondents highlighted the scope for the EBCP to help build skills – including in communication:

Finally, the different consultation strands flagged issues around the expertise and competence of health professionals caring for cancer patients and the variation across Europe in terms of clinical excellence, knowledge, skills and attitudes. It was felt the EBCP might address quality of training for cancer surgery; radiotherapy; interventional oncology and nuclear medicine as above but also more widely. There was also a suggestion that the EBCP support training to improve communication between health professionals and patients and among professionals themselves as a critical component of quality treatment and care. Areas to tackle would include attitudes to patients; dynamics within care teams; and referrals to specialists and other supportive care services.

Additional issues 3: Treatment for cancer

The main group of ‘additional’ issues that emerged were around the scope for **synergies with other initiatives** (with organizations responding online and in direct consultation emphasizing their willingness to contribute). Specific areas where links might usefully be made include:

- On access to cancer medicines: links between the EBCP and the WHO Regional Office for Europe,

its HQ and IARC were flagged, with WHO suggesting the EBCP could tap into its work on pricing and impacts to help improve EU availability and affordability of cancer medicines;

- On quality of cancer care and innovation: here respondents encouraged reference to the DG RTD report 'Towards a cancer mission in Horizon Europe' and its priorities and strategies for building infrastructures and policy support as well as to the EACS Science Policy Committee; and
- On exchange of best practices at the EU level: the EC initiative on breast cancer (ECIBC) was identified as a potential model for EBCP work with its evidence-based approach, good communication with MS and work on updating guidelines and harmonizing standards.

Pillar 4: Quality of life for cancer patients, survivors and carers

This discussion of the fourth pillar is relatively short but this should not be mistaken for a lack of stakeholder interest. One of the recognized strengths of the EBCP is its comprehensive take on cancer issues and here there was a strong sense that this much neglected area is an important one for EU action, as well as considerable consensus around the priorities.

Those affected by cancer were particularly keen for the EBCP to promote concrete tools and practices to support survivors and carers: Those consulted were very clear on the range of practical steps the EBCP might promote. They identified a need for survivorship follow-up care plans; infrastructures and interoperable IT tools. There were also calls for the EBCP to take the Survivorship Passport model forward; integrate survivorship issues into cancer pathways (reflecting CanCon JA recommendations); and give MS guidance on long-term monitoring. There were frequent references to the EBCP's role in incorporating patients' experiences into all developments and building capacity.

Several respondents also highlighted that survivorship and carer needs were often neglected in NCCPs. They encouraged an EBCP focus on how to improve the physical and medical health and quality of life of cancer survivors, their families and carers, and suggested that the EU could encourage NCCPs to step up. Several suggested that the EBCP (and NCCPs) could include explicit thinking on patients who overcome the disease but who have to live with the side-effects of

interventions and co-morbidities and with unmet needs for psychosocial care and services.

There was a call for the EBCP to recognize the particular needs of different patient groups: Those consulted flagged equity and cases with special characteristics including children, adolescents and young adults (and those up to age 40 years) and asked for reference to their specificities in the EBCP. It was also hoped the EBCP would foster tailored planning for younger people's needs at the MS level.

Patients highlighted the key role of psychosocial and practical aspects of survivorship: The non-medical aspects of care and their impact on quality of life of patients and families, survivors and carers were seen as neglected, yet very significant, long-term issues. Respondents asked that the EBCP specifically address stigma and discrimination. There were more concrete requests for the EBCP to tackle the financial implications of survivorship including return to work, insurance and mortgage issues (that might be addressed through the right-to-be-forgotten).

Cross-sectional areas

There were themes that emerged repeatedly in discussion of the individual pillars with overarching relevance. They chime with the repeated calls by those consulted for a joined-up approach to beating cancer and for the EBCP to foster synergies across pillars and players.

Equity

Many of the stakeholders would like the EBCP to tackle equity within and between countries: Throughout the consultation there were repeated and 'consistent' calls for action on uneven access to prevention, early diagnosis, treatment and other care. Those raising the issue were very diverse but shared a depth of concern about equity. Prime issues within MS were inequity in risk factors and around access to preventive and curative services. There were specific mentions of availability of services in remote areas; vulnerable groups; blocks to access for the elderly, people with disabilities or mental health issues; and overt and unintended discrimination with concerns on minority ethnic risk factors as well as access. Respondents also flagged access and outcomes disparities between MS. They recognized the financial issues but also attributed some of the outcome 'gaps' (particularly in paediatric cancers) to poor

implementation of well-established and relatively low-cost treatments.

Stakeholders want the EBCP to use monitoring to address inequities: Those consulted were aware of the limits of the EU's jurisdiction vis a vis MS but clearly advocated an EBCP role. They suggested monitoring all aspects of access to diagnosis, treatment and quality care as a tool for further action.

There is also strong support for EBCP action on risk factors: Many shared concerns about alcohol, diet, obesity and lack of physical activity and their profound equity dimensions. Here the EBCP was seen as the legal framework to allow the Commission to foster work across sectors and industries, and with employment, education, trade and others to overcome inequality.

Knowledge, data and scientific evidence

An EU-wide approach to data is believed to have huge value and the EBCP was asked to promote this: Contributors to the consultation, from a range of entry points, called for the EBCP to support systematic and epidemiologically sound cancer data collection and sharing. There were calls to foster: high-quality, interoperable metrics and sustainable population-based and clinical data registries; monitoring of outcomes and inequalities; and forecasting of trends. It was also hoped the EBCP could encourage adequate funding and (better) connectivity across clinical, screening and survivorship data and encourage measurement to go beyond traditional outcomes of mortality and survival.

Two recurring (linked) suggestions were that the EBCP provide support to data sharing infrastructure and platforms and promote availability of information for decision-making at MS and EU level. Other more granular proposals to improve practice and information systems included EBCP action to:

- Differentiate outcome measures by stage, co-morbidities, socioeconomic level, performance status, response indicators and person-centred, patient reported experience and outcomes;
- Promote harmonized interpretation of EU General Data Protection Regulation across MS to assure data interoperability and enable cross-border, multi-centre work by ERNs and other networks; and
- Develop standards and guidance to facilitate the direct capture of data from electronic health records,

to improve the efficiency, quality and quantity of data reporting.

Respondents felt the EBCP could promote collaboration across registries: Those consulted felt the EBCP might act as a catalyst for more collaboration across DG SANTE, ENCR (via the EC JRC secretariat), EMA (including HMAs) and WHO-IARC. There was seen to be scope for a shared approach to strengthen data collection and data use for cancer research.

The EBCP was seen to have a role in fostering synergies on AI: A number of those participating in the consultations felt the EBCP could usefully promote communication and collaboration on artificial intelligence (AI). There were suggestions the EBCP might link European-level efforts to develop AI-based algorithms in prevention, early detection and management; take a lead in developing the very large repositories of data, images and biospecimens that AI requires; and also tackle the full range of legal, ethical and equity issues. Ethical principles and the implications of AI were highlighted with the EBCP asked to consider transparency on use of patient data, particularly with paediatric cancers.

The EBCP was also asked to consider initiatives to link **genomics and outcome data** and to encourage standardized registries on an EU level that would be accessible to public and private research institutions (bearing in mind ethical concerns) and help strengthen Europe as an innovation centre. Some also flagged the importance of the EBCP in encouraging investment in and the use of tools to harness big data and innovative technologies in analysis, research and understanding of the challenges of treatment and after-care. Here there were also calls for the EBCP to focus on big data around environmental and wider risk factors including: exposure to contextual and occupational toxicants; consumption and eating habits (perhaps in collaboration with veterinary and agricultural services); and drug intake; as well as to spot 'clusters'.

Stakeholders felt the EU Joint Research Centre (JRC) is an important instrument: Respondents agreed the JRC had an important role in EU cancer control actions and felt the EBCP could usefully inject additional expertise and resources to boost operational capacity and better support MS.

Additional issues 4: Research

Many of those consulted flagged opportunities for the EBPC to learn from, contribute to and link with existing research. Potential areas for action were:

- Fostering patient-centred research: with the EBPC encouraging new approaches driven by priority clinical questions for cancer patients rather than drug-centred research and encouraging review of how newly approved treatments work in practice for patients;
- Bridging cancer research in Western and Central-Eastern Europe: for example, through the EACS and Central-Eastern European Academy of Oncology and their 'twinning' pilots; and
- Coordinating clinical trials: to improve clinical guidelines; quality-assurance; collaboration across types of registry; and to encourage the evaluation of benefits through outcomes research, effectiveness and efficiency.

Fostering innovation

The issue of innovation was not raised often but it did feature under the different pillars with some emphasis on the fact it ought not be restricted to pharmaceutical or technological aspects.

There was a view that the EBPC could address the ethical and equity dimensions of innovation:

The ethical considerations of AI and big data and of personalized medicine and precision medicine networks were felt to be issues to be covered by the EBPC. There were also seen to be ethical issues around the capacity of different MS to test and take up new diagnostic methods (imaging, genomics, liquid biopsy, minimum invasive strategies) and genomics. It was suggested the EBPC could address cost-effectiveness and facilitate EU-wide access. There was also a clear appetite for the EBPC to support ERNs in offering access to innovation in the field of paediatric, rare and ultra-rare cancers.

Stakeholders hope the EBPC will encourage innovation beyond technology and pharmaceuticals:

There were some hopes that the EBPC would foster innovative research to look at **prevention measures** and make the links with the **equity** concerns flagged throughout. There was commitment to innovation in organizational terms (structure, delivery of services, approach to training and staffing amongst others) and in terms of respecting and supporting patients in their

journey. There were also some suggestions that the EBPC might support work on quality of life improvements (compared to established standards of care); proper shared decision-making models; and the patient experience.

Patient involvement

Patient involvement is widely seen as essential and an element to be reflected throughout the EBPC and, ideally, in NCCPs:

All the strands of the consultation felt the EBPC should promote patient involvement, empower patients, survivors, carers and families, and take the voices and experiences of patients into account along the whole pathway and in developing, implementing and evaluating cancer and health policy. It was also hoped the EBPC could encourage MS to accommodate patient involvement in their NCCPs' development, preparation, monitoring and evaluation.

There were frequent calls for the EBPC to support the provision of clear, **accessible information** in formats that work for patients and their carers and in ways that are mindful of their different backgrounds and native languages. Secondly those consulted asked that the EBPC support **appropriate patient education and training** including in-group working to enable the involvement of all patients (and not just their advocates) in the diagnostic and therapeutic process.

There were also specific requests that the EBPC involve patients in **setting priorities; structuring cancer care;** and **quality assurance** mechanisms and in thinking more widely on initiatives across the Commission with specific suggestions that it support:

- Patient input to the development of patient pathways to ensure the patient journey (and the information provided) reflects their and their families' needs.
- Consultation with patients to develop more patient-relevant and patient-meaningful outcome and experience measures (with respondents suggesting these be introduced as key indicators of quality of care at national, regional and institutional level alongside 'standard' data).
- Engaging patients in efforts to strengthen multidisciplinary teams to improve responsiveness.
- Patient involvement in setting quality standards (continuing initiatives such as the ECIBC).
- More initiatives to involve patients, survivors and carers in addressing survivorship and rehabilitation issues like physical and medical needs; quality of

life; long-term side-effects and co-morbidities; and financial protection, at the European level.

It was suggested the EBCP consider action to detach patient advocacy groups (PAGs) from industry and expand their role: Many consulted felt that PAGs were made vulnerable by the fact they were not publicly funded and were obliged to accept interest-based funding which could make them appear to be ‘a voice of the industry’. A number of stakeholders wanted the EBCP to link them to public funding to help assert their independence. The kinds of roles that these respondents felt the EBCP might encourage in independent (and publicly funded) patients’ associations included as

- Automatic referral points for patients on receiving a diagnosis;
- Patient support, filling information gaps and developing the skills needed for patients to play active and autonomous roles in managing their data, medical care and research engagement;
- Patient advocates, representing patient experience and helping to shape the patient journey and pathways and encouraging patient-centred services; and
- A voice at the European level, through European patient advocacy groups.

Communication

Linked to the above were a cluster of issues around communication as part of prevention; as a need for health professionals; and as an opportunity to inform policy-makers.

The EBCP is seen to have an opportunity to support prevention and early detection through health and digital literacy: Those consulted felt that building health literacy in the population as a whole was a way the EBCP could support and enable those at risk and those in the earliest stages of cancer.

There was a hope the EBCP could improve health professionals’ communications: Respondents felt that there was scope for Europe-wide approaches to improve the uneven nature of standards, training and expectations around communication. Suggested ‘targets’ of EBCP training and initiatives were public health professionals working in prevention; health professionals in clinical settings dealing with diagnosis, treatment options and psychosocial functioning, and health advocates.

Stakeholders suggested better risk communication needs to target policy-makers as well as populations:

It was felt that the EBCP could encourage a better understanding of risk and that planners and decision-makers were a particularly important audience if they were to have the information needed to develop appropriate long-term policy.

Development of health health professionals

Another issue that emerged under different pillars and was seen as a European concern was the training of health professionals (for communications, see above).

The EBCP might help foster multi-professional teams: Stakeholders identified multi-professional and inter-disciplinary working as key but felt that this was often underdeveloped with nurses in particular not being adequately valued. It was hoped the EBCP would sponsor initiatives to promote inclusive teamworking and facilitate the collaboration needed to support patients across care pathways.

European training standards were suggested as a way of enhancing both quality and equality: Common European frameworks for education in cancer care were cited a number of times as a way of addressing unevenness in approach and quality, not least in primary care and prevention, nursing and psychosocial support. It was suggested that the EC could also encourage continuous education and twinning schemes, perhaps through the ERN mechanism.

Other issues

The cross-cutting issues above provide a comprehensive overview of the concerns that featured repeatedly and across pillars. A small group of additional issues were mentioned in specific settings and contexts, but still resonated across the strands and themes.

It was suggested the EBCP be mindful of the costs of innovative treatment: There were concerns about the costs of (and access to) promising but extremely expensive treatments and it was hoped the EU (through the EBCP) could find ways to mitigate these. There were suggestions the EBCP might facilitate cooperation between disciplines to critically assess the value of treatments and improve priority setting in research and champion questions (on treatment duration, combinations, sequences and so on) to allow policy-makers to better identify medical added value and make informed choices.

There were also suggestions for European action and further cooperation on **combined purchasing**, exchange of **coverage schedules and price arrangements**, as for example with the European Fair Pricing Network. These were seen to fit with EBCP support on cancer services' sustainability.

Stakeholders saw Health technology assessment (HTA) as a key tool for identifying 'best' treatments and diagnostics:

Those contributors interested in the evaluation of treatments, including multidisciplinary interventions, stressed the importance of independent research and assessment against clinically meaningful endpoints (for cancer patients). They suggested the EBCP support collaboration between national HTA bodies and foster transparency on medicines and clinical interventions. The need to develop EU-level economic evaluation strategies was also flagged. The EBCP was seen as a way of structuring research and optimizing treatments to achieve a better balance between commercial and independent research.

It was also felt the EBCP could address the ethical dimensions of HTA:

HTA applied differently in different countries opens up inequities in access across MS and it was suggested that the EBCP could play an important role in addressing this. Respondents felt a more coordinated HTA at the EU level could incorporate an ethical dimension alongside the 'traditional' assessment of cost and effectiveness and support better decision-making, as well as reducing inequalities between MS. It was suggested the EBCP might support the new types of datasets required and new models to reflect the needs of cancer patients and of the medical community (with evidence free of commercial interest).

Cervical cancer was mentioned with suggestions that the EBCP could make more of a contribution to the Global Strategy for Elimination of Cervical Cancer and help address the unacceptably high burden in Baltic states and Eastern Europe by direct support to countries on vaccination and HPV testing. Updating cervical cancer screening guidelines was also seen as a worthwhile priority.

Geriatric oncology was also an area where an increasing burden was identified and where the EBCP was seen to have considerable potential. It was suggested more emphasis could be placed on it.

There were also calls for the EBCP to encourage more support for cancer surgery, radiation therapy, interventional oncology and nuclear medicine.

The wider international context and parallel initiatives

Those consulted welcomed the fact that the EBCP seeks to be a plan for the whole Commission fostering strategic action at EU level and supporting and guiding European-level prevention and comprehensive control of cancer. This overview therefore looks at a range of recommendations, deliverables and consensus generated by other EU initiatives.

Stakeholders believe finding synergies with existing initiatives is key to the EBCP:

Respondents from all constituencies identified consistency in institutional messages across the EC and cohesion across all players implicated in the different pillars as fundamental to the EBCP's credibility. They also stressed the need for synergy in European initiatives, including where these touch on investment in research. They flagged a number of programmes and tools that can serve to support EBCP implementation including: the results of the last iPAAC Joint Action; the proposals by the Joint Research Centre; the update of the European Code Against Cancer and other related initiatives.

There is no space for a detailed mapping of cancer initiatives across the EU, but the following overview can help in flagging synergies and in spotting potential gaps. It was suggested that a more granular review would help the EBCP to further focus efforts, prioritize funding and maximize synergies.

- **European Cancer Organisation:** There is a range of areas covered by ECCO that support the direction of the EBCP and chime with interests flagged by the consultation process. The European Code of Cancer Practice coincides with concerns expressed under the treatment and care pillar and around communications and patient involvement. ECCO work on quality (in the Essential Requirements for Quality Cancer Care papers) is also pertinent while its response to the EU Pharmaceutical Strategy Roadmap consultation touches on the HTA and access issues above.
- **ENVI committee inputs:** The European Parliament's Committee on the Environment, Public Health and Food Safety has developed a very comprehensive set of recommendations that includes much of relevance for cancer prevention and control. The topics covered are wholly consistent with concerns raised by the roadmap, public and stakeholder consultations with prevention research and action (including on tobacco, alcohol, healthy

lifestyles and vaccines), risk prediction, screening and early detection all covered, as well as treatment, quality and survivorship needs.

- **DG RTD Mission Board for Cancer:** This initiative is an integral part of the Horizon Europe Framework Programme for Research and Innovation (2021–2027) and the only mission focusing on a single group of diseases. It seeks to set common goals and propose concrete targets and timelines through its report: ‘Conquering Cancer: Mission possible’.⁵ Again, there is a high degree of consistency with stakeholder thinking with proposed recommendations looking across the whole cancer control continuum and including all populations (children, the elderly, the vulnerable or isolated) and all MS. The thirteen priorities identified have a high degree of synergy with the EBCP, particularly as they touch on prevention strategies, screening programmes, early diagnosis, quality of life, survivors, carers and families, and in their concerns for better communication and for equity across the EU and across the continuum of the disease.
- **Joint Actions on cancer and the current JA iPAAC (innovative Partnership for Action Against Cancer):** JA iPAAC grew from a 2009 initiative with different JAs since then focusing on issues ranging from health promotion to research to integrated care to NCCPs. The work generated (overview of cancer control policies⁶, definitions of CCCNs and survivorship and key policy papers) fits well with the pillars of the EBCP. Respondents felt the current JA and its work on the introduction of the Roadmap will be a useful tool in EBCP implementation with valuable reflection on past and ongoing experience. Elements seen to coincide most closely with stakeholders’ concerns (and that allow mutual learning or can be ‘transferred’ directly) include screening, population-based registries, quality indicators, accreditation, NCCPs and collaboration across MS.
- **Other relevant topics in EU research related to cancer:** In addition to the Mission Board’s research agenda there are a number of other initiatives, relevant to cancer research and the EBCP, including JRC projects such as the **European Commission’s Initiative on Breast Cancer** (completed 2018) and the similar ongoing project on colorectal cancer and the **Innovative Medicines Initiative (IMI)** which is in its second ‘edition’ and involves a public-private partnership (PPP) with industry.
- **Other relevant links across the EU related to cancer:** Stakeholders consulted were very aware of the many other Directorates and EC initiatives that impact on cancer. They suggested that, further to its HiAP thinking, the EBCP use the EU Health Policy Platform to communicate across the EC as well as with MS and citizens to share the efforts being made to align investment, agriculture, employment, social affairs, education, and cytotoxic safety to beat cancer.

5 Mission Board for Cancer (2020) Conquering cancer: mission possible. Luxembourg, European Commission. <https://op.europa.eu/en/publication-detail/-/publication/b389aad3-fd56-11ea-b44f-01aa75ed71a1/>

6 Martin-Moreno JM, Albrecht T, Radoš Krnel S. (2013) *Boosting innovation and cooperation in European cancer control: key findings from the European Partnership for Action Against Cancer*. Ljubljana: National Institute of Public Health of the Republic of Slovenia; Brussels: World Health Organization on behalf of the European Observatory on Health Systems and Policies. https://www.euro.who.int/__data/assets/pdf_file/0014/235211/Boosting-Innovation-and-Cooperation-in-European-Cancer-Control.pdf

Conclusions

There is very strong support across Europe for the EBCP. Citizens, the cancer community, public health professionals and others all have high hopes for it. They are all clear that the EU dimension has huge added value because of the Commission's ability to work across sectors and on a HiAP basis on everything from risk factors to the financial implications of survivorship. They are also hopeful that the different threads of EU action will come together to form a coherent whole.

This focus on the 'holistic' or joined-up care is echoed in approval ratings for the four pillars. EU citizens and the cancer community see the potential of the EBCP in strengthening early diagnosis and improving screening practice; for promoting better treatment and encouraging health professionals to deliver that treatment effectively and with humanity; as well as in supporting survivors in a range of practical ways. There is also shared commitment to the role of the EU in cancer research; improving data; sharing knowledge; and, perhaps above all in strengthening European Reference Networks.

Inclusivity and equity are a strong feature throughout, with respondents insisting that the EBCP be for all those affected by cancer from paediatric to geriatric cases to minority ethnic and marginalized communities. European stakeholders repeatedly expressed concerns about the large variations in access, quality and outcome of cancer care, in and across countries. They are calling for the EBCP to address equity through systematic evaluation of actions and gaps and through efforts to overcome obstacles to appropriate care at the EU and MS level.

The consultations showed a strong desire to ensure that the EBCP is effectively implemented with those taking part calling for **realistic and measurable** goals and systematic evaluation. They also suggested a balanced

scorecard with a **dashboard of indicators** that can be monitored to support ongoing improvement.

Monitoring notwithstanding, the public's expectations of the EBCP will be difficult to meet in that they come from multiple perspectives and have almost limitless ambition. The EBCP cannot solve each and every problem related to cancer prevention and care, not

least because of the current state of knowledge and the distribution of competences between the EU and the MS.

Nonetheless, the very real enthusiasm expressed in discussions of this initiative creates an impetus towards progress for all Europe's patients and all citizens. The EBCP is perceived as a huge opportunity and as a positive model of collective EU action on a challenge that faces the whole of European society.