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## COMMISSION STAFF WORKING DOCUMENT

## STAKEHOLDER CONSULTATION - SYNOPSIS REPORT

Accompanying the

Communication from the Commission to the European Parliament and the Council Europe's Beating Cancer Plan

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## SYNOPSIS REPORT

#### 1. Introduction: Objectives and Stakeholders

This report presents the outcome of the four strands of consultation conducted for Europe's beating-cancer plan. The consultation process was launched on World Cancer Day on 4 February 2020.

The **consultation strategy** was designed to gather EU-wide input on the four pillars of Europe's response to cancer, as outlined in the mission letter to Stella Kyriakides, European Commissioner for Health and Food Safety: (i) prevention; (ii) early detection and diagnosis; (iii) treatment; and (iv) care and quality of life for cancer patients, survivors and carers (plus knowledge and scientific evidence). Specifically, the consultation strategy aimed to create different entry points into the process to ascertain the main: trends, expectations; and concerns of stakeholders and the public. Each part of the strategy was tailored to: capture specific responses; identify areas of broad agreement; and identify points of significant difference.

The process therefore included the following.

- Feedback on the roadmap (4 February 3 March).
- A public online consultation (4 February 22 May).
- Targeted stakeholder consultations, including a 'townhall' meeting over the summer.
- Engagement with: (i) public authorities through the Commission's Steering Group on Health Promotion and Disease Prevention; (ii) the European Parliament, through the Special Committee on Beating Cancer; and (iii) the Mission Board of the proposed Horizon Europe Mission on Cancer. There were also additional ad hoc contributions, provided primarily through meetings with Commission officials.

The consultation process drew on the **stakeholder mapping** which identified the key groups, citizens and patients:

- NGOs representing the cancer community, typically patient groups or European professional scientific bodies;
- European public-health organisations;
- professionals and professional associations;
- industry;
- researchers;
- Member States, including public authorities and European Parliament members;
- international agencies.

The consultation strategy and process reached all the above groups. It recognised that groups cannot be discretely separated (individuals, patients, professionals, patient associations and professional bodies are separate categories in theory, but they overlap in practice). It also ensured that all the key stakeholders identified in the mapping had opportunities to contribute.

The consultation took place against the backdrop of the COVID-19 pandemic, which diverted the attention of many participants. This situation was mitigated by extending the public-

consultation timeframe and delaying the roll-out of the targeted stakeholder consultations. Meetings were carried out virtually, and were sometimes delayed.

As the pandemic's impact on cancer patients and cancer care became clearer, a series of three webinars was organised. The goal of these webinars was to better understand the pandemic's implications and gain insights into the situation in Member States to inform the further development of the plan.

#### 2. METHODOLOGY AND TOOLS

The Commission gathered feedback on both its roadmap and public consultation through online questionnaires.

The feedback on the roadmap was analysed quantitatively and qualitatively, drawing on machine learning and manual analysis to identify themes for each of the four pillars, and in particular the fourth pillar on knowledge, data and scientific evidence.

The online public consultation combined a mix of closed questions (where respondents choose from a pre-determined selection of answers) and open questions (where they are free to write any response they choose of up to 600 characters per response). Responses to this public consultation were analysed using MS Excel and text-analysis tools. Some responses were re-classified using the name of the respondent's organisation and information on the respondent's website to allow for a clearer distinction between relevant types of stakeholders (e.g. patient organisations, health professionals, etc.). Where relevant, thematic coding and grouping were applied to free-text responses to determine grouping and frequency. This involved a degree of interpretation. There was limited duplication of free-text responses (i.e. instances where different respondents wrote similar free-text responses); this was the case for only 5% of entries).

The targeted stakeholder consultations took place with: (i) patient representatives; (ii) the cancer community (scientific and expert associations); (iii) the European public-health community; (iv) professional associations; (v) the healthcare industry; and (vi) international agencies. These consultations were supplemented by four expert-informant interviews. Invitees were identified for expert consultation based on: (i) their expertise in cancer or their activity in the field of cancer treatment; and (ii) their ability to represent an EU-wide or group perspective. Before the targeted stakeholder consultations, the organisers circulated questions based on: (i) the roadmap; and (ii) expert knowledge of the constituency being consulted. The organisers also facilitated discussion in the targeted stakeholder consultations. Notes from the targeted stakeholder consultations were sent to invitees after the consultations in the form of key messages for further comment. These comments were then consolidated and analysed. A public 'townhall' consultation provided further checks and inclusivity.

#### 3. CONSULTATION ACTIONS

## a. FEEDBACK ON THE COMMISSION ROADMAP

In total, 387 comments were received from stakeholders in 25 EU Member States (89%)<sup>1</sup>, and 10 comments were received from stakeholders in non-EU countries (11%)<sup>2</sup>. The responding stakeholders represented a great variety of sectors. Close to one third of responses (32%) came from non-governmental organisations (NGOs), followed by the EU general public (23%), companies/business organisations and associations (22%), and research/academic institutions (7%). The low response rate from public authorities (2%) was noteworthy.

The respondents broadly endorsed the initiative set out in the beating-cancer plan. There was particularly strong support for the prevention pillar (tobacco legislation and addressing workplace exposure to environmental risks), but there was overall enthusiasm for the other pillars as well. Respondents also made suggestions on strengthening the beating-cancer plan. In addition, the respondents raised other issues, suggesting greater emphasis should be placed on:

- paediatric cancers, including innovation in medicines, work on genetic mutations that play a role in cancer, and survivorship strategies;
- integration of real-world evidence and innovations such as artificial intelligence for personalised care;
- improving training standards for medical professionals;
- health literacy for patients, carers and the public;
- equal opportunities for EU citizens to access cancer prevention and care;
- high-quality monitoring and surveillance systems at EU level to inform policies;
- sharing of best practices by Member States within the EU.

A summary of the feedback was published.

## **b.** FEEDBACK ON THE PUBLIC CONSULTATION

2 078 responses were received through the online platform, with a further 27 responses received via email. These 27 email responses were prompted by the publication of the questionnaire, but they did not all follow the suggested format. All EU countries were represented in responses by the general public and organisations, and 184 (9%) of all responses stated that the respondent's country of origin was outside the EU. 1 341 responses were from individuals, while 737 contributed on behalf of organisations.

Among the organisations responding, the largest share (35%) was engaged in academic research, followed by patient organisations (25%) and associations of health professionals (10%).

Overall, the public consultation attracted a wide variety of inputs. There was some evidence of a small number of concerted responses by interest groups. There was clear consensus in many areas, and nearly all respondents felt the EU should do more across all four pillars.

No comments were received from stakeholders based in Estonia and Slovenia.

From non-EU countries, the most comments came from the United Kingdom (17 respondents), Switzerland (10 respondents), and the United States (6 respondents).

In prevention, the top three areas highlighted were tobacco, diet and carcinogenic substances, with many members of the public noting a lack of information on cancer prevention. Respondents said they would like public authorities and national governments to address cancer prevention through multiple mechanisms, such as: (i) providing funding; (ii) passing legislation and regulations that are compatible with health in all policies; and (iii) reducing inequalities in the determinants of health that increase the risk of cancer. In the 'early diagnosis' section (pillar 2), there was broad support among respondents for extending recommendations for screening to other types of cancer, where screening can also be effective. In the section on treatment (pillar 3), respondents said that the EU could: (i) improve access to – and the quality of – cancer services; and (ii) promote universal health coverage across all Member States (a breakdown by country revealed large differences in the availability of support – both inside and outside of healthcare settings – for patients across Europe). Finally, in the section on quality of life and life after cancer (pillar 4), survivors and families said they experienced multiple challenges in daily life coupled with a lack of support (in psychological assistance, medical follow-up, and social integration).

There was also considerable support among the respondents for greater focus on:

- paediatric cancer;
- tackling risk factors, and alcohol in particular;
- setting uniform care standards across Member States;
- monitoring the implementation of the plan.

Respondents wanted to see effective implementation with: (i) improvements in outcomes on population health and user experience; and (ii) greater support for people affected by cancer.

A summary of the results of the public consultation was published https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Plan/public-consultation.

## c. TARGETED STAKEHOLDER CONSULTATION

The Commission used this stage to explore the issues in more depth and detail. Despite the qualitative nature of the targeted stakeholder consultations, there were surprising levels of consistency across the groups in their views on the four pillars. Many respondents also raised the same cross-cutting issues. Their views are summarised below under five headings: prevention (pillar 1); early detection and diagnosis (pillar 2); treatment and care (pillar 3); life after cancer (pillar 4); and additional issues.

*Prevention (pillar 1):* there were widespread calls from different constituencies for: (i) a 'health in all policies' approach; (ii) a comprehensive approach to risk; (iii) protecting and promoting health through multi-sectoral action; and (iv) addressing behaviour through multi-sectoral action. Respondents called for particular focus on:

- tougher regulation of alcohol, tobacco and food;
- regulations on environmental and occupational risk;
- supporting the European code against cancer;
- addressing: (i) commercial determinants of health; (ii) cross-border marketing; and (iii) digital communications;

- protecting children and young people, including through effective vaccination (for example through the vaccine for human papillomavirus HPV);
- fostering EU synergies to support Member States in implementation;
- bolstering the share of government budgets allocated to public health and disease prevention across the EU;
- encouraging systematic impact assessment.

Early detection and diagnosis (pillar 2): were widely agreed to be areas the EU could and should strengthen through EU-wide standard setting. Respondents believed the following areas were particularly suitable for this:

- developing comprehensive early-diagnosis programmes, high-quality diagnostics, laboratory capacity, guidelines, and regulation;
- improving screening through: standard setting, risk categorisation, quality assurance, encouragement of best practices, targeted interventions, monitoring, and research;
- helping to improve data collection, monitoring and analysis.

Treatment and care (pillar 3): respondents from different stakeholder groups tended to prioritise slightly different actions in this area. Nonetheless, there was widespread consensus on the importance of:

- treatment standards and guidelines to promote quality comprehensive care (including quality-assurance mechanisms and accreditation);
- addressing rare cancers through European reference networks and cross-border care;
- treating paediatric cancers (and transition to adult-care services);
- treating multi-morbid and geriatric patients;
- expanding the role and funding of European reference networks and their links to national reference centres;
- ensuring that the patient experience is taken into consideration when developing the
  patient 'pathway' (the series of steps and clinical encounters taken by patients from first
  diagnosis through to treatment and after care), and including psychosocial care and mental
  health in these pathways;
- encouraging integrated multidisciplinary care teams and better communication;
- addressing workforce education and staff shortages, and recognising professional qualifications;
- investing in surgery, radiation therapy, interventional oncology and nuclear medicine;
- appropriate and coordinated research.

Life after cancer (pillar 4): this area was of particular concern to patient representatives, but their concerns were echoed by others with a common interest in EU action on survivors' physical, medical, psychosocial, employment and wider needs. Specific issues raised in the targeted stakeholder consultations included:

- cancer-survivorship design and planning, with integration into the cancer-care pathway;
- implementing follow-up care plans, infrastructures and interoperable IT tools for cancer survivors, including a survivorship 'passport';
- managing the long-term side-effects of cancer treatment and cancer co-morbidities;

- addressing stigma, discrimination and financial implications (the 'right to be forgotten');
- the importance of considering the needs of families and carers;
- addressing the needs of paediatric and younger patients.

Additional issues: there was a high degree of overlap in the additional issues flagged by participants in the targeted stakeholder consultations. These additional issues echoed issues raised online and in interviews with key informants. The main additional points included the following views.

- Collaboration and **coordination across the EC** should be encouraged, and **synergies between EU initiatives** should be exploited.
- The EU adds significant value by promoting: (i) the exchange of **best practices**, (ii) consistent and coherent **quality standards**; and (iii) EU-level **monitoring and evaluation**.
- The EU also has a significant role to play in: (i) the exchange and interoperability of **data** and information; (ii) data-sharing infrastructure(s); and (iii) standards and work across registries.
- The coordination and funding of research should be encouraged. In particular, translational and organisational research should be studied to support the implementation and development of policies that are informed by patients.
- The EU plays a useful role in fostering **innovation**. This innovation should cover new diagnostics, cancer-related genomics, big data, and artificial intelligence (AI). It should also ensure: (i) ethical and fair access to cancer treatment for all people; and (ii) an appropriate balance between public and commercial interests.
- European research networks are an important mechanism with great potential if adequately funded to play a much wider role.
- **Health-technology assessment** would benefit from centralised action to: (i) encourage quality and consistency; and (ii) broaden the focus to include clinically meaningful endpoints.
- Repeated reference was made to the European scope for action on: (i) **fairness** and access (to trials, early diagnosis and treatment); (ii) quality of care; and (iii) outcomes. In these references, respondents hoped that the EU could: (i) address unfairness in risk factors to tackle the socioeconomic and commercial determinants of health, risk behaviours, and the needs of vulnerable groups; (ii) raise quality and consistency, certify cancer-care centres, and promote value-based care; and (iii) consider greater price transparency and combined arrangements for purchasing and pricing.
- An EU role to foster patient empowerment and **patient-centredness** was advocated.
- Respondents advocated a European focus on: (i) communication and health; and (ii) digital literacy (including in native languages, and with and through patient organisations).
- The EU was encouraged to help the **Patients Association to be independent** of industry.
- Stakeholders also called for the EU to support: (i) the education and training of health **professionals**; and (ii) **multi-professional** approaches including in public health and communications.

• Finally, all groups advocated systematic monitoring and evaluation to support the plan.

The COVID-19 crisis started to worsen a few weeks after the launch of the consultation process. Because of this, there was no particular focus on COVID-19 in the feedback on the roadmap and the public consultation. The Commission therefore organised a series of three webinars with key stakeholder organisations, which revealed that COVID-19 had an impact on the entire community of professionals working in cancer prevention and cancer care.

Summaries of each of the targeted stakeholder consultations were published [include hyperlink].

## d. AD HOC CONTRIBUTIONS

<u>Steering Group on Health Promotion, Disease Prevention and Management of Non-</u>Communicable Diseases

Input was sought from EU Member States as well as from Norway and Iceland through the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases. The steering group discussed Europe's beating-cancer plan in four of its meetings. The aim of seeking this input through the steering group was to: (i) understand national priorities on cancer with reference to the roadmap's pillars; and (ii) get insights into the types of actions Member States considered to be part of an EU-level response.

In total, 27 EU Member States plus Norway: (i) responded to a survey circulated to the steering group, which was launched on 2 July and closed on 21 September 2020; and/or (ii) shared feedback on the initiative in other ways. Member States among others described their national priorities, and selected topics for which they considered EU involvement to be a priority. Almost all Member States considered the four main pillars of Europe's beating-cancer plan as a high or very high national priority, and all pillars are expected to gain importance over the next 5 years. As challenges for implementing actions across the four areas Member States most often reported the challenges of insufficient funding and staff levels.

In the prevention pillar (pillar 1), almost all Member States identified promotion of a healthy lifestyle as a main national priority, with a focus on raising public awareness about behavioural risk factors. When asked to rank in which areas of prevention EU involvement should be prioritised, they most often considered that working on a 'generation prevention' was a priority, thereby targeting behavioural risk factors of young people. Other high priorities were: 'tobacco', 'environmental pollution', 'vaccination, such as against HPV and hepatitis B', 'paediatric cancers' and 'alcohol'.

For the pillar on early detection and diagnosis (pillar 2), specific cancer-screening programmes were mentioned most frequently as national priorities, with some Member States aiming to increase access to existing screening programmes, whereas others focus on quality of the screening or initiate a new screening programme. At EU level, the highest ranking priority areas included the quality of screening (also encompassing assured timelines), better

links between cancer-screening data and cancer registries and diagnostics (including timing, availability and standards).

On treatment (pillar 3), 'national coordination of centres of excellence/expertise' and 'the availability and affordability of medicines' were at national level, which were raised most often by Member States. This latter topic was seen as a priority for shared action at EU level, by ensuring EU-wide access to (affordable) medicines and treatments. A second EU level priority in this pillar was 'sharing validated best practice'.

For the pillar for survivorship and life with/after cancer, (pillar 4), Member States most often referred to their national priority of establishing a holistic and multidisciplinary follow-up for cancer survivors, while also pointing to psychosocial issues of both patients and their families, as well as palliative care. In line with this prioritisation, Member States also ranked 'quality of life of survivors' and 'social protection' most highly as EU level priorities, ('social protection' addresses issues such as the 'right to be forgotten' and protecting survivors from financial discrimination), closely followed 'paediatric cancer survivors, including relatives as informal carers', and 'reintegration in the working environment'.

All Member States said that action at EU level has added value, emphasising that EU action was especially helpful in the field of knowledge, data and scientific evidence. The Member States were also in favour of supporting research, data exchange and knowledge-sharing, for example through the European health-data space. They also stressed that the EU could add value by harmonising Member State efforts to reduce cancer and inequalities.

Member States identified a number of topics as suitable priorities. On prevention (pillar 1), almost all Member States said that 'work on a generation prevention' was a high priority. Other high priorities were: 'tobacco', 'environmental pollution', 'vaccination, such as against HPV and hepatitis B', 'paediatric cancers' and 'alcohol'. On early detection and diagnosis (pillar 2), Member States ranked two topics most highly: 'screening' (including quality and assured timelines) and 'better links between cancer-screening data and cancer registries'. On treatment (pillar 3), Member States ranked 'EU-wide access to (affordable) medicines and treatments' and 'sharing validated best practice' most highly. On the pillar for survivorship and life with/after cancer (pillar 4), Member States ranked 'quality of life of survivors' and 'social protection' most highly ('social protection' addresses issues such as the 'right to be forgotten' and protecting survivors from financial discrimination).

Member States also pointed to two ways in which the Commission had an enabling role: (i) promoting international academic research; and (ii) strengthening data sharing and collaboration between cancer registries. They stressed the added value of initiatives like the European Network of Cancer Registries and the supporting role of the European Commission's Joint Research Centre. On training, most Member States stressed the importance of training healthcare professionals in multidisciplinary collaboration.

Fairness was considered a concern for most Member States, and almost all Member States indicated that COVID-19 had at least some impact on cancer services in their country.

A summary was published of the Member State feedback.

Engagement with the European Parliament

On 15 June, the European Parliament Committee on the Environment, Public Health and Food Safety published a report, *Strengthening Europe in the fight against cancer*. The report outlines a comprehensive set of recommendations, and covers topics which echo concerns raised in the consultation about: (i) research and action on cancer prevention (including by focusing on tobacco, alcohol, healthy lifestyles, and vaccines); (ii) risk prediction, screening and early detection; and (iii) treatment, quality of care, and the needs of cancer survivors.

The newly established European Parliament Committee on Beating Cancer also presented a working document as input to the plan on 27 September, and exchanged views with Commissioner Kyriakides.

On 12 October, members of the committee committed to supporting the development of a common standard for fighting cancer. This reflects the committee's understanding that many advances in the field of cancer require common policy driven at European level. The working document of 27 October 2020 is consistent with the other strands of the consultation. It emphasises: (i) global prevention (through action on tobacco, alcohol, diet, exercise, environment and links to the Green Deal); (ii) screening and early detection; (iii) equality of access to patient-oriented treatments (with reference made to the role of the European medicines market); and (iv) the need to support patients and caregivers. The working document also identified the following avenues for action: (i) holistic research and innovation; (ii) exchanging knowledge and best practices, including through European reference networks and cancer registries; and (iii) work on training and communication. Committee members also voiced their concern about the impact of COVID-19 on the treatment of patients and of the potential postponement of early diagnosis.

# Meetings of Commissioner Kyriakides with key stakeholders

In January 2020, Commissioner Kyriakides began meeting with key stakeholders engaged on the issue of fighting cancer. These stakeholders' positions echoed those expressed above.

## Other outreach activities

At DG level, the Directorate-General for Health and Food Safety has participated in conferences and meetings of stakeholder organisations. Stakeholders expressed positions very closely aligned to those gathered through other consultation activities.

# e. Interdependencies and consistencies in the contributions from stakeholders

There is a high degree of consistency between the stakeholder contributions across the different groups and between the findings emerging from each of the consultation strands. The primary concerns of stakeholder groups are listed below.

Patients, patient groups, survivors, and the public: Many of the concerns expressed by individuals, patient groups, survivors and carers were about the quality of care. These groups called for a more patient-centred approach and more consistent standards. They also called for psychosocial and mental-health support and for training health professionals so they could work in multidisciplinary teams and communicate better. This group also said that the voice of patients should be taken into consideration when designing pathways of cancer care and

wider policy. In addition, these groups were more concerned than any other stakeholder group about helping cancer survivors.

Like other stakeholder groups, patients, patient groups and the public also advocated for an EU role in data sharing, harmonising standards, and fostering innovation. They also showed a strong commitment to addressing inequalities between and across countries. They made specific and repeated calls for: (i) greater attention to be paid to paediatric cancers; (ii) a stronger role for European reference networks; and (iii) the EU to address commercial determinants.

Patient groups also shared specific concerns about: their role; the scope for independent funding; health literacy; and communications.

**Professionals and professional associations**: There was considerable overlap between the concerns of this group and the concerns of patients and survivors. Professionals and professional associations had a clear focus on prevention and strong concerns about fair access for all patients to treatment, particularly for medicines. Professionals also recognised the need to support multidisciplinary working (and the importance of nurses, general practitioners and specialists) and better focus on patients. Paediatric cancers also featured strongly among the concerns of professionals and professional associations.

This group shared the concern around data also felt by patients and survivors. However, professionals and professional associations placed greater stress on: (i) the role of the EU in fostering data interoperability; (ii) the role of cancer registries and cancer registry collaboration; and (iii) the scope for European-wide work on digitalisation and big data. This resonated with their interest in the EU's potential for fostering appropriate research including: (i) cross-border clinical trials; (ii) translational, implementation and organisational research; and (iii) outcome-based research. Professionals and professional associations also called for the development and validation of new diagnostic methods with a focus on efficiency and cost-effectiveness.

**Research, scientific and public-health organisations:** this group of stakeholders also echoes some of the concerns of the other two stakeholder groups. Issues of particular importance to research, scientific and public-health organisations included prevention, diagnosis and treatment.

On prevention, this stakeholder group focused strongly on the action that needed to be taken against risk factors (particularly alcohol, but also smoking, diet, exercise, and exposure to carcinogenic substances). They also focused on HPV vaccination. In addition, this stakeholder group stressed the role of information, awareness, education and health literacy. The group also raised specific points about: (i) using risk-assessment tools to better target cancer screening; (ii) new diagnostic and assessment tools; (iii) EU work on the harmonisation of treatment protocols to ensure common standards and quality of care; and (iv) paediatric cancers. Research and innovation were important to these stakeholders. For example, they brought up: (i) the use of genetic information and personalised treatment; (ii) support for understudied cancers; and (iii) drug development. These stakeholders also called for the EU

to: (i) promote reference networks; (ii) encourage networking and data sharing; and (iii) foster international academic research platforms via the Horizon Europe cancer mission.

These stakeholders agreed that equality of access across countries and universal health coverage were EU issues. They hoped for more centralised health-technology assessment and a European cancer fund.

Industry and the private sector: These stakeholders focused most on: (i) innovative approaches; (ii) personalised medicine; (iii) the use and reimbursement of biomarkers; and (iv) real-world evidence platforms for personalised solutions. They called for action to cut the time taken to deliver innovation ('time to patient access') across Member States, including by 'smoothing' perceived barriers in the regulation process. They supported the cancer mission and hope to see the EU foster: (i) public-private partnerships in health care; (ii) pan-European multi-stakeholder fora; (iii) pan-European fast-track funding/reimbursement models; and (iv) the use of structural and cohesion funds to equalise access to innovation for resource-constrained countries.

They also shared common ground with the other stakeholders, particularly in emphasising the importance of patients and carers; long-term survival and co-morbidities; and paediatric cancers. This stakeholder group also promoted value-based care. On screening and on biomarkers, they wished to go beyond the areas suggested by the cancer community. However, like the cancer community, this stakeholder group stressed the importance of early diagnosis. They were also enthusiastic about the prospect of: (i) EU action on data sharing; (ii) a pan-European, electronic cancer registry; and (iii) monitoring of the implementation of the plan through a 'dashboard' to capture progress. Some industry groups suggested that vaping was a suitable harm-reduction measure, a view also present in online comments.

**Member States and public authorities:** the views of this stakeholder group are presented in some detail above, but there is considerable overlap between their views and those of the other stakeholders consulted. Member States placed the greatest emphasis on research and on data sharing as key areas of EU added value.

International agencies: The International Agency for Research on Cancer, the Organisation for Economic Cooperation and Development and the World Health Organization (Regional Office for Europe and Headquarters) agreed strongly with the other stakeholders. These three organisations emphasised: (i) prevention; (ii) encouraging the setting of standards for early diagnosis and evidence-based screening; (iii) endorsing a European approach to patient centredness; (iv) data sharing and data harmonisation; (v) the use of non-traditional outcome measures; and (vi) support for registries. They also expressed interest in value-based care, and were particularly keen to see synergies across European initiatives and agencies.

### f. MAIN MESSAGES FROM THE CONSULTATION PROCESS

Overall, there is very strong support across the EU for Europe's beating-cancer plan and stakeholders called for a high-level of ambition for this plan. Stakeholders felt that a particular strength of the plan was its attempt to address cancer across the entire cancer-control continuum. This support for a holistic approach is echoed in the high approval ratings that stakeholders gave to all four pillars of the plan and by stakeholders' commitment to monitoring and evaluation to ensure the plan helps creates real change. Stakeholders also

consider that an EU dimension in addressing cancer adds significant value, highlighting the Commission's ability to work across sectors and with a 'health in all policies' approach.

Addressing **risk factors** in a comprehensive way was widely held to be important. Cancer prevention is expected to pay dividends by reducing the effects of other chronic non-communicable diseases.

There was also consistent support for an EU role in **optimising existing screening programmes** (validating and strengthening the organisation, quality and monitoring of these programmes). The community was also positive about the EU's role in developing new, effective and efficient screening programmes, although there was disagreement on what to screen for. Stakeholders saw **early detection** as another area where the EU had an important role to play in promoting standardisation, evidence-based best practices, quality, and fairness.

Stakeholders also felt that the EU was well placed to identify **best practices**, **treatment and** 'stratified' patient pathways. They encouraged the EU to look beyond treatment to wider patient pathways, covering the entire patient experience from start to finish, including survivorship and social experience.

The **European reference networks** were valued by all stakeholders. There was widespread support for greater funding to extend the pioneering role of these networks from work on rare diseases, paediatric and rare cancers to: (i) wider research; (ii) sharing of best practices and guidelines; and (iii) collaboration.

Stakeholders also stressed the importance of **supporting cancer survivors**. Groups highlighted a range of (patient-informed) approaches, including: (i) survivorship follow-up; (ii) care plans and infrastructures; and (iii) interoperable IT tools. They hoped that EU support would help to roll out best practices to all patients, regardless of their income.

Stakeholders worried that it was not always possible to ensure **equal access for all to quality cancer care** and they all hoped that Europe's beating-cancer plan would address this. All groups stressed the importance of inclusivity, so that **all patient groups** (including children and the elderly) and **vulnerable populations** could be appropriately covered.

Finally, stakeholders stressed their belief that the EU has a key role to play in **cancer research**. They believe that coordinated European action is the route to efficient, effective and rapid solutions to existing and emerging challenges.

#### 4. HOW FEEDBACK WAS TAKEN INTO ACCOUNT

Stakeholder views on Europe's beating-cancer plan were analysed and taken into account as much as possible. These views covered the plan's structure, key principles, implementation and governance.

After the stakeholders gave their overall endorsement of the plan, the Commission maintained and refined its holistic method across the four pillars and using its 'health in all policies' approach. It did so to take account of cross-cutting issues and to improve connections between the pillars for greater impact.

The Commission is considering strong, cross-sectoral actions to prevent cancer. It is aware that not all measures suggested during the consultation process will be politically feasible. A

key focus of Commission actions in the area of early detection and screening will be to update and further implement existing screening recommendations. It will also consider – on the basis of solid and robust evidence – extending these recommendations to other cancer types. The Commission recognises the great importance attributed by stakeholders to the sharing of best practices across the entire cancer-control continuum. They also understand stakeholders' particular commitment to the importance of areas such as quality of life for cancer patients and survivors. The Commission has noted the strong call to strengthen and build on the existing European reference networks, and will consider this call. The Commission will also consider other initiatives supported through the EU4Health programme and other funding instruments.

In addition, the stakeholders highlighted several issues, which appear not to have been sufficiently addressed in the roadmap. These issues include paediatric cancers, upskilling the health workforce, improving health information, and the impact of communicable diseases (COVID-19) on cancer patients and care. These will be considered in the development of the plan.

Stakeholders also underlined the importance of the EU's role in: (i) cancer research; (ii) improving data and sharing knowledge; and (iii) facilitating cross-country collaboration. The Commission is now reflecting on this role and how it can further develop it. The Commission continues to develop the whole plan while keeping in mind cross-cutting issues on: (i) patient-centred and citizen-centred approaches; (ii) access to all stages of the cancer-care continuum; and (iii) fairness across the entire care continuum.

The consultation also showed a strong desire for the plan to be effectively implemented based on realistic goals that are systematically monitored and evaluated.

Many actions proposed by stakeholders in the consultation touch upon – or are the exclusive competence of – Member States. Implementing these actions will therefore depend on Member States' ambition to take comprehensive cancer action. The Commission is prepared to support and complement Member State actions in this area.

The consultation also revealed a variety of different views, many of which were very detailed and technical. It will be more appropriate to consider these views during the implementation phase of the plan, and several of the proposed actions will require separate impact assessments for the implementation phase. Results from this implementation may alter the approach taken at EU level over time. However, it must also be acknowledged that the complete set of suggestions from stakeholders is almost limitless in its overall ambition.