

# **Policy Paper on Tackling Social Inequalities in Cancer Prevention and Control for the European Population**

R. Peiró Pérez, A. Molina Barceló, F. De Lorenzo, T. Spadea, S. Missinne, F. Florindi,  
N. Zengarini, K. Apostolidis, M. P Coleman, C. Allemani, M. Lawler

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# 1 Recommendations at a glance

## Capacity-building for cancer prevention and control

**Recommendation 1:** Embed equity within the cancer prevention and control policies in all European Union Member States.

Specific Recommendation (S.R.) 1.1: Formulate specific objectives that aim to tackle social inequalities in cancer across the whole population with additional emphasis on socially vulnerable groups.

S.R. 1.2: Include indicators of social inequality within the quality criteria established for cancer prevention and control programmes.

**Recommendation 2:** Align cancer prevention and control policies with a Health in all Policies approach.

S.R. 2.1: Create a multi-sectoral working group that includes experts on social inequalities in health to embed a Health in all Policies approach within cancer policies.

S.R. 2.2: Assess the impact of current and new policies, programmes, and health services on social inequalities in cancer.

S.R. 2.3: Produce a report on social inequalities in cancer, and make it available to the public.

**Recommendation 3:** Adopt a Health Equity Impact Assessment framework.

S.R. 3.1: Assess the evidence on social inequalities in cancer and identify any gaps in knowledge.

S.R. 3.2: Introduce a unique national identifier to facilitate safe record linkage between different databases in each European country in order to monitor social inequalities in cancer.

S.R. 3.3: Collect information on patient reported outcome measures (PROM), and link this information with cancer registry data.

S.R. 3.4: Use the Health Equity Impact Assessment tool to assess systematically the impact of policies on social inequalities in cancer.

**Recommendation 4:** Engage and empower communities and patients in cancer prevention and control activities.

S.R. 4.1: Involve communities and patient associations in decision making processes.

S.R. 4.2: Ensure that socially vulnerable groups are involved in the design, implementation and evaluation of health policies related to cancer prevention and control.

S.R. 4.3: Ensure that all patients receive up-to-date and accurate information and are proactively involved in their care.

**Recommendation 5:** Promote the exchange of good practice and support development of professional expertise in social inequalities in cancer in all European Union Member States.

S.R. 5.1: Foster exchanges of professional experience in all European Union Member States in tackling social inequalities in cancer.

S.R. 5.2: Provide appropriate training for cancer prevention, care, and rehabilitation professionals to tackle social inequalities in cancer.

**Recommendation 6:** Support the development of European research programmes that help deliver equity in cancer prevention and control in all European Union Member States.

## Primary and secondary cancer prevention policies

**Recommendation 7:** Implement proportionate universalism policies to develop and maintain living environments favouring compliance with the European Code Against Cancer.

S.R. 7.1: Ensure that tobacco and alcohol control policies, as well as other interventions promoting healthy behaviours, are addressed to the whole population, with additional emphasis among socially vulnerable groups.

**Recommendation 8:** Improve equitable access and compliance with cancer screening programmes.

S.R. 8.1: Provide screening processes that address the whole population with additional emphasis among socially vulnerable groups.

S.R. 8.2: Ensure the development and implementation of guidelines for quality assurance in cancer screening, which must include equity as a quality criterion.

## Cancer treatment, survivorship and rehabilitation policies

**Recommendation 9:** Ensure equitable access to timely, high-quality and multi-disciplinary cancer care.

S.R. 9.1: Implement an integrated model of cancer care management, whereby primary and secondary care are seamlessly linked.

S.R. 9.2: Implement measures to ensure access to and use of appropriate treatments that are addressed to the whole population with additional emphasis on socially vulnerable groups

S.R. 9.3: Ensure the development and implementation of guidelines in all involved disciplines, which must include equity as a quality criterion.

**Recommendation 10:** Ensure equitable access to high-quality surgical care in all European Union Member States.

S.R. 10.1: Establish optimal benchmarking standards for surgical oncology in all European Union Member States to help reduce the current inequalities experienced by cancer patients.

S.R. 10.2: Promote the creation of national information sources on the volume of surgeries per cancer centre, to provide patients with accurate activity data to aid in their choice of surgical centre.

**Recommendation 11:** Ensure availability of sufficient radiotherapy capacity with appropriate technology innovation in all European Union Member States.

**Recommendation 12:** Ensure that all patients have timely access to appropriate systemic therapy.

S.R. 12.1: Promote access to innovative therapies that deliver value-based, effective care, by harmonising Health Technology Assessment in all Member States.

**Recommendation 13:** Develop national cancer rehabilitation and survivorship policies, underpinned by an equity perspective.

S.R. 13.1: Make survivorship and rehabilitation an integral component of the patient care pathway from the time of diagnosis.

S.R. 13.2: Raise awareness about late effects, with the aim of providing recommendations to all patients and tailoring information specifically for socially vulnerable groups.

S.R. 13.3: Integrate employment programmes into follow-up survivorship care, with additional emphasis among socially vulnerable groups, to support return to work after acute treatment.

S.R. 13.4: Develop financial incentives to help employers introduce adaptations to work environments/situations in order to accommodate survivors' return to work.

## 2 Executive Summary

Europe is characterised by unacceptable disparities in access to cancer care and by significant social inequalities between and within European countries, which deeply impact cancer incidence, survival and mortality. Wide social inequalities in cancer incidence and survival exist both between and within European countries. All European Union Member States are affected by inequalities in cancer care between various population groups. Survival is often much lower in Southern and Eastern European countries than the European average. Important geographic differences in survival also exist within Western and Northern European countries, indicating that access to quality cancer care is not uniform across all European regions and that more privileged groups have better outcomes, due to a combination of lower exposure to risk factors, better access to screening programmes, better access to health services, and better capacity to absorb the social and financial consequences of cancer. Disadvantaged groups in all EU countries are at higher risk for most of the common cancers.

Social inequalities in cancer outcomes also have significant financial consequences for individuals and their families, and major economic consequences for Member States and the European Union. These costs account for 15% of social welfare system costs and 20% of the overall cost of health systems in the EU. Social inequalities in cancer are thus not only unethical, but also have significant consequences for the financial sustainability of healthcare budgets in all EU Member States. Since social inequalities in cancer have common roots, both across the continent of Europe and between social groups within the European population, they should be addressed at the European level. The European Union can play a crucial role in addressing inequalities in cancer care, by planning joint actions in all EU countries and by implementing effective measures to minimise inequalities in cancer incidence and survival.

This policy paper is one of the deliverables of the Joint Action on Cancer Control (CanCon), an initiative of the European Commission with partners from 17 European countries. It provides practical recommendations on which the European Commission and Member States can base concrete actions designed to reduce social inequalities in cancer. These recommendations reflect the analysis of contributing experts regarding the challenges facing EU Member States. They reflect the shared learning that can be achieved from the approaches that individual Member States have already taken to address some of these challenges. The recommendations are also informed by a survey completed by Member States. The policy paper includes 13 general recommendations, grouped into 3 main focus areas: capacity-building; primary and secondary prevention; and cancer treatment, survivorship and rehabilitation.

The first area of focus of the recommendations describes actions that the EU can take to support capacity-building for cancer control and prevention. There is a need to strengthen cancer prevention and control policies across the EU, by developing valid indicators of equity and then formulating objectives that are specifically designed to improve equity in cancer outcomes. EU countries can also build upon the Health in all Policies approach, and adopt a Health Equity Impact Assessment framework to promote the assessment of the impact of current and new policies, programmes and health services on social inequalities in cancer. This process requires the engagement and empowerment of patients and communities, to ensure that socially vulnerable groups are fully involved. Capacity-building can also be supported by promoting professional expertise and the exchange of good practices to tackle cancer inequalities at the EU level. European research programmes that can help deliver equity in cancer prevention and control should also be developed.

The second area of focus aims at promoting equity in primary and secondary prevention policies. The implementation of proportionate universalism policies to develop and maintain living environments that facilitate compliance with the European Code Against Cancer is recommended. Furthermore, actions must be implemented to improve equity in access to and compliance with cancer screening programmes. These actions and policies must be addressed to the whole population, but with additional emphasis on socially vulnerable groups.

The third area of focus relates to the promotion of equity in access to cancer care and to survivorship and rehabilitation services. Equity in access to timely, high-quality and multi-disciplinary cancer care is essential. This requires an integrated model of cancer care management, and inclusion of equity as a quality criterion in cancer care guidelines. Equity in access to high-quality surgical care is also recommended, with particular efforts to be made in establishing benchmark standards for surgical oncology and providing information to patients on the volume of surgeries performed at each cancer centre.

Investments in radiotherapy equipment and training are also necessary to ensure sufficient radiotherapy capacity across the EU. Unacceptable inequalities exist in access to systemic therapy (including essential chemotherapies and innovative personalised medicines), which can be targeted by harmonising Health Technology Assessment procedures across Member States. Finally, Member States should adopt and implement national cancer survivorship plans. These plans should become an integral component of each patient's care pathway. They should also include programmes designed to enhance return to full employment and financial incentives to ensure reintegration of cancer survivors into active life.

## Concepts and glossary of terms used in this document

**Social inequalities in health:** refer to differences in health that are systematic, socially produced, unnecessary and avoidable and are considered unfair and unjust (1). The European Commission recommends using the term social inequalities in health instead of social inequities in health, because it is more readily understood by the general public, and the term health inequities does not have a direct translation in all languages (2). These inequalities exist both between countries and/or regions and among social groups (3).

**Equity in health:** implies that each person should attain his/her full health potential and that no one should be disadvantaged from achieving this because of their social position or other socially determined circumstances. This refers to every citizen and not just to a particularly disadvantaged population segment (1).

### **Place of residence (including municipalities, regions and countries):**

The habitual place of residence of each cancer patient at the time of diagnosis is the geographic basis of cancer registration from which all metrics of cancer incidence, prevalence and survival are derived. It is also a stratifying factor for socially determined circumstances. The role of the place of residence in determining health goes beyond socioeconomic status. Many of the differences in health outcomes related to place of residence are avoidable if the necessary infrastructure is in place. When the difference is related to distribution of services such that services are not available to populations living within certain areas, this can be considered unfair (4). Other socially stratifying factors that are determinants of health include: race/ethnicity, culture, language, occupation, sex and gender, religion, education, socioeconomic status, and social capital (4).

**Social gradient in health:** the social gradient runs from the top to the bottom of the socio-economic spectrum. The social gradient in health means that health inequalities affect everyone (3).

**Socially vulnerable groups:** refer to subgroups of the population that- because of their position in the social structure- are at higher risk of multiple exposures to cancer risk factors, both clustered cross-sectionally and accumulated longitudinally throughout the life course (5) (e.g. people with mental, physical, and/or psychosocial disabilities, illiterate persons, refugees, prisoners etc.)

**Social inequalities in cancer:** refer to health inequalities that span the full cancer continuum and involve social inequalities in the prevention, incidence, prevalence, detection and treatment, survival, mortality, and burden of cancer and other cancer-related health conditions and behaviours (6).

**Proportionate universalism approach:** based on universal action but with a scale and intensity that are proportionate to the level of disadvantage (7).

### 3 Introduction

There is an urgent need for policies that support improved cancer prevention and control to be at the top of the European public health agenda. In 2012 approximately 3,450,000 European citizens were diagnosed with cancer, with over 1,750,000 dying from cancer (8). In 17 out of 28 EU countries, cancer has now overtaken cardiovascular disease as the leading cause of premature death (9). Cancer also places a significant social and economic burden on European citizens and societies.

In addition to these statistics, there are unacceptable social inequalities that exist across Europe in terms of cancer prevention, care, survival, and rehabilitation. There are also social inequalities- including geographical inequalities- related to cancer incidence, survival and mortality both between and within European countries (10-13). The situation is particularly challenging in Eastern Europe, with survival for many cancers below the European average (11). Western and Northern European countries also show inequalities in cancer care. This is reflected in lower survival from lung, colorectal and ovarian cancers in the UK and Denmark when compared to Norway and Sweden (14).

Social inequalities in cancer also occur within European countries (15-17). Social inequalities refer to the way in which differing social circumstances across the lifespan generate a social gradient in health through a myriad of complementary mechanisms (18). In terms of cancer, this means that more privileged groups have better outcomes because they have fewer risk factors for cancer, can take advantage of new interventions and screening programmes more quickly, have easier access to health services, and can minimise the social and financial consequences of cancer when it occurs (19). For example, disadvantaged groups are at greater risk for cancers of the lung, stomach, upper aero-digestive tract, and cervix (20). Lower participation in cancer screening programmes and delayed diagnosis has been reported for those with lower socio-economic status (21-23). Socially vulnerable groups, such as people with mental health problems, a physical handicap, children and adults with intellectual and or psychosocial disabilities, illiterate persons, refugees, and prisoners, also suffer from social inequalities in cancer (24-27). Social inequality is also associated with comorbidity, because socially vulnerable groups have greater exposure to multiple risk factors, which makes them more vulnerable to both cancer and other diseases.

Social inequalities in cancer can have their origin in childhood, when social conditions can influence longer-lasting exposures that may lead to increased risk of developing cancer in later life. Behavioural risk factors can be transferred from parents to children, and there is significant evidence that a healthy lifestyle is influenced by positive experiences in early childhood (18, 28, 29). This implies that improving social conditions in early life is likely to confer health benefits for the rest of an individual's lifetime (30).

Unacceptable inequalities exist in the provision of cancer care. A significant proportion of European citizens have inadequate access to surgery, radiotherapy and systemic therapies. These treatments have been shown to prolong lives and can achieve long-term cures (31, 32). Access to innovative treatments, including personalised medicine, a number of which have demonstrated substantial therapeutic benefit, is also denied to a significant number of European citizens (33).

Cancer care and control does not stop when initial treatment ends. Living with and beyond cancer must be underpinned by cancer policies that support survivorship and rehabilitation. For many people who survive cancer, transitioning to a normal and productive life can be extremely challenging. It may also involve suffering from discrimination because of perceived stigma related



to the disease. Socially disadvantaged groups face greater unmet need for rehabilitation services (34), and they have more difficulties returning to work (35).

Social inequalities in cancer outcomes also have significant financial consequences for individuals and major economic consequences for Member States and the European Union. They account for 15% of social welfare system costs and 20% of the cost of health systems in the EU (36). The societal burden of cancer in Europe is also reflected in huge losses in productivity due to early death (€42.6 billion a year) and lost working days (€9.43 billion a year) (37). Analysis of GLOBOCAN figures from 30 European countries confirms the significant lost productivity costs due to premature cancer-related mortality (38).

The economic burden of home or family care of cancer patients is substantial (39) and might be even more costly in terms of time spent in caregiving, learning caregiving skills and sacrifice of leisure time in families without resources to hire a formal caregiver (40). Caregiving also leads to reduced working hours (41), wage penalties (42), and disbursements for medical treatments (43). As female family caregivers report higher levels of stress and burden than male caregivers (44), caregiving for cancer patients is also related to gender inequality.

A central tenet of this paper is that social inequalities in cancer are not only financially intolerable but unethical. The EU thus has a responsibility to patients and the wider population to take measures to address these inequalities, both for the 3 to 4 million citizens who develop cancer every year, and more generally for the entire European population, up to half of whom will be expected to develop cancer at some point in their lives.

Social inequalities in cancer have common roots, both across the continent of Europe and among different social groups within the population. They should therefore be addressed at the European level, through strengthened collaboration between Member States, European institutions and key European and national stakeholders. Policy makers, health and social care professionals, and civil society must become aware of the unfair and avoidable nature of these inequalities. There are many examples that show the way in which EU-level cooperation can be of added value in cancer control, for example the European Partnership for Action Against Cancer (45).

This policy paper is a product of Work Package 5 (WP5) of the Cancer Control Joint Action initiative of the EU. It provides practical recommendations on which the European Commission and Member States can build and implement concrete actions to reduce social inequalities in cancer. It aims to promote equity-oriented policy making related to cancer prevention and control by highlighting practical actions to tackle social inequalities in cancer at the European and national levels, thus ensuring that reducing social inequalities in cancer is a top priority within European and national strategies on cancer prevention and control, especially through the National Cancer Control Plans.

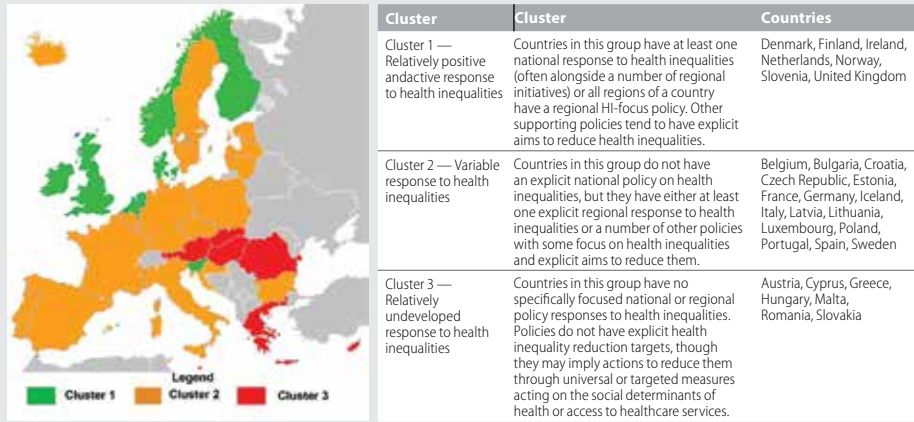
These recommendations reflect contributing experts' analysis of the current challenges that are faced by EU Member States and the shared learning that can be achieved from the approaches which individual Member States have taken to address these challenges. In addition, the recommendations are informed by a survey that was sent to Member States (see Table 1). A call for experts was launched in July, 2015 by the European Commission, and 23 experts were selected in order to review the policy paper drafts. A literature review was performed between September and October of 2015 to identify evidence of cancer inequalities and any regional, national and European-wide strategies designed to tackle them.

In 2016 Member States were surveyed on their experiences in tackling social inequalities in cancer. We received 7 completed surveys, and the information was incorporated into this policy paper with the reference “Member States Survey, 2016”. Examples identified from the literature review have been included to illustrate all of the recommendations in this paper. Information provided by Member States in the survey was used to complement these examples.

**Table 1. Survey sent to Member States to determine the current situation and collect experiences on tackling social inequalities in cancer.**

<p>1. Has the equity perspective been included in the cancer control plan or cancer policy of your country?                  Yes <input type="checkbox"/> Partially <input type="checkbox"/> No <input type="checkbox"/> Short comment _____  <i>(in all questions of this survey these answer options were included)</i></p>
<p>2. Has evidence of cancer inequalities in your country been assessed?</p>
<p>3. Have any information gaps in cancer inequalities been identified in your country?</p>
<p>4. Have the cancer policies related to health promotion and prevention targeted health inequalities?</p>
<p>5. Is the cancer policy/strategy of your country linked to a “Health in all Policies” strategy? (working beyond the health sector)</p>
<p>6. Has a cancer trans-disciplinary working group been organised, including inequalities experts?</p>
<p>7. Are the cancer professionals of your country being trained to address special needs of vulnerable groups in the population?</p>
<p>8. Have community and patient participation mechanisms been implemented during the process of cancer policy development?</p>
<p>9. Has equity been embedded in every cancer programme or service at the level of public health and healthcare provision? (For example by using an equity assessment tool)</p>
<p>As causes of cancer inequalities are multiple and inter-related, the action to tackle them needs to be interconnected across levels and sectors. Therefore, we are also interested in examples of actions and policies to address health inequalities carried out in your country. Regarding this issue, we have available the following information extracted from a complete study carried out by Sir Michael Marmot and published in the report: “Health inequalities in the EU — Final report of a consortium.” Consortium lead: Sir Michael Marmot. European Union 2013 <a href="http://ec.europa.eu/health/social_determinants/docs/healthinequalitiesineu_2013_en.pdf">http://ec.europa.eu/health/social_determinants/docs/healthinequalitiesineu_2013_en.pdf</a></p>
<p>Please check the following figure, explained in the table, and answer the question below.                  From your knowledge and experience in your ministry:</p>
<p>10. Does the response to health inequalities in your country remain in the same cluster?                  Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><input type="checkbox"/> It has improved</p>
<p><input type="checkbox"/> Now It is in cluster: 1, 2, 3</p>
<p><input type="checkbox"/> It has worsened</p>
<p><input type="checkbox"/> Now It is in cluster: 1, 2, 3</p>

If you have any good experience related to health inequalities responses that could be shown as an example, please write a short description or send us any document attached or link:



Although research groups that analyse data on social inequalities in cancer do exist in many countries, results are not pan-European, and a formal commitment by governments or governmental agencies to monitor and act on social inequalities in cancer is very rare.

This policy paper has 13 general recommendations that focus on 3 main areas: capacity-building; primary and secondary prevention; and cancer treatment, survivorship and rehabilitation. Each general recommendation includes a background based on evidence, specific recommendations, and examples identified through the Member States Survey, experts' knowledge, and the literature review.

This policy paper advocates for the need to explore the basis for social inequalities in cancer in Europe, and makes recommendations for policy makers that focus on addressing social inequalities that exist across the cancer continuum. Each Member State should adapt the recommendations to their specific policy needs, based on knowledge of the cancer profile of the population and the economic and social context.

## 4 Recommendations

### Capacity-building for cancer prevention and control

**Recommendation 1:** Embed equity within the cancer prevention and control policies in all European Union Member States.

Including equity targets in cancer prevention and control policies raises awareness at all levels of action. Initiatives that tackle health and cancer inequalities such as those undertaken by the Commission on the Social Determinants of Health (46) have influenced the policy agenda at many levels. Universal coverage requires that every individual within a country or region can access the same range of optimal quality services, according to needs and preferences, regardless of income level, social status, or residency, and that people are empowered to use these services. It extends the same scope of benefits to the whole population (46). A recent review of National Cancer Control Plans in Europe concluded that key goals to achieve equity are notably absent and that there is no explicit mention of how equity goals will be met, (47) thus highlighting the challenge that EU nations face.

Well intentioned universal policies and welfare programmes may inadvertently worsen social inequalities (5, 48-50) because more privileged groups are better equipped to take advantage of new knowledge and have access to interventions at an earlier stage (51, 52). To reduce the steep social gradient in health, a proportionate universalism approach (7) is needed. Actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage. In this approach health services are universally available, not only for the most disadvantaged, and they are able to respond to the level of presenting need (7). It is essential to identify barriers to equity in cancer, to define goals to improve equity and to identify the obstacles faced by specific groups allowing the subsequent design of tailored strategies to address these barriers and needs (1, 53).

**S.R. 1.1: Formulate specific objectives that aim to tackle social inequalities in cancer across the whole population with additional emphasis on socially vulnerable groups.**

Examples:

The third National Plan Against Cancer 2014-2019 in France promotes equity in prevention, care, rehabilitation and cancer research. Objectives related to equity include:

"[...]To combat inequality in uptake of and access to screening, and to increase the efficiency of programmes, in order to reduce avoidable deaths and the more severe treatments associated with delayed care", and "[...]To reconstitute and analyse patient care trajectories by shedding light on their association with risk factors (behavioural, environmental, or professional) and social determinants (level of education, employment, income level, etc.) so as to reduce inequality and adapt public policy to needs."<sup>1</sup>

As reported by the Member States Survey (2016) the National Cancer Strategy in Spain focuses on gender inequalities in cancer. In Poland, the National Health Programme aims to undertake actions targeted at reducing health inequalities in all areas of the healthcare system, including cancer control. Austria has a specific target that aims to provide equity in health promotion and care to the whole population independent of age, sex, origin and socioeconomic background.

<sup>1</sup> Available at <http://www.e-cancer.fr/Expertises-et-publications/Catalogue-des-publications/Plan-cancer-2014-2019>.

**S.R. 1.2: Include indicators of social inequality within the quality criteria established for cancer prevention and control programmes.**

**Example:**

Most European health systems are based on the principle of equity (54). However, it is difficult to find indicators that systematically measure results according to socio-economic variables. Some examples exist in which institutions have included equity as a quality criterion: for example, every hospital and long-term care home in Ontario is required to submit formal Quality Improvement Plans (QIPs) (54). This simple requirement signals a commitment to high-quality care across the health system, and it has positive implications for an equity-oriented quality strategy. By introducing equity as an element of the QIP process, institutions will be encouraged to incorporate equity as an essential element of quality, and best practices can be shared. For example, in “Measuring-Up” (a yearly report on the health of Ontarians and how the health system is performing), inequalities are highlighted both regionally and amongst different populations. The institution also believes that equity cannot just be implicit in its work—equity needs to be explicitly reflected in its quality efforts (55).

**Recommendation 2:** Align cancer prevention and control policies with a Health in all Policies approach.

The many causes of social inequalities in cancer are inter-related, so the actions to tackle the causes must also be interconnected, both across sectors and across intervention levels (56). The Health in all Policies approach involves coordinating policy sectors to address the social determinants of health that are the root causes of social inequalities in cancer (46, 57). The existence, and long-term persistence, of social inequalities in cancer and other non-communicable diseases suggests a prolonged failure of society to develop and implement policies to foster healthy household and community environments, facilitate healthy lifestyles and diet, and to deliver high-quality healthcare to all citizens (58). For an effective impact on the cancer-related social gradient in health, the involvement of non-health sectors is also needed, especially from the many sectors that have a direct impact on health, including education, social policy, environment, labour and immigration, housing, urban and regional planning, transportation and active mobility, and the economy (59, 60). A successful Health in all Policies approach could be facilitated in several ways. However, it is of primary importance that there are mechanisms of engagement such that different sectors that impact health are committed to working to support health and health equity (60), including citizens. Concerted and coordinated action on the social determinants of health requires strong political leadership at the local, national and international levels (60).

**S.R. 2.1: Create a multi-sectoral working group that includes experts on social inequalities in health to embed a Health in all Policies approach within cancer policies.**

**Example:**

From the Member States Survey (2016): Under a new 2015 law on public health, the next National Health Programme in Poland will be a multi-sectoral action coordinated by many ministries and governmental agencies. The Steering Committee of this programme will monitor and coordinate the actions undertaken during implementation of the programme, including the Minister of Health and the Undersecretary of State in other ministries. The Council on Public Health, including healthcare experts, will serve as an opinion-giving and advisory body of the Minister of Health for issues related to the programme. In this way, a focus by non-health ministries and sectors on the social determinants of health can help to provide a wider perspective on equity issues.

**S.R. 2.2: Assess the impact of current and new policies, programmes and health services on social inequalities in cancer.**

**Example:**

The “Apprendre et Agir pour Réduire les Inégalités Sociales de Santé” in Toulouse (France) is a health equity impact assessment umbrella programme to analyse and modify interventions related to cancer- which are already underway- in terms of their potential impact on health inequalities. It relies on partnership between researchers and other actors in the health field, including policy makers. Many partners have rallied around this program, which has been shown to be feasible and acceptable by partners and health actors (61).

**S.R. 2.3: Produce a report on social inequalities in cancer, and make it available to the public.**

**Examples:**

The National Cancer Equality Initiative (62) in England published a report on inequalities in cancer titled Reducing Cancer Inequality: Evidence, Progress and Making it Happen (2010). It compiled the most accurate figures in order to identify gaps in knowledge, and thus to increase awareness about social inequalities in cancer.

In England a study (2013) analysed the effectiveness and the equity impacts of town-wide cycling initiatives, showing that after a major investment in more deprived areas, the situation improved in all studied areas, with larger relative changes in deprived areas (63).

**Recommendation 3: Adopt a Health Equity Impact Assessment framework.**

Knowledge is crucial to inform policies designed to influence population health and welfare, particularly in terms of policy effectiveness, efficiency, and equity (64). Information on the social determinants of cancer risk and outcomes in a population can be used to monitor trends and allow for comparison of the ways in which cancer affects different social groups (46). Long-term monitoring of cancer inequalities contributes to the evidence base for comprehensive policies on cancer control. Population-based cancer registries can support a wide range of studies on cancer inequalities in the EU, although not all cancer registries collect individual socio-economic data (65); in some cases, area-based indicators have been used (66). Difficulties have also arisen in gaining access to data for research, due to national legislation on confidentiality, which anticipated the approval of the European regulation on protection of data (67). It is therefore important to harmonise data gathering and processing to address inequalities in cancer, in order to foster comparisons of cancer incidence and survival trends. Although research groups analysing data on social inequalities in cancer do exist in many countries, the results do not cover all of Europe, and formal commitments by governments and governmental agencies to monitor social inequalities in cancer are rare.

Health Equity Impact Assessment is a useful tool to develop public policies designed to promote equity in health (68, 69). It aims to identify potential health impacts (positive or negative) of a plan, policy or programme on socially vulnerable or disadvantaged groups within the general population. Several tools have been designed to provide systematic steps for health policy makers, programme planners, and researchers to assess their initiatives through the lens of a health equity perspective (70-72).

**S.R. 3.1: Assess the evidence on social inequalities in cancer and identify any gaps in knowledge.****Example:**

Results from the Member States Survey (2016) suggest that social inequalities in cancer have been assessed mainly in terms of geographic or regional differences in incidence and mortality within a country (Spain, Poland and Lithuania). Spain also reported that inequalities in cancer have been assessed by gender. Austria reported the identification of gaps in information on social inequalities in cancer, and has also partially assessed these inequalities.

**S.R. 3.2: Introduce a unique national identifier to facilitate safe record linkage between different databases in each European country in order to monitor cancer inequalities.****Example:**

In the framework of the Turin Longitudinal Study (Italy), the cancer registry, screening programmes, and breast cancer treatment regional databases have been individually linked to socio-economic indicators from the census through an anonymous unique regional code, thus providing detailed information about social inequalities in access to screening and in cancer incidence, treatment and survival in Turin (73-75).

**S.R. 3.3: Collect information on patients' reported outcome measures (PROMs), and link this information with cancer registry data.****Example:**

The patient reported outcome measures (PROMs) of the National Health Service of England is a mandatory national data collection system, the purpose of which is to gather key information on the health status of patients before and after their operation. A report titled Quality of Life of Cancer Survivors in England was published in 2012 (75), piloting a survey using PROMs. This survey was commissioned by the Department of Health as part of the National Cancer Survivorship Initiative (NCSI). The survey was conducted by the Quality Health Department in conjunction with three cancer registries in England. The first aim was to assess the feasibility and acceptability to cancer survivors of collecting information on quality of life (QoL) with PROMs. The second aim was to assess the overall QoL of representative samples of cancer survivors with four different tumour types (breast, colorectal and prostate cancer, and non-Hodgkin lymphoma) at four different time points after diagnosis (approximately one, two, three or five years) (76).

**S.R. 3.4: Use the Health Equity Impact Assessment tool to assess systematically the impact of policies on social inequalities in cancer.****Example:**

A paper from England gives an example of how this tool can be used by urban planners, health policy decision makers and other municipal authorities to support the health and equity assessment of policies and interventions affecting air pollution. These tools aim at identifying the various modifiable factors that can be mobilised to increase the positive impact of policies and interventions. It can be used by those who may not necessarily have or need a sophisticated epidemiological model (77).

**Recommendation 4:** Engage and empower communities and patients in cancer prevention and control activities.

The Ottawa Charter for Health Promotion (78) highlighted the importance of effective community action in setting priorities for health, including in decision making and the development and implementation of strategies to improve the health of citizens. Subsequent publications have reinforced this perspective (78-81). Community participation is a means and a necessary step to improve the health of the population and to increase the capacity for interventions related to the social determinants of health. Empowerment has been found to improve the social acceptability of interventions and cancer-related outcomes (82). This requires a shift in emphasis, from provision of information to the population, to fostering their participation in decision making processes. This, in turn, requires in-depth knowledge of the population, to facilitate outreach and engagement on the part of health professionals, community workers and lay health advocates. Providing a voice to the population can help ameliorate social inequalities by incorporating the needs of different social groups into cancer programmes.

Patient-centred care in cancer requires a multi-level approach, in order to understand patients' concerns, needs and expectations, all of which can change during the many stages and cycles of diagnosis and treatment (83). There are many aspects related to patients in the process of cancer care; the individual patient's view of his or her disease, as well as the treatment process; the interaction with the family, friends and caregivers; the relationship with the surrounding society and culture (84), and finally, communication barriers with the healthcare provider, especially with respect to unmatched health belief models and understanding of treatment goals (85, 86). Empowerment is fundamental to the principles and approaches of patient-centred care. Healthcare providers should adopt a partnership style with patients. They should provide healthcare that is respectful of patients, in order to support informed patient decision making (87).

#### **S.R. 4.1: Involve communities and patient associations in decision making processes.**

##### **Examples:**

The principles of the European Cancer Patients' Bill of Rights (BoR) promote three main rights for all cancer patients in Europe.

- 1 The Right of every European citizen to receive the most accurate information and to be proactively involved in his/her care.
- 2 The Right of every European citizen to equal and timely access to appropriate specialised care, underpinned by research and innovation.
- 3 The Right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable healthcare.

The Bill of Rights, developed by the European Cancer Concord (a coalition of patient groups and healthcare professionals) and the European Cancer Patient Coalition (ECPC), is a beacon for the work of many national and local patient associations in Europe and represents a useful stepping stone for the implementation of truly patient-centred cancer care in Europe (88, 89).<sup>2</sup>

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<sup>2</sup> Available at: <http://www.ecpc.org/activities/policy-and-advocacy/policy-initiatives/138-european-bill-of-cancer-patients-rights>.



The Member States Survey (2016) showed that in Spain, cancer patient associations are members of the Monitoring and Evaluation Committee of the National Cancer Strategy, and they participate actively in the elaboration, implementation and evaluation of the strategy. Austria reported that a patient representative had been involved during the entire development period of the National Cancer Framework Programme.

**S.R. 4.2: Ensure that socially vulnerable groups are involved in the design, implementation and evaluation of health policies related to cancer prevention and control.**

**Example:**

A literature review identified numerous cases where cancer patients were engaged in health policy and planning in the UK, Scotland and in other countries. The participation of patients from minority ethnic groups was specifically sought out in the United States and in Australia (90).

**S.R. 4.3: Ensure that all patients receive up-to-date and accurate information and are proactively involved in their care.**

**Example:**

In the UK, Evans (91) identified the different forms that user involvement can take in cancer services and explored the necessary elements for effective patient engagement. They found a range of factors that influence cancer service users' participation in service development and delivery that can be taken into account in European countries.

**Recommendation 5:** Promote the exchange of good practice and support development of professional expertise in social inequalities in cancer in all European Union Member States.

Encouraging exchange of good practice and sharing expertise between countries to tackle social inequalities in cancer is vital to long-term improvement in cancer outcomes (92).

Better training for cancer professionals is required to support a shift towards improved equity in cancer care and to help guarantee the right to health for the whole population. The Social Determinants of Health approach (46) and education about the importance of achieving equity should form part of the educational curricula for undergraduate and postgraduate degrees in all disciplines that play a role in cancer prevention, care and rehabilitation.

**S.R. 5.1: Foster exchanges of professional experience in all European Member States in tackling social inequalities in cancer.**

**Example:**

The EURO COURSE action (Europe Against Cancer: Optimisation of the Use of Registries for Scientific Excellence in Research) (93) aims to develop necessary standards to support use of registry data in research. This is part of the infrastructure to streamline data collection by European cancer registries, in order to provide better cancer statistics for Europe. Best practices will be documented and recommendations will be drafted on the issues of ethics, evaluation of the effectiveness of screening programmes using data from cancer registries, and the design of population-based genetic studies using biobanks.

### **S.R. 5.2: Provide appropriate training for cancer prevention, care, and rehabilitation professionals to tackle social inequalities in cancer.**

#### **Example:**

The French National Cancer Institute (INCa) has hosted a “Cancer equity task force” for several years. This think tank gathers professionals from virtually all INCa services and cancer-related professional groups. It has helped foster reflection about how to improve equity and how to ensure that measures included in the cancer plan are equitable by design.

**Recommendation 6:** Support the development of European research programmes that help deliver equity in cancer prevention and control in all European Union Member States.

There are enormous differences in research capacity across Europe, both between countries and between disciplines (94). Research on social inequalities in cancer is underfunded, both in Member States and across the European Union. Adequate support for research is crucial to generate evidence for evidence-based decision making (46). Data and evidence on the social determinants of health may come from many disciplinary backgrounds and methodological traditions, including social history, economics, social policy, politics, sociology, environmental science, and epidemiology. This pluralistic approach is essential in order to produce systematic studies of the effects of policies on social inequalities in cancer (95).

Cancer research in Europe is of a high standard, but fragmentation and lack of sustainability are the greatest barriers to implementing innovation in cancer care. Integration of research data from many data sources across the complete continuum of cancer care represents a powerful research tool for Europe but is difficult to achieve. Solving this problem would substantially improve the study of inequalities in cancer outcomes between countries (96). Standardisation of data collection, interoperability between cancer information systems and support of internationally standardised protocols are pre-requisites for success. This would enable more effective evaluation of prevention policies, as well as mapping variations in the standards of care and in cancer survival. Data on patient values and preferences could also be added to the database to incorporate the cancer patient’s perspective (97, 98).

#### **Example:**

In the Member States Survey (2016), France reported that it supports research designed to improve understanding of factors and processes that create inequalities across the cancer continuum (e.g. higher exposure of lower social classes to cancer risk factors such as smoking etc.) This is one of the equity objectives in the National Plan on Cancer.

## **Primary and secondary cancer prevention policies**

**Recommendation 7:** Implement proportionate universalism policies to develop and maintain living environments favouring compliance with the European Code Against Cancer.

Social inequalities in cancer related to incidence and mortality are associated with the socially patterned distribution of the main modifiable risk factors for the most common types of cancer: smoking, alcohol, diet and exercise, viral infections, occupational exposures and reproductive behaviours (99-101). These risk factors are largely avoidable or preventable, but they are disproportionately prevalent in poor and disadvantaged communities. The European Code Against Cancer focuses on actions that individual citizens can take to help prevent cancer (102).

Many population health interventions focus on unhealthy behaviours that are key contributors to the cancer burden, but successful cancer prevention requires various levels of action (individual, legislative, etc.) supported by government policies (102, 103). Without targeted prevention programmes, intervention or communication campaigns can inadvertently contribute to widening inequalities via the so called “Inverse Prevention Law” under which more educated or affluent groups of society can more readily access or interpret messages about prevention or screening and are better able to act on them to change their behaviour and reduce their risk (48, 104).

Interventions to promote healthy behaviours are a potentially powerful contribution to the primary prevention of cancer. Among risky behaviours, smoking is certainly the risk factor that accounts for the highest burden of disease in cancer and in general morbidity. Social inequalities in smoking follow the so-called “smoking epidemic”, with higher socio-economic classes adopting this habit very early and successively abandoning it, while smoking becomes progressively more common among lower socio-economic groups (105). In women, these patterns have usually lagged 10–20 years behind those of men. Various countries are in different stages of this epidemic, therefore there are quite different patterns in the social gradient by gender across Europe. Unfortunately, however, there is some evidence that general tobacco control policies are more effective among higher socioeconomic groups, and they may therefore contribute to widening inequalities unless specific targeted actions are undertaken (106). Research is needed to develop interventions that explicitly focus on socially vulnerable groups.

**S.R. 7.1: Ensure that tobacco and alcohol control policies, as well as other interventions promoting healthy behaviours, are addressed to the whole population with additional emphasis on socially vulnerable groups.**

**Examples:**

A recent project supported by the EU Public Health Programme aimed at evaluating the implementation of the EU Strategy on nutrition, overweight and obesity, has assessed the equity impact of interventions encouraging healthy diet and physical activity.<sup>3</sup> The report found some evidence that providing healthy foods at schools can reduce the social gradient in unhealthy diets and is an effective strategy in the long term. More generally, actions developed under the life-course approach, focusing on crucial stages of life (e.g. gestation and early childhood) have great potential to reduce inequalities in obesity, which are increasingly affecting women more than men, and also affect children.

A systematic review of interventions to promote healthy eating that evaluate the differential impacts by socioeconomic position found that upstream policies- such as those that combine taxes on unhealthy foods with subsidies for healthy foods- appeared to decrease social inequalities. By contrast, individual interventions, especially dietary counselling, seemed to increase social inequalities in dietary fat intake (106).

The Hungarian government’s public school food policy mandates a reduction in unhealthy foods such as salt and red meat and an increase in the proportion of healthy foods such as vegetables and fruit.<sup>4</sup> Among other actions (development of standards and guidelines, restrictions on marketing of food or sweet drinks on school premises, etc.), the programme includes provision of food at

3 Available at [http://ec.europa.eu/health/nutrition\\_physical\\_activity/docs/pheiac\\_nutrition\\_strategy\\_evaluation\\_case\\_study\\_en.pdf](http://ec.europa.eu/health/nutrition_physical_activity/docs/pheiac_nutrition_strategy_evaluation_case_study_en.pdf).

4 Available at [https://ec.europa.eu/jrc/sites/jrcsh/files/jrc-school-food-policy-factsheet-hungary\\_en.pdf](https://ec.europa.eu/jrc/sites/jrcsh/files/jrc-school-food-policy-factsheet-hungary_en.pdf)

schools. The programme is free for socially vulnerable groups of children during the school term as well as during school holidays. In parallel, more time has been devoted to physical education in primary and secondary schools in order to reduce obesity and improve general health.

**Recommendation 8:** Improve equitable access and compliance with cancer screening programmes.

Population-based screening programmes reduce mortality from cancer of the breast, cervix and large bowel (colon and rectum). Socio-economic and geographic inequalities in access to timely diagnosis and high-quality treatment are likely to be key determinants of inequalities in cancer survival, especially for cancers with a good prognosis (23). Evidence suggests that population-based screening programmes that include comprehensive quality assurance of diagnostic services and personalised invitations to all individuals in the eligible target population (107) ensure greater equity in access to timely and high-quality diagnosis than is possible with opportunistic screening (108, 109). Population-based screening programmes are more effective at channelling screen-detected patients into a protected, effective and evidence-based pathway of care (75). However, social inequalities in participation in cancer screening still arise within population-based screening programmes. For example, participation rates are often lower in lower socioeconomic groups (110), minority ethnic groups (111), people with intellectual disability (112), and people living in underprivileged areas (108, 110-116). Participation in and the performance of population-based screening programmes varies widely between countries (117-120), indicating inequalities in access to and the effectiveness of some of these programmes (116-122).

Some strategies have been shown to enhance access to screening among lower socioeconomic groups (7, 120). These strategies include offering free testing, elimination of geographical barriers to access (such as introducing mobile screening units), greater involvement of primary care physicians, and communication strategies tailored to specific groups of the population in which uptake of screening is known to be poor.

**S.R. 8.1: Provide screening processes that address the whole population with additional emphasis among socially vulnerable groups.**

**Example:**

The Reference Centre for Epidemiology and Cancer Prevention in Piedmont (Italy) coordinates the regional programme for female cancer and colorectal cancer screening. To promote participation in cervical cancer screening of immigrant women, the programme undertook initiatives aimed at improving the quality of communication and access to screening facilities. A multi-disciplinary team was created including medical doctors, community health workers, members of associations working in the field of immigration and cultural mediators. Leaflets and posters in eight languages (Romanian, Russian, Arabic, Chinese, Albanian, English, French and Spanish) were produced and disseminated in clinics, pharmacies, medical offices, cultural centres and associations in Piedmont and were included in a wider mass campaign with posting on regional transport systems (buses, trams, trains).<sup>5</sup>

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5 Available at: <http://www.cpo.it/en/articles/show/prevenzione-serena-integration-also-in-prevention/>.

### S.R. 8.2: Ensure the development and implementation of guidelines for quality assurance in cancer screening, which must include equity as a quality criterion.

#### Example:

The two main goals of the European Commission Initiative on Breast Cancer (ECIBC) are to develop the European guidelines for breast cancer screening and diagnosis and the voluntary European Quality Assurance scheme for Breast Cancer Services. The Quality Assurance Scheme Development Group is working on the definition of quality requirements and indicators that will address quality domains related to clinical effectiveness, facilities, resources and workforce, personal empowerment and experience, and safety. Equity is a transversal item that has been included as a quality indicator (121).

## Cancer treatment, survivorship and rehabilitation policies

**Recommendation 9:** Ensure equitable access to timely, high-quality and multi-disciplinary cancer care.

The European Action Against Cancer (EPAAC) ([www.epaac.eu](http://www.epaac.eu)) has set out the need for multi-disciplinary cooperation to improve the care of cancer patients. Multi-disciplinary care has rapidly become a standard approach to the management of cancer patients since 2000 (123). A multi-disciplinary team (MDT) can be defined as a team of medical and health professionals who manage patients with a specific type or group of tumours, such as brain tumours or lymphomas. The MDT is characterised by professional collaboration, evidence-based clinical decision-making and coordination of the delivery of care throughout the cancer patient pathway. Furthermore, MDTs should encourage an active role of patients and caregivers in cancer management. Cancer care is increasingly complex, and MDTs involve a growing number of specialist disciplines, including areas as diverse as psychosocial support, genetics and frailty. In this context, consensus decision making becomes particularly important (124). A systematic review showed that multi-disciplinary cancer teams produce better clinical and process outcomes for cancer patients, in terms of survival and reduced waiting time from diagnosis to treatment, reducing social inequalities in care (125).

Organisational models of cancer care have a great impact on outcomes. The EPAAC and CanCon projects have examined organisational models designed to improve outcomes. One literature review of networks as an organisational model has suggested that they have the potential to improve the quality of healthcare services, equity of access, knowledge transfer and the cost-effectiveness of health services. Networks also have the potential to provide more patient-centred services.

Socio-economic disadvantages in access to optimal treatments exist across Europe. Well-documented examples of lack of access to optimal treatment exist for lung, colon, pancreas, prostate, oesophageal and breast cancer in different European countries (126-128). Patients in lower socioeconomic classes show higher levels of comorbidity and lower levels of adherence to treatment, which greatly affect survival (129). The EURO CARE Project (11) and International Cancer Benchmarking Partnership (14) indicated lower survival for patients over 65 years of age, reflecting a potential ageism in the delivery of cancer care and possible widening of the survival gap between older and younger patients in Europe. In many European countries there is increasing evidence that older patients are under-treated and that this lack of equity in access to cancer care is leading to poorer outcomes (130). This may have an even greater impact in countries without universal health coverage.

In addition to implementing the EPAAC recommendations on multi-disciplinarity in cancer care, two other key factors play a role in facilitating equitable access to multi-disciplinary care: patient navigation programmes and clinical practice guidelines.

Patient navigation programmes are increasingly being used to address inequalities in healthcare, and in cancer care in particular. Successful patient navigation includes instrumental interventions to identify and meet patients' needs (e.g. insurance, transportation, information) and relationship interventions to enhance the interaction between patients and clinicians. It has been shown to be effective in helping women to access cancer screening, to receive more timely diagnostic resolution after an abnormality has been detected during breast or cervical cancer screening, to initiate treatment sooner, to receive appropriate treatment, and to improve quality of life after a cancer diagnosis. The patient navigation model has been most widely adopted in the USA, but several schemes have been implemented in the UK and the Nordic countries, in collaboration with oncology nurses (131). In other EU countries, cancer patient associations may arrange for volunteers to provide navigation services where the health-care institution cannot provide this intervention. Collaboration between cancer patient organisations, hospitals and universities could promote training and education for patient advocates or survivors as volunteer patient navigators. This could improve the integration of patient navigators into the cancer care pathway.

The implementation of clinical practice guidelines that have been developed through international consensus among clinicians can help reduce social inequalities in cancer by minimising differences in the quality of care. This requires equal access to screening, early diagnosis and treatment. The many factors that can act as barriers to the effective implementation of clinical guidelines need to be addressed. These include provision for training of specialists who are expected to deliver guideline-compliant treatment, and formal guidance on organisational aspects of their implementation.

**S.R. 9.1: Implement an integrated model of cancer care management, whereby primary and secondary care are seamlessly linked.**

**Example:**

The chapter on integrated care in the CanCon Guide developed within Work Package 6 (WP6) uses as an example of better access to quality cancer care the creation of Comprehensive Cancer Care Networks (CCCN) at the national level. CCCNs reconcile the expertise of high-volume specialised referral centres with the greater accessibility of general hospitals and of other healthcare institutions (imaging centres, community care centres, etc.) as well as of primary care providers (general practitioners, home nurses, and others). In terms of social inequalities, the contributors to the CCCN could facilitate access to quality cancer care for patients who may be less likely to seek specialised healthcare in existing comprehensive cancer centres. CCCNs may effectively address territorial inequality in access. Access points to a CCN should be clearly defined; i.e. access points should be as close as possible to where patients reside, and uniformly optimal care should be provided as close to home as possible.

An analysis of physician utilisation by income in 21 OECD countries, drawing on data from national surveys or the Community Household Panel, reported no inequalities in primary care physician visits and an inequality in specialist consultations that favoured those with high incomes (132).

**S.R. 9.2: Implement measures to ensure access to and use of appropriate treatments that are addressed to the whole population with additional emphasis on socially vulnerable groups.**

**Examples:**

The patient navigator experience addresses emotional, informational and instrumental barriers to treatment (133-136). A review of cancer patient navigation identified four major areas in which patient navigators can intervene, building on the construct of social support, including 1) overcoming health system barriers, including coordination, scheduling and help with paperwork (i.e. instrumental support); 2) providing health education, including written information, discussion and answering questions (i.e. informational support); 3) addressing patient barriers, such as lack of transportation, financial and insurance barriers, lack of childcare, low literacy and language translation (i.e. instrumental support); and 4) providing psychosocial support (i.e. emotional support) (133).

In a public health system financial difficulties may be associated with cancer patient outcomes such as quality of life and survival. A group of Italian researchers pooled data from 16 multicentre trials in lung, breast and ovarian cancer (a total of 3,670 patients). They analysed the patients' reported financial difficulties following cancer treatment (so-called "financial toxicity"), and found that 22% of patients reported financial toxicity that was significantly associated with an increased risk of death (approximately 20%) (137).

**S.R. 9.3: Ensure the development and implementation of guidelines in all involved disciplines, which must include equity as a quality criterion.**

**Example:**

The Centre for Clinical Practice at NICE is committed to eliminating unlawful discrimination, advancing equality of opportunity, and fostering good relations. "Positively equal" was designed as an essential tool to help inform consideration of equality issues as a systematic and integrated part of the clinical guideline development process (138).

**Recommendation 10:** Ensure equitable access to high-quality surgical care in all European Union Member States.

Surgery is a key component of multi-disciplinary cancer care and contributes significantly to improved survival in Europe. It is estimated that 80% of all new cases of cancer in 2015 will require surgery, some several times (31). However, variations in the quality of surgery delivered and unequal access to appropriate surgical interventions across Europe leads to significant differences in cancer outcomes between groups of people within countries and between countries (24, 25).

Complex treatment of cancer requires a minimum number of procedures to be performed, appropriate infrastructure, and human resources at the Member State and EU levels. The best opportunity for ensuring improved outcomes relies on delivery of surgical care in cancer centres where specialised surgical oncologists perform a sufficient number of procedures with appropriate complexity (based on the number of cases treated per year (139) in an environment with access to other treatment modalities (radiotherapy, chemotherapy) and appropriate supportive care (140).

This is particularly true for rare cancers and cancers requiring highly complex surgery (e.g. cancers of the lung and pancreas). In these cases, patients should be treated in centres of excellence in order to ensure that they benefit from high-quality surgical expertise, thus increasing their chances of survival. In this respect, the creation of a European Reference Network (ERN) on rare cancers, foreseen by the Cross-border Healthcare Directive, could represent an important development (141).

It remains a priority to strengthen surgical systems through investment in public sector infrastructure, education, and training (31) and by facilitating patients' access to cancer centres with a high annual volume of surgical procedures for cancer. Access to innovative surgical procedures should also be implemented, provided that efficient innovation is sustainable and brings sufficient added value to cancer patients (31). Investments in innovative surgical procedures should be paired with solid analysis and reallocation of resources to ensure overall sustainability of cancer care. The CanCon Policy Paper on *"Enhancing the Value of Cancer Care Through a More Appropriate Use of Healthcare Interventions"* defines this practice as a systematic attempt at identifying low-value items of care that represent an inappropriate use of healthcare resources. At the same time, disinvestment requires developing coherent initiatives aimed at eliminating or reducing their use, with the general expectation of supporting the use of more effective procedures and interventions and sustaining the adoption of valuable diagnostic and therapeutic innovations. In implementing disinvestment policies, a critical factor influencing their success is a balanced, patient-centric evaluation of the equilibrium between the cost of health services and the benefit to patients. To achieve this goal, adequate resources and skills should be put in place by Member States to identify low-value interventions and to design disinvestment plans. Those plans should be based on the key criteria of multi-disciplinarity and consultation, in particular with patients and their organisations.

**S.R. 10.1: Establish optimal benchmarking standards for surgical oncology in all European Union Member States to help reduce current inequalities experienced by cancer patients.**

**Examples:**

A study on breast cancers diagnosed in the period from 1996 to 1998 revealed large differences in care for breast cancer across Europe. Delivery of "standard-of-care" surgery ranges from 78% (France) to 9% (Estonia), and inequalities were evident, even between countries with medium to high expenditure on health. National protocols had been developed and disseminated during the late 1990s, but standardised European guidelines were still not available (32).

The European Registry of Cancer Care (EURECCA) (140) is an international multi-disciplinary platform of clinicians and epidemiologists aiming to improve the quality of cancer care by ensuring data registration, promoting and incorporating feedback, forming plans for improvement and sharing knowledge of performance and science. The mission of EURECCA is to achieve and assure high-quality multi-disciplinary cancer management in Europe, accessible to all patients through the development and support of an international quality assurance structure- which is an audit structure- using anonymous patient data and compliant with national and international laws.



**S.R. 10.2: Promote the creation of national information sources on the volume of surgeries per cancer centre, to provide patients with accurate activity data to aid in their choice of surgical centre.**

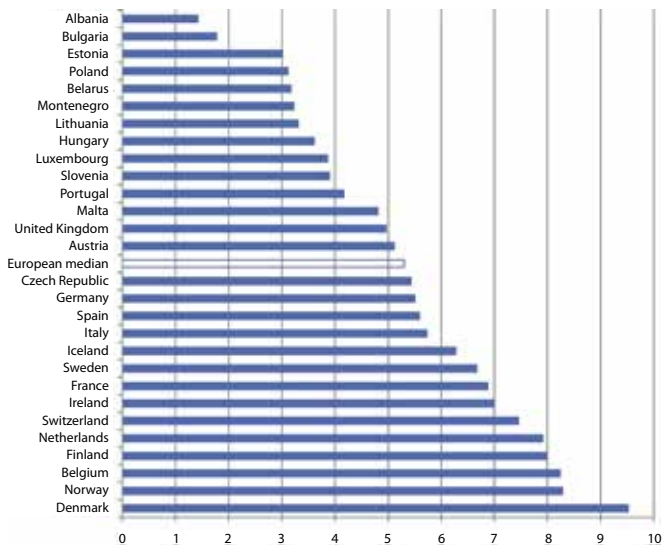
**Example:**

The Italian Oncoguida<sup>6</sup> is an information service produced by the Italian Association of Cancer Patients (AIMaC) in collaboration with the Italian Institute of Health and the Italian Ministry of Health. Oncoguida provides detailed, patient-oriented information on Italian hospitals and cancer centres providing cancer care, including volume of surgeries performed per tumour site, availability of psychological and physical rehabilitation services and contact details of patient associations involved at the hospital level. The Oncoguida should act as a blueprint for other Member States to produce similar national directories.

**Recommendation 11:** Ensure availability of sufficient radiotherapy capacity with appropriate technology innovation in all European Union Member States.

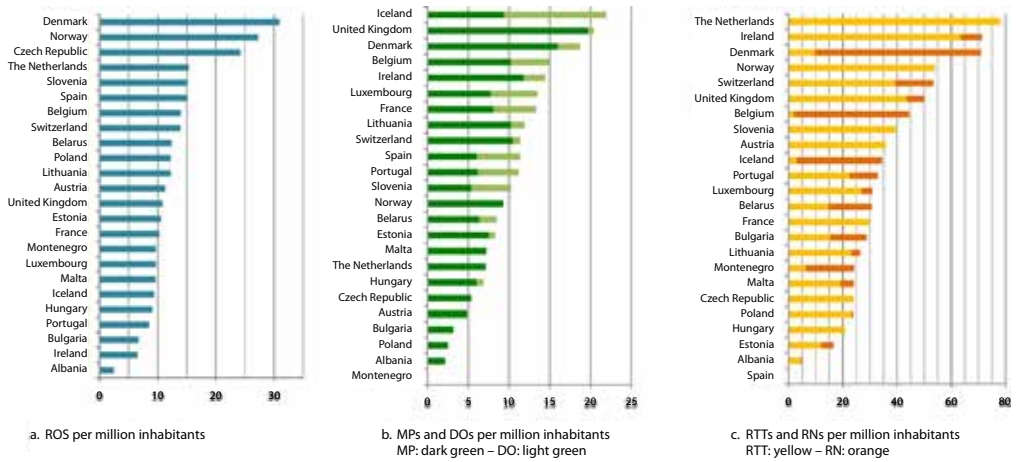
Radiotherapy is a key pillar of treatment and is essential in more than half of all cases of cancer, to cure localised disease, palliate symptoms and control disease in incurable cancers. A large discrepancy exists between the actual and the optimal availability and use of radiation therapy between European countries (142-145), as well as between socio-economic groups (146). When staffing levels or access to modern radiotherapy equipment are evaluated, the results are similar (144, 145) and show unequal access to cancer care for European patients. These deficiencies are experienced not only in Southern and Eastern European countries (particularly Bulgaria, Macedonia and Romania), but also in some Western European countries such as Portugal and the UK (Figure 1, Figure 2).

**Figure 1** Number of radiotherapy units per million inhabitants.



6 <http://www.oncoguida.it/html//home.asp>

**Figure 2** Figure 2 : Number of radiation professionals per million inhabitants



**ROs:** radiation oncologists; **MPs:** medical physicist; **DOs:** dosimetrists; **RTTs:** radiation therapists **RNs:** radiation nurses

**Recommendation 12:** Ensure that all patients have timely access to appropriate systemic therapy.

While many cytotoxic medicines have been shown to be effective treatments for cancer patients, there are significant social inequalities in access to these treatments across Europe. A recent survey indicated that over 50% of European hospital pharmacists have experienced significant shortages in access to life-preserving and life-sustaining cytotoxic regimens (ranging from 33% in Northern Europe to 59% in Western and Southern Europe and 65% in Eastern Europe) (147). Unfortunately, information on the causes of medicine shortages is not currently consistently collected and reported across Europe, thus it is difficult to develop potential solutions.

Increased understanding of disease biology is fuelling a “personalised cancer medicine” revolution (148). However, providing innovative treatments in a timely fashion to European cancer patients is hampered by a pricing/reimbursement approach that differs markedly between individual European countries, thus accentuating inequalities between countries in access to optimal cancer care (33). In many EU countries cancer patients have experienced extended delays in access to innovative treatments due to the lengthy decision-making process for pricing and reimbursement. Such decisions are normally due within 180 days from the European Medicine Agency (EMA) decision on market authorisation, in line with the relevant EU binding regulation. In certain cases (149), this has led to significant discrepancies in access, which may have a detrimental effect on survival, although more research is required in this area (150).

**S.R. 12.1: Promote access to innovative therapies that deliver value-based, effective care, by harmonising Health Technology Assessment in all Member States.**

Examples:

For some essential cancer drugs, there are marked differences in time to approval/reimbursement in all EU Member States, which vary from few days from the EMA market authorisation to more than 12 years from EMA approval (149). In 10 out of 28 EU countries, it has taken 2 years or more to provide some drugs to patients in the metastatic setting, further demonstrating the unacceptable

delays in accessing this essential cancer drug. One of the reasons for such delays relates to the heterogeneity of procedures and methodologies used by Member States to assess relative effectiveness (REA) and cost-effectiveness of new medicines.

More than 5,000 patients annually with metastatic melanoma in Europe do not have access to new life-saving drugs. A recent study presented at the European Society of Medical Oncology (2016) reported unacceptable differences in access to lifesaving innovative melanoma medicines across Europe. At least 70% of patients with metastatic melanoma in Western Europe were treated with innovative medicines. In Central Europe only 41% of patients had access to these innovative drugs, while only 10% of patients had access to these medicines in Southern and Eastern European countries (150).

**Recommendation 13:** Develop national cancer rehabilitation and survivorship policies, underpinned by an equity perspective.

The end of cancer treatment does not signal the end of cancer care. It is important to raise awareness of potential late effects of cancer treatment and of early detection of cancer recurrence and secondary tumours. Key elements in the prevention of cancer recurrence include the maintenance of a healthy body weight, healthy diet and physical exercise. Avoidance of the use of tobacco, excess sun exposure, and alcohol are also important elements, just as they are for primary prevention. Rehabilitation is a key component to ensure that cancer survivors have the best chance of returning to a normal life. Rehabilitation must be understood to include not only physical rehabilitation, but also psychological, cognitive, sexual, spiritual and professional rehabilitation. These principles must be enshrined in every National Cancer Control Plan in the form of Survivorship Care Plans to ensure the fullest possible recovery of all cancer survivors. This is especially important for those in situations of social vulnerability, because they face greater challenges in terms of access to care and health behaviours.

Many cancer survivors are at risk for loss of employment, which can lead to significant financial and social burdens, and reduction in quality of life. Surviving cancer patients may suffer unacceptable discrimination in relation to employment and other areas of society, including access to insurance, mortgage approval and social re-integration (151). Geographical and social isolation may make it more difficult for rural or otherwise socially vulnerable patients to access social and practical support. European and national authorities have a role to play, by allocating adequate financial resources to support services and in implementing adequate survivorship and rehabilitation services for all social groups, as well as in informing the public and raising awareness.

It has been shown that cancer survivors with a low socio-economic position are more often unemployed (25) or take early retirement, which can act as a substitute for disability leave or unemployment (153). Emerging research also suggests the existence of social inequalities in the ability of cancer survivors to return to work (154). Working conditions and psychosocial conditions of a manual job can act as additional barriers (155). Furthermore, women often become informal caregivers to family members with cancer and are more at risk of unemployment and early exit from the labour market.

**Examples:**

A few best practices have shown good results in reintegrating cancer survivors into an active life (152). Those practices should be shared across the EU. For example, in 2016, France introduced a new policy under the national cancer plan, giving cancer survivors the right to obtain loans or insurance without surcharge or restriction, once a certain period has passed since their diagnosis. Furthermore, the same French NCP legislates that survivors of malignancy in childhood (0-14 years) whose treatment finished 5 or more years prior and adults with any cancer whose treatment finished 15 years prior are not required to declare the disease when applying for a mortgage or health insurance.

**S.R. 13.1: Make survivorship and rehabilitation an integral component of the patient care pathway from the time of diagnosis.**

**Examples:**

Attenuating the economic consequences of cancer to support the living standards of patients and their families is an imperative that should make use of various levers. The French National Cancer Plan (2014-2019) provides a reduction in the patient's contribution toward the cost of breast reconstruction and an increase in the reimbursement rate for wigs and mammary prostheses.<sup>7</sup>

In Italy, a new regulation facilitates claims for social security or invalidity/handicap benefits when submitted by cancer patients (156). As a result, the time to disability and handicap recognition has been reduced from 12 months to just 15 days, which means economic and societal benefits are payable at an earlier stage. Claims are submitted online by family doctors, which speeds up processing and guarantees equal treatment of individuals nationwide. This allows the National Social Security Body to pay out the relevant benefits within four months (157).

**S.R. 13.2: Raise awareness about late effects, with the aim of providing recommendations to all patients and tailoring information specifically for socially vulnerable groups.**

**Example:**

Cancer survivors' follow-up, late effects management and tertiary prevention need to be anticipated, personalised and implemented into care pathways, with active participation of survivors and relatives. The CanCon recommendation on survivorship and rehabilitation provides solid evidence on the need to create personalised survivorship care plans (SCPs) to provide clear information to cancer survivors. In particular, the role of the general practitioner (GP) has been demonstrated to be crucial to ensure more equitable and simple access to key information on survivorship. In the Netherlands, a recent study demonstrated that cancer patients prefer to discuss diet, fatigue, relationship difficulties, sexuality, return to work and physical fitness with the GP rather than with their oncologist (158). SCPs can be managed according to different models of care coordination with a common starting point of an MDT specialist follow-up having a holistic and integrated approach to survivors' health.

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<sup>7</sup> Available at <http://en.e-cancer.fr/The-Cancer-Plan-2014-2019>

**S.R. 13.3: Integrate employment programmes into follow-up survivorship care, with additional emphasis on socially vulnerable groups, to support return to work after acute treatment.**

**Examples:**

The employment provisions of the Equality Act 2010 (UK) protect anyone who has- or has had- a disability (including people affected by cancer). The act requires employers to make reasonable adjustments for employees with a disability, and it also includes important provisions to prevent discrimination arising from disability, including indirect discrimination and discrimination against carers.

A major achievement in Italy in the field of job protection for cancer survivors and their families is a regulation passed in 2003 (159) prescribing the opportunity for cancer patients who work in the private sector to switch from a full-time to a part-time position while they are under treatment, and to revert to a full-time position in due course according to their needs and capability. The same right has been extended to public employees (160). Family members of cancer patients are given priority for part-time applications as long as there are positions available.

**S.R. 13.4: Develop financial incentives to help employers introduce adaptations to work environments/situations in order to accommodate survivors' return to work.**

**Example:**

In Denmark, two municipalities were involved in an individually tailored occupational rehabilitation intervention (controlled trial) for cancer survivors, focusing on enhancing readiness for return to work. The trial showed that the intervention (implemented in one of the two municipalities) provided benefit to the patients, by delivering timely occupational rehabilitation that was much earlier initiated than in the control group. Furthermore, the active involvement of the employers was also instrumental in the rapid reintegration of patients in the workplace. Vulnerable cancer survivors particularly benefitted from this approach, and the effects of social inequality on workability were reduced (152).

## 5 Conclusions

Unacceptable inequalities in cancer prevention, treatment and care, and survivorship still affect millions of cancer patients across Europe. This paper provides evidence-based recommendations to address those factors related to inequalities in cancer care for which strong pan-European collaboration is required. This paper proposes an equity-oriented approach to developing policies for cancer prevention and control, based on universal action, but with a scale and intensity that are proportionate to the level of disadvantage of the population in question. We thus highlight practical actions to tackle social inequalities in cancer at the European and national levels in the form of 13 recommendations that span the areas of capacity building; primary and secondary prevention; and treatment, survivorship and rehabilitation. The recommendations are based on a review of available scientific evidence in addition to experiences identified through our survey of Member States.

Our recommendations can serve as a guide for action for national and European policy makers to tackle social inequalities in cancer prevention and control in Europe. However, implementation of the recommendations will require appropriate resources, first and foremost to adapt the recommendations to each country, thus respecting the profile of the population and the social and economic context of each country.

While social inequalities in cancer in Europe are significant and formidable, important experience exists in addressing them, supporting the urgent need for action highlighted by patient organisations consulted during the drafting of this paper. The role of European institutions is also extremely important, particularly cancer institutions. Several Member States have already taken action in this direction, and their efforts can serve to strengthen and expand work on reducing social inequalities in cancer. Despite the principles of subsidiarity, which places healthcare as a shared competence between Member States and the European Union, the European Code Against Cancer and the Equity Joint Action strongly impacted the development and implementation of national cancer plans. For the recommendations to be successful, it is necessary that social inequalities in cancer are placed at the top of the European public health agenda, therefore maximising the impact of future EU initiatives on cancer.

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## Authorship

Rosana Peiró Pérez, FISABIO, Valencia, Spain and CIBER of Epidemiology and Public Health (CIBERESP), Madrid, Spain; Ana Molina Barceló from DGSP, FISABIO-Public Health, Generalitat Valenciana, Spain; Francesco De Lorenzo, Francesco Florindi, Kathi Apostolidis from European Cancer Patient Coalition; Teresa Spadea, Nicolás Zengarini from Epidemiology Unit ASL TO3, Turin, Italy; Sarah Missinne from Belgian Cancer Centre in the Belgian Scientific Institute of Public Health (WIV-ISP); Mark Lawler from Queen University Belfast & European Cancer Concord, Belfast, Northern Ireland, Michel P Coleman and Claudia Allemani, London School of Hygiene and Tropical Medicine, UK

## Experts

Affeltranger, Bastien (France), Alguacil, Juan (Spain), Amati, Camilla (Italy), Dhanda, J (England), Frohlich, Katherine (Canada), Kowalski, Christoph (Germany), Lievens, Yolande (Belgium), Lillini, Roberto (Italy), Lovey, Jozsef (Hungary), Luque Fernandez, Miguel (England), Salas, Dolores (Spain), Sant, Milena (Italy), Satge, Daniel (France), Selby, Peter (England)

## Expert groups

Association of European Cancer Leagues  
European Cancer Organization  
European Commission's Expert Group on Cancer Control