

# Taking action on cancer together: *delivering the future of cancer medicines in Europe*

## Introduction

This working paper sets out a strategic vision for how joint action by the European cancer community can deliver better cancer care for patients in Europe. The priorities for change and ideas for actions presented in this paper stem from a pan-European conversation, initiated by EFPIA and its members, involving over 150 cancer experts, including representatives from over 30 cancer patient organisations, more than 50 clinicians and more than 20 policy-makers, officials and payers.<sup>1</sup> As an EFPIA initiated process, improving access to cancer medicines has been the initial focus of this conversation with stakeholders. However, the ideas for collaboration set out in this paper reflect the beginning of a joint dialogue on how the cancer stakeholder community can work together to improve outcomes for patients across Europe.

Following a series of stakeholder roundtables, the following organisations have been involved in the development of the priorities and ideas for collaboration set out in this paper: Cancer Drug Development Forum (CDDF), European Association of Dermato Oncologists (EADO), European CanCer Organisation (ECCO), European Cancer Patient Coalition (ECPC), European Cancer Leagues (ECL), EuropaColon, European Oncology Nursing Society (EONS), European Society for Paediatric Oncology (SIOPE), Melanoma Patient Network Europe (MPNE), Youth Cancer Europe (YCE) and the Workgroup of European Cancer Patient Advocacy Networks (WECAN). More information about this process is contained in the Appendix.

## Views from the European cancer community

*“Every stakeholder in cancer care is concerned about how to ensure a sustainable future in which continuous improvements in treatment and care remain affordable, while at the same time improving equity of access. ECCO, the European CanCer Organisation, works on numerous initiatives to help provide solutions to these challenges. As such, we have been pleased to offer our suggestions in the development of this Discussion Paper. Improving participation in clinical trials; understanding how to better allocate the resources we have in cancer care; increasing awareness and knowledge about the oncology data landscape and its potential for improving care and treatment; and creating more incentives to achieve best practice in cancer care. These are all objectives ECCO can fully support. Joining forces in order to turn such aspirations into reality is more than desirable.”*

**Philip Poortmans, President, European CanCer Organisation (ECCO)**

*“Youth Cancer Europe is the voice for cancer survivors who are of a working age, eager to take a proactive role in their disease management, are not shy about using e.health and m.health solutions and are vocal to challenge the stagnant healthcare systems. We find that the Discussion Paper is both reflective of the barriers the cancer community is suffering from and provocative enough to promote feasible ideas that should drive policy discussions. If we are collectively becoming more successful in taming life-threatening diseases it is only fair to demand that healthcare systems and policies should enable cancer patients not to fall out of their usual activities on social, professional and physical domain and to safeguard that patients in the EU should not be discriminated against the medical progress that is available to the patients in another Member State.”*

**Šarūnas Narbutas, Chair, Youth Cancer Europe (YCE)**

*“Patients are the ultimate beneficiaries of cancer diagnosis, treatment and care, and this paper rightfully acknowledges the central role patients have in the development of future cancer care. Their unique knowledge, perspectives and experiences improve and encourage innovation in oncology, and their contributions should be recognised. As we have continuous innovation in cancer research, diagnosis and treatment, equally we need patient-centered innovation in cancer policies, care delivery and transform the way we finance it in order to ensure that cancer medicines are accessible to all who need them. The European Cancer Patient Coalition, the largest*

*cancer patient umbrella organization in Europe, is proud to have contributed to the development of this Discussion Paper and sees many opportunities for collaboration with other stakeholders to find solutions to sustainable access to innovative cancer treatments which offer the potential to save, extend and improve the quality of the lives of millions of people living with cancer in Europe.”*

**Francesco De Lorenzo, President, European Cancer Patient Coalition (EPC)**

*“Access to timely, acceptable, and affordable health care is one of the fundamental human rights, so the development of patient-oriented research, development, market access and reimbursement/insurance coverage mechanisms in the future would be necessary to improve the current situation of disparities throughout Europe. European Association for Dermato Oncology established Task Force for access to innovation in skin cancer care in order to develop cooperation with other oncological organizations, patients’ advocacy organizations and pharmaceutical industry for a joint action toward improving the current situation. This Discussion Paper indeed is a step toward this aim and, during the process of its development, we were happy to provide our suggestions and ideas that were implemented in its final version. It can serve as a foundation for further actions that involve all stakeholders in the process for the development of sustainable and high-quality cancer care throughout Europe.”*

**Claus Garbe, President, European Association of Dermato Oncology (EADO)  
Lidija Kandolf Sekulovic, EADO Task Force for access to innovation in skin cancer care**

*"The Cancer Drug Development Forum (CDDF) is working to support and accelerate cancer drug development by bringing together all the respective parties around the table : industry, academia, regulatory authorities, HTA bodies, patient advocacy groups, payers or insurance companies. That’s critically important in cancer drug development because the view of someone working e.g. in HTA is very different than that of someone working in academia, and both need to be heard if our efforts are going to be successful. Collaboration is key and by contributing to this discussion paper, CDDF hopes that it will provide a persuasive and factual evidence of the priorities to bring new and effective treatments to patients around Europe as rapidly as possible."*

**Heinz Zwierzina, Managing Director, Cancer Drug Development Fund (CDDF)**

## Context for cancer care in Europe: progress and remaining challenges

Every year, more than 3.4 million people are diagnosed with cancer in Europe and, if trends continue, cancer will soon become the biggest cause of disease burden in Europe.<sup>2,3,4</sup> Yet there are also grounds for optimism. Outcomes are improving for some types of cancer. Over 66,000 more Europeans diagnosed with cancer in 2012 will live for at least five years after diagnosis, when compared to a decade ago.<sup>5</sup>

We can credit this progress to improved prevention, vaccination and early diagnosis programmes, more comprehensive and evidence-based care pathways, access to specialist multi-disciplinary teams as well as more and effective treatments that are helping people live longer and, crucially, with better quality of life.

Scientific advances in cancer care also offer the prospect of further improvement in cancer outcomes. The number of therapy options available to adult patients has risen significantly; between 1996 and 2016, the number of pharmaceutical treatments available to patients with lung cancer increased from four to 19.<sup>6</sup> New treatments with fewer side effects have also helped support efficiencies in cancer care, reducing hospital stays and enabling people to receive care at home or in the community.<sup>7</sup> Investment in cancer research and innovation also delivers an overall economic benefit for society of nearly €40 billion in France, Germany, Sweden and the UK alone.<sup>8</sup> Such examples reflect how the collective endeavour of scientists, clinicians, nurses, industry and patients has transformed the outlook for cancer across Europe and can continue to do so in the future.

However, big challenges remain. More people are being diagnosed with cancer and its impact on society is growing. More than one in four deaths in Europe is due to cancer<sup>9</sup> and, for some types of cancer including paediatric cancers, progress has been frustratingly slow. There are also significant variations in the standard of cancer care, access to screening, access to innovation and outcomes for patients across Europe.<sup>10</sup> Survival may be improving in every country but big differences remain.<sup>11,12</sup> Cancer survival is influenced by a range of factors, including levels of vaccination and early diagnosis, but countries that are higher users of newer cancer treatments often report better outcomes.<sup>13,14,15</sup>

Scientific progress requires appropriate changes in the funding structures or even additional funding. While a cure is still a far reaching goal, today, many patients survive and cancer becomes a manageable chronic condition.<sup>16,17</sup> Among cancer survivors, there is an increasing number of patients who have become cured. These patients have already reached the same life expectancy of the general population and are estimated at around 27% in Italy, for example<sup>18</sup>. This has increased the interest in initiatives reducing wastage but also raised questions about medicines prices and what fair pricing should look like.

Today, expenditure on cancer care as a proportion of the overall health service budget has remained broadly consistent.<sup>19</sup> Nevertheless, additional new treatment options and the rising incidence will have an impact on health budgets which requires proper planning and a societal dialogue about investing in the health of the population. The following priorities represent a framework for further discussion with all stakeholders on improving cancer care across Europe. It has developed from the pharmaceutical perspective and represents the first step in this dialogue with the aspiration to achieve a comprehensive multi-stakeholder paper on how the European cancer community can work together to improve outcomes for patients.

## Priority areas for change

Three clear priority areas for change emerged from the pan-European multi-stakeholder cancer conversation, involving over 150 cancer experts:

### **Priority 1: Improving the sustainability and integration of cancer care**

The growing incidence and increasing prevalence of cancer creates cost and capacity pressures on national healthcare systems, which can only be overcome if the necessary investment and infrastructure is in place. Consensus is needed on how best to resource and design cancer services, where current pathways are weak and need to be improved, how best to share and incentivise good practice and appropriately support the cancer workforce. This should include aspects across the entire cancer care pathway including timely patient access to screening, diagnosis, surgery, radiotherapy and cancer medicines.<sup>20</sup> As a matter of principle, cancer services should be systematically organised to address the treatment and care outcomes that matter most to patients. This will require putting patients at the heart of conversations and decisions about cancer treatment and care.

### **Priority 2: Accelerating the time it takes to get new treatments to patients**

Faced with a cancer diagnosis, patients and their carers understandably want rapid access to the most promising and effective new medicines. As treatments are becoming more targeted, they are also becoming more complex and often come to market when data are still maturing to enable patients to benefit at the earliest opportunity. This poses challenges to traditional models for approving, assessing and paying for cancer treatments, but cannot be allowed to create additional delays or barriers to access. There is significant variation in delays in patient access to treatment across Europe with patients in Portugal having to wait six times as long as patients in Germany to access new treatments.<sup>21</sup> These delays can result in disease progression, reduced quality of life and distress for the patient and carers, and potential additional cost to the healthcare system. Regulatory, healthcare technology assessment (HTA) and payer decision-making processes need to evolve, recognising the need for patient-focussed assessments of benefit, including Quality of Life, consideration of surrogate endpoints, comprehensive patient involvement, appropriate data monitoring to confirm expected benefits, and with accountability for timelines. Consensus is needed on how to address these issues, how to ensure that scientific development is reflected in the assessment processes and that access follows patients' needs and patient focused assessment by specialist healthcare providers.

### **Priority 3: Developing tailored pricing and reimbursement models for cancer medicines**

Tailored pricing and reimbursement models which reflect scientific developments can overcome existing hurdles for new cancer medicines which sometimes result from traditional pricing and reimbursement processes. Alternatively, because of their nature, tailored access agreements address various goals at the same time such as timely patient access, budget predictability and future innovation. In addition to Managed Entry Agreements, through tailored access agreements patients can benefit from rapid access to new medicines, when the evidence is promising but limited. However, consensus is needed on what these tailored arrangements should look like in practice, in particular in case of outcomes-based agreements, what real world data and patient-reported outcomes should be captured and how these outcomes should be rewarded. Innovative approaches will be particularly important in the complex area of pricing and reimbursement for medicines with multiple indications and combination treatments. Further dialogue is also needed on how policies such as External Reference Pricing (ERP), or parallel trade, can lead to access challenges, and whether differential pricing could help to address the inequalities that exist in cancer care and the varying ability to pay for it across European countries.

## Call to action

Participants in the discussions agreed on a shared ambition:

***“To work further together to achieve consistent high standards in patient outcomes for cancer care across the whole of Europe”***

In our commitment to this and the priorities above, we have identified a number of ideas where collaborative action could make a difference. These suggestions are set out below – some of which are already being implemented – with an explanation of how they could translate into practical solutions to ensure a better future for cancer patients in Europe.

## List of ideas for collaboration

Collective action can take many different forms. Below are some ideas which have been identified for further discussion.



### **Priority 1: Improving the sustainability and integration of cancer care**

#### ***Idea A: Develop a good practice guide for resource allocation in health and in cancer care***

Across Europe, information on the clinical effectiveness and cost of some cancer interventions is missing. This hinders informed decisions on investment. A better understanding of the epidemiology of cancer is also needed to understand the healthcare need and inform cancer care planning. A good practice guide for resource allocation could help to assist this.

The guide could include an assessment of the epidemiology of cancer in the future and implications for health systems. It could also set out principles for resource allocation and where to find information on clinical benefits and costs. Other areas to explore could include processes for managing difficult trade-offs and who should be involved in decisions on resource allocation. This should be developed in the context of the work of other initiatives, including *The Joint Action on Cancer Control – CanCon, All.Can and RECaN*, to identify potential synergies and avoid resource duplication.<sup>22,23 24</sup>

#### ***Idea B: Produce an analysis of best practice in cancer service design across Europe against the backdrop of National Cancer Control Plans to optimise patient outcomes***

It would be helpful to analyse different designs of cancer care pathways across Europe, explore how they relate to patient outcomes and examine any commonalities. This would help identify best practice in cancer service development, how this is addressed and informed by national cancer control plans and ways in which it can be replicated across Europe.

Such an analysis should make clear that patients should be involved in decisions about the future of cancer care, ensuring that services are designed in a way which meets their needs and address areas where national patient outcomes are lagging behind. It could also inform the development and refreshing of national cancer control plans and initiatives to implement the CanCon joint action.

#### ***Idea C: Map initiatives to improve data collection and usage, share experiences of successes and blockages and consider what action can be taken to accelerate progress***

Data collection and analysis is already improving the quality and affordability of cancer care. Industry is committed to making further progress in the collection and use of cancer data across Europe through a detailed health data mapping exercise. The project will bring together different initiatives on cancer data collection currently under way across Europe and compare their scope and content; examine potential blocks to the collection, sharing and usage of data and consider ways to coordinate and accelerate future progress.

#### ***Idea D: Develop a shared vision for cancer care that delivers best outcomes for patients, considering what would change in cancer services, how good practice could be incentivised and how accountability for improvements could be encouraged***

Cancer services should be designed to deliver the outcomes that matter most to patients. By setting these out, together with how the different partners in cancer care could be aligned to make progress against them, it would then be possible to examine the gap between the vision and current reality. From this, discussions could take place around the incentives which could be established to bridge this gap, any disincentives that might hinder this (such as payment for activity rewarding interventions which are not necessarily required) and what steps should be taken at a national level to achieve this vision.





## Priority 2: Accelerating the time it takes to get new treatments to patients

### ***Idea A: Assess options to improve participation in clinical trials within the EU***

Some patients are being required to fund the costs of their ‘standard’ care if they wish to participate in a clinical trial being organised in another EU country – an unfair situation that runs counter to the spirit of the Cross-Border Health Directive. An alternative approach should be developed, whereby there is a true single market for clinical trials.

To achieve this, we need to first quantify the scale of the problem, including documenting examples of where patients are being denied access to trials which may benefit them. In this regard, we have undertaken a survey among stakeholders and initiated a working group. The next step could be to develop and advocate an alternative approach, including working with sponsors of trials to seek guarantees that ‘out of country’ participants will not be denied access to the trial.

### ***Idea B: Assess current systems to understand what works and what does not across countries, and measure performance using the following criteria: level of access, quality of coverage and delays***

A number of initiatives to accelerate access to new treatments are already under way across Europe, from which we could learn. Gathering them in one place could be helpful in giving policymakers and stakeholders a reference point to evaluate their own system and assess the gap between regulatory approval, HTA and commissioning of care.

Particularly in areas of high unmet need, such as in paediatric and adolescent cancers, this could also include initiatives to accelerate clinical trial and development pathways to provide incentives for scientific research and improve patient access to innovation.<sup>25</sup> A review of associated regulatory approval processes and comprehensive implementation of the Paediatric Regulation (EC) No 1901/2006 to ensure pragmatism and efficiencies are important steps towards improving authorisation of treatments for children and adolescents affected by cancer.

Further dialogue is also needed on how joint clinical assessments, as set out in the 2018 European Commission proposal on HTA, could help speed up patient access to treatment and avoid resource duplication at national level.<sup>26</sup>

In discussing potential solutions, policymakers, representatives of the cancer clinical and nursing community, patient representatives and payers would be able to refer to approaches which have proven effective in other countries, but adjust them to meet the particular situation in their country.

### ***Idea C: Develop a model process for accelerating the time it takes for patients to benefit from a new cancer medicine that better integrates regulatory approval and reimbursement decisions***

A model process for introducing new medicines could be developed to which national systems could refer in developing their own processes. This would set out why and how the systems should change. Highlight the importance of patient involvement in all regulatory and reimbursement decisions and showcase concrete examples from Member States where patients have a central role in these decision-making processes. Outline how it can be increased following the examples of NICE (UK), ZINL (Netherlands) and G-BA (Germany) and propose the hierarchy of outcomes to be used for regulatory, HTA and payer purposes.



The model process could include considerations for how HTA processes should evolve, for example to include validated surrogate endpoints for particularly promising new treatments where the data are still maturing and where awaiting overall survival data would significantly delay patient access. These would need to be accompanied by appropriate data monitoring and the collection of real world evidence to ensure that the endpoints are indeed surrogates for patient outcomes.

A set of principles for change could be developed to support the model process. These might include (but not be limited to): speed of access to new treatments; equity of access; and suitability of access.



### **Priority 3: Developing tailored pricing and reimbursement models for cancer medicines**

***Idea A: Develop a consensus framework for tailored access agreements, identifying good practice examples and continue to raise awareness for the importance of data infrastructure for these agreements***

There is interest in tailored access schemes but little wider understanding of how they could help improve access to innovative cancer treatments on the basis of limited evidence while creating budget predictability, and function as a potential bridge to reimbursement models which cover multiple indications and combinations.

Consensus is also needed on when tailored access schemes should be offered, how they can be developed and what they should look like in practice. This should be supported by improved data infrastructure to enable comprehensive collection of real world evidence and patient reported outcomes to inform and ensure the long-term benefit of the agreed access schemes.

A consensus framework for use in developing schemes would be one route to address this knowledge gap. This could be supported with a digest of examples of schemes already in place in European countries, which others could emulate or adapt.

***Idea B: Set up a workshop to discuss the challenges of and opportunities for innovative approaches to combination treatments and how to handle patient access in terms of pricing and reimbursement***

Combination pricing has been recognised as a particularly complex issue which is yet to be fully explored and addressed. Further dialogue, involving a range of stakeholders bringing different expertise and perspectives, will be essential in determining how best to overcome the challenges presented by combination pricing. To address this, a workshop was organised bringing together experts from clinical communities, patient advocacy groups, healthcare economics, payer and policy backgrounds, stimulating further stakeholder dialogue and collaboration on the issues presented by the development of combination therapies.

***Idea C: Work together to advocate the benefits of differential pricing across Europe to patients and the issues which are preventing this from occurring***

There are significant disparities in patient access to comprehensive cancer care and treatment across Europe due to the varying ability of European countries to pay for them.<sup>27</sup> Differential pricing offers an approach to address this by adapting prices of medicines to the ability to pay in different geographical or even socio-economic segments.<sup>28</sup> This could offer a win-win situation in terms of generating dynamic efficiencies that contribute to both the sustainability of healthcare systems and enabling patient access to treatment across Europe.

Stakeholders in the cancer care community should form a consensus on how to enable differential pricing, address challenges that can occur from potential trans-border sales and guarantee broader access to patients in the context of ERP and supply chain disruptions.

There may then be opportunities to adopt a shared position on differential pricing, advocating it as a pragmatic and immediate solution to the access challenges and inequalities that exist in cancer care.

## Appendix: The genesis of this paper – a pan-European cancer conversation

The ideas presented in this paper stem from a pan-European cancer conversation, initiated by EFPIA and its members, involving:

- Over 150 cancer experts, including representatives from over 30 cancer patient organisations, more than 50 clinicians and more than 20 policy-makers, officials and payers<sup>29</sup>
- 12 roundtable discussions on the future of cancer care in 10 countries across Europe<sup>30</sup>
- Structured interviews with experts from leading European cancer organisations including: the European Cancer League (ECL), the European Cancer Organisation (ECCO), the European Oncology Nursing Society (EONS), the European Cancer Patient Coalition (ECPC), the European Society for Paediatric Oncology (SIOPE) and the European Organisation for Research and Treatment of Cancer (EORTC)<sup>31</sup> on how the challenges in enabling future patient access to optimal cancer treatment and care can best be addressed
- Workshops involving six European cancer organisations, including, ECCO, ECL, ECPC, EONS, Europa Colon, Melanoma Patient Network Europe (MPNE) and SIOPE, to discuss the potential for collaborative action to address some of the themes identified by the pan-European cancer conversation

Conversations were informed by the *Comparator report on patient access to cancer medicines in Europe revisited*, which reviewed the evidence on changes in cancer outcomes, treatments and costs across Europe. Developed by the Institute for Health Economics (IHE), the report provided an invaluable stimulus and baseline for informed discussions. Key findings from the report are set out below.

### Comparator Report on Patient Access to Cancer Medicines in Europe Revisited

#### Key findings



##### The burden of cancer

- Cancer incidence in Europe has increased by 31% over the past decade, with 700,000 more people being diagnosed with the condition in 2012 than in 1995<sup>32,33</sup>
- Whilst advances in screening, diagnostics and medical treatment have helped improve overall cancer survival, more than one in four deaths are caused by cancer<sup>34, 35</sup>
- This is the second highest share after cardiovascular disease, with cancer likely to become the biggest cause of death and disability in Europe<sup>36</sup>



##### Cancer expenditure

- Though sales of cancer drugs have more than doubled from €9.5bn in 2005 to €19.8bn in 2014, the direct health cost of cancer has remained stable around 6% of the total health expenditure over the last 20 years despite increasing disease burden<sup>37</sup>
- This has predominantly been led by a shift from in-patient to ambulatory and home care, enabled by the introduction of less toxic cancer medicines, oral agents and supportive drugs<sup>38</sup>
- However, as Jönsson et al. note, today, we start from a different magnitude of expenditures on cancer drugs, and the transformation from in-patient to ambulatory cancer care will produce less savings in the

future. It will therefore be increasingly difficult to finance further investments in new treatments without an increase in the share of health expenditures devoted to cancer care<sup>39</sup>

- Cancer spending varies considerably across Europe with a six-fold difference between the highest (Luxembourg, €311 per capita) and the lowest (Romania, €53 per capita) spending countries<sup>40</sup>

### Uptake of medicines

- An increasing number of cancer medicines are being developed with 95 new treatments approved by the EMA over the past 20 years<sup>41</sup>
- Uptake of new medicines (launched within the last three years) remains slow with only 8% of overall medicines sales<sup>42</sup> and varies considerably across Europe.<sup>43</sup> Beyond the Comparator Report, it has also been noted that EU regulatory frameworks are not optimal for ensuring timely access to treatments for rarer cancers and more personalised medicines<sup>44</sup>
- Delays in patient access vary considerably across Europe with up to four years in Portugal compared to only five months in the Netherlands.<sup>45</sup> Levels of access to other forms of innovations in cancer care beyond medicines also vary considerably across Europe<sup>46</sup>
- The importance of access to treatment supported by specialist nurses to facilitate effective care following treatment administration

Progress has already resulted from this engagement. Conversations in Portugal have stimulated a new consensus on the next steps for cancer care.<sup>47</sup> The Slovakian Secretary of State for Health has made a personal commitment to improving patient access to treatments by introducing a national cancer plan in Slovakia.<sup>48</sup>

To complement this paper, EFPIA will be publishing a short report containing examples of national initiatives to address some of the challenges outlined in this paper.

## References

- <sup>1</sup> Please see EFPIA, Summary Slide deck for exact breakdown of stakeholder organisations engaged in the conversation
- <sup>2</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 15; [http://portal.research.lu.se/ws/files/11713673/IHE\\_Report\\_2016\\_4\\_.pdf](http://portal.research.lu.se/ws/files/11713673/IHE_Report_2016_4_.pdf)
- <sup>3</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 28
- <sup>4</sup> European Cancer Patient Coalition, *The Value of Innovation in Oncology 2017* – page 15
- <sup>5</sup> Calculations based on incidence figures quoted in Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 - page 16: 2000-2002 5-year survival rate in all cancers in Europe: 51.55% 2000-2007 5-year survival rate in all cancers across Europe: 54%; Incidence in 2012 in Europe: 2,707,000
- <sup>6</sup> QuintilesIMS Institute, *Global Oncology Trends 2017, Advances, Complexity and Cost*, 2017 – page 19
- <sup>7</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – Exec Summary iv: the direct health cost of cancer has remained around 6% of THE over the last 20 years. A major contributing factor is the shift from in patient to ambulatory and home care and the development of less toxic cancer medicines
- <sup>8</sup> Sebastian Salas-Vegas and Elias Mossialos in Health Affairs, *Cancer drugs provide positive value in nine countries, but the United States lags in health gains per dollar spent*, May 2016, accessible at: <http://www.ncbi.nlm.nih.gov/pubmed/27140987>
- <sup>9</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 4: In 2012 the burden of cancer disease was second greatest with more than one in four deaths due to cancer
- <sup>10</sup> For approximately every 650 people invited for regular screening, one bowel cancer death will be prevented’, statistic provided by EuropaColon
- <sup>11</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 61: Between 1990 and 2007 there was a steady increase in cancer survival rates in all countries, yet disparities remain between wealthier countries with higher survival rates and poorer countries with lower survival rates
- <sup>12</sup> The European CanCer Organisation (ECCO), *Survival after cancer diagnosis strongly associated with government’s spending on health care”, 2013*
- <sup>13</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 16: There is a rather clear pattern of wealthier countries to record higher survival rates, whereas poorer countries record lower rates
- <sup>14</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 144: Low national income and health care spending per capita are major obstacles for access to new cancer drugs
- <sup>15</sup> Journal of Cancer Policy, *Towards sustainable cancer care: Reducing inefficiencies, improving outcomes – A policy report from the All.Can initiative*, 2017 – page 48: “Cancer patients in Europe live a paradox: the personalised medicine revolution has produced several extremely effective new treatments for cancer patients, but not all patients who would benefit from them have access to innovation (Professor Francesco De Lorenzo, President, European Cancer Patient Coalition)
- <sup>16</sup> Taylor D (2015), *A Deadly Cancer Becoming a Chronic Disease; Conquer*; <https://conquer-magazine.com/a-deadly-cancer-becoming-a-chronic-disease/>
- <sup>17</sup> Jönsson B (2016), *Comparator report on patient access to cancer medicines in Europe revisited*; <http://www.ihe.se/access-to-cancer-medicines-in-europe.aspx>
- <sup>18</sup> Epidemiol Prev. 2014 Nov-Dec;38 - 6 Suppl 1:1-122. Italian cancer figures, report 2014: Prevalence and cure of cancer in Italy. PMID: 25759295
- <sup>19</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 33: The direct health cost of cancer has remained more or less flat around 6% of total health expenditure over the last 20 years
- <sup>20</sup> For approximately every 650 people invited for regular screening, one bowel cancer death will be prevented’, statistic provided by EuropaColon, accessible at [http://www.europacol.com/news.php?Action=News&News\\_ID=1107](http://www.europacol.com/news.php?Action=News&News_ID=1107), Dec 2017
- <sup>21</sup> EFPIA Market Access Delays Analysis, *Patients W.A.I.T. Indicator*, March 2018, accessible at: <http://www.hull.hr/wp-content/uploads/2018/04/Market-Access-Delays-2017-Final-140318-1.pdf>
- <sup>22</sup> The Joint Action on Cancer Control – CANCON, 2018; <http://www.ecpc.org/activities/policy-and-advocacy/ecpc-eu-commission/240-canon>
- <sup>23</sup> All.Can, *Changing cancer care together*, 2018: <http://www.all-can.org>
- <sup>24</sup> RECaN project: *Recognising European cancer nurses*, 2018, <http://www.cancernurse.eu/research/recan.html>
- <sup>25</sup> European Commission, *TOPIC: Creation of a pan-European Paediatric Clinical Trials Network*, 2016; <http://ec.europa.eu/research/participants/portal/desktop/en/opportunities/h2020/topics/imi2-2016-10-04.html>
- <sup>26</sup> Proposal for a Regulation of the European Parliament and of the Council on health technology assessment and amending Directive 2011/24/EU, 2018; [https://ec.europa.eu/health/sites/health/files/technology\\_assessment/docs/com2018\\_51\\_en.pdf](https://ec.europa.eu/health/sites/health/files/technology_assessment/docs/com2018_51_en.pdf)
- <sup>27</sup> European Cancer Patient Coalition, *Challenging the Europe of disparities in cancer, a framework for improved survival and better quality of life for European cancer patients*
- <sup>28</sup> *European Commission, Study on enhanced cross-country coordination in the area of pharmaceutical product pricing, final report, 2015*
- <sup>29</sup> Please see Summary Slide deck for exact breakdown of stakeholder organisations engaged in the conversation
- <sup>30</sup> This includes: 1<sup>st</sup> EU stakeholder roundtable, UK, Germany, the Netherlands, Bulgaria, Portugal, Poland, Sweden, Italy, Slovakia, 2<sup>nd</sup> Portuguese roundtable, 2<sup>nd</sup> UK roundtable
- <sup>31</sup> Interviews were conducted with ECL, ECCO, EONS, ECPC, EORTC, IMI, Sheffield University, and iSPOR
- <sup>32</sup> *Comparator Report evidence pack*, slide 24 & 29
- <sup>33</sup> Incidence since the 1980s, the global WSR of registered cancers in children aged 0–14 years has increased from 124.0 (95% CI 123.3–124.7) to 140.6 (140.1–141.1) per million person-years. Steliarova-Foucher E et al., *International incidence of childhood cancer, 2001–10: a population-based registry study*, *Lancet Oncol.* 2017 Apr 11. pii: S1470-2045(17)30186-9. doi: 10.1016/S1470-2045(17)30186-9
- <sup>34</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 6
- <sup>35</sup> Eurostat, *World Cancer Day: 1 in 4 deaths caused by cancer in the EU*, 2017
- <sup>36</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 9: The epidemiological development in other leading causes of death, in particular the decline in cardiovascular diseases in recent decades, influences cancer mortality figures. Since more people reach an advanced age, this leaves more people at risk of getting cancer and eventually also die from cancer (external reference: Honoré BE et al, *Competing Risks Models and the War on Cancer*. *Econometrica.* 2006;74(6):1675–98)
- <sup>37</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 33: The direct health cost of cancer has remained more or less flat around 6% of total health expenditure over the last 20 years
- <sup>38</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited*, 2016 – page 33: The direct health cost of cancer has remained more or less flat around 6% of total health expenditure over the last 20 years

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- <sup>39</sup> Jönsson B et al. (2016), The cost and burden of cancer in the European Union 1995-2014; *European J Cancer* 66:162-170
- <sup>40</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited, 2016* – page 33
- <sup>41</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited, 2016* – page 10
- <sup>42</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited, 2016* – page 10
- <sup>43</sup> Bengt Jönsson et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited, 2016* – page 10
- <sup>44</sup> European Cancer Patient Coalition, *The Value of Innovation in Oncology 2017* – page 9
- <sup>45</sup> Europe Economics, External Reference Pricing, 1 July 2013, page 16, accessible at: [http://www.europe-economics.com/publications/external\\_reference\\_pricing\\_-\\_final\\_report.pdf](http://www.europe-economics.com/publications/external_reference_pricing_-_final_report.pdf)
- <sup>46</sup> The European CanCer Organisation (ECCO), *Identifying critical steps towards improved access to innovation in cancer care: a European CanCer Organisation position paper, 2017*
- <sup>47</sup> Following their second roundtable Apifarma is planning to launch a national stakeholder white paper to highlight the consensus reached through an engagement exercise with national policy-makers
- <sup>48</sup> AIFP, Future of Cancer Care in Slovakia: Better Data and Equal Access to Innovative Treatment, 16 May 2017