

BACKGROUND AND IMPLEMENTATION PLAN FOR THE EUROPEAN CANCER PATIENT'S BILL OF RIGHTS, 2016 **(ARCHIVE)**

ECC Members

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▪ Leadership team members

▲ Chairmen

• Executive committee members

INTRODUCTION AND BACKGROUND

The European Cancer Concord® (ECC) prepared and launched the European Cancer Patient's Bill of Rights® (BoR) in February 2014 (Appendix 1)^{1, 2}. We have updated the BoR and included a vision, implementation plans and goals and these were presented in 2016 (Appendix 2) and especially adapted it as a resource to support the development of National Cancer Control Plans (NCCPs). This document was presented in Brussels and Strasbourg on World Cancer Day 2016 and is being published by ESMO Open before 31 December 2016. The ECC and BoR were developed under the stewardship of the Society for Translational Oncology® (STO). Following the publication of the Bill of Rights®, STO continued its support of the ECC by awarding a 2 year grant from October 2015 and appointing Peter Selby (PS) as ECC President (September 2014 – September 2017) to establish and lead a small Leadership team with two ECC Vice-Presidents, Mark Lawler (ML) and Ian Banks (IB) and Kate Law as Consultant Advisor, that would, with ECC members, develop a Strategic Plan and Implementation Strategy and an independent Europe based organisation. In June 2016, we appointed Sadia Aslam as Project Officer and Nicole Goldman as secretary. This small leadership team of four people consists of equal numbers of cancer patients and cancer professionals.

The team have consulted widely and used a range of discussion documents. It is essential to establish the reputation of ECC as a collaborative source of useful initiatives focused on improving outcomes and avoiding duplication. We are working to establish a long term shared strategic approach, to promote the implementation of the BoR to improve cancer care in Europe. ECC works in collaboration with other organisations and we intend that we will often add value through our contributions to work which is led by other organisations. The ECC and its leadership team have supported and contributed to the work of the EU Member State Joint Action for Cancer Control (CanCon) in several work packages and Tit Albreht (coordinator of the CanCon initiative) is an ECC member.

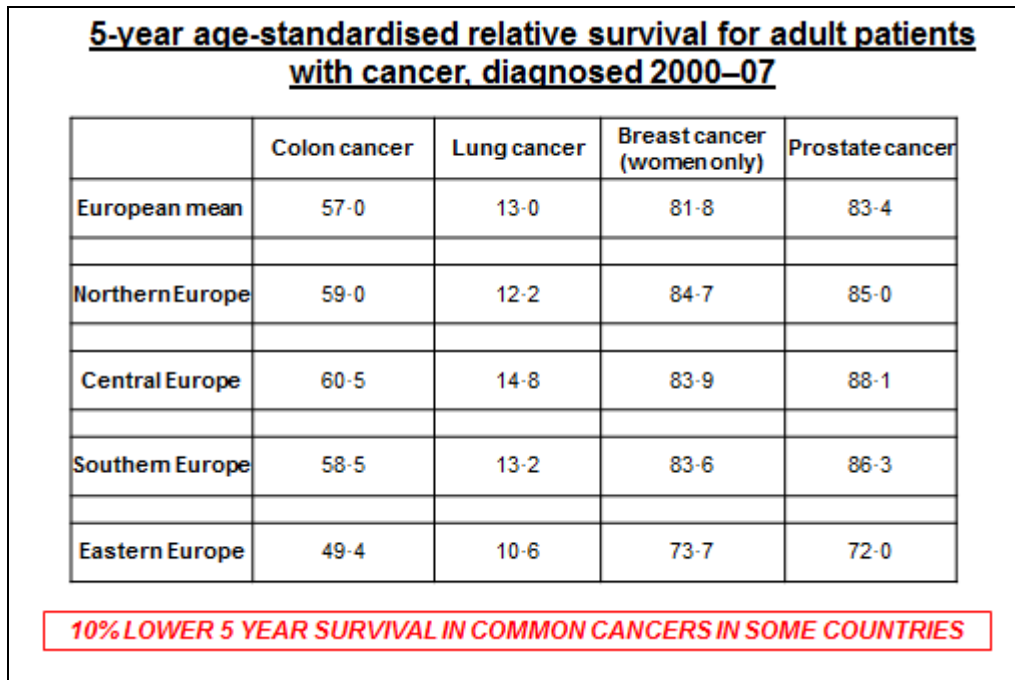
The task of implementing the BoR is truly challenging. Disparities in European cancer care and outcomes are very substantial¹⁻⁵. The European landscape of governmental and non-governmental organisations with a cancer focus is complex. These organisations have to deal with diverse remits and differing levels of resource. We have established a useful position for the ECC as a productive forum for patients and professionals. We have identified areas in which we believe we can add value and our contributions have been generally welcomed so far, as evidenced by invitations to present at the meetings/congresses of the majority of the existing cancer organisations, attend their Board meetings and contribute to their discussions. Nevertheless, if we are to make a difference to cancer outcomes in Europe, we will have to be realistic, develop a credible collaborative style, and be selective of where our best efforts should be placed. We must avoid duplication or competition in our work. Much excellent work is already ongoing both at the European level and at national

levels. Success in improving cancer outcomes will be much more likely to occur if all the relevant organisations work together in a collaborative fashion and recognise that the major common pathways towards improved cancer outcomes are delivered at a national level.

Three examples serve to demonstrate the diversity of outcomes for European cancer patients.

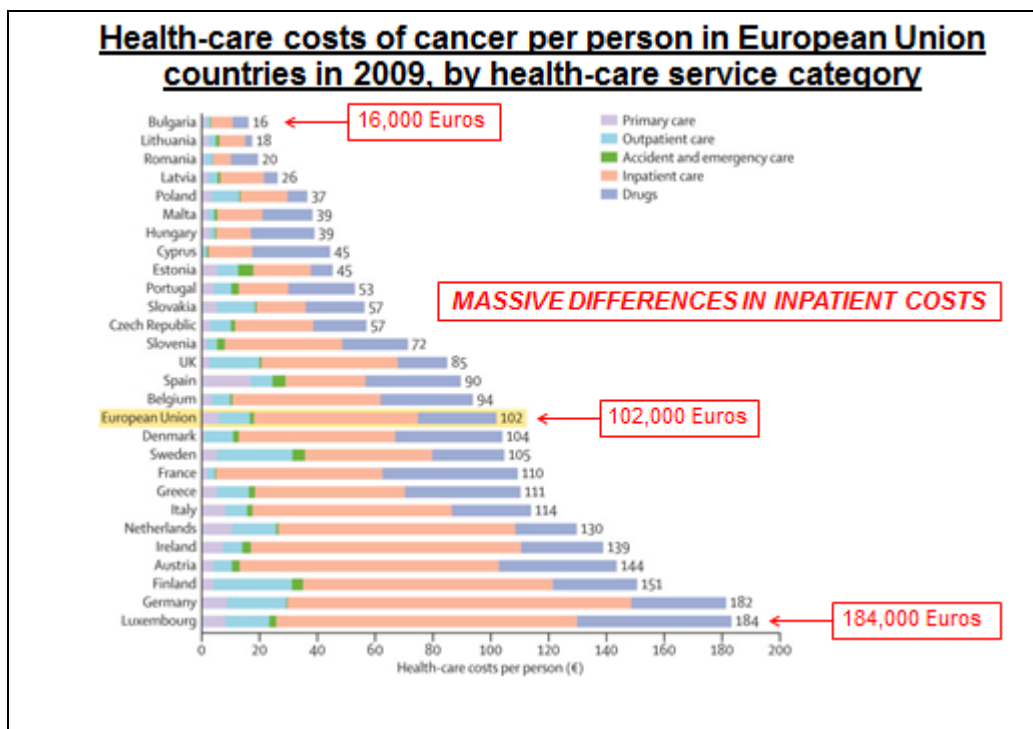
- 1) Cancer survival in Europe 1999-2007 by country and age: Results of EUROCARE-5 - a population-based study. DeAngelis R, Sant M, Coleman MP et al. Lancet Oncology 2014; 15:23-34³. (Figure 1)

Figure 1



- 2) Economic burden of cancer across the European Union: a population-based cost analysis. Luengo-Fernandez R, Leal J, Gray A, Sullivan R. Lancet Oncology 2013; Nov;14(12):1165-74⁴. Figure 2. Richard Sullivan is an ECC member and is developing further economic studies with ECC input.

Figure 2



3) Potential for Improvement in Cancer Management: Reducing Mortality in the European Union. La Vecchia C, Rota M, Malvezzi M, Negri E. The Oncologist 2015; 20:495-498 (Appendix 3)⁵. Carlo La Vecchia is an ECC Executive member

Since the peak rate reached in 1988, overall age standardized cancer mortality rates in the European Union (EU) have declined by approximately 20% in 2010 (17% in women, 22% in men). Smoking cessation in men, other favorable lifestyle and environmental factors, and improved cancer management led to a 20% decline in cancer mortality in the EU between the peak rate of 1988 and 2010, corresponding to the avoidance of more than 250,000 cancer deaths in 2010 alone and approximately 2.2 million deaths over the 22 year period 1989–2010. There are still substantial differences in cancer mortality and survival across various EU countries. Assuming that overall cancer survival in all 28 EU countries could be raised above the median, approximately 50,000 additional cancer deaths would be avoided per year, or more than 100,000 assuming that overall survival in all countries could be raised to the top quartile.

The Global and European Burden of Cancer and the Positives and Negatives of cancer control in Europe were summarised in the 2014 Bill of Rights^{1, 2}. The continuing evidence of disparities has been highlighted by the European Cancer Patients Coalition⁶. Examples of disparities are given in Table 1. Key publications have appeared on current global/European activities in cancer surgery⁷, primary care⁸, radiotherapy⁹ and cancer research^{10, 11}. An important overview of cancer control in Europe has provided a strong indication of the need for innovation and cooperation¹².

Table 1. Disparities in cancer health care in Europe

Patient-oriented cancer education
Access to information and support
National/regional cancer prevention strategies
Access to comprehensive evidence-based cancer screening programs
Structured national/regional cancer care delivery, including availability of new and existing diagnostics and therapies
Pricing of cancer drugs and therapies
Clearly articulated and appropriately resourced cancer research and innovation strategies
Access to appropriate pain management
Comprehensive citizen-focused strategies on long-term follow-up and survivorship
Provision of comprehensive and compassionate palliative/end-of-life care

Early diagnosis as a keystone for improving outcomes

In the updated Bill of Rights and in the work of the ECC, we have emphasised the importance of early diagnosis and therefore the vital role of primary care and the importance of close interactions between primary, secondary and tertiary cancer care in delivering early diagnosis, prompt access to excellent multidisciplinary patient-centred care and therefore improved outcomes. We have welcomed Peter Vedsted, Research Director of the Research Unit for General Practice at Aarhus University and David Weller, Chair of the Cancer and Palliative Care Special Interest Group of the World Organisation of Family Doctors to join the ECC to offer us advice on strategic developments in this area. For example, colleagues in Denmark have tackled some relatively low long term survival figures in that country by a strategic approach to make a diagnosis of cancer earlier in the course of the patient's natural history. Their preliminary results are showing significant improvements in cancer diagnosis times¹³ through a comprehensive strategic approach based on the view that cancer diagnosis should be seen as an acute medical challenge.

Advancing the Cancer Agenda in an Era of Economic Austerity

Strengthening health care systems is key to delivering strategies that will gain traction in optimizing cancer outcomes. In addition to the increasing health burden, the need to consider affordability and methods to “bend the cancer cost curve” must be addressed¹. Policy leaders, health care professionals, pharmaceutical and medical technologies industries, patients, and patient advocacy organisations must engage constructively to deliver tangible solutions. The American Society of Clinical Oncology has “identified the rising cost of cancer care as an opportunity to sharpen the focus on the need to ensure high-quality care while reducing unnecessary expense for our patients, their families, and society at large”^{1, 4}.

In Europe, increasing cancer incidence has not been matched by proportionate rises in cancer-related spending within European health budgets, as is particularly evident with the differences in the percentages of gross domestic product spent on health care. There are significant differences in cancer budgets across Europe^{1, 4}, particularly in cancer health care spending in Central and Eastern Europe^{1, 4}, and these differences, combined with the inability to provide standard-of-care technologies in different European countries at prices based on national purchasing power, contribute to a lack of equity that must be addressed. A study of the economic burden of cancer in the EU-27 countries (EU members from January 2007 through June 2013) found major differences in spending per cancer capita between countries^{1, 4}. Richard Sullivan has published extensively in the area of the cost effectiveness of cancer care and healthcare systems (Figure 2). A complex picture emerges in which it is clear that resource allocations have a central role in determining outcomes, but that many other factors contribute and some interventions and national approaches are more cost effective than others.

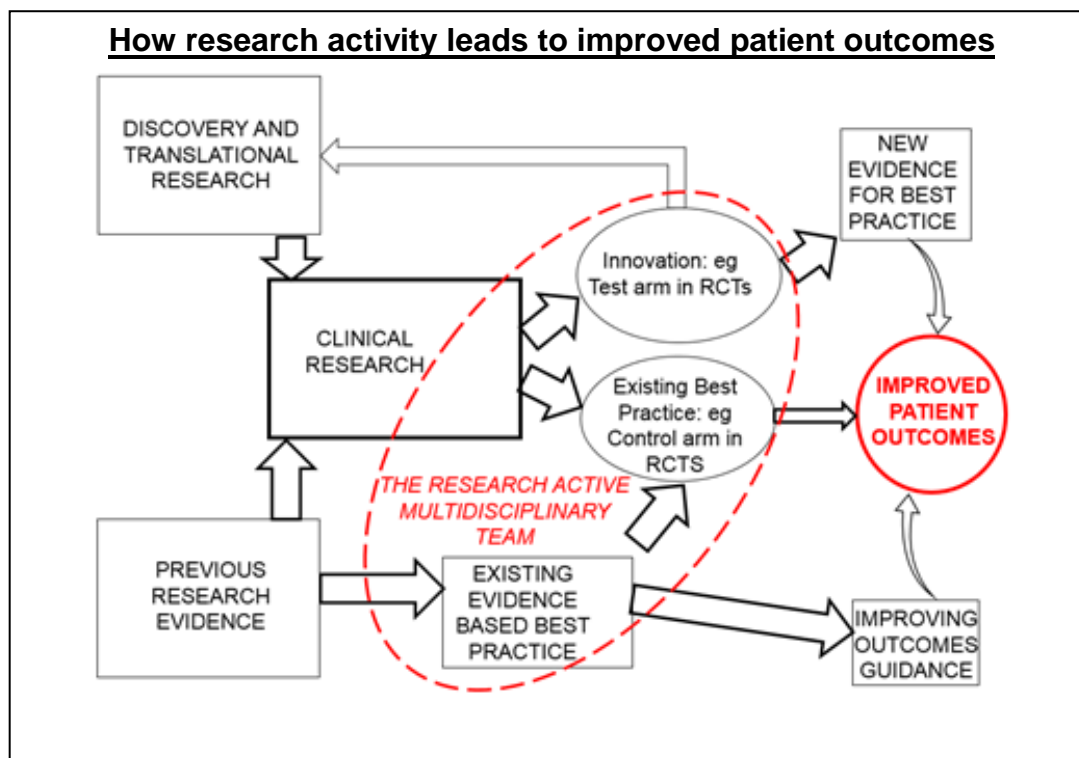
We believe that countries contemplating investments can learn from European experience of affordable, effective interventions to identify the best chance of improving outcomes.

Innovation as a Key Driver of Improved Cost-Effective Cancer Care

The economic burden of cancer worldwide is now approaching €1 trillion, and the associated lost years of life and productivity mean that cancer now places the largest economic drain on the global economy of any disease in the world. Cancer diagnostics (imaging, biomarkers) and therapies (surgery, radiation, new medicines and vaccines and devices) have led to statistically significant increases in 1-year and 5-year survival rates and improvements in cancer outcomes, with significant quality adjusted benefit achieved at a fraction of the economic cost of increased morbidity, mortality, and loss of productive life-years. A clear example of this progress is breast cancer, for which more effective management by innovative diagnostic and therapeutic approaches has been accompanied by approximately a fivefold increase in return on investment. In France, it is estimated that diagnostic and therapeutic innovation has contributed to a significant decline in cancer mortality rates in the period 2002–2006. It is important to stress, as voiced by many participants at an Institute of Medicine workshop, that diagnostic and therapeutic innovation can increase the value of improved health and outweigh the additional costs, only if implemented with a structured, cost-effective approach that emphasises measurable improvements in outcome for the cancer patient.

Research and innovation are central to improving outcomes and bring about improvements through new knowledge and by promoting the uptake of knowledge through research participation^{14, 15}. Figure 3 illustrates the routes by which research and innovation lead to improved outcomes.

Figure 3



National Cancer Plans

The European Partnership for Action Against Cancer (EPAAC) and the Member State Cancer Control Joint Action (CanCon) have drawn attention to the central role of National Cancer Control Plans (NCCPs) in improving improved cancer control and outcomes. They have noted “Since the World Health Organisation first published its National Cancer Control Programmes: Policies and Managerial Guidelines in 2002, the role of these plans in national cancer policy has grown tremendously, particularly in Europe. Whereas only three Member States of the European Union had implemented a National Cancer Control Programme (NCCP) in 2002, virtually all EU countries have taken decisive steps in this direction now, in part thanks to the leadership of EU-led initiatives such as the European Partnership for Action Against Cancer (EPAAC¹²). At their core, NCCPs aim to improve cancer control through better planning and coordination of the range of cancer services offered through national health systems, from prevention and health promotion to rehabilitation and palliative care services. This complex task requires action at all levels of the health system and beyond, including aspects related to:

- Leadership and vision;
- Policy development and management;
- Financing, resource generation and allocation;
- Coordination of health and social services;
- Social participation, including patient participation;
- Better use of scientific evidence; and
- Monitoring, evaluation and oversight.

The past decade in Europe has generated innovative policy approaches to NCCPs, wherein each country has attempted to adapt the main principles (quality, cost-effectiveness, equity and accessibility) to its own national context. These circumstances have given rise to a plethora of organisational and financing models, which provide great opportunities for benchmarking, analysis and mutual learning.”

The European Cancer Patient’s Bill of Rights¹ builds on other cancer-focused initiatives, particularly the Charter of Paris but also the World Cancer Declaration of the Union for International Cancer Control, the European Code Against Cancer, and the “Stop Cancer Now!” campaign, launched by the European School of Oncology following the World Oncology Forum in Lugano, Switzerland. The commitment to establishing a charter for cancer patients, achieved through a vibrant and equal partnership among health care professionals, cancer patients, and their representatives and bolstered by robust health economic principles, aims to deliver a unique “Wealth is Health” initiative that promotes optimal cancer care and research, reduces loss of productive life-years, enables active survivorship and rehabilitation, and increases health care innovation, thus leveraging wider benefits for European citizens and societies. The principles of equity and transparency will underpin all aspects of the European Cancer Patient’s Bill of Rights, culminating in the translation of health and societal benefit directly to the European citizen (Appendix 1 and 2).

WHAT IS THE ECC DOING FOR 2017?

The BoR update 2016 sets out the overall approach and goals.

<http://www.europeancancerconcord.eu/>

The European Cancer Patient's Bill of Rights, Update and Implementation 2016. Lawler M, Banks I, Law K, Albrecht T, Armand J-P, Barbacid M, Barzach M, Bergh J, Cameron D, Conte P, de Braud F, de Gramont A, De Lorenzo F, Diehl V, Diler S, Erdem S, Geissler J, Gore-Booth J, Henning J, Højgaard L, Horgan D, Jassem J, Johnson P, Kaasa S, Kapitein P, Karjalainen S, Kelly J, Kienesberger A, La Vecchia C, Lacombe D, Lindahl T, Löwenberg B, Luzzatto L, Malby R, Mastris K, Meunier F, Murphy M, Naredi P, Nurse P, Oliver K, Pearce J, Pelouchová J, Piccart M, Pinedo B, Spurrier-Bernard G, Sullivan R, Tabernero J, Van de Velde C, van Herk B, Vedsted P, Waldmann A, Weller D, Wilking N, Wilson R, Yared W, Zielinski C, zur Hausen H, Le Chevalier T, Johnston P, Selby P. ESMO Open. Accepted for publication.

The ECC will work in several workstreams (WS) to be a catalyst for change and to embed the principles of the BoR into work to improve cancer outcomes in Europe:

- 1) Work with other organisations to advocate a formal sustained strategic approach to improve cancer control and outcomes based on identifying, evaluating and sharing good practice**
- 2) Collaborate with and support other organisations at European and national levels to advance cancer control and research and innovation**
- 3) Deliver evidence-based papers to inform improvements of cancer care**
- 4) Initiate specific workstreams, often in collaboration with relevant cancer organisations to achieve improvement in patient outcomes**
- 5) Work to bring about a virtual or actual Europe based centre which will identify and validate and share best practice and help the intensification of Research and Innovation.**

1) Work with other organisations to advocate a sustained strategic approach to improve cancer control and outcomes

In this complex area, we believe there is potential for considerable added-value if the multiple European cancer organisations agree a shared strategy with short, medium and long term goals. Implementation of such a strategy would require energetic, innovative and properly resourced work to be performed by many organisations. This could be integrated and incorporated into long term sustained strategic plans based on identifying, sharing and continuously evaluating good practice underpinned by excellent research and innovation.

This work would ultimately have to take account of and potentially influence National Cancer Control Plans and priorities, and learn from the experience of individual European countries. This is being attempted through the mechanism of a Member State anti-cancer Joint Action (CanCon). This work needs to be sustained and extended. A 5 year cycle of work is likely to result in larger impacts on cancer outcomes. The work needs to be resourced to provide a comprehensive identification, validation and dissemination of good practice.

The diversity of outcomes and the variability in cancer care systems across Europe represents a challenge but is also a source of valuable knowledge about the approaches in individual countries, which if more widely adopted, could deliver optimal outcomes. This knowledge represents an important resource - the superior cancer outcomes seen in certain European countries with five to ten year survival in the order of 60% for all patients, demonstrate that the knowledge exists to allow many more countries achieve comparable outcomes. If that knowledge is managed, marshalled and disseminated appropriately, we could see quite rapid improvements in outcomes. Further improvements towards 70% 10 year survival are

feasible but they will require the comprehensive adoption of good practice and an active international effort in research and innovation in cancer.

We have developed a framework for discussion which describes a “whole systems” approach to improving outcomes for cancer patients (Figure 4). This framework is intended as an aid to planning, discussion, consultation and collaboration. ECC and other organisations may find it useful as a model for an overall collaborative effort.

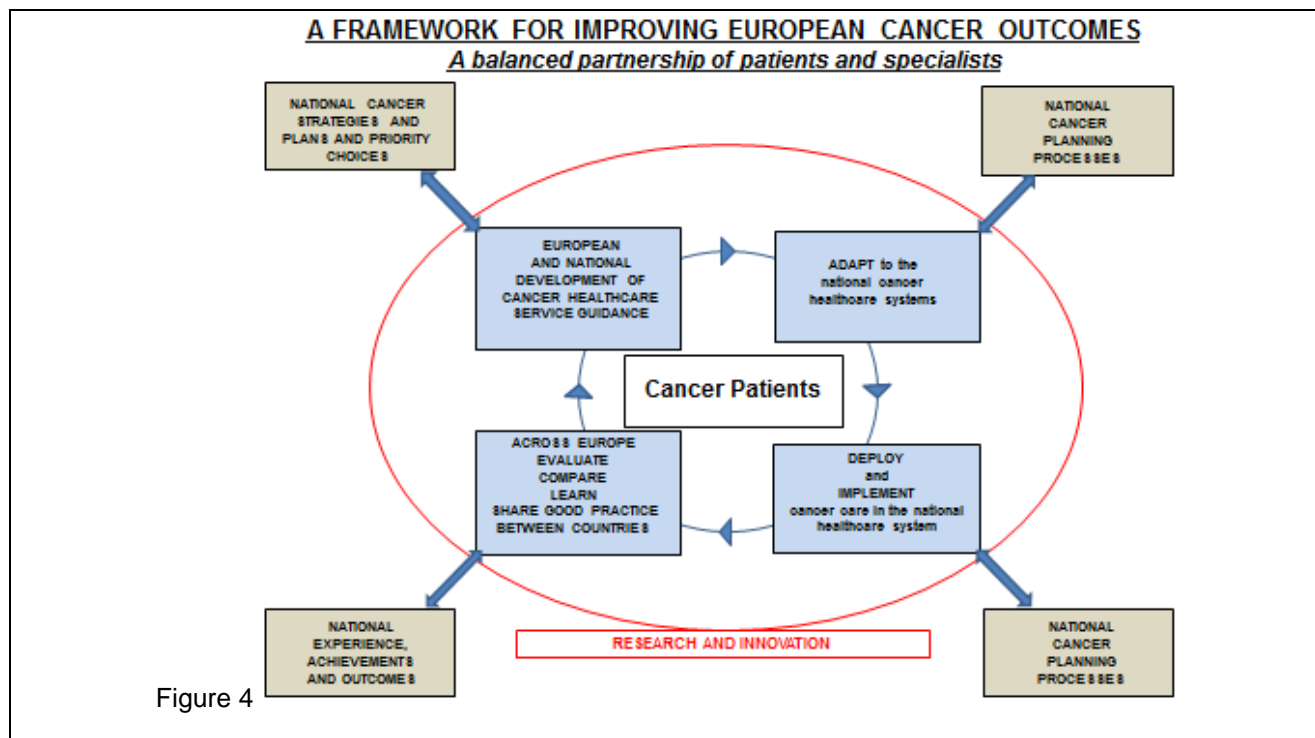


Figure 4

Features of this framework include:

- A continuous improvement cycle for cancer control at European and national levels, to ensure knowledge-based development of good practice for the benefit of patients, and the sharing of good practice between countries.
- Knowledge based patient-focused cancer guidance which requires adaption to suit national healthcare systems. Cancer healthcare service guidance has been and is being developed at European and national levels.
- Underpinning by Research and Innovation, which provides the knowledge-base for cancer care and may directly improve outcomes.
- Across Europe, and within each nation, a continuous process of evaluation of outcomes (survival, quality of life, care delivery and economic consequences) so that these may be compared, associations of improved outcomes with good practice can be made and good practice can be shared. This will tell us what is working; where it is working and what is needed to implement it.
- Each component of this cycle must relate to activities at a national level and countries must set their own priorities and initiatives. Individual national cancer planning processes are often of high quality. Improvements in Europe often result from drawing on national experience and sharing good practice.

A shared “whole system” Framework can promote the continuous development of knowledge-based guidance, flexibly developed for adaptation by different healthcare systems and deployed at a national level to deliver clear benefit for the European cancer patient.

2) Collaborate with and support other organisations at European and national levels

The ECC and the BoR were constructed to be **catalysts** for change and work best by collaboration. Ongoing examples of this approach include

i) Collaboration with national cancer charity Cancer Focus Northern Ireland to promote equality of access for cancer patients to best quality of care and innovative treatments

In Northern Ireland, the local charity Cancer Focus Northern Ireland adopted the BoR, with a specific emphasis on BoR Article 2 “The right of every European citizen to optimal and timely access to appropriate specialized care, underpinned by research and innovation.” A partnership between Cancer Focus Northern Ireland and ECC mediated through ECC Vice-President Prof Mark Lawler was initiated to address a specific national inequalities issue, access to innovative treatments.

A cancer inequalities access campaign across Northern Ireland in partnership with a national newspaper led to the delivery of 30,000 signatures to the Northern Ireland Health Minister on the steps of the Parliament Building. This resulted in the Health Minister announcing a review of the process, a public consultation and the very recent establishment of a more equitable assessment process and a Specialist Medicine Fund. This example demonstrates exactly what ECC is trying to achieve – a Bill of Rights at European level which acts as a catalyst for change at national level.

ii) Collaboration with European Men’s Health Association (EMHA) and others to support universal HPV Vaccination approach to reduce cancer mortality

A second initiative where ECC is providing added-value is in the area of cancer prevention. ECC is partnering with the European Men’s Health Forum and Human Papilloma Virus Action Group (HPV- Action). ECC attended the EMHF convened HPV Symposium: *Key Issues in HPV Prevention and Early Diagnosis* which took place on 21 April 2015 in the Royal Institute of Public Health in London and brought together 50 opinion leaders on HPV prevention and early diagnosis, with the aim to identify, better understand and make recommendations about areas where action could be taken to improve the prevention of HPV infection and the early diagnosis of HPV-related disease. Following this successful symposium, a Round Table was convened in Government Buildings in Belfast, hosted by Member of the Northern Ireland Parliament Paula Bradley as part of International Men’s Health Week 2015. This Round Table was addressed by ECC Vice-President Prof Ian Banks, while Prof Lawler acted as rapporteur, and a multi-stakeholder alliance was formed at this Round Table to “prevent the preventable”, by developing an introducing a universal vaccination programme that will protect both men and women from HPV driven disease. This approach is gaining traction, with both British and Northern Ireland Health ministers recently announcing vaccination programmes for Men who have Sex with Men (MSM) and increasing recognition of the beneficial effects of a universal HPV vaccination strategy for adolescent girls **and boy**¹⁶.

iii) Collaboration with the European Organisation for Research and Treatment of Cancer (EORTC) to highlight the central role of Research & Innovation to improve outcomes

The European Organisation for Research and Treatment of Cancer (EORTC www.eortc.org) has for many decades led a highly influential portfolio of clinical cancer research which continues to shape cancer care in Europe and worldwide. ECC is collaborating with the EORTC to demonstrate to policymakers that high quality Research and Innovation (R&I) of this kind, is a key element in service improvement and saving lives. The EORTC is analysing the links between its research portfolio and improved cancer outcomes. Evidence is emerging that EORTC trial patients, adjusting for casemix, have improved outcomes compared to non-trial patients. We will collaborate in a meta-analysis of evidence that clinical cancer research intensive hospitals have better outcomes than research inactive hospitals¹⁴. We are drafting a joint overview with EORTC of the mechanisms by which research and innovation improve outcomes based on published work^{14, 15}.

iv) Collaboration with European Cancer Patients Coalition (ECPC) on their work to reduce Disparities in European Cancer Control

The European Cancer Patient Coalition (ECPC www.ecpc.org) brings together patient organisations across Europe and has had a major leading role in the ECC and the preparation of the BoR. ECC was represented in the ECPC Disparities Working Party by Ian Banks and Mark Lawler (Chair) which resulted in the important ECPC publication on the Europe of Disparities in Cancer ⁶.

v) Collaboration with European Cancer Leagues and the European Organisation for Research and Treatment of Cancer and others on health economic aspects of improved cancer outcomes

The European Cancer Leagues (ECL www.europecancerleagues.org) represents 23 country's cancer leagues and is supporting the work of CanCon, of the European Parliament's MEPs Group Against Cancer, and a number of initiatives aimed at improving cancer control. ECC is developing a close working relationship and understanding with ECL which will include collaboration on the economic aspects of cancer care in Europe.

A specific piece of work with ECL and EORTC will focus on the economic consequences of improving cancer outcomes.

vi) Collaboration with the European Cancer Organisation (ECCO) in their Oncopolicy work and to establish a 2 year plan for Patient Advocacy

The European Cancer Organisation (ECCO www.ecco-org.eu) has developed a substantial programme of work on Oncopolicy and on the development of guidance for cancer care. ECC members are fully supportive of the ECCO strategy and programmes. Collaboration with ECCO on the development of its Oncopolicy is led by ECC Vice-President Ian Banks, who chairs the ECCO Patient Advisory Committee. Professor Banks is a member of the core ECCO group on Oncopolicy.

vii) Collaboration with Cancer Control Joint Action (CanCon) as a stakeholder and to support their plans for a long term sustainable approach to cancer control

The Cancer Control Joint Action (CanCon) is funded by the European Commission (www.cancercontrol.eu). CanCon has identified key conceptual themes:

- Creating **guidance** based on the best available evidence
- **Different concepts of** integration of services – moving from the concept of a Comprehensive Cancer Centre to a **Comprehensive Care Network**
- Shift from “how long” people live after diagnosis to “**how well**”. **Survivorship, rehabilitation and palliative care**
- Improved **community cancer care**

CanCon is developing its work on these themes through a series of workstreams, each led by organisations in individual European countries. The workstreams are 1) Coordination; 2) Dissemination; 3) Evaluation; 4) Guide coordination; 5) Links to member states; 6) Integrated cancer control; 7) Community-level cancer care; 8) Survivorship and rehabilitation and 9) Screening. The ECC is now a stakeholder in CanCon. The work of CanCon is linked to the work of a European Cancer Expert Group also supported by the European Commission. Peter Selby is representing ECC as a stakeholder in the CanCon Stakeholder Group and providing expert opinion to two WS. Additionally Mark Lawler is a member of WS5 on Cancer Inequalities. We hope CanCon will be able to draw on work done by ECC members on the identification of avoidable cancer deaths³, on the importance of research and innovation to underpin service improvement in collaboration with EORTC, and work on the Economic Consequences of improved cancer outcomes, which ECC is developing with EORTC and ECL.

viii) Improving Outcomes and Change Management Strategies (ECCO and EHMA)

A great deal is known in individual units, regions and countries about improving cancer outcomes often in readily deliverable and affordable ways. However, such knowledge is often not widely disseminated or used because of organisational or professional barriers. Different European countries and organisations have experience of a wide range of approaches attempting to change health care systems to improve cancer outcomes. Central guidance or direction, educational initiatives, hospital/centre accreditation, targeted investments, peer review processes, league tables and research participation have all been explored. Changing clinical behaviours is always challenging. We are exploring this experience and have discussed a workshop on this theme.

ix) ESMO

The European Society for Medical Oncology (ESMO www.esmo.org) has major roles in oncology and training and education in oncology in Europe and more widely and has high quality knowledge management guidelines. We have agreed with ESMO that the 2016 update of the BoR will be published in ESMO Open and we will explore further future collaborations.

x) ESSO

The European Society for Surgical Oncology has a central role to play in improving cancer outcomes. Surgery remains the main curative modality for cancer treatment. Mark Lawler is working with ESSO on patient advocacy.

xi) OEIC

The Organisation of European Cancer Institutes (OEIC) is a non-government, non-profit organisation whose primary aim is to bring together the cancer research and care institutions of the European Union, in order to create a critical mass of expertise and competence. It is a European Economic Interest Grouping (EEIG) which may have relevance in relation to our work on the economics of cancer outlined above. OEIC aims to reduce fragmentation and increase competitiveness through a coordinated approach that emphasises the value of cooperative, coordinated, comprehensive cancer care. ECC are partnering with OEIC utilising the BoR as a vehicle to help move forward in this area.

Important specific activities to monitor cancer outcomes in Europe and the process of care for cancer patients continue to be conducted by, for instance, EURO CARE (www.eurocare.it). EURO CARE provides data openly and their data was used by Professor La Vecchia in his excellent recent paper⁵ which supports the work of ECC and the implementation of the BoR.

3) The delivery of evidence based papers to inform improvements of cancer care

We will be a source of discussion papers and perspectives which will underpin improved cancer services and outcomes for cancer patients. These will be reviews and opinion pieces and will not normally involve the generation of new data or new analyses. They will often be produced in collaboration with other organisations. Our primary source of co-authors will be the members of the ECC from whom we seek interest in preparing these documents. In the absence of co-authors emerging from among our membership, we would invite other qualified individuals to contribute. We would aim to produce four of these papers per year.

Work-in-progress for 2017:

- The economics of cancer care – diversity and affordable practice
- Access to information for cancer patients in Europe
- The role of research and innovation in improving outcomes
- The vital role of early diagnosis in improving cancer outcomes

are being developed with ECC members.

4) The initiation of specific workstreams, often in collaboration with relevant cancer organisations

These pieces of work are more substantial than those listed under Section 3. They are selected to add value to work ongoing in Europe that will benefit cancer patients by highlighting aspects which are not currently receiving sufficient emphasis and by generating new data, or analysing existing data in ways that support the case for patient-focused change and fit in with the strategic framework.

We have identified three such workstreams, one of which has been conducted by an ECC member and his team and led to a valuable and influential publication. The three selected areas at present are:

- Work on the identification of **avoidable cancer deaths** and the improvements for cancer patients that might follow from raising the performance of cancer care services in each European country up to the European average. This work by ECC Member Professor Carlo La Vecchia has been published and is attracting considerable interest⁵ (Appendix 3).
- Developing specific publication(s) on the impact of **research and development and clinical trials** and studies on healthcare outcomes which we would hope will be published in 2016. The lead organisation for clinical research and innovation in cancer in Europe is the European Organisation for Research and Treatment of Cancer (EORTC) who have published widely in this area^{10, 11, 13}
- A study of the **economic consequences of improved cancer outcomes** drawing on the model of improved outcomes developed by ECC Member Professor La Vecchia, the economic analysis conducted by ECC Member Professor Richard Sullivan and colleagues and with the input of appropriate health economics information. This work is at an early stage of discussion and development. In Europe, there is diversity of outcomes for cancer patients and variability of investment in cancer care. The relationship between the two is not clear and Professor Sullivan is currently studying aspects of this relationship. Any initiatives to improve cancer care and cancer outcomes in Europe will need to be firmly grounded in an analysis of deliverability and affordability in the current period of austerity. This is a challenge but it is also an opportunity. We envisage working towards a portfolio of studies which explore the relationships between patterns of care, outcomes, and the cost of care in order to identify initiatives which improve outcomes and which would constitute good value for money for hard pressed European economies.
- A workshop on **Improving Outcomes and Managing Change** is planned in 2017. It will aim to identify effective ways to ensure existing knowledge is used widely and effectively.

It may be possible to develop a flexible model for the economic consequences of changes in the prevention, diagnosis and treatment of cancer which could be shared with many countries to allow the evaluation of innovation and change in cancer control. Difficult choices between initiatives can be informed by their evidence of effectiveness and affordability especially in less wealthy countries.

For example, disparities in spend on cancer care in Europe, arise substantially from differences in the spend on inpatient care. Some of that spend is inevitable for the safe and essential delivery of appropriate high quality care. But modifying healthcare systems to increase the delivery of care in outpatients is also feasible. Anecdotally, there are European countries and regions of European countries which have failed to exploit the potential for high quality cost effective chemotherapy to be delivered as an outpatients' procedure.

5) A European Centre for identifying and sharing best practice

Ensuring that successful and less successful practice in the development of systems and strategies to improve cancer outcomes is a long term, systematic challenge. We believe that such an opportunity to look at the best practices across Europe would be beneficial to most countries and regions. The identification, evaluation and validation of best practice is essential and requires a long term approach. We believe that this should be established as a long term function, probably requiring a location to base the work. Such an Implementation Workstream would fit well into a future Joint Action against Cancer or similar vehicle, supported by the EU and by non-EU European countries. We are exploring a model for such a Centre.

ORGANISATIONAL DEVELOPMENT FOR THE ECC IN EUROPE

To strengthen ECC and maintain its value as a prestigious, independent innovative forum for discussing policy and strategy for cancer in Europe and to maintain its expertise, we believe the ECC should grow to include additional leaders of Europe's cancer community and have a wider representation from more countries. We will aim to increase patient representation and add to ECC expertise in several areas such as healthcare management, nursing, primary care, diagnostics and health economics.

The support of the Society for Translational Oncology, which is a legal entity in the USA, for ECC has been essential and has been very gratefully received. They have agreed core funding for the small operational team for 2 years. Additional and future funding will come from European sources. The characteristics of the ECC as an organisation or component of an organisation as enshrined in our Constitution, have to remain:

- An equally balanced partnership between patients, carers, patient advocates and professionals.
- A collaborative and supportive style of working in which primacy can be conceded to other organisations in the interests of delivering good outcomes for patients.
- Professional delivery of high quality work informed by the best Research and Innovation and drawing on the best experience in Europe.
- Strong connections into the individual national cancer care systems of each European country.
- Multi-professional approaches.

We will continue to evolve our organisational framework toward a Europe-based governance and funding during 2017. The ECC has identified through consultation a larger balanced Executive Committee with patients, patient advocates, carers and professionals with wide geographical coverage in Europe in order to oversee the implementation strategy. This will grow further to include more representation from Eastern Europe. We will steadily grow the ECC membership to include representation from more European Countries.

We are developing the European Cancer Concord as a charitable foundation. The first step will be a UK based Charitable Incorporated Organisation in mid 2017; other developments will follow. We will also explore the identification of a key partner organisation which can act as a "host" for the ECC.

We should seek to influence European and national plans and activities especially through national cancer leagues but also through patient organisations, professional bodies, and health management organisations, both governmental and non-governmental. The involvement of the EU Health Commissioner and his team will be vital to future success. Proposals will be underpinned by patient-centred priorities and lead to the implementation of the BoR (which the previous Commissioner endorsed at the launch on World Cancer Day 2014). The current Commissioner has already shown commitment to improve cancer outcomes through his involvement in the ECCO 2015 Congress in Vienna.

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