

## The European Cancer Concord (ECC)

### Annual Report on 2015

#### 1. **Background**

Cancer and the provision of cancer care places a significant and growing burden on patients, citizens, and economies. Europe provides some of the best cancer care in the world and conducts high quality, globally recognized cancer research. There are still significant disparities, however, in public information about cancer, accessing cancer care, delivering optimal treatment, supporting cancer survivorship, and integrating cancer research and innovation across European countries. There are major disparities in the quality, expenditure and outcomes for European Cancer Patients. In addition, costs of current treatments and long term follow-up are placing significant economic burdens on European health care systems. Improvements in quality of care, translation of research discoveries, and promotion of innovation will have to be achieved within affordable economic models.

In the context of these challenges and, under the stewardship of the Society for Translational Oncology® (STO), the European Cancer Concord (ECC®) was established, comprising European oncology leaders in a unique partnership with cancer patients, care-givers, and their advocates. In order to provide tangible benefits for European cancer patients, the ECC produced a “European Cancer Patient’s Bill of Rights®,” a patient charter that underpins equitable access to an optimal standard of care for Europe’s citizens. This was launched at the European Parliament and endorsed by the EC Health Commissioner on World Cancer Day (4<sup>th</sup> February 2014) and published shortly thereafter [Appendix 1 and 2].

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 Professor Peter Selby (PS) as ECC President to establish and lead a small Executive Group with two ECC Vice-Presidents (Mark Lawler (ML) and Ian Banks (IB) and Kate Law as a Consultant Advisor that would, with ECC members, develop a Strategic Plan and Implementation Strategy. This small leadership team consists of equal numbers of cancer patients and cancer professionals.

The ECC recognises that much excellent work is already ongoing both at the European level and at national levels. Success in improving cancer outcomes will, to a large extent, depend on the relevant organisations working together effectively and much of the ECC Executive’s activities, to date, have been in support of these aims.

Influenced by the ECC commissioned publication, *Potential for Improvement in Cancer Management: Reducing Mortality in the European Union by Carlo La Vecchia et al* [Appendix 3] and after discussions with ECC members, ECC has formulated a strategy to move, through collaborations with many European and national cancer organisations, towards improving cancer outcomes, patients’ quality of life and post treatment experience. ECC have chosen a single example outcome to demonstrate a challenging but achievable long term target for a 70% 10-year survival across Europe, by 2035 (**the 70:35 Vision**).

## 2. Progress/Achievements 2014/15

### 2.1 Bill of Rights and Implementation Strategy

The initial launch of the European Cancer Patient's Bill of Rights has been met with considerable interest and engagement. We have identified areas in which we believe we can add value and our contributions have been generally welcomed, 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 (Tables of Activities).

We are now updating the BoR to make it a shorter and more accessible document and render it a useful resource for national cancer control plans (Appendix 4). In parallel, we have developed a Background and Implementation Plan for the European Cancer Patient's Bill of Rights, 2016 (Appendix 5). These documents will be circulated to ECC members for comment in January and then finalised for a formal launch planned for World Cancer Day on February 4<sup>th</sup> 2016.

The principal reason for updating the BoR is to provide a shorter and more generally accessible document, but also to retain the principles of the BoR and aid the development of national cancer control strategies and plans and to link the BoR to a clear Implementation Strategy.

The updated BoR includes our high level objective to radically improve cancer outcomes and summarises the mechanisms by which these improvements may be achieved.

The Background and Implementation Plan for the European Cancer Patient's Bill of Rights, 2016 describes how the ECC will work in several workstreams (WS) to be a catalyst for change and to embed the principles of the BoR into activities that will improve cancer outcomes across Europe:

- WS1) Work with other organisations to advocate a formal sustained strategic approach to improve cancer control and outcomes based on identifying, sharing and evaluating good practice
- WS2) Collaborate with and support other organisations at European and national levels
- WS3) Deliver evidence-based papers to inform improvements of cancer care
- WS4) Initiate specific workstreams, often in collaboration with relevant cancer organisations

The ECC can only make a significant impact via partnerships with existing organisations and significant progress has been made in this direction, most notably with the Association of European Cancer Leagues (ECL). Successful delivery of the BoR will require participating nations to incorporate the principles of the Bill into their national cancer plans and the ECL is the only organisation to have the required level of influence at national and European levels and is the host of Members of the European Parliament (MEPs) Against Cancer.

From a UK perspective, Peter Selby (PS) has been in constructive discussions with Cancer Research UK (and will start talks with Macmillan in the New Year). It would considerably strengthen the UK position in any European-wide initiatives relating to the BoR should one or both organisations join the ECL.

The relationship with European Cancer Patient Coalition (ECPC) is an important one, given that it is the largest pan European group with a patient specific mandate, its influence within the European Parliament and within European initiatives including CanCon. In its Annual Report for 2014, ECPC has extensive coverage on the joint (ECPC and ECC) launch of the BoR and ECC will be supporting ECC activities in Brussels on World Cancer Day in 2016.

PS has received a formal request from Professor Lucio Luzzatto to provide expert advice to CanCon's Work Package (WP) on Comprehensive Cancer Care Networks - the output from which will be a chapter in the principal CanCon publication. Additionally, Mark Lawler (ML) and Peter Selby (PS) have been invited to be experts for CanCon's WP on Cancer Inequalities.

Ian Banks' (IB) chairmanship of ECCO's Patient Advisory Committee (PAC) has provided excellent opportunities to promote the ECC's goals, in particular in the development of the programme for the 2017 Congress in Amsterdam and ECCO's Oncopolicy Forum.

We need to ensure that ECC's value as a prestigious, independent forum is maintained and, to this end, a number of additional members from Europe's cancer community have been accepted to join the Concord during 2015. These include, Paul Nurse, Tomas Lindahl, both Nobel Laureates in Cancer Research, Tit Albrecht, the coordinator of CanCon, Peter Vedsted, an authority on early cancer diagnosis, David Weller, the chair of the Cancer and Palliative Care Group of the World Organisation for Family Doctors, Denis Lacombe, the new Director-General of EORTC and Rebecca Malby, an expert on cancer care management.

We would anticipate further expansion of membership in 2016 onwards and, in addition to increasing patient representation will be looking to increase expertise in areas such as healthcare management, nursing, primary care, diagnostics and health economics.

## 2.2 Organisational Development

The support of STO has been essential and has been very gratefully received, by ECC members and European colleagues. However, at the strategic retreat of ECC and STO leaders in February 2015, we agreed that ECC should be recognized, as soon as was possible, as having its "ownership" within Europe. We will evolve our organisational framework toward a Europe-based governance and funding during 2015-2017 and, as part of that process, a formal constitution (in draft, Appendix 6) has been written. Options for future funding arrangements are discussed in the Background and Implementation Plan for the European Cancer Patient's Bill of Rights, 2016.

Ongoing discussions between the ECC and ECL have resulted in a MOU between the two organisations. We are also exploring a strategically important proposal for the ECC to share office space and a website presence with ECL. If agreed, these moves would greatly strengthen the position of ECC in Europe.

## 2.3 Funding

STO's commitment to funding 2 years core support for the ECC has been essential in establishing an Executive Team that would drive the direction of ECC going forward. Once fully activated, the grant will be used to employ a project manager (underway) and provide financial support for secretarial work, consultancy fees and travel.

Negotiations between STO and Leeds University with respect to the level of overheads have caused some delays, however, the financial agreement between STO and Leeds University was signed in December 2015 and should ensure release of the first STO payment early in 2016.

## 3. Future Plans

The year will start with a full programme of events in both Brussels and Strasbourg (where the European Parliament will be sitting) on February 4<sup>th</sup>, World Cancer Day. ECC leadership will be involved at both locations (with CR-UK, ECCO, ECL and SIOP in Strasbourg and with ECPC in Brussels) and we are planning the formal launch of the updated BoR and Implementation Strategy.

The launch of the updated BoR will provide the impetus to drive change through influencing 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.

We will continue to pursue a policy of active engagement with key organisations and individuals and a specific priority for 2016 will be to consolidate a more formal relationship with ECL. Future Annual Reports will include progress on attracting funding for ECC, the formal aligning of activities between ECC and ECL and, potentially, other European organisations.

The ECC will identify, through consultation, a larger balanced Executive Committee consisting of 8-10 members with patients, patient advocates, carers and professionals with wide geographical coverage in Europe in order to oversee the implementation strategy. We will grow our membership cautiously to reflect the broad interests required to bring about change in healthcare systems.

We will have a face-to-face meeting towards the end of 2016 and explore colocation with ESMO, ECCO or ECL annual meetings. This meeting will explore policy and strategies, together with ECC members own priorities for good practice, research and innovation.

In order to ensure its credibility it is important that ECC maintains a high profile and, over the next two years, ECC anticipates involvement in a number of meetings, presentations, reports and publications including:

- *Health Economics to guide choices for cancer care strategies and plans (Mark Lawler, Richard Sullivan and Carlo La Vecchia leading)*
- *Improving outcomes – modelling the impact of good practice and promising innovations (Mark Lawler, Ian Banks, Peter Selby leading)*
- *The impact of patient participation in research on service outcomes (Mark Lawler and Peter Selby jointly with colleagues in EORTC)*
- *We have presentation invitations at ESMO (2016) and ECCO (2017)*
- *Oncopolicy Forum report: 'Inequalities in treatment outcomes' led by Mark Lawler and Ian Banks*

The ECC has made a solid start in gaining recognition across Europe. We fully appreciate that there are many challenges ahead in that we are proposing a complex whole system change where ECC is only one among many contributing agencies. We will continue to seek routes to implementation that are based on good collaborations, excellent work and have a clear output that will benefit patients.

Measuring success in such a complex system will not be straightforward, however, we would expect steady improvements in cancer outcomes in Europe and we expect our activities to have a positive impact for patients. The impact of ECC work will be evidenced through the documentation of successful collaborations and patient-focused outputs, the use and citation of our work and the roles and influence of ECC members.

## Appendix 1

A catalyst for change: the European Cancer Patient's Bill of Rights. Lawler M, Le Chevalier T, Murphy MJ Jr, Banks I, Conte P, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Armand JP, Barbacid M, Barzach M, Bergh J, Bode G, Cameron DA, de Braud F, de Gramont A, Diehl V, Diler S, Erdem S, Fitzpatrick JM, Geissler J, Hollywood D, Højgaard L, Horgan D, Jassem J, Johnson PW, Kapitein P, Kelly J, Kloezen S, La Vecchia C, Löwenberg B, Oliver K, Sullivan R, Tabernero J, Van de Velde CJ, Wilking N, Wilson R, Zielinski C, Zur Hausen H, Johnston PG. *The Oncologist*. 2014 Mar;19(3):217-24

## Appendix 2

European Cancer Concord (ECC). A Bill of Rights for patients with cancer in Europe. Lawler M, Le Chevalier T, Banks I, Conte P, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Murphy MJ, Johnston PG; *Lancet Oncology*. 2014 Mar;15(3):258-60.

## Appendix 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 4

A Catalyst for Change: The European Cancer Patient's Bill of Rights, Update 2016 - Updated Draft January 2016

## Appendix 5

Background and Implementation Plan for the European Cancer Patient's Bill of Rights, 2016

## Appendix 6

Draft formal constitution

## Tables of Activities