

# ECRM

## European Cancer Research Managers Foundation

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**Nonprofit Business Plan**  
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ECRM

European Cancer Research  
Managers Foundation

Linking Europe's Cancer  
Researchers



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# Executive Overview

## INTRODUCTION TO THE ECRM

The ECRM was created in response to the European Commission's initiative, *Towards Greater Coherence in Cancer Research* in 2001 through an Accompanying Measure grant from Framework Programme 6. The ECRM aspires to:

- *The provision of high quality intelligence to address key emerging policy issues in cancer research*
- *Conduct and disseminate policy research relevant to cancer that influences the political process*
- *Cultivate a global policy research network for cancer research.*

## THE VALUE OF THE ECRM AND ITS POLICY WORK

Cancer research is a global effort operating from multiple paradigms. Policymaking in cancer research requires high quality intelligence to create effective strategies. It is the ECRM's founding goal to provide such intelligence and policy support through high quality research, the provision of all data freely in the public domain and its practical dissemination to policy-makers and the public.

The ECRM's strategy is a distinctive blend of four elements -

**1. *A focus on policy issues directly relevant to the progress of cancer research***

The ECRM has focused on delivering two major reports into cancer research funding and outputs that have had a direct impact on policy-making at European and Member State level<sup>1</sup>. This is the core of its activities and with its strategic partnerships in Europe, USA and more recently Australia and Canada will continue to be prosecuted. Currently the ECRM also has major projects in place on cancer centres and the impact of cancer research (on the media and clinical guidelines).

**2. *High quality information gathering, analysis and an open, transparent dissemination of data***

ECRM has distinguished itself by the collection of high quality information that can be fed into the policy analytical process. We work hard to avoid GIGO ('garbage in, garbage out'). We work with a network of key academic collaborators, and in an iterative manner with cancer research leaders to shape the final policy documents. It is the founding principle of the ECRM that all data should be placed freely in the public domain and disseminated in a manner fit for policymakers and the research community.

**3. *Embracing a network approach to policy research by working with leading international cancer researchers***

ECRM focuses explicitly on linking and working with a wide range of international members of the cancer research community from leading researchers, senior management, and policymakers in both industry and the public sector. This network has been developing since the ECRM's formation in 2001 and continues to grow with recent link-ups' to Australia and Canada.

**4. *Delivering the strategy through a low cost model with the minimisation of administrative "time-sink"***

ECRM has expressly built its organisation along minimalist lines, focused on a working model that utilises the minimum core administration whilst accessing the expertise of a network of collaborators in the research and policy community.

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<sup>1</sup> *European Cancer Research Funding Survey, Sept 2005 & Investment and Outputs of Cancer Research: from the Public Sector to Industry, Sept 2007.* (available at [www.ecrmforum.org](http://www.ecrmforum.org))

## Success in Policy Programmes: Key Statistics

### Membership

- The forum network is composed of over 175 funders and their associated cancer managers from the global cancer research community.

### Policy Reports

- Two major funding reports
- Major peer reviewed publications arising from these reports, e.g. PLoS Medicine Vol. 3, No. 7, e267, Global Forum for Health Research chapter, ASCO New & Views (April 2008:40); British J Cancer (2008, 98: 1944-50)
- 30,000 website hits with over 800 CD's and 1150 hard copies of funding reports disseminated. Following publication of second report over 4700 e-copies were downloaded in two months.

### Collaborative Projects

- Major collaborations (n > 8) with European Cancer Organisation, European Forum for Good Clinical Practice and International Union for Control of Cancer to host workshops lobby around the impact of regulations.
- The ECRM has facilitated similar studies in brain and care of the elderly research. The latter network (led by Prof Bayaens) is currently being reviewed for funding by European Commission.
- The ECRM provided lead funding data for EUROCAN+ project looking at the co-ordination of cancer research in Europe.

### International Engagement

- ECRM policy work has been invited to present at over 10 major conferences since first report was launched in 2005, e.g. ASCO 2006, OEIC 2006 and UICC 2006.
- The Forum has been invited to an additional 8 national policy meetings with key policymakers since 2005.
- Our work has had a marked impact on many national cancer research policies, e.g. Ireland (see <http://www.neurope.eu/articles/77857.php>)

### Communication

- 30,000 website hits with over 800 CD's and 1150 hard copies of these reports disseminated
- Policy reports generated substantial web-site coverage with over 53 sites carrying the story
- Substantial broadsheet newspaper coverage across the EU, including Daily Telegraph, Research Europe (Issue 240 4 Oct 07. P.2).
- Substantial TV and radio coverage e.g. RTE (Ireland), German, and UK
- Second ECRM report launched at European Parliament (Host MEP Arlene McCarthy) with press coverage and afternoon policy meeting with over 30 major policymakers.
- ECRM findings used in major policy op-ed articles, e.g. Molecular Oncology (1, 2007, 131-134), Cancer World (July-Aug 2005) and American Cancer Society Cancer Atlas (2006, section 19), Global Forum for Health Research, amongst many others.

# 1

## Rationale and Competitive Context

### THE VALUE OF THE ECRM

When the scientist and philosopher Michael Polyani visited Nikolai Bukharin, principle framer of the Soviet Constitution in Moscow in the mid-1930's he was appalled by the over-management of scientific research and returned convinced that the freedom of science to choose its content, subject and means of work was paramount<sup>2</sup>. The ability of science to choose its own path relies on the active participation of the research community in setting its own policies and strategies.

The rise of biomedical research has driven science and technology (S&T) to the heart of socio-political activities in all developed countries. Research activity has been translated into much public benefit, from new preventative strategies to a vast array of new medicines. Indeed cancer research is now at the leading edge of **all** biomedical research.

Cancer is one of the most serious public health issues facing both developed and developing nations. The facts and figures speak for themselves -

- By 2020 the global burden of cancer will be 15 million new cases per year, an increase of 50% on today.

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<sup>2</sup> Holton, G. Michael Polyani and the history of science. Keynote address to Harvard Divinity School, February 28 1992.

- There are 3 million people alive in Europe who have had a diagnosis of cancer in the last five years. World-wide this figure is around 25 million
- This equates to some 12,600 people per day in Europe and USA being told they have cancer.
- Cancer is the second leading cause of death in children (after accidents).
- There are 7.6 million premature deaths due to cancer world-wide every year. This is greater than all TB, AIDS and malaria deaths combined.
- The gap between outcomes for the most deprived and affluent parts of society is rising.

Cancer research is a global effort operating from multiple paradigms. Policymaking in cancer research requires high quality intelligence to create effective strategies. It is the ECRM's founding goal to provide such intelligence and policy support through high quality research, the provision of all data freely in the public domain and its practical dissemination to policy-makers.

## THE DEMAND FOR A NEW POLICY RESEARCH APPROACH

The ECRM was created in response to the European Commission initiative *Towards Greater Coherence in Cancer Research* in 2001 through an Accompanying Measure grant from Framework Programme 6<sup>3</sup>. The Forum aspires to:

### ***1. The provision of high quality intelligence to address key emerging policy issues in cancer research***

There has been a dramatic increase in global cancer research activities with more funders and a greater range of funders (governmental, charitable, and industrial). All this has spurred ever more complex regulations and policy initiatives. The emergence of these new, more complex policy challenges in cancer research demands, i) expertise beyond the traditional circle of policy research (e.g. RAND), ii) the development of cancer-specific policy research programmes within the research community and iii) a more open, collaborative method of working.

Current policy research groups, while fulfilling many specific and necessary needs are not intellectually equipped to address the breadth of policy issues facing cancer research today. In contrast the ECRM has a proven track record of providing high quality policy research and dissemination that is directly relevant to the policy needs of cancer research. In addition its network into the research community and funders provides "on the ground" experience and insights. Whilst there is an ongoing programme of cancer research policy

projects the structure of the ECRM allows new projects to be quickly prosecuted.

## ***2. Conduct and disseminate policy research relevant to cancer research that influences the political process***

While a few key groups have been founded by creative thinkers to shake up policy research the dominance of large, long-standing generic policy research organisations tend to discourage the formation of new organizations with new approaches. The ECRM is a virtual policy research group that has arisen out of the specific need for the cancer research community to engage with policymakers and set its own agenda. The Forum was created by a broad and inclusive group of prominent cancer researchers to produce evidence to support a wide variety policy issues. Key to this activity were two founding principles:

- All data collected should be placed freely in the public domain to promote co-operation in policy making
- All reports produced by the Forum should have a relevance to policymakers and should be disseminated in such a way as to have the maximum long-term impact.

## ***3. Cultivate a global policy research network for cancer research.***

The ECRM is building a new model in which networks of cancer researchers, representational bodies (ECCO, ECPC, Europa Donna, EFGCP, etc) and other policy research groups can be harnessed to provide intellectually rigorous analysis and insights to key cancer research policy issues.

Already the Forum has worked with a wide range of partners (EFGCP, FECS [now ECCO]), outside agencies (Evalumetrics – a bibliometric research group) and numerous key opinion leaders in the cancer research community to produce its two reports to date. There is a clear demand for such a policy approach in cancer research where networking across a broad range of expertise lends a high degree of credibility to the policy messages.

## **COMPETITIVE ANALYSIS**

To fully appreciate the power of the ECRM approach, it is important to view it in the context of other organisations that engage in similar activities.

In a review of over 45 policy research groups in Europe and the USA we have not found a single unit dedicated solely to cancer research, even such august bodies such C-Change in the USA have no dedicated policy support, instead relying on ad hoc support from the Institute of Medicine. However, it has taken an ECRM report to update funding and output figures for C-Change as their last policy research in this area was some ten years out-of-date. Whilst the American Cancer Society has a strong policy unit it's activities

nevertheless reflect the predominant mission of the charity, namely cancer services and outreach.

At the European level there are a number of politically affiliated and independent (but **for profit**) policy units. This include the RAND(Europe) Eurobarometer, and the Joint Research Centre (JRC) of the European Commission.

RAND (Europe) is a for-profit policy research organisation that, whilst having substantial methodological expertise particularly in healthcare systems does not have the in-depth knowledge of cancer research. Both Eurobarometer and the JRC cannot be tasked outside the Commission and so have little utility value for the cancer research community, furthermore the same critique applies to them as for RAND (Europe) namely their lack of expertise and networking in the cancer research community

A number of representational organisations for cancer research and control programmes have conducted policy research, for example FECS (now renamed ECCO) led on a study of the degree of harmonisation around Europe following the 'Clinical Trials' Directive (unpublished as yet). However, policy research has tended to be very *ad hoc* and no organisation currently has a dedicated policy research group or even mission statement. Industry in Europe and the USA are, naturally, better organised in terms of policy research and its dissemination. PhARMA (USA) and EPHIA (Europe) as representational bodies have both produced cancer research-relevant policy pieces but the main drawbacks of these groups are, a) only industry focused and b) by definition they are only concerned with a narrow range of issues (medicines) that effect cancer research.

Across Europe there are many policy research groups, particularly within the University system. Policy research units are also to be found embedded in charities and governmental systems. However, none of these operate at the European level nor do they often cover research issues being mostly concerned with service delivery issues specific to their geography.

# 2

## ECRM's Strategy and Projects

### THE ECRM STRATEGY

The ECRM's strategy is a distinctive blend of four elements -

**1** *A focus on policy issues directly relevant to the progress of cancer research*

The ECRM has focused on delivering two major reports into cancer research funding and outputs that have had a direct impact on policy-making at European and Member State level. This is the core of its activities and with its strategic partnerships in Europe, USA and more recently Australia and Canada will continue to be prosecuted. Currently the ECRM also has major projects in place on cancer centres and the impact of cancer research (on the media and clinical guidelines). The ECRM's governance structure allows further policy research issues can to be addressed in the future, e.g. cancer research mobility, the continuing impact of the 'Clinical Trials' Directive, impact of human tissue regulations, etc.

**2** *High quality information gathering, analysis and an open, transparent dissemination of data*

ECRM has distinguished itself by the collection of high quality information that can be fed into the policy analytical process. We work hard to avoid GIGO ('garbage in, garbage out'). We work with a network of key academic collaborators and in an iterative manner with cancer research leaders to shape the final policy documents. It is the founding principle of the ECRM that all data should be placed freely in the public domain and disseminated in a manner fit for policymakers and the research community. The ECRM will look to embrace other analytical tools and information sources in the next stage of its development, particularly around strategic intelligence. On the communication side the ECRM will look to develop, in partnership, policy documents for patient groups.

### *3 Embracing a network approach to policy research by working with leading international cancer researchers*

ECRM focuses explicitly on linking and working with a wide range of international members of the cancer research community from leading researchers, senior management, and policymakers in both industry and the public sector. This network has been developing since the ECRM's formation in 2001 and continues to grow with recent link-ups' to Australia and Canada. Key has been the direction setting and involvement of the cancer research community in the ECRM's work. We aim to improve this networking and strategic partnerships in the next stage by setting up dedicated, topic specific policy networks, for example as has already begun to happen informally around the impact of the 'Clinical Trials' Directive. Better outreach into the USA is also a key objective during the next stage of the ECRM.

### *4 Delivering the strategy through a low cost model with the minimisation of administrative "time-sink"*

ECRM has expressly built its organisation along minimalist lines, focused on a working model that utilises the minimum core administration whilst accessing the expertise of a network of collaborators in the research and policy community. The number of projects that can be run in parallel is highly dependent on funding, up to a limit of five projects at any one time. With development of e-communications (website, email, on-line journals such as e-cancermedicalsciences) dissemination costs can be kept low with real meeting-hard copy communication tools only being deployed for the most important policy presentations (anticipated to be one annually).

## COUNTERING STRATEGIC CHALLENGES

- **Funding.** One risk is failing to achieve a level of funding that sustains and expands the ECRM's work. We have addressed this by seeking unrestricted educational grants to maintain our core infrastructure which will allow us to seek larger project-related and capacity building funding in line with the ECRM's strategy
- **Quality Membership.** A second risk is failing to energise current Forum members and obtain the necessary high quality input to the analytical work so essential for the creation of good intelligence. We have mitigated against this by an up-front commitment from a wide range of senior members of the cancer research community and representational bodies, as well as national funders to supporting the continued work of the ECRM (letters of support available on request)

- **Substantive contribution.** A major risk is failing to incubate projects of a substantial content value to policymakers in cancer research. The ECRM has now completed two major funding reviews and whilst this is a core ongoing objective the Forum has diversified into other critical policy areas e.g. cancer centres, where substantial contributions can be made.
- **Strategic partnerships – maintaining a relevant network.** By its very nature the ECRM is the product of the collective of funders and cancer researchers who input data and critique to the Forum’s output. The ECRM has a strong history of collaboration – FECS (now ECCO), EFGCP, UICC etc – which it will continue. In addition further strategic partnerships will be sought within patient groups. As part of this business plan the ECRM is fully open to integration as a Policy Research Unit within major European organisations, subject to discussion on operating procedures and governance. In addition unrestricted, transparent strategic partnerships will also be forged with industry
- **Risks of a small team.** The core ECRM unit is very small with only two core staff. The work of the ECRM is structured in such a way that management and continuation would be possible by any organisation, group or individuals. Part of creating this business plan is to address the organisational weakness of long term planning and succession.

## RESEARCH PROJECTS AND EXPECTED POLICY CONTRIBUTIONS

The core of the ECRM’s work is the collection, processing and dissemination of global cancer research funding. This is a continuous activity as the new funders are identified through the Forum (see below). In addition the ECRM has a number of ongoing projects that have been identified as key policy areas by the Forum. The projects listed below are active. At the end of this group we have also identified other key areas that are at the development stage.

### *Identification of the Global Funding of Cancer Research*

We will begin to work with colleagues in Canada and Australia to create a full picture of their funding. In addition we are forging strategic partnerships in the Far East and creating new bibliometric approaches to assessing research funding (this is particularly challenging as most of their outputs are in country-specific databases). The overall aim of this project is to create a ‘live’ network of the major cancer research funders.

### *The Impact of Cancer Research: studies of the media and clinical guidelines*

There is increasing socio-political attention on demonstrating the impact of cancer research funding. Outside traditional metrics such as patients recruited to clinical trials and research publications there has been little research into

the wider public impact of cancer research. The media (printed, TV and website) are now a key conduit for the dissemination of research publications and other results (e.g. conference abstracts) into the public domain, however, almost nothing is systematically known about how and what the media reports in terms of cancer research stories.

An ongoing project is focused on a pilot Member State – the UK – and the major source for cancer research stories, the British Broadcasting Corporation (BBC). The BBC through its news website has a national impact and its syndication means that stories carried on its website are disseminated into other national and international media. The ECRM's longitudinal study (looking at the BBC archive from 1998 to 2006) will study the site-specific nature and type (e.g. lifestyle, drugs etc) of cancer research stories carried, as well as the origin of the research and key commentators.

We are also looking at different ways of analysing newspaper coverage of cancer research in European countries. There are two levels of coverage that might be considered: one of 8 papers in total (one each in France, Germany, Italy, the Netherlands, Spain, Sweden, Switzerland and the UK), and one of about 18 papers (one also from Austria, Belgium and Poland, and additional ones from France, Germany, Italy, Spain and the UK). This would cover a single year of coverage and two modes of operation. One is for the recorders to buy, or otherwise obtain access to, selected newspapers and then scan them for relevant items and record their details. The second stage is to read the story and record the basic data on a spreadsheet. The third stage is to try and identify the cited papers, which may be difficult and depend on clues obtained from other papers. The second mode is for the recorders to cross check an electronic database of newspaper texts to search for relevant articles.

Another area for demonstrating impact is the citation of research into clinical guidelines. One way in which biomedical research can be put into practice is through clinical guidelines, which are increasingly used to guide the most effective treatment for patients. In UK cancer service delivery there are 43 guidelines published to date, each of which has an evidence base in the form of references, many of which are papers in peer-reviewed journals. This pilot project aims to identify and analyse all these in order to determine their geographical provenance and type of research, in comparison with oncology research overall published in the peak years of guideline references (1999-2001).

Both these pilot impact projects, if successful will provide the methodology to role these out into other countries. The overall aim is to provide the research community with an suit of evidence to demonstrate impact in their efforts to lobby for cancer research funding.

***Cancer Research Productivity: a high-resolution study of UK trends from 1995 to 2004***

This ECRM project is a sub-part of a major investigation into cancer research outputs and the funding of cancer research in Europe. The UK is the only country in Europe that has high-resolution validated data on all non-commercial funding (by site and domain) through the Common Scientific Outline approach developed by the NCI. The outputs of researchers with at least one Welsh address are being compared with those in Scotland, in the UK as a whole, and world-wide. This study is looking at the relative level (how basic or clinical research publications are), impact factors and overall volume of publications.

With the devolution of the UK specific cancer research strategies are being developed in each country. This baseline study was designed to provide pilot the methodology for similar situations in other countries, e.g. Germany and provide data for high resolution studies of cancer research policy, funding structures and cultures in different countries.

***Cancer Research Centres in Europe and the USA: A Comparative Study***

There are widely different models of cancer research organization across Europe and the USA from centre-specific approaches to collaborative networks. The development of cancer centres has a long history both in the USA (through the National Cancer Institute) and Europe (mostly along Member State lines although an overarching European group – Organisation of European Cancer Institutes – does exist). Whilst there have been various *ad hoc* expert commentary on these models there is no systematic objective intelligence on the current state of any of these centres.

This project uses bibliometrics to provide objective data on the trends in size, productivity, research level and impact of all major cancer centres in Europe (n=92) and the USA (n=61) over a ten year period (1996-2005). In particular this major study is collecting data on –

- integer and fractional count annual outputs from each centre
- mean research level (RL) of the centres' outputs
- mean potential citation impact (PCI) of the centres' outputs, determined from the mean citation counts in a five-year window to papers in the journals used
- actual citation impact (ACI) of the centres' papers, based on a large sample of papers published in 2001 and cited in 2001 thru 2005
- distributions of the mean RL and mean PCI values for the UK, EUR and US centres in the ten individual years
- trends in the mean RL of UK cancer centres over the decade

- percentages of papers from each of cancer centres that are co-authored with foreign researchers, and with authors from the leading foreign countries (to study co-operation trends)

The data from this project will be the first definitive comparative review of Cancer Centres in Europe and the USA.

*The Economic Burden of Cancer in Europe (pending joint project with the University of Oxford)*

In economics, a cost or burden of illness study estimates the resources consumed in disease prevention, detection, and treatment. It aims to provide a potentially useful decision making aid for setting priorities in health care research. Cancers have an economic impact in the health care system, in family and friends who provide care for cancer patients, and on economic productivity because a large proportion of patients with cancer and the people who care for them would otherwise be in paid employment.

The primary objective of this study is to provide accurate economic costs of cancers for all the 27 countries of the EU (**the currently reported OECD figures are not accurate**) by including direct health care costs, informal care costs, and productivity loss, and to estimate the proportion of cancer costs due to the four main forms of cancer, i.e. lung, colon and rectum, female breast, and prostate.

*How this is different from current estimates used in policy circles?* Only 17 EU countries that are members of the OECD are currently covered. As a result 10 countries currently in the EU are not covered. This study would cover all existing 27 EU members. In previous work for Europe data from 8 countries (Germany, France, Netherlands, UK, Sweden, Czech Republic, Hungary and Poland) are used to calculate direct healthcare costs of cancer in the other EU members of the OECD. For example, it is estimated that the average proportion of healthcare costs devoted to cancer in the above 8 countries is 6.6%. This figure is then applied to all other European countries so as to be able to derive the total healthcare expenditure on cancer; in our study, we would estimate the healthcare expenditure on cancer, country by country, without using such assumptions, as countries can vary widely.

Furthermore, in this study we would clearly report, by country, how much is spent on each area of healthcare, i.e. primary care, outpatient care, inpatient care, pharmaceuticals etc..., reporting also the resource use for each healthcare category (e.g. number of hospital bed days due to cancer) and the unit costs for each resource category (e.g. cost per bed day). The Karolinska report mentions that not many studies estimate the indirect costs of cancer (i.e. losses due to early death or sickness). Our proposed study would not only estimate these indirect costs for each of the 27 countries, but would also estimate the informal care costs associated with cancer (i.e. the costs associated with friends and family caring for cancer patients). Finally, the Karolinska report uses data from different studies, using different methodologies, to estimate

cancer costs. As a result, comparisons between countries are difficult. In our study we will use the same methodology across countries, which will enable better comparisons on, for example, how much of a country's health care budget is devoted to cancer.

**Impact of the 'Clinical Trials' Directive.** This project continues the work started in 2004 to collect impact data on the European 'Clinical Trials' Directive<sup>4</sup>. Of all regulations this Directive has had the most deleterious effect on non-commercial and commercial clinical research in the EU. Cancer has been particularly affected and all current policy data on the impact of this Directive is derived from oncology studies. This project will collate and analyze data already collected by a previous, but unpublished FECS study. In addition we will repeat high-resolution studies for two-four Member States using the same methodology that we have previously published on.

**Access to oncology drugs: are current registration and economic assessment strategies failing patients? A comparative study of the USA and EU systems.** The pricing and health economic assessment of oncology drugs and other health technology interventions are major current policy issues. However, there has been almost no policy research into the industrial strategies around the timing and filing for registration and subsequent health economic assessments. This small project will look at these strategies for a range of oncology drugs (n=21) and companies.

**Global Surgical Cancer Research, with a special emphasis on Breast Cancer**  
This study examined the outputs of papers in two subject areas within cancer research, namely cancer surgery and breast cancer for the ten years, 1996-2005. This study, in conjunction with a broader social review will collect and analyze data on:

- numbers of papers per year in surgical cancer research (and specifically on breast cancer), and comparison of growth with that of all cancer research and of biomedical research overall.
- outputs of the leading countries, using fractional counting.
- their relative commitment to research into cancer surgery, compared to their outputs of cancer research.
- the research levels of the cancer surgery papers from different countries, based both on individual paper titles and on the titles of all papers in the journals in which they were published
- the potential citation impact of the papers from different countries, based on the mean citation scores of papers in the journals in which they were published in a five-year time window.

### **Role of Funding and Policies on Innovation in Cancer Drug Development**

The global organisation and funding of cancer research follows many different models. The global flow of knowledge, innovation, research and

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<sup>4</sup> published by Sullivan R and Hearne J in *European Journal Cancer* 2007, 42: 8-13.

development has dramatically increased the complexity of cancer research. Since the mid-1950's anti-cancer drug development has become the dominant area of cancer research. The clinical need to find drugs to prevent cancer, suppress recurrences (adjuvant), downstage tumours for surgery (neoadjuvant), treat metastatic disease and palliate has driven the development of new molecular entities be they chemicals or biologicals. However, the vast complexity of this nexus coupled to the widely different paradigms that appear to operate across Europe, USA and the Far East do not easily lend themselves to strategic analysis. In particular what models of funding and management have, or have not been successful. What is the most efficient, creative and innovative model for public-industry cooperation and collaboration. What policies should Europe be developing to support drug development in cancer, and to whom should these be directed (government, NGO's etc)

The aims of this project which is a collaboration with LSE Health and has an unrestricted educational grant from Novartis are to map out the current funding and management structures for cancer drug R&D in Europe and the USA, with particular reference to the public-private interplay, and following a review of current strategies put forward new policies to improve cancer drug innovation.

# 3

## Organisational Model and Team

### ORGANISATIONAL MODEL

The ECRM was originally formed in 2001 with a small grant from the 5<sup>th</sup> Framework Programme and following its subsequent hosting by the UK charity, Cancer Research UK is now an independent not-for-profit Foundation dedicated to open evidence-based policy-making in cancer.. The ECRM runs an academic model with public benefit policy research that is made unconditionally and freely available. Depending on the future financial support the ECRM would be able to formally establish a not-for-profit incorporation, however, the principles of unrestricted policy research and dissemination would be inviolable.

### ECRM Directors and Board of Advisors

The ECRM was created and launched by Prof Richard Sullivan as Chair with Mr Seth Eckhouse MPH as Chief Project Officer with a diverse Board including, Professors Luigi Chiecho-Bianci (Italy), Kenneth Nilsson (Sweden), Francoise Meunier (EORTC), Elias Castanas (Greece), Brian Moulton and Helga Ogmensdottir (Iceland and EACR).

Following the publication of the ECRM's first report in 2005 the Board was formally dissolved and an Advisory team was put in place during the work on the second report published this year (Sept. 2007). The future governance structure will continue to evolve. At present core policy lead is Prof Richard Sullivan with Mr Seth Eckhouse now as Director. In addition there is a interim advisory board composed of Professors Kenneth Nilsson (Sweden), Gordon McVie (UK/Italy) and Brian Moulton (Ireland)

Over the next year the Foundation will create a permanent advisory board.

### TEAM

The ECRM has built up a major network within the cancer research community and cancer research managers in governmental / non-governmental funding organisations (detailed in recent ECRM Report).

# 4

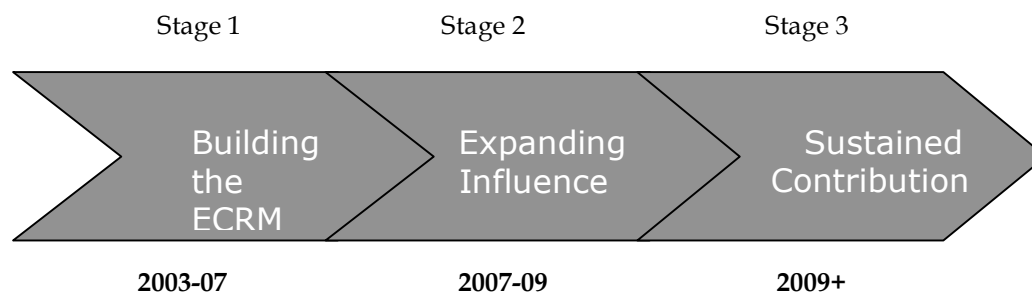
## Growth and Financing Plan

The ECRM has built itself in three distinct phases. Originally founded with a grant from the European Framework Programme under the leadership of a broad advisory board the ECRM has delivered credibility and performance through the completion and launch of two major funding and output policy projects, both of which have had a high media and policy impact. In addition during the building phase the ECRM has also initiated important new projects around the impact of cancer research (particularly in clinical management guidelines and the media) and a major project to analyse cancer centres in Europe and the USA.

This section sets out the ECRM's goals, policy deliverables and indicative budget that it is seeking.

### THREE STAGES OF GROWTH (2001-2009+)

ECRM breaks down its development into three key stages from inception to sustained activity. Within each stage there are three key areas of growth – Research, Outreach and Finance. Below is a brief overview of ECRM's growth and development strategy, with goals and objectives outlined for each stage.



<b>Stage 1: 2003-2007</b>		<input type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <i>None Partial Complete</i>
<i>Building the ECRM</i>		
<b>Strategic Gaols</b>	<b>Progress</b>	
<ul style="list-style-type: none"> <li>•• <b>Research:</b> deliver major policy documents on the funding &amp; productivity of cancer research</li> <li>•• <b>Outreach:</b> establish strategic partnerships with European funders, and representational groups</li> <li>•• <b>Finance &amp; Institution-Building:</b> solidify membership base and representatives from cancer funders, organise advisory board &amp; project committees</li> </ul>	<input checked="" type="radio"/>   <input checked="" type="radio"/>	<input checked="" type="radio"/>   <input checked="" type="radio"/>
<b>Operational Objectives</b>		
<ul style="list-style-type: none"> <li>•• Establishment of a website</li> <li>•• Provide all data in open access freely available manner</li> <li>•• Present ECRM findings at 4 major conferences</li> <li>•• Engage other strategic groups through collaborative projects</li> <li>•• Determine programme of policy research activities beyond stage 1</li> </ul>	<input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/>	<input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/>

<b>Stage 2: 2008-2009</b>		<input type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <i>None Partial Complete</i>
<i>Expanding Influence in the Cancer Research Policy Community</i>		
<b>Strategic Gaols</b>	<b>Progress</b>	
<ul style="list-style-type: none"> <li>•• <b>Research:</b> increase ECRM project portfolio particularly around key strategic areas such as clinical trials and cancer centres</li> <li>•• <b>Outreach:</b> establish key strategic partnership on policy matters, and expand into providing policy support for patient groups</li> <li>•• <b>Finance:</b> Pursue unrestricted grant funding to support ECRM for next stage of development.</li> </ul>	<input checked="" type="radio"/>   <input checked="" type="radio"/>	<input checked="" type="radio"/>   <input type="radio"/>
<b>Operational Objectives</b>		
<ul style="list-style-type: none"> <li>•• Improve website with development of policy area (including strategic links to European Observatory and other key European partners)</li> <li>•• Hire additional support of analytical work around cancer centres</li> <li>•• Implement a regular schedule of publications, meetings and policy op-eds</li> <li>•• Solidify ECRM's international ties and develop relationships with cancer research funders in Far East</li> </ul>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>

<b>Stage 3: 2009+</b>	
<div style="border: 1px solid black; border-radius: 10px; padding: 5px; display: inline-block;"> <input type="radio"/> <input type="radio"/> <input checked="" type="radio"/>  <i>None Partial Complete</i> </div>	
<i>Sustained Contribution</i>	
<b>ECRM aims to provide public policy support to further and support cancer research through a non-traditional think-tank approach</b>	
Strategic Goals	Progress
<ul style="list-style-type: none"> <li>•• <b>Research:</b> Host a major cancer research policy symposium within a major EU and / or USA cancer research conference. Deliver 3<sup>rd</sup> <b>global</b> cancer research funding and productivity policy report</li> <li>•• <b>Outreach:</b> establish comprehensive strategic alliances out of cancer area and with other research areas</li> <li>•• <b>Finance:</b> Reduce volatility of short term planning through acquisition of major grant funding.</li> </ul>	<input type="radio"/>   <input type="radio"/>  <input type="radio"/>
Operational Objectives	
<ul style="list-style-type: none"> <li>•• Ensure that ECRM provides full policy support across all relevant areas</li> <li>•• Continue to conduct high impact policy projects, including re-audit of previous projects.</li> <li>•• Demonstrate that ECRM has delivered tangible policy impact through funding and / or changes to regulations.</li> </ul>	<input type="radio"/>  <input type="radio"/>  <input type="radio"/>

## INDICATIVE BUDGET

As a non-profit group the ECRM operates through grants and donations for its work. In return it offers high quality work and tangible association benefits that can be fitted to the aspirations and requirements of the funder. However, the principle *modus operandi* of the ECRM – to provide free, independent, transparent policy research in cancer – remain inviolable. The Foundation will consider specifically funded policy projects as long as they fall within the frame and principles of its work

The Forum seeks as a core budget £67, 752 (EURO 97,274), **for each fiscal year**. A typical budget breakdown is given below.

Budget Line*	Cost (£, per month)	Cost (£, per year)	Comments
Salary	3,500	32,000	<i>Includes all on-costs (at 14.5%) for 1.2fte. 1fte to support Chief Project Officer and 0.2fte clerical support.</i>
Travel & Meetings (inc. conferences)	500	7,000	<i>Registration fees, travel and accommodation for AACR, ASCO, ECCO, and 3 invitation countries</i>
Post & Office	171	2,052	<i>General office supplies: fax, printer, etc.</i>
IS	258	3,100	<i>Fees for Combined Media website hosting, update and development</i>
Communication	150	1,800	<i>Land lines and mobile communications (inc internet connectivity)</i>
Special Projects		8,000	<i>Fees for bibliometric / OECD database access for specified projects (centres and impact) &amp; analysis</i>
Hosting Policy Meetings		3,800	<i>Hosting one major Policy meeting per year to launch one major study (inc. printing costs)</i>
<b>Total (per annum)</b>		<b>67,752</b>	

\* Budget for 2008 is based on actual costs for fiscal years 05/06 and 06/07 phased equally over 12 months. The core budget will support the ongoing projects into cancer centres and impact studies which will be delivered in the next year. **However, additional funding are also being sought for the following add-on projects over the next year (2008/09):**

Project	Total Project specific costs (£)	Comments
Economic Burden of Cancer in Europe	27,000	<i>Collaboration with University of Oxford.</i>
Impact of the 'Clinical Trials' Directive	7,500	<i>Additional databases access costs. Collaboration with major EU law firm</i>
Global Surgical Cancer Research	4,300	<i>Costs for database access</i>
Trans-European media study	32,000	<i>This is a one year study purchasing access to databases and utilising pre-graduate students to review newspapers</i>
<b>Total</b>	<b>66,800</b>	