



Eurocancercoms

A Two Year FP7 Project
(**Coordinating Action**) of the
European Commission



**euro
cancer
coms**



The Need



- Europe has an increasing number of cancer patients, due to aging
- Europe has poorer outcomes for care despite better research output than the USA
- Outcomes (eg survival) are unacceptably variable in different countries
- Poor communication is blamed for all the above (Eurocan study for the EU Parliament, 2008.)

Purpose



- To establish one efficient communications for all those involved in cancer
- (“a EuroGoogle-cancer”!?)
- Wolfram Alpha for Europe?
- (a “one stop shop “ for all cancer customers!?)
- (a dedicated SkyEuroTV, multimedia, website linked, interactive BigC network?)

Key Players

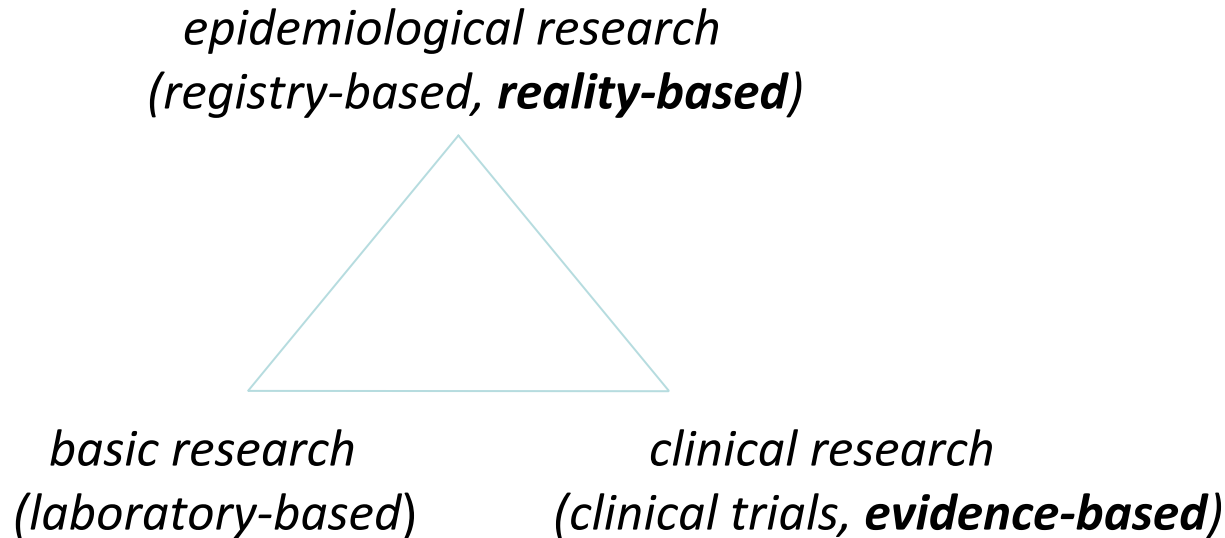
- Basic Researchers/academia and industry
- Clinical Researchers/ ditto
- Clinical Professionals, inc Public Health
- Funders/charity, govt, industry
- Publishers, established and online
- Media/ paper, internet, TV
- Public and patient



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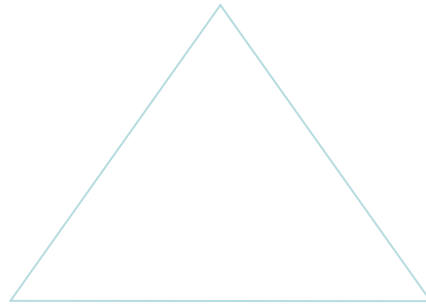
The triangle of translational research:



A comprehensive cancer center should perform high quality research on basic, clinical and epidemiological research. Broad field disease registries with inclusion of several quality registries should preferably be located in close relation to solid clinical and basic research milieus, - representing the third corner in the triangle of translational research.

The triangle of translational research: FUNDING

epidemiological research
Govt, charity

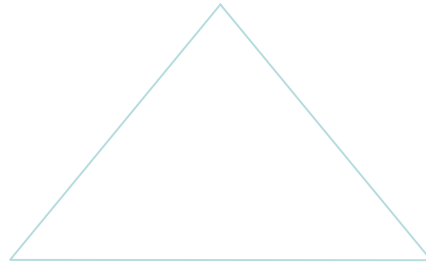


basic research
Govt, Pharma

clinical research
Pharma, Charity, Govt

The triangle of translational research: Communication of Results

epidemiological research
(Specialist journals, paper, delay 6m English)



basic research
(Nature, Cell..paper
delay 6m, English)

clinical research
(JCO,Lancet, NEJM, EJC Annals,
paper Delay 6m, English)

At no point does anyone communicate with the public or patient!!!

Their news comes from non paper source, minimum 6 m late

The first 3 languages in Europe are Russian, then German, then English

ALL science from Govt and Charity is paid directly by the public

Latest Internet Usage (New Statesman 2 May 2009)

- From 2004 and 2008 (figures in millions)
- USA 202 and 220
- China 87 and 253
- Germany 47 and 53
- UK 35 and 43
- Brazil 14 and 68

Barriers to Communication

- Self interest/careers, promotion (researchers)
- Profit (industry, researchers, charity, govt)
- Protectionism (societies, Pharma, institutes)
- Self promotion (researchers, charity, politicians, industry)
- Language/ sector specific (all parties!)
- Language/ 67 different languages spoken in EU
- Social/ (education status, elderly, children, deprived, displaced)

Plan



- Two groups of working groups
- One is the provider (professional societies in research and care, Industry, public health) plus the consumers. They define the issues
- Two is the technical team (internet, grid, TV, media, publishing) and the policy experts. They provide the solution(s)



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GE Healthcare



BRANDCASTMEDIA

LONDON MADRID



PHILIPS

www.ecancer.eu





British Lions

4 countries = 1 team
(Wings, centres, half
backs, hookers, props,
locks, flankers)

Barbarians

22 countries = 1 team





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Principal Investigator
Prof. Veronesi
European Institute of
Oncology



WP1
Project Management.
IEO, ECCO, ecaner

Independent
Ethical Committee
Prof G Boniolo

Coordinator 1
Scientific Process.
ECCO

Coordinator 2
Scientific
results' dissemination
and publishing.
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WP2
Communications
between basic
scientists.
EACR

WP3
Communications
from translational to
clinical and
epidemiology.
EORTC

WP4
Assimilation of
results for guidelines
and health care
delivery.
ECCO

WP5
Dissemination of
relevant results to
patients and families.
OEIC

WP6
New technologies for
dissemination to all
consumers.
ecancer

WP7
Policies required for
optimal
dissemination of
cancer science.
ECRM

Tools and Methods



- Questionnaires (online)
- Open debates (online)
- Surveys of researchers' issues (basic, clinical and care delivery)- in academia and industry
- Surveys of patients' and family' issues (NGO's)
- Scrutiny of existing publication/comms issues, conventional and virtual
- Testing new solutions using ecancer as testbed
- Consensus forming on policies needed to improve future developments

WP 1 Project Management

IEO



- Report on status of research publishing in Europe and internet use by those stakeholders in the cancer science process
- Demonstration of a portal for optimal dissemination of cancer science information throughout Europe.
- Report at 12 months and final report at 24 months, preceded by a large open public presentation of the findings of the CA.
- Ethics final report

WP 2 : Science Information Flow

EACR

- Position paper on current use of communication systems, barriers to such use and proposed solutions
- Report on influence of funding agencies including industry on reporting of science, at whatever stage, in journals and media.



WP 3: Dissemination of Findings of Science EORTC

- Inventory of cancer research databases and their usage, including clinical trials and access to them.
- Report on barriers and solutions to communication of translational research findings, clinical trials and epidemiological studies with particular focus on childhood cancer and aged, infirm, socially deprived and ethnic minority patients
- Report on cancer professionals' accreditation across Europe and proposal to overcome this barrier to creation of a virtual forum across Europe



Issues for Industry/ ESMO

- Suppression of 80% research output
- Suppression of negative data
- Influencing researchers/institutes
- Influencing clinicians
- Influencing patients and advocacy groups
- Influencing govts
- Failure to get their message across

WP 4: Consensus Forming and Application ECCO



- Report on current groupings, producing guidelines at local, regional, national and international level and analysis of methods of consensus forming in oncology.
- Recommendations on patient and consumer involvement in consensus and guideline processes.
- Proposals for improvements of methodology of implementation of evidence based cancer medicine .
- Report on communication of ‘risk’ particularly relating to early clinical trials, genetic data and familial cancer.

WP 5: Current Use of IT, its Deficits and Ideal Solutions OECI

- A consensus position statement from patients and consumer groups on their information needs, and their ideal vehicles with which to access that information.
- Report on accuracy of information accessed by health professionals, patients, consumer groups and industry, and credibility of different sources.
- Publication on degrees of uptake of new multimedia sources by stakeholders.



WP 6: Exploiting New Technologies to Meet the Challenge ecancer



- Report on current informatics technologies, in industry and academia which could facilitate fast, comprehensive and secure cancer information dissemination.
- Mock-up portal of a one-stop-shop on ecancer.eu, legally competent, ethical and capable of portraying understandable, relevant content and signposting to all desired locations to satisfy consumers across Europe.
- Recommendations for optimal use of electronic support by scientists in Europe, and cancer patients and their carers, addressing ease of access, language, ease of interactive communication and online toolkits for self help.

WP 7: Policy Recommendations

ECRM

- Recommendations on Open Access publication of all scientific data funded in the public or private sector, costs, fraud, conflict of interest, impact factor issues and Peer Review.
- Policy paper on strengthening confidence of consumers in the reliability, understandability and applicability of cancer science data.
- Policy paper on e-integration and e-dissemination of relevant information from funders of European cancer research to enhance mobility of scientists and clinicians, and to facilitate all trans European projects
- Publication on defects of existing European cancer research policy, and recommendations for improvements in areas such as confidentiality of data, human rights, storage of human tissue, and entry into clinical trials with no apparent benefit for volunteer patients, and other relevant ethics issues.





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