

# Implementing together the long term sustainable childhood cancer plan

Gilles Vassal  
CCI, Malmö 2015

## Childhood cancer survival in Europe 1999–2007: results of EUROCARE-5—a population-based study

Gemma Gatta, Laura Botta, Silvia Rossi, Tiit Aareleid, Magdalena Bielska-Lasota, Jacqueline Clavel, Nadya Dimitrova, Zsuzsanna Jakab, Peter Kaatsch, Brigitte Lacour, Sandra Mallone, Rafael Marcos-Gragera, Pamela Minicuzzi, Maria-José Sánchez-Pérez, Milena Sant, Mariano Santaquilani, Charles Stiller, Andrea Tavilla, Annalisa Trama, Otto Visser, Rafael Peris-Bonet, and the EUROCARE Working Group\*

Lancet Oncology, December 2013

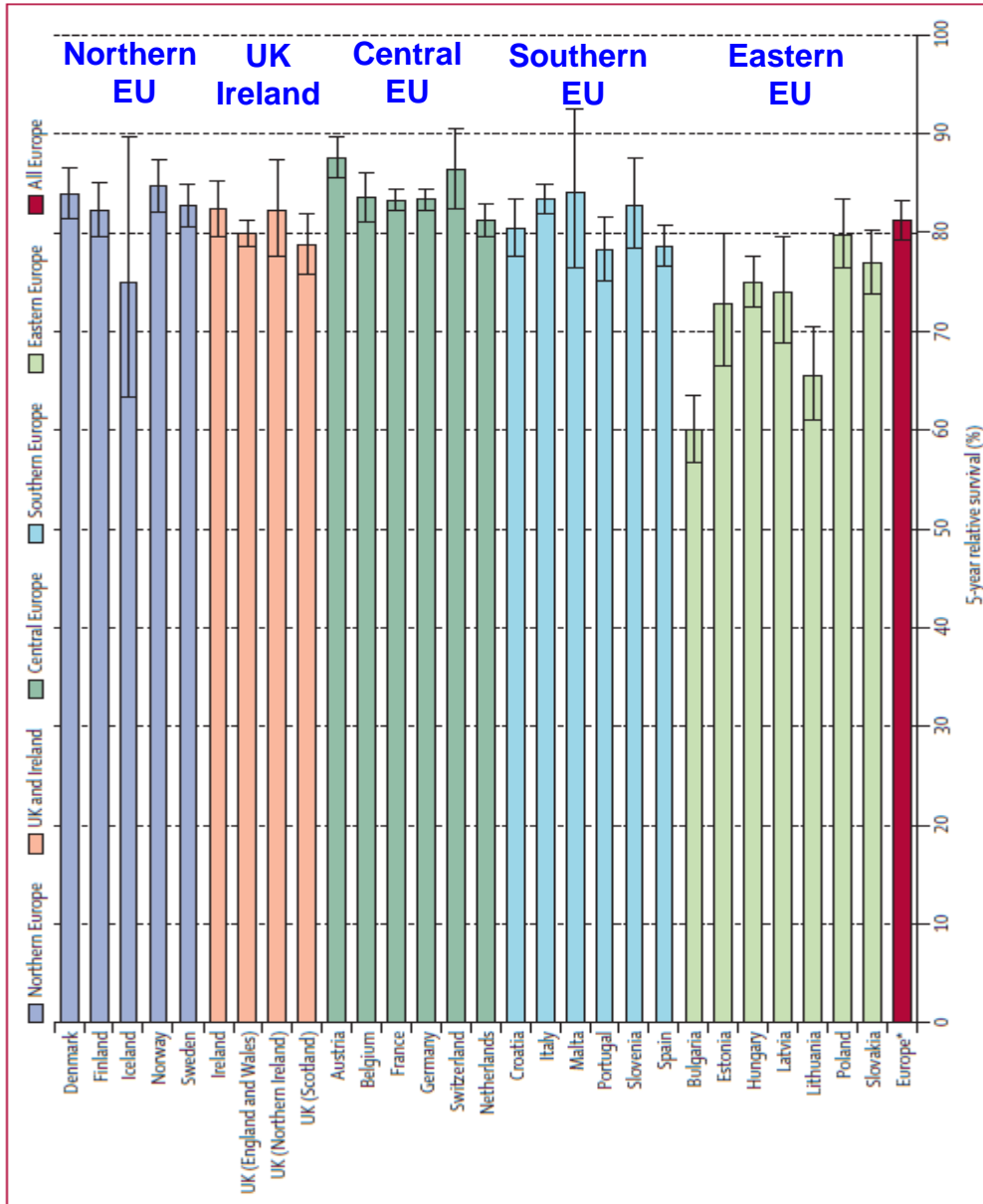


Figure 3: 5-year survival for all cancers combined (CNS tumours excluded) diagnosed in 2000–07 in children, by country. Includes data for 50 080 cases. Data adjusted for age, sex, casemix, and period of diagnosis. \*Country-weighted.

- **Inequality:** 10% to 20% less in survival at 5 years across Europe
- Little progress in difficult-to-treat diseases over the last 10 years
- 2/3 survivors have long – term effects

EU countries are missing eg Bosnia Herzegovinia

79 registries in 29 countries

## EU Cancer Research for children and adolescents

### The Roadmap to the horizon 2020

durable joint structure – long term sustainability

## 7 medical and scientific objectives

- To increase cure rate in poor prognosis malignancies
- To increase quality of life (cure) in survivors

To tackle inequalities



# The 7 Horizon 2020 objectives

1. Introduce **innovative treatments** (new drugs, new technologies) in multidisciplinary standard care
2. **Precision medicine** in healthcare  
Driving therapeutic decision by improved risk classification and use of molecular characteristics (tumour, patient)
3. Increase **biology knowledge** on pediatric tumors
4. Increase **equal access** across Europe to standard care, expertise and clinical research
5. Address the specific needs of **teenagers and young adults** jointly with adult oncology
6. Improve **quality of survivorship**
7. Understand the **causes of pediatric cancers** and set up prevention where possible

**No ranking – objectives have equal importance and weight**

# SIOPE-ENCCA Conference 2014

18-19 September 2014, Brussels

Joining Efforts for a Brighter Future for Children and Adolescents with Cancer - The European Roadmap to Horizon 2020

**Paediatric Haematology Oncology:  
the European Roadmap  
to Horizon 2020**

September 2014

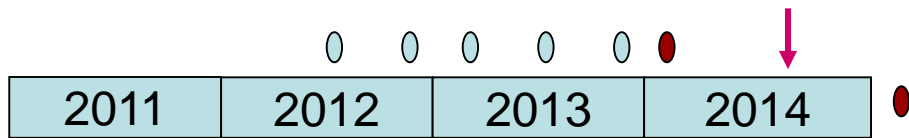
**A European Childhood  
Cancer Plan**



- Approx. **160 participants**
- From **31 countries**
- Multistakeholder event:
  - Parents/patients/survivors
  - Industry
  - Charities
  - Research/Academia
  - Regulators
  - EU decision-makers

<http://www.siope.eu/wp-content/uploads/2014/05/Paediatric-Haematology-Oncology-The-European-Roadmap-to-Horizon-2020.pdf>

# Conference



Working Group (5 meetings)

Presentation/discussion to  
EFCTGs, PPAC ENCCA, ECRC,  
SIOPE GA, ICCPOEurope

**Draft 1** – 7 medical and scientific objectives  
(august 2014)



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Children and Adolescents with Cancer -  
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  - EU decision-makers

Launched at the  
European Cancer Congress  
Vienna 2017

ENCCA/ECRC meeting  
15 January 2015

Validation

**December 2014**  
Scientific Advisors, ENCCA, ECRC

**Draft 2** – including actions, platforms,  
Programms (october 2014)

# Cross tumors platforms and programs

- Clinical research platform to **facilitate implementation of ECTGs research** strategy within the new regulation
- Clinical epidemiology program for outcome research  
– The **PICORET project**
- Quality Assurance in radiotherapy program  
– The **QUARTET project**
- **Multistakeholder platform** for new oncology drug development – (CDDF – ITCC – SIOPE – ENCCA)
- **Ethics and Social Sciences** programm
- **Oncopolicy** programm
- European IT platform ( & EUPID)



- the European Society of Paediatric Oncology
- care, research and training in paediatric haematology oncology as well as oncopolicy.
- **Mission:**
  - To coordinate the implementation of the European agenda/roadmap in research, care and education
  - To steer integration and facilitate funding
  - To ensure that the European legislative process facilitates this agenda
  - To strengthen partnerships with all stakeholders



# Long term sustainable strategic plan

## The Roadmap to Horizon 2020 and beyond

### Implementation

## Objective:

Increasing equal access across Europe to standard care, expertise and clinical research

Health is a member state competence



## European Expert Paediatric Oncology Research Network for Diagnostics and Treatment



**(Q4 2015 Call)**



Towards reducing inequalities: European Standards  
of Care for Children with Cancer<sup>☆</sup>



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<sup>f</sup> Institute of Child Health, University College London, UK

## Population Improvement in Childhood Cancer outcome through Research, Evaluation and Training

- Monitor and evaluate progresses
- Use real world data captured through registries and observational studies that apply to standard therapies
- Renal tumors, Neuroblastoma, Medulloblastoma
- Standardised clinical guidelines
- Standardisation and Quality
- Twinning program
- Infant dosing
- Data privacy
- Impact assessment

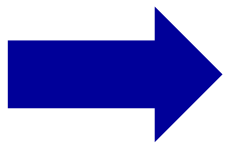


Submitted April 21st, 2015

# QUARTET

## Quality Assurance in Radiotherapy

- To improve the quality of radiation therapy (both efficacy and long term effects)
- To build a cross tumor program for online Quality assurance in Radiotherapy for children and adolescents participating in trials



**The QUARTET project  
In collaboration with  
EORTC  
575 patients per year**

**Tom Boterberg (Belgium)**

Geert Janssens (The Netherlands)

Yasmin Lassen (Denmark)

Henry Mandeville (UK)

Kristina Nilsson (Sweden)

Giovanni Scarzello (Italy)

Gilles Vassal (France)

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Rolf-Dieter Kortmann (Germany)

Karin Dieckmann (Austria)

Hans Merks (The Netherlands)

Kieran McHugh (UK)

Stefaan Van Gool (Belgium)

# Ethics and social sciences programm

JC Dupont

## 4 Topics

- **Return of research results.**
- **Personal data in care and research environments.**
- **Access to medical innovation.**
- **Care and healthcare pathways.**

## Principles

- **Objective assessment of the non-technical issues tied to the care and quality of survival of children and adolescents with cancer**
- **Community-based participatory research (CBPR)**

EUROPEAN COMMISSION  
DIRECTORATE-GENERAL FOR HEALTH AND FOOD SAFETY



Public health

**Programme Management and Diseases**

## An action on Rare Cancers in the European Union: A possible Joint Action in the framework of the EU Health Program

- In discussion

**Objective:**

**Improve quality of survivorship**



# Survivorship and long-term follow up



## The survivorship passport:

- summary of medical history
- Recommendations for follow up (breast cancer, cardiomyopathy)
- Collecting information



## Pancarelife and Pancersurf

- Evaluation of long-term sequellae
- Genetic risk
- Guidelines for follow up

2015 - 2020

## Passport

- Recommendations
- Implementation

## Model(s) of care

## Objective:

Introduce innovative treatments in  
multidisciplinary care

Access to innovation  
in the relapse and newly diagnosis setting

# Better access for patients

- Increase patients access to innovative therapies across Europe
  - Increase the number of trials
  - facilitate referral of patients to investigating centres
- More than one out of 2 patients with non curable relapse in ITCC centers has access at least to one new drug
- Speed up innovation

# The Innovation and PCM program

**1. A tumor molecular profile for patients at relapse**

Whole Exome and  
RNA sequencing  
methyloome/immuno

**Molecular Matching Trials**

**M  
A  
T  
C  
H**

**2. Match treatment and tumor molecular profile**

Clinical trials  
New agents  
Single agent or  
combinations

**SHARE**

**EU Clinico  
Biological  
Data Base**

**Pediatric  
New  
Drug  
Development**



**With ECTGs**

**3. Generate new knowledge, new druggable pathways**

# The ITCC PCM program

## 1. Generate individual molecular information

### Molecular Matching Trials

#### MAPPYACTS

(France, Spain, Denmark, Italy)

INFORM (Germany)

iTHER (Netherland)

COMET (UK)

M  
A  
T  
C  
H

## 2. Match treatment and tumor molecular profile

Phase 1 Trials (industry and ISTs)

Phase 2 Trials (industry and ISTs)

Genentech Roche  
Matrix Trial

eSMART trial

IST multi-agent from multi-company

European Proof-of-Concept Therapeutic Stratification Trial of Molecular Anomalies in Relapsed or Refractory Tumors in children (ESMART)

SHARE



With ECTGs

EU Clinico  
Biological  
Data Base



Pediatric  
New  
Drug  
Development

Submitted April 21st, 2015

3. Generate new knowledge, new druggable pathways



# eSMART trial

A multi-agent from multi-company IST

**European Proof-of-Concept Therapeutic Stratification Trial of Molecular Anomalies in Relapsed or Refractory Tumors in children (ESMART)**

15 to 20 innovative compounds

From  $\geq 3$  pharmaceutical companies

Phase 1 / 2 trials, including combinations

Enriched through WES RNA sequencing

250 patients in 3 years



# Multistakeholder Paediatric Oncology Platform



Created in Dec 2013

- Goal: To improve oncology drug development for children and adolescents
- Principle : **ALL stakeholders**
  - Academia, Industry, Parents, Regulatory
- Objectives:
  - Prioritisation
  - MOA/Biology – driven development
  - Changes in the regulation
  - New incentives
  - Long term follow up measures







# Oncopolicy Programm

## Regulations and Directives

- Cross border healthcare Directive - implementation
- Clinical trial regulation – implementation
- Pediatric Medicine regulation – revision 2017
- New : incentive for specific pediatric medicines
- Data protection directive – being prepared
- Joint Action Rare Cancers – being prepared

Signing  
the clinical trials  
regulation



# Mobilizing ALL stakeholders for co-funding



National  
Grants

Industry

Charities

**Funding projects AND structure**



Childhood  
Cancer  
International

Europe Region Committee



ICCPO ([@IntChildCancer](https://twitter.com/IntChildCancer))

09/05/14 18:32

@SIOPEurope We both can't do it alone. The alliance of SIOPE and ICCPOE

is the key to improve ped.onc care and research all over Europe.





Childhood  
Cancer  
International

Europe Region Committee

## Memorandum of Understanding

SIOPE and CCI Europe Regional Committee wish to enter into a **co-operative relationship** in order to **implement the established European long-term strategic plan** and to **raise awareness** on cancer in children and adolescents.

- **Areas of cooperation**

- Social sciences and ethics
- Access to standard of care and expertise
- Improvements to the regulatory and political environment at the pan-European and national level
- Research and development (R&D)

**Save the Date**  
25 - 29 September 2015



**ECCO 18**

18<sup>th</sup> ECCO - 40<sup>th</sup> ESMO  
**European Cancer Congress**  
*Reinforcing multidisciplinary*  
VIENNA, AUSTRIA, 25 - 29 SEPTEMBER 2015

**ESMO 40**

ESTRO ESMO 35 EACR SIOPE

[www.ecco-org.eu](http://www.ecco-org.eu)

**Why join ?**

- Benefit from the special SIOPE member registration rate
- Discuss innovative approaches and their implications
- Gain new insights in every area: from genetics to survivorship
- Enhance young oncologists' expertise for future practice & career development
- Get an all-access pass to comprehensive multidisciplinary sessions

**Paediatric Oncology Track  
@ ECC, Vienna, Austria**

**SIOPE**  
SIOPE Europe  
the European Society for Paediatric Oncology

**European Cancer Congress 2015**

**See you in Vienna!**



**Track Chairs**

Gilles Vassal	Paediatric Oncology
Stefan Bielack	Paediatric Oncology
Karin Dieckmann	Paediatric Oncology
Martin Schrappe	Haematology
Pamela Kearns	CT & Regulatory

**Experts**

Christian Carrie  
Angelika Eggert  
Andrea Ferrari  
Daniel Kelly  
Ruth Ladenstein  
Andy Pearson  
Claudia Rossig  
Dan Stark  
David Walker

**encca**  
European Network of Cancer Centres & Clinics in Paediatrics

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# European Cancer Congress 2015

Vienna  
25-29 september  
2015