



# World Cancer Leaders' Summit

.....  
**2015**  
.....

17 - 18 November | Istanbul, Turkey  
Effective International Collaboration

# Breakout 1 - Blue

*‘Overcoming the challenges of cross border collaboration’*

- > Co-hosted by Cancer Research UK (CRUK) and World Cancer Research Fund International (WCRF)



World Cancer  
Leaders' Summit

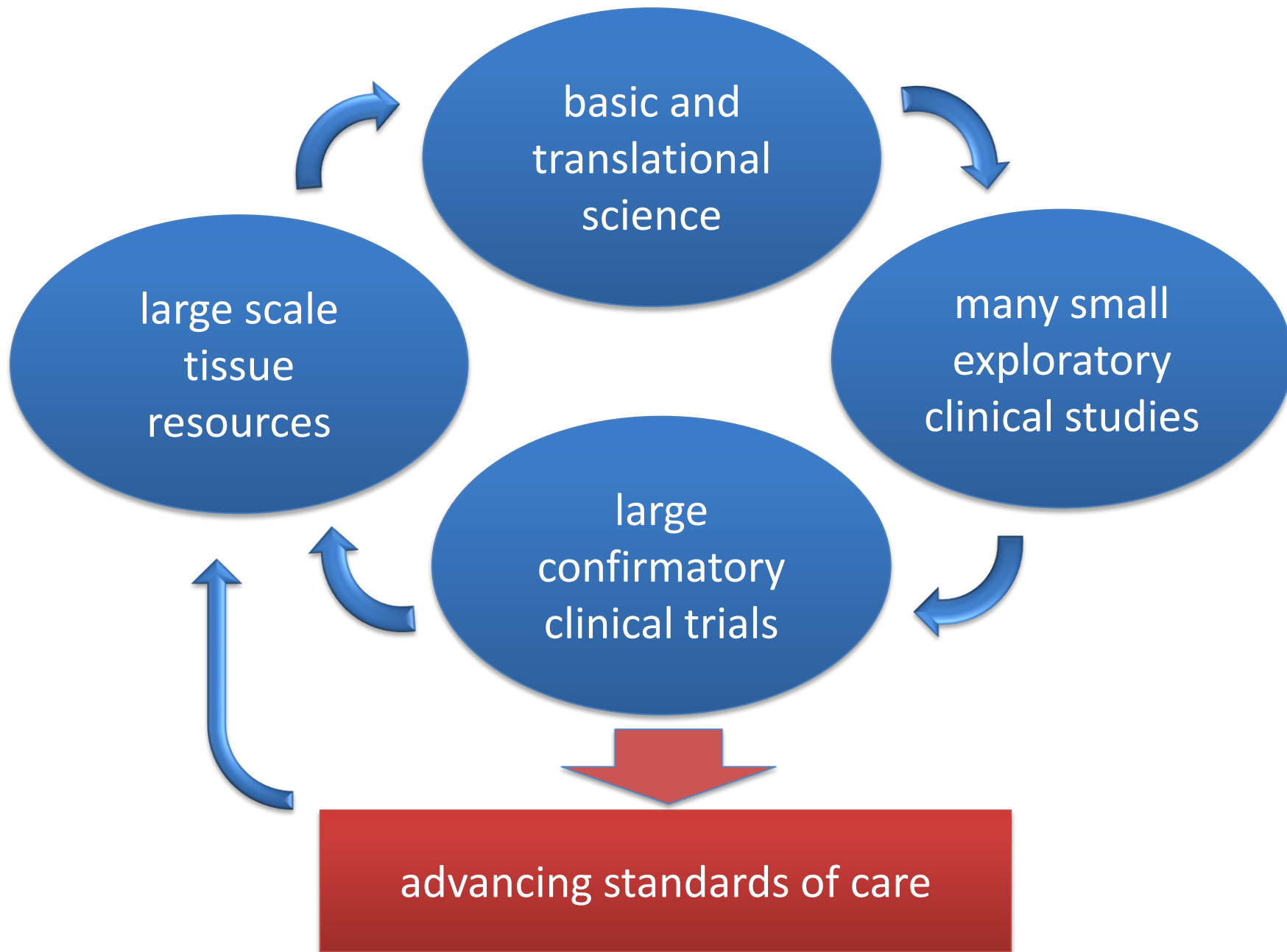
# IRCI

## International Rare Cancers Initiative

a global partnership for rare cancer research

UICC World Cancer Leaders' Summit  
18 November 2015, Istanbul

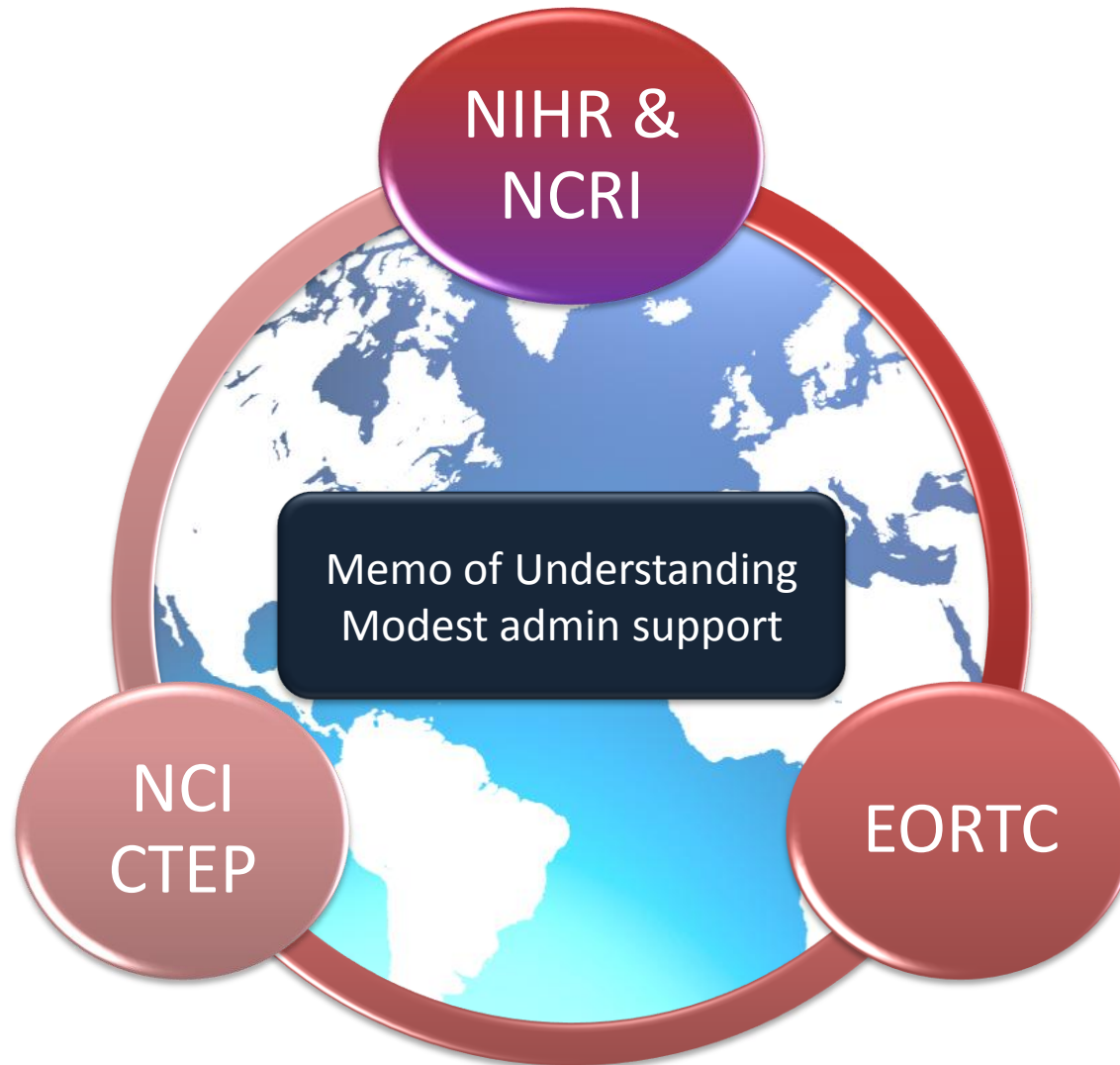
- “Rare Cancer”:
  - ASR < 6/100,000 new cases/yr
  - together, account for over 20% cancer diagnoses
  - ...which is more than any single common cancer (breast 16%, lung 13%, colorectal 13%, prostate 12%)
- Average outcomes inferior to common cancers:
  - worse mortality and survival
  - less improvement over time



# The objectives of IRCI

- to develop international clinical trials advancing the treatment of patients with rare cancers
- to identify and overcome barriers to international trials so that IRCI trials can run smoothly
- to encourage innovative trial methodology maximising the potential to answer research questions in uncommon populations

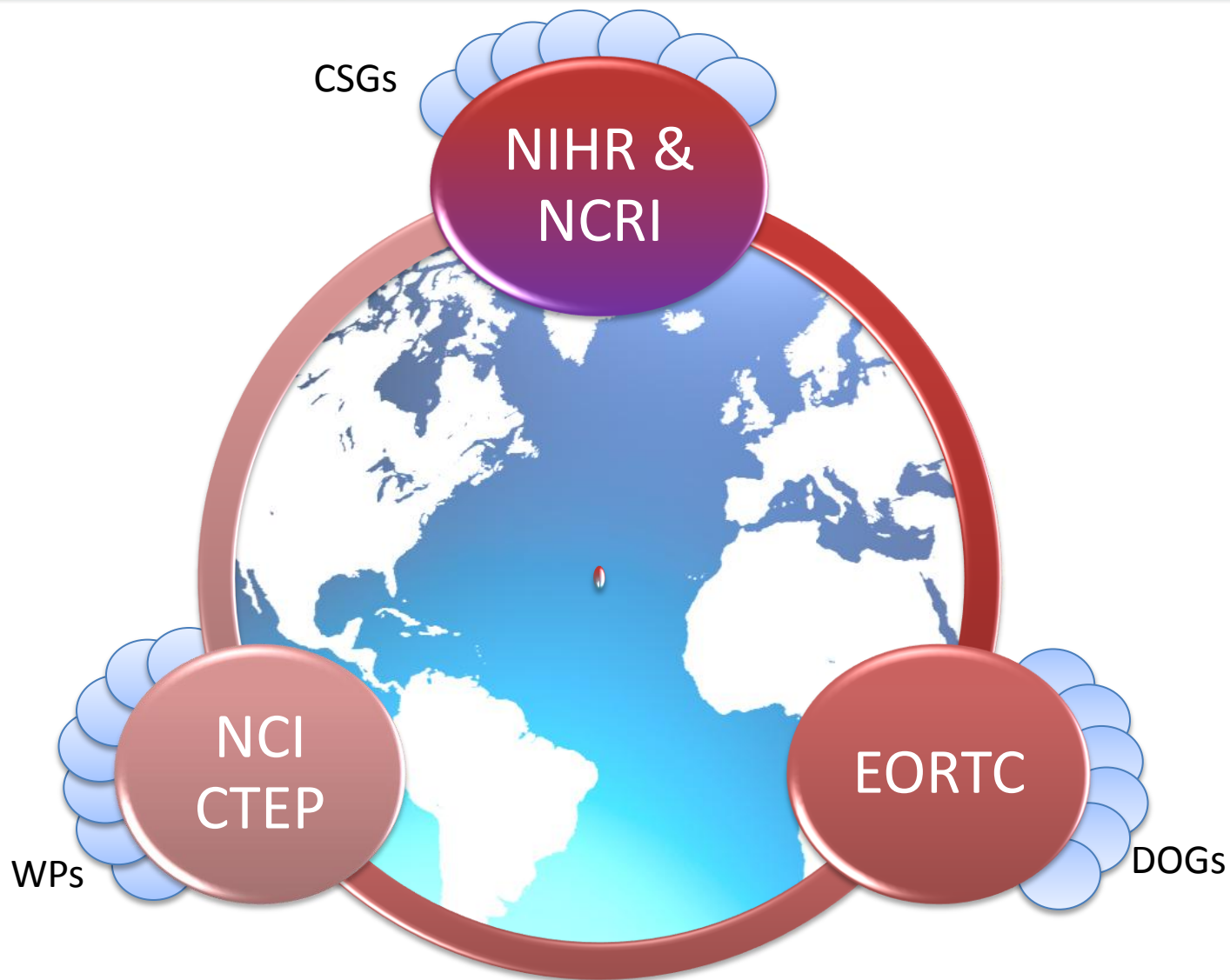
# Founding partners



# Clinical Communities

IRCI

International Rare Cancers Initiative

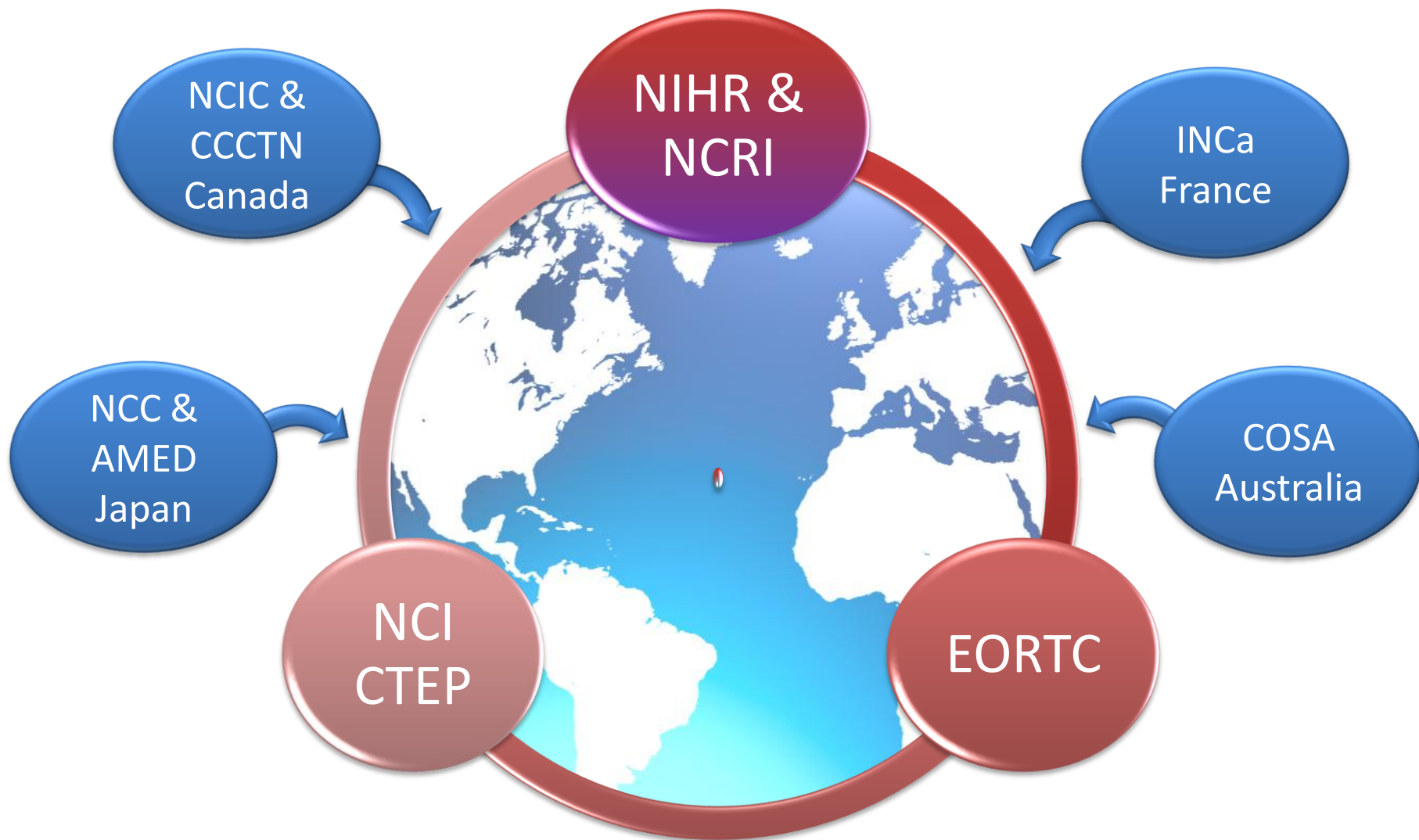


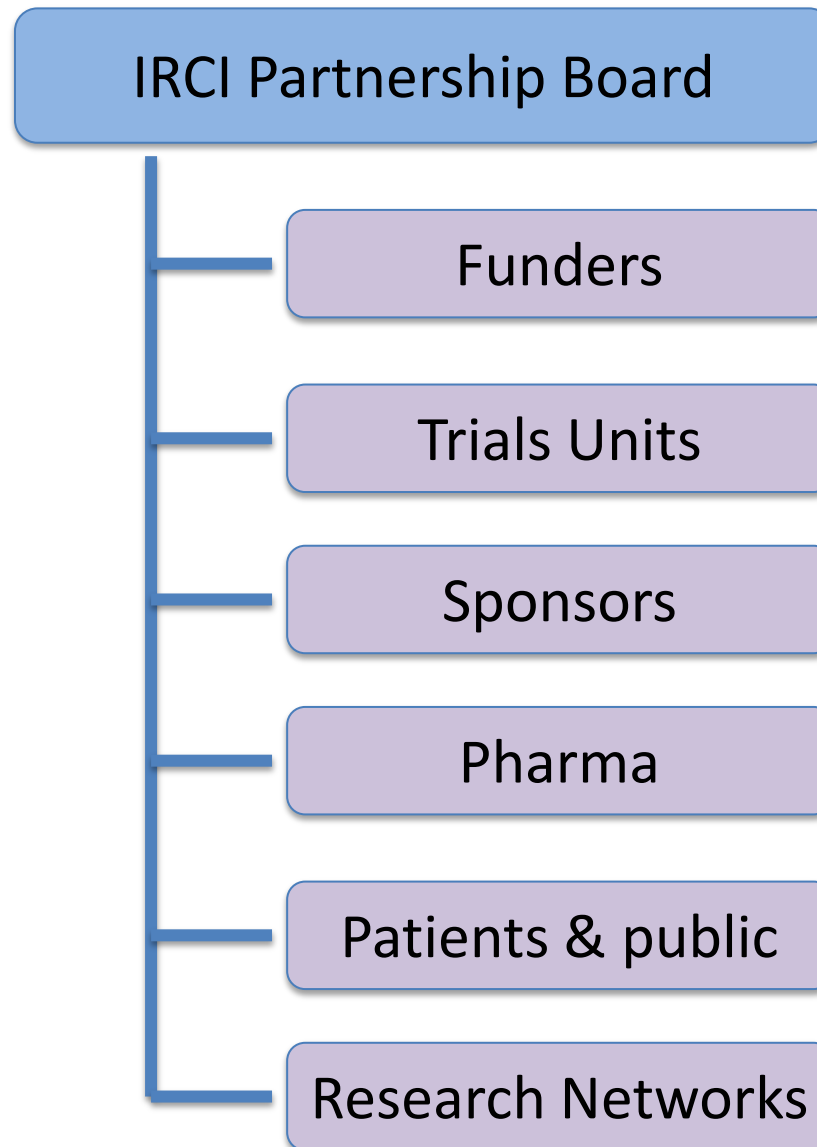


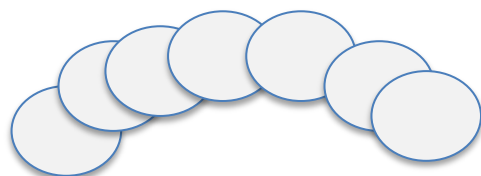
# Growing partnership

IRCI

International Rare Cancers Initiative







Clinical Communities



Expressions of interest



Interest from  $\geq 2$  member groups



IRCI Board prioritises and launches new study groups

## Criteria for setting up an IRCI Group

### **Rarity:**

- low incidence (appx  $\leq 2/100,000/\text{yr}$ )
- ...but enough for a trial to be feasible
- not molecular sub-types already included in 'normal' trials

### **Need:**

- no existing international trial group
- no (or inadequate) existing trials

### **Potential:**

- potential for  $\geq 1$  interventional trial (usually randomised)
- enthusiastic champions within  $\geq 2$  of the partner organisations

# IRCI Groups



fibrolamellar hepatoma

anaplastic thyroid cancer

gynaecological sarcomas ( 2 types)

small bowel adenocarcinoma

penile cancer

ocular melanoma, Merkel cell cancer

thymoma

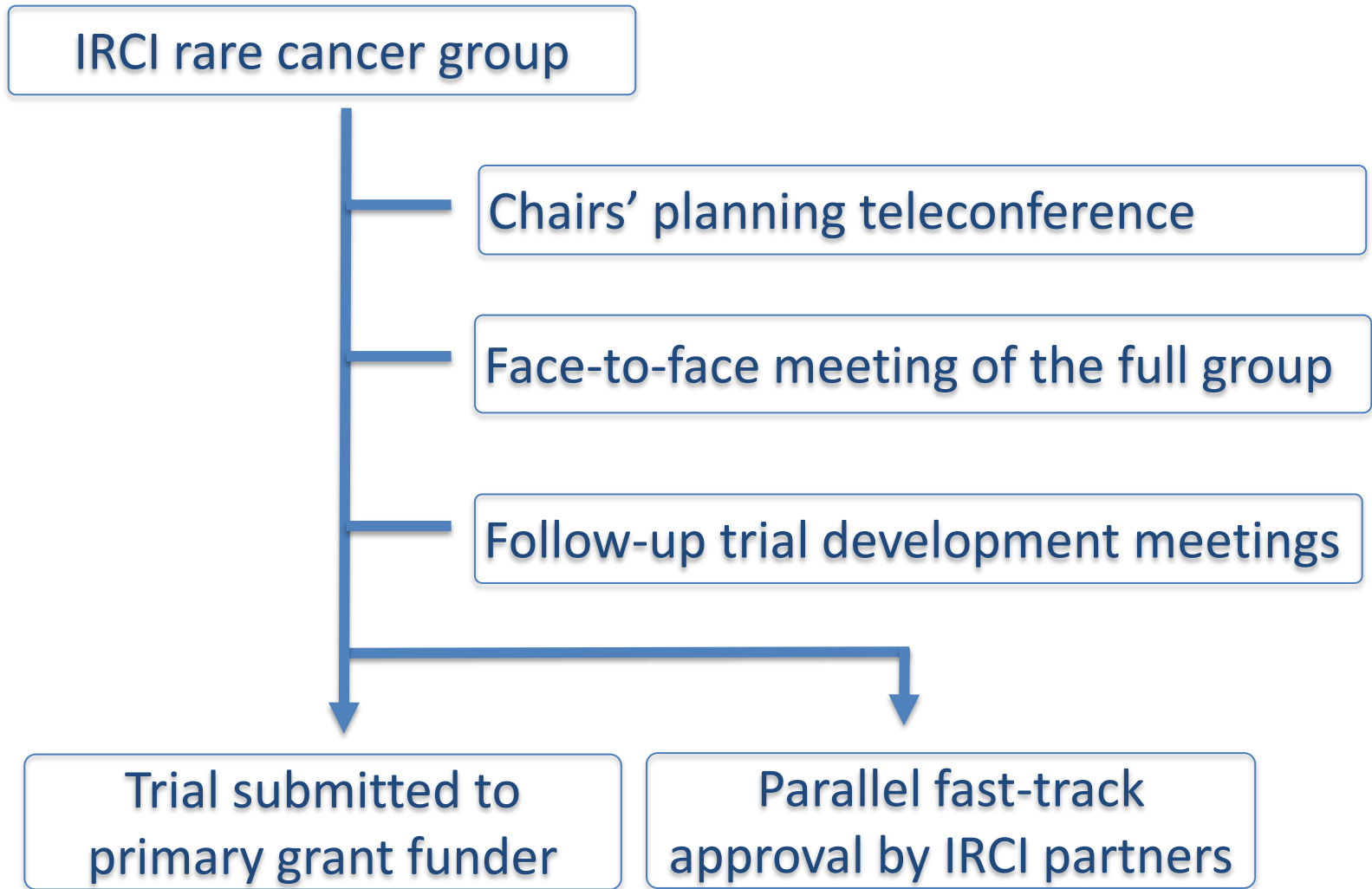
relapsed anal cancer

DSRC tumours

rare brain tumours

relapsed Ewing's

# IRCI Rare Cancer Groups



# IRCI approaches



ASR cases per 100,000

0.9

0.8

0.7

0.6

0.5

0.4

0.3

0.2

0.1

salivary gland  
cancer

small bowel  
adenocarcinoma

uveal  
melanoma

high-grade  
uterine sarcoma

anaplastic  
meningioma

Merkel cell  
skin cancer

metastatic  
anal cancer

penile  
cancer

uterine leiomyosarcoma

thymoma

DSRCT

novel statistics:

Bayesian priors, relaxed power,  
adaptive and multi-arm  
designs

conventional designs  
using national networks and  
international collaboration  
to increase numbers

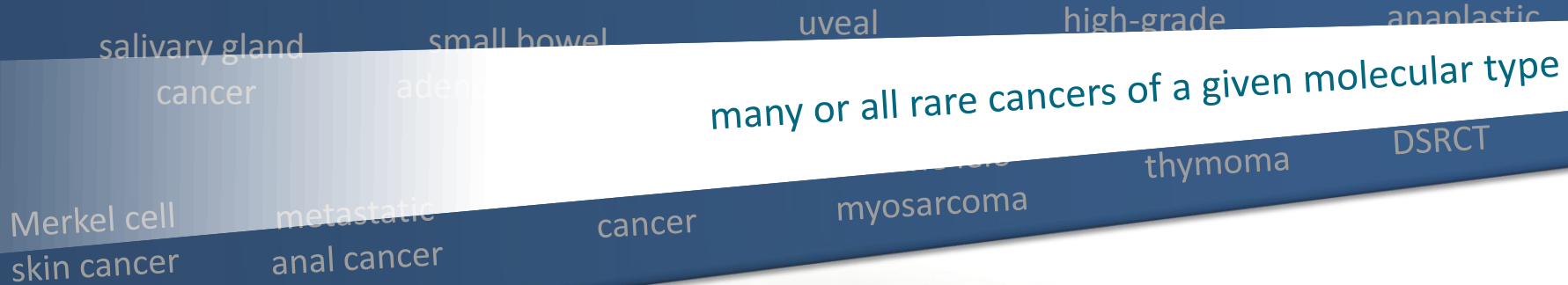
bucket trials  
non-randomised phase III trials  
biological endpoints

genomic-led target identification

# IRCI approaches



ASR cases per 100,000  
0.9      0.8      0.7      0.6      0.5      0.4      0.3      0.2      0.1



conventional designs  
using national networks and  
international collaboration  
to increase numbers

novel statistics:  
Bayesian priors, relaxed power,  
adaptive and multi-arm  
designs

bucket trials  
non-randomised phase III trials  
biological endpoints

genomic-led target identification

European Journal of Cancer (2015) 51, 271–281



ELSEVIER

Eur J Cancer 2015; 51:271-81

journal homepage: [www.ejcancer.com](http://www.ejcancer.com)



Review

## Clinical trial designs for rare diseases: Studies developed and discussed by the International Rare Cancers Initiative



Jan Bogaerts<sup>a,1,\*</sup>, Matthew R. Sydes<sup>b,1</sup>, Nicola Keat<sup>c</sup>, Andrea McConnell<sup>c</sup>, Al Benson<sup>z</sup>, Alan Ho<sup>d</sup>, Arnaud Roth<sup>aa</sup>, Catherine Fortpied<sup>a</sup>, Cathy Eng<sup>e</sup>, Clare Peckitt<sup>f</sup>, Corneel Coens<sup>a</sup>, Curtis Pettaway<sup>e</sup>, Dirk Arnold<sup>g</sup>, Emma Hall<sup>h</sup>, Ernie Marshall<sup>i</sup>, Francesco Sclafani<sup>f</sup>, Helen Hatcher<sup>j</sup>, Helena Earl<sup>j</sup>, Isabelle Ray-Coquard<sup>k</sup>, James Paul<sup>l</sup>, Jean-Yves Blay<sup>k</sup>, Jeremy Whelan<sup>m</sup>, Kathy Panageas<sup>d</sup>, Keith Wheatley<sup>n</sup>, Kevin Harrington<sup>h</sup>, Lisa Licitra<sup>o</sup>, Lucinda Billingham<sup>p</sup>, Martee Hensley<sup>d</sup>, Martin McCabe<sup>q</sup>, Poulam M. Patel<sup>ab</sup>, Richard Carvajal<sup>d,2</sup>, Richard Wilson<sup>r</sup>, Rob Glynn-Jones<sup>ac</sup>, Rob McWilliams<sup>s</sup>, Serge Leyvraz<sup>t</sup>, Sheela Rao<sup>f</sup>, Steve Nicholson<sup>u</sup>, Virginia Filiaci<sup>v</sup>, Anastassia Negrouk<sup>a</sup>, Denis Lacombe<sup>a</sup>, Elisabeth Dupont<sup>w</sup>, Iris Pauporté<sup>x</sup>, John J. Welch<sup>w</sup>, Kate Law<sup>c</sup>, Ted Trimble<sup>w</sup>, Matthew Seymour<sup>y</sup>



# What is working well

- Clinical researcher engagement:
  - huge enthusiasm from oncologists and others
  - commitment to developing trials
- Research funder engagement:
  - charities and some public sector research funders
  - funding for national-level activities in some countries
- Consumer engagement:
  - ... at a national and local level

# What is a challenge

- Core funding of organisation:
  - no research funding body with global scope/interest
- International sponsorship/contracts:
  - protracted trial set-up
  - acceptance of ‘in principle’ benefits of global scope
- Review body understanding
  - globally agreed control arms
  - accepting novel methodologies
  - need for pragmatism and ‘bucket’ research approaches
- Vulnerability to ‘multiple jeopardy’:
  - mutual acceptance of review processes unaccepted to some
- Industry engagement:
  - low priority; perceived low return on investment
- Consumer engagement:
  - consumer input needed for the IRCI site-specific groups

## Rare Cancers



Together, rare cancers account for more than 20% of all cancer diagnoses. This is more than any single common cancer. Unfortunately, the average outcome for patients with a rare cancer is inferior to those with more common cancers. In an attempt to address this issue, the International Rare Cancers Initiative (IRCI) was established early in 2011.

### IRCI Progress Report and Newsletters



-  [IRCI Progress Report](#)
-  [Newsletter 2012 Q4](#)
-  [Newsletter 2013 Q2](#)
-  [Newsletter 2013 Q4](#)
-  [Newsletter 2014 Q2](#)

[www.irci.info](http://www.irci.info)



National Cancer Institute (USA)  
National Institutes of Health

NCIC Clinical Trials Group  
NCIC Groupe des essais cliniques



# International Cancer Benchmarking Partnership (ICBP)

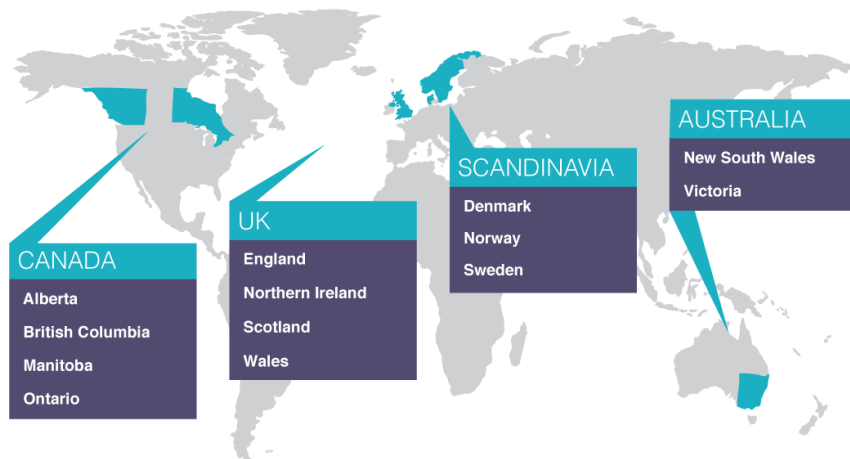
Overcoming the challenges of international collaboration

# International Cancer Benchmarking Partnership is...



A unique collaboration of **clinicians, researchers, data experts** and **policy makers** – across 13 jurisdictions in 6 countries.

By learning from the **experience of others, sharing ideas, comparing outcomes** and **good practice** it is possible to identify and build a strong case for how **cancer services can be improved.**



# What is the ICBP looking at?

The **first of its kind** to be seeking to understand not only **how cancer survival varies** between jurisdictions, but crucially **what factors could be driving these differences**.

Using a range of approaches over **5 research modules**.



1  Core cancer survival benchmarking

2  Public awareness, beliefs and attitudes to cancer

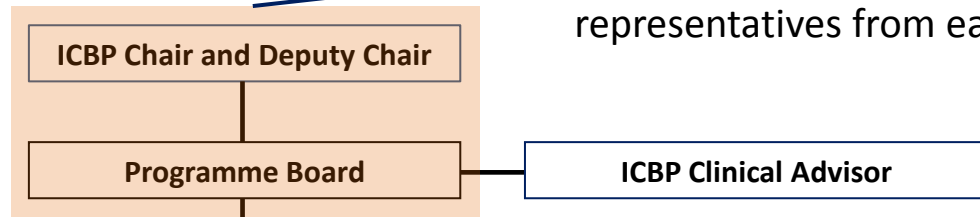
3  Role of primary care doctors and health systems in diagnosis

4  Measuring time intervals & pathways from symptoms to diagnosis & treatment

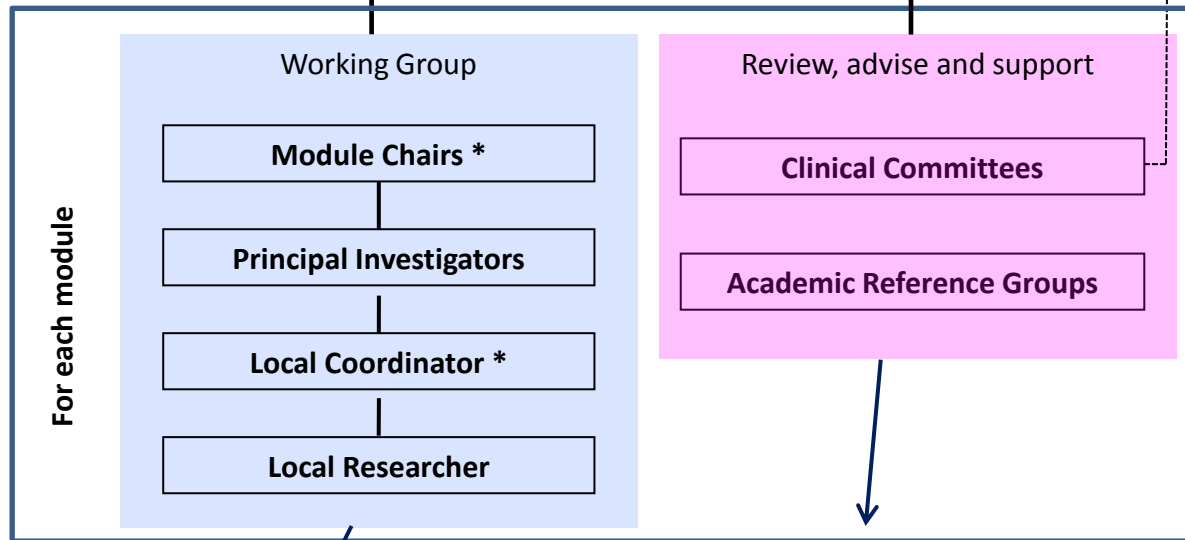
5  Exploring the impact of comorbidities on short term outcomes

# ICBP Coordination

Overall leadership and direction;  
multidisciplinary membership;  
representatives from each jurisdiction



Central coordination,  
facilitation and  
support;  
communications



Review and advise the  
PI and Board  
concerning the rigor of  
methods and analysis

Development of research methods and tools, data  
collection, analysis and interpretation; local collaboration

CHALLENGES	LESSONS LEARNED
<p><b>International comparisons are complex and require careful consideration and planning</b></p>	<ul style="list-style-type: none"> <li>• A central programme management team funded by all partners and by Cancer Research UK</li> <li>• Extended timescales: due to the complex nature of the research and the time required to develop new research tools</li> </ul>
<p><b>A funding model that is fair to all and enables progress</b></p>	<ul style="list-style-type: none"> <li>• Module by module funding tends to slow down progress and those who sign up early have had to wait for others</li> <li>• Moving to a funding model based on population size</li> <li>• Providing predictable cost estimates over multiple years</li> </ul>
<p><b>Timezones and business hours</b></p>	<ul style="list-style-type: none"> <li>• Rotate call times to share unsocial hours</li> <li>• Regular meetings schedules set at least 6 mths in advance</li> <li>• Bandwidth hours - 6am and 10pm</li> </ul>
<p><b>Lack of face to face contact</b></p>	<ul style="list-style-type: none"> <li>• Catch up at international conferences</li> <li>• Planning to host regular ICBP Summits</li> </ul>



# Additional benefits of collaboration

- Access to a network of key contacts in a range of jurisdictions
- ‘Off-shoot’ analyses using ICBP data
- Academic collaborations are developing and maturing
- Learning from partners about how local health systems are similar / different
- Research that is designed to influence policy and practice across multiple jurisdictions

# ICBP Findings

- Relative survival (1995-2007) **improved** for patients across all four cancers in all jurisdictions
- Similar **awareness** of cancer symptoms and **beliefs** about cancer in the public across all jurisdictions – although awareness of **age as a risk factor** was low everywhere.
- Health care in jurisdictions have many common features but some **subtle differences** may merit further investigation, e.g. patient contribution to healthcare costs.
- Correlation between readiness of primary care doctors to **investigate potential cancer symptoms** at the patient's first consultation and **survival** for lung, colorectal and ovarian cancer.

# ICBP Impacts

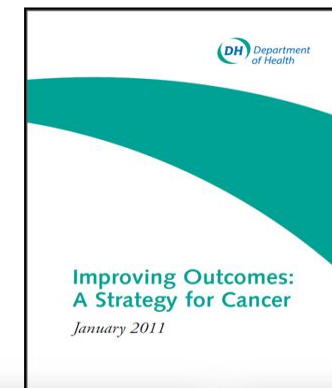
As a **multidisciplinary** partnerships all partners and collaborators are closely involved in:

- The design and delivery of the research
- Providing valuable local insights to enable meaningful interpretation of results
- Disseminating findings and communicating with key audiences

This leads to greater opportunities to translate **ICBP findings** and **insights** in to policy and practice

# ICBP Impacts – Policy Reach

- **England, Canada and Norway:** provided new evidence for cancer plans and identifying priorities update confirming the ‘survival gap’
- **NSW, Ontario, England and Wales:** underpins projects to improving cancer data completeness and availability
- Confirmed evidence underpinning public awareness campaigns **England, Scotland** and provide insight for potential campaigns in **Wales, Northern Ireland**
- Contributed evidence for ACE in **England** which is exploring innovative diagnostic referral pathways



# ICBP Impacts - Academic Reach

The partnership has:

- ❖ Pioneered a range of methods and research tools to enable robust and unique international comparisons
- ❖ Published 12 quality peer reviewed papers
- ❖ Findings commonly cited at conferences and in the rationale for other research studies
- ❖ Completed the first international comparisons of:
  - Cancer survival and stage at diagnosis using routine data
  - Cancer survival and public awareness, attitudes and beliefs (at this scale)
  - Cancer survival and primary care referral behaviour and health system

# Overcoming the challenges of international collaboration

*The EU Tobacco Products Directive (and international tobacco control more generally)*



Florence Berteletti, SFP Director

# This presentation



- Introducing SFP
- The Kingdon Model
- Key success factors in the new TPD
- Lessons learned



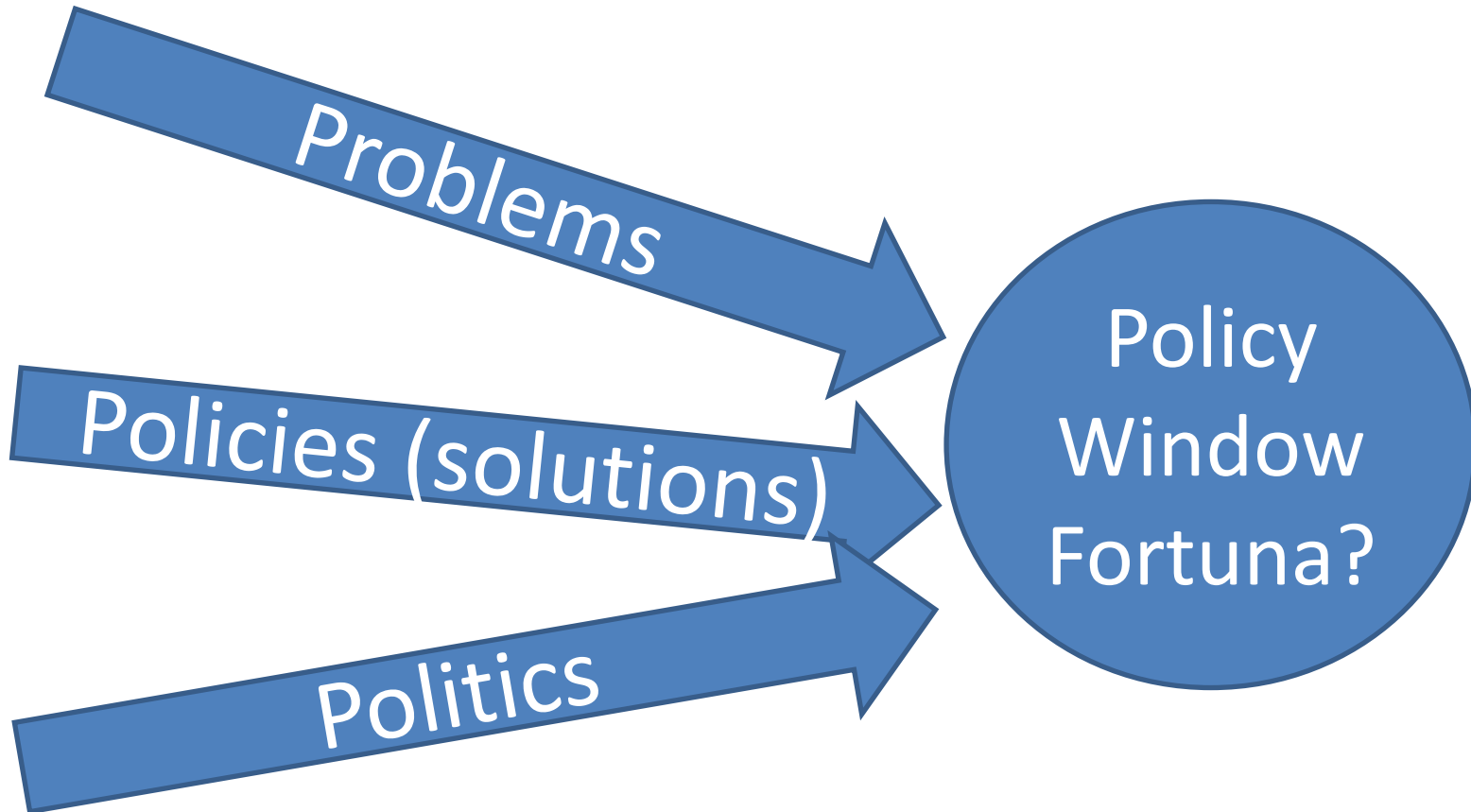


# This presentation



- Introducing SFP
- **The Kingdon Model**
- Key success factors in the new TPD
- Lessons learned

# The Kingdon Model



# Which priorities within the TPD?



## (PS) SFP priorities



Measures that help prevent children and young people from taking up smoking

A **pack** that tells the truth

A **taste** that tells the truth

# (PS) Key misconceptions about TPD measures

*TPD = Increased illicit trade*



*TPD = Farmers go out of business*



*TPD = bad for business and jobs*



*TPD = no evidence of effectiveness*



# (SPO) TPD: Political and policy context

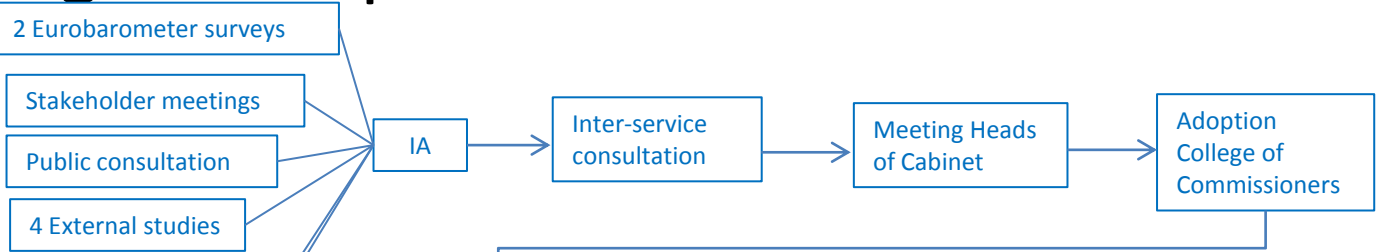


- **FCTC obligations**
- EU lagging behind in tobacco control
- TPD 2001 growing out of date
- Slow rate of adoption of pictorial warnings in MS
- Evolving tobacco market
- Commission commitment to review TPD during current legislature
- Larger Parliament and Council
- Countdown to European elections 2014

# EU Legislative process and the TPD

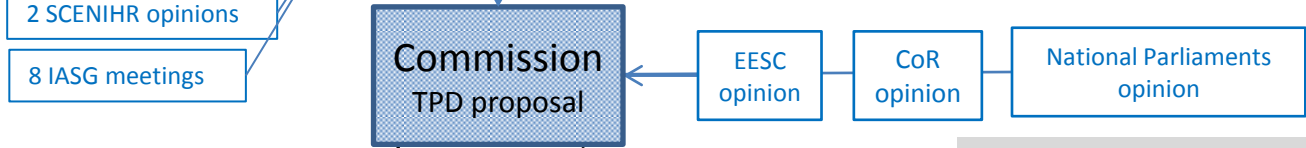
## DRAFTING PHASE

(European Commission,  
Feb 2009 – Dec 2012)



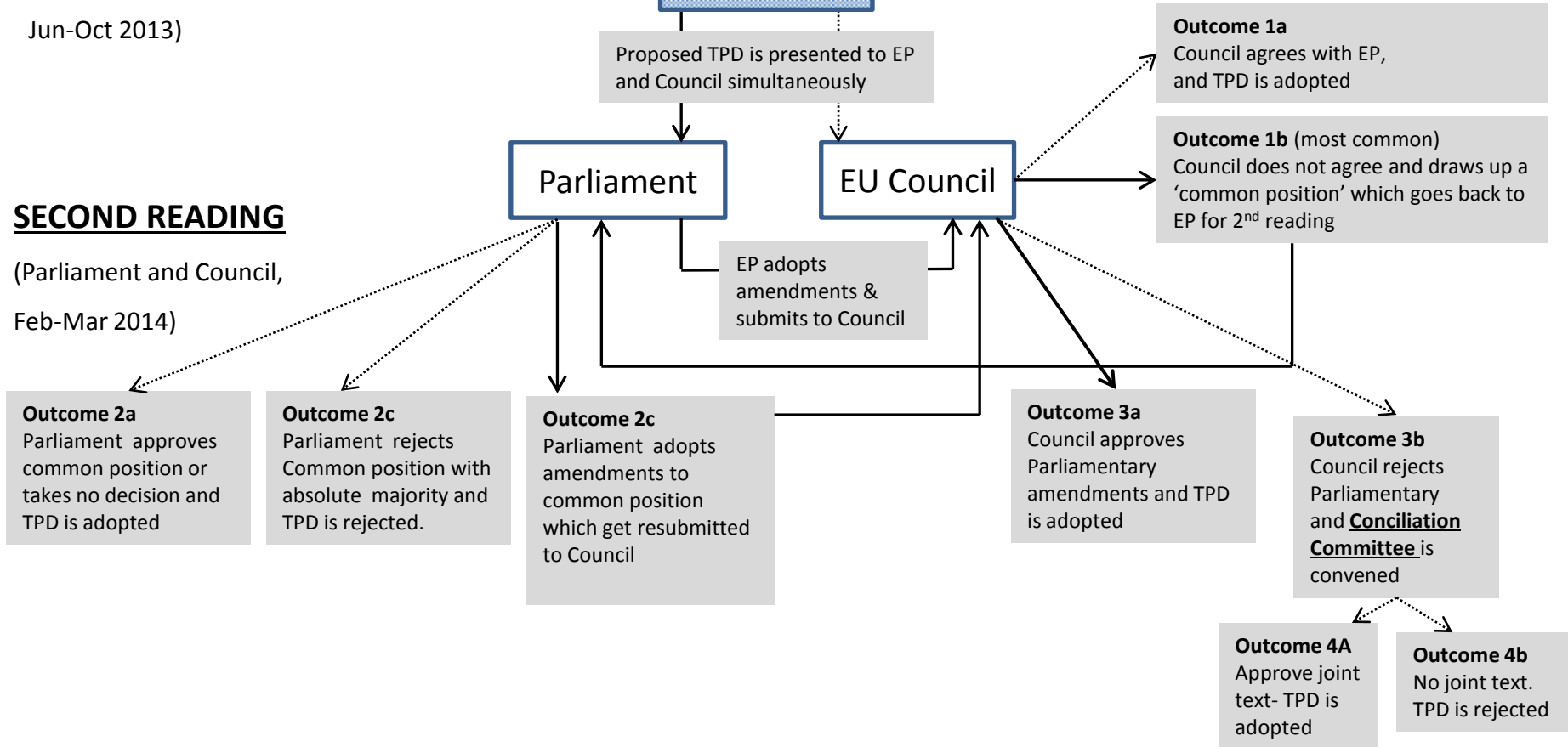
## FIRST READING

(Parliament and Council,  
Jun-Oct 2013)

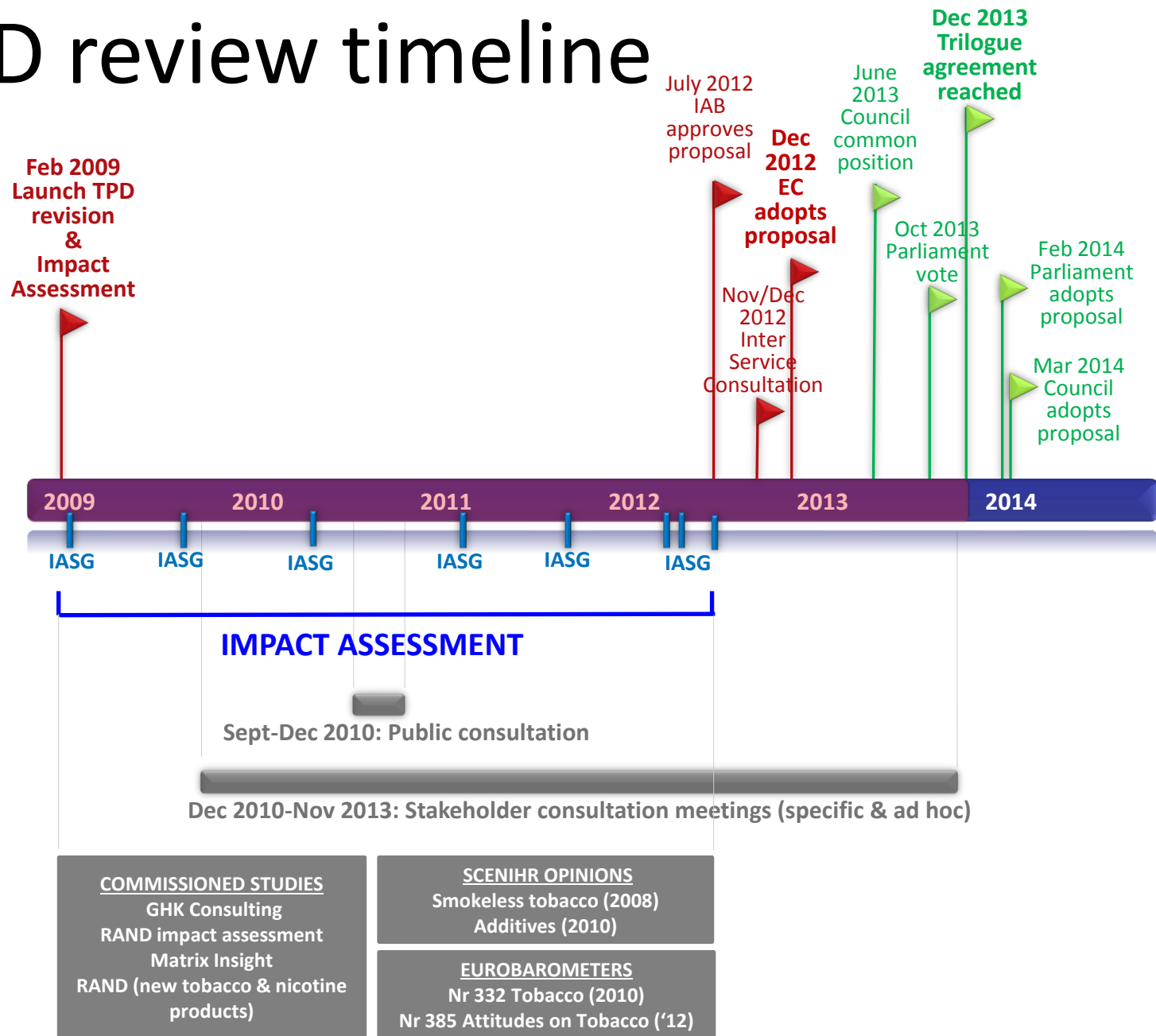


## SECOND READING

(Parliament and Council,  
Feb-Mar 2014)



# TPD review timeline



*Revised  
TPD  
expected  
to come  
into force  
in May  
2014*



# This presentation



- Introducing SFP
- The Kingdon Model
- **Key success factors in the new TPD**
- Lessons learned

# TPD Key Success Factors



1. The Commission's tobacco team (*Stream of Politics*)
2. The Irish Presidency (*Stream of Politics*)
3. The EP Rapporteurs (*Stream of Politics*)
4. The united front made by the NGO community
5. The Dalli Gate (Stream of Problems)
6. The Industry Leaks

# The united front made by the NGO community



## SMOKE FREE PARTNERSHIP BRIEFING

TOBACCO PRODUCTS DIRECTIVE  
FACT NOT FICTION



## Spotlight on the Labelling and Packaging of Tobacco Products

Articles 11 and 13 of the FCTC

ISSUE EIGHT / MAY 2013

8 OCTOBER 2013  
WHAT WILL YOU VOTE FOR?

A healthy future  
for our children

or tobacco  
interests?



**75% warnings at the top edge of the pack** reduce the attractiveness of cigarette packs

**SUPPORT AMENDMENT 54**



**50% warnings at the bottom edge of the pack** do not prevent Big Tobacco from attracting kids

**REJECT AMENDMENTS 97, 98, 120, 142, 150**

Dear Member of the European Parliament

**RE: Plenary vote on the Tobacco Products Directive**

Ahead of the plenary vote on the report of the representatives of the public health

Following the unfortunate delay in the adoption of the position adopted by the ENVI committee, in the face of intensive lobbying by the tobacco industry, measures and tobacco remains the leading cause of deaths each year in the EU, **we call**

In particular, we call on you to support the following:

**1. Large pictorial health warnings of the pack (Article 9)**

**Please vote in favour**

**Please reject amendments 158, 159**

**Why?**

Pictorial and text warnings of 75% or more are proven to be more effective in reducing the attractiveness of tobacco products to children and young people.

SMOKING IS AN ADDICTION OF CHILDREN AND YOUNG ADULTS  
**MAKE A DIFFERENCE NO EXCUSES, NO DELAYS.**



# Result of coalition work achieved by SFP



8 OCTOBER 2013  
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SMOKING IS AN ADDICTION OF CHILDREN AND YOUNG ADULTS  
MAKE A DIFFERENCE  
NO EXCUSES, NO DELAYS.



design: tvivincemills.be

# Lessons learned



- Even a very small group can make a large difference if it works strategically
- Working together has never been more important
- Never, ever give up: for every challenge, there is an opportunity
- Generating media coverage at key points in the process and when faced with unpredictable events was very useful
- Every vote counts, even when 766 available in the Parliament and 352 in the Council

# Recommendations:



- **Some funded coordination is essential**
- Play to each others strengths and respect the different remits and levels of resources that each can bring
- Develop consensus by reviewing the evidence, assessing the politics, agreeing the objectives and tactics
- Be prepared to work collaboratively and sometimes **let others take the credit**
- **Remember the common goal and the common enemy-when we are not united, the tobacco industry wins**

# The TPD outcome

## TC community asks



## TPD outcomes



SMOKING IS AN ADDICTION OF CHILDREN AND YOUNG ADULTS

THANK YOU FOR  
MAKING A DIFFERENCE



A healthy future  
for our children:



Tobacco interests:



**75%** warnings  
at the **top edge of the pack**  
reduce the attractiveness  
of cigarette packs



**50%** warnings at  
the **bottom edge of the pack**  
do not prevent Big Tobacco  
from attracting kids





World  
Cancer  
Research  
Fund International



Norwegian Institute of Public Health

## International collaboration on policy to prevent cancer and other nutrition- related NCDs

World Cancer Leaders' Summit November 2015

Professor Knut-Inge Klepp  
Executive Director, Norwegian Institute of Public Health

## Overview

*Improving international collaboration to advance the evidence for policy around nutrition*

- ◆ The role of evidence in the policy process
- ◆ Policy Advisory Group
- ◆ NOURISHING framework & policy database

## The role of evidence in the policy process

*Evidence is vital in the formation, implementation and evaluation of policy actions*

- ◆ How does the role of evidence differ from country to country?
- ◆ What does the policy-making community really need in order to act? What is the role of evidence in this?
- ◆ What forms of evidence are needed?
- ◆ What evidence is needed to overcome barriers to action?
- ◆ How should the evidence be framed so that it can be most effectively used by policy makers?
- ◆ What outputs would be most useful and how could they be most effectively communicated?

# The Norwegian School Fruit Programme



Bere et al. *International Journal of Behavioral Nutrition and Physical Activity* (2015) 12:139  
 DOI 10.1186/s12966-015-0301-6



International Journal of Behavioral Nutrition and Physical Activity

## RESEARCH

Open Access



## One year of free school fruit in Norway – 7 years of follow-up

Eling Bere<sup>1\*</sup>, Sævik J. te Velde<sup>1</sup>, Milada Cvancarova Småstuen<sup>1</sup>, Jos Twisk<sup>2</sup> and Knut-Inge Klepp<sup>3</sup>

### Abstract

**Background:** It is important that health-promoting efforts result in sustained behavioural changes, preferably throughout life. However, only a very few intervention studies evaluate long term follow up.

**Objective:** The aim of the present study is to evaluate the overall and up to seven years effect of providing daily one piece of fruit or vegetable (FV) for free for one school year.

**Methods:** A total of 38 randomly drawn elementary schools from two counties in Norway participated in the Fruit and Vegetables: Make the Marks project. Baseline (2001) and follow-up surveys were conducted in May 2002, 2005 and 2009 (n = 320 with complete data) to assess FV and unhealthy snack intake. Mixed models were used to analyze the data.

**Results:** Statistically significant adjusted overall effects of the intervention were revealed for FV intake (15.2 times/day) but this weakened over time. A significant adjusted overall effect (-1.54 consumptions/week) and a significant seven-year follow-up effect (-2.02 consumptions/week) was found for consumption of unhealthy snacks for pupils of parents without higher education.

**Conclusions:** One year of free school fruit resulted in higher FV intake and lower unhealthy snack intake, however this weakened over time for FV intake and became stronger for snack intake. More follow-up studies with larger samples and lower attrition rates are needed in order to further evaluate the long-term effect.

**Keywords:** Fruit and vegetable, School-based intervention, Long-term follow-up

## Policy Advisory Group

- ◆ A new initiative launched April 2015
- ◆ Advice on developing a process of updating, interpreting and communicating the evidence for policy
- ◆ Provides insight into a range of challenges associated with policy development and implementation in different contexts & countries
- ◆ High level, geographically diverse

Aim: meet the evidence needs of policymakers to support the development and implementation of more effective policy action to promote healthy diets



## MEMBERS



**Ms Sondra Davoren**  
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Victoria, McCabe  
Centre for Law and  
Cancer  
Australia



**Professor Sir Trevor Hassell**  
Healthy Caribbean  
Coalition  
Barbados



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Health  
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**Dr Tim Armstrong**  
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Organization



**Dr Francesco Branca**  
World Health  
Organization



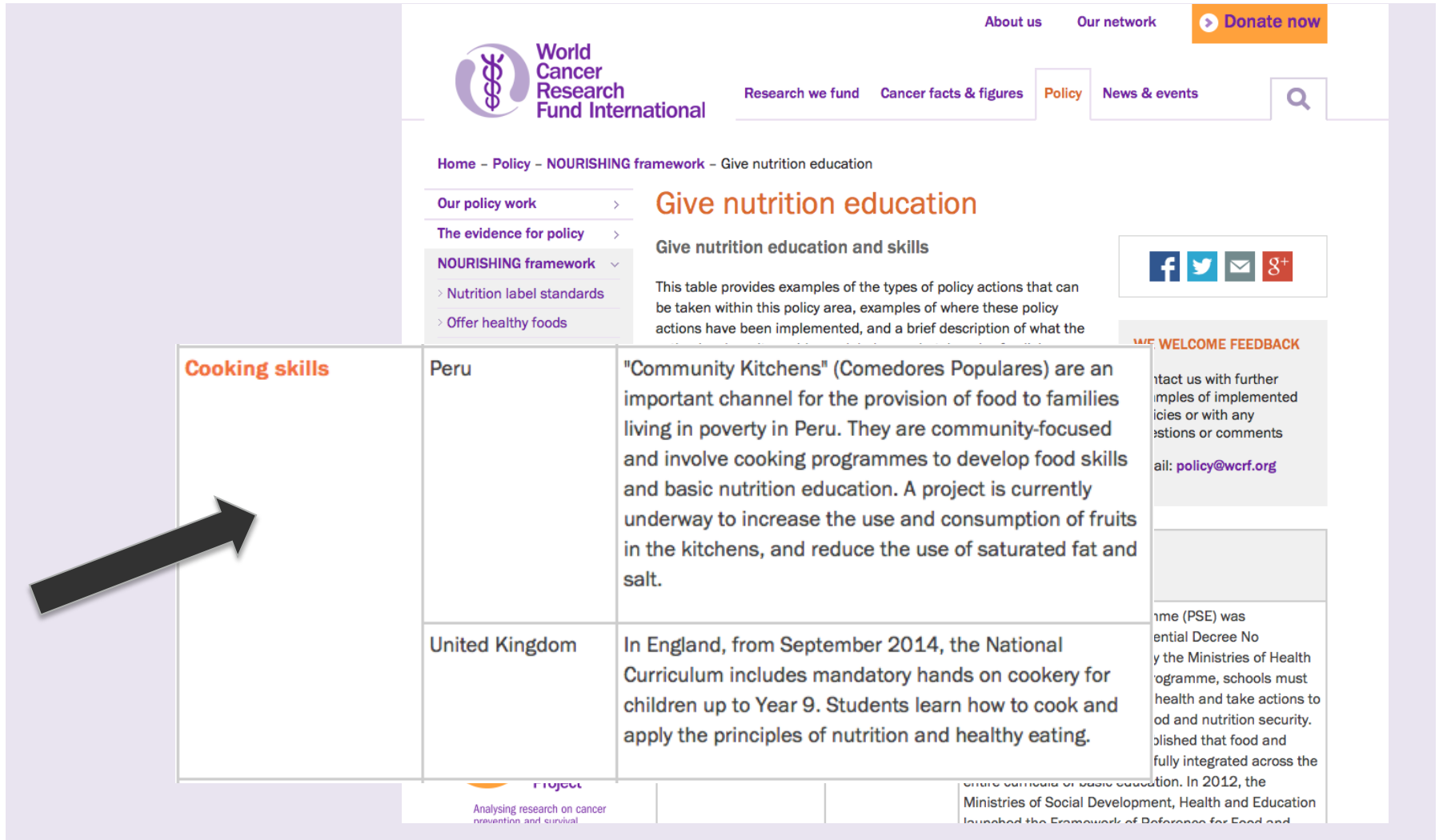
**Dr Heather Bryant**  
UICC

## OBSERVERS

- Platform for advancing the evidence for policy
- An 'Instrument for change'

<b>N O U R I S</b>		<b>H</b>	<b>I N G</b>
FOOD ENVIRONMENT		FOOD SYSTEM	BEHAVIOUR CHANGE
	POLICY AREA		
<b>N</b>	Nutrition label standards and regulations on the use of claims and implied claims on foods		
<b>O</b>	Offer healthy foods and set standards in public institutions and other specific settings		
<b>U</b>	Use economic tools to address food affordability and purchase incentives		
<b>R</b>	Restrict food advertising and other forms of commercial promotion		
<b>I</b>	Improve nutritional quality of the whole food supply		
<b>S</b>	Set incentives and rules to create a healthy retail and food service environment		
<b>H</b>	Harness supply chain and actions across sectors to ensure coherence with health		
<b>I</b>	Inform people about food and nutrition through public awareness		
<b>N</b>	Nutrition advice and counselling in health care settings		
<b>G</b>	Give nutrition education and skills		

# 255 actions across 100 countries



World Cancer Research Fund International

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Home - Policy - NOURISHING framework - Give nutrition education

Our policy work >

The evidence for policy >

NOURISHING framework ▾

- > Nutrition label standards
- > Offer healthy foods

## Give nutrition education

### Give nutrition education and skills

This table provides examples of the types of policy actions that can be taken within this policy area, examples of where these policy actions have been implemented, and a brief description of what the

[f](#) [t](#) [e](#) [g+](#)

WE WELCOME FEEDBACK

Contact us with further examples of implemented policies or with any questions or comments

Email: [policy@wcrf.org](mailto:policy@wcrf.org)

Topic	Country	Description
Cooking skills	Peru	"Community Kitchens" (Comedores Populares) are an important channel for the provision of food to families living in poverty in Peru. They are community-focused and involve cooking programmes to develop food skills and basic nutrition education. A project is currently underway to increase the use and consumption of fruits in the kitchens, and reduce the use of saturated fat and salt.
	United Kingdom	In England, from September 2014, the National Curriculum includes mandatory hands on cookery for children up to Year 9. Students learn how to cook and apply the principles of nutrition and healthy eating.

Project  
Analysing research on cancer prevention and survival

entire curriculum of basic education. In 2012, the Ministries of Social Development, Health and Education launched the Framework of Reference for Food and



## Summary

- Evidence for policy process is complex and differs between contexts & countries
- But many similarities and parallels as well – NOURISHING helps to clarify complex process
- The Policy Advisory Group provides insight into challenges associated with policy development & implementation and provides *policy relevant evidence* to accompany implemented actions included in NOURISHING

**The outcome: international collaboration around nutrition policy to influence government action**

# Thank you!

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