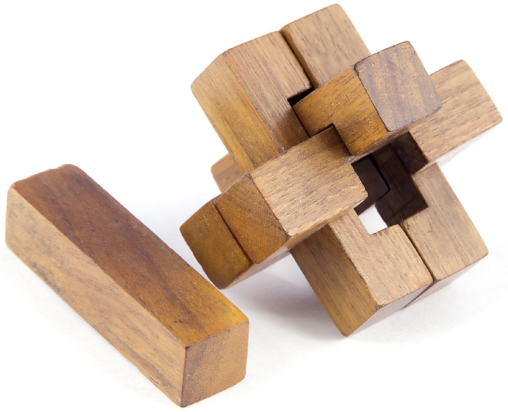


The International School
on Research Impact Assessment

ADVOCACY

'making the case' for research

Paula Adam

AQuAS

Organised by:

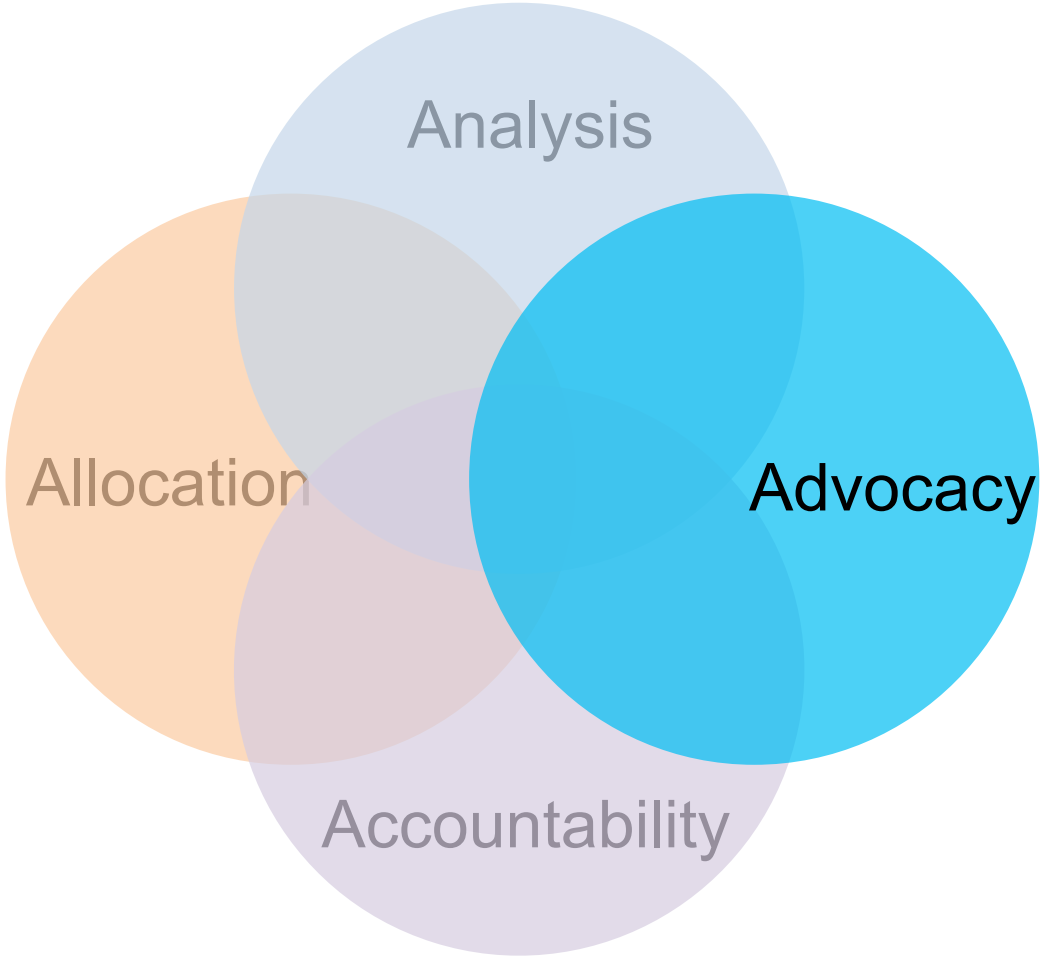
Agència de Qualitat i Avaluació Sanitàries de Catalunya
AGENCY FOR HEALTH QUALITY AND ASSESSMENT OF CATALONIA

Generalitat de Catalunya
Departament de Salut

RAND EUROPE

Alberta Innovates Health Solutions

Why assess research impact?



Learning objectives

- ‘Estimates’ of the value of research: methodological challenges

- Evidence-based case studies versus cherry-picked anecdotes

- Patient advocacy movements versus RIAP

Contents

- Preliminary considerations
- Historical review of biomedical research advocacy
- The challenge of estimating the ‘value’ of research
- The challenge of selecting evidence-based best cases

Selection of historical advocacy races for biomedical research

JFK baby death in 1963 sparked medical race to save preemiers and the rise of a new speciality, neonatology

"Patrick died just 39 hours after his birth, a victim of what was then the most common cause of death among premature infants in the United States, killing an estimated 25,000 babies each year: hyaline membrane disease, now known as respiratory distress syndrome"

"Over the next decade or so, innovations from physicians, nurses and others led to bold and successful treatments for babies of increasingly lower birth weights. In particular, scientists discovered that hyaline membrane disease resulted from a deficiency of surfactant, a substance that lines the air sacs in the lungs. Surfactant replacement shortened the length of ventilation therapy. This and other advances gave rise to a new specialty, neonatology. "

President John F. Kennedy holds hands with his wife Jackie as they leave the Otis Air Force Base hospital, Aug. 14, 1963, where the first lady gave birth on Aug. 7. The baby boy died 39 hours later.

Bettmann/Corbis

By LAWRENCE K. ALTMAN, M.D.
Published: July 29, 2013

The New York Times

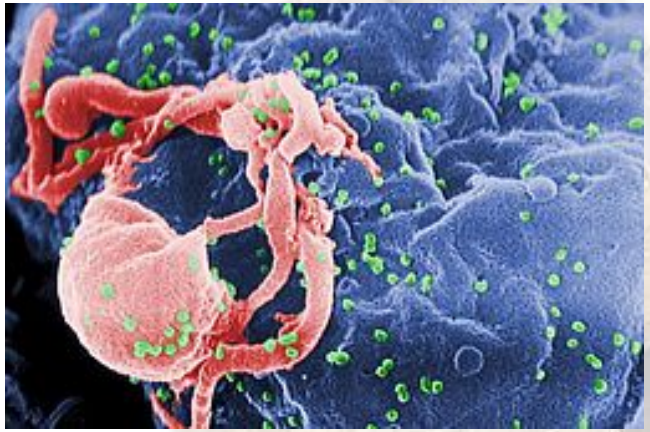
Booming battle against breast cancer in the 70s

- The boom started in the 70s, with popular champions and the feminist group support
- Betty Ford (wife of President Gerald Ford) were noted for raising breast cancer awareness following her 1974 mastectomy.
- Large events, like walkatons, the Breast Cancer Awareness Month, the pink ribbon movement promote breast cancer awareness and research

HIV/AIDS advocacy movements

- Patient advocacy groups have been key in fund-raising

- … but the support of popular champions like Fredy Mercury, Rock Huston or Nureyew were fulminant in research fund-raising



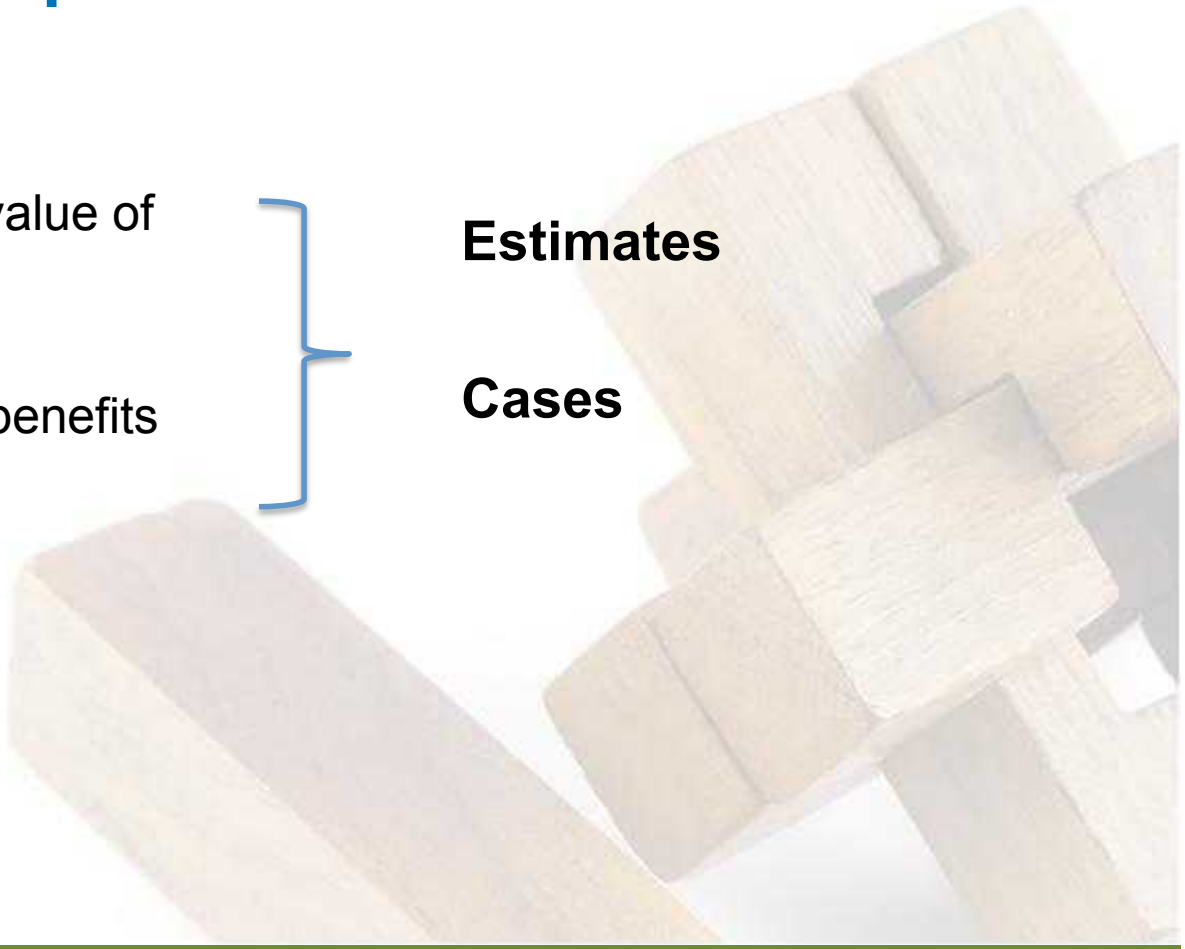
Advocating for research using research impact assessment

- How can we **explain** the value of research?

- How can we **quantify** the benefits from research?

Estimates

Cases



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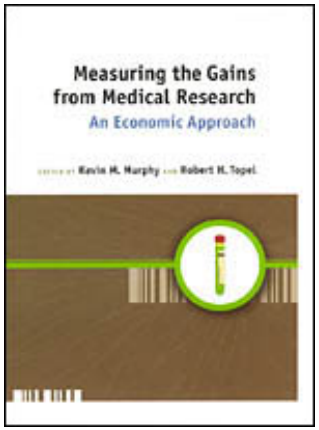
THE CHALLENGE OF ESTIMATING THE VALUE OF BIOMEDICAL RESEARCH

Estimates: challenges

- The unit of measure depends on the type/scope or research (e.g. biomedical research, criminology, computer science, humanities)
- Using estimates is complex, usually requires taking assumptions and needs to control unobservable (un-measured) factors
- Understanding how the cause-effect works in theory is key - using a logic modeling approach might be helpful
- Other measurement issues (time lag, etc)
- The theory of change might be crucial when adopting assumptions

Estimates: Top-down econometrics



- US “exceptional returns” study (Murphy & Topel 2003)
  - < $25 billion in investment contributed to about $ 500 billion estimated health improvement
  - The return is 20 times greater than average annual spending on medical research
- Australia “exceptional returns” (Access Economics, 2003)
  - For every dollar invested, you get $5 back –a return of 500%

Estimates: Bottom-up approach

- Medical Research: What's it worth? 2008

Cardiovascular disease

- **Health gain** (1985-2005), total number of QALYs gained due to research based interventions
- **Time lag**
- **Spillovers**

9% + 30% = 39%

Different elements of economic returns

‘Spillover’ or GDP gain

- Direct and indirect impact on the economy from medical research
- Estimates to date are disease independent
- Previously estimated gains to be 30%, based on review of the literature

+

Health gain

- Monetised health gains net of the health care costs of delivering them
- Estimates to date are disease dependent, hence estimating for cancer

To calculate the health gain element, they made four key estimates

Time lag between research investment and net health gain

Research investment

Net health gain

The proportion of UK research spend that can be attributed to UK health gain

Resulting total return dramatically lower than the other studies

UK study	US study	Australia I study
39%	"20 times"	"500%"

The US and Australia I studies	The UK Consortium study
• Take a top-down approach – Look at overall gains in mortality & morbidity —not linked to interventions – Attribute half of these to R&D	• Uses a bottom-up approach – Identifies research-based interventions – Then quantifies health impact
• Compare research spending and health benefits in the same year – This implies that the health gains from research are instant	• Assumes a lag of 17 years between research spending and health gains – Normally as the time lag increases, the return will fall
• Do not net off the health-services costs needed to achieve the gains	• Does net off the needed health-services costs
• Use a high 'willingness–to–pay' value of a life year—3 times that used in our study for a QALY	• Uses a lower 'willingness-to-pay' value (as used by UK Government)

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EVIDENCE-BASED CASE STUDIES:

Preliminar consideration: What are the drivers of research?

- Curiosity-driven research
- Social needs-driven research
- Market-driven research
- Meritocratic driven research

Shergold M, Grant J. Health Research Policy and Systems 2008; 6:2, i en Salter AJ, Martin BR. Research Policy 2001; 30:509

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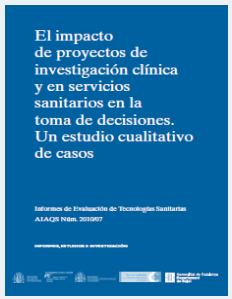
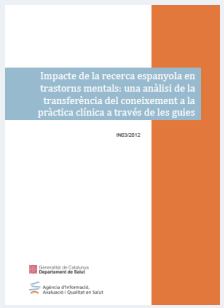
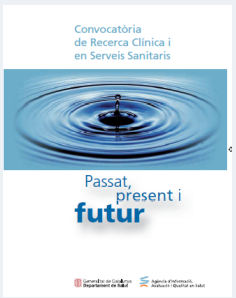
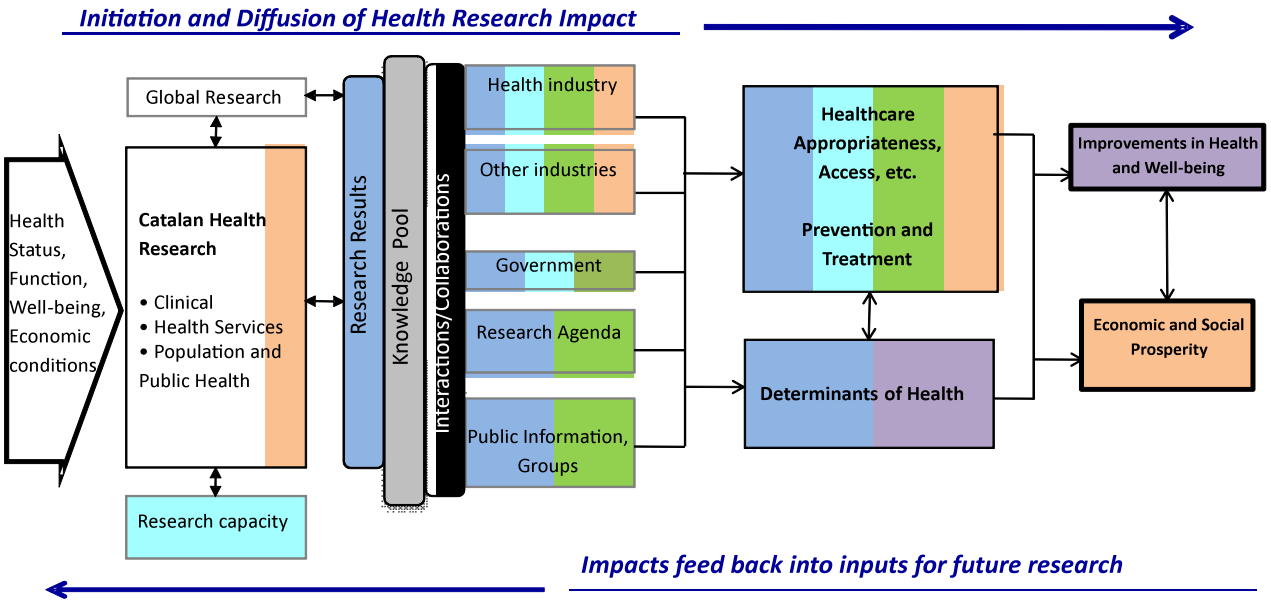
ADVOCATING FOR HEALTH SERVICES RESEACH IN CATALONIA

Catalan health services call: Context, purposes and methods

	Accountability	Analysis	Advocacy
Socio-economic context	1996-2008 Generous R+D spendings	2007 Change in economic cycle	2010-13 Austerity
			
Survey questionnaires	√		
Bibliometry	√		
Case studies		√	
Peer review			√

CAHS framework was used to map impacts and to advocate for health services research



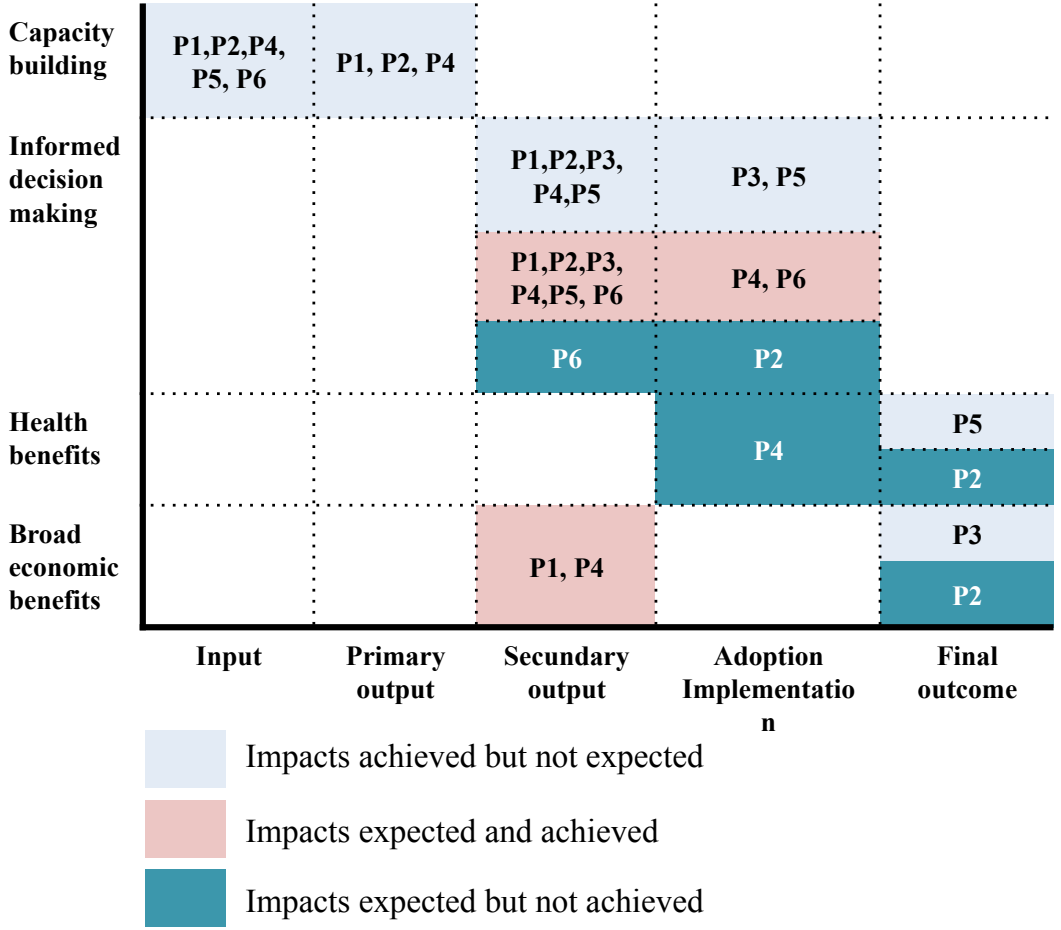
Advancing Knowledge
Capacity Building
Informing Decision Making
Health Benefits
Economic Benefits

Canadian Academy of Health Sciences

ISOR project: Selection of examples for dissemination and raising awareness

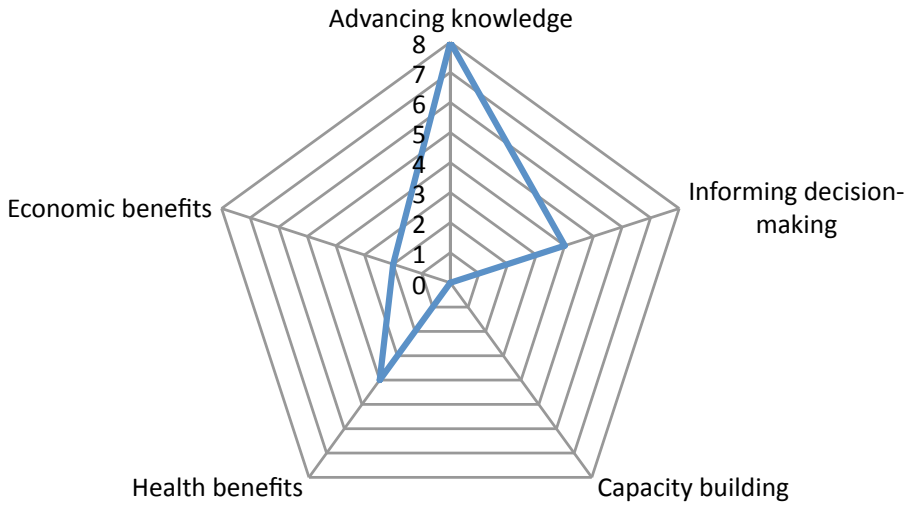
Impact of funded projects on clinical and health services research on respiratory disease

Solans et al (2013)



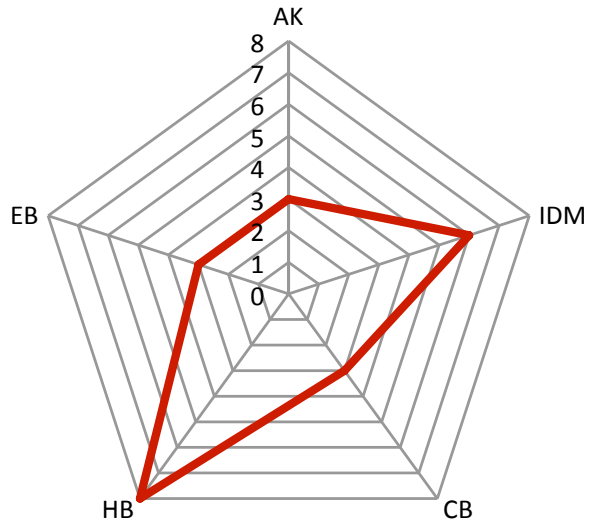
ISOR project: Selection of examples for dissemination and raising awareness

Study on pericardial disease (Permanyer-Miralda et al)



Study with high value in terms of advancing knwledge and yet moderate adoption, implementation or health impact

Outcomes of coronary artery surgery in Catalonia (Permanyer-Miralda et al)



Study with little rellevance in advancing knwledge and yet a high health impact

Both diagrams have the same scale, with a theorretical maximum of 10. Scores are based on non-controlled and un-standardised procedure

ISOR project: careful selection of best cases

Open questions

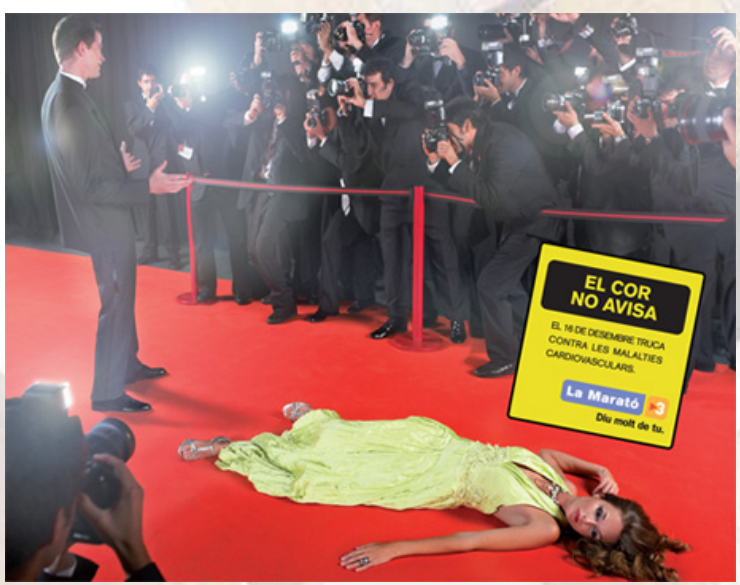
•Did any of the RIA studies awake new advocates for health services research?

• Politics versus evidence-based cases

• What is more powerful, social movements or RIA studies?

Catalan telethon for biomedical research

La Marató 3



New project:
Catalan telethon: from fund-raising to patient advocacy

- Advocacy activities for fund-raising are considered as inputs in the model

- Mapping new impact levels in the CAHS Framework

- New impacts are being studied:

  - Disease awareness
  - Patient empowerment
  - Awakening (new) donors

Key messages

- Choice of evidence-based cases is crucial
- Evidence is important, but politics might be more important.
- Effective communication / champions is crucial
- Raising disease awareness and social movements might be more effective than RIA plans?