



Public and Social Policy of e-Oncology

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Multiple and Byzantine Policy ‘Domains’



Public Policy

Legislative (1995 Data Protection Directive)
Governance ('local' implementation)
Funding policies (research & infrastructure)
Funders policies (open access)
Indirect (e-society, i.e. technology driven)¹

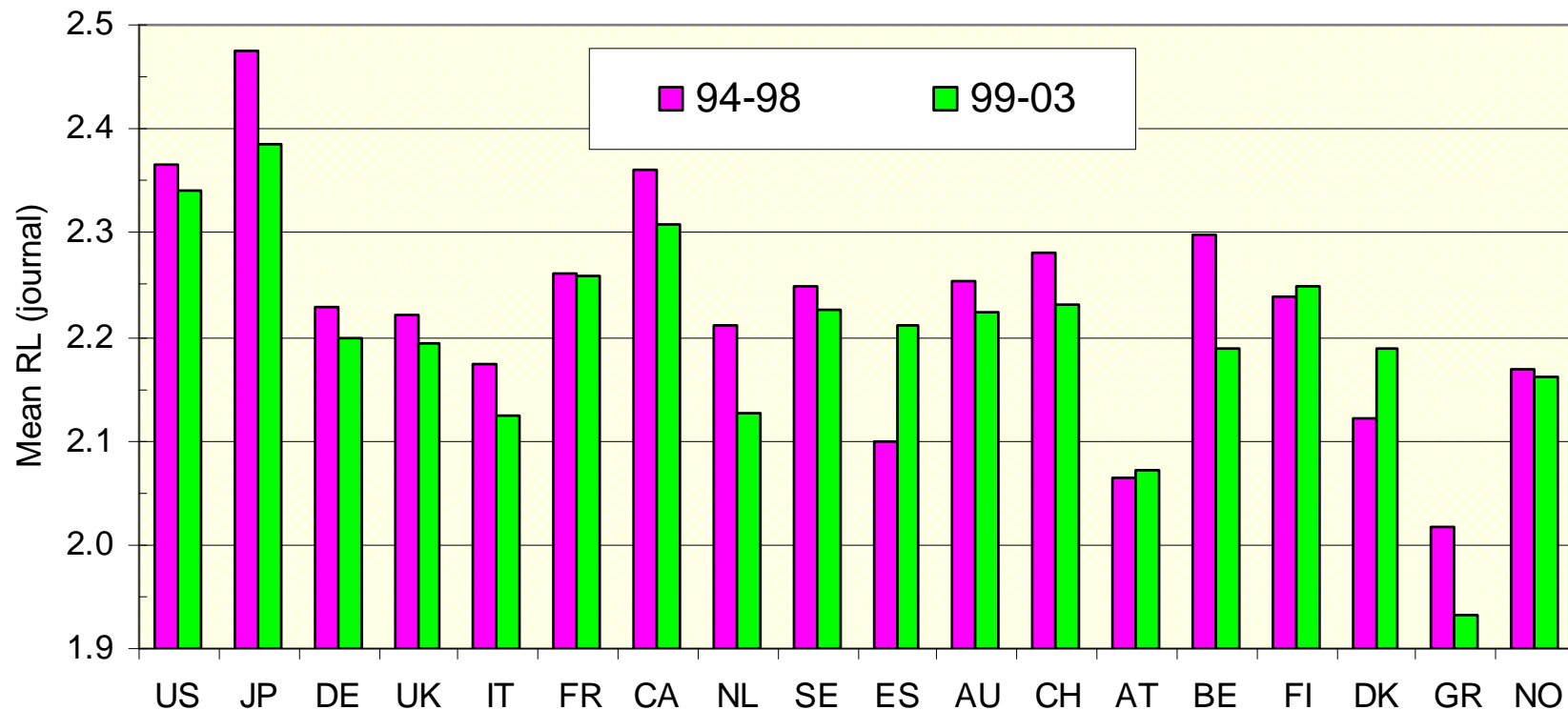
Social Policy

Societies attitudes²
Media
Technophile/phobic

¹ Avery P. Data grids. *Phil Trans R Soc Lond* 2002, 360: 1191

² Barrett, G *et al.* National survey on the British Public's views on use of identifiable patient data by cancer registry's. *BMJ* 2006, 332: 1068

Multiple drivers for policy(s) - e-oncology is part of a wider trend of social and public utility in healthcare and research¹



Source: ECRMF (in press)

Focusing on Public Policy

Legislation

- > legislative and governance mismatch ¹

Governmental policies outside legislation

- > e-healthcare² and research

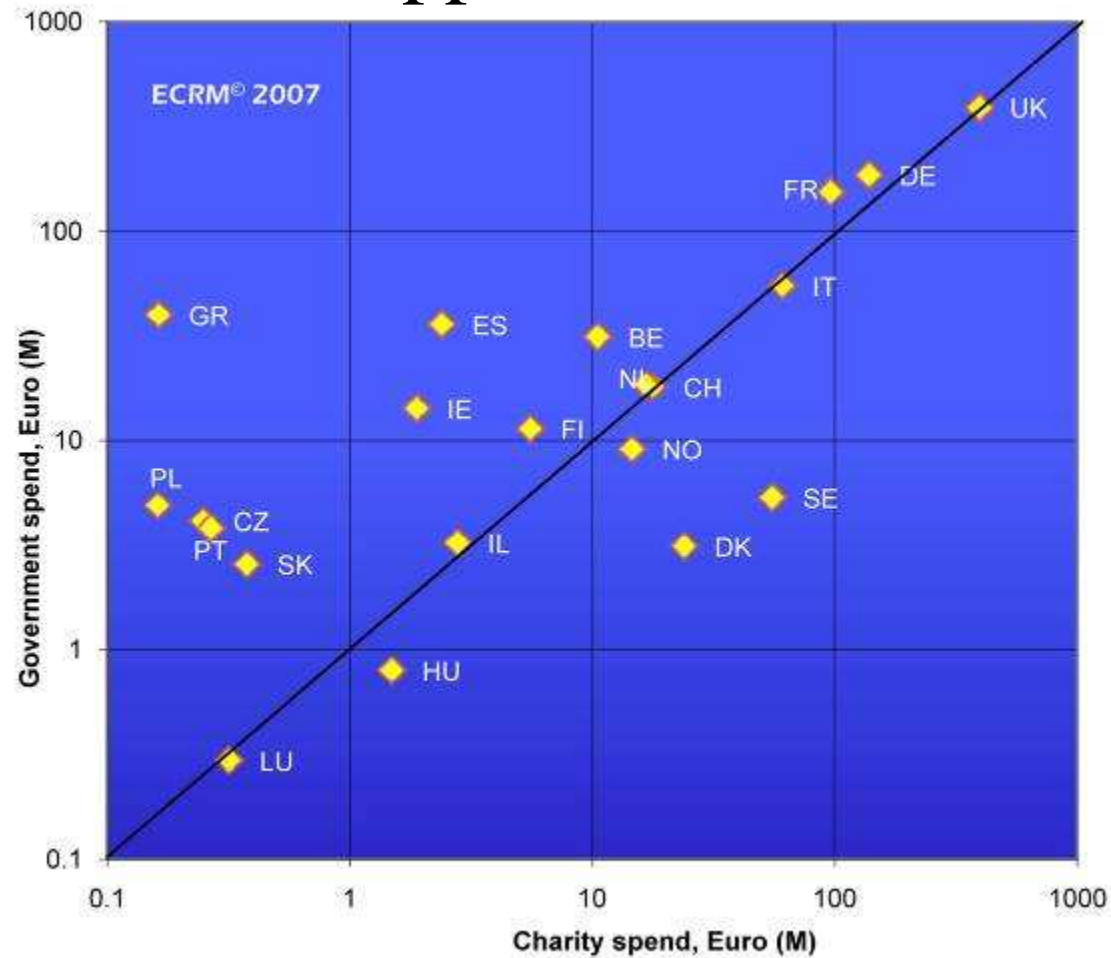
Research Funding Organisations

- > supporting open access
- > promoting e-oncology

¹ Italian Personal Data Protection Code (Legislative Decree no. 196 of 30 June 2003); UK Data protection Act 1998 & Health and Social Care Act 2001

²Cognetti, G et al. E-oncology & health portals. J Exp Clin Cancer Res, 2003, 22:677

Opportunities **but** currently disconnected & support is modest



Despite the urgent need across service delivery
& all domains of research

**< 1.2% income
to major cancer
Centres goes to
E-oncology**

Focusing on Social Policy

Media

> e-oncology can provide a new paradigm ¹

Public Engagement

> with patient groups² and policymakers

Bridging social norms, privacy & utility

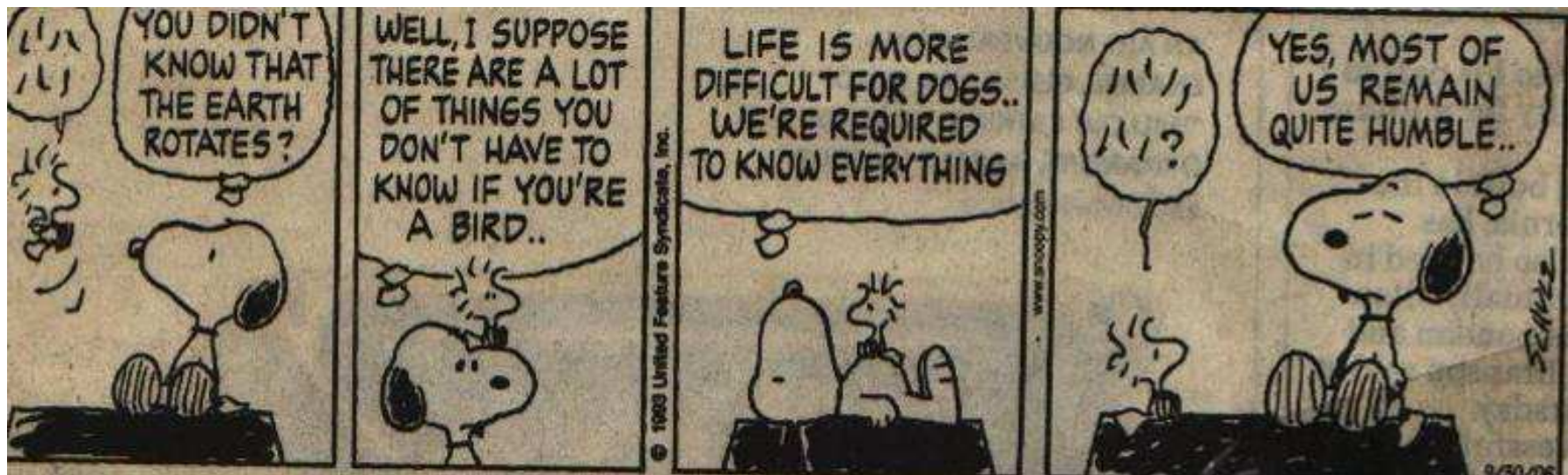
> contextual integrity

¹ Lewison G et al. How do the media report cancer research. BJC 2008, 99: 569

² Responding to the Challenge of Cancer in Europe: European Observatory 2008.

We have strong social foundations for e-oncology

- > Information best protected by medical services, doctors & public institutions¹.
- > Lacunae in public knowledge about e-society.....



Putting this into practise... Strategic Data Planning for e-oncology

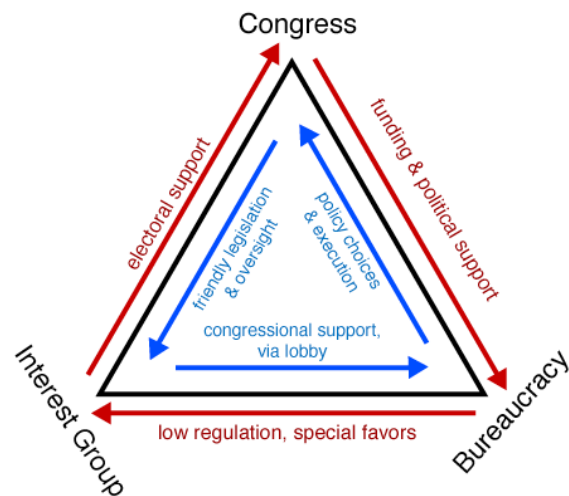
1. Implementation of integrated systems
2. Data architecture
3. Identifying systems priorities
4. Rethinking processes
5. Education & communication
- 6. Improving patient outcomes**

Dale Goodhue et al. Strategic data planning: lessons from the field

MIS Quarterly 1992, March: 11

What is the ‘ideal’ policy model for e-oncology? No right or wrong answer

Pulitzer’s “Iron Triangle”



Heclo’s “Issue Networks”

