* New/potential EU Directives and the Impact on the UK

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Data Workshop 11th February 2016

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The European *Data Protection Regulation*

To Protect The Citizen’s Rights to Privacy;

- European harmonisation; same rights for all citizens
- Regulation, not guidance, to enable enforcement
- Protection of personal, *identifiable* data
- All data; family, jobs, finances, shopping, internet use, health, qualifications, travel, immigration, security…
- Who has access, why and how?
- What does “identifiable” mean?

EUROBAROMETER 359: Attitudes on Data Protection and Electronic Identity in the European Union

Published June 2011

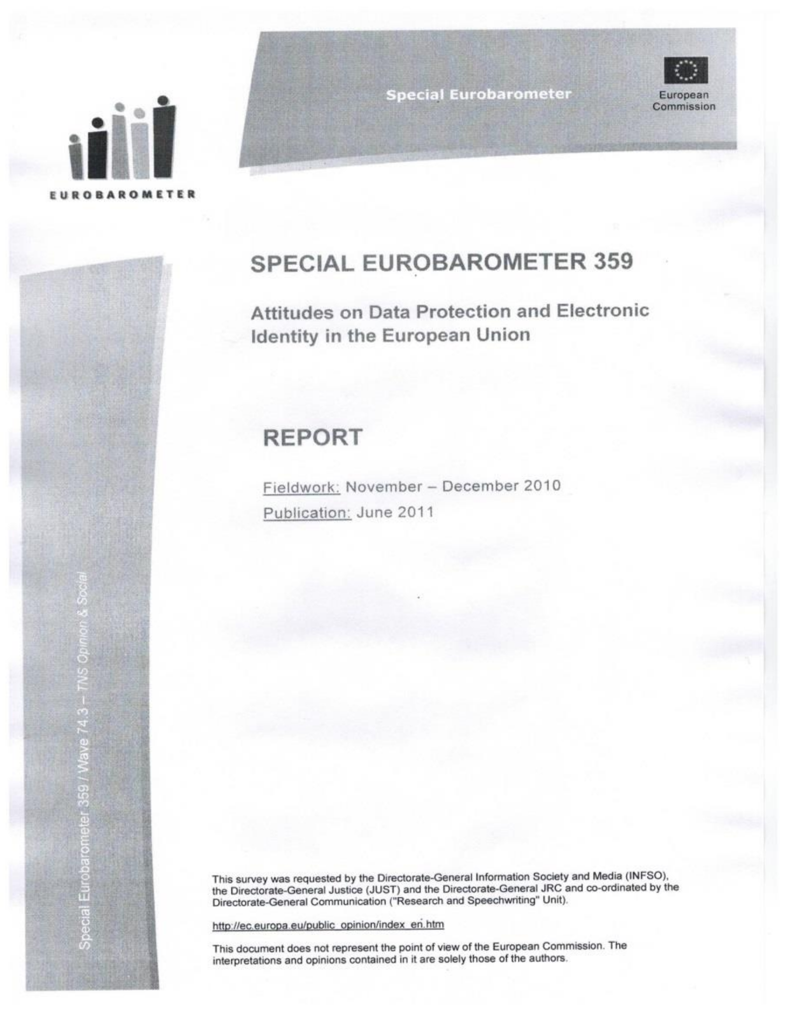
N = 26,574 European Citizens aged 15+

From all 27 member states

"A large majority of the European interviewees see patient records and health information as personal. This answer comes first in five Member States: Ireland (93%), Slovenia (90%), Sweden (89%), Belgium (84%), and France (82%). In Austria, the same number of respondents considered medical information and home address as personal (75%).

"Vast majorities of respondents who believe that medical information is personal are also found in the Czech Republic, Germany, Denmark (each 87%), the Netherlands (86%), Slovakia (84%), the United Kingdom (83%), Estonia (81%), Finland (80%), Malta (79%) and Latvia (77%).

"Countries where only around half of the respondents think so are Poland (46%), Portugal and Romania (each 50%) and Bulgaria (52%)."



Special Eurobarometer

European Commission

EUROBAROMETER

Special Eurobarometer 359 / Wave 74.3 – TNS Opinion & Social

SPECIAL EUROBAROMETER 359

Attitudes on Data Protection and Electronic Identity in the European Union

REPORT

Fieldwork: November – December 2010

Publication: June 2011

This survey was requested by the Directorate-General Information Society and Media (INFSO), the Directorate-General Justice (JUST) and the Directorate-General JRC and co-ordinated by the Directorate-General Communication ("Research and Speechwriting" Unit).

http://ec.europa.eu/public_opinion/index_en.htm

This document does not represent the point of view of the European Commission. The interpretations and opinions contained in it are solely those of the authors.

* Putting The Case…

Providing Personal Data and Cancer Survival – The Rights of Patients. We Have The Right …

- ✓ To require that our data is used for our own benefit.
  (We expect our clinicians and our hospitals to do that.)
- ✓ To require that our data is used to benefit other patients.
  (We expect researchers and the medical world to do that.)
- ✓ To be involved in decisions about us, our data and using it.
  - What data? (Anonymised or pseudonymised? Consent?)
  - Who holds it? (Safety/confidentiality? Shared access?)
  - Who wants it? (Access or takeaway? All or part?)
  - What for? (Regulated medical research? Improving services? Increasing our understanding?)

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* The Rights of Patients And Active Citizens; Principles Suggested by UK Cancer Patients

- ☺ There is no data about us without us, so use our data to help us. We expect our own data to be available to clinicians who treat us.

- ☺ We have the Right to have our privacy protected, but we also have the Right to Donate data to help others as well as ourselves. For many diseases researchers have a duty to use our data.

- ☺ Health and medical data therefore cannot be treated in the same fashion as financial or other personal data.

- ☺ Put patients at the heart of the matter; empower us as Active Citizens. It's our data and we want to share it; so let us share in making the decisions about who gets it and why.

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* The Rights of Patients And Active Citizens; Practical Suggestions From UK Cancer Patients

- ☺ Use existing laws and regulations to protect us – they are enough
  - ✓ Take advice from Wellcome Trust, Cancer Research UK et al

- ☺ Awareness/Education Programmes for Patients & Public
  - ✓ Our rights and opportunities as active citizens (PHE; ECPC)

- ☺ Patient/Citizen Involvement
  - ✓ Data Access Committees
  - ✓ Funding Committees, Management Bodies, Regulators
  - ✓ Research – Trial Management Groups, Data/Safety Committees

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Europe Listened!

- ☺ Final agreed wording of the new regulations safeguards individual privacy, with exemptions to support scientific research for the benefit of the wider community
- ☺ It is close to the current UK system and our existing Data Protection Act
- 😐 However this does not change our situation in the UK and the problems with data flow that we currently face
- 😐 It also does not yet address the issue of involving patients in decisions about storage and access
- ☺ It has brought new and closer links between European Patient Groups and also groups and advocates within UK

* BUT - Europe Listened!

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