



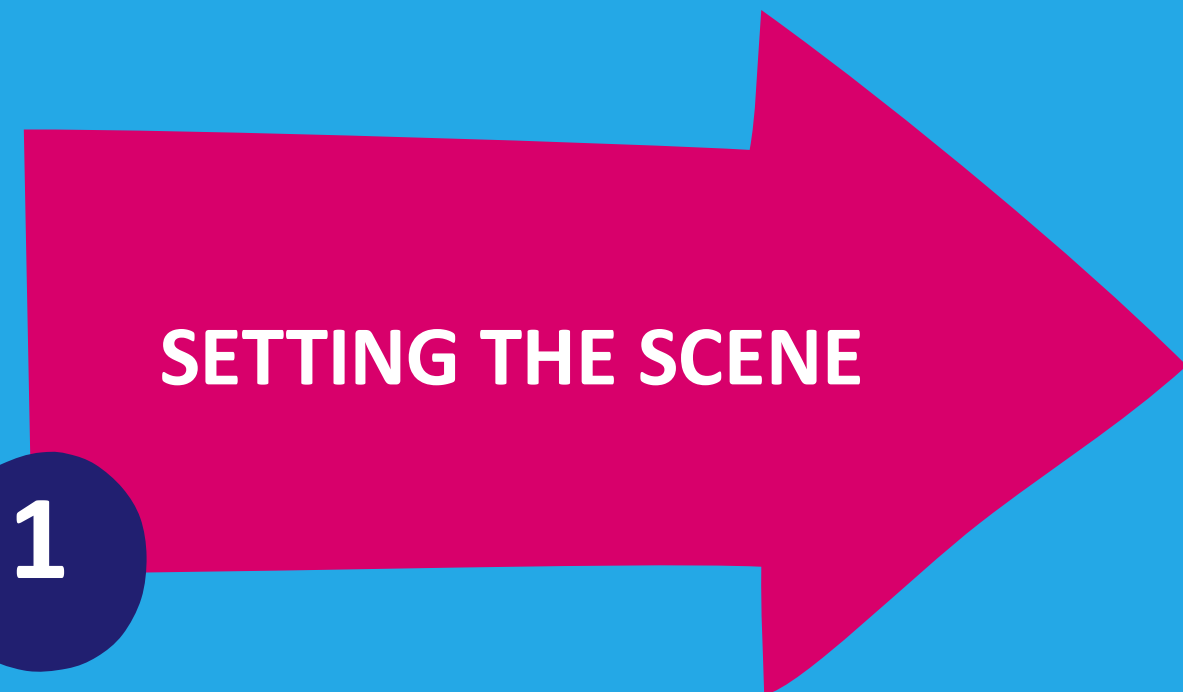
Personal Data & Research: consent in the EU DPR

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CANCER RESEARCH UK, 28 JANUARY 2015

Contents

What I'll Talk About Today :

- Setting the scene: why and how personal data is used in research
- The draft EU Data Protection Regulation – what are the issues? And why does it matter?
- How did we get here? And what needs to happen?



SETTING THE SCENE

1

Why personal data is used in research

PERSONAL DATA SAVES LIVES

How personal data is used in research

Privacy



Consent

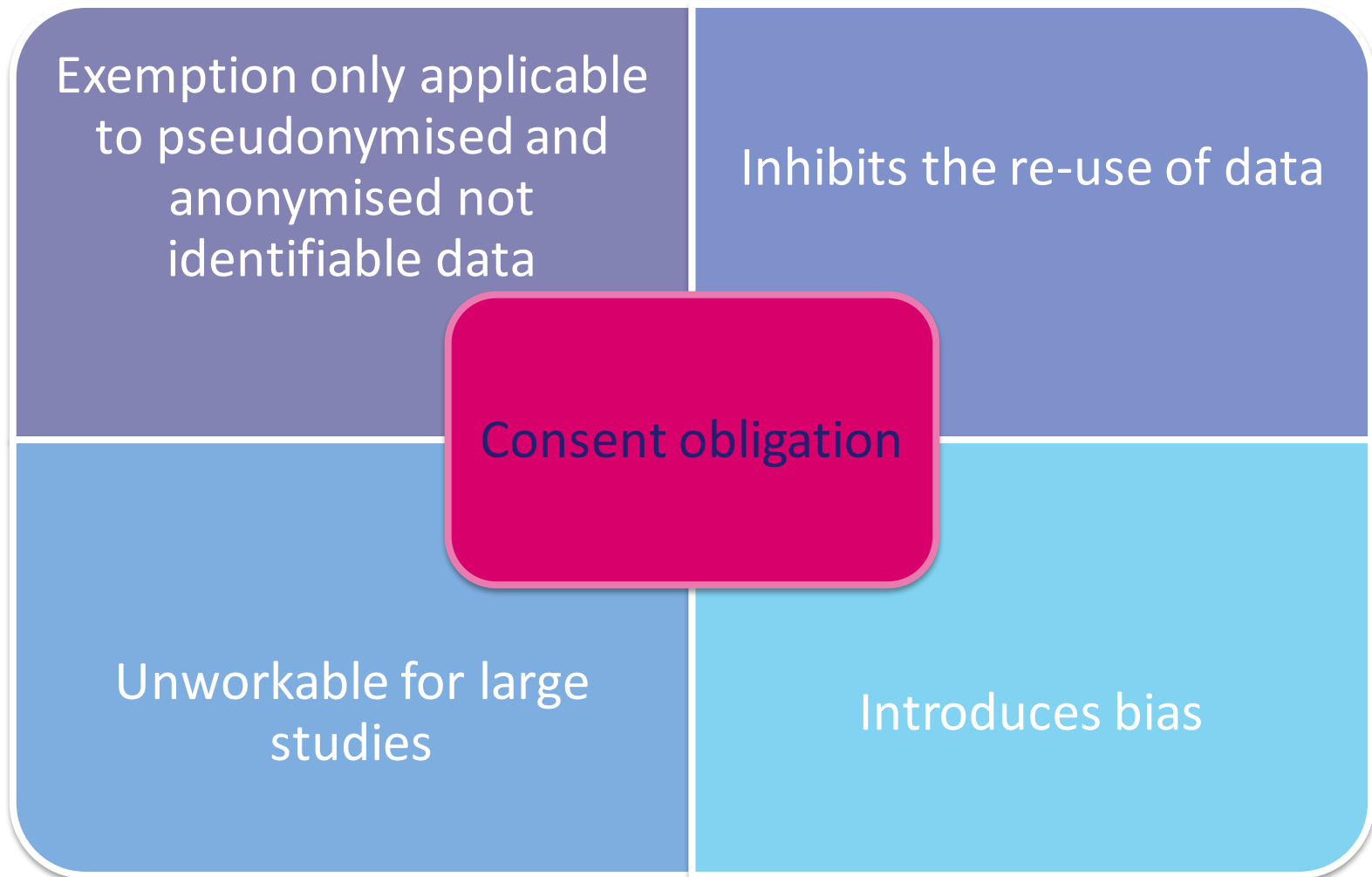


**DPR – WHAT IS THE
ISSUE AND WHY DOES IT
MATTER ?**



2

The EP position on EU DPR – what is the issue?



...and why does it matter?

- **Bad news for health** Will change how research is done in Europe...and could stem health breakthroughs.

- **Bad news for Europe** Will limit Europe's ability to compete on a global stage through research.



**HOW DID WE GET HERE?
AND WHAT NEEDS TO
HAPPEN?**



3

A big part of the problem...



The reality

The Data Protection Regulation

The Patient View



...and another part of the problem



Top 5 List

- 1.
- 2.
- 3.
- 4.
- 5.

What next

A BALANCE CAN AND MUST BE STRUCK BETWEEN ENSURING PRIVACY AND SAFEGUARDING RESEARCH

- ✓ The Council needs to continue prioritising health and research issues in ongoing talks
- ✓ The European Parliament must do more to accommodate needs of research
- ✓ **There must be an exemption from specific consent for research in the final text, subject to effective safeguards**

A quick plug!

EUROPEAN DATA IN HEALTH RESEARCH ALLIANCE

[HOME](#) [NEWS & RESOURCES](#) [CASE STUDIES](#) [WHO WE ARE](#)

PERSONAL DATA SAVES LIVES



Researchers use personal data to make life better for all of us. It is vital that the Data Protection Regulation does not limit the use of this data.

[WHO WE ARE](#)

WHAT WE STAND TO LOSE



This prostate cancer study is a major collaboration that has significantly expanded knowledge of how likely a person is to develop prostate cancer from their genes.

[VIEW CASE STUDY](#)



LATEST UPDATES

Balancing the right to privacy and the right to health



The right to privacy and the consequent need for data protection is an aspiration of the great majority of people living in Europe. The draft Data Protection Regulation (DPR) is designed to provide the legislative framework for protecting peoples' right to privacy and generally it does a very good job, writes **Professor Richard Frackowiak - Chair - Science Europe.**

Safeguarding the status quo: privacy and possibility in research



Individuals' health data is vital resource for health research and researchers have used this data for decades to understand more about the factors underpinning health and disease.

Patient Data: A Vital Resource for Cardiovascular disease researchers



Laurent Louette, Policy Officer for Patients & Research at European Heart Network, explains why the EU data protection regulation must ensure vital research into cardiovascular disease can continue.

POSITIONS & RESEARCH

 Press Release - Alliance response to Council of Ministers PGA: December 2014

 European Data in Health Research Alliance - Position



THANK YOU!

cruk.org

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