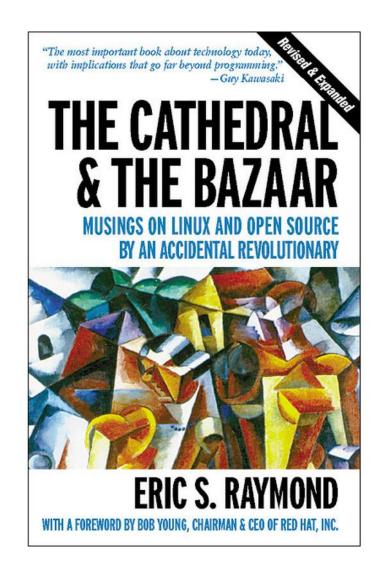
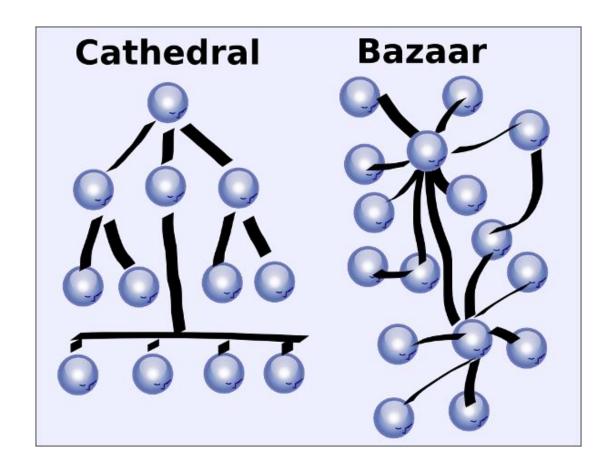
# 

## Legal aspects of data-sharing

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### The lessons for data-sharing infrastructure

**BOTTOM UP** 

**TOP DOWN** 

Central authority organises the repository

User fills the data he/she consideres relevant

The central authority seeks, selects and chooses content

Organizes it for the convenience of end user



### Data sharing design and law

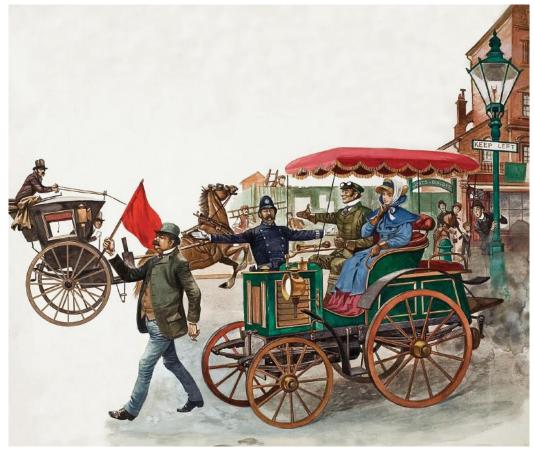
# Law is predominantly based on the presumption of "top down" design

- It is easy to identify person with responsibility/liability
- It is easy to attribute "ownership"



Law is very bad at anticipating the potential of technology

Short term concerns outweigh long term potential





# The emergence of "bottom up" in IT brings us new tools, that we are still learning to use

- Safe harbor regimes
- Codes of conducts
- Free licenses



### Main legal issues in data-sharing

### Intellectual property rights

- Authorship of database
- Sui generis database rights
- Rights to primary data (maybe in the future)

### Data protection rights, Privacy

GDPR, general privacy rules

### Right to access to information

- Public sector information
- Knowledge rights
- Data-mining exceptions



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# Intellectual property rights

WHO OWNS THE DATA?

### WHO OWNS THE DATA?

Is a very inaccurate question

Ownership is possession of the storage medium

Does not grant the exclusive rights

Better question is "who owns IP rights to the data"



### IP RIGHTS TO THE DATA

### Database Authorship

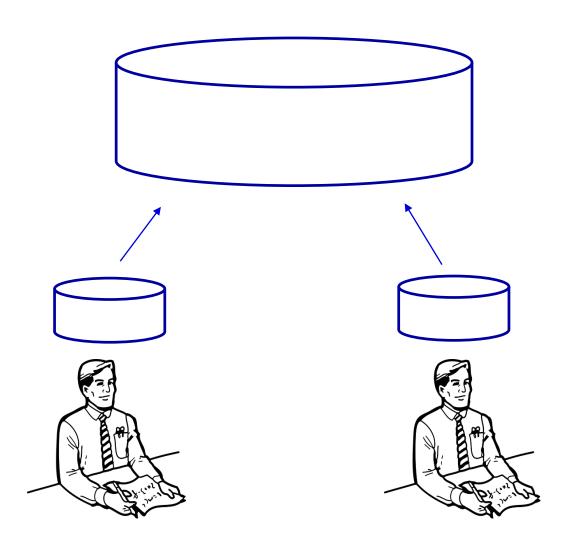
Protects creative input to collection of the data

### Sui generis database rights

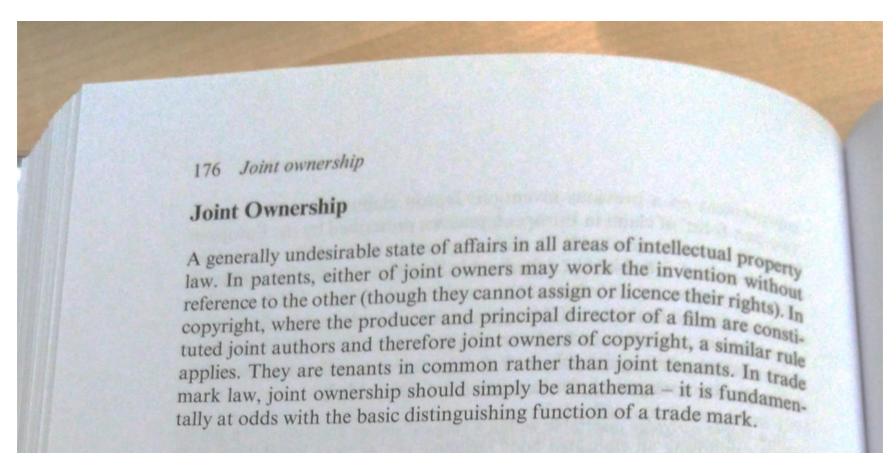
Protects the investment

### Not every dataset is protected !!!

### Bottom up approach is a challenge



### Owning the data jointly



### **Possible outcomes**

1+1=1 - desired outcome - merging two databases into one "joint database "

1+1=0 – merging two databases without substantial investment might create dataset without "database right protection"

1+1=2 – mere process of merging two databases does not constitute a substantial investment or original element. Therefore the two database rights exist independently

1+1=3 – the newly created database gains protection but the two original databases are still protected

0+0=1 – ideal situation – the datasets which would not be protected individually are protected as a whole

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### DATA PROTECTION RULES

### Major concerns of research institutions

#### Consent:

- Open consent
- Blank consent
- Re-consent

### Anonymisation, pseudonymisation

- fluid concepts
- blurred obrder

#### Biological samples

- Is the sample itself personal information
- Cultivated samples
- National provisions on biobanking and tissues

# Archiving and processing records of qualitative research

 Sociological, Psychological, Ethnological,

Heritage data

Data sharing, Open data,

#### Deceased persons

 Persons presumed to be deceased

#### Medical research

- Analysis of data by provider
- Analysis of data by researcher outside hospital
- Merging data from several providers

#### **Public interest**

- Whaich research is in public interest?
- Is research public interest itself?

Access to data by third authorities

Interference with the physicians – patient priviledge

# GDPR an actual opportunity for bottom up approach

It does not prescribe sets of measures to be taken

It puts the person who controls the data into driving seat

It is up to him to determine what is necessary to protect the data

It allows for sector specific codes of conduct

Demonstrate compliance with the obligations of the controller.

Mitigating factor in enforcement

#### **CODES OF** CONDUCT

Associations and other bodies representing categories of controllers or processors may prepare codes of conduct

Monitoring and certifications

# 

Right to know (?) and information access

# There are other rights that have to be balanced towards "restrictive rights"

Freedom of speech

Freedom of information

Freedom of the arts and sciences

Transparency of public sector



### Strong message from the EU

It is not desirable to monopolize or proprietise mere information.



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# Thank you