

**Data protection and ethical risks
management in **European projects****

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Identifying the risk?

Some definitions?

Data privacy: Data privacy involves the right of any individuals to expect that personal information collected about them will be processed securely and will not be disseminated in any form without their written consent. Furthermore, data privacy must not be subject to "mission creep" (This means information being collected with permission for one purpose and being used without permission for another reason).

Data protection: Data protection consists of a framework of security measures designed to guarantee that data are handled in such a manner as to ensure that they are safe from unforeseen, unintended, unwanted or malevolent use. Data protection is the technical mechanism to ensure data privacy. Data protection concerns: Access to data - Conservation of the data – Accuracy & integrity of the data – International data transfer

Identifying the risk?

What is data protection and ethical risk about ?

The most common data centered Project Risks

Collection risk	Structure risk	Usage risk	Access risk	Conservation risk
<ul style="list-style-type: none">▪ Right to collect (children/vulnerable persons/ e.g : treatment of illiteracy)▪ Protected data (minutiae, biometric data)▪ Consent/assent▪ Information	<ul style="list-style-type: none">▪ Type of data collected is legit (secondary usage = do you have the right to collect this data = census data)	<ul style="list-style-type: none">▪ Mission creep▪ Unforeseen of undeclared usage▪ Data Merge	<ul style="list-style-type: none">▪ Unwanted access▪ Malevolent usage	<ul style="list-style-type: none">▪ Data discrepancy (data need to be circulating to be up to date)

Identifying the risk?

Where is the issue hidden?

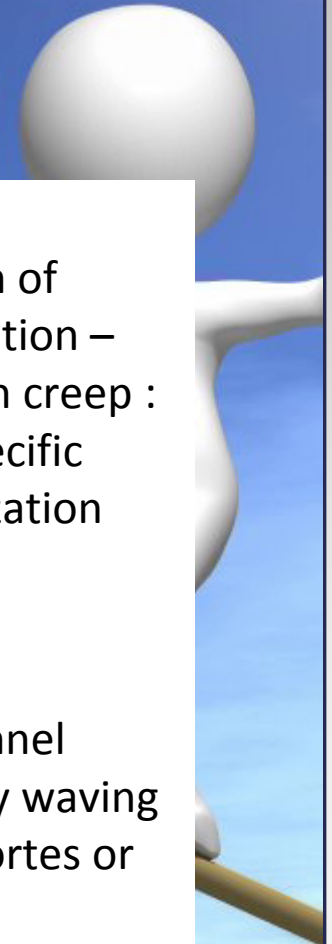
- ✓ Within the project

Data creation (origin, reason, method, using who or what : the question of personal data, healthy volunteers data, patient data) – Data transformation – Data acquisition – Data international transfer – Again beware of mission creep : data must be collected for a specific purpose...All reuse is subject to specific authorization – Data impact : data whose leakage might lead to ostracization (information on pathologies)

- ✓ In and around the project

Human resources, researcher data : using students, researchers, personnel attached or dedicated to the project as test bed does not constitute any waving of the law...the fact that the test is not implemented using specific cohortes or the general public also...

- ✓ An issue that survives the project – as long as the data is kept

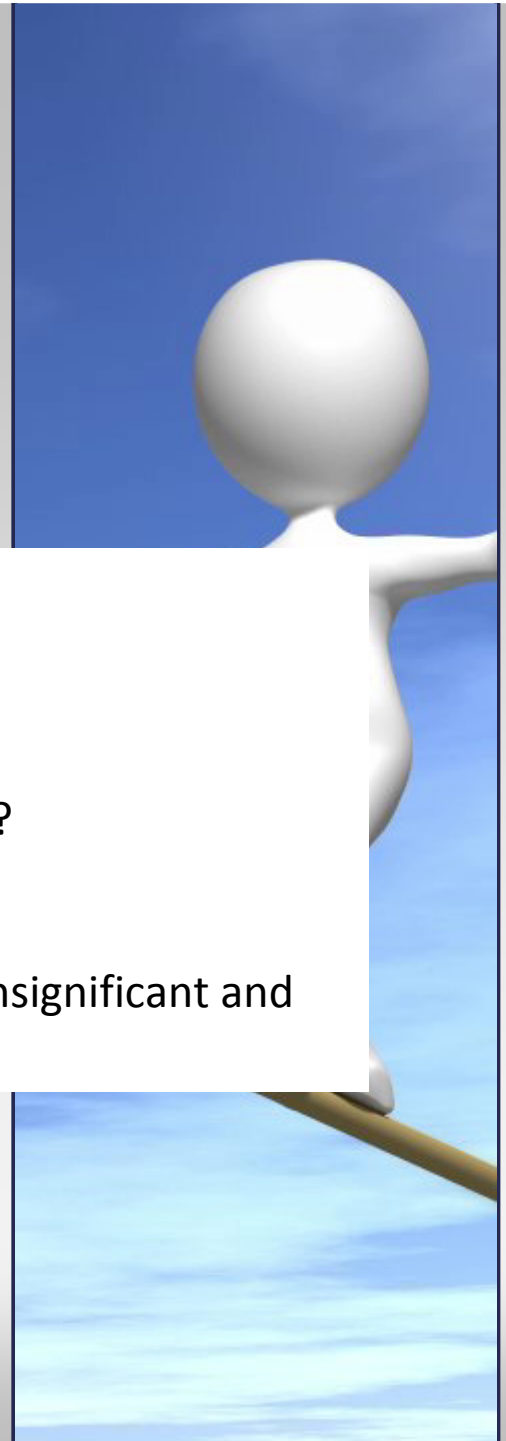


Identifying the risk?

Where is the issue hidden?

✓ After the project

1. Will the data be kept for future use?
2. For how long?
3. Will the data be transferred (within Europe, outside Europe)?
4. Will the data be shared?
5. Will the data be subjected to commercial usage?
6. Will the data be aggregated? (as a data set per se might be insignificant and take a whole other sense or meaning while aggregated)



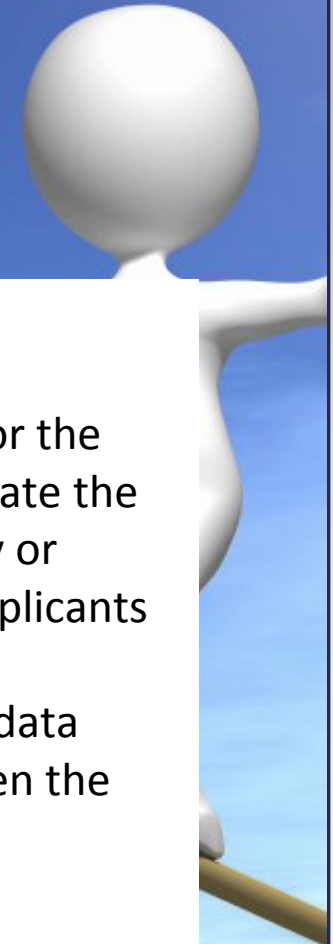
Identifying the risk?

Where is the issue hidden?

✓ After the project

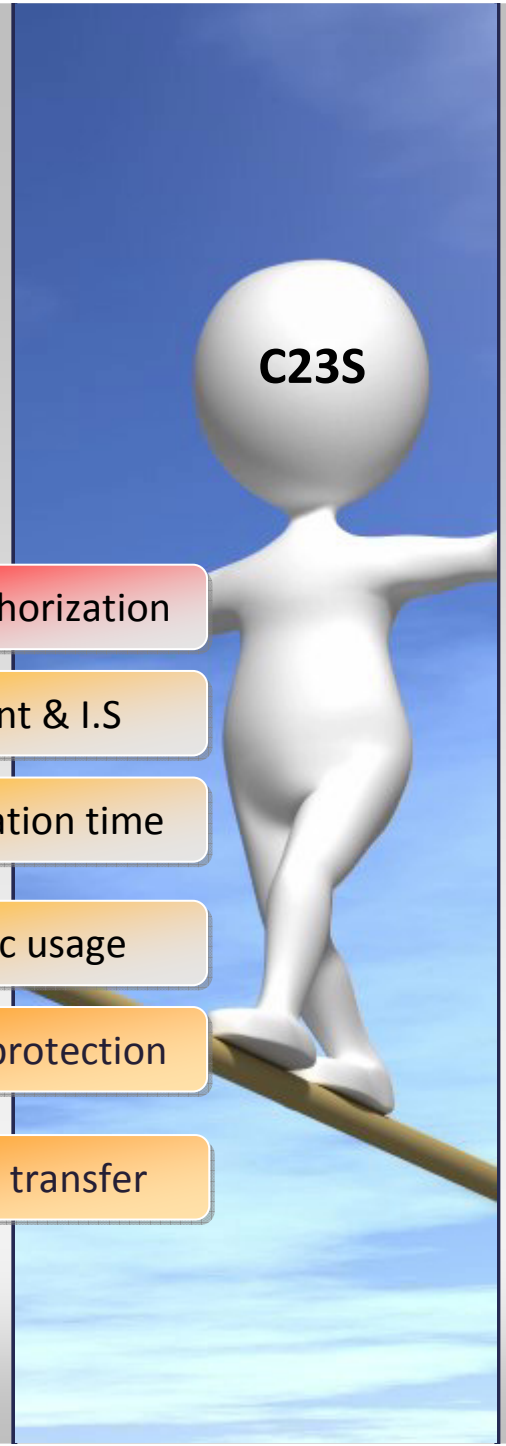
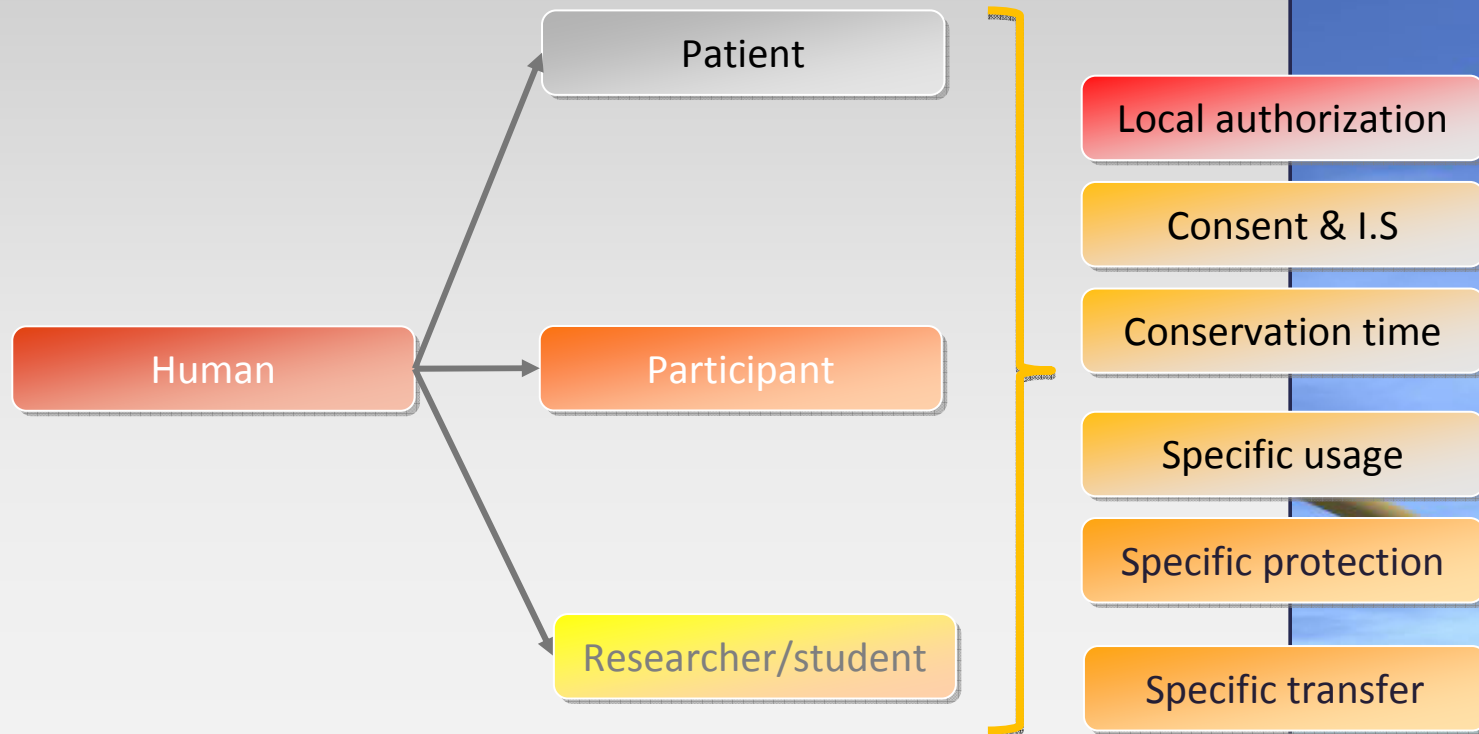
Applicants are responsible of the data they gathered or kept not only for the duration of the project but also after the end of it. They need to anticipate the fact that if any kind of malevolent use is made of the data generated by or created for the project, they will be deemed responsible. Therefore, applicants should offer a strategy :

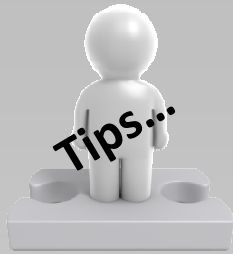
- 1.either to destroy the data at the end of the project (i.e to render the data impossible to use, as complete data destruction is quite impossible when the data is kept under electronic form)
- 2.or make the necessary effort to offer a complete protection for the anticipated conservation period.



Identifying the risk

What is data about ?





**Filling the puzzle...
Tips to talk with the competent
local/national authority...**

**When asking for your
local/national authorization...**

**DO NOT ASK
For an ethical authorization....**

DO ASK

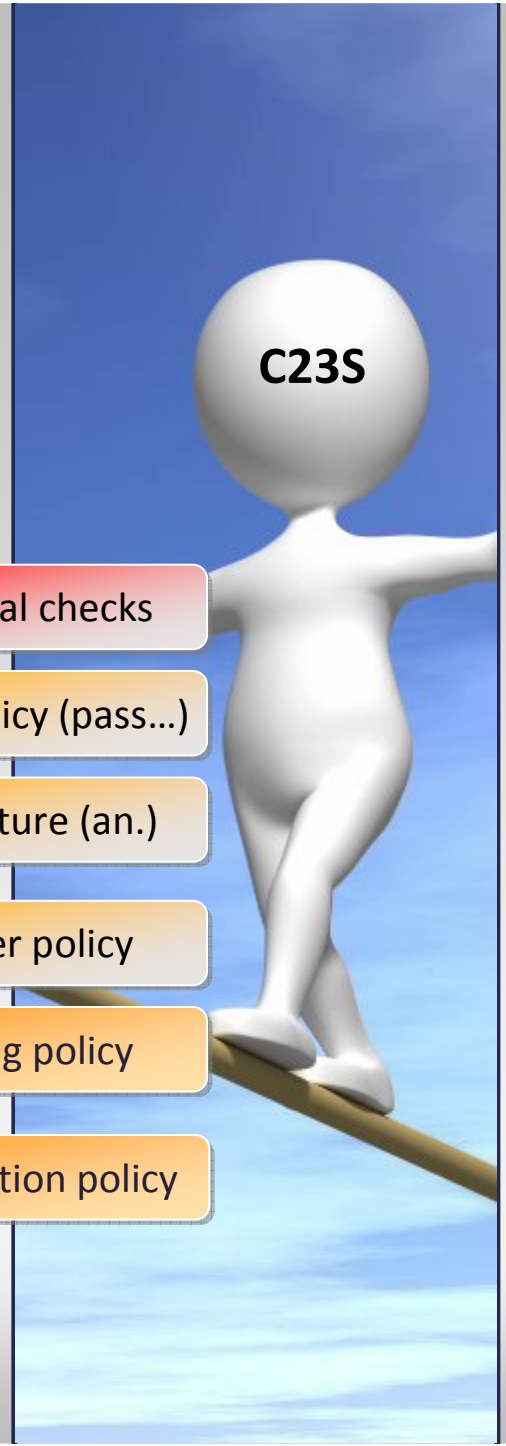
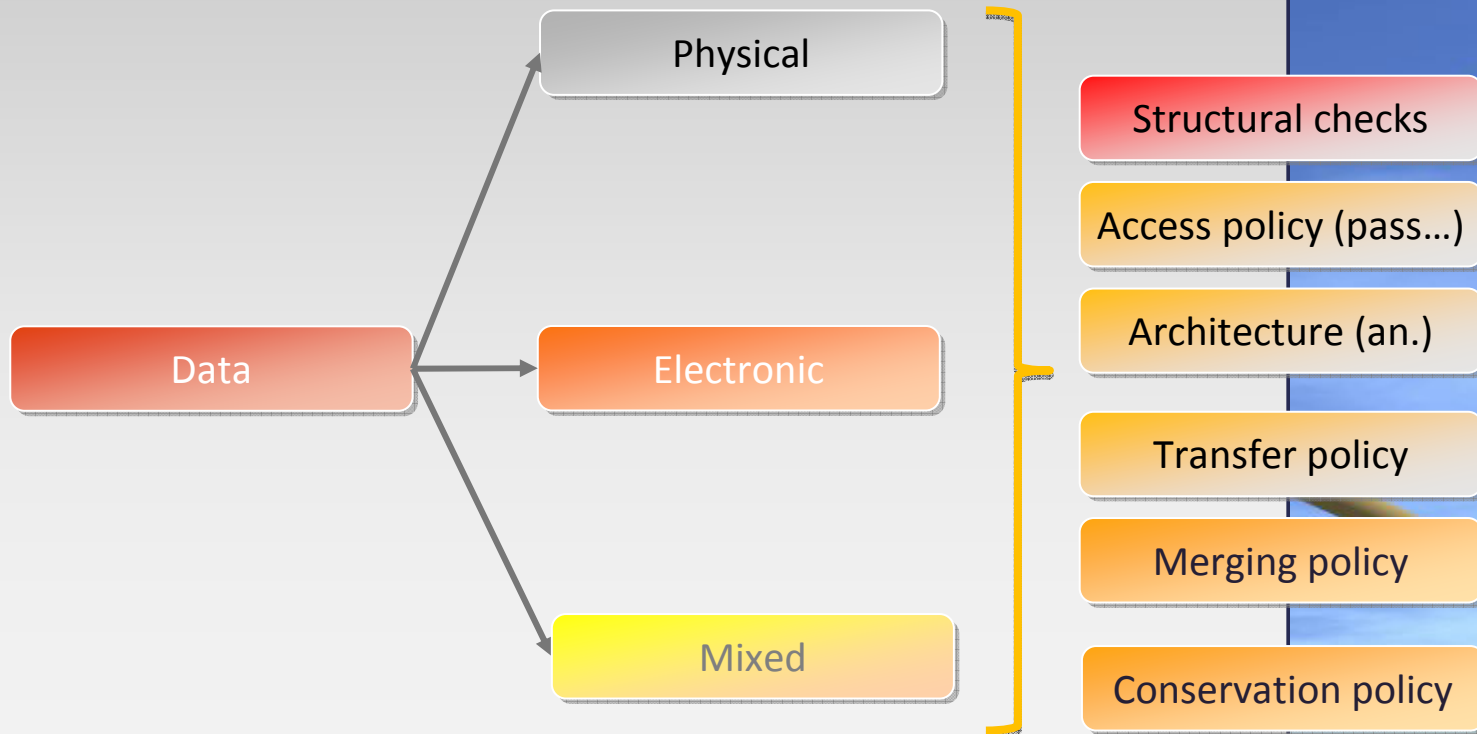
**For the right to collect, use, merge,
keep, transfer the data as fit for the
research....and provide all the needed
documents....**

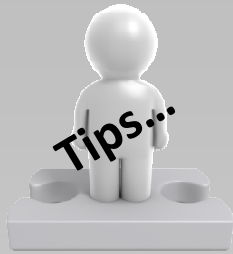
A lawyers talk...



Identifying the risk

What is structure about ?



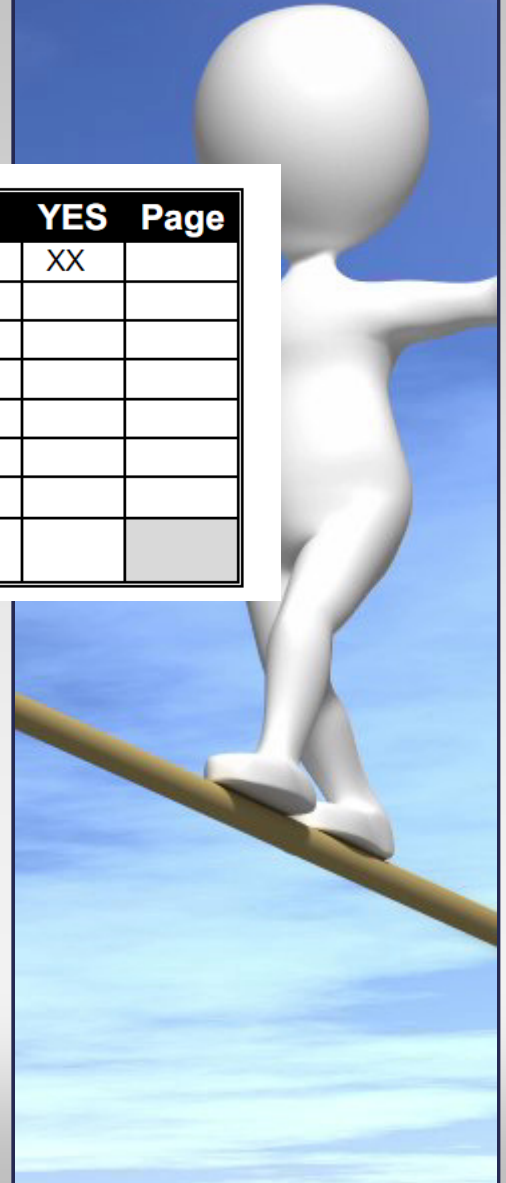


**Filling the puzzle...
Tips to talk with the competent
local/national authority...**

Research on Humans		YES	Page
*	Does the proposed research involve children?	XX	
*	Does the proposed research involve patients?		
*	Does the proposed research involve persons not able to give consent?		
*	Does the proposed research involve adult healthy volunteers?		
	Does the proposed research involve Human genetic material?		
	Does the proposed research involve Human biological samples?		
	Does the proposed research involve Human data collection?		
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL		

**When the project is collecting data
from...
Patients/Stakeholders/End
Users/Researcher/Volunteers/Conferen
ce participants...**

Whenever data is collected...



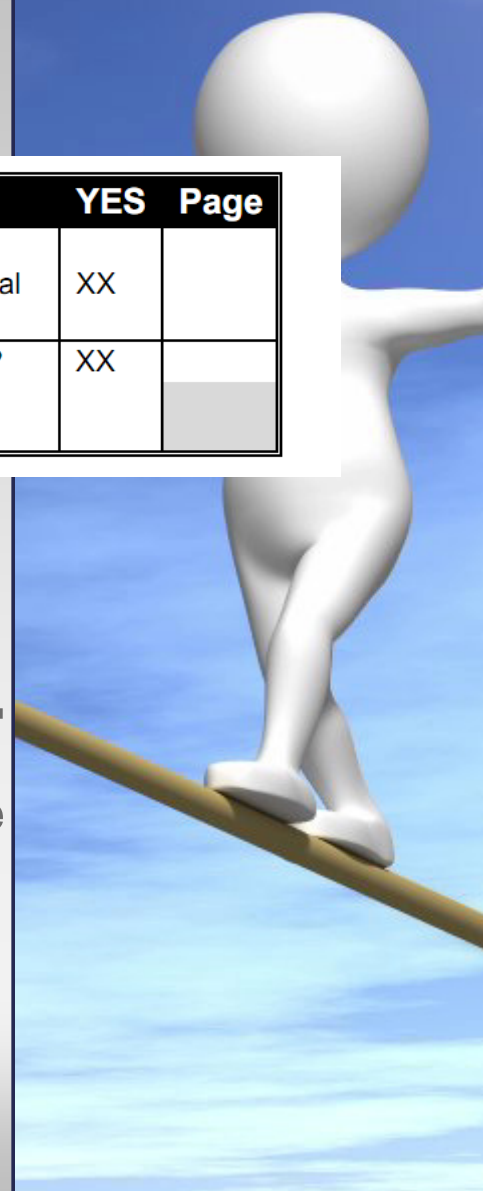


Filling the puzzle... Tips to talk with the competent **local/national authority...**

Privacy		YES	Page
<input type="checkbox"/>	Does the proposed research involve processing of genetic information or personal data (e.g. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)?	XX	
<input type="checkbox"/>	Does the proposed research involve tracking the location or observation of people?	XX	
<input type="checkbox"/> I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL			

**When the project is processing data from...
Patients/Stakeholders/End
Users/Volunteers/Researcher/Conference
participants...**

Whenever data is processed...



Filling the EIT properly = proper project risk anticipation

✓ Walking on moving grounds : Vast number of references....

Always changing = normal = moving at the same pace than technology.
All actual directives are being amended or modified – **Telecoms package**

*directive amending : Access Directive (2002/19/EC) - Authorization Directive (2002/20/EC) - Framework Directive (2002/21/EC)

* directive amending : Universal Service Directive (2002/22/EC) - Personal Data and Protection of Privacy Directive (ePrivacy) (2002/58/EC)

* directive creating a Body of European Regulators of Electronic Communications

[DIRECTIVE 2009/136/EC OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 25 November 2009](#)

Supposed to be transfered in 2011 (and in some case already opposable... cf : France)

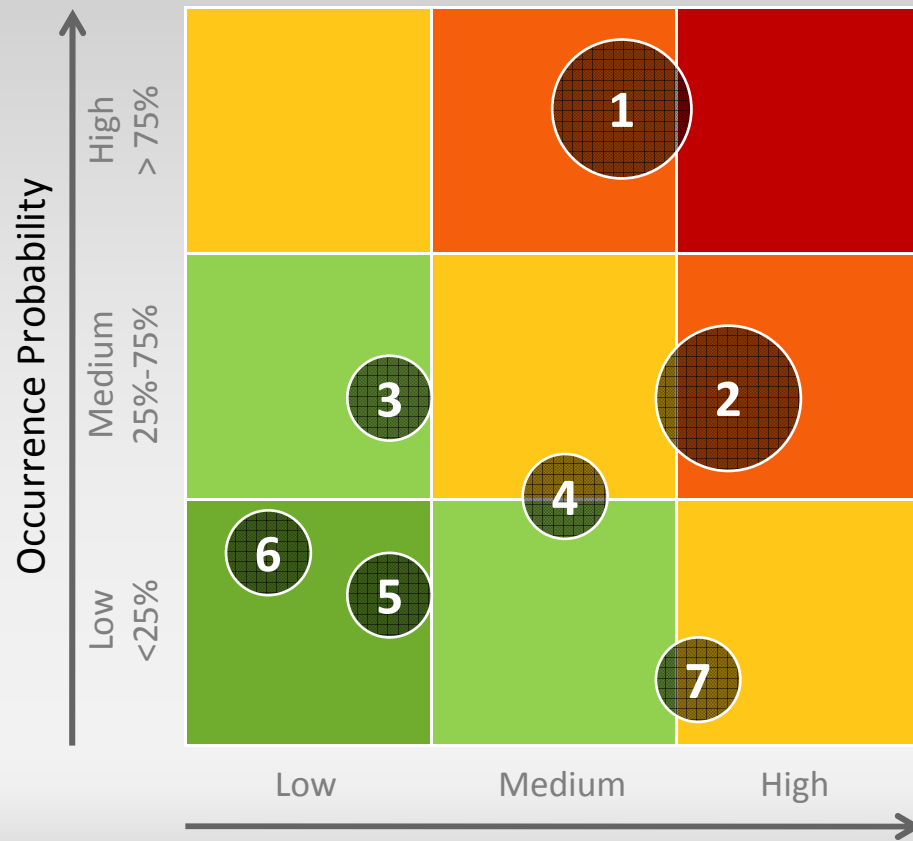
Filling the EIT properly = proper project risk anticipation



Collection risk	Structure risk	Risk Category (Assessment 1-5)	Usage risk	Access risk	Conservation risk
<text>	<text>	5	<text>	<text>	<text>
<text>	<text>	4	<text>	<text>	<text>
		3			
		1			



Filling the EIT properly = proper project risk anticipation





**Thank you for your
attention...**

**Questions?
More Information?**

<ftp://ftp.cordis.europa.eu/pub/fp7/docs/privacy.do>

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