

Whose consent is it really?

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- Patients have a right to access data about them
- Patients have a right to obtain portable copies of that data
- Patients have the right to demand data deletion - the right to be forgotten (but not for research - art 17 (30 (d)))
- Limited consent - foreseen in rec. 33 but unclear

BUT



- No right to decide who has access
- No right to limit access
- No engagement after signature
- Need to re-consent for changes to usage
- In the case of research – national derogations may be enacted = fragmentation

'Consenting' the patient



Dynamic Consent

What – is dynamic consent

- a new approach to engaging individuals about the use of their personal information, for research or care.
- It is ‘dynamic’ because it allows interactions over time; it enables people to alter their consent choices in real time as their circumstances change and to have confidence that these changed choices will take effect.

How can it be done?

- An interactive personalised interface that allows participants to engage as much or as little as they choose and to alter their consent choices in real time.
- consent preferences travel securely with their data so that third parties know the scope of the consent that applies.
- Available preferences can be adapted to suit the capabilities and needs of institutions, researchers and participants.

.... and we already have lots of working models





Thank you

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