




Safe sharing of research data: the role of legal agreements when anonymising

*Thursday 25th April 2019
IET London, 2 Savoy Place, London*

MRC Regulatory Support Centre



Safe sharing of research data: the role of legal agreements when anonymising

Medical Research Council, Regulatory Support Centre

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Research – for the public good

We do some strange things with data / information!

- We collect data we know is 'out of date'
- We do not usually make any decisions about people on the basis of the information we hold
- We are often interested in the unusual
- We look for small changes and subtle, complex relationships – we often need lots of data
- We have ethics approval, peer review etc
- Research is very collaborative (internationally)

- we share data




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Today's objectives

Network and share

- ✓ Determine how it is possible to anonymise information
- ✓ Explore the risks of information sharing to support research
- ✓ Identify some specific parameters that should be considered when 'calculating' such risk
- ✓ Explore how to mitigate risk
- ✓ Explore how we can build 'trustworthiness' within and between organisations

Intended output – to add to our draft Identifiably Guidance (with buy-in from Regulators)



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Legal frameworks

Common law of confidentiality – governs who has access to confidential information (in line with 'reasonable expectations')

General Data Protection Regulation (new Data Protection Act) – governs when and how personal data is processed (fairly, lawfully and transparently)

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What makes information identifiable?



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What makes information identifiable?

Year of birth



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What makes information identifiable?

Gender



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What makes information identifiable?

First part of postcode



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What makes information identifiable?

Place of birth



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What makes information identifiable?

Year of birth
Gender
First part of postcode
Place of birth



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What makes information identifiable?

Year of birth	1965
Gender	Female
First part of postcode	EH32
Place of birth	Bristol



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Identifiability



Content (weak or strong identifiers)

Context (What other information do you have access to? Beware of the rare or unusual)

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Identifiability – a 'grey scale'

Anonymous

Identifiable

Content (weak or strong identifiers)

Context (What other information do you have access to? Beware of the rare or unusual)



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Identifiability – law is binary

Anonymous

Identifiable

Content (weak or strong identifiers)

Context (What other information do you have access to? Beware of the rare or unusual)



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Identifiability – reality of working with scale

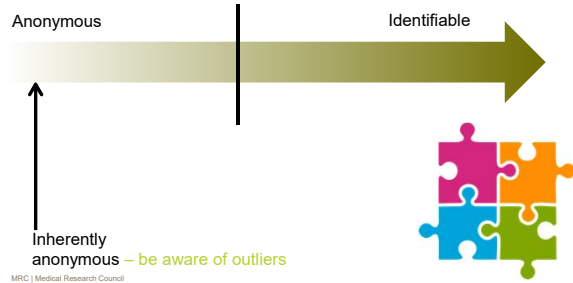
Anonymous

Identifiable

Inherently
anonymous

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Identifiability – reality of working with scale



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Identifiability – reality of working with scale...?



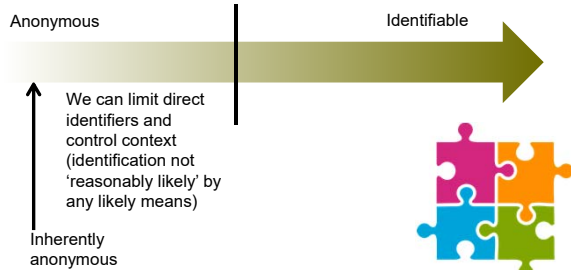
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Identifiability – reality of working with scale

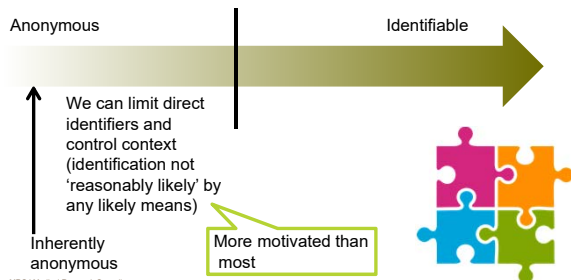


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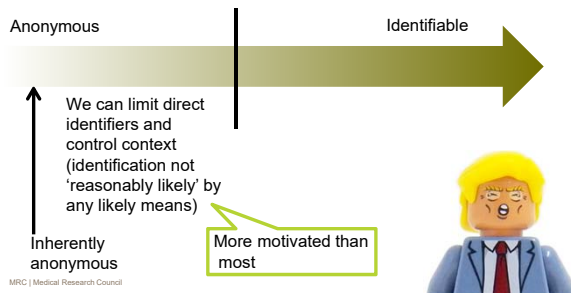
Identifiability – reality of working with scale



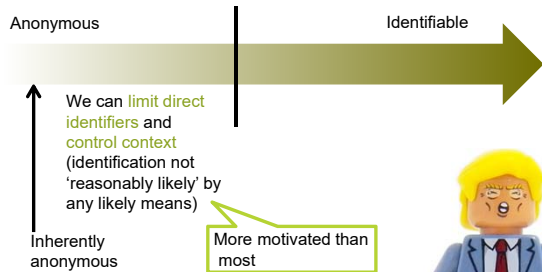
Identifiability – reality of working with scale



Identifiability – reality of working with scale



Identifiability – reality of working with scale



Rachel Merrett

Head of Stakeholder Engagement

NHS England



Data terminology



- NHS England is reviewing the words used by Information Governance (IG) professionals when describing the **identifiability** of data.
- There are for example nearly **30 different terms used** in IG documents which include legal and colloquial terms.
- The aim is to **ensure greater clarity, reduce duplication and improve consistency**.
- The approach will **align with GDPR** and focus on whether the data described is in scope (personal) or out of scope of GDPR (anonymous).
- Guidance and a simple flow diagram will help IG professionals select the appropriate term.

Victoria Cetinkaya

Senior Policy Officer - Engagement (Public Services)

Information Commissioner's Office



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Introduction to workshops

We are being asked to manage the risk of:

1. being in breach of common law
2. being non-compliant with GDPR

when sharing research information (between research groups) *by ensuring information is anonymous*



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Risk – likelihood vs severity of hazard happening

Probability (of occurrence of harm)	Severity				
	Negligible	Minor	Serious	Critical	Catastrophic
Frequent	Medium	Medium	High	High	High
Probable	Low	Medium	High	High	High
Occasional	Low	Medium	Medium	High	High
Remote	Low	Low	Medium	Medium	Medium
Improbable	Low	Low	Low	Low	Low

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Introduction to workshops

We are being asked to manage the risk of:

1. being in breach of common law
 2. being non-compliant with GDPR
- when sharing research information (between research groups) *by ensuring information is anonymous**

**Other ways of mitigating risk - Consent and ensuring lawful, fair and transparent*



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Risk assessment

Risk of breaking the law vs risk of not sharing information



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Workshop 1 – risk of not sharing

What is the risk of not supporting the sharing of information to support research?

Identify the hazards...to your organisation

I will ask each table to give us **ONE** hazard identified per table...



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Risk assessment

Risk of breaking the law vs risk of not sharing information



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Workshop 2 – Risk of non-compliance

What is the risk of being:

1. In breach of common law, and
2. Non-compliant with GDPR when sharing information?

We have provided some broad hazards: can you identify what might contribute to the size of risk associated with these hazards? This includes an assessment of what makes a breach more likely and what would make the impact of such a breach more severe?

Please use your own, day-to-day experiences...
No verbal feedback – please use paper provided to write down main points



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Risk assessments

- Case by case?
- Fall into broad groups: types of dataset, types of transfer etc?
- All instances the same?



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The level of risk will change with time...(likelihood)

'Today, 30 years on from my original proposal for an information management system, half the world is online. It's a moment to celebrate how far we've come, but also an opportunity to reflect on how far we have yet to go...'

Sir Tim Berners-Lee



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Risk assessments

- Case by case?
- Fall into broad groups: types of dataset, types of transfer etc?
- All instances the same?
- Future proofing?



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Risk assessment

Risk of breaking the law vs risk of not sharing information



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Kerina Jones

Associate Professor of Population Data Science

Swansea University



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Risk assessment

Risk of breaking the law vs risk of not sharing information

How do we mitigate the risk?



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Risk assessment

Risk of breaking the law vs risk of not sharing information

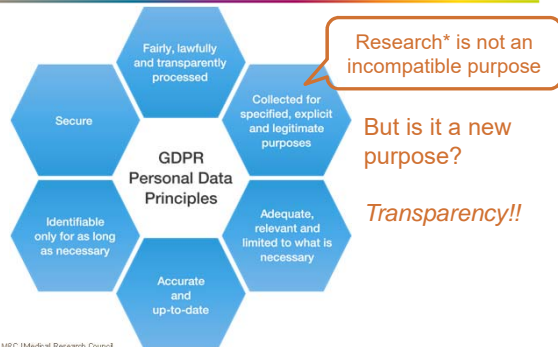
How do we mitigate the risk?

If possible: Obtain consent and ensure fair, lawful and transparent etc



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Principles - Research*



Controls

If consent and transparency are not possible – must rely on sharing only anonymous information, therefore must

- ✓ Limit the content of the information to be shared
- ✓ Limit the context in which the information will be viewed

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Controls

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Build mutual trustworthiness



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Limiting the content of information to be shared

- Information must still be useful
- Justify what needs to be shared
- Implications of linkages proposed etc conducted by recipients
- Beware of outliers....

Who is best placed to do this?

Who understands the data sufficiently?

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Limiting the content of information to be shared

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Workshop 3 – Assurances from researchers

What assurances should you take from your local researcher(s)?
How do they demonstrate trustworthiness to you?

I will ask for feedback on

1. Assurances for which issues would you wish to seek in most cases? Give number from handout!
2. An ideas about what these assurances might involve
3. How do we avoid increasing bureaucracy? (*One idea*)



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Controls

If consent and transparency are not possible – must rely on sharing only anonymous information, therefore must

- ✓ Limit the content of the information to be shared
- ✓ Limit the context in which the information will be viewed

Build mutual trustworthiness



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Alastair Nicholson

Senior Development Manager

Health Research Authority



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Workshop 4 – Control of context

How should we control the context in which the transferred information is viewed? How do we ensure researchers can trust us?

Between organisations or within organisations?

Should it be risk informed?

How do you link the risk assessment conducted in workshop 2 and the mitigations discussed in workshop 3 with these measures?

I will ask for feedback on

1. An issue already met when using agreements to manage anonymisation, and
2. How do we ensure we are risk proportionate in terms of controlling context? (One idea per table)



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Ouputs from today

RSC will:

- ✓ Analyse all of your input from today and use this to inform further development of 'Identifiability, anonymisation and pseudonymisation' guidance note
- ✓ Consult further with regulators to finalise a revised version of guidance for publication (on our website)

*Any further feedback on the draft guidance? Please email:
info@rsc.mrc.ac.uk*

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Regulatory
Support
Centre

For support and guidance with:

- Consent, ethics and governance;
- Confidentiality, data protection and data access;
- Translational research (e.g. medicines, devices, in vitro diagnostics, cell and gene therapies etc.)
- Human tissue; and more.

mrc.ukri.org/regulatorysupportcentre

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