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Health-y Sharing of Human Data

Sarah OLESEN

Australian National Data Service

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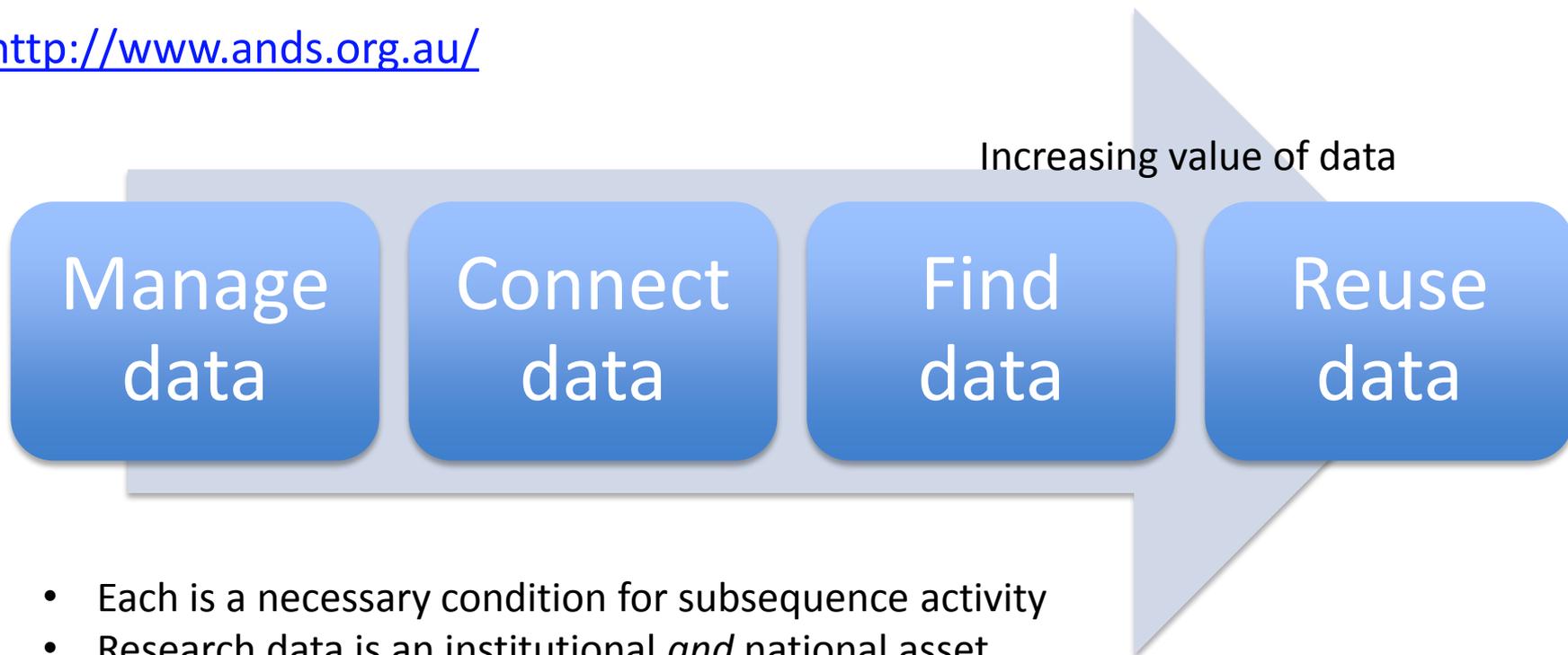
Health-y sharing of human data

Dr. Sarah Olesen

30 SEPTEMBER 2015, SMU Library

Australian National Data Service

<http://www.ands.org.au/>



- Each is a necessary condition for subsequence activity
- Research data is an institutional *and* national asset

- Data publication and sharing
- Sensitive data
- Why?

Plan ahead
& you can Share responsibly
& reap the rewards!

006186.1	70	AGELARD..SIYYVDANASIQEMLNVMEEHQVRRVPVI . SEHRLVGIVTEADIARHLPE	125
Q72EX3.1	33	LSSLVLH..PPLTLDRETSLGEAAARMVEAQVSAVLVG. EATRPEGIITERDITRLVAE	88
Q7MRX3.1	4	IQSLIDK..KIEPLGLGATLKEVHERIKESGCGAVAFIDEESRPVGILTERDISRLLFE	60
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Q7NYA0.1	143	IRDLPGP..PARALPAAAGPREAMSLMREQGLSALAVA. LDDGGHGIVTQRDVLRLWLAS	198
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Lets talk about research data



Key questions about publishing and sharing **human** data

What are sensitive data?

How do my guidelines support/conflict with sharing health data?

Where does health data sit within open access agenda?

What if the data come from multiple (health) sources?

What are my obligations to participants?

Will the Institutional Review Board approve?

Where does Privacy laws come in?

How do I licence sensitive health data?

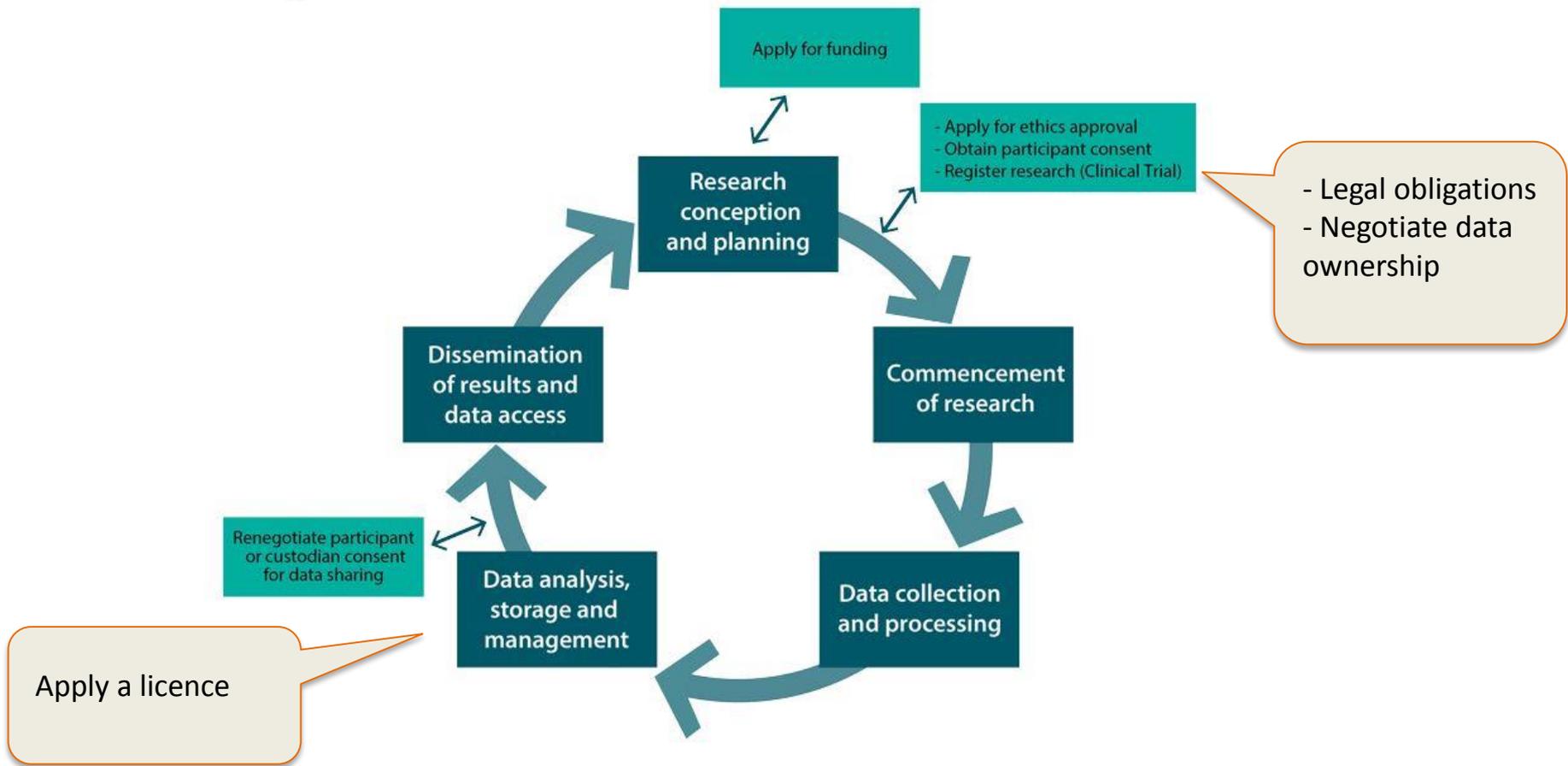
How/do these data have to be modified before they can be shared?

What makes data sensitive?



Personal information + potential for harm or discrimination

Why are sensitive data often trickier to
publish and share?



Australia's National Health & Medical Research Council: Statement on Data Sharing

Image from: <https://www.nhmrc.gov.au/grants-funding/policy/nhmrc-statement-data-sharing>

Definitions: Legal

Personal Data Protection Act 2012

Personal data refers to data, whether true or not, about an individual who can be identified from that data; or from that data and other information to which the organisation has or is likely to have access.

Cannot be disclosed without ***consent***

Definitions: Research ethics

'any data that contain information that can be used to identify an individual and introduce a risk of discrimination, harm, or unwanted attention.'

ANDS Guide to Publishing and Sharing Sensitive Data

<http://www.ands.org.au/datamanagement/sensitivedata.html>

Group membership ? Cultural practices

What kinds of data are sensitive?

Medical records ? Interview transcripts

? Social surveys Financial details

What kinds of sensitive data do you deal with?

1. *Informed* consent before sharing
2. Avoid harm by removing minimising sensitivity
 - Modify data to protect privacy *if possible*
 - Confidentialising data
 - Conditions around access to data
3. Institutional approval (SMU Institutional Review Board)

Confidentialised data

‘removing or altering data so that people or the subjects of the data cannot be identified’

ANDS Guide to Publishing and Sharing Sensitive Data

<http://www.ands.org.au/datamanagement/sensitivedata.html>

Define

> Sensitive data identifies individuals, species, objects or locations, and carries a risk of causing discrimination, harm or unwanted attention

Do I have sensitive data?

NO

If you are collecting new data, start planning for sharing in your application to ethics committees: ands.org.au/guides/sensitivedata.html#ethic
For data management resources, visit: ands.org.au/resource/data-management-planning.html

YES

Data collection

Previously collected by you?

NO

You should cite data collected by others. Check out ANDS resources for data citation at: ands.org.au/cite-data and ands.org.au/guides/sensitivedata.html#ethic

YES

Ownership

If data ownership is unclear:

> use ANDS resources for copyright and IP, visit: ands.org.au/guides/copyright-and-data-awareness.html
> check with your institutional IP policies

Do you have the right to publish?

NO

You may be able to publish metadata alone if it does not include identifiable info. For more info about using metadata, visit: ands.org.au/guides/metadata-awareness.html#meta

YES

Confidentialise

> For help deciding whether your data can be confidentialised (and if so, how), visit: ands.org.au/guides/sensitivedata.html#human

Can the data be made non-sensitive?

NO

YES

Research ethics

> For info about how privacy laws interact with data sharing and your ethical obligations for sharing data, visit: ands.org.au/guides/sensitivedata.html#legal and ands.org.au/guides/sensitivedata.html#ethic

Was consent for data sharing given by research participants?

NO

In some cases confidentialised data may still be shared if this was not precluded in the info given to participants. Consult your ethics committee, and for more info, visit: ands.org.au/guides/sensitivedata.html#ethic

YES

Was data publication approved by an Ethics Committee?

NO

YES

Licensing

> To find out more about applying a licence to your data, visit: ands.org.au/guides/sensitivedata.html#license and ands.org.au/publishing/licensing.html ausgoal.gov.au

Is the data licensed for re-use and attribution?

NO

Licensing removes uncertainty around how your data can and can't be re-used

YES

Discoverability

> To find out how to make your data discoverable, visit: ands.org.au/guides/metadata-awareness.html and ands.org.au/guides/sensitivedata.html#deposit

Can you publish data with metadata?

NO

Most metadata can be made publicly available. You can place conditions around access or re-use of data. For more info, visit: ands.org.au/guides/metadata-awareness.html#meta

YES

Publishing & sharing

> To see some examples of published data with conditional access, visit: ands.org.au/guides/sensitivedata.html#cs

- > Publish your data and metadata according to participant consent, ethics approval and licensing
- > For confidentialised sensitive data, it is often appropriate to have public metadata and conditional access to the data itself
- > Cite your data along with your other scholarly outputs

- What to do when you already have data
- Questions to ask before you publish/share
- Example 1: interviews
- Example 2: Judy Ford

← Return to search

All Fields ▾ related_party_one_search:(judy ford)

✕ 🔍 Search

■ Open data only

Advanced Search Map Search



De-identified dataset of the PALS (Pregnancy and Lifestyle Study), a community-based study of lifestyle on fertility and reproductive outcome.

University of South Australia

Dr Judith Ford (Principal investigator)

Dataset

Viewed: 82 Accessed: 17

Go to Data Providers

Cite

Save to MyRDA

Licence & Rights



View details



Full description

In order to assess the possible effects of lifestyle on fertility and reproductive outcome, the PALS (Pregnancy and Lifestyle study) collected data on a broad range of parameters termed lifestyle factors from couples who were planning a natural (non-assisted) pregnancy during their planning months. There was no intervention.

Participants were recruited over a six year period from 1988 to 1993 in response to extensive promotion in the local media. Male and female

partners were interviewed independently and all interviews were conducted prospectively before the couple attempted to conceive. The results of each month of fertility assessment and pregnancy were confirmed by ultrasound for

Similar datasets you may be interested in:

Collection for the PALS (Pregnancy and Lifestyle Study), a community-based study of lifestyle on fertility and reproductive outcome

Male-Call Project Data

Australian Nucleotide (DNA/RNA) and Protein sequences from the Australian research institution, The Queen Elizabeth Hospital

Northern Adelaide social capital survey responses

Executive board papers

Sticky carrots

- Funding bodies, e.g. NIH, NHMRC
- Publishers, e.g. PLOS, BMJ
- Local & institutional policies

Examples: <https://grants.nih.gov/grants/sharing.htm>

<https://www.nhmrc.gov.au/grants-funding/policy/nhmrc-statement-data-sharing>

<http://journals.plos.org/plosone/s/data-availability>; <http://www.bmj.com/content/350/bmj.h2373>

Carrots for researchers

5. **Efficiency** – time and cost
6. **Ethics** – participant fatigue, getting needed information out there quickly



What this looks like in the real world

First, can human data be open access?

- Depends on consent, identification, institutional approval
- Often 'conditional'/'mediated'/'restricted'/'shared' access in data repositories or between peers



‘Open / Shared / Closed: The world of data’
CC-BY-SA Open Data Institute [link](#)



Epidemiology of chronic ankle problems in the community dataset

The University of Sydney

The University of Sydney (Associated with) Arthritis and Musculoskeletal Research Group (Managed by)

Viewed: 32

Go to Data Provider

Cite

Save to MyRDA

Licence & Rights

[View details](#)

Access rights

Contact the manager of this data collection to discuss the terms and conditions of access. Requests for access must be approved by the Arthritis and Musculoskeletal research group at the University of Sydney.

Contact Information

Faculty of Health Sciences
Cumberland Campus C42
The University of Sydney
PO Box 170
Lidcombe NSW 1825
AUSTRALIA

Brief description

The epidemiology of chronic ankle problems in the community dataset is the output of an epidemiological study conducted in NSW. A random sample of participants from NSW were recruited in order to measure the occurrence rate of ankle injury in the community, and measure the impact of the those injuries on people's lives.

Data was collected by telephone interview. Information regarding participants' history of injury and/or impairment, and the impact on their health and lifestyle was recorded. Transcripts were analysed using text files, SPSS and excel. The analysed data was coded and de-identified in order to enable sharing and re-use.

For further information please refer to the associated publications.

Storage & repository options



<http://www.alsw.org.au/>

HRS HEALTH AND RETIREMENT STUDY

A Longitudinal Study of Health, Retirement, and Aging
Sponsored by the National Institute on Aging

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Data Products

What's Available (Public)

A comprehensive listing of HRS Public and Sensitive Health data products.

- Biennial Datasets
- Longitudinal Datasets
- Off-Year Studies
- Sensitive Health data

Access to Public Data (Registration required):

Register and download data products from these categories.

- HRS Public Data
- Sensitive Health Data (with approved application)
- HRS Restricted Data (documentation only)
- Researcher Contributions
- **RAND** Contributions

Screenshot: <http://hrsonline.isr.umich.edu/index.php?p=data>

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Melbourne Institute
The Household, Income and Labour Dynamics in Australia (HILDA) Survey

Ordering the Data - Release 13

Release 13 of the HILDA data (which includes waves 1 to 13) is now available. The release DVD includes Stata, SAS and SPSS datasets with extensive documentation.
For individuals whose organisation has an Organisational Licence, please contact your [Data Manager](#) to obtain the latest Deed of Confidentiality.
For all other users, please see [Completing an Order](#) section below.

Licensing Arrangement

Organisational Licence: [List of organisations and data managers](#).
Users affiliated with these organisations need to contact their Organisational Data Manager to obtain and sign a Deed of Confidentiality.

Individual Licence: Users from all other organisations will need to sign an Individual Deed of Licence.

HILDA Home
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Documentation and Support [More](#)
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Screenshot:

<https://www.melbourneinstitute.com/hilda/data/>



Yale University Open Data Access (YODA) Project

Take away

- It can be done!
- Plan ahead
- Ask about: participant consent? instit approval? modify data first?
- Access: Conditional? Open? What restrictions?
- Increasing benefits for researchers and institutions

