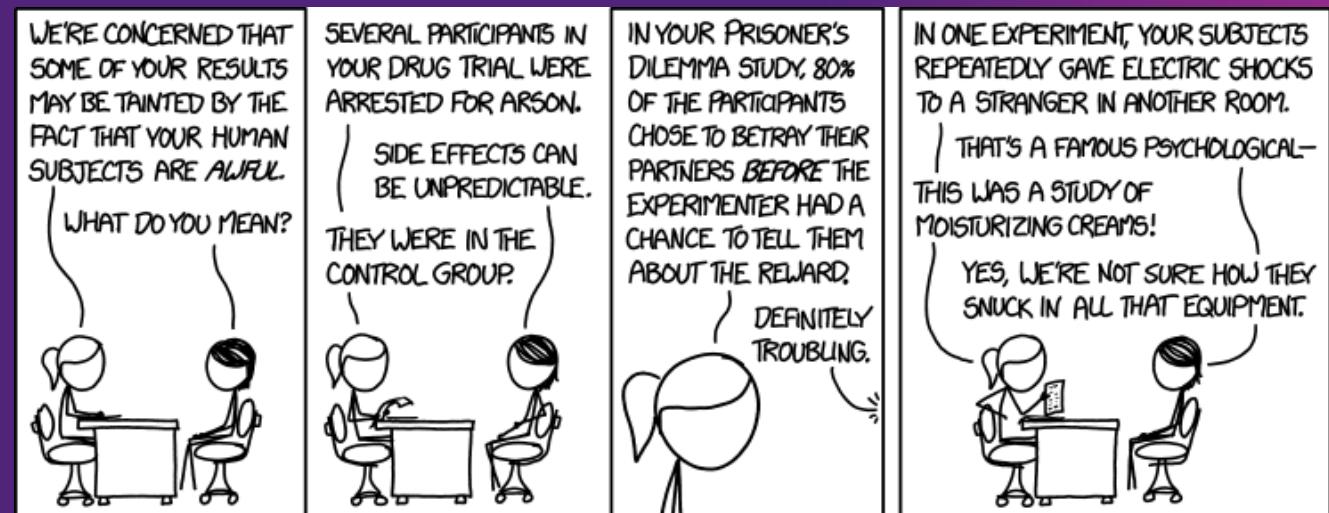


REIT6811 | Research Methods

Lecture 8: Research with Humans

Prof Markus Barth

Slides adapted from
Prof Janet Wiles, Dr Jacki Liddle,
Dr Monique Tourell



xkcd.com/1594

Acknowledgement of Country

I acknowledge the Turrbal and Yuggera peoples as the Traditional Owners and custodians of Meanjin, the lands on which this course was developed and where we meet today.

I pay my respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country.

I recognize that these lands have been a place of teaching, learning, research and collaboration for tens of thousands of years before the establishment of a UQ campus.

Sovereignty was never ceded.

The Brisbane River pattern from A Guidance Through Time
by Casey Coolwell and Kyra Mancktelow.

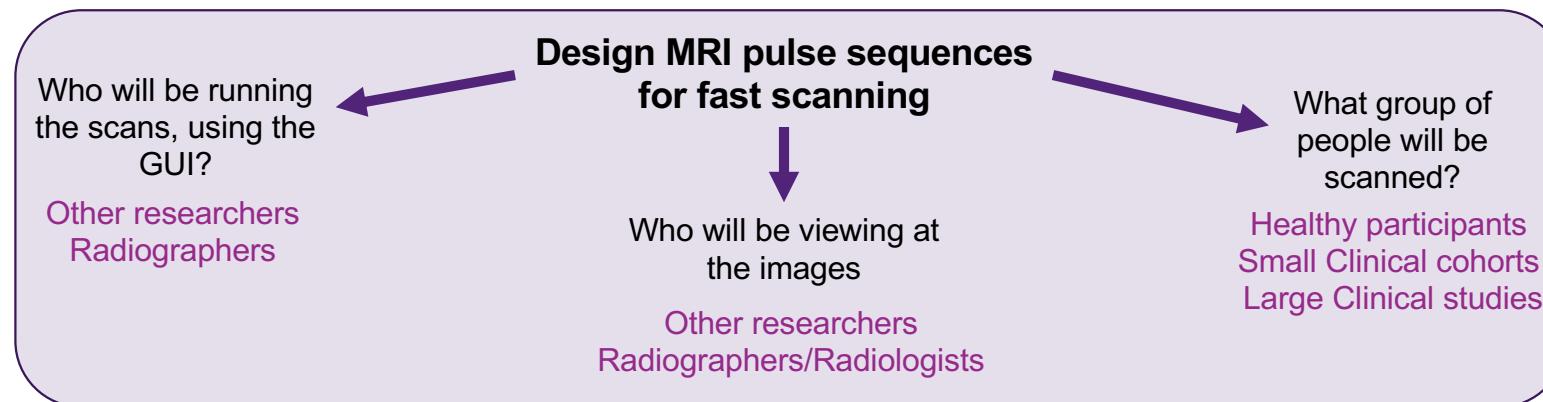


Why involve people in technology research?

- Many technologies have/require human users
- Many technologies aim to solve a human problem or improve a human situation
- Many datasets use data from/about humans
- Many automated solutions, have intended and unintended consequences on people

If/how will depend on how far along in the translation process your research question

- What I think about in my work:





THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

CREATE CHANGE

Journal Activity

Watch Uninvited Guests: <https://vimeo.com/128873380>

In your Journals Answer:

- Does the technology work as designed?
- Is the technology likely to create the outcomes it aims to (safety, health)? Why?/Why not?
- How would research find out useful information about this technology?

When you don't include people...

“A Disability Dongle is a well intended elegant, yet useless solution to a problem we never knew we had”

- Liz Jackson

- When we don't engage with people – what we create can be problematic
- Deficit focused (often symptoms)
- Narrow, stigmatising, passive (a problem to be solved)
- Solving a problem that doesn't exist
- Doesn't focus on what people want to do
- Often not usable, cost-effective or sustainable
- Doesn't support inclusive society (the problem belongs to the disabled person)
- Doesn't build on the great solutions/strategies disabled people have created.
- **Engage with users before building!**
- Example: stair climbing wheelchair vs ramps/accessible buildings

NYT Health - Jul 18, 2019
 Remember Google Glass? Stanford University researchers are exploring whether it can help teach autistic children to make eye contact and recognize emotions.



nytimes.com
 Google Glass May Have an Afterlife as a Device to Teach Autistic...
 Privacy concerns caused the computerized eyewear to fail with the general public. But researchers believe it could help autistic ...

Laura - #SaveOFMD
 @MissTwinPeaks82 - Follow

Why not focus on getting non-autistic people to accept differences in social communication rather than forcing autistics to conform? Eye contact can be painful and difficult and isn't a necessity for communication or for recognising emotions.

7:48 PM · Jul 18, 2019

64 Reply Share

Read 3 replies

The value of people in design and evaluation research

Human Research Can...	By...
Observe and document current states	Observational, ethnographic, contextual inquiries, surveys
Compare and contrast	Controlled trials, experiments
Investigate complex systems and make predictions	Computational modelling, longitudinal studies, cross-sectional studies, epidemiological research
Create change	Critical analysis, design-focused research, participatory action research
Improve practice	Translational research, application of implementation science, consensus-building processes, design optimization, pragmatic evaluations

The value of people in design and evaluation research

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Improve practice	Translational research, application of implementation science, consensus-building processes, design optimization, pragmatic evaluations

Working with humans when solving human problems enables you to:

- Develop something that is more likely to solve the problem
- Have evidence that validly reflects the user perspective/situation
- Dig into why something works or doesn't work
- Solve the issues of when something works in the lab, but doesn't work for the user
- Explore whether the technology leads to the outcomes you proposed (i.e. does it improve independence, reduce health costs etc).

Research with humans – the general process

Finding the Research Gap and Literature Review – Week 3 & 5

Developing Research Questions – Week 6

Developing Research Methodology

Ethics Approval

Recruiting Participants

Participant Consent

Data Collection – Week 6 & 7

Managing Data and Identifiable Information – Week 6 & 7

Data Analysis, Interpretation and Reporting – Week 6 & 7

Research with humans – the general process

Finding the Research Gap and Literature Review – Week 2 & 4

Developing Research Questions

Developing Research Methodology – Week 5

Ethics Approval – making appropriate changes to research methods and getting approval for research

Recruiting Participants

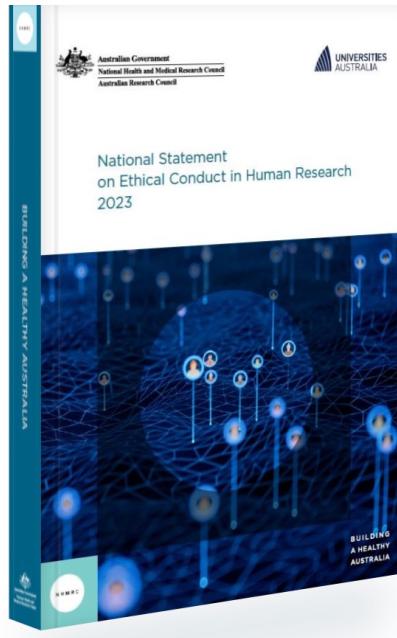
Participant Consent

Data Collection – Week 6 & 7

Managing Data and Identifiable Information – Week 6 & 7

Data Analysis, Interpretation and Reporting – Week 6 & 7

Additional Codes for Human Research



The National Statement on Ethical Conduct in Human Research sets out a series of guidelines for ethical research involving human participants.

The Code sets out principles that define ethical human research:

Merit and Integrity – justifiable potential benefit, follows research integrity

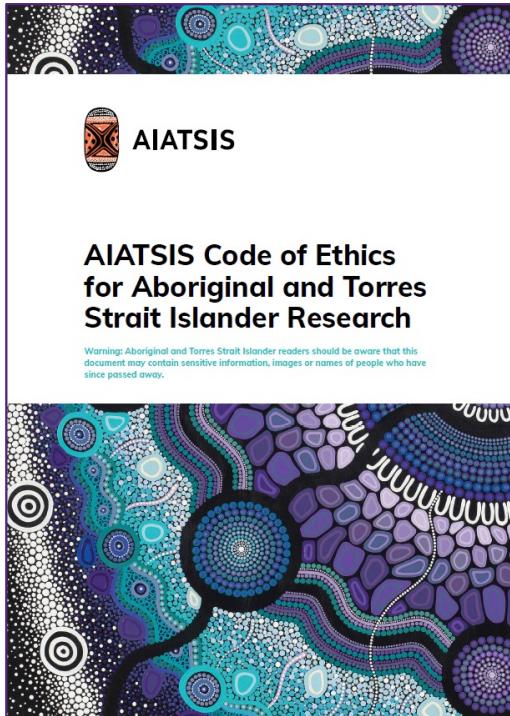
Justice – research, inclusion and treatment of participants is fair

Beneficence – Minimizing risk/harm/discomfort, maximizing benefit

Respect – due regard for the welfare, beliefs, perceptions, customs and cultural heritage of participants

<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2023>

Additional Codes for Human Research



In addition, there is the *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research* which provides further guidance of the application of research ethics to Aboriginal and Torres Strait Islander research.

<https://aiatsis.gov.au/research/ethical-research/code-ethics>

This includes guidelines on:

- Risk, benefit and consent
- Considerations when designing and developing methodology
- Considerations for involving certain groups such as pregnant people, children, Aboriginal and Torres Strait peoples and more
- Institutional responsibilities and processes for ethical human research

Why does UQ need an ethics committee?

Separating Ethics in Decision Making

As researchers we cannot decree for ourselves that our research is free of ethical issues or potential harm to people/animals

- Danger of actual, potential, or perceived conflict of interest
- An independent “disinterested” body is better able to judge whether there are ethical issues
- Governance ('oversight') of research ethics is based around principle of separating ethical approval from researcher(s) themselves

Institutions have independent Ethics Committees which meet regularly to review proposals to ensure they adhere to the values and principles of ethical human research.

Studies including humans or human data

The National Statement on Ethical Conduct in Human Research defines human participation as the involvement of human beings in the following activities:

- surveys, interviews or focus groups;
- psychological, physiological, or medical testing or treatments;
- observation by researchers;
- having their personal documents or other materials accessed;
- collection and use of their body organs, tissues or fluids (e.g. skin, blood, urine, saliva, hair, bones, tumor and other biopsy specimens), or their exhaled breath; and
- their information (individually identifiable, re-identifiable or non-identifiable) as part of an existing published or unpublished source or database being accessed.

UQ's requirements and processes related to obtaining ethics approval for human research are detailed in Human Research Ethics Procedure (<https://policies.uq.edu.au/document/view-current.php?id=346>)

Human Ethics at UQ

If your research involves human data then you need to consider Ethics Approval

The process your proposal goes through depends on the project risk

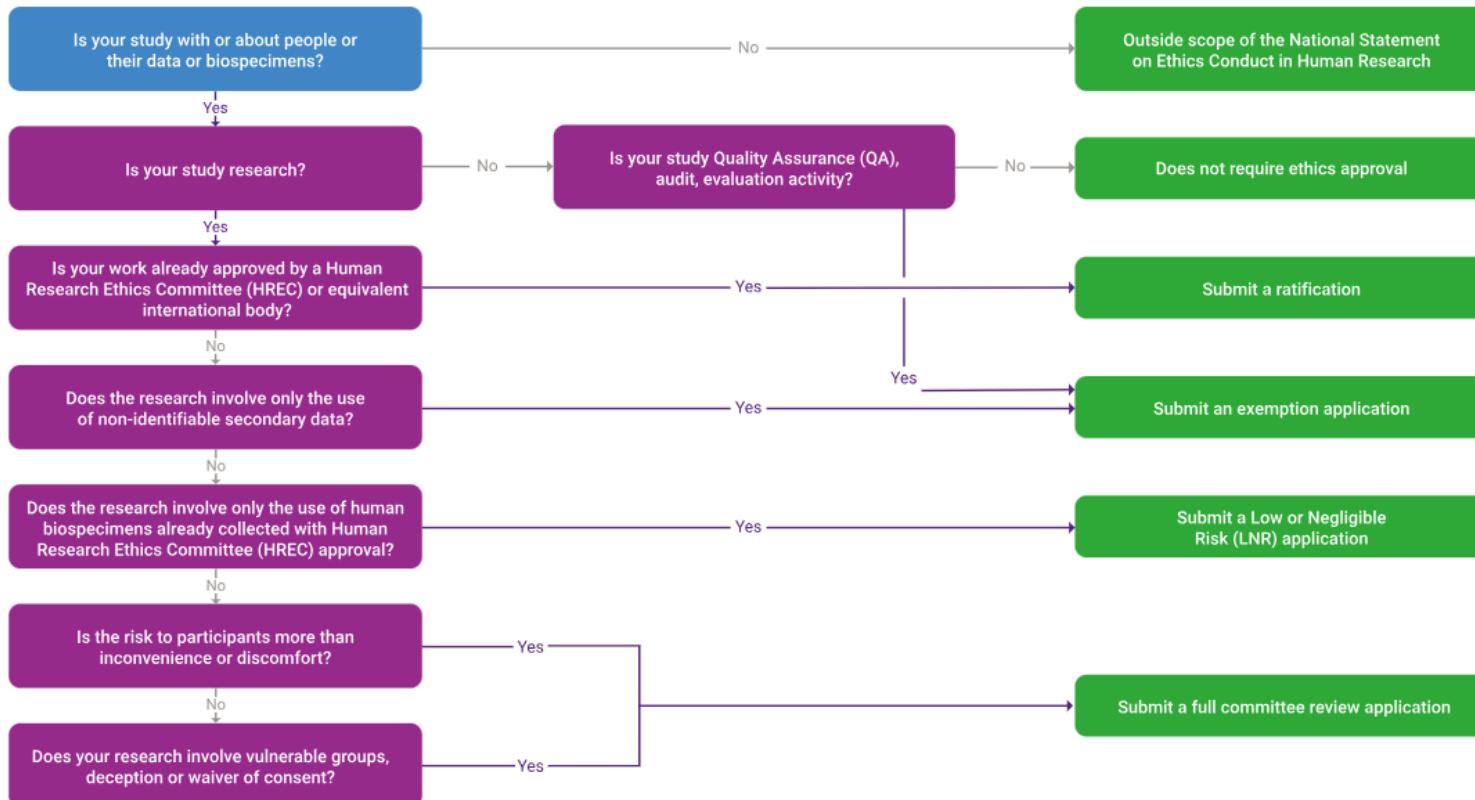
- **Human Ethics Exemption** – Negligible risk involving data records only under certain conditions
- **Low or Negligible Risk** – Reviewed by Faculty-based ethics review panels
- **Full Committee Review** – Above low risk, or one of the identified research areas that always requires full HREC review

There is a UQ website with all the resources you need to handle human ethics applications, trained officers can help you: <https://www.uq.edu.au/research/research-support/ethics-integrity-and-compliance/human-ethics>

Failure to have proper ethics approval for research using humans or animals is a form of research misconduct. Ethics approval cannot be granted retrospectively

Human Ethics at UQ

UQ decision support tool:
<https://content.learn.uq.edu.au/research/ethics/>



Human Ethics at UQ

Applications are done through UQ's MyResearch Portal

- **Research Proposal:** Develop a detailed research proposal outlining the study's objectives, methodology, participant recruitment, and data handling procedures (data management plan)
- **Conflicts of Interest:** In the project methodology, participant recruiting, data handling etc
- **Informed consent documents:** How you will inform your participants about the study
- **Risks:** Risks in the research, benefits justifying risks, mitigation and management of risks. **Risks can be physical, psychological, social, economic, legal**

Amendments

- Can be made to minor changes Small changes made to the ethics approval that do not increase the risk to the humans involved
- Major changes in methodology that result in significantly greater risks to the participants, e.g. changes in methodology, changes in cohorts need new applications

Human Ethics at UQ

Conducted through MyResearch portal

- Lists a **Chief Investigator** (supervisor)
- **Co-investigators**
- **Ethics Approval Number** – often quoted in grant applications, journal articles, when recruiting participants
- Name of the **approving Committee or Sub-committee**

Requirements for Consent

Studies involving human subjects and data must obtain consent

- Must inform participant fully about what will happen to them (including how their data will be used)
- Must ensure participant understands the information
- Must allow participant to make a voluntary choice on whether to participate or not
- Consent is an ongoing process – the participant understands they can withdraw at *any* stage without penalty

Voluntary written informed consent

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Bethesda, Md. *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. Superintendent of Documents, 1978

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Studies which may require a **waiver of consent** (usually in relation to accessing personal information) or involve studies where participants have a **limited ability to give informed consent** must go through the **full Human Ethics Committee Review process**.

Content Warning for Next 2 slides

The next slides contain a brief discussion on the **history of informed consent in research**, centered around important guidelines and documents.

They do refer to topics that include unethical practices, exploitation, and human rights abuses, since these topics prompted the current guidelines. These include references to WWII and treatment of people of colour in human research.

If you are feeling distressed by this content, support is available at UQ by contacting Student Central (<https://my.uq.edu.au/contact/student-central>)

A History of Informed Consent

- **The Nuremberg Code (1947):** Established after WWII when German officers were prosecuted for (among other things) conducting experiments on thousands of concentration camp prisoners without consent. **First international document that emphasized voluntary consent and informed consent.**
- **Declaration of Helsinki (1964):** Developed by the World Medical Association, ethical guidelines for medical research involving human subjects, reinforcing the principles of informed consent.
- **Belmont Report (1979):** Partly in response to the Tuskegee Study (1932-1972), where African American men with syphilis were left deliberately left untreated, without their consent or knowledge of their diagnosis. **This report outlined key ethical principles for research with human subjects, including respect for persons, beneficence, and justice. It solidified the requirement for informed consent.**



HHS Public Access
Author manuscript
J Health Care Poor Underserved. Author manuscript; available in PMC 2015 March 10.
Published in final edited form as:
J Health Care Poor Underserved. 2010 August ; 21(3): 879–897. doi:10.1353/hpu.0.0323.

More than Tuskegee: Understanding Mistrust about Research Participation

Darcell P. Scharff, PhD^a, Katherine J. Mathews, MD, MPH, MBA^b, Pamela Jackson, MA, RN^c, Jonathan Hoffsummer, MPH^d, Emeobong Martin, MPH^e, and Dorothy Edwards, PhD^f

^aDepartment of Community Health, School of Public Health, Saint Louis University
^bSouthern Illinois Healthcare Foundation
^cWashington University Alzheimer's Disease Research Center
^dCenter for Practice Excellence, Barnes-Jewish Hospital Research Center
^eCongressional Research Service
^fDepartments of Kinesiology, Neurology, Medicine and the Wisconsin Alzheimer's Institute, University of Wisconsin-Madison

Mistrust due to studies like the Tuskegee Study is still a major barrier to African American participation in research studies today

Informed Consent is a key requirement in modern Human Research. Prior to this, research without the knowledge or consent of participants disproportionately affected people of colour and underrepresented groups.

Not just a thing of the past...

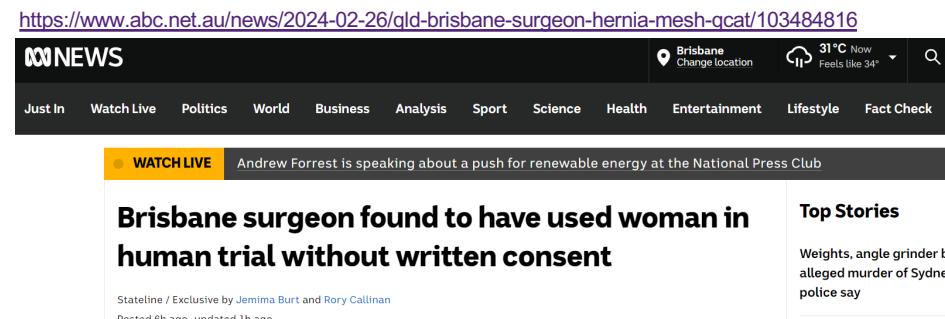
"A prominent Brisbane surgeon used a woman in a human trial without her written consent while operating on a hernia that may have never existed, medical board documents reveal." - ABC

Surgery happened in 2010, complaint lodged in 2011, findings handed down in 2013.

"...the lead plaintiff says she and 60 other members of the Pictou Landing First Nation participated in an MRI in 2017 for a medical research project... But after the test finished, staff at the hospital in Halifax kept her for a second test."

Reported 26/02/2024

<https://www.abc.net.au/news/2024-02-26/qld-brisbane-surgeon-hernia-mesh-qcat/103484816>



The screenshot shows the ABC News homepage with a search bar at the top. Below it, a banner for "WATCH LIVE" with the text "Andrew Forrest is speaking about a push for renewable energy at the National Press Club". The main headline is "Brisbane surgeon found to have used woman in human trial without written consent". Other news items and a weather forecast for Brisbane are visible.

Reported 27/02/2024

<https://www.theguardian.com/world/2024/feb/26/medical-experiment-indigenous-canadians-lawsuit>



The screenshot shows the Guardian's international news section. The main headline is "Indigenous people sue over alleged Canadian secret medical experiment". A sub-headline states "First Nation members say in lawsuit that radiologists subjected them to a secret study without their knowledge or consent". The Guardian's logo is prominently displayed on the right.

Informed Consent Example

Information Sheet and Consent Form

- Explains the study/experiment/scan in lay terms.
- Ensures the participant has
 - read the info sheet**
 - had the opportunity to ask questions, and knows they can always ask more questions**
 - Knows they can withdraw at any time**
- Ethics Approval Number
- Handling of data
- This is an example for an approved study.
- UQ has templates and checklists for consent and project descriptions etc: <https://research-support.uq.edu.au/resources-and-support/ethics-integrity-and-compliance/human-ethics/ethics-application/lower-risk-research>

<p>Information sheet - Eth</p> <p>Testing of Magnetic Resonance Imaging System</p> <p>Team Leader: Professor David Reutens</p> <p>A MRI scanner is a large magnet with a tunnel in the middle of the magnet. To obtain a scan, the person is required to lie for up to 120 minutes.</p> <p>At times, it is necessary to test the equipment, or new methods for this study for which you are volunteering is to ensure that the equipment parameters are optimized for a specific purpose. There may be no study is essential for the overall operation of the research program.</p> <p>MRI is a safe procedure for carefully selected individuals. No X-rays are some potential discomforts involved with a MRI scan. The turn will be removed from the tunnel immediately. Head movement so you will be asked to keep your head as still as possible. It is unhistory of metal fragments in the eyes to enter a MRI machine. This by qualified staff.</p> <p>Some objects must not be taken into the magnetic field, including volunteers before they enter the scanner room. Credit cards, whilst personal items will be locked away during your visit.</p> <p>On rare occasions, the magnet may cease to function, due to the imaging procedure, you will be removed from the scanner.</p> <p>The type of testing is an ongoing requirement of the operation of pool of volunteers, who are available for this type of testing. The between sessions will vary. However, you are under no obligation to participate in follow-up sessions for the same study. If you decide to withdraw from the project at any stage. If at anytime you feel uncomfortable, you will be removed immediately from the magnet, and one of the investigators will never be under any coercion to participate in your discomfort. You will never be under any coercion to participate in your discomfort.</p> <p>Any images or records will be maintained in strict confidentiality. reports or publications; your information will be referred to by a</p> <p>If you would like any further information about the study, or if you do not hesitate to ask one of the researchers. Contact details for the</p> <p>Contact Details: Professor David Reutens, Centre for Advanced Imaging, The University of Queensland</p> <p>Doc Ref: [REDACTED] Procedure Owner: [REDACTED] Prof. David Reutens</p>	<p>Centre for Advanced Imaging</p> <p>CONSENT FORM - Ethics:20050005020</p> <p>I agree to participate in the above named project and in so doing acknowledge that:</p> <ol style="list-style-type: none"> I have read the attached Participant Information Sheet outlining the nature and purpose of the project and the extent of my involvement, and have had these details explained to me. I have had the opportunity to ask further questions and am satisfied that I understand. I am aware that, although the project is directed to the expansion of knowledge generally, it may not result in any direct benefit to me. I am aware that this project may involve multiple sessions in the magnet, and that the reason for a particular session may differ from other sessions. The length of the session and the interval between sessions will vary. I am also aware that I am under no obligation to participate in any particular session, whether or not I have participated in a previous study for the same purpose. I have been informed that I may withdraw from the project at my request at any time. I have been advised that the University of Queensland Research and Ethics Committees have given approval for this project to proceed. I am aware that I may request further information about the project as it proceeds. I understand that, in respect of any information including audiovisual records obtained during the course of the project, confidentiality will be maintained to the same extent as for any Hospital records and that, in the event of any results of the project being published, I will not be identified in any way. <p>DATE: PARTICIPANT'S NAME:</p> <p>Signature</p> <p>NAME OF WITNESS:</p> <p>Signature</p> <p>Doc Ref: [REDACTED] S:\Research\Ethics\Archive\2. Human ethics_CAI200500502 Galloway2020 Amendment Procedure Owner: [REDACTED] Prof. David Reutens Version: 2.0 Effective Date: 01/01/2019</p>
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Research with humans – the general process

Finding the Research Gap and Literature Review

Developing Research Questions

Developing Research Methodology

Ethics Approval

Recruiting Participants

Participant Consent

Data Collection

Managing Data and Identifiable Information

Data Analysis, Interpretation and Reporting

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Questions to ask when forming your methodology

Should we involve people?

Is what we are doing safe, ethical and appropriate?

What people?

Who needs to be involved in conducting the research, do we have the expertise?

Who do we need to collect data from?

What data should we collect?

Are we answering the research question?

Qualitative, quantitative or both?

How should we collect it?

Are we using established methodology?

Do our processes guard against biases?

How should we store our data?

Identifiable/de-identified data

Back-ups

How do we describe our human related data?

What methods will we use to analysis and interpret it?

Modelling, Statistics?

How do we define research quality?

- Depends on research type and research question
- Important that enough detail in methodology is shared so you can judge others work, and they can judge yours!

Critical aspects of quality in research (more info Lecture 6):

- **Rigour** –The care taken in the research design, execution, and analysis to ensure the research is methodologically sound.
- **Reliability/ Dependability** – How stable and consistent results over multiple observations or measurements (requires rigour!)
- **Validity/ Credibility** – Extent to which research findings reflects reality (requires rigour and reliability!)
- **Generalizability/ Transferability** – The extent to which the findings can be applied to scenarios beyond what is studied.

Reliability

Reliability is the degree to which a measurement or test consistently produces the same results,

Example: Predicting Student Final Grades from Lecture Attendance in first year engineering at UQ.

Internal: If you are measuring student effort using multiple indicators (attendance, participation, assignment submissions) you want to ensure these measures are consistent with each other. If these measures are correlated there is **high internal consistency**.

Test-retest: If attendance patterns remain consistent (i.e. students who attended regularly early in the semester continue to attend regularly later), your attendance measure has **high test-retest reliability**.

Interrater: If two different staff are responsible for recording student attendance, you would want to ensure that both consistently record attendance in the same way. If both raters agree on how often each student is attending lectures, then your study has **high inter-rater reliability**.

Some ways to measure reliability in a study:

Internal: Assesses the consistency of results across items within a test. Are items that should be correlated, correlated?

Test-retest: The test is repeated on the same subject, with the same researchers in the same conditions usually within a few minutes of the first test.

Interrater: Evaluates the agreement among different observers assessing the same data or phenomenon

Reliability

Reliability is the degree to which a measurement or test consistently produces the same results,

Repeatability: consistency of results within the *same study* under the *same conditions* and *same researchers*

Replicability: consistency of results in a *different study* under the *same conditions* and *different researchers*

Reproducibility: consistency of results in *different study* under *different conditions* and *different researchers*

What supports it:	What reduces it:
Established tools to measure outcomes	Asking/Testing in different ways
Standardized protocols/processes	Fatigue, characteristics of tool
Transparency in methods/data/analysis reporting	Not checking data, not involving independent checking
Management of biases	Biases in methodology, analysis

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Interrater: Evaluates the agreement among different observers assessing the same data or phenomenon

Validity

The accuracy and truthfulness of the measurement. A test is valid if it measures what it intended to measure.

Example: Predicting Student Final Grades from Lecture Attendance in first year engineering at UQ.

Face Validity: reasonable to assume that students who attend more lectures would perform better in their final grades, study has **high face validity**.

Some types of validity in a study:

Construct: Does the test really measure what we want to measure?

Face: does the content of the test appear to measure what we want to measure?

Content: Is the test fully representative of all we want to measure?

Criterion: Do the results accurately measure the concrete outcome, how well do they approximate the results of another valid test?

Internal: Does the test show a trustworthy cause-and-effect relationship between the treatment and the observed outcome, free from confounding variables.

External: applicability of the study's findings beyond the specific conditions of the study.

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Content Validity: Ignoring other factors that contribute to final grades (such as participation, exam scores, outside commitments), study has **low content validity**.

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Construct Validity: Lecture attendance is a measure to reflect a student's effort or engagement in the course. Some students may attend without paying attention, others might spend the lecture time doing their own study. The study has **low construct validity**.

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External Validity: Study is done at a single university with a particular group of students. The study has **low external validity**.

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Validity

The accuracy and truthfulness of the measurement. A test is valid if it measures what it intended to measure.

What supports it:	What reduces it:
Participant, peer checking	Context
Design of research involving stakeholders	Measurement approaches
Management of biases	Recruitment approaches
Recruitment, engagement time	Biases in methodology/ analysis

Some types of validity in a study:

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Biases can affect Research Quality

Bias in research – something that distorts the results and conclusions of a study

- Oxford University – Centre for Evidence Based Medicine
- <https://catalogofbias.org/about/>

Bias in thinking/acting (bias in life) – error in thinking, prejudice towards or against something

In human-centred research in particular, biased research/data can (and often does) enhance the impact of bias in society!

The general process

Finding the Research Gap and Literature Review

Developing Research Questions

Developing Research Methodology

Ethics Approval!

Recruiting Participants

Participant Consent!

Data Collection

Storing and Managing Data and Identifiable Information

Data Analysis, Interpretation and Reporting of Results

All these process can be affected by bias – systematic errors in study design, data collection or analysis that encourage one outcome over another. When not acknowledged or accounted for, this can lead to inaccurate conclusions reducing the quality of your research!

Examples of Some Biases

Social
desirability
bias

Attrition bias

Hawthorne
effect

Confirmation
bias

Recall bias

Missing data/
non response;

Volunteer bias

Selection bias

Examples of Some Biases

Participants feel pressured to give socially acceptable answers, not their true thoughts

Participants drop out of a long-term study at different rates due to the study itself

Participants alter their behaviour as a result of being observed

Favouring information that confirms pre-existing beliefs

Participants do not remember past events or experiences accurately

Participants fail to provide all or some of the expected information

Certain demographic of participant is more or less likely to volunteer for your study

Participants selected for the study are not representative of the target population

Examples of Bias – Autism in Girls

- Autism is more frequently diagnosed in males
- One explanation for this is that early diagnostic criteria for autism was based on observations of males.
- Subsequent studies recruited more males than females because the diagnostic criteria was biased towards male symptoms - we don't know what autism in girls looks like!
- Other evidence also suggests that girls are better at masking – actively hiding their autism symptoms.

Neuropsychology Review
<https://doi.org/10.1007/s11065-023-09630-2>

REVIEW

Is There a Bias Towards Males in the Diagnosis of Autism? A Systematic Review and Meta-Analysis

Sara Cruz^{1,2}  · Sabela Conde-Pumpido Zubizarreta³ · Ana Daniela Costa⁴ · Rita Araújo⁴ · Júlia Martinho⁵ · María Tubío-Fungueirín^{3,6,7,8} · Adriana Sampaio⁴ · Raquel Cruz^{3,8} · Angel Carracedo^{3,7,8,9} · Montse Fernández-Prieto^{3,6,7,8}

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Cruz, Sara, et al. Neuropsychology Review (2024): 1-24.

What biases do you think are present in studies about autism symptoms?

- A – Volunteer bias**
- B – Selection bias**
- C – Selection and Hawthorne bias**
- D – Volunteer and Hawthorne bias**

Hawthorne Effect/Social Desirability Bias

Mitigation can include

- Prolonged Engagement – build trust
- Dummy runs – get used to being observed
- Control groups
- Anonymity

In some cases you might decide that in order to get the results you need, participants cannot fully know what you are doing or studying:

Ethics Approval:

- Justify the Need for Deception
- Minimize Harm
- Debriefing Plan

Informed Consent:

- Partially Inform
- Consent to Deception
- Assess Understanding

The Journal of Medicine and Philosophy, 47: 558–571, 2022
<https://doi.org/10.1093/jmp/jhac014>
Original Research

OXFORD

Deceiving Research Participants: Is It Inconsistent With Valid Consent?

DAVID WENDLER*

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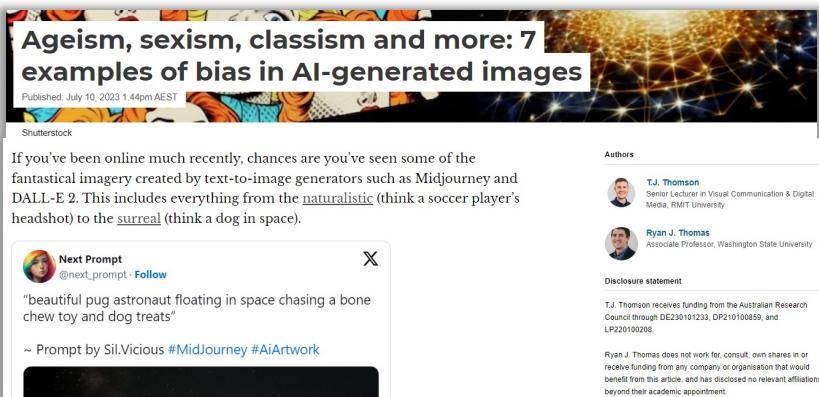
It is widely assumed that the use of deception in research is always inconsistent with obtaining valid consent. In addition, guidelines and regulations permit research without valid consent only when it poses no greater than minimal risk. Current practice thus prohibits studies that use deception and pose greater than minimal risk, including studies that rely on deceptive methods to evaluate experimental treatments. To assess whether these prohibitions are justified, the present paper evaluates five arguments that might be thought to support the assumption that deception is always inconsistent with valid consent. Analysis of these arguments reveals that deception is frequently, but not always, inconsistent with obtaining valid consent for research. This conclusion suggests that, in order to avoid unnecessarily blocking valuable research, current policies and practice should be revised to recognize the conditions under which the use of deception can be consistent with obtaining research participants' valid consent.

KEYWORDS: *deception, valid consent, rights*

Wendler, David. "Deceiving research participants: Is it inconsistent with valid consent?." *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*. Vol. 47. No. 4. US: Oxford University Press, 2022.

Algorithmic Bias

- Algorithmic bias is systematic and unfair discrepancies in the output of algorithms. It can result from prejudiced assumptions, unrepresentative data, or flawed decision-making criteria.
- It is a **very big** talking point in AI at the moment, particularly around data sets.



Ageism, sexism, classism and more: 7 examples of bias in AI-generated images

Published: July 10, 2023 1:44pm AEST

Shutterstock

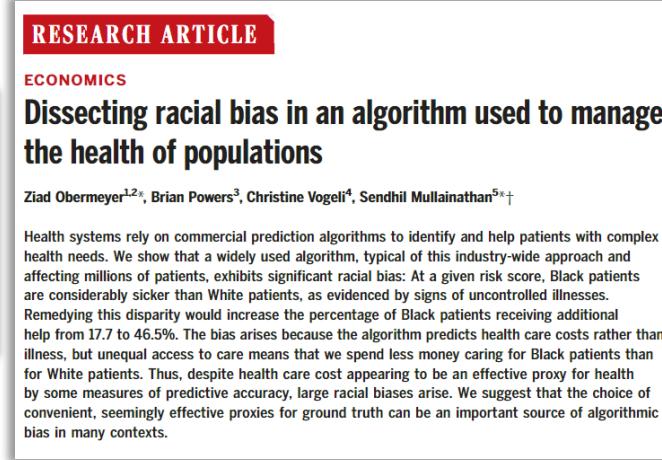
If you've been online much recently, chances are you've seen some of the fantastical imagery created by text-to-image generators such as Midjourney and DALL-E 2. This includes everything from the naturalistic (think a soccer player's headshot) to the surreal (think a dog in space).

Next Prompt **@next_prompt · Follow**

"beautiful pug astronaut floating in space chasing a bone chew toy and dog treats"

~ Prompt by Sil.Vicious #MidJourney #AiArtwork

<https://theconversation.com/ageism-sexism-classism-and-more-7-examples-of-bias-in-ai-generated-images-208748#:~:text=There%20were%20also%20notable%20differences,of%20more%20fluid%20gender%20expression>



RESEARCH ARTICLE

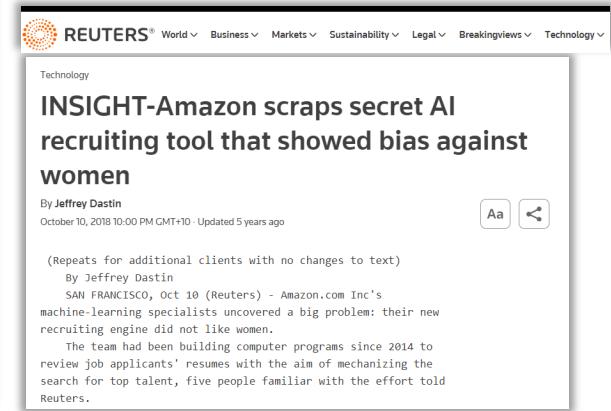
ECONOMICS

Dissecting racial bias in an algorithm used to manage the health of populations

Ziad Obermeyer^{1,2*}, Brian Powers³, Christine Vogeli⁴, Sendhil Mullainathan^{5*}†

Health systems rely on commercial prediction algorithms to identify and help patients with complex health needs. We show that a widely used algorithm, typical of this industry-wide approach and affecting millions of patients, exhibits significant racial bias: At a given risk score, Black patients are considerably sicker than White patients, as evidenced by signs of uncontrolled illnesses. Remediating this disparity would increase the percentage of Black patients receiving additional help from 17.7 to 46.5%. The bias arises because the algorithm predicts health care costs rather than illness, but unequal access to care means that we spend less money caring for Black patients than for White patients. Thus, despite health care cost appearing to be an effective proxy for health by some measures of predictive accuracy, large racial biases arise. We suggest that the choice of convenient, seemingly effective proxies for ground truth can be an important source of algorithmic bias in many contexts.

<https://www.science.org/doi/epdf/10.1126/science.aax2342>



REUTERS World ▾ Business ▾ Markets ▾ Sustainability ▾ Legal ▾ Breakingviews ▾ Technology ▾

Technology

INSIGHT-Amazon scraps secret AI recruiting tool that showed bias against women

By Jeffrey Dastin

October 10, 2018 10:00 PM GMT+10 · Updated 5 years ago

(Repeats for additional clients with no changes to text)

By Jeffrey Dastin

SAN FRANCISCO, Oct 10 (Reuters) - Amazon.com Inc's machine-learning specialists uncovered a big problem: their new recruiting engine did not like women.

The team had been building computer programs since 2014 to review job applicants' resumes with the aim of mechanizing the search for top talent, five people familiar with the effort told Reuters.

<https://www.reuters.com/article/amazoncom-jobs-automation/rpt-insight-amazon-scaps-secret-ai-recruiting-tool-that-showed-bias-against-women-idINL2N1WP1RO/>



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

CREATE CHANGE

Journal Activity

You have developed a virtual reality (VR)-based therapy program aimed at reducing symptoms of anxiety disorders. The study aims to assess the feasibility and preliminary effectiveness of the VR therapy compared to traditional cognitive-behavioral therapy (CBT).

Participants with diagnosed anxiety disorders were recruited from online support groups. Participants were randomly assigned to either the VR therapy group or the CBT group. Outcome measures included self-reported anxiety levels, and satisfaction with the treatment.

What biases might be present in this study?

How could you mitigate them?

Enhancing the validity of participant feedback

- Informed about the technology/ system (clear, no jargon, transparent)
- Have feedback be anonymous or not collected by the creator of the technology
- Ask enough questions to see what people are concerned about, what they like, would they use it
- Consider instruments (e.g. TAM – technology acceptance model questionnaire) but also delve into why
- Ask a wide enough variety of people, people who don't have a stake, people who would be your users
- Check your biases in your analyses

Technology Acceptance Model <i>Perceived Usefulness (PU)</i>	Likely				Unlikely			
	Extremely	Quite	Slightly	Neither	Slightly	Quite	Extremely	
1. Using [this product] in my job would enable me to accomplish tasks more quickly.								
2. Using [this product] would improve my job performance.								
3. Using [this product] in my job would increase my productivity.								
4. Using [this product] would enhance my effectiveness on the job.								
5. Using [this product] would make it easier to do my job.								
6. I would find [this product] useful in my job.								

Perceived Ease-of-Use (PEU)	Likely				Unlikely			
	Extremely	Quite	Slightly	Neither	Slightly	Quite	Extremely	
7. Learning to operate [this product] would be easy for me.								
8. I would find it easy to get [this product] to do what I want it to do.								
9. My interaction with [this product] would be clear and understandable.								
10. I would find [this product] would be clear and understandable.								
11. It would be easy for me to become skillful at using [this product].								
12. I would find [this product] easy to use.								

Lewis, James R. "Comparison of Four TAM Item Formats: Effect of Response Option Labels and Order." Journal of Usability Studies 14.4 (2019).

Data Sharing

Where does raw data go?

- Research studies have protocols (get approved)
- Participants consent to this
- Depends on context

Keep for a specified period of time

May have checking and then destroyed process

Cannot keep or share without permission

How can you prevent it being sold?

- Generally, access is to specified group only
- Not able to sell (most funding)
- Cannot sell without permission
- Be careful about use of commercial platforms

UQ Research Data Manager (RDM) allows you to create projects for human identifiable data

These can not be shared or accessed on the HPC. If you do want to share data then you will can create two projects. One for identifiable and one for de-identified data!

The label is required and must consist of 6-20 alpha numeric characters, and underscores in length.

Storage description *										
Storage description is required										
Type of data being stored / used *										
<input checked="" type="checkbox"/> This storage allocation will not be used to store identifiable human data, nor does it require HPC facilities <input type="checkbox"/> This storage allocation will be used to store human identifiable data <input type="checkbox"/> The storage allocation will be used to store data that needs to be accessed by UQ HPC facilities										
Data retention										
Select how long do you intend to retain your data for after the completion of the project										
<input type="checkbox"/> This storage allocation will contain confidential information <input type="checkbox"/> Yes <input type="checkbox"/> No										
<input type="checkbox"/> This storage allocation will contain data related to humans <input type="checkbox"/> Yes <input type="checkbox"/> No										
Permissions										
<table border="1"> <thead> <tr> <th>Name</th> <th>Email</th> <th>Read / Write</th> <th>Read Only</th> <th>No access</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Name	Email	Read / Write	Read Only	No access					
Name	Email	Read / Write	Read Only	No access						

Should you share?

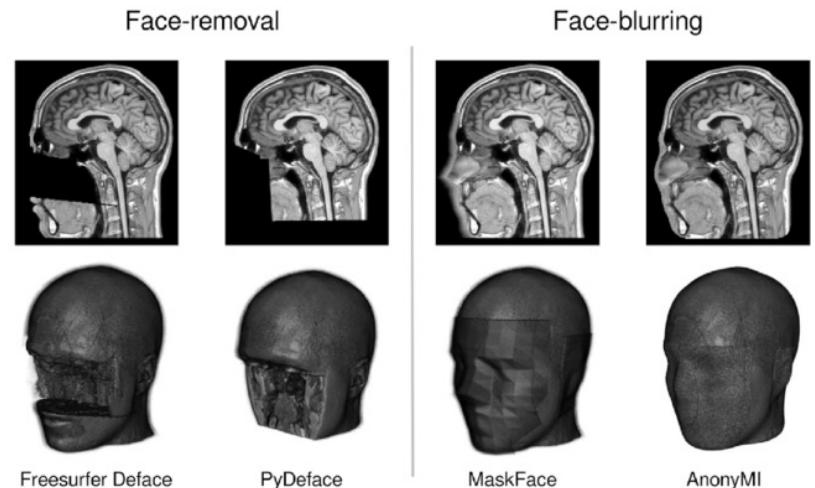
- Open source, open access
- Cost effectiveness in publicly funded research

But

- Consent for sharing and subsequent use?
- Privacy/anonymity – what is stored in the metadata, what is stored in the *actual* data (e.g. photos of identifiable birthmarks, tattoos)
- What might be done with it?
- Data use agreements

At UQ we can publish datasets from the UQ RDM to UQ epspace as “open access” or “mediated access”

In MRI and other biomedical imaging we not only have to remove any identifiable information from image headers and other metadata, but sometimes need to remove faces in scans too!



Eke, Damian, et al. "Pseudonymisation of neuroimages and data protection: Increasing access to data while retaining scientific utility." *Neuroimage: Reports* 1.4 (2021): 100053.

Consent and Data Sharing

If you are planning to share your human data then your participants need to know!

- Participants can withdraw from your study at anytime, and you will no longer be able to use their data
- But once you've published a data set, you may have limited control over who is using the data and for what and it is unlikely data can be destroyed or withdrawn fully.
- **You must get consent to share data beyond your research**
- Participants must know when giving consent if there is a point at which they can no longer have their data withdrawn
- This an example data sharing information sheet.



Centre for
Advanced Imaging

Data Sharing

according to published guidelines of Open Brain Consent at
<https://open-brain-consent.readthedocs.org/en/latest/ultimate.html>

The data and samples from this study might be useful for other and future research projects in addition to the study you are currently participating in. Those future projects can focus on any topic that might be unrelated to the goals of this study. If you consent, we will give access to the data we are collecting, including the imaging data, to other investigators and the general public via the Internet and a fully open database.

To the best of our knowledge, the data we release to the general public will not contain information that can directly identify you. The data will not have your name on it, only a code number, so people will not know your name or which data are yours. In addition, the data will not include data that we think might help people who know you guess which data are yours, such as your facial features or the date that you participated. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

If you change your mind and withdraw your consent to participate in this study (the details of the principal investigator is provided via the information sheet), we will not collect any additional data about you. We will delete your data if you withdraw before it was deposited in the database. However, any data and research results already shared with other investigators or the general public cannot be destroyed, withdrawn or recalled.

By agreeing to participate, you will be making a free and generous gift for research that might help others. It is possible that some of the research conducted using your information eventually could lead to the development of new methods for studying brain, new diagnostic tests, new drugs or other commercial products. Should this occur, there is no plan to provide you with any part of the profits generated from such products and you will not have any ownership rights in the products.

By signing below, you agree to provide your data for future research. You agree that these may be shared with other investigators at other institutions from around the world. The details, results, and implications of these studies are unknown.

DATE:

PARTICIPANTS NAME:

Signature

Doc Ref:	S:Research\Ethics\Archive\2_Human ethics_CAI\2005000502 Galloway\2020 Amendment	Version:	v2.0
Procedure Owner:	Prof. David Reutens	Effective Date:	01/01/2019

Examples of types of shareable data sets

- Quantified self; Self regulated/Crowd sourced sharing
- Government datasets (census, gocard)
- Governed datasets e.g. Sydney Memory and Ageing Study, UK biobank, Human Connectome Project
 - Applications
 - Ethics approval
 - Specific data only shared
 - Participants consent to use
- Apply professional ethics when accessing shared data



HCP Young Adult

Study Home About This Study Data Documentation Contact

>> HEALTHY ADULT STUDIES > HCP YOUNG ADULT > DOCUMENTATION DETAIL

Extensively Processed fMRI Data

Release Date: Jul 21, 2017
Type: Data Release

HCP_S1200_GroupAvg_v1 Dataset (1096, 1003, 812 and 997 Subjects): This dataset (2.3 GB zip file) includes group-average structural and functional MRI data for the final HCP S1200 data release, including group average volumes, structural maps, Cohen's D effect-size maps for task contrasts, and links for viewing seed-based dense functional connectivity. Composite files containing maps for all 1096 MSMAll-registered individual subjects enable efficient between subjects comparisons of folding, 'sulc', myelin, and thickness data. To facilitate viewing and comparing data, the dataset includes a [Connectome Workbench](#) scene file, associated tutorial, and published cortical parcellations for reference, including the HCP-MMP1.0 (Glasser et al. 2016).

[Download in ConnectomeDB](#) (Login Required)

Data Use Resources

Need help using HCP data?

- [Sign up for the HCP-Users email forum](#)
- [HCP-Users FAQ](#)
- [MEG Data FAQ](#)
- [HCP Data Dictionary for Behavioral and Individual Difference Measures](#)
- [HCP Data Public Resources Wiki](#)
- [How to Cite HCP Data Use](#)

Understanding the Mound and Moat Effect

