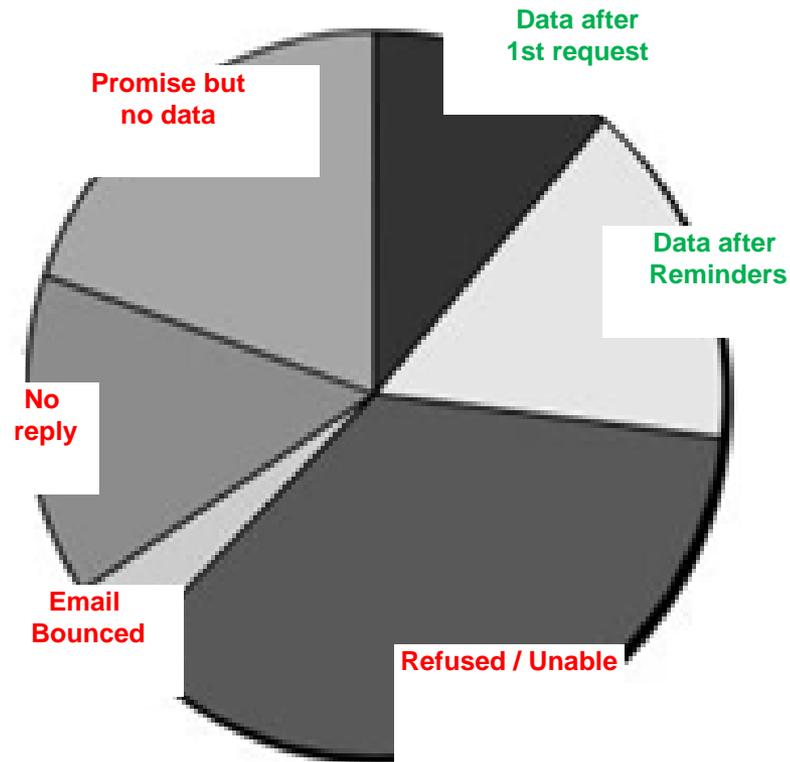


# Sharing and Re-use of Human Volunteer Data

**Rik Henson & CBU Open Science Committee**

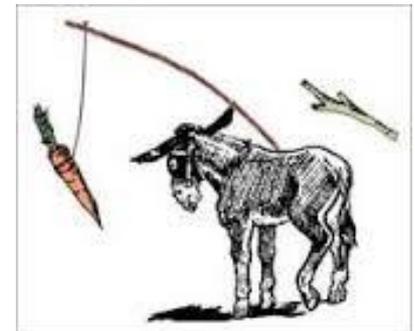
MRC Cognition and Brain Sciences Unit (CBU)  
Clinical School  
University of Cambridge

# Why share data (in science)?



Wicherts, Borsboom, Kats & Molenaar (2006). The poor availability of psychological research data for reanalysis. *American Psychologist*, 61(7), 726.

- We deal with identifiable data from human volunteers (e.g, IQ, brain scans)
- We ask volunteers for consent to share the data with anyone who requests
- Consent is more likely if volunteers know some constraints on its re-use: “managed” rather than “open” access (light-touch data usage agreements)
- University repository (Apollo) fine for anonymous data, but not sufficient (in 2016) for managed access
- So we created our own CBU Managed Access Data Repository
- **Mandatory** for all publications involving CBU authors
- Unpopular with some members, and extra work entailed, but tried to persuade them that beneficial to their own work (data management)



## CBSU Publications

### Open Data Repository

This page shows all 88 data sets currently available in our Open Data repository

To search for specific data sets, please use the CBSU Bibliography [search](#) form

Showing page < 3 > of 9



**The missing link? Testing a schema account of unitization**

Authors: TIBON, R., GREVE, A., HENSON, R.  
Reference: *Memory & Cognition*  
Year of publication: In Press  
CBU number: 8267  
Open Data available, [click](#) to request

**Impact of Culture on Autobiographical Life Structure in Depression**

Authors: Jobson, L., Miskon, N., DALGLEISH, T., Hill, E., Golden-A-M., Zulkefly, S., & Mukhtar, F.  
Reference: *British Journal of Clinical Psychology*

- Care with Personally Identifiable Data (PID)\*

*\* ie Name, Address, Postcode, NHS No., Email address, Date of Birth, Telephone number, IP address, National Insurance No., as defined by Clinical School...*

- However, some data are inherently unique to an individual, e.g, a structural T1-MRI scan (even after de-facing)
- Or multiple data points could be used to triangulate an individual (e.g, 93-year, left-handed woman in Cambridge with dyslexia)?
- GDPR makes it clear that such data are still “personal data”
- Personal data can be shared (for research), but you need **consent** (and consent needs to be properly **informed**)

- From 2017 (approved by Local Ethics Committee):

*“I understand that my personal data\*, such as my name, address and date of birth, are treated as highly confidential by the research team and kept in a secure computing areas and/or locked filing cabinet.”*

*“I understand that my research data\* will be kept in the long-term, may be combined with data from other CBU studies to answer new research questions, may be shared with other researchers, or may be made ‘Open’ without new consent being sought from me.”*

*\* As defined in Participant Information Sheet (PIS)*

From 1 July 2017 to 30 Nov 2018: >2500 consent forms signed, **NONE** refused to agree to above statement about sharing their data.

## What happens to my data?

You have provided us with two types of data. *Personal data* includes your name, address and date of birth – information from which you could be identified and that we use to contact you, calculate your age and so on. *Research data* includes information like the buttons you pushed on a computer task, information from a brain scan and your answers on a questionnaire; in other words, information from which it would not be possible, **or would be very difficult**, to identify you personally. We separate your personal data and your research data, and treat these two types of information very differently.

Personal data are either entered directly into a secure area of our computer system... etc etc...

## What happens to my research data?

Your research data, typically combined with similar information from other volunteers, will be used for scientific purposes. The results are typically presented in scientific papers and talks, in teaching and in explaining our science to health professionals, school groups and the public in general...

Undertaking scientific studies is expensive and relies on the generous contribution of time from volunteers. To make the most of your research data, we plan to look after it for the long term and may use it to answer research questions beyond those for which it was originally collected. This may include combining research data from this study with research data from other studies in the CBU in which you have been involved. In addition to our own analyses, we agree with the principle that research data, often collected with public money, are a public good, produced in the public interest, which should be made openly available with as few restrictions as possible in a timely and responsible manner. Many of the bodies that fund our research insist that we follow this principle. In line with this, we may also share research data with other researchers in the UK and around the world, free of charge. This is important for the scientific process, so that other researchers have the opportunity to check our results, or conduct new analyses. It also helps avoid research duplication.

We are aware that, very rarely, research data could be used to identify an individual (for example, questionnaire responses about life events could identify a particular person to someone who knows him or her; or the precise shape of your brain could be used to identify you in the unlikely event that someone else already had another scan of your brain). In such cases, we take great care to reduce the chances of such identification by omitting critical details, such as removing the face from an MRI scan. Moreover, in most cases, we will require people who access research data to agree to a “data usage agreement”, where they agree not to try to identify anyone, and not share the data with anyone else. However, on occasion, there is a need to make the data fully “open”. If research data are made open, then we have no control over how that information is used.

**You should only agree to participate in this study if you have understood and consent to this re-use and sharing of research data.**

If you change your mind and later withdraw your consent to participate in this study (you can call <PI name> at <phone number> to do this), and we will not collect any additional data about you. We will delete your data if you withdraw before the study was published or shared with others. However, any research data already published or shared with other investigators cannot be destroyed, withdrawn or recalled.

Home The Unit Research People Take part Studentships News Events Contact us

## CBSU Publications

### Data Request

Title

Data Set ID

Please complete the details below to request a copy of this data set. All fields are required, and requests cannot be considered if any of the fields are blank. Once we receive your request it will be evaluated by a member of staff based on criteria such as the scientific merit of the proposed data use. We will contact you with the result of this evaluation, and if your request is approved we will provide you with a link you can use to download a copy of the data.

Name

Institution

E-mail

Please outline the project for which the data are requested. Please include details of the scientific questions addressed, methods used, publication strategy, the organisation funding the research, and how data sources, funders, etc will be acknowledged

By requesting this data set, you agree to the following terms and conditions:

- I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact any of the participants.
- I will not publish or disclose any information in a way that would allow the identity of any individual participants to become known.
- I will only use the data for the purposes of non-commercial, ethically approved research or teaching as specified above. I will seek approval from the MRC CBSU if I wish to use the data for any other purpose.
- I agree to store the data securely.
- I will not disclose the data to any third parties beyond my immediate research team
- I will require any members of my team with whom I do share the data to comply with these terms and conditions
- I will comply with any rules and regulations imposed by my institution and its institutional review board when requesting and using the data.
- I understand that determining whether ethical approval is needed for the use of the data and gaining that approval is my responsibility.
- I understand that the CBSU cannot guarantee exclusive use of these data or police potential overlaps of interest between researchers who request the data.
- I understand that it is my responsibility to check the data for errors, and that the MRC CBSU is not responsible for any consequences of unreported errors in the data.
- I agree to make any errors that I discover in this data known to MRC CBSU as soon as possible.
- I agree to acknowledge the MRC CBSU in any output arising from the use of the data.
- I agree to make any publications that arise from use of the data open-access.
- I agree that should any data I derive from this data set appear in a publication, I will make that derived data, as well as any processing scripts used to produce that derived data, available on a suitable open-access data repository. I will also notify the MRC CBSU where the data has been made available.

Request data set

- I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact any of the participants.
- I will not publish or disclose any information in a way that would allow the identity of any individual participants to become known.
- I will only use the data for the purposes of non-commercial, ethically approved research or teaching as specified above. I will seek approval from the MRC CBU if I wish to use the data for any other purpose.
- I agree to store the data securely.
- I will not disclose the data to any third parties beyond my immediate research team
- I will require any members of my team with whom I do share the data to comply with these terms and conditions
- I will comply with any rules and regulations imposed by my institution and its institutional review board when requesting and using the data.
- I understand that determining whether ethical approval is needed for the use of the data and gaining that approval is my responsibility.
- I understand that the CBU cannot guarantee exclusive use of these data or police potential overlaps of interest between researchers who request the data.
- I understand that it is my responsibility to check the data for errors, and that the MRC CBU is not responsible for any consequences of unreported errors in the data.
- I agree to make any errors that I discover in this data known to MRC CBU as soon as possible.
- I agree to acknowledge the MRC CBU in any output arising from the use of the data.
- I agree to make any publications that arise from use of the data open-access.
- I agree that should any data I derive from this data set appear in a publication, I will make that derived data, as well as any processing scripts used to produce that derived data, available on a suitable open-access data repository. I will also notify the MRC CBU where the data has been made available.



JOIN/RENEW

LOGIN

SEARCH...

News Research Topics Conventions Journals Observer Magazine Members Employment & Career About

Observer > 2013 > November > The Subterranean War on Science

## The Subterranean War on Science

STEPHAN LEWANDOWSKY, MICHAEL E. MANN, LINDA BAULD, GERARD HASTINGS, AND ELIZABETH F. LOFTUS

TAGS: COGNITIVE PSYCHOLOGY | EXPERIMENTAL PSYCHOLOGY | FALSE MEMORY | PREJUDICE

Science denial kills. More than 300,000 South Africans died needlessly in the early 2000s because the government of President Mbeki preferred to treat AIDS with garlic and beetroot rather than antiretroviral drugs (Chigwedere, Seage, Gruskin, Lee, & Essex, 2008). The premature death toll from tobacco is staggering and historians have shown how it was needlessly inflated by industry-sponsored denial of robust medical evidence (Proctor, 2011). The US now faces the largest outbreak of whooping cough in decades, in part because of widespread denial of the benefits of vaccinations (Rosenau, 2012). According to the World Health Organization, climate change is already claiming more than 150,000 lives annually (Patz, Campbell-Lendrum, Holloway, & Foley, 2005), and estimates of future migrations triggered by unmitigated global warming run as high as 187 million refugees (Nicholls et al., 2011). A common current attribute of denial is that it side-steps the peer-reviewed literature and relies on platforms such as internet blogs or tabloid newspapers to disseminate its dissent from the scientific mainstream. In contrast, the publication of dissenting views in the peer-reviewed literature does not constitute denial.

The tragic track record of denial has stimulated research into its political, sociological, and psychological underpinnings (Dunlap, 2013; Jacobson, Targonski, & Poland, 2007;



## About the Authors

**Stephan Lewandowsky** is with the Department of Psychology at the University of Bristol, UK, and University of Western Australia; **Michael E. Mann** is with the Departments of Meteorology & Geosciences at Penn State University; **Linda Bauld** and **Gerard Hastings** are with the Centre for Tobacco Control Research at the University of Stirling, UK; and **Elizabeth F. Loftus** is with the Department of Psychology and Social Behavior at the University of California, Irvine.

## Related



### MYTH: EYEWITNESS TESTIMONY IS THE BEST KIND OF EVIDENCE

Activities in this unit reveal how eyewitness testimony is subject to unconscious memory distortions and biases even among the most confident of witnesses. ... More



### MYTH: TRAUMATIC MEMORIES ARE OFTEN REPRESSED AND LATER RECOVERED

This provides students with an opportunity to see that, often, analyses may lead to conclusions

[Home](#) [The Unit](#) [Research](#) [People](#) [Take part](#) [Studentships](#) [News](#) [Events](#) [Contact us](#)

## CBSU Publications

### Data Request

Title

Data Set ID

Please complete the details below to request a copy of this data set. All fields are required, and requests cannot be considered if any of the fields are blank. Once we receive your request it will be evaluated by a member of staff based on criteria such as the scientific merit of the proposed data use. We will contact you with the result of this evaluation, and if your request is approved we will provide you with a link you can use to download a copy of the data.

Name

Institution

E-mail

Please outline the project for which the data are requested. Please include details of the scientific questions addressed, methods used, publication strategy, the organisation funding the research, and how data sources, funders, etc will be acknowledged

By requesting this data set, you agree to the following terms and conditions:

- I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact any of the participants.
- I will not publish or disclose any information in a way that would allow the identity of any individual participants to become known.
- I will only use the data for the purposes of non-commercial, ethically approved research or teaching as specified above. I will seek approval from the MRC CBSU if I wish to use the data for any other purpose.
- I agree to store the data securely.
- I will not disclose the data to any third parties beyond my immediate research team
- I will require any members of my team with whom I do share the data to comply with these terms and conditions
- I will comply with any rules and regulations imposed by my institution and its institutional review board when requesting and using the data.
- I understand that determining whether ethical approval is needed for the use of the data and gaining that approval is my responsibility.
- I understand that the CBSU cannot guarantee exclusive use of these data or police potential overlaps of interest between researchers who request the data.
- I understand that it is my responsibility to check the data for errors, and that the MRC CBSU is not responsible for any consequences of unreported errors in the data.
- I agree to make any errors that I discover in this data known to MRC CBSU as soon as possible.
- I agree to acknowledge the MRC CBSU in any output arising from the use of the data.
- I agree to make any publications that arise from use of the data open-access.
- I agree that should any data I derive from this data set appear in a publication, I will make that derived data, as well as any processing scripts used to produce that derived data, available on a suitable open-access data repository. I will also notify the MRC CBSU where the data has been made available.

[Request data set](#)

Please outline the project for which the data are requested. Please include details of the scientific questions addressed, methods used, publication strategy, the organisation funding the research, and how data sources, funders, etc will be acknowledged

- Volunteers less likely to agree to sharing for profit-making?  
(CLIMB study: <https://www.isrctn.com/ISRCTN37444142> )

By requesting this data set, you agree to the following terms and conditions:

- I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact any of the participants.
- I will not publish or disclose any information in a way that would allow the identity of any individual participants to become known.
- **I will only use the data for the purposes of non-commercial, ethically approved research or teaching as specified above. I will seek approval from the MRC CBU if I wish to use the data for any other purpose.**
- I agree to store the data securely.
- I will not disclose the data to any third parties beyond my immediate research team
- I will require any members of my team with whom I do share the data to comply with these terms and conditions
- I will comply with any rules and regulations imposed by my institution and its institutional review board when requesting and using the data.
- I understand that determining whether ethical approval is needed for the use of the data and gaining that approval is my responsibility.
- I understand that the CBU cannot guarantee exclusive use of these data or police potential overlaps of interest between researchers who request the data.
- I understand that it is my responsibility to check the data for errors, and that the MRC CBU is not responsible for any consequences of unreported errors in the data.
- I agree to make any errors that I discover in this data known to MRC CBU as soon as possible.
- I agree to acknowledge the MRC CBU in any output arising from the use of the data.
- I agree to make any publications that arise from use of the data open-access.
- I agree that should any data I derive from this data set appear in a publication, I will make that derived data, as well as any processing scripts used to produce that derived data, available on a suitable open-access data repository. I will also notify the MRC CBU where the data has been made available.

By requesting this data set, you agree to the following terms and conditions:

- I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact any of the participants.
- I will not publish or disclose any information in a way that would allow the identity of any individual participants to become known.
- I will only use the data for the purposes of non-commercial, ethically approved research or teaching as specified above. I will seek approval from the MRC CBU if I wish to use the data for any other purpose.
- I agree to store the data securely.
- I will not disclose the data to any third parties beyond my immediate research team
- I will require any members of my team with whom I do share the data to comply with these terms and conditions
- I will comply with any rules and regulations imposed by my institution and its institutional review board when requesting and using the data.
- I understand that determining whether ethical approval is needed for the use of the data and gaining that approval is my responsibility.
- I understand that the CBU cannot guarantee exclusive use of these data or police potential overlaps of interest between researchers who request the data.
- I understand that it is my responsibility to check the data for errors, and that the MRC CBU is not responsible for any consequences of unreported errors in the data.
- I agree to make any errors that I discover in this data known to MRC CBU as soon as possible.
- I agree to acknowledge the MRC CBU in any output arising from the use of the data.
- I agree to make any publications that arise from use of the data open-access.
- I agree that should any data I derive from this data set appear in a publication, I will make that derived data, as well as any processing scripts used to produce that derived data, available on a suitable open-access data repository. I will also notify the MRC CBU where the data has been made available.

- Why wait until publication....?
  - Data available to reviewers/editors
  - Filing Drawer problem (null results)
  - “Scooping”, really?



## The Open Scoop Challenge

*Posted 2014-02-25 by Greg Wilson in Community, Open Science.*

- Incentives for sharing...

- Data Papers

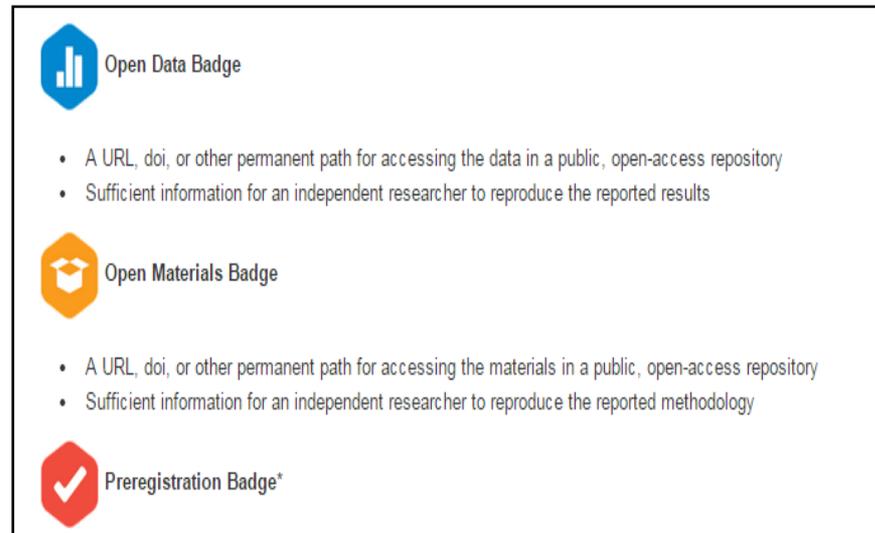


- Reproduction Papers

(e.g., “Verification Reports” in Cortex:

[https://www.elsevier.com/\\_\\_\\_data/promis\\_misc/VR\\_GuideForAuthors.pdf](https://www.elsevier.com/___data/promis_misc/VR_GuideForAuthors.pdf))

- Kite Marking



- Sharing unreadable data is no help at all - FAIR principles (<https://www.go-fair.org/fair-principles/>)
- Agreed formats, e.g, BIDS for imaging data
- Checking on researcher ID (internet bots? Human checking of requests practical if 1000s per week?)
- Commercially-sensitive data?

- *What are some of the impacts of sharing data and of its subsequent reuse?*
  - Mandatory! (for science)?
  - Always potential for errors (get over ego!)
  - Potential (mis)use?
- *Does the researcher who shared their data openly benefit?*
  - Science benefits! (Reproducibility papers)
  - Citations of data paper/protocol paper
  - Reputation (for transparency)
- *What are the essential properties of a reusable dataset?*
  - Easy (Quick) Access
  - (Web-based) Data Usage Agreement
  - FAIR principles



MRC Cognition  
and Brain  
Sciences Unit



UNIVERSITY OF  
CAMBRIDGE

---

End

Until 2017, default Consent forms at CBU included:



*“I understand that the research data may be accessed by other researchers **approved by the CBU in similar ethically approved studies** but that at all times my personal data will be kept confidential in accordance with data protection guidelines”*

(requiring many-page legal Collaboration / Data Transfer Agreements etc...)

- In 2018, GDPR enforced, and whereas data previously viewed as “owned by researcher” or “owned by funder”... now clearly “owned by participant”
- Neuroimaging researchers realized that most Consent Forms (and PISs) insufficient, particularly in explaining (in plain speech) what type of data are shared and any potential risks (“de-identified” not sufficient)

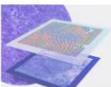
← → ↻ [onlinelibrary.wiley.com/doi/full/10.1002/hbm.25351](https://onlinelibrary.wiley.com/doi/full/10.1002/hbm.25351)

← → ↻ [open-brain-consent.readthedocs.io/en/stable/ultimate.html](https://open-brain-consent.readthedocs.io/en/stable/ultimate.html)

**Wiley Online Library**

Search

Advertisement



Free virtual seminar | Now on-demand  
**Spatial sequencing-based integration of single cell data**

**HUMAN BRAIN MAPPING** Open Access

EDITORIAL | [Open Access](#) |

**The Open Brain Consent: Informing research participants and obtaining consent to share brain imaging data**

Elise Banner, Gareth Barker, Valentina Borghesani, Nils Broeckx, Patricia Clement, Kyrre E. Emblem, Satrajit Ghosh, Enrico Glerean, Krzysztof J. Gorgolewski, Marko Havu ... [See all authors](#) ▼

First published: 01 February 2021 | <https://doi.org/10.1002/hbm.25351> | Citations: 1

Authors belong to the Open Brain Consent working group: Working group collaborators in alphabetic order.

**Funding information:** European Cooperation in Science and Technology, Grant/Award Number: CA-18206; National Institute of Health, Grant/Award Number: NIH-NIBIB P41 EB019936; National Science Foundation, Grant/Award Number: NSF 1429999; EU INTER-EXCELLENCE program, Grant/Award Number: LTC20027; NIMH, Grant/Award Number: R01MH096906; International Laboratory of Social Neurobiology ICN HSE RF, Grant/Award Number: 075-15-2019-1930

☰ SECTIONS PDF TOOLS SHARE

**Abstract**

Having the means to share research data openly is essential to modern science. For human research, a key aspect in this endeavor is obtaining consent from participants, not just to take part in a study, which is a basic ethical principle, but also to share their data with the scientific community. To ensure that the participants' privacy is respected, national and/or supranational regulations and laws are in place. It is, however, not always clear to researchers what the implications of those are, nor how to comply with them. The Open Brain Consent (<https://open-brain-consent.readthedocs.io>) is an international initiative that aims to provide researchers in the brain imaging community with information about data sharing options and tools. We present here a short history of this project and its latest developments, and share pointers to consent forms, including a template consent form that is compliant with the EU general data protection regulation. We also share pointers to an associated data user agreement that is not only useful in the EU context, but also for any researchers dealing with personal (clinical) data

**Open Brain Consent**



stable

Search docs

Sample consent forms  
Recommendations

- ☰ **Ultimate consent form**
- ☰ English
- ☰ Translations
- GDPR edition
- Anonymization tools
- Contribute
- Contact information
- Acknowledgement
- Discussions



**New typing biometrics authentication method to replace SMS 2FA codes. Free for the first year**

Sponsored - Ads served ethically

Docs » Ultimate consent form

[Edit on GitHub](#)

**Ultimate consent form**

The following consent form has been put together, by merging best parts of existing consent forms and consulting with experts in research ethics.

**English**

**Single access type version (all data shared publicly; recommended)**

Version: OBC-ULT 1.0.0

The data and samples from this study might be used for other, 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. We will give access to the data we are collecting, including the imaging data, to the general public via the Internet and a fully open database.

The data we share with the general public 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, we will not share any other information that we think might help people who know you guess which data are yours.

If you change your mind and withdraw your consent to participate in this study (you can call <PI name> at <phone number> to do this), 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.

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. However, by using additional data linked to your name (for example brain scans obtained from your medical records) one could potentially associate your imaging or other information in our database back to you. In addition a security breach (break in or cyber attack) might lead to someone being able to link