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Global Drug Survey Data Sharing Agreement

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Document purpose

The purpose of this document is to describe the requirements for GDS to share data with any organisation or individual outside the GDS Core Research Team (CRT). It includes the Data Sharing Agreement that needs to be signed and fully complied with in all instances of data sharing.

1.0 Introduction and Background to GDS

Global Drug Survey (GDS) is an independent research organisation with information processing as a fundamental part of its purpose. It is important, therefore, that the organisation has a clear and relevant Information Security Policy, allowing it to comply with information legislation.

1.1 GDS Methods and Mission

1.1.1 GDS Mission

Our mission is to make drug use safer regardless of the legal status of the drug. All our research is approved by university research ethics committees. All our data is anonymous. In our annual GDS surveys IP addresses are not collected and we record no personal details that allow identification of living persons in our linked data bases*

*All information is anonymous. A subset of participants (approximately 20%) provide their e-mail address which are stored in a separate encrypted stored database and consent to take part in future GDS projects. In such cases, anonymous data can be linked to e-mail addresses only after dual de-encryption and linkage by the Chief Technical Officer (CTO).

1.1.2 GDS Methods

GDS uses encrypted web surveys to gather data on drug use trends to inform public policy. Our data supports individuals and communities to adopt safer strategies regarding the consumption of psychoactive substances including alcohol. Anonymity, data security and confidentiality are central to everything we do.

GDS uses its data to create free harm reduction resources and apps. We also support the development of young researchers and produce academic peer reviewed publications and data based reports for government, public health and corporate organizations. We do not take funding from tobacco or alcohol industries.

2.0 Data Sharing Principles

The lawful and proper treatment of data collected by GDS is extremely important to the success of our business and in order to maintain the confidence of the people who participate in our surveys, use our free resources and use our data report and consulting service. We share data only after extensive assessment of the purpose for which the data is to be used, the credibility and reliability of potential partner an only after data security requirements have been met. We share data to support research, policy and treatment initiatives.

In order to access any GDS data a direct approach is required to the CEO. After consideration of the request and discussion with members of the CRT – the following agreement will be sent out (adapted if required to meet jurisdictional requirements or corporate request)

2.1 Data sharing agreement

Dear

Thank you for your support and partnership with Global Drug Survey (GDS). This letter outlines the requirements that must be agreed to before GDS consents to share any data files or research output with you and your team. We have instituted this process to ensure that all our networks comply with appropriate with data storage and security protocols.

Please read this document carefully, ensure you can meet all the data security and information sharing protocols, then print, sign and return a copy to me by email (a scanned PDF returned by email will suffice).

Once we have received this communication we can commence the process of releasing the requested files to you as the named individual. An anonymous pooled dataset will be shared securely either through encrypted file transfer or password protected access to an on-line data store.

GDS data security and sharing requirements.

You agree to:

- Store the data on a secured server and keep no copies on non-encrypted computers or external hard devices and laptops
- Not share access to the data with any other person (except nominated research team members) who will comply with the same data storage requirements)
- Only conduct analysis related to the research topic specified below
- Create and share code/syntax to produce the results of the analysis with GDS for future replication if required
- Delete the data file on completion of the project, or as agreed through your ethics committee process
- Seek permission from Adam Winstock before commencing any work for publication or public presentation
- Submit drafts of related journal articles and/or conference presentations to Adam Winstock and/or other members of the GDS Core Research Team (Jason Ferris, Monica Barratt, Larissa Maier) for comment and opportunity for contribution and co-authorship
- If this work is being conducted as part of a funded project please disclose the nature of this funding to Adam Winstock
- You agree not to supply any versions of the output of this work to any third party without written permission from GDS

- This letter of offer is valid for 14 days Should you be requested to provide reports based on GDS data you direct the groups to us. No money can be made from GDS data reports to third parties without prior approval from GDS

I the undersigned agree to comply with the data security and storage requirements above and to notify Adam Winstock immediately should there be any divergence from full compliance with these requests.

Name

Title

Position

Organization

Your intended output from analysing GDS data

[Insert output and datasets to be used here]

The intended recipient of this planned output
Academic journal
Presentation at conference (with prior discussion)

Signature

Dr Adam R Winstock MD Founder and Director Global Drug Survey 2017

3.0 Scope

3.1 Personnel within the Scope of this Document

Personnel associated with GDS are within the scope of this document:

- Core Research Team
- Senior Academic Mentor Group
- International Academic Partner Network
- Staff working on behalf of GDS when involved in GDS linked projects.

4.0 Roles and Responsibilities

4.1 Chief Executive

Overall accountability for procedural documents across the organisation as they relate to data security and corporate lies with the CEO. As the Accountable Officer they have overall responsibility for establishing and maintaining an effective document management system and the governance of information, meeting all statutory requirements and adhering to guidance issued in respect of information governance and procedural documents

4.2 Core Research Team Members

- Determine the academic credentials of researchers requesting data
- Assess the purpose for which for which data is being requested
- Nominate a GDS CRT member to monitor progress and compliance with GDS information governance policies.
- Provide clear lines of report and supervision for compliance with data protection and handling
- Provide training for all staff members who handle GDS data and ensure access to further guidance and support
- Carry out regular checks to monitor and assess new data handling including analyses of research data

4.3 GDS partner responsibilities

4.3.1 All partners

All partners within the GDS network who have access to the survey development site, survey data or app data will, through appropriate training and responsible management:

- Sign the data sharing agreement
- Observe all forms of guidance, codes of practice and procedures about the collection and use of survey and app data outlined in the data sharing agreement.
- Understand fully the purposes for which GDS uses the data that it has been granted access to.
- Ensure the information is destroyed (in accordance with the provisions of the Act or research ethics committee requirements) when it is no longer required.

5.0 Transfer of information

5.1 Encrypted cloud service transfer

Care must be taken in transferring information to ensure that the method used is as secure as it can be. Encrypted cloud service transfer is the most reliable method. In most instances a Data Sharing/Information Sharing, Data Re-Use or Data Transfer Agreement will have been completed before any information is transferred. The Agreement will set out any conditions for use and identify the mode of transfer. For further information on Data Sharing Agreements see Policy 5

5.2 Outside transfer

Transferring patient information by email to anyone outside approved persons working on named GDS projects may only be undertaken by using encryption and with written permission from the CEO.

5.3 Passwords

Must be kept secure and must not be disclosed to unauthorised persons. Person working on GDS projects must not use someone else's password to gain access to information. Action of this kind will be viewed as a

serious breach of confidentiality. If you allow another person to use your password to access GDS data this constitutes a disciplinary offence.

6.0 Distribution and Implementation

- This document will be made available to all persons working on GDS projects via direct e-mail.
- A global notice will be sent to all persons working on GDS projects notifying them of the release of this document.

7.0 Monitoring

7.1 Compliance

Compliance with the policies and procedures laid down in this document will be monitored via the SIRO together with independent reviews by both Internal and External Audit on a periodic basis.

7.2: The CEO is responsible for the monitoring, revision and updating of this document on a 3-yearly basis or sooner if the need arises.

Note: As part of its development this document and its impact on equality has been analysed and no detriment identified.

8.0 Associated Documents

8.1 Supporting documents

The following documents will provide additional information.

REF NO	DOC REFERENCE NUMBER	TITLE
P01	V2	Information Governance Policy
P02	V2	Data Security Policy
P03	V2	Confidentiality Policy
P04	V2	Information Security Policy
SER_1	V1	Drinks Meter Server Compliance Document

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