Health Research Board

Terms and Conditions for requesting the use of National Health Information Systems (NHIS) data

and

Data Request Form

2022

Terms and conditions for request and the use of data from the HRB NHIS

1. All data request forms received for NHIS data shall be reviewed on the basis of the information supplied on the form. The person(s) requesting the information shall be informed of the decision whether or not to release the data. In the event of a request for data being accepted by the HRB, the persons obtaining the data shall agree to abide by the terms and conditions outlined hereunder.

2. Upon receipt of the requested data, the person(s) named on the request form shall check to ensure that all data requested has been received. The NHIS team shall be notified at once of any omissions..

3. The data received by the person(s) requesting the information is for the sole purpose outlined in the request form and shall not be used for any other purpose.

4. The data shall be used only by the person(s) named on the request form and access to the data shall be permitted only to those named. Access to the data by any other third party is prohibited.

5. The data shall not be used to contact families or identify individuals. Numbers of five or less cannot be presented in any publication, so no individual can be identified from the study.

6. The data shall not be linked to any other data unless this has been specified on the request form.

7. The data shall not be taken outside the country or released outside the country to other users unless these users have been identified and the purpose of sharing the data has been provided on the requested form.

8. Appropriate security arrangements for the storage of, and access to, the data are the responsibility of the person(s) listed in the request form. Details of such security measures must be provided on the form.

9. The NHIS may request updates from time to time regarding the data and progress relating to any associated publications/reports/papers/analyses. The person(s) named on the request form shall ensure that all such updates are supplied to the HRB.

10. Reports/papers arising from the data obtained shall be forwarded to the HRB ***prior*** to publication. The HRB reserves the right to comment on reports/papers ***prior*** to publication to preserve the integrity/anonymity of the data and to ensure the accurate interpretation of data. In so doing, the HRB reserves the right to request that the author(s) of any such reports/papers carry out all requested amendments ***prior*** to publication.

11. Where appropriate, any NHIS staff member who assisted with any analysis, writing, or reviewing of the paper should be invited to become an author on any peer-reviewed publication if they meet the authorship criteria of the proposed journal/s..

12. Copies of publications arising from data provided by the HRB must be lodged with the HRB. Publications using drug-related data must be lodged with the National Drugs Library (where appropriate).

13. Any publications arising from the data obtained shall reference the national health information system from which the data was obtained and clearly acknowledge the HRB as the data source. Where individual tables from annual reports or additional data/analyses from a national health information system are being used as part of an external report/paper, a footnote acknowledging the source should be provided in the following format: Source: HRB followed by the name of the national health information system followed by year of data.

14. The person(s) listed on the request form shall ensure that the data or associated publications/reports/papers/analyses do not lead to the identification of any individual or household.

15. The HRB reserves the right to obtain access to the data supplied to the persons listed on the request form at all times.

16. While rigorous quality assurance checks and validation measures are carried out on the data there is no guarantee that all data is error free. The HRB shall be notified at once of any errors discovered in data received.

17. After the study/research has been completed, the data, including any paper or electronic copies, must be destroyed by a date agreed with the HRB. This date must fall within five years from the date of completion of the study. The HRB must be informed in writing that the study has been completed and that the data has/will be destroyed by the agreed date.

18. Any breach of the terms of the conditions shall result in all data and associated reports/analyses, including copies thereof, being returned to the HRB.

Data Request Form

Please complete all sections of this form. If you are returning this form electronically please type in your name where signature is requested or use electronic signature, to indicate that you have read and understand the conditions attached to receiving the data.

Section A: Applicant details

1. Name of Applicant:
2. Address:
3. Contact Telephone Number:
4. Email Address:
5a. Name of agency/academic institution (where applicable): **5b. Type of organisation/agency *(please tick all that apply)***

Academic – (*please specify institution)*		Media	
Department of Health		Pharmaceutical	
Other government department: *(please specify)*		Commercial organisation *(please specify)*	
HSE - *(please specify area)*		Student	
HSE Hospital		Other	

6. Is this research being carried out in part requirement of a thesis/dissertation for an undergraduate or postgraduate course?

Yes ☐ **No** ☐

6a. If Yes, please give details of your supervisor's name and address:

7. Please supply details of other members of the research team, if applicable:

8. Please provide name of research study (if applicable) with the aims and objectives of study or analysis. A brief summary of the study and research questions should be provided. ***A copy of the research proposal may be attached.***

9a. Was ethical approval sought by you/your agency/organisation/institution/college to carry out this work? Please tick all that apply.

		Yes	No
1	Sought		
2	Received		
3	Refused		
4	Not required		

9b. If Yes to 1, or 2, please indicate the name of the ethics committee/group and the date of receipt of ethical approval:

Name: _____ Date: _____

9c. Please confirm that a copy of your approval from an ethics committee is attached

Yes ☐

Section B: Details of data required

10a. Name of national health information system/s from which data sought:
Please tick all that apply.

Systems:	
NIDD (National Intellectual Disability Database)	
NPSDD (National Physical and Sensory Disability Database)	
NASS (National Ability Supports System)	
NDRDI (National Drug-Related Deaths Index)	
NDTRS (National Drug Treatment Reporting System)	
NPIRS (National Psychiatric Inpatient Reporting System)	

10b. Details of type of data required – please specify in detail the data items required, the years for which data are required (where applicable), and the proposed use of the data.

11. Details of analysis required (if applicable).

12. How will the data be stored? Please outline security arrangements for storage and access to the data.

13. Name of individual who will be primarily responsible for security of the data?

14. What type of publication/report do you see arising from the data?
Please tick all that apply.

Journal article	
Dissertation/thesis	
Internal report	
External report	

Section C: Data agreement

If I am given access to this data, I undertake to agree to the 'Terms and conditions' above. **Signature of Applicant**: **_____** **Date: _____**
Request approved: _____ **Date: _____**
Date sent: _____ **Date: _____**