**Appendix B**

UKSeRP

**HealthWise Wales (HWW)**

**DATA ACCESS AGREEMENT**

**(VERSION 1.0)**

**The HealthWise Wales**

**Data Access Agreement**

As a result of a successful study application, this agreement governs the terms on which access will be granted to the data stored in the HealthWise Wales researcher database.

In signing this agreement, you are agreeing to be bound by the terms and conditions of access set out in this agreement.

For the sake of clarity, the terms of access set out in this agreement apply both to the User and the User’s Authorising Institution. User and User’s Authorising Institution are referred to within the agreement as “You” and “Your Institution” and shall be construed accordingly.

**Definitions:**

*Anonymous* means data from which personal identifiers have been removed and that the removed identifiers are not held, in any form or place by the organisation holding the remaining data.

*Authorising Institution* is the organisation to which the user is affiliated and which signs the data access agreement.

*Data* means all data made available from HWW.

*Data Provider* means the organisation that has agreed to share data with HWW.

*Data Subject* means an anonymised person to whom the data pertains.

*Information* means any knowledge, insights or opinions that have been informed by the use of the HWW data.

*Publication* means, without limitation, articles published in print journals, electronic journals, reviews, books, posters and other written and verbal presentations of research.

*HWW* HealthWise Wales

*SAPPHIRe* The UKSeRP partition provided as a portal for researchers to access the HWW resource.

*User Institution* means the organisation at which the User is employed, affiliated or enrolled.

*User* means a researcher whose Authorising Institution has previously completed this Data Access Agreement and has received acknowledgement of its acceptance.

**Terms and Conditions:**

In signing this Agreement:

1. You agree to use the data only according to the study outline in the HWW research project application form and understand that any amendments to this protocol must be passed through the HWW Scientific Steering Group for approval. Use of the data for any unapproved purposes is strictly prohibited and will result in disciplinary action.
2. You agree to the statement of the procedures, as given in the [National Statistics Code of Practice: Protocol on Data Access and Confidentiality](https://www.statisticsauthority.gov.uk/archive/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf)[[1]](#footnote-1), adopted by Welsh Government to protect the confidentiality of personal data, and confirm that in any use made of this data, the User will follow these procedures, both in letter and spirit, to the maximum extent that they apply. Breaches will be recorded on a risk log and reported to relevant external bodies. HWW will work with all custodians to assist them enact any measures, including penalties, that apply.
3. Any disputes arising between the providing and beneficiary organisations will be resolved initially between the principals to the agreement. Otherwise, outstanding issues will be referred through the HWW Scientific Steering Group, whose judgement will be final in the matter.
4. You agree to abide by the terms outlined in the HWW 'Publications Policy'.
5. You accept that the data is protected by and subject to international laws, including but not limited to the General Data Protection Regulation (GDPR), The Data Protection Act 2018[[2]](#footnote-2), the common law duty of confidentiality and the Human Rights Act 1998 and that you are responsible for ensuring compliance with any such applicable law. The HWW Scientific Steering Group reserves the right to request and inspect data security and management documentation and arrangements.
6. You accept that access cannot be granted to anyone currently being investigated for any data protection contravention, or anyone who has been found to have been breach of any relevant policy or law.
7. This agreement shall be construed, interpreted and governed by the laws of England and Wales and shall be subject to the non-exclusive jurisdiction of the courts.
8. You agree to follow the principles

* *You will use the information entrusted to you for the public good - to improve health and health (and allied) services.*
* *You will acknowledge the origins of the information you use and will respect the rights of patients and their information guardians.*
* *You will never make deliberate attempts to discover the identity of any individual from the information to which you have access.*
* *You will never make public the results of your analysis that might result in an individual, or small groups of individuals, being identified.*
* *You will not attempt to match or link HWW data to any data from another source that may lead to the disclosure of information about individual units, households or businesses.*
* *You will abide by and try to exceed all relevant laws and codes of practice current at the time.*
* *You will only use HWW data for genuine research for the public good, in line with your project scope agreed by the HWW Scientific Steering Group. You will never use HWW data for purely commercial purposes (e.g. market research).*
* *You will treat the information you may view responsibly and take proper precautions with regard to the security of the information.*
* *You will conduct your analysis thoughtfully and only make public results that have been carefully judged to be fair and unbiased.*
* *You will use the results of our analysis fairly and equitably, and will not enter into campaigns or arguments that are not pursued solely in the public interest.*
* *You will try and help improve the quality of routinely collected health information, by passing on the lessons you learn.*
* *You will not allow the information to be used to embarrass, coerce or performance manage organisations or the departments or individuals that work within them.*

1. You agree to preserve, at all times, the confidentiality of information and data pertaining to data subjects. In particular, you undertake not to use, or attempt to use the data to compromise or otherwise infringe the confidentiality of information on data subjects and their right to privacy.
2. You will consult The HWW Team in writing before taking any step that could put at risk the confidentiality or security of the data.
3. You understand and acknowledge that use of the data granted under this Agreement should not be construed as conferring ownership of the data, which are protected by copyright and other intellectual property rights.
4. You understand that no data, results, or any product derived from the data, may be copied, by any means and for any purposes, from SAPPHIRe without it having first been submitted for approval by a designated HWW member. Data must not be released as part of a study output that could identify an individual or could be used to identify an individual. This includes all statistical findings, summary figures, counts, percentages, presentations, publications, papers and analysis. The final decision in respect of release of outputs remains with HWW.
5. You are required to notify HWW of all disseminations of findings and to provide a copy of all final publications (e.g. papers, reports, abstracts and posters) to HWW as soon as they become available. Publications should be submitted by email to [healthwisewales@cardiff.ac.uk](mailto:healthwisewales@cardiff.ac.uk)
6. Any reference to the use of HWW data in any publication, poster, or presentation prior to approval by the Scientific Steering Group, must be clearly described as “Pending approval”.
7. You agree to adhere to the Publication Policy (footnote to weblink) in acknowledging HWW in any published paper or presentation, which is based wholly or partly on the data.
8. You accept that HWW, the original data creators or guardians, depositors or copyright holders, or the funders of the data or any part of the data supplied: a) bear no legal responsibility for the accuracy or comprehensiveness of the data; and b) accept no liability for indirect, consequential, or incidental, damages or losses arising from use of the data, or from the unavailability of, or break in access to, the data for whatever reason.
9. You agree that on request you will submit a short report suitable for sharing within the public domain on progress with or the outcomes of your project. HWW will use this information (amongst other purposes) in reports to their funders and on their website.
10. You agree that you and your collaborators agree to make any reasonable changes to the products of your work involving the HWW data, as requested by the Scientific Steering Group. The Scientific Steering Group will only request such changes if, in its opinion, your work infringes the spirit of the agreement or the principles of collaboration that HWW has with its data provider organisations.
11. You accept that data will be refreshed from time to time, with notice given.
12. You accept that it may be necessary for HWW or its appointed agent to alter the terms of this agreement from time to time in order to address new concerns. In this event, HWW or its appointed agent will contact you to inform you of any changes.
13. You accept that the user account created for you will be used by yourself only and no other individual. By logging on you reaffirm your agreement to uphold data confidentiality and security in terms of this Agreement.
14. You agree that HWW data shall not be electronically copied or distributed.
15. You agree to ensure that your computer operating system, used to access SAPPHIRe, is updated with the latest security patches, and that you will run reliable, effective and up-to-date anti-virus software. Failure to do this will result in your access privileges being revoked.
16. You agree that if you suspect that the availability, integrity or security of the SAPPHIRE system is compromised in any way you will immediately notify the HWW team. You will also inform the team if you detect weakness in the SAPPHIRE system which could result in it being compromised. The SAPPHIRE/HWW team can be reached via [healthwisewales@cardiff.ac.uk](mailto:healthwisewales@cardiff.ac.uk)
17. You agree to demonstrate that you have satisfactorily completed an approved safe researcher training course. You will re-attend training every 2 years if expiry of your certificate occurs within the time period of your study.
18. Offences and Penalties
19. You accept that this agreement will terminate immediately upon any breach of this agreement by you. In this event, you would be required to destroy any analysis and products derived from this data.

HWW reserves the right to suspend access to data if it considers that any User is perpetrating or attempting to perpetrate any breach of the terms of this Agreement.

HWW retains discretionary powers over the application of penalties for self-reported breaches.

The following are illustrative of the type of penalty that may be applied for a breach that is not self-reported:

* Using the service and/or data for unapproved commercial purposes – permanent suspension
* Infringing HWW security protocols - first offence - 6 months suspension
* Transferring log in details to another user – more than one offence - permanent suspension

The above list is illustrative and not exhaustive.

There shall be a right of appeal to the HealthWise Wales Scientific Lead the initial decision to apply a sanction. The decision of the Scientific Lead on appeal is final.

**HWW RESEARCHER DATABANK**

**DATA ACCESS AGREEMENT**

I have read the terms and conditions set out in the HealthWise Wales Data Access Agreement version 1.0 and agree to be bound by them. I declare that I am not currently being investigated under the Data Protection Act 2018 and have not been found to be in breach of the Act.

Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Job Title: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Organisation: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Head of Department/Authorising Institution Approval**

I confirm that I am happy for this applicant to have access to HWW data and I am aware of the penalties arising from breaches of these terms and conditions.

Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Job Title: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Organisation: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. [https://www.statisticsauthority.gov.uk/archive/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf](http://www.statistics.gov.uk/about/national_statistics/cop/protocols_published.asp) [↑](#footnote-ref-1)
2. https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/ [↑](#footnote-ref-2)