



Doeth am Iechyd  
Cymru  
HealthWise  
Wales



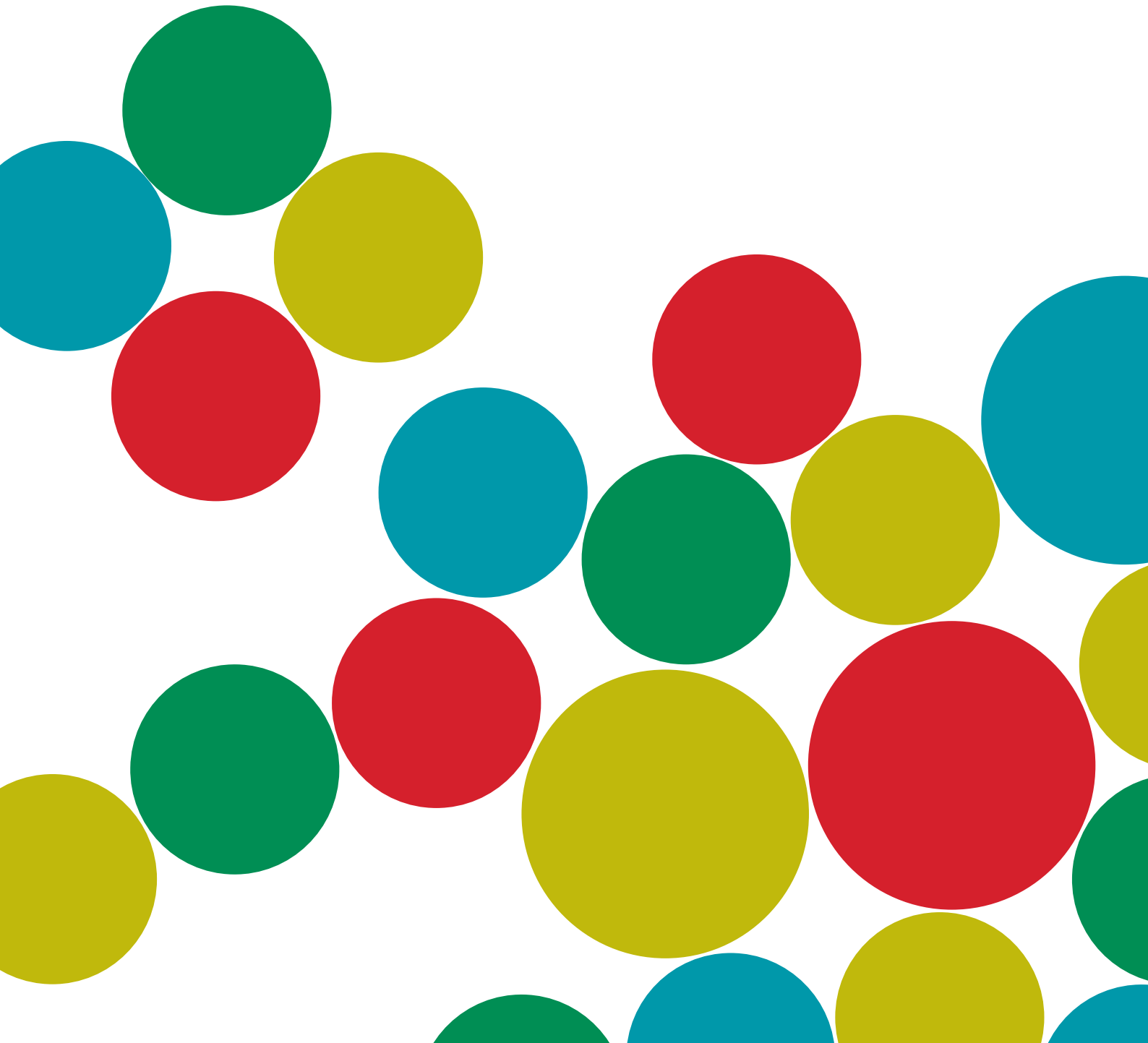
Llywodraeth Cymru  
Welsh Government



JANUARY 2019

# HealthWise Wales

## Resource Access Guidance for Researchers



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## Abbreviations

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HWW	HealthWise Wales
SSG	Scientific Steering Group
PPI	Patient and Public Involvement
UKSeRP	UK Secure eResearch Platform
SAIL	Secure Anonymised Information Linkage
IG	Information Governance
SAPPHIRE	Secure Analysis Portal and Protected HWW Information Repository
IS	Information Systems

## Definitions

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HWW Resource	HWW Participants/participant data
HWW Platform	Web site, Web application; Data repository
HWW Portal	Means of access for researchers to UKSeRP HWW data repository
PPI	Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them

# What is HealthWise Wales?

**HealthWise Wales (HWW) is a national, online, population survey funded by Health and Care Research Wales. The aims of the project are to:**



Create a register of people living in Wales who are willing to be contacted to take part in research.



Study the interplay between biological, social and environmental factors that lead to disease.



Increase public involvement and engagement in Wales with Health and Social Care Research.

HWW recruits adults (aged 16 or above) who are resident in Wales or are receiving healthcare in Wales (See pages 5-6 for HWW cohort characteristics). Participants are required to give consent for the research team to access their NHS record, and regular contact to obtain information that is not routinely available from other sources about their health, wellbeing and specific exposures (e.g. behavioural risk factors). HWW aims to recruit at least 100,000 individuals living in Wales between 2015-2020. Participants are contacted every six months and asked to complete a suite of questions about their health, well-being and lifestyle. Participants are also contacted on a more regular basis with regards to information about current research studies that they can participate in. Therefore, HWW is also a register of potential research participants, which can be searched according to various eligibility criteria to identify potential participants for specific health and social care studies.

# The HealthWise Wales Resource

## HealthWise Wales has three components: People, Platform and Portal.

HWW People comprise researchers and research support staff at Cardiff University, associates at Swansea University (SAIL and UKSeRP) and at Health and Care Research Wales. HWW has Patient and Public Involvement (PPI) partners across Wales. The most important people who contribute significantly to the HWW resource are the 28,000+ participants. (For the purposes of this document HWW team refers to the research team based at Cardiff University).

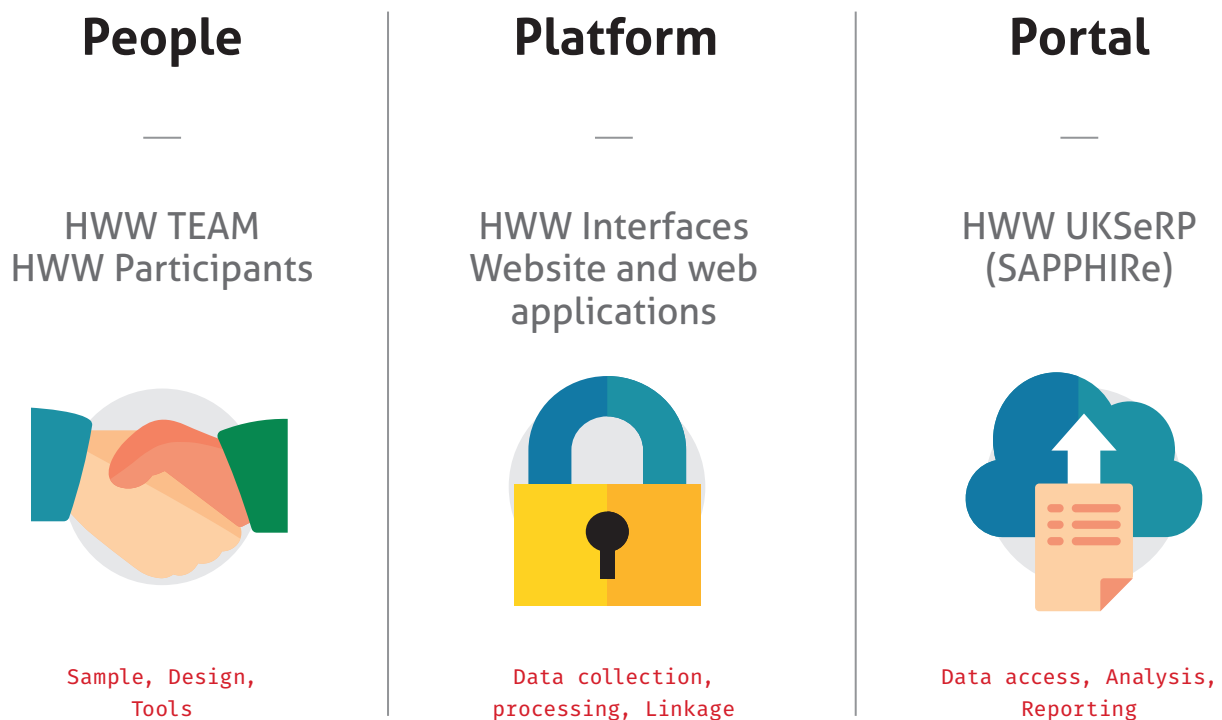
The HWW team are available to advise and assist you to decide which aspects of the HWW resource are appropriate to your research idea and to guide you through the application process. Upon acceptance, the HWW team will involve you in advertising

your project to HWW participants, help you make key decisions as your research questionnaire is transformed into a web form or assist you to select and access the data you require to answer your research questions. All research conducted via HWW must include a statement acknowledging HWW involvement (see Page 17 for the section on publication and reporting arrangements).

The HWW Platform is the survey's virtual online interface comprising the HWW Website and Web Application (data collection tool). The HWW website provides relevant information, news and events, as well as hosting the web application through which participants access their individual accounts and questionnaire modules.

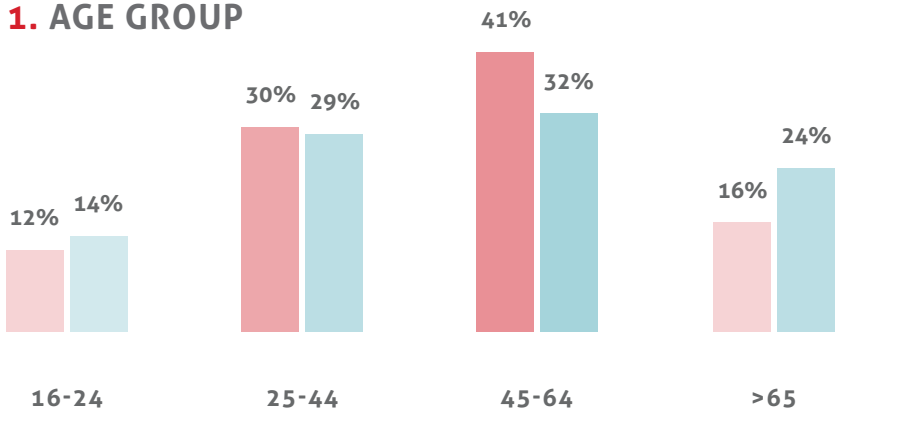
Data collected from HWW participants are securely stored at HWW before being batch cleaned and exported via Secure Anonymised Information Linkage (SAIL) for matching with routinely collected health care data and stored on the Secure Analysis Portal and Protected HWW Information Repository (SAPPHIRE). All data are accessed and analysed via SAPPHIRE which is the HWW area of the UK Secure eResearch Platform (UKSeRP).

→ The infographic on page 05 shows the characteristics of the first 10,000 participants recruited to HWW.

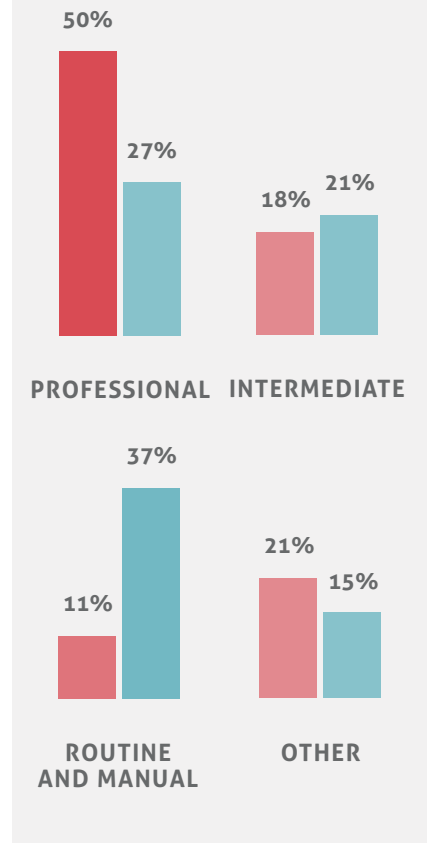


# Demographic

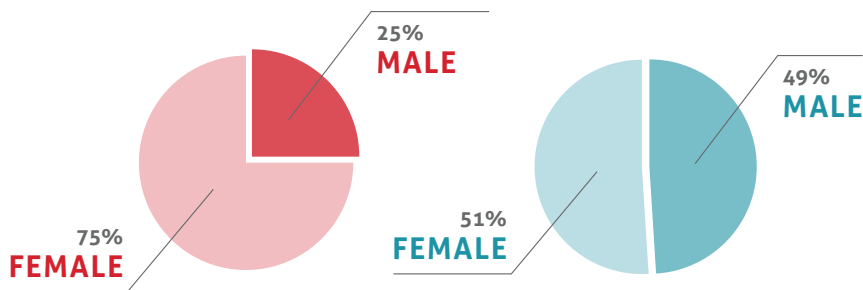
## 1. AGE GROUP



## 2. OCCUPATIONAL CLASS

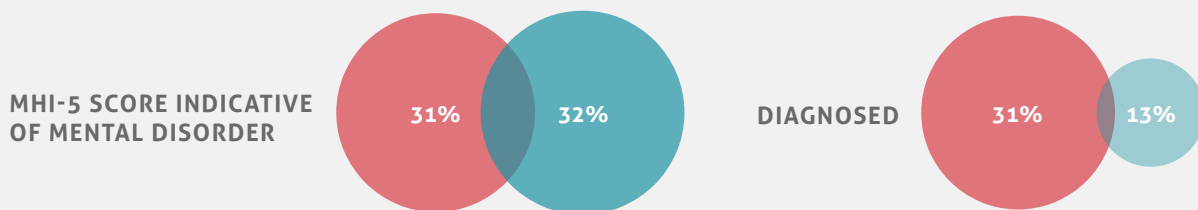


## 3. GENDER



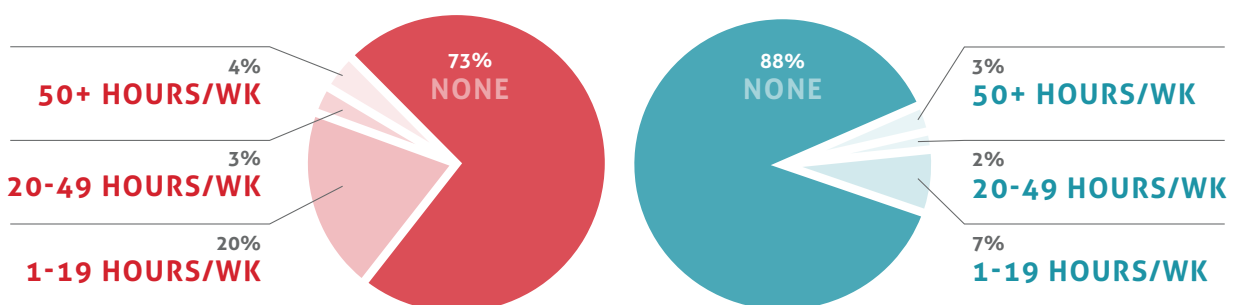
# Mental Health

## 1. MHI-5 SCORE INDICATIVE OF MENTAL DISORDER \*



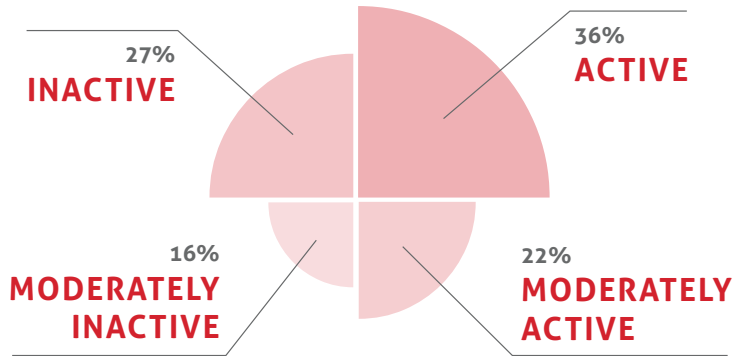
\*MHI5: Mental Health Inventory (five questions)

## 2. PROVISION OF UNPAID CARE

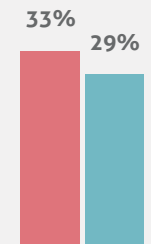
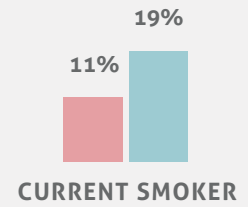


# Lifestyle Behaviour

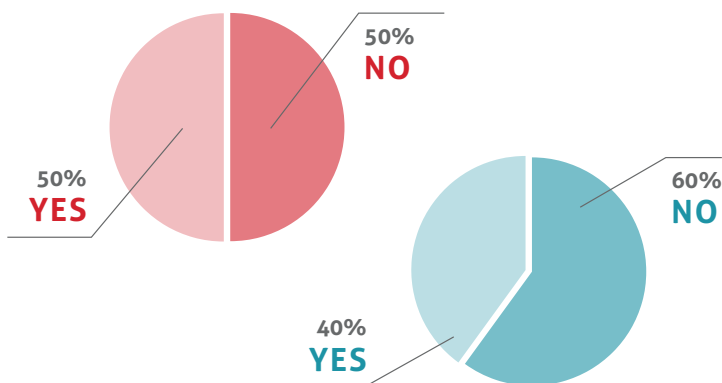
## 1. PHYSICAL ACTIVITY



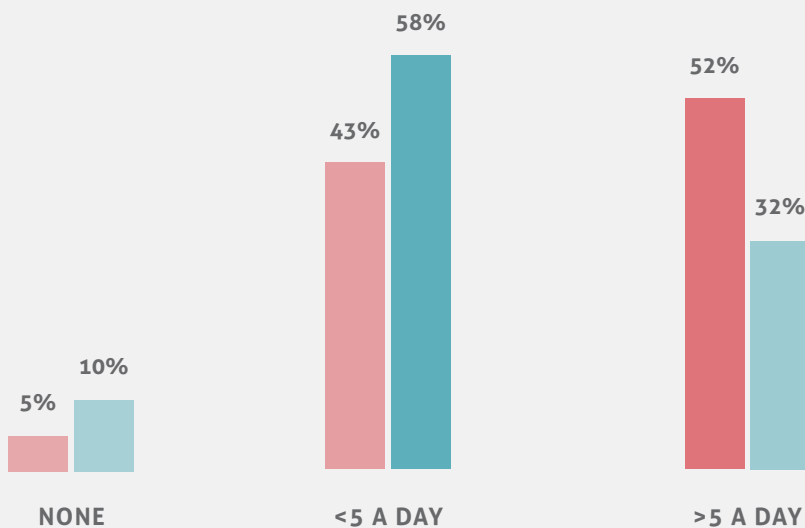
## 2. SMOKING HABIT



## 3. DRINKING ABOVE GUIDELINE LEVELS



## 4. FRUIT AND VEG INTAKE



### KEY



HealthWise Wales



Population data for Wales from published sources

# HealthWise Wales Ethos

## Patient and Public Involvement (PPI)

HWW is all about creating a partnership between researchers and the public, where everyone can be an active and equal contributor. HWW aims to raise public awareness of research and increase opportunities for the public to:

- have an equal say in research priorities and in the conduct of research
- participate actively in research projects
- influence the translation of research findings into practice

Patient and Public Involvement (PPI) is an important component of every aspect of HWW and we involve members of the public in consultation and in collaboration with the project management of HWW. Therefore, members of the public are involved in scrutinising all research proposals.

All researchers applying to use the HWW resource must demonstrate that they have involved patient or public representatives in developing their proposed research project. A lack of evidence of PPI in the development of your research proposal is sufficient for it to be rejected. Demonstration of PPI in all aspects of the research process is

becoming an important feature of the research landscape. Increasingly, funding providers expect to see evidence of PPI in research applications and this aspect of HWW is therefore of significant benefit to researchers applying for funding to do research based on the HWW Platform.

The HWW team strongly suggest that you consider contacting the Public Involvement and Engagement team, Health and Care Research Wales for further information and support [www.healthandcareresearch.gov.wales/research-route-map/develop-a-research-idea/involving-the-public-in-your-research](http://www.healthandcareresearch.gov.wales/research-route-map/develop-a-research-idea/involving-the-public-in-your-research)

INVOLVE is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. Read the briefing notes for Researchers: Public Involvement in NHS, public health and social care research [www.invo.org.uk/resource-centre/resource-for-researchers](http://www.invo.org.uk/resource-centre/resource-for-researchers)

There are also national PPI standards, which we would recommend that you follow, to ensure that the public are involved in research in a meaningful way, throughout the life cycle of the research study [www.invo.org.uk/posttypepublication/national-standards-for-public-involvement](http://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement)





# Researcher engagement with HealthWise Wales

## Making your application to HWW

We strongly advise that any researcher planning to apply to use the HWW resource should contact the HWW research team before submitting their application. The HWW team can provide guidance and any additional information that you may need for completing the application process. The application form can be downloaded from the Researcher tab on the HWW website.

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### We encourage applications from researchers to use the HWW resource in the following ways:

Identification of potential participants for health and social care research projects (HWW participant sample).

Analysis of HWW cohort data to answer health and social care research questions (HWW linked data).

Data collection on specific topics through the submission of researcher-led questionnaires (Questionnaire module).

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This document provides guidance for researchers applying to use the HWW resource in the three ways outlined above. The steps to achieve this are explained below and illustrated in the flow diagram.

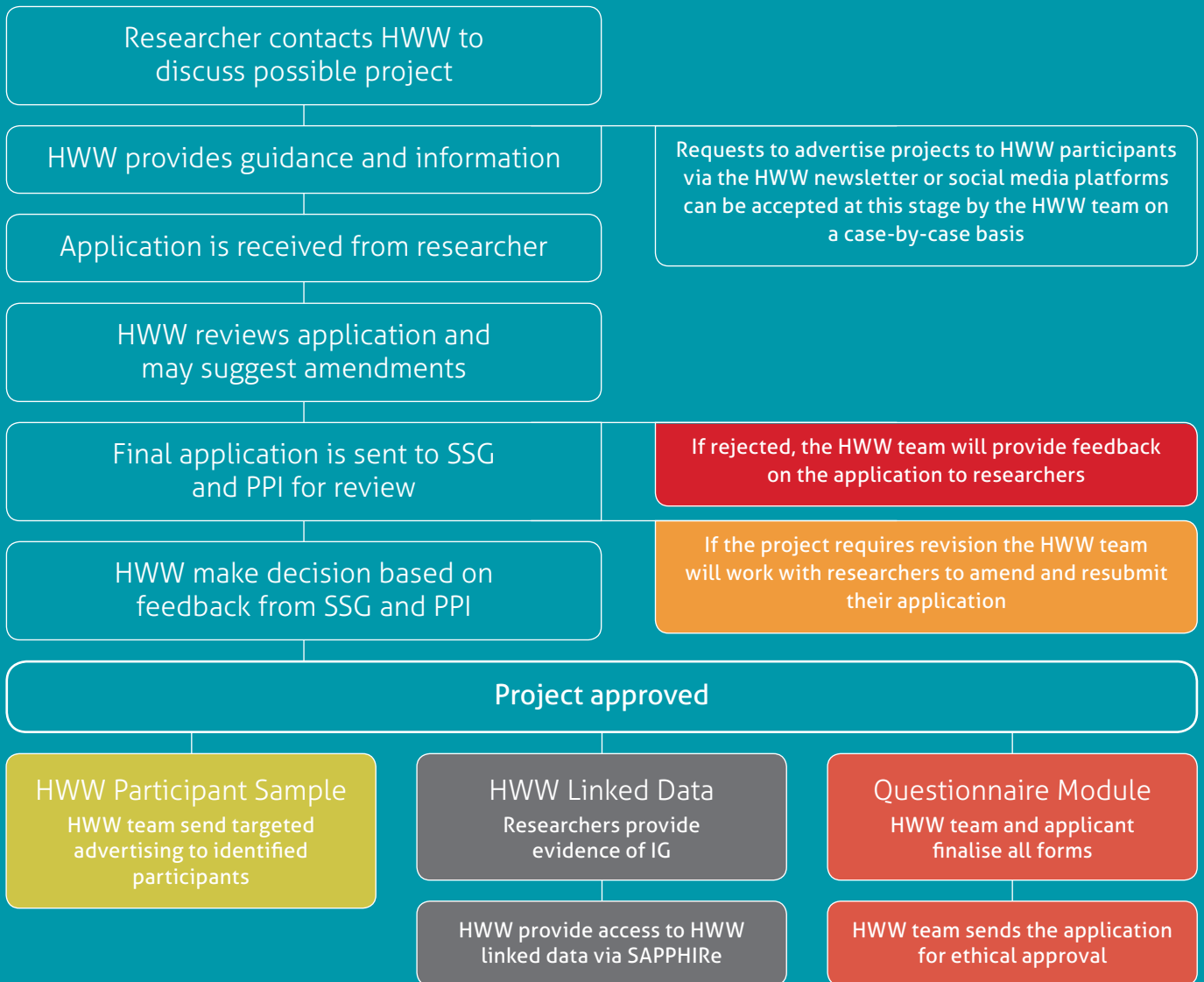
Any research that uses the HWW Platform needs to be in the public interest and fit within the ethos and following research themes of HWW:

- Impact of social inequalities on health and wellbeing
  - Environment, neighbourhood and health
  - Maintenance of health and wellbeing in the working age population
  - Wellbeing in later life
  - Innovation in health and social care service
- 

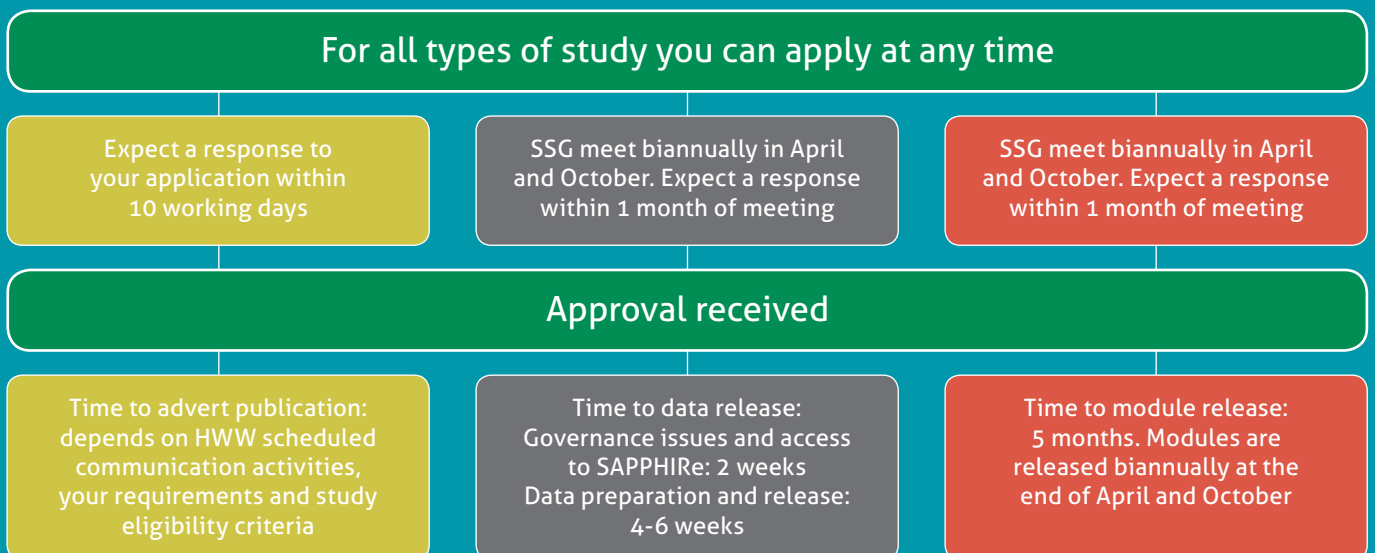
### We are keen to receive proposals with a focus on:

- Cancer
- Mental Health
- Dementia
- Pregnancy
- Early childhood health and development

# Flow diagram showing the application process for all activities



## Timelines



# Using the HWW Resource

## Participant Recruitment

### Identification of Potential Participants for Health and Social Care Research Projects (HWW participant sample)

#### Activity 01

You can apply to use the HWW resource for advertising relevant studies to the HWW cohort as potential participants for your projects. For such applications, you should complete sections A and D of the application form.

If you are applying to use the HWW resource as a way to contact and recruit HWW participants for specific research projects, you should provide the eligibility criteria for your study in your application to HWW.

Upon initial submission, the HWW team will review the proposal to clarify requirements and determine fit with the HWW ethos and priorities. Approved applications will be reported to the HWW Executive Committee.

The HWW ethical approval and participant consents, permit HWW to advertise research projects which fit with the ethos and scope of the HWW initiative to HWW participants. It is your responsibility to obtain ethical approval for the conduct of your specific study including use of the HWW resource to help recruit participants.

#### HOW IT WORKS

Once approved, the HWW team will liaise with you to determine an appropriate participant sample. Participants will be invited to contact you or your study manager to find out more and consent to participate via your study protocols.

#### WELSH TRANSLATION

All communication with participants, including study documentation (e.g. advert, participant information sheet), must be made available in both English and Welsh. You are encouraged to organise Welsh translation or negotiate this with the HWW team (a charge may be applied for this service).

#### LAY SUMMARY

As part of the application form, you will provide a lay summary which will be used to promote your study and explain it to participants and other stakeholders. This will be published on the HWW website or on promotional materials e.g. newsletters.

#### RESPONSE RATES

Response rates cannot be guaranteed. The HWW team will work with you to optimise the information sent to participants to ensure that the highest response rate possible can be achieved.

#### FEEDBACK AND ACKNOWLEDGEMENTS

Researchers are required to provide HWW with information on response/recruitment rates achieved via HWW advertising. The use of the HWW resource should be acknowledged in publications about your study (see page 17).

## Case Study

HWW recently promoted an online survey on death and dying. The study aimed to collect information on public attitudes to death and dying in Wales.

Public views play an important role to form the public policies that create more useful future health care delivery plans. Existing research is not enough in size and quality and there remains a lack of public openness about death in the UK. Moreover, no study has been

conducted so far that involves only Welsh people to get their views on death and dying.

This study aimed to reduce the existing research gap by conducting an online survey in Wales. HWW promoted the study via newsletter and social media. The researchers aimed to have 600 responses to the survey. After advertising this study via HWW they received over 2,200 responses.

# Using the HWW Resource

## Data Analysis

Analysis of HWW cohort data to answer health and social care research questions (HWW linked data)

### Activity 02

You can apply to use data held in the HWW data repository for specific research questions. Data available include information collected from HWW participants from core questionnaire modules, researcher-led modules (except where the researchers have requested time limited exclusive use of these data) and linked routinely collected healthcare data. For such applications, you should complete sections A and C of the application form. A data dictionary is available on request.

#### **MAKING YOUR APPLICATION**

Your application should include clearly stated aims and justifications for the data you require; the research question you intend to answer and an outline of your analysis plan.

#### **REVIEW**

Upon initial submission, the HWW team will review the proposal to clarify requirements before submitting the proposal to the Scientific Steering Group (SSG) and PPI for review. The SSG is responsible for providing advice and scrutiny for the development and delivery of the HWW initiative. The SSG reviews any HWW proposals submitted and advises on their approval. The SSG meet twice a year and its membership is available on the HWW website in the 'About' tab under Governance. Electronic applications are reviewed remotely on an ongoing basis to ensure timely processing of applications. The SSG will ensure that the application fits with the research themes and priorities of HWW and will provide feedback. These comments, along with feedback from the HWW team and PPI representatives, will be provided to the you. Once your application is approved by the SSG you will need to comply with our Information Governance (IG) requirements. You will need to provide evidence that you are a bona fide researcher (see the data agreement on the HWW website in the Researcher tab for further details) and have appropriate training in Research Data and Confidentiality ([www.ecmcnetwork.org.uk/events/training/mrc-e-learning-research-data-and-confidentiality-online](http://www.ecmcnetwork.org.uk/events/training/mrc-e-learning-research-data-and-confidentiality-online)) procedures in order to gain access to the HWW data repository via SAPPHiRe. Information on data storage and

access to SAPPHiRe are provided below on page 15 in the section 'Access to data collected via the HealthWise Wales Resource'. HWW will provide access to anonymised data extracts that are specifically tailored to the requirements of your research project via remote portal access (SAPPHiRe). All analyses will be conducted within this environment and will be in line with UKSeRP and HWW governance procedures.

#### **ANALYSES**

Only analyses outlined in the application can be conducted and published. HWW has the right to cross check any publications with the original application. The HWW team will need to be notified of any additional analyses you wish to conduct, before completion. Removal of all analysis outputs must be approved according to the IG procedures described in the SAPPHiRe access request document. For further information on accessing SAPPHiRe, and terms and conditions of using the HWW data, please consult the data agreement on the HWW website.



# Using the HWW Resource

## Data Collection

Data collection on specific topics through the submission of researcher-led questionnaires

### Activity 03

You can apply to use the HWW resource by submitting a questionnaire to be included on the HWW Platform. For such applications, you should complete sections A and B of the application form. The HWW team will work with you to design questionnaires that are topic specific or to address specific research questions proposed. Proposed research should fit within the research themes of HWW.

#### **MAKING YOUR APPLICATION**

Upon initial submission, the HWW team will review the proposal in more detail and assess resourcing, timescales, recruitment, any case selection requirements, participant overload and other practical and ethical considerations. At this point, you may be asked to modify your application before it goes to the Scientific Steering Group (SSG) for review.

#### **REVIEW**

The SSG is responsible for providing advice and scrutiny for the development and delivery of the HWW initiative. The SSG reviews any HWW proposals submitted and advises on their approval. The SSG meet twice a year and its membership is available on the HWW website in the 'About' tab under Governance. Electronic applications are reviewed on an ongoing basis remotely so as to ensure timely processing of applications. The SSG will ensure that the application fits with the research themes and priorities of HWW and has scientific merit. Feedback from the SSG and PPI representatives will be provided to you.

#### **ETHICAL APPROVAL**

The HWW team will work with you to prepare the application for submission to ethics. This will be a cyclical process between you and the HWW team until the application is approved.

HWW has been reviewed and approved by the Wales Research Ethics Committee 3 (reference 15/WA0076). The new questionnaire will be submitted by the HWW team for ethical approval as a substantial amendment. Information Systems

(IS) development will not begin until approval has been obtained. You should allow for a six-month lead in time to coincide with the six monthly module releases on the HWW website (currently October and April).

#### **PILOTING**

If the questionnaire has not been validated or piloted for use as an online questionnaire in a similar population to the HWW population we encourage you to pilot your questions to ensure acceptability and ease of understanding of the proposed questions.

#### **WELSH TRANSLATION**

All questionnaires must be made available in both English and Welsh. Once the questionnaire has been agreed and finalised, a Welsh translation will be organised (a charge may be applied for this service).

#### **QUESTIONNAIRE INFORMATION / LAY SUMMARY**

You will provide a lay summary as part of the application which will be published on the HWW website. You will also need to ensure any additional participant information is provided. This will need to be provided in both English and Welsh.

#### **QUESTIONNAIRE TO WEB FORM**

You should be aware that paper-based questionnaires may need to be significantly revised to improve the user experience of completing them on-line. Once the content of the questionnaires has received a favourable ethical review the HWW team will begin working on transforming the questionnaires into web based forms. Where this involves substantial modification of the questionnaire format the HWW team will liaise with you to ensure the fidelity of questions to your data requirements whilst maximising the user experience. For all questionnaires HWW may involve HWW participants to pilot questionnaire modules during development.

Modules will be made available for review by researchers on the HWW test site at least one week before modules are released to live.

→

This shows the steps to implement a questionnaire module and access data.

### RESPONSE RATES

Response rates cannot be guaranteed. The HWW team will work with you to optimise the questionnaire and information sent to participants to ensure maximum response rates are achieved. Furthermore, the HWW team will discuss with you the end point for the questionnaire on the HWW Platform. This can be after a certain number of participants have completed the questionnaire or after a fixed time period.

### RESTRICTED DATA ACCESS

New data collected can be made available only to yourself as the applicant for a period of exclusive access, on request (up to 12 months following the availability of the collated data for analysis). Following this period of time other interested researchers may access these data as part of the HWW datasets.

### QUESTIONNAIRE DATA LINKAGE

Questionnaires included on the HWW Platform can be linked to the participants' routinely collected healthcare data (NHS record) that is available in the SAIL dataset. Please see 'Types of data available for analysis and rules governing access' section below for further details.

### ACCESSING DATA COLLECTED VIA RESEARCHER-LED MODULES

The process for accessing data which has been collected via your researcher-led module is similar to the process for accessing HWW data. An extension of your original application is required which lists all the data (variables) that you need to answer your research questions. This process will need approval from the SSG before a data extract can be made available to you via SAPPHiRe. All other data access procedures will apply as per Activity type 2 above and the section entitled 'Access to data collected via the HealthWise Wales Resource' below.

HWW team and applicant finalise all forms

HWW team sends the application for ethical review

Following the ethical approval, HWW team work with the researcher to modify and test the questionnaire for online platform

Metadata completed and tested

Welsh translation completed

Questionnaire goes live on website and remains active for agreed length of time

Researchers fill in application to HWW for specific variables and provide evidence of IG to obtain access to HWW data

Questionnaire data is linked to healthcare data via SAIL and specified variables are made available to researchers via SAPPHiRe

Researchers access their questionnaire data linked to specified health care data through SAPPHiRe for limited time period

After 12 months the questionnaire data is made available to other researchers who apply to HWW

This example shows how a questionnaire module is presented to participants.

The diagram illustrates the navigation from a questionnaire menu to a specific questionnaire module. It consists of three main panels:

- Top Panel (Menu):** A list of questionnaire modules. The second item, "Questions for cancer research", is highlighted with a blue dot and a white arrow pointing to the middle panel.
- Middle Panel (Overview):** A detailed view of the "Questions for cancer research" module. It shows a progress indicator: "You have currently completed 0/8 questionnaires". Below this, a list of questions is shown, with "Sunbed use and sun exposure" highlighted with a blue dot and a white arrow pointing to the bottom panel. Other visible questions include "Bowel symptoms", "Bowel cancer awareness", and "my family and cancers".
- Bottom Panel (Questionnaire):** A detailed view of the "Sunbed Use and Sun Exposure" questionnaire. It features a teal header with the title "Sunbed Use and Sun Exposure". The question asks: "Which, if any, of the following methods of sun protection do you use?". Below the question is a list of five options, each with an unchecked checkbox and a horizontal line for selection:
  - Never go out in the sun
  - Avoid the mid-day sun
  - Where practical, stay in the shade
  - Cover up
  - Wear a hat

# Access to data collected via the HealthWise Wales Resource

## Hosting of the HWW data repository



The UKSeRP (UK Secure eResearch Platform) infrastructure provides 'safe havens' for ehealth research. One of these UKSeRPs holds the SAIL (Secure Anonymised Information Linkage) databank. The SAIL databank holds routinely collected health data about people living in Wales (see Appendix). The HWW data resource occupies a separate UKSeRP.

We are able to copy data about HWW participants from the SAIL databank to the HWW data repository because HWW participants have consented to this. If you wish to use the HWW data repository (by methods 2 and 3 outlined above) you will do so via SAPPHiRe which holds HWW questionnaire data and the linked healthcare data. You can access a data extract in SAPPHiRe that is relevant to your research question and has been approved as part of the application process.

SAPPHiRe will operate as a research data safe haven for HWW, obeying the principles laid out by the 2008 Data Sharing Review and Dame Fiona Caldicott's review: Information: To share or not to share? The Information Governance Review ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/192572/2900774\\_InfoGovernance\\_accv2.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_accv2.pdf)). The 2008 Data Sharing Review recommended the creation of 'safe havens' and the Caldicott Review called for the establishment of 'accredited safe havens' that comply with a set of data stewardship requirements. These requirements include compliance with ISO27001.

### FORMAL ACCESS PROCEDURE

Access to SAPPHiRe must be made through the formal procedures as described in this document and is subject to eligibility, funder's terms and conditions and Cardiff University and UKSeRP (Swansea University) policies and procedures. You will need to apply to have your own access to SAPPHiRe (User Account Request Form). Once you have a user account you may apply for access to more than one dataset. Datasets are constructed and made available only after a successful application has been made (Activity type 2 above).

### SECURE DATA ACCESS

Subject to data user verification, a data access agreement, and physical and procedural controls, data users are assigned a time-limited account to access your data remotely via SAPPHiRe. System safeguards include a fire-walled Virtual Private Network (VPN), enhanced user authentication, and configuration controls to ensure that data cannot be removed or transferred unless authorised.



**DATA ACCESS AGREEMENT**

The applicant and any individuals who will have access directly to the data will sign a confidentiality/data access agreement form.

**RESEARCHERS**

All applicants and their collaborators must be bona fide researchers with an established scientific record, who must conduct high quality, ethical research when using this resource.

We will use the MRC definition of a bona fide researcher <https://mrc.ukri.org/publications/browse/mrc-policy-and-guidance-on-sharing-of-research-data-from-population-and-patient-studies/>, page 24.

Proposals for access may be refused. Reasons may include the following:

- data are not yet available;
- applicant not a bona fide researcher;
- proposed work is outside the scope of the HWW ethos and research themes.

**CONFIDENTIALITY**

Any breaches of data security must be reported to the HWW Programme Manager at [healthwisewales@cardiff.ac.uk](mailto:healthwisewales@cardiff.ac.uk). Breaches could include:

- An unauthorised individual gaining access to the resource
- Sharing log-in details to SAPPHiRe
- An attempt to re-identify a participant

**INTELLECTUAL PROPERTY**

Cardiff University owns the data generated using the HWW resource, with the exception of data available through linkage with routinely collected NHS data that has been copied from the SAIL databank to the HWW Platform. Data generated through an approved project (including derived variables) must be returned to HWW via SAPPHiRe for inclusion in the HWW resource so as to encourage ongoing use by the research community. For details, contact [sapphire@swansea.ac.uk](mailto:sapphire@swansea.ac.uk)

More information relating to the definition of Intellectual Property, ownership and protection according to Cardiff University can be found in section 4 of Cardiff University's Research Integrity and Governance Code of Practice document: Research Integrity and Governance Code of Practice [www.cardiff.ac.uk/research/our-research-environment/integrity-and-ethics](http://www.cardiff.ac.uk/research/our-research-environment/integrity-and-ethics)

**TYPES OF DATA AVAILABLE FOR ANALYSIS AND RULES GOVERNING ACCESS**

A range of data is available through SAPPHiRe to provide you with anonymised datasets for analyses that are tailored to specific project requirements. HWW collects data directly using web-based questionnaires (core-modules). These data can be linked to routinely collected NHS data that are held in the SAIL databank. The data dictionary includes details on the data currently collected via questionnaires (available on request).

Data that are currently being collected or going through the preparation process will be listed with dates of future availability. Any questions related to HWW data will be dealt with by the HWW team.

Data collected from a HWW core module will be made available via SAPPHiRe as soon as data collection for that module has been cleaned, catalogued and released. Currently, data are extracted every 10,000 recruits, but special arrangements can be made according to the needs of researchers who submit questionnaire modules e.g. some modules may be active for a certain time period to provide data for a specific follow-on grant cycle; other module data may be restricted to the researcher for a specified time period before being released for wider use. Depending on the complexity of the dataset, extracts take four to six weeks to process.

**PROJECT PROPOSALS**

It is your responsibility to determine whether the research you are proposing is already being worked on by another researcher by viewing the publications and approved projects listed on the website. We will not consider the issue of potential publication overlap between research projects. Instead the website will provide an up-to-date list of publications using the resource and all approved applications for use of this resource.

Data dictionaries are available which provide detailed information on what data are available from HWW and will be a useful tool for you in deciding if the HWW resource is appropriate for individual projects.

**UNIQUE PROJECT IDENTIFIERS**

For each project a unique set of identifiers is created by the HWW Platform Administrators. These are encrypted-Anonymised Linking Fields (ALF\_PE) to create a project specific ID to ensure researchers working on multiple projects on the Platform cannot cross-link their datasets.

## PUBLICATION AND REPORTING ARRANGEMENTS

You are required to provide a lay summary of the study findings for publication on the HWW website. Any publications related to the use of HWW resource must be sent to the HWW team.

All researchers using HWW should use the following standard text for acknowledgement: "This study was facilitated by HealthWise Wales, the Health and Care Research Wales initiative, which is led by Cardiff University in collaboration with SAIL, Swansea University."

Researchers using the HWW resource who use SAIL data in their project must acknowledge SAIL using the following wording "This study makes use of anonymised data held in the Secure Anonymised Information Linkage (SAIL) system, which is part of the national e-health records research infrastructure for Wales. We would like to acknowledge all the data providers who make anonymised data available for research." and should cite the relevant primary SAIL publications;

- Ford DV, Jones KH, Verplancke JP, Lyons RA, John G, Brown G, Brooks CJ, Thompson S, Bodger O, Couch T, Leake K. The SAIL Databank: building a national architecture for e-health research and evaluation. *BMC Health Services Research* 2009;9:157

- <http://www.biomedcentral.com/1472-6963/9/157>

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Researchers using the HWW resource whose work has not involved SAIL data need to acknowledge the UKSeRP infrastructure which powers SAPPHIRE and should cite the publication below;

- Jones KH, Ford DV, Jones C, Dsilva R, Thompson S, Brooks CJ, Heaven ML, Thayer DS, McNerney CL, Lyons RA. A case study of the Secure Anonymous Information Linkage (SAIL) Gateway: A privacy-protecting remote access system for health-related research and evaluation. *Journal of Biomedical Informatics* 2014; 50:196-204.

Users should note that HWW bears no responsibility for the further analysis or interpretation of these data, over and above that published by HWW.

Unless HWW has participated in the preparation of the finished report, it must be stated that the responsibility for the interpretation of the information supplied is the authors' alone. HWW staff involvement which meet international guidelines for authorship must be suitably included in outputs.

Copies of publications (abstracts, papers and posters etc) using data from HWW must be sent to HWW on acceptance for publication.

## FUNDING

It is your responsibility to ensure funding is in place to complete any research for which you propose to use the HWW resource.

## CHARGES

The cost for using HWW will be determined on a case by case basis depending on the complexity of the proposed project. This will be negotiated with the HWW team during development of the application.



# Appendix

Data collection on specific topics through the submission of researcher-led questionnaires

## **PATIENT EPISODE DATABASE FOR WALES (PEDW)**

This has administrative data for hospital inpatient stays. This records date and length of stay, hospital, details of admission and discharge. Each uninterrupted period of stay is called a spell. A spell is composed of one or more episodes of care, so a patient may be moved between departments and each of these would be an episode.

Associated with each episode is a series of diagnosis codes (in ICD 10 format) so for each episode there is a primary and up to 13 secondary codes and operation/procedure codes (in OPCS4 format) with a primary and up to 11 secondary codes.

This covers all of Wales (except mental hospitals) since 1999.

## **OUTPATIENT ATTENDANCES**

This dataset holds administrative information about outpatient visits including time and date of the visit. There is a speciality code for the clinic as well as a clinic name (which may or may not be informative). There is very little clinical information.

## **EMERGENCY DEPARTMENT DATASET (EDDS)**

This covers accident and emergency attendances since 2009. This has coding for diagnoses, anatomical areas, treatment, investigation, and anatomical site. There is also coding for road use (9 categories) and sport (29 types) and there is an alcohol indicator.

## **GP DATA**

Each GP practice holds its own database for its patients and controls its own data so the practice has to sign up to SAIL. Currently the number of practices signed up is around 80%. GP events are coded mostly in V2 Read codes and there are codes for diagnoses, observations (including patient circumstances, symptoms, blood pressure and height and weight), laboratory test results, prescriptions, vaccinations, treatments, monitoring of chronic conditions, and many administrative codes covering referrals, administration of treatment, issue of fit notes and many other functions.

GPs function as “gatekeepers” of patient care, and so they also keep and record details of care in other settings, such as diagnoses made in a hospital setting. Unfortunately these may consist of scanned documents and are not always coded.

The extract of GP datasets held in SAIL does not include narrative text fields and only has, for each coded event, a code, a date and a value (for example a laboratory test, blood pressure, height or weight).

## **WALES CANCER INTELLIGENCE AND SURVEILLANCE UNIT (WCISU)**

This is a national cancer register. It holds detail about site of the cancer (ICD10 coding), morphology (ICD0 coding), laterality, and whether the cancer caused death. Cancer stage is coded as pathologically and clinically assessed (tumour, nodes and metastases codes). Other special coding schemes are used in a small number of cases (eg; Dukes, Clarks-Breslow, and Gleason). Treatments are coded with OPCS4.

## **SCREENING DATASETS**

### **BOWEL**

Invitations are recorded, including recall type and kit type. Results of tests are coded.

This covers the period from 2008 onwards.

### **CERVICAL**

Invitations for cervical cytology testing and the type of recall are coded. Test results are recorded of all tests from 1990 onwards. Assessments are recorded, which are details of all appointments offered in colposcopy out-patient departments from 2001 onwards, including the results, treatment, and future management.

If you have any further questions please contact the HWW team to discuss: [HealthWiseWales@cardiff.ac.uk](mailto:HealthWiseWales@cardiff.ac.uk)



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