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1 **Cohort Profile: HealthWise Wales. A research register and population health data platform**
2 **with linkage to National Health Service datasets in Wales**

3

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13

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15

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17

18 **Keywords:** Research database, data linkage, adults, life-course epidemiology, public

19 involvement

20 **Abstract**

21 **Purpose:** Recruitment and follow-up in epidemiological studies is time-consuming and
22 expensive. Combining online data collection with a register of individuals who agree to be
23 contacted about research opportunities provides an efficient, cost-effective platform for
24 population-based research. HealthWise Wales (HWW) aims to facilitate research by recruiting
25 a cohort of individuals who have consented to be informed about research projects,
26 advertising studies to participants, supporting data collection on specific topics, and providing
27 access to linked healthcare data for secondary analyses. In this paper, we describe the design
28 of the project, ongoing data collection, methods of data linkage to routine healthcare records,
29 baseline characteristics of participants, the strengths and limitations of the register, and the
30 ways in which the project can support researchers.

31 **Participants:** Adults (aged 16 and above) living or receiving their healthcare in Wales are
32 eligible for inclusion. Participants consent to be contacted for follow-up data collection and
33 for their details to be used to access their routinely-collected NHS records for research
34 purposes. Data are collected using a web-based application, with new questionnaires added
35 every six months. Data collection on socio-demographic and lifestyle factors is repeated at
36 two-to-three year intervals. Recruitment is ongoing, with 21,779 participants alive and
37 currently registered.

38 **Findings to date:** 99% of participants have complete information on age and sex, and 64%
39 have completed questionnaires on socio-demographic and lifestyle factors. These data can
40 be linked with national health databases within the Secure Anonymised Information Linkage
41 (SAIL) databank, with 93% of participants matching a record in SAIL. HWW has facilitated the
42 recruitment of 43,826 participants to 15 different studies.

43 **Future plans:** The medium-term goal for the project is to enrol at least 50,000 adults.

44 Recruitment strategies are being devised to achieve a study sample that closely models the

45 population of Wales. Potential bio-sampling methods are also currently being explored.

46

47 **Strengths and limitations**

- 48 • More than 20,000 individuals with a diverse socio-demographic profile have registered,
49 and recruitment is ongoing.
- 50 • Matching rates of participant data with routinely-collected healthcare records are very
51 high.
- 52 • Participants are “research ready”, with HWW facilitating the recruitment of 43,826
53 participants to 15 different studies to date.
- 54 • Men, individuals below 25 and over the age of 65, and participants from the most
55 deprived wealth quintiles are currently under-represented. Recruitment strategies to
56 increase the number of participants in these groups are currently being devised.
- 57 • Currently, bio-samples are not collected from participants, although options for this are
58 currently being explored.

59

60 **Introduction**

61 High-income countries continue to face major public health challenges, including persistent
62 inequalities in health and wellbeing and the complex needs of ageing populations (1, 2).
63 Meeting these challenges requires a strong research infrastructure to ensure that high quality
64 evidence is generated, for example, on preventing the onset and progression of non-
65 communicable diseases and providing effective and efficient health and care services (3).
66 Large-scale longitudinal studies are an essential resource for studying health and wellbeing
67 throughout the life course. It is estimated that around 3.5% of the UK population are current
68 or recent contributors to cohort studies (4). Using web-based technologies potentially makes
69 recruitment and retention of subjects in such long-term studies less time-consuming and
70 expensive (5). Combining online data collection with a register of individuals who have
71 volunteered to be contacted with opportunities to take part in research also confers
72 additional efficiency (such as the Scottish Health Research Register, SHARE (6)), and can
73 create a platform to increase public involvement and engagement with research. Increasing
74 awareness of the purpose of research and opportunities for participation should result in
75 increased recruitment to research studies, better quality research to inform policy and
76 practice, and ultimately improved population health outcomes (7).

77

78 Wales has a population of over three million people, within clearly defined geographical
79 boundaries and with relatively low levels of migration in or out (8). It faces major challenges
80 from a post-industrial legacy of socio-economic deprivation and a high prevalence of
81 unhealthy behaviours (3, 9). High-quality, population-based research in this setting has
82 already provided important evidence for policy and practice in the United Kingdom and

83 beyond (10). HealthWise Wales (HWW) aims to provide an integrated cost-effective platform
84 for conducting population-based research, by:

85

86 1. Establishing a cohort of individuals who have consented to be contacted with information
87 on research studies that they may wish to contribute to (so-called “research-ready”
88 individuals);

89 2. Collecting longitudinal data from participants on self-reported exposures and outcomes;
90 and

91 3. Using routinely-available healthcare data through record linkage (11, 12).

92

93 Overall, HWW plans to contribute to shape the health and wellbeing of future generations in
94 Wales, and help the National Health Service (NHS) in Wales plan for the future. In this paper,
95 we describe the design of the project, ongoing data collection, methods of data linkage to
96 routine healthcare records, baseline characteristics of participants, the strengths and
97 limitations of the register, and the ways in which the project can support researchers.

98

99 **Cohort Description**

100 *Setting*

101 Recruitment into HWW is ongoing and dynamic, with individuals joining (or leaving) on a
102 continuous basis and with varying levels of participation during their life course. Recruitment
103 started during a pilot phase (March 2015 to February 2016), followed by a public launch on
104 February 29th 2016. Recruitment protocols have been designed to ensure representation
105 across all areas of Wales. Overall, the distribution of HWW participants by residence is
106 representative of Wales. For example, census data show that 67% of the Welsh population

107 live in urban areas (defined as settlements of at least 10,000 people) (13), compared with 63%
108 in HWW.

109

110 *Eligibility criteria and participant recruitment*

111 Adults (aged 16 or above) who are usually resident or receive their healthcare in Wales are
112 eligible to join, and are invited to be:

113

- 114 1. Followed up at regular intervals to obtain information about their health, wellbeing and
115 specific exposures (such as behavioural risk factors), and allow record-linkage with their
116 routinely-collected health records;
- 117 2. Entered onto a database of potential participants for research studies;
- 118 3. Contacted to take part in specific research studies;
- 119 4. Actively engaged and involved in dialogue to shape the priorities of the research
120 programme.

121

122 Television, radio and social media advertising campaigns have been undertaken to issue an
123 open invitation to potential participants to register. The project has been promoted at a wide
124 range of events across Wales (for example, cultural events such as the Eisteddfod and
125 agricultural shows such as the Royal Welsh and Anglesey shows) and in different settings
126 (such as NHS hospitals, general practices, pharmacy outlets, and large employers). Mass
127 postal mail-outs have also been piloted in one Health Board area, and there are plans to
128 extend this method of communication about the project to other areas of Wales.

129

130 There are three core recruitment methods that are adapted for use as appropriate in different
131 settings. Participants can give their consent to join the project through an online web
132 application, which is accessed via the project's website (www.healthwisewales.gov.wales, see
133 Figure 1). They can also be recruited face-to-face using tablets or paper-based sign-up forms
134 at events and various locations across Wales, or can give their consent to be contacted by
135 individuals from the Participant Resource Centre at Cardiff University who can provide them
136 with further information about HWW by email or telephone. Protocols describing the use of
137 these recruitment methods and relevant study materials in various settings have been
138 developed and have been implemented by HWW champions (members of the public who
139 have volunteered to engage and involve other members of the public) and
140 facilitators/research assistants (Health and Care Research Wales and NHS support and
141 delivery staff). A range of recruitment and data collection strategies have also been developed
142 for individuals who do not have internet access and/or may not have been exposed to the
143 advertising campaigns. These have included study recruiters using mobile technologies with
144 an internet connection to collect data at community-based locations, or telephone-based
145 consent and data collection.

146

147 The medium term goal is to enrol at least 50,000 adults. This proposed sample size will be
148 significantly larger than current population-based surveys in Wales, providing more precise
149 estimates of the prevalence of exposures and outcomes in different socio-demographic
150 groups, and adequate power to answer a range of different research questions about the
151 determinants of health and wellbeing.

152

153 *Research themes*

154 The project has five research themes:

155

156 1. Impact of social inequalities on health and wellbeing;

157 2. Environment, neighbourhood and health;

158 3. Maintenance of health and wellbeing in the working age population;

159 4. Wellbeing in later life; and

160 5. Innovation in health and social care services.

161

162 These themes are broad to guide data collection and facilitate use of the HWW platform by a
163 wide range of health and social care researchers. Across these themes, there is a focus on
164 four health areas (cancer, mental health, dementia and family life, pregnancy and early
165 childhood health and development).

166

167 *Methods of data collection and follow-up*

168 Data are collected using a web-based application, designed specifically for the project, which
169 is accessible to participants through the main HWW website. New questionnaires are added
170 every six months. These either collect information on items relevant to the research themes
171 outlined above, or bespoke data to facilitate researcher-led projects that are aligned to the
172 research themes. Descriptive information on the core research questionnaires, their
173 availability to participants since the project launched in 2015, and completion numbers are
174 presented in Table 1. These collect data on socio-demographic factors, lifestyle factors, home
175 life, and mental health at baseline and will be repeated at two-to-three year intervals as
176 appropriate. There is also an additional set of modified core questionnaires that collect
177 information from pregnant women on their health and care.

178

179 Outcome data are obtained in two ways. First, data are collected on the HWW platform for
180 patient-reported outcome measures and those relevant to conditions likely to be under-
181 represented in routinely-collected data (for example, infections, metabolic diseases,
182 psychiatric conditions and wellbeing). Second, outcome information can be obtained through
183 record linkage with national health databases (such as the Patient Episode Database for Wales
184 and general practice data) within the Secure Anonymised Information Linkage (SAIL) databank
185 (11, 12). Future phases of the project will also include linkage with other administrative
186 datasets.

187

188 The NHS Wales Informatics Service (NWIS, a trusted third party) uses the personal details of
189 participants (with their consent) to generate an anonymised linking field (ALF_E) based on
190 their name, address, gender and date of birth. This is used to link participants' data with
191 routinely-collected healthcare data sets, with 93% of active participants matching with a
192 record in SAIL. The SAIL databank and the Secure Access Portal and Protected HWW
193 Information Repository (SAPPHIRE) are stored in separate areas of the UK Secure e-Research
194 Platform (UKSeRP, (14)). Figure 2 shows the flow of project data, showing SAPPHIRE within
195 UKSeRP where project-specific, anonymised HWW data can be accessed.

196

197 *Patient and public involvement*

198 HWW has a specific focus on increasing public involvement and engagement in health and
199 social care research. To ensure these aims are achieved, the project is overseen by a Public
200 Involvement Delivery Board (PIDB), which is chaired by an independent member of the public
201 and whose membership is predominantly comprised of members of the public. The PIDB

202 provides scrutiny and assurance that the project is operating in the public interest, and
203 provides advice and support in delivering best practice in accordance with the National
204 Standards for Public Involvement (<https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/>). The Board and the research team co-produced the
205 project's Patient and Public Involvement (PPI) policy and implementation plan. The research
206 team has a dedicated PPI lead who is responsible for maintaining the policy document and
207 ensuring compliance with it. All research team members are trained on facilitating public
208 involvement. There are two PPI members of the research team, who have agreed objectives
209 for their role and attend monthly meetings where they are actively involved in discussions
210 and decision-making relating to research team activities. We have also trained 78 local health
211 board members as facilitators to engage the public and recruit participants to HWW.

213

214 Involvement opportunities (including participation in media promotions or development and
215 user-testing of data collection questionnaires) are regularly offered to participants through a
216 quarterly e-newsletter. As a result, three participants became the faces of the advertising
217 campaign in March 2017, others have participated in social media promotions, and 156
218 agreed to be members of a user-testing panel.

219

220 PPI is an essential criterion for all studies that use HWW, and researchers are required to
221 describe the PPI they have undertaken when applying to use the data or the platform. PPI
222 research team members scrutinise this element of applications as part of their overall
223 assessment of all new projects.

224

225 *Ethical approval and governance arrangements*

226 The project is overseen by an Executive Group, which provides oversight and decision making
227 on the overall delivery of initiative, and receives advice from a Scientific Steering Group (SSG)
228 and the Public Involvement Delivery Board. The role of the PIDB has been described above.

229

230 HWW received ethical approval from Wales Research Ethics Committee (REC) 3 on 16th
231 March 2015 (reference 15/WA/0076). Substantial amendments are submitted when new
232 questionnaires are added or if there is a substantial change to the content of participant-
233 facing materials or recruitment model, in line with current guidance from the committee. The
234 data collection system and study processes are designed to safeguard the integrity and
235 confidentiality of data collected and generated for HWW research, and appropriate systems
236 have been established and tested to report any failures in these respects. Standard Operating
237 Procedures (SOPs) are in place to ensure that HWW is conducted within research governance
238 regulations and compliant with the General Data Protection Regulation (GDPR) (EU)
239 2016/679. The research team meet with the HWW Data Guardian every six months to review
240 the data governance processes in place and any matters arising.

241

242 *Funding*

243 HWW is funded by Health and Care Research Wales.

244

245 **Findings to date**

246 There are currently more than 20,000 active participants (alive and currently registered).
247 Ninety-nine percent of registered participants have complete information on age and sex, and
248 at least 64% have completed the other core questionnaires. Table 2 shows the characteristics
249 of active participants compared with data from published sources of Welsh data. Compared

250 with the population of Wales, there is a higher percentage of participants who are 45 to 64
251 years old. The percentage of women is higher than in the general population (72% compared
252 with 51%). The percentage of participants in non-white ethnic groups (2%) is the same as in
253 the general population. Fifty percent of participants are classified as being in higher
254 managerial or professional occupations, compared with 27% of the population of Wales. In
255 terms of health-related behaviours: 56% are classified as active or moderately active; 10% are
256 current smokers (compared with 19% of the general population); and 50% drink more alcohol
257 than recommended by UK guidance (compared with 40% of the general population). Twenty-
258 eight percent of participants have a Mental Health Inventory score consistent with a common
259 mental disorder and 32% have been diagnosed with or treated for a mental health condition
260 (compared with 13% of the general population). Figure 3 shows the distribution of
261 participants according to the Welsh Index of Multiple Deprivation compared with the
262 population of Wales. There is a good representation of participants in each deprivation
263 quintile, although a higher percentage of participants are from the least deprived quintile.

264

265 **Research activities**

266 HealthWise Wales supports researchers in three ways by: advertising relevant studies to
267 participants; providing access to cohort data for secondary analyses via the researcher portal;
268 and supporting data collection on specific topics within the platform that can then be linked
269 with healthcare data. To date, seven studies have used the database to inform potential
270 participants of an opportunity to take part in their research (see Table 3), with recruitment
271 for each of these exceeding the required target. Nine studies have used the platform to
272 collect data on study-specific questionnaires (see Table 4), with more than 5,000 participants
273 providing data for each of these. In total, HWW has facilitated the recruitment of 43,826

274 participants to 15 different studies to date, with many of the 21,779 registrants taking part in
275 multiple studies. Results from these studies are now being published including, for example,
276 an analysis of patients' reasons for consulting a general practitioner when they had a dental
277 problem (15). Links to all publications that have used HWW to recruit participants will be
278 included on the project website.

279

280 **Strengths and limitations**

281 There are several strengths of HWW as a resource for research. More than 20,000 individuals
282 with a diverse socio-demographic profile have already registered, and recruitment is ongoing.
283 Matching rates of participant data with routinely-collected healthcare records are very high.
284 In contrast with other population-based cohorts in the UK (4), HWW participants are younger,
285 with most between 30 and 60 years old. This provides an opportunity to conduct longitudinal
286 population studies with data collected pre-disease onset. Participants are also "research
287 ready"; the examples given above demonstrate that the platform provides an effective way
288 for the research community to reach an engaged, responsive cohort. A targeted retention
289 plan is being developed with PPI representatives and a wider stakeholder group to encourage
290 continued active participation in the project. Strategies found by other studies to be effective
291 will be adapted to suit the HWW cohort, including the provision of real-time feedback to
292 participants when they provide data, the development of an online community where
293 participants can share their research experiences, and regular, diverse public engagement
294 events to disseminate emerging results.

295

296 Men are currently under-represented in the cohort; only 28% of registered participants are
297 male. Similarly, there are fewer individuals below 25 and over the age of 65 than in the

298 general population, and a smaller percentage of participants from routine and manual
299 occupations and in the most deprived wealth quintiles. To address this, we are currently
300 undertaking qualitative research using a stratified sampling frame (based on age and gender)
301 in deprived areas of Wales. We are recruiting engaged and disengaged participants with the
302 aim of understanding motivations and barriers to participating in HWW and collecting
303 suggestions from them for future communications, marketing and interactive activities that
304 would appeal to under-represented segments of the population. Focus group participants will
305 be asked to comment on recruitment strategies that are currently being considered including
306 arts-based workshops, and celebrity and local ambassador programmes. Our retention and
307 recruitment strategies will inform and reinforce each other. A key feature of both will be
308 participant involvement in design and development of these activities to promote a two-way,
309 dynamic flow of information between the research team, participants and members of the
310 public to encourage greater public involvement with research. The aim is to achieve a study
311 sample that closely models the population of Wales, with sufficient numbers in socio-
312 demographic subgroups to allow for the selection of populations for research from those
313 groups. For example, the cohort currently includes 5,000 men, providing a substantial sample
314 size that will be adequate for some analyses.

315

316 Research registers, such as SHARE Scotland (6), are increasingly recognised as an effective and
317 efficient way of supporting recruitment for research. Not all registers operate in the same
318 way. For example, SHARE Scotland uses information from the NHS records of their registrants
319 to determine their suitability for individual projects. HWW plans to offer this option to
320 researchers in future. SHARE Scotland does not collect self-reported exposure and outcome
321 information from participants, whereas HWW does. Lastly, SHARE Scotland gives participants

322 the opportunity to consent to the storage and use of “spare” blood (blood remaining from
323 tests taken within the NHS), which can then be used in approved medical research. Currently,
324 bio-samples are not collected from HWW participants. Formative research examining the
325 willingness of individuals to provide different types of biological samples for research as part
326 of their participation in HWW showed that 83% would be willing to do so. Options for a
327 strategic approach to bio-sampling across Wales, and therefore a future enhancement that
328 will increase the value of this cohort, are currently being explored.

329

330 **Collaboration**

331 Figure 4 shows the application process for all research activities that can be undertaken using
332 the HWW platform. All documentation informing researchers of how to apply to use the
333 HWW platform was made public in June 2018, and access to the data has been possible since
334 September 2018. A guide for researchers giving full details of the application and review
335 process, and a copy of the application form, are available on the study website
336 (www.healthwisewales.gov.wales/for-researchers).

337

338 Requests to advertise projects to HWW participants via newsletters or social media are
339 reviewed on a case-by-case basis by the HWW research team. The HWW ethical approval and
340 participant consent permit HWW to advertise research projects to registered participants as
341 long as they fit with the ethos and scope of the initiative. It is the responsibility of applicants
342 to obtain ethical approval for the conduct of their specific study before HWW advertises it to
343 participants. This ethical approval should specify that HWW will be used to help recruit
344 participants.

345

346 Applications to use HWW for data collection or analysis are reviewed by the SSG and by PPI
347 representatives, to assess that the project fits with the ethos of HWW, is scientifically sound,
348 and that adequate PPI input has been sought in the development of the proposal. Once
349 approved, researchers work closely with the HWW research team to deliver the project,
350 including working together to prepare the application for a substantial amendment to the
351 HWW ethical approval (which is needed for all new data collection). Researchers will need to
352 provide evidence that they are bona fide researchers and have appropriate training in
353 Research Data and Confidentiality procedures in order to gain access to the HWW data
354 repository via SAPPHiRe.

355

356 Further details on how to apply, and the requirements for access and acknowledgements for
357 publication, can be found in the Researcher Guidance document on the Researcher tab of the
358 HWW website: www.healthwisewales.gov.wales/for-researchers/. Researchers should
359 contact the research team (on healthwisewales@cardiff.ac.uk or 0800 9172 172) before
360 submitting their application to obtain guidance on how best to use the platform in their study,
361 patient and public involvement processes, ethical requirements, questionnaire development,
362 implementation and promotion.

363

364 In conclusion, HWW is a research database of adults (aged 16 and above) living or receiving
365 their healthcare in Wales that can support researchers by: advertising relevant studies to
366 registered participants; providing access to cohort data for secondary analyses via the
367 researcher portal; and supporting data collection on specific topics with record-linkage to
368 healthcare data if required. It has been successful in recruiting a “research ready” cohort in
369 Wales, and to date has facilitated recruitment of 43,826 participants into 15 studies.

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376 Welsh Government Communication team for their contribution to the Communications Plan.
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378 Wales Executive group, the Public Involvement Delivery Board, Chris Stock, the Centre for
379 Trials Research and Professor Mike Robling (Data Guardian). We also thank the participants.

380

381 **Contributorship statement**

382 SP is the principal investigator of HealthWise Wales. LH, PAW, JT, LH, LC, MA, JH and SP
383 contributed to the conceptualization of the project, data collection and analysis methods, and
384 recruitment and retention methods. LH and SP wrote the first draft of this paper. LH, PAW,
385 JT, LH, LC, MA, JH and SP contributed to the text of the paper, subsequent revisions and the
386 production of the final version of the paper.

387

388 **Competing interests**

389 The authors declare no competing interests

390

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392 HealthWise Wales is funded by Health and Care Research Wales.

393

394 **Data sharing statement**

395 The application process for all research activities that can be undertaken using the HWW
396 platform (including data collection, analysis and advertising of research projects to HWW
397 participants) is described in the paper. A guide for researchers giving full details of the
398 application and review process, and a copy of the application form, are available on the study
399 website (www.healthwisewales.gov.wales/for-researchers).

400 **References**

- 401 1. Marmot, M. The health gap. The challenge of an unequal world London: Bloomsbury
402 Publishing; 2015.
- 403 2. Prince M, Wu F, Guo Y, Robledo L, O'Donnell M, Sullivan R, et al. The burden of disease
404 in older people and implications for health policy and practice. The Lancet. 2015; 385(9967):
405 549-62.
- 406 3. Chief Medical Officer. Chief Medical Officer for Wales Annual Report 2015-16.
407 Rebalancing healthcare. Working in partnership to reduce social inequity. Cardiff: Welsh
408 Government; 2016.
- 409 4. Medical Research Council. Maximising the value of UK population cohorts. MRC
410 Strategic Review of the Largest UK Population Cohort Studies. London: Medical Research
411 Council; 2014.
- 412 5. Manolio T, Weis B, Cowie C, Hoover R, Hudson K, Kramer B, et al. New models for large
413 prospective studies: is there a better way? American Journal of Epidemiology.
414 2012;175(9):859-66.
- 415 6. McKinstry B, Sullivan F, Vasishta S, Armstrong R, Hanley J, Haughney J, et al. Cohort
416 profile: the Scottish Research register SHARE. A register of people interested in research
417 participation linked to NHS data sets. BMJ Open. 2017;7(2):e013351.
- 418 7. Staley K. 'Is it worth doing?' Measuring the impact of patient and public involvement
419 in research. Research Involvement and Engagement. 2015;1(1):6.
- 420 8. Office for National Statistics. Statistical Bulletin. Population estimates for the UK,
421 England and Wales, Scotland and Northern Ireland: mid-2017. London: Office for National
422 Statistics; 2018.

- 423 9. Chief Medical Officer. Chief Medical Officer for Wales Annual Report 2014-15.
424 Healthier, happier, fairer Cardiff: Welsh Government; 2015.
- 425 10. Elwood P, Galante J, Pickering J, Palmer S, Bayer A, Ben-Shlomo Y, et al. Healthy
426 lifestyles reduce the incidence of chronic diseases and dementia: evidence from the Caerphilly
427 cohort study. PLoS One. 2013;8(12):e81877.
- 428 11. Ford D, Jones K, Verplancke J, Lyons R, John G, Brown G, et al. The SAIL Databank:
429 building a national architecture for e-health research and evaluation. BMC Health Services
430 Research. 2009;9(1):157.
- 431 12. Lyons R, Jones K, John G, Brooks C, Verplancke J, Ford D, et al. The SAIL databank:
432 linking multiple health and social care datasets. BMC Medical Informatics and Decision
433 Making. 2009;9(1):3.
- 434 13. Office for National Statistics. 2011 Census Analysis - Comparing Rural and Urban Areas
435 of England and Wales. London: Office for National Statistics; 2013.
- 436 14. Jones K, Ford D, Jones C, Dsilva R, Thompson S, Brooks C, et al. A case study of the
437 Secure Anonymous Information Linkage (SAIL) Gateway: a privacy-protecting remote access
438 system for health-related research and evaluation. Journal of Biomedical Informatics.
439 2014;50:196-204.
- 440 15. Cope A, Wood F, Francis N, Chestnutt I. Patients' reasons for consulting a GP when
441 experiencing a dental problem: a qualitative study. Br J Gen Pract. 2018;68(677):e877-e83.
442

443 **Tables**

444

Table 1: Outline of data collection questionnaires, timelines and summary of completions

Core module themes*	Brief overview of module content	Data collection period						Status in Sept-18
		Apr-15	Apr-16	Oct-16	Apr-17	Oct-17	Apr-18	
Registration	- Consent, personal details including date of birth, gender and postcode (for the assignment of Welsh Index of Multiple Deprivation)							21779
Socio-demographic information	- Ethnic group - Occupation and social class (National Statistical Socio-economic Classification, NS-SeC)							14433
	- Family life: relationship status, children, caring responsibilities							11004
Behavioural risk factors	- Physical activity (General Practice Physical Activity questionnaire, GPPAQ)							14633
	- Smoking (current smoking, second-hand smoke exposure, e-cigarette use)							
	- Alcohol (frequency in past 12 months, binge drinking in past 7 days)							
	- Anthropometry (self-report of weight and height)							
	- Diet (self-report on whether diet is healthy, fruit, veg and sweetened beverage intake yesterday)							14206
Mental health	- Mood over the past month, measured using the five-item Mental Health Inventory (MHI-5)							14581
	- Resilience Research Centre Adult Resilience Measure (RRC-ARM 28)							3125
	- Buckner Neighbourhood Cohesion Scale							3206
	- Warwick-Edinburgh Mental Wellbeing Scale							Oct 18

* Pregnant women complete modified versions of the core modules

Key to modules:

	Live modules
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Table 2: Characteristics of the HealthWise Wales cohort and population data from published sources for Wales

Characteristic	HealthWise Wales	Population data for Wales from published sources
Total who have completed registration form	21,779	
Age group:		
16-24 years	10%	14% ¹
25-44 years	30%	29%
45-64 years	38%	32%
65+ years	22%	25%
Completed by (% of those registered)	N=21,746 (99%)	
Sex:		
Male	28%	49% ²
Female	72%	51%
Completed by (% of those registered)	N=21,737 (99%)	
Ethnic group:		
White	98%	98% ³
Other	2%	2%
Completed by (% of those registered)	N=14,912 (69%)	
Standard occupational classification⁴:		
1 (Higher managerial, administrative and professional occupations)	50%	27% ⁵
2 (Intermediate occupations)	18%	21%
3 (Routine and manual occupations)	11%	37%
Other (Never-worked, long-term unemployed and full-time students)	21%	15%
Completed by (% of those completing questionnaire)	N=13,268 (97%)	
Physical activity (GPPAQ):		
Active	35%	No comparable data found
Moderately active	21%	
Moderately inactive	15%	
Inactive	29%	
Completed by (% of those completing questionnaire)	N=13,647 (98%)	
Smoking:		
Current smoker	10%	19% ⁶
Ex-smoker	35%	29%
Never smoked	55%	52%
Completed by (% of those completing questionnaire)	N=13,881 (99%)	
Binge drinking in past week:	23%	24% ⁷
Completed by (% of those completing questionnaire)	N=12,229 (88%)	
Drinking alcohol above guideline levels:	50%	40% ⁷
Completed by (% of those completing questionnaire)	N=12,229 (88%)	
Mental Health Inventory (MHI-5) score:		
Score consistent with common mental disorder ⁸	28%	
Completed by (% of those completing questionnaire)	N=13,694 (99%)	
Diagnosed with or treated for a mental health condition?	32%	13% ⁹
Completed by (% of those completing questionnaire)	N=13,837 (99%)	

- ¹ Mid-year population estimates for Wales 2017, Office for National Statistics (from StatsWales, <https://statswales.gov.wales/>)
- ² Mid-year population estimates for individuals aged 16+ in Wales 2017, Office for National Statistics (from StatsWales)
- ³ Population estimates for individuals aged 16+ in Wales 2011, Office for National Statistics (from StatsWales)
- ⁴ Using the National Statistics Socio-Economic Classification (NS-SEC, Office for National Statistics)
- ⁵ Population estimates for individuals aged 16-74 in Wales, 2011 UK Census
- ⁶ Estimates for individuals 16+yrs from the National Survey for Wales 2017-18 (https://gov.wales/statistics-and-research/national-survey/?tab=el_home&topic=population_health&lang=en)
- ⁷ Data for individuals aged 16+ from the Welsh Health Survey 2015
- ⁸ Kelly MJ, Dunstan FD, Lloyd K and Fone D. (2008) Evaluating cut-points for the MHI-5 and MCS using the GHQ-12: a comparison of five different methods. *BMC Psychiatry* 2008, 8:10
- ⁹ Data for individuals aged 16+ from the Welsh Health Survey 2015; asked whether they were currently being treated for “*depression, anxiety or another mental health illness*”

Table 3: Engagement of HWW participants with research advertised via the HWW platform

Researcher	Study aim	Number of responses
Dr Tapio Paljarvi et al National Centre for Population Health and Wellbeing Research (NCPHWR)	To validate data on physical activity collected using mobile devices	60
Professor Ian Jones National Centre for Mental Health (NCMH)	To recruit participants to the NCMH cohort for mental health research	1,100 (phase 1) 600 (phase 2)
Dr Anwen Cope^{1,2}; Dr Fiona Wood³; Dr Nick Francis³; Professor Ivor Chestnutt² ¹ Cardiff and Vale University Health Board; ² School of Dentistry, Cardiff University; ³ School of Medicine, Cardiff University	To describe the barriers patients experience when trying to access dental care, and to explore factors that influence patients' choice of healthcare provider when experiencing a dental problem	80
Dr Dikaïos Sakellariou School of Healthcare Sciences, Cardiff University	To improve care for disabled people	8
Professor Annmarie Nelson Marie Curie Palliative Care Research Centre	A survey to understand attitudes to death and dying in Wales	2004
Victoria Shepherd NIHR Doctoral Fellow, Cardiff University	To understand decision making involving adults lacking capacity	2
Professor Petroc Sumner School of Psychology, Cardiff University	To examine the prevalence of dizziness and vertigo in the general population and the potential relationship with other conditions (e.g. migraine)	2400
Dr Patricia Masterson Algar School of Health Sciences, Bangor University	To examine the experience of young adults who live in families affected by stroke, multiple sclerosis or dementia and investigate their support networks and their engagement in peer support	2
Dr Kathryn Peall Division of Psychological Medicine and Clinical Neurosciences, Cardiff University	To establish an international registry for Myoclonus Dystonia (a rare childhood-onset hyperkinetic movement disorder that can potentially impact function, daily living, and cause significant pain and psychological problems), to characterise the condition and facilitate research.	141

Table 4: Examples of researcher-led questionnaire modules on the HealthWise Wales platform

Module name	Researcher	Main aim of research	Module availability				Status in Sept-18
			Oct-16	Apr-17	Oct-17	Apr-18	
Theme: Improving health services							
Care for coughs and colds	Francis et al School of Medicine, Cardiff University	To examine patterns of and beliefs relating to consulting behaviours for respiratory tract infections					8886
Medicines and their cost	Yemm et al School of Pharmacy and Pharmaceutical Sciences, Cardiff University	To examine the acceptability of putting the costs of medicines on dispensing labels					6279
Re-use of medicines	McRae et al Cwm Taf University Health Board	To investigate public views on the potential for re-dispensing medicines returned unused to pharmacies					5476
Oral health in children	Kemp et al School of Medicine, Cardiff University	To examine oral health behaviours and impact of dental disease on children and families					5037
Theme: Cancer research							
Sun exposure and sun bed use	Abbott R Cardiff and Vale University Health Board	To assess awareness of skin cancer, preventative behaviours and knowledge of vitamin D					6115
Bowel symptoms and cancer awareness	Dolwani et al School of Medicine, Cardiff University	To investigate factors affecting screening, prevention and early diagnosis of bowel cancer					5617

Key to modules:

	Live modules
	Module expiry date

Figure legends

Figure 1: Website and Consent

Figure 2: HealthWise Wales Data Flow

Figure 3: Proportion of participants resident in each quintile of the Welsh Index of Multiple Deprivation, compared with the general Welsh population

Figure 4: Flow diagram showing the application process for all HWW activities