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Developing and evaluating a model of public involvement and engagement embedded in a national longitudinal study: HealthWise Wales

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Abstract

Introduction
Worldwide large cohort studies have invested in community engagement to promote studies and aid recruitment. HealthWise Wales, a national population study, aims to create a register of 'research ready' participants and provide long-term follow up data on health behaviours, outcomes and wider social and environmental determinants. Public involvement and engagement was key to the development of HealthWise Wales. We describe how a model for promoting HealthWise Wales was co-produced with members of the public.

Methods
Members of the public were invited to take part in a workshop, either in North or South Wales, to discuss public involvement in long-term cohort studies. Information on community engagement, projects that had used the concept of "citizen scientists" to promote involvement, and other large longitudinal studies was provided to 15 members of the public prior to the meeting. Eight of these attended the workshops, to explore the concept of citizen scientist and how it may relate to HealthWise Wales.

Results
Data from two workshops was used to draft a protocol for involvement that was reviewed and refined by members of the public. The protocol describes two levels of public involvement, HealthWise Wales Champion or Supporter. The Champion is a more formal role that requires promoting the project at public events, whereas Supporters pledge to promote the study to friends and family. Training was provided to 17 of the 26 members of the public who had expressed interest in becoming HWW Champions. Twelve trained Champions attended 41 events to promote the study and collect 'consent to contact' forms from members of the public.

Conclusions
It is possible to develop a model of community engagement with members of the public to promote and raise awareness of a national population study in Wales. It is essential that adequate resource is provided to support the concept.

Keywords
longitudinal; public involvement; public engagement; population health

Background

The positive impact of public engagement and involvement in research is largely accepted [1]. The public have provided important insight into the design and methodology of studies, and ensured research questions are relevant [2, 3]. They have also successfully assisted in conducting research and improved recruitment by providing greater access to communities and ascertaining successful ways to identify participants [4, 5].

Across the world, several large cohort population studies have invested in public engagement activities to promote the study and enhance recruitment [6–11]. In the USA, the National Children's Study invested in community engagement and engaged with key local stakeholders as a strategy to optimise recruitment to a population study prior to approaching pregnant and potential pregnant women to participate in the study. Study centres employed community outreach and engagement officers, who spent up to two years arranging activities, events and also enlisted the help of trusted local ambassadors to promote the study and build trust with local people, to maximise recruitment [10].

The South East Asia Community Observatory (SEACO) study, in Malaysia also undertook an extensive process of community engagement prior to data collection [8].

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In this study, community members volunteered to co-ordinate activities that brought people together and allowed discussion to take place about the SEACO study. Establishing relationships with community members and maintaining these relationships was critical to the success of the project. Local data collectors were also essential in achieving the 85% recruitment rate to the study [8].

Another strategy of engaging with study participants to promote recruitment to a large longitudinal study was adopted in the Third Generation Cohort of the Framingham Heart Study. In this study, current participants were asked to supply contact details of relatives to allow researchers to contact them as potential participants [11].

HealthWise Wales (HWW) is a national initiative that has four main aims. The first is to create a register of people who are willing to take part in health and social care research studies; the second, to establish a population based cohort study which collects follow-up data on health behaviours, outcomes and wider social and environmental determinants; the third is to form a cohort who have provided consent to link their data with routinely collected data through the Health Data Research UK Centre at Swansea University; the fourth, to raise awareness of the importance of research to improve health and wellbeing.

The ethos of public involvement and engagement is embedded throughout HWW. The UK standards for public involvement have provided a framework to ensure a consistent and high-quality approach [12]. Patient and Public Involvement (PPI) members were part of a Task and Finish Group set up by Health and Care Research Wales (HCRW) that agreed the scope, aims and protocol for HealthWise Wales. The project was publicly launched in March 2016, and to date over 40,000 participants have been recruited using an online platform. Study participants are aged 16 years and over, and live or access their primary health care in Wales. The study aims to engage people living in Wales with research, to increase knowledge of, and participation, in research studies, with the ultimate aim of improving the health and well-being of the nation. Participants who register to join HWW provide consent to be contacted about future research and permission for their data to be linked to routinely available healthcare data.

This paper describes how the HWW research team initiated a model of public involvement and engagement. The objective was to establish a model of co-production with PPI members in Wales, to create and implement a protocol of community public engagement, to raise awareness of HWW, research in general, and promote the study with other members of the public, with the ultimate aim of increasing recruitment. The need to raise awareness of HWW, although not assessed formally, was recognised following a number of public engagement events where attendees consistently reported not having heard of the project prior to attending the event.

Methods

Definitions

The definition of public involvement in this paper reflects the INVOLVE definition of research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them [13]. The term co-production as used in this paper, is based on the key principles described in the guidance published by INVOLVE. [14]

Collaborative workshops

Invitations to take part in a workshop to develop a protocol of community public engagement to promote recruitment were distributed to all members of the Involving People Network, Health and Care Research Wales [15]. The purpose of the workshops was to co-produce a methodology for raising awareness of the study and research in general, with the ultimate aim of increasing recruitment to HWW. Interested participants were emailed information about HWW, the concept of citizen scientist and some examples of how large numbers of the public have been successfully involved in research previously, for example, in Cancer Research UK's Cell SliderTM study [16]. Members of the public were asked to read the information and consider some key questions prior to attending a workshop. Examples of questions included 'Why would someone want to be a citizen scientist?', 'What do your friends and family think of the idea?', and 'What is important to members of the public when considering taking part in a research project?'. To aid understanding of the concept of citizen scientist members of the public were provided with a link to the explanation of the concept on Wikipedia (https://en.wikipedia.org/wiki/Citizen_science). In brief, citizen science (also known as crowd science, crowd-sourced science, civic science, volunteer monitoring or networked science) was defined as scientific research conducted, in whole or in part, by amateur or nonprofessional scientists. This concept was used as a starting point to explain how members of the public had been involved in research, with particular regard to studies that could not otherwise have been conducted. For example, Stall Catchers, where volunteers play a video game to identify stalled blood flow in mice to aid Alzheimer's research [17].

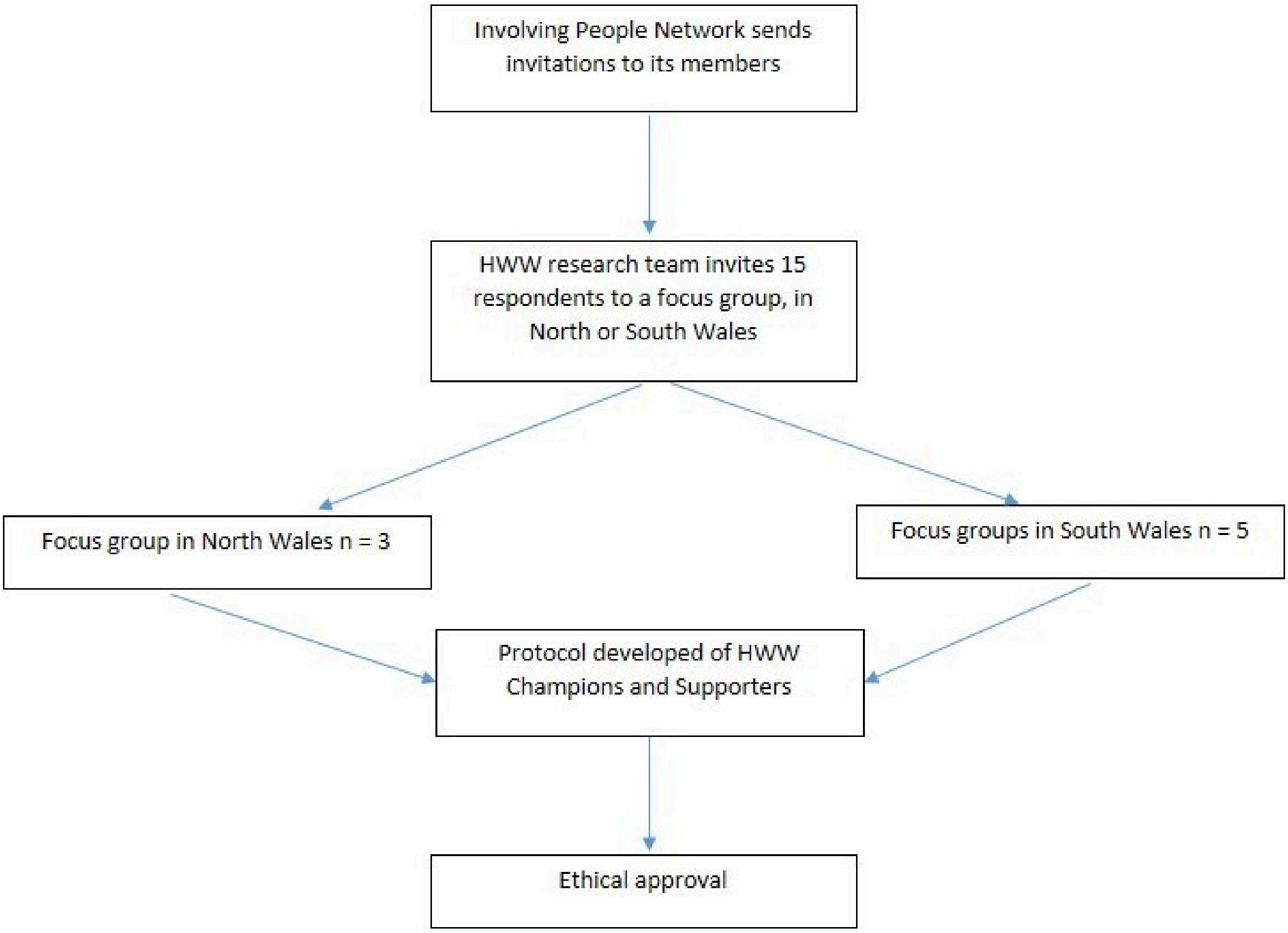
Figure 1 Illustrates the methods adopted to develop a protocol of community public engagement for HWW.

A topic guide was developed to be used at the workshops, with an introduction to the project, describing data linkage and how administrative data is collected routinely in Wales. The topic guide also included an overview of how members of the public were successfully involved in other research projects and the concept of citizen scientist. Discussion was directed towards addressing the potential facilitators and barriers of the public working on the project as ambassadors and what training and support might be required. Particular focus was targeted towards whether or not activities would be limited to promotion of the study or whether it could include taking informed consent and recruiting other participants. Finally, questions were posed as to what these individuals should be called and what their role, aims and objectives should be, and whether remuneration for involvement would be required.

Developing a community public engagement protocol

Data collected from both groups were combined and key points used to draft a protocol. The draft protocol was circulated to

Figure 1: Flow chart illustrating the methods used to develop the protocol



members of the public in both groups for comments. It was revised and refined based on the comments from both groups, with a final version agreed by all members, prior to submitting for an amendment to the main ethics approval. The protocol was approved by Wales REC 3 ethical committee, May 2016.

Results

Overall, 15 individuals across Wales expressed interest in taking part in the workshop. To aid attendance two workshops were organised, one in South Wales, attended by five individuals and one in North Wales attended by three.

Protocol for community public engagement

The finalised protocol described two levels of opportunity for HWW participants and their involvement with HWW. The first was to act as a HWW 'Champion' and the second a HWW 'Supporter'.

HealthWise Wales Champions

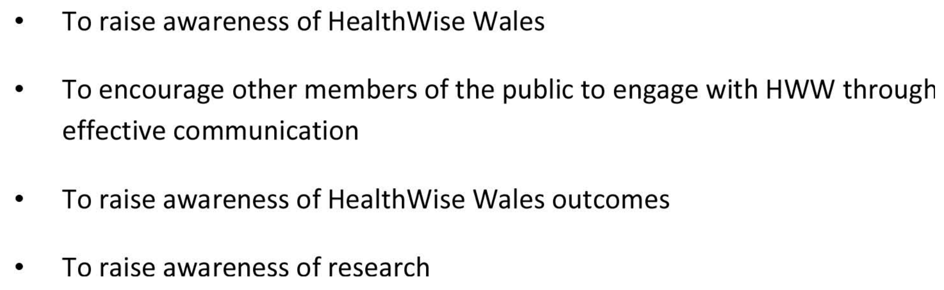
The role of 'Champion' was described as a relatively formal role where individuals made a commitment to promote the study to other members of the public, not necessarily their own networks of friends and family. This activity could take place in a number of venues, such as GP practices as well as large public events, such as food festivals. Members of the public overwhelmingly agreed that training should be provided for those wishing to undertake the role of 'Champion', to ensure that they could effectively communicate about the study, specifically about the more complex concepts of data linkage, the use of routinely collected data and data security. Members of the public were not comfortable with taking informed consent to participation in research, but were happy to ask others to provide "consent to contact". Consent to contact is the collection of contact details, which allows researchers to contact the individual at a later date, discuss the study and take informed consent if willing to participate. It was agreed that Champions should be remunerated for the role, in line with the Involving People Network honoraria payment.

HealthWise Wales Supporters

The role of 'Supporter' was agreed to be more casual, where participants would be asked to make a pledge to talk to others about the study, but no formal evaluation or monitoring of this activity would be undertaken and no training would be required.

Both roles were entirely voluntary, with no obligation on the part of the volunteer to meet any specific targets or to

Figure 2: Role of Champions and Supporters



- To raise awareness of HealthWise Wales
- To encourage other members of the public to engage with HWW through effective communication
- To raise awareness of HealthWise Wales outcomes
- To raise awareness of research

undertake a specific level of activity. Individuals were able to dedicate as much or as little to the role as they wished. However, unlike the 'Champion' role, they were not reimbursed for their time.

Potential HWW 'Supporters' and 'Champions' were informed of the opportunity via the HWW newsletter. This newsletter was only circulated to those who had already registered as a HWW participant, approximately 4000 individuals at that time, and therefore the role of Supporters and Champions were only offered and subsequently undertaken by those who were also participants. Only Champions were trained and had their activities recorded, therefore the following results relate to Champions only.

Pilot of Champions

It was agreed that an initial pilot of the concept would be carried out, over a four month period (July 2016 to October 2016), with five members of the public (and HWW participants) who had expressed an interest in becoming a HWW Champion.

Training of Champions

An initial training session for Champions was held in Cardiff (June 2016), and attended by five HWW participants, communications specialists and HWW team members who support recruitment and engagement activity.

The training sessions provided an overview of the project, discussed the role of a Champion and specific relevant communication skills. One member of the public co-produced with the HWW research team the aims and objectives for being a HWW Champion (Figure 2).

Small sections of text to describe the project were provided to aid Champions. A role-play session allowed HWW Champions an opportunity to practice what they would say in various scenarios at events. Data protection, which is paramount to the project, was also covered and consideration was given of the logistics of collecting the 'Consent to Contact' forms in a public space without contravening data protection legislation. To conclude, the expectations of the HWW research team of Champions were discussed, including what the role entailed, how many events they were likely to be asked to attend, and how they would provide feedback following events.

Following the apparent success of the initial pilot, it was agreed to increase the number of Champions and to offer a second wave of training. In January 2017, two training days were held, one in North Wales and one in South Wales, increasing the number of Champions to 17. Five others wished to be trained but were not able to attend these particular dates.

Champion activity

In total, 26 Champions were recruited, of whom 17 have been trained to attend events. Of these, 12 attended events. There are twice as many Champions in South Wales (n= 17), compared to North Wales (n = 8), (1 unknown location). In the pilot period, July 2016 to December 2016, five Champions, attended 11 events. After the second wave of training, 12 Champions attended 40 events. Activity has included "manning the stand" at high footfall events, such as the Royal Welsh Show and the Cardiff Food Festival; organising and presenting at their own events; engaging and presenting to Year 12 and 13 secondary school students; as well as supporting events organised by the HWW team and partners.

Figure 3 shows where Champion activity has taken place across Wales.

At events, Champions have engaged in conversation with other members of the public, explaining what HealthWise Wales is and asking them to complete 'Consent to Contact' forms, which allow members of HWW team to contact potential participants at a later date.

Impact

Table 1 shows the total number of consent to contact forms that have been completed at events attended by HWW Champions and the subsequent conversion rate to registered study participants. Conversion rates ranged between 9.8% and 33.3% across events, although higher rates were observed in events that had smaller numbers of attendees. Conversion rates at events with a higher footfall were about 11%, which is consistent with response/recruitment rates in other large scale studies [18].

Overall, 130 (1.5%) people who registered for HWW have indicated that it is because of an activity where a Champion had been promoting HWW. However, this is based on data where participants have answered a non-mandatory question about how they heard about HWW and is therefore likely to be an underestimate of the impact that Champions have had on recruitment to HWW.

Figure 3: Map illustrating where Champion activity has taken place

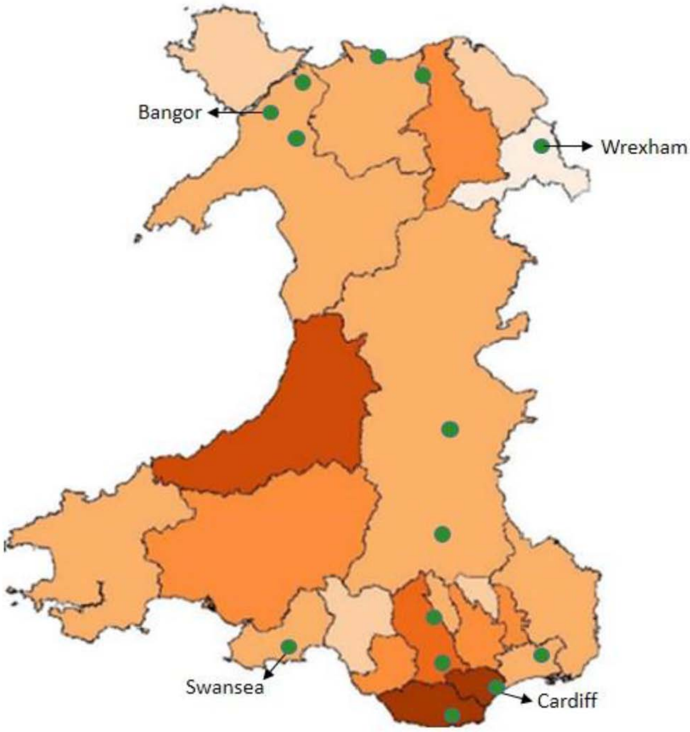


Table 1: Conversion rate from consent to contact forms to registered participants from events where HealthWise Wales was promoted.

Event	Consent to contacts	Registrations	Conversion rate (%)	Champion activity
Stroke conference	27	9	33.3	✓
Coleg gwent	10	2	20	
Welsh government	50	6	11.8	✓
Grangetown festival	56	7	12.5	✓
Cardiff food festival	291	34	11.6	✓
Antenatal	18	2	11.1	✓
Health board	132	13	9.8	
Cardiff & Vale UHB	11	0	0	
Total	**596**	**73**	**12.2**	

Review

A review of the Champion model was undertaken after 16 months of activity, which involved a review by researchers and a review meeting comprising Champions and other members of the public involved in the management and governance of HWW. Overall, Champions reflected that they enjoyed the role and felt their contribution was worthwhile.

> *'Thus far my experience working with HWW has been great. My regret is that on one occasion I have been prevented from getting to an event and feel I have let you down.'* (PPI 8)

To date, one HWW Champion has resigned from the position. Some of the challenges they experienced are reflected in this quote.

> *'The lack of enthusiasm from the general public needs to be addressed, especially when you mention research, people do not understand the concept of the whole process.'* (PPI 7)

The research team have valued the Champion's commitment and passion regarding the project and appreciate their hard work to engage other members of the public. It was recognised that communication was at the heart of building trust and effective relationships with PPI members. However, this can easily be compromised through misunderstandings, slow communication and lack of up to date information about the project.

Cost

HWW Champions were reimbursed for their out of pocket expenses and time in accordance with the guidance provided by INVOLVE and the Involving People Network (Wales). [13, 15] The total cost was £2975, which equates to £73 per event (£2975/41) and £40 per conversion (£2975/73).

Discussion

This study has shown that it is possible to establish a model of PPI to promote a national cohort study and engage other members of the public, to aid recruitment and increase knowledge regarding the potential benefits of this type of research. The success of the model relies upon effective communication, building rapport and establishing trust with members of the public. A degree of flexibility, autonomy and pragmatism is required as we recognise individual Champions' activities occur in a number of different ways and settings. Whilst some preferred to deliver a presentation on the project to an audience within their own networks, others preferred more casual one to one encounters at events organised by the research team. Therefore, if more Champions are recruited and trained, it is important to recognise and support individual Champions' own skill and expertise.

Overall, sufficient resource is vital to establish and maintain the successful relationships created. Initial training was an essential component, but ongoing support was also required for Champions to ensure they could represent the study effectively. In particular, we encountered challenges regarding accurate description of the HWW project using language accessible to other members of the public. Champions were required to describe a number of complicated concepts correctly and clearly, for example, how data is linked anonymously, how data security is maintained, as well as how longitudinal studies can improve the health and well-being of a nation. Another challenge Champions faced was describing a study which does not focus on a particular disease area, which perhaps makes it more difficult for other members of the public to relate to. Champions were particularly effective once they had acquired the confidence to respond to other members of the publics' questions and reassure them over any concerns, for example, how their medical records would be used in the study.

Effectively measuring the impact of the HWW Champions and Supporters model has been challenging, as experienced in a number of other studies [19]. The range of impact is difficult to quantify and there is a danger that impact is assessed on easily measured outcomes, such as the number of participants recruited to the study due to Champion activities, which is challenging when the Champions do not directly recruit participants. In our example, this outcome relies on new participants completing an additional field on the online database, which is likely to lead to an underestimate of the effect of the Champions. Impact may be occurring in ways that are impossible to evaluate, for example, increasing the public's exposure to, understanding of and engagement with research in general. The value of evaluating the impact of PPI involvement in research has been questioned, given that it is a highly complex and context-dependent process [20]. However, it could equally be argued that funders are unlikely to support an activity if there is no demonstrable impact.

As the HWW project is ongoing, it may not be possible to fully evaluate the true impact of the Champions and Supporters model for many years. An emerging component of the Champions model, that could be have potential impact, is the dissemination of results. Previously, researchers have been criticised for carrying out research and not effectively feeding back results to participants in an accessible manner [21]. This has been said to have caused some members of the public to disengage with research as they feel they have taken part, but not been party to the results and how the research may have directly improved participants' or community health. HWW Champions could be an effective method for ensuring that results from the project are directly and effectively fed back to other members of the public, with the potential to enhance recruitment and retention.

It could be argued, from the figures presented, that the HWW Champion and Supporters model was relatively ineffective in increasing the number of people recruited to the project, and that other methods, for example, large mail outs to households in Wales, were a more cost-effective approach. There are few examples in the literature of successful recruitment to national longitudinal cohort studies using an online platform, and involving data linkage. However, the PRIDE study who targeted sexual and gender minority people for a national longitudinal study in the USA successfully recruited nearly 14000 participants in two years by creating PRIDEnet. This involved eight ambassadors who worked within their established networks to influence and actively engage this specific community, primarily through digital communications [22]. This suggests that adjusting our model to include Champions with reach to previously established networks, using electronic communication, may be a more cost-effective approach in the future for recruiting participants to HWW.

Following the recent decision of HCRW to suspend a significant portion of the funding attributed to HWW, the protocol for Champions and Supporters is unable to continue as originally intended, as there is no longer a budget to reimburse members of the public in this role, or to maintain the resource needed to support the Champions. As the project works towards implementing a 'cost-recovery' model, maintaining the online platform and facilitating researchers who wish to use HWW data or contact HWW participants for their own research projects, has become a necessary priority. As other funding options are explored, it may be possible in the future, to re-engage with the HWW Champions and Supporters who were invested and committed to the project.

Conclusion

We have developed and implemented a model of working with members of the public to promote the study and increase participation, which will be useful to other studies planning large scale population based studies that require meaningful public involvement and engagement. However, the importance of securing funding to maintain this type of model is paramount to its success and continuation.

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Statement of conflict of interests

The authors declare that they have no competing interests.

Ethics

Ethic approval for HWW was granted by Wales REC 3, reference 15/WA/0076.

Availability of data and material

All data generated are included in this published article.

Authors' contributions

JT: Wrote the manuscript and was the responsible person for conducting the workshops and developing the protocol with members of the public. JD: Developed the HWW Champions protocol, as a member of the workshops, and commented on all drafts of the manuscript. LH: Facilitated the workshop in South Wales, commented on all drafts of the manuscript and provided expert knowledge on recruitment and retention in epidemiological studies. PAW: Is the project manager and commented on all drafts of the manuscript. SP: Is the Scientific Lead for HWW, commented on all drafts of the manuscript and provided expert knowledge on recruitment and retention in epidemiological studies. All authors read and approved the final manuscript.

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List of abbreviations

HCRW:	Health and Care Research Wales
HWW:	HealthWise Wales
PPI:	Patient and Public Involvement
SEACO study:	South East Asia Community Observatory study