International Journal of Population Data Science

Journal Website: www.ijpds.org





Protocol for implementing the concept of citizen scientists for HealthWise Wales: a national population study

Townson, Julia^{1*}

¹Cardiff University

Objectives

HealthWise Wales is a national cohort study, aiming to recruit 260,000 people, over 16, living in, or accessing health services in Wales, within 5 years. The aims are; to create a cohort with longitudinal follow up data on behavioural and environmental exposures, using data linkage to healthcare datasets and outcomes; create a register of potential research participants; actively engage the public in research, inviting them to identify priorities. Research areas of importance include impact of social inequalities on health and well-being; effect of environment/neighbourhood on health; maintenance of health and well-being in the working age population and later life. Successful recruitment relies on public engagement strategies, engaging community members to engage others in their immediate community, and using local people to collect data and act as citizen scientists.

Approach

Involving People Network members were invited to take part in an advisory group to discuss the possibility of members of the public acting as citizen scientists for HealthWise Wales. An advisory group was established in North and South Wales to inform this protocol. Researchers, through meetings and communication, directed members to other citizen scientist projects and 3rd sector groups that have utilised similar methods. The advisory group also considered online citizen scientist projects.

Results

Members of the group agreed that the term champion was more appropriate than citizen scientist. Levels of commitment and the role were discussed and members concluded that overall they thought it was a good idea. They stressed training would be necessary, as well as concise and clear messaging to allow HWW champions to talk confidently about the project. They felt it was important champions decide their own level of commitment and involvement. Two levels of champions were agreed: the first level where people will commit to finding out more about the project by either attending a training session or watching an online video; and the second where they pledge to engage members from their existing networks and communities through events, clubs and activities which they might already participate in.

Conclusion

The concept of HealthWise Champion is agreeable to members of the public but appropriate training and support will need to be provided. Materials will be developed in conjunction with the advisory group members to ensure that HealthWise Wales Champions are able to clearly and confidently disseminate the more difficult elements of the study to others e.g data linkage. An evaluation will be available by July.



http://dx.doi.org/10.23889/ijpds.v1i1.125

^{*}Corresponding Author: *Email Address:* townson@cf.ac.uk (J. Townson)