**Participant Information Leaflet**

**Unlocking data to inform public health policy and practice: decision-maker perspectives on the use of cross-sectoral data as part of a whole-systems approach**

Lead researchers: Dr Emily Tweed and Prof Peter Craig

|  |
| --- |
| You are being invited to take part in a research study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. Ask the researcher/s if there is anything that is not clear or if you would like more information. Take some time to decide whether or not you wish to take part. |
| **What is the purpose of the study?** |
| We want to find out how administrative data – that is, data collected routinely by organisations like the NHS, local authorities, and other public services – can best be used to make decisions about society that improve our health, and what changes need to be made to achieve this.  To do this, we plan to work together with people from local authorities, the NHS, Scottish Government, the third sector, universities, and the public in three workshops, to explore the following questions:   1. How do decision-makers in areas relevant to health use administrative data in their work now, and how might they use it in future? 2. What can we learn from real life examples of using administrative data in research to improve people’s health? 3. How can we solve the current problems with using administrative data, to get the greatest benefit for health?   To make sure that the results are as useful as possible, the workshops have been planned in close collaboration with the people and organisations that use such the data - like Public Health Scotland, the Convention of Scottish Local Authorities, and local public health teams. We’ll work with these partners to share and discuss our results with key organisations that fund research; collect, store, or manage administrative data; and use research in their work. |
| **Why have I been invited to take part?** |
| You’ve been identified as an individual or representative of an organisation whose views are relevant and important to this project. We need a variety of perspectives from across different sectors in order to ensure we capture the most important factors in how data are, and could be used, for better decision-making on policies and services that affect our health. |
| **What does taking part involve?** |
| You will be invited to three interactive workshops taking place virtually via Microsoft Teams, during autumn/winter 2021. Each workshop will last approximately three hours (including breaks) and will include a mix of presentations, whole-group activities, and smaller group activities in break-out rooms. Participants may be asked to read some short materials in advance of workshops or to contribute to preparatory activities like brainstorming, mapping, and polling. We will seek to make any necessary adjustments to ensure these workshops are accessible to you.  Workshops will explore various questions about how evidence from administrative data can be used in decision-making to improve the public’s health. The projects which will serve as case studies at the workshops deal with potentially sensitive topics such as homelessness, justice involvement, substance use, mental health, social care use, and child protection, though the primary focus will be on the use of routine data in these studies. You will not be asked any sensitive or personal information about your own health or interactions with public services such as healthcare or social care. Participation is voluntary and you can withdraw at any time. |
| **How will information from the study be used?** |
| The workshops will be recorded (both sound and video) and transcribed into text using a combination of auto-transcription within Microsoft Teams and review by an approved company with whom we have a confidentiality agreement. The completed transcripts will have personal information (such as people’s names) removed, and any other potentially identifiable information (such as organisation names) will be removed or replaced with pseudonyms as far as possible whilst still ensuring the data are meaningful. These text files, and any other workshop outputs (such as maps or poll results), will be analysed by the research team to identify key findings. All recordings, transcripts, and analysis files will be stored on secure University of Glasgow servers in folders accessible only to the research team.  Once analysis is complete, we will provide a written report and presentation to the funder (National Institute of Health Research) and submit articles for publication in peer-reviewed publications. We may also produce briefing papers and blogs for a wider audience. No personally identifiable information will be included in these outputs.  Information we gather in this study may be valuable to other researchers. In order to maximise the benefits of this research, we plan to deposit an anonymised version of the data generated in the study (i.e. the workshop transcripts and other outputs like maps and polls) in a secure repository like the UK Data Service or the University of Glasgow’s Enlighten archive, where approved researchers can apply to access and use it for other projects. Any such sharing of anonymised study data will be subject to user agreements with these other researchers in which they agree to keep the data confidential and only use it for the approved research purposes. |
| **How will my personal details be kept confidential?** |
| The only personal information we will collect in this study is your name, email address, and (where relevant) job title and organisation. This information will only be used for the purposes of administering the study and will not be included in any anonymised datasets or study outputs. All personal information will be stored separately from the data generated in the workshops in a secure folder accessible only to the research team, and will be securely deleted after completion of the study and all outputs.  As part of the workshops, information may be divulged which could potentially identify individuals or organisations – this will be removed from anonymised transcripts and outputs as far as possible whilst ensuring the data remains meaningful. However, participants should be aware that confidentiality may be impossible to guarantee if they describe in detail a particularly unusual or a unique situation or set of circumstances which might allow their identity – or that of organisations or other individuals – to be deduced, and we would encourage them to be mindful in this regard.  Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies. |
| **Who is funding the research?** |
| The study is funded by the Public Health Research Programme of the National Institute of Health Research (ref NIHR133585). |
| **Who can I contact for more information?** |
| For more information on the research: contact the lead researchers, Dr Emily Tweed ([emily.tweed@glasgow.ac.uk](mailto:emily.tweed@glasgow.ac.uk)) or Prof Peter Craig ([peter.craig@glasgow.ac.uk](mailto:peter.craig@glasgow.ac.uk))  To pursue any complaint about the conduct of the research: contact the College of Social Sciences Ethics Officer, Dr Muir Houston, email: [Muir.Houston@glasgow.ac.uk](mailto:Muir.Houston@glasgow.ac.uk) |