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**Are you interested in being a public advisor for a research study about the sharing of patient data?**

We are carrying out a study exploring the way that information about patients is transferred between the NHS and local government, in order to help them plan future services most effectively (please read Plain English Summary below).

We are looking for five people to join a public advisory group to help with the study.

**Who do we want to join the advisory group?**

We are looking for members of the public who are interested in the way that patient data is shared between different organisations in the UK.

We try to get a mix of different types of people in the group in terms of age, gender and background, so younger people and ethnic minorities are particularly welcome.

This opportunity would be ideal for people who are new to a public advisory role, as you do not need knowledge of any particular health problem or services.

**What will I be asked to do?**

You will join a public advisory group and come to online meetings. At the meetings we will ask for your thoughts and comments on the way that we are carrying out the study. We will ask for your help designing information for members of the public.

**How much time is needed?**

We are expecting that there will be three virtual group meetings between May this year and March next year. These meetings will last between 1 – 1.5 hour. Towards the end of the study there may be the opportunity to help with producing summary materials and presentations/short videos etc. This is optional, and only if you would like to do it.

**Will I be paid?**

We offer payment for your time. This is usually £25 per hour.

**When will it start?**

We are expecting the first online meeting will take place in May.

**Optional training**

Members of the group will be offered an optional 1-hour, ‘Introduction to health economics’ training session. They will also have access to two free e-learning courses.

**How do I apply?**

If you are interested in joining the group please let us know **by email to**

* Why are you interested in the topic of patient data sharing
* Whereabouts in the country do you live
* Are you in the age bracket 18-25, 26-40, 41-60, or over 60
* Do you have any background experience which might be particularly relevant?

**s.k.baxter@sheffield.ac.uk**

In the email **please include:**

**Or** go to <https://scharr.eu.qualtrics.com/jfe/form/SV_5au9HghCda7gaJ8>



* You will receive a confirmation email to let you know we have received your response.
* We will look at everyone who has offered to help, and try to choose a good mix of different experiences and people living in different places. We will let you know if we are inviting you to join.
* If there is no opportunity for you this time, we will ask whether you might be interested in being contacted about other groups in the future.

**Plain English Summary of the research**

**Background**

In England, many services that are paid for using taxpayers’ money are decided on and funded by local government such as Local Authorities (LAs) and Clinical Commissioning Groups (CCGs). LA’s are responsible for publicly funded social care (e.g. home-based services) and some public health services (e.g. sexual health services). CCG’s are responsible for funding most NHS services in local areas. All local decision makers aim to fund services which promote and protect health and prevent ill health in their locality. At the same time, they want to provide ‘value for money’ for taxpayers.

Such services and local decision makers often collect data to inform their processes. This data is used to support the services provided for individuals, but also for administrative reasons. This data could be used more often to help inform improvements to current services and funding of new services. This data could include potentially personal and sensitive information. As a result, it is important that such data is protected and only used or shared in circumstances when there is a clear and legal reason that would benefit the public.

**What do we hope to achieve?**

We hope to understand:

- what data is available to local decision makers;

- how they currently use it;

- how data could be used and potentially shared with parties who want to use it to benefit the public.

We hope to explain how to best use and share data legally with clear reasons for its use. An example would be to help local decision makers calculate which services are considered ‘value for money’ and which are not. We hope that this will allow local decision makers to make the best use of money available to them.

**How do we intend to achieve it?**

We will first identify examples of when data has been used and legally shared to inform local decision making. We will then produce a detailed list of what data these local decision makers have available. These examples and data will then be discussed with people who work within the LAs and CCG – we have already identified people who are happy to be involved in our proposed project. This will allow us to further explore things to consider when using such data to inform local decision making. We will then explore and describe ways this data could be used to calculate what services are potentially providing ‘value for money’ when producing benefits for the public in local and regional areas. We will also explore and describe how the use of such information could be made more transparent and understandable for the public.

**How long will this project take and what will we produce?**

We will complete the project within 10 months in line with the National Institute for Health Research request. We will produce a report and slide pack in collaboration with the Universities, LA’s, CCG’s, and PPI members of this research group. We will be share findings nationally through our existing relationships and the NIHR groups.

**Patient and the public involvement in the project**

A lay co-applicant has helped to develop the research proposal and will be involved throughout the duration of the project. We will set up a public advisory group to meet with the research team and share their views.

**How will this research change health and social care?**

We believe that our research could start to change and improve how researchers and local decision makers use locally available data to decide which services to fund to benefit communities