Use of registry data in the UK

In the UK, the data sought for this project’s objectives will involve review and assessment of routinely collected data (i.e. will not involve any data collection beyond what is currently done as standard practice), such as is collected by national registries including those overseen by NHS Digital. This will include individual patient level data concerning both the occurrence and timing of any deaths and cancers, as well as data regarding in-patient hospitalisations including: major cardiac events (such as heart attacks), strokes, procedures to open blocked arteries, advanced kidney disease, admissions to hospital with acute kidney damage and infections; all of which are classed as ‘personal sensitive data’ as per the General Data Protection Regulation (GDPR) (Article 9(2)(j)).

In order to obtain this data from NHS Digital, identifiable data from the participants in the SHARP trial (NHS Number and Date of Birth supplied during the trial to NHS Digital from the Oxford researchers) is used to trace and link to Hospital Episode Statistics data, Office for National Statistics mortality data (which includes cause and date of death) and cancer registry data for each individual. NHS Digital remove directly identifiable data including NHS number, name, address and date of birth before supplying the data back, along with a member number (which is unique to the participant) to the researchers at the University of Oxford.

The data received by the University of Oxford will be in a format to ensure that UK SHARP study participants are not directly identifiable to the University of Oxford researchers. The data does contain the unique member number which could be used to link to identifiable data held from the SHARP trial. However, the researchers neither intend to use the data to re-identify nor have any requirement to re-identify participants for this particular project.

The data will be held securely at the University of Oxford and analysed by appropriately qualified clinicians and statisticians. The data will only be used to address the study’s listed objectives and will not be shared with any third parties. The data controller for this project is the University of Oxford and the legal basis for processing is classed as 'task in the public interest' in accordance with the GDPR (Article 6(1)(e)). The data will be retained for a period of 25 years following completion of the study.

Should you want further information or do not wish for your data to be used in this way, please inform the SHARP team contacting us on telephone number 01865 743743 or by writing to:

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