

## ISCOMAT Study Update June 2017

First of all, many thanks for agreeing to be part of the ISCOMAT study. We hope you are continuing to recover after being in hospital.

If you agreed to be interviewed, you will have been visited by Hanif or Beth to discuss your experiences with your medicines since leaving hospital. Many thanks for your time taking part in those interviews. You may also have taken part in one of our four co-design groups working on improving services.

We are now entering a new, exciting phase of our study during which we will be using a set of tools developed by patients and staff in the co-design groups to improve how services for patients could be improved.

### 1. Information collected for the study

You might remember that when you joined the study you agreed to our researchers collecting some information from your medical notes, from your GP practice, from an organisation called National Institute of Cardiovascular Outcomes Research (known as NICOR), and from a place called the Health and Social Care Information Centre (known as the HSCIC) which holds information from all the NHS hospitals in England. HSCIC recently changed its name to NHS Digital.

We want to make sure you know what we plan to do, so here is an update to the information we gave you when you signed up for the study. This information is relevant

people who gave their consent for the 'patient pathway' part of the study, which involved keeping a diary and being interviewed, and to those who only gave their consent for us to access their data.

### How will you access my data?

Your medical records are held electronically by your GP practice and your hospital. Different systems are used to hold the data and we would like to obtain certain data from these systems which researchers think is important to your heart condition. Some information may be duplicated in the different systems, but some data may only be on one which is why we need to use the different systems. If we cannot find the data in the electronic systems, a researcher will go directly to the hospital or GP practice to try to obtain the data.

We will share your identifiable data with the following providers to obtain data relevant to your heart condition, the care you have received and medications:

#### **NHS Digital)**

NHS Digital (formerly known as The Health and Social Care Information Centre) holds the records of all patients admitted to NHS hospitals in England – this data is known as 'Hospital Episode Statistics' or 'HES' and includes data such as the date of an admission to hospital and the reason for admission.

#### **Office for National Statistics**

**(ONS):** The ONS holds data on the UK population including data on the

date and cause of death. This data is obtained via the HSCIC.

**NICOR:** The National Institute for Cardiovascular Outcomes Research (NICOR) collects clinical information from hospitals across the UK on care received by patients who are admitted to hospital because of their heart disease.

**Primary Care Data Provider:** Most GP practices use a system provided by TPP (SystemOne) or EMIS Health to record information about your health and medications.

**Community pharmacy records:** Most community pharmacies electronically store limited information about the medicines they dispense to you.

A full version of the current patient information leaflet is available for download from:  
[www.bradford.ac.uk/iscomat](http://www.bradford.ac.uk/iscomat)

Having read this, if you do not wish us to go ahead and gather this data, please contact the study co-ordinator using the contact details on Page 2.

### Confidentiality

Please remember that the information will collect about you will be safe and no-one apart from the research team will see it. Any results from the study will be completely anonymous.

## 2 Keeping you informed about the study results

Once we have finalised the recommendations made for improvements to care by patients and staff members we will send you a

summary of the results, unless you ask us not to.

You don't need to do anything if you would like to receive these but if you change home or email address please let us know (see study contacts on Page 2).

We also hope to publish the results in a journal next year and present our progress at conferences and meetings.

## 3 Contact us

If you have any questions about the ISCOMAT study or you wish to tell us that you do not wish us to link your data, or you do not want to hear about the results, please contact the study co-ordinator.

### Study Co-ordinator

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Remember, you should contact Beth if:

- You don't want us share your identifiable data to allow us to link your data now that you have read this update.
- You don't want to hear about the study results.

**Thank you for being part of the ISCOMAT study**  
[www.bradford.ac.uk/iscomat](http://www.bradford.ac.uk/iscomat)