# Embedded Project stand-alone document 3 Participant information sheet

UCL Research Ethics Committee Approval ID Number: \_\_\_11793/001\_\_ Version 1 Jan 2018 IRAS 241442

#### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### Title of Study: Embedded models of knowledge co-production in the NHS.

Department: Primary Care and Population Health Name and Contact Details of the Researcher(s): [to be inserted] Name and Contact Details of the Principal Researcher: Professor Martin Marshall, Department of Primary Care and Population Health, UCL Medical School, Upper 3<sup>rd</sup> Floor, Royal Free Campus, Rowland Hill Street, London, NW3 2PF martin.marshall@ucl.ac.uk

## Embedded models of knowledge co-production in the NHS

# **Participant Information**

#### Invitation to participate in our project.

We would like to invite you to participate in this research project. Before you decided it is important for you to understand why the research us being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### The project's purpose: aims and benefits of this research

Managers and clinicians in the NHS are under growing pressure to improve and redesign services in a way that both improves health outcomes and controls costs. There is huge potential for health services research to make a larger contribution to this process but there is a disconnect between what is known about how best to design and deliver high quality health services and what actually happens in practice. This has challenged policy makers, academics and front-line staff for several decades.

A number of different approaches have been devised to address this issue. One approach involves 'embedding' research expertise within health service settings so that researchers, managers, clinicians and service users can work together to co-produce knowledge. Relatively little is known, however, about whether and how these embedded initiatives support knowledge coproduction, service redesign or service improvement, or how best to design and implement them.

This research is designed to address these issues. It has two main aims. The first is to understand more about initiatives in which researchers are embedded within health service

settings. The second is to produce practical guidance on the design and implementation of these initiatives for managers and clinicians in the NHS, their academic partners and people who use services. As a result of the research we will be able to explain how embedded researchers support knowledge co-production and provide clear guidance on how best to design and implement initiatives so that researchers, managers, clinicians and service users can co-produce knowledge.

The research is divided into four areas of work:

- 1) Reviewing the literature on embedded research and knowledge co-production
- 2) Identifying and describing embedded researcher initiatives in operation in the UK
- 3) In-depth case studies of four embedded researcher initiatives
- Devising recommendations, guidance and training templates for those interested in developing and using embedded researcher initiatives

#### Why have you been chosen to participate?

We are inviting all those with a role in an embedded research initiative in the UK to take part in this study. We are inviting you because we think you are part of an embedded research initiative.

#### Agreeing to take part

It is up to you to decide whether or not to take part. You are under no obligation to take part.

If you have been invited and agree to take part in activity 1 (providing written information as described below), you do not need to sign anything and can simply send us the relevant information. If you have been invited and agree to take part in any of the other activities we will ask you to complete a consent form.

If you have completed a consent form and later decide that you do not want to continue taking part, you can withdraw from the study by contacting us at any time. You do not have to provide a reason. If you decide that you no longer want to take part, we will not collect any further information from or about you but you will be unable to withdraw any information that you have already provided.

#### What we are asking you to do if you agree to take part

We are inviting participants to take part in one or more of the following activities. Please see the accompanying email for details of which activities we are inviting you to participate in.

- 1) Providing written information and documentation about the embedded research initiative you are part of
- 2) Take part in a short telephone interviews about the embedded initiative you are part of
- Take part in a half-day workshop to discuss embedded research and to co-produce data collection tools
- Take part in follow-up interviews about the embedded initiative you are part of and your patterns of networking
- 5) Complete a diary (or online journals) to record day-to-day embedded research activities
- Allow the research team to observe key activities being undertaken in the embedded initiative

Interviews will be recorded on a digital recording device and uploaded to a secure server at the University of St Andrews (activity 2) or University of Nottingham (activity 4). Interviews will be transcribed by a member of the research team or a transcription service who will be required to treat recordings as confidential. Transcriptions will be anonymised by the research team.

#### Possible risks and benefits

There is a risk that the time that you spend providing us with information may interfere with your other work. To reduce this risk we will try to make sure that taking part in this project fits in with the rest of your work and that any interviews take place at a time and place that are convenient for you. It is also possible that you will make critical comments about the work that you are involved in and this might offend your colleagues. We will minimise this risk by ensuring that whatever you tell us is dealt with in confidence (see 'How we will protect your identity and information' below).

The benefit of taking part is that you will be contributing to the development of new ways of increasing the impact of research on practice and therefore contributing to improvements in the care received by patients. It is likely that getting involved in this research will give you new insights into your own embedded work and that will help you to improve what you are doing.

#### What we will do with the information you provide

University College London is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information Martin Marshall PI for this study at <u>martin.marshall@ucl.ac.uk</u>

The Universities of St Andrews and/or Nottingham will collect information from you for this research study in accordance with our instructions.

The Universities of St Andrews and/or Nottingham will keep your name, and contact details confidential and will not pass this information to UCL. They will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, to oversee the quality of the study. Certain individuals from UCL and regulatory organisations may look at your research records to check the accuracy of the research study. UCL will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

The Universities of St Andrews and/or Nottingham and/or UCL will keep identifiable information about you from this study for 5 years after the study has finished.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

## Funding of our Research

Our research is funded by National Institute for Health Research (NIHR)

**Contact for further information and complaints Process** 

This project has been reviewed and approved by an ethics committee at University College London

If you would like to discuss the project further or have any questions at any time or complaint, please contact:

Professor Martin Marshall, Principal Investigator, UCL at martin.marshall@ucl.ac.uk

Dr Vicky Ward, Co-investigator, University of St Andrews at viw4@st-andrews.ac.uk

Professor Justin Waring, Co-investigator, University of Nottingham at Justin.waring@nottingham.ac.uk

If you feel that your complaint has not been handled to your satisfaction (e.g. by the PR or the supervisor) you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

You will be given a copy of the information sheet and, if appropriate, a signed consent form to keep.

Thank you for reading this information sheet and for considering taking part in this research.