INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: ***LRS-18/19-12587***

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study

An independent study exploring the local operation and impact of Healthwatch in England

Invitation Paragraph

We would like to invite you to participate in an interview and/or observational research about your views and experiences and routine practices related to the work of your local Healthwatch.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

We are carrying out an independent study to explore and enhance the way in which local Healthwatch work. In particular, we would like to hear about your work at Healthwatch, the activities that Healthwatch undertakes and the ways in which it maintains relationships with other key organisations and bodies.

With your help, our study will contribute to understanding and improving the way local Healthwatch organisations work by generating practical recommendations on how to ensure meaningful patient and public voice in the commissioning and provision of NHS services.

Why have I been invited to take part?

You are being invited to participate in this study because you work at a Healthwatch.

What will happen if I take part?

In order to keep any disruption to your work to a minimum, we are likely to use a mix of one-to-one, paired or group interviews. We will check with you first in which of those settings you are happy to be interviewed. If you decide to take part, we will arrange an interview with you at a time convenient to you. The interview may take up to 90 minutes, depending on the number of interviewees and the time you have available. With your permission, we would like to audio record the interview.

Our interviews will cover topics such as:

- your work at Healthwatch and your relationships within the organisation;
- your relationship with other key stakeholders (e.g. CCGs, NHS Trusts, local authorities, patients etc);
- your views on the challenges your local Healthwatch currently faces.

Some members of staff will also be invited to take part in observational research of routine practice. This will be a researcher 'shadowing' you, intermittently, for a part of your work day. The researcher will take notes of what s/he has observed. We will take care to arrange for observation to be at times and time periods convenient and comfortable for you and in a way that minimise interruptions to your work. For some staff, we might request a further observation of different routine practices as the study progresses. Our observations of practice will help us understand what is involved in the day-to-day work of your Healthwatch.

We may also ask permission to take photographs of routine group activities. No photographs will be taken of you during or immediately after interview.

We can provide you with a more detailed topic guide on request.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, we will ask you to sign a consent form before the interview begins and you will be given a copy of this consent form to keep. We will give you at least 48 hours to consider the information in this sheet before contacting you again to ask if you would like to take part.

What are the possible risks of taking part?

We believe there are no direct disadvantages to taking part. We appreciate that participating will take up some of your time and we will do our best to minimise any inconvenience to you. Our conversation with you will not touch upon sensitive, personal or potentially distressing matters.

What are the possible benefits of taking part?

Taking part in the study may not help you directly. But we hope to learn from your experience to make recommendations on how to optimise patient and public voice in NHS commissioning and service provision. We hope to generate insights into how Healthwatch works and this may be useful for you or your organisation.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

It is likely that other staff will know if you take part in an interview. However, everything you say will be treated as confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else. If you are interviewed with other members of staff, we will request that you respect confidentiality for each other.

We will anonymise all data. This means that if we use extracts from the interview or observation notes in any presentations or publications, we will not use your name, and we will do all we can to ensure neither you nor the Healthwatch you work for can be identified.

The information collected by the researcher (the audio recording of the interview and notes) will be kept locked in a secured location. If you appear in any photographs of routine group activities, these images will be pixilated immediately after taking to ensure that all personal and organisational identifiers are removed from the image.

To analyse the interviews in detail, we need to transcribe them (type up the full text of the interview word by word). If you agree, we will send the recording to a transcription company (outside of the University), who will do this task. We use a reputable company who have signed a confidentiality agreement. If you do not agree with us using a transcription company, you may still take part and the research team will transcribe the interview themselves.

King's 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.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways 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 here:
https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research.aspx

Individuals from King's College London and regulatory organisations may look at your research records to check the accuracy of the research study.

The only people at King's College London who will have access to information that identifies you will be members of the research team or people who are asked to audit the data collection process.

King's College London will keep identifiable information about you from this study for 7 years after the study ends.

Data Protection Statement

The data controller for this project will be King's College London (KCL). The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the King's College

London Data Protection Officer Mr Albert Chan info-compliance@kcl.ac.uk. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

You are free withdraw at any point of the study, without having to give a reason, by contacting the named researcher at the end of this information sheet. Withdrawing from the study will not affect you in any way. The default position would be that all data provided by you up to the point of withdrawal would not be used in the study. With your permission however, if you withdraw from the study, or if anything happens to you which means you are no longer able to give informed consent, we would like to continue to use any information you have given us up to that time. We will ask you for permission for this use if you withdraw but you are under no obligation to approve this request.

You can withdraw your data from the study up until July 2020, after which withdrawal of your data will no longer be possible due to our report-writing demands and timetable.

How is the project being funded?

The study is funded by the National Institute for Health Research's Health Service and Delivery Research programme (Study ID 17/05/110).

What will happen to the results of the study?

The results of the research will be used to build an evidence base of how Healthwatch works and will generate generalisable principles and recommendations. These will be disseminated for use by NHS managers, local and national Healthwatch and local authorities to improve the impact of local Healthwatch work in health care planning and provision. This will take the form of written and oral reports.

The research will be published by the National Institute of Health Research in the form of a publicly accessible report. It will also be published open access peer-reviewed academic journals.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Dr. Amit Desai
King's College London
Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care
57 Waterloo Road, London SE1 8WA

Tel: 07950252350

Email: amit.desai@kcl.ac.uk

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information: **The Chair, PNM Research Ethics Panel, rec@kcl.ac.uk**

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