**PARTICIPANT INFORMATION SHEET**

**PRACTITIONER INTERVIEWS WITH GP CANCER LEADS, GP MANAGERS, CARE COORDINATORS**

**University of East London**

Stratford Campus

Water Lane E15 4LZ

**Research Integrity**

The University adheres to its responsibility to promote and support the highest standard of rigour and integrity in all aspects of research, observing the appropriate ethical, legal and professional frameworks, obligations and standards.

The University is committed to preserving your dignity, rights, safety and well­being and, as such, it is a mandatory requirement of the University that formal ethical approval, from the appropriate Research Ethics Committee, is granted before research with human participants, human material, human data, personal and/or sensitive data, pre-existing data collected from humans without their knowledge of inclusion of the information in a research project or non-human animal commences.

The purpose of this Participant Information Sheet is to provide you with the information that you need to consider in deciding whether to participate in this research project.

**The Principal Investigator/Director of Studies**

Dr Darren Sharpe

Institute for Connected Communities

The University of East London

Stratford Campus, Water Lane

London, E15 4LZ

Tel: +44 (0)20 8223 2167

**The organisation that is supporting the research**

Saira Parker-Deeks

Programme Manager for Primary Care

NHS North East London (Cancer Alliance)

Part of North East London Health and Care Partnership

Unex Tower, 5 Station Street, London, E15 1DA

Email: saira.parker-deeks@nhs.net

The purpose of this Participant Information Sheet is to provide you with the information that you need to consider in deciding whether to participate in this research project.

**Project Title**

Evaluation of the North-East London Primary Care Network Facilitator Service for Cancer

**Project Description**

The purpose of this interview is to build evaluative evidence and insights into the Primary Care Network (PCN) Facilitator Service for Cancer commissioned by the North-East London Cancer Alliance. The PCN Facilitator Service for Cancer comprises of three full-time Cancer Facilitators and aims to support PCNs and primary care providers to deliver quality improvements, support early diagnosis of cancer and increase uptake of national cancer screening programmes across the 48 PCNs in the 7 boroughs of North-East London (NEL). The Cancer Facilitators provide practical support to deliver the NHS Long Term Plan to diagnose cancer at an earlier stage and the Early Diagnosis Primary Care Network Direct Enhanced Service (PCN DES) requirements.

The goal of the evaluation is to better understand the delivery processes and outcome/impacts of the service and the value of the Cancer Facilitator role. We hope this will help us to better understand the needs of primary care services when it comes to supporting early diagnosis of cancer and increasing the uptake of national cancer screening programmes. Your feedback will be used as part of the evaluation to help inform a business case and improve the service design for the Primary Care Network (PCN) Facilitator Service for Cancer.

All the information provided will be fed directly into the evaluation being undertaken by the Institute for Connected Communities based at the University of East London.

**If you are interested in participating**

Please inform the person who gave you this information sheet that you are interested to take part in the project.

**Whether you decide to take part**

If you agree to take part, you retain the right to withdraw from the interview at any stage for any reason. You just need to tell the team member of your decision. You will not be asked to explain the reasons for withdrawing.

**What will happen if you agree to take part:**

If you agree to take part in the interview you will be asked to sign a consent form and return it to a member of the research team; please email the completed consent form to Nora Morocza (N.Morocza@uel.ac.uk) or the Principal Investigator (D.Sharpe@uel.ac.uk). Alternatively, if you prefer to give oral consent your response will be recorded by a member of the team in the participant consent log. The interview itself will occur online or over the telephone (whichever is more convenient for you) on a day and time convenient to you and last no longer than 60 minutes. The interview will be audio recorded with your permission.

We will ask you questions about your views on the PCN Facilitator Service for Cancer and your experience of working with the Cancer Facilitators.

**Whether there are any risks involved (e.g., side effects from taking part) and if so what will be done to ensure your wellbeing/safety:**

The topics/themes that will be discussed in the interview should not involve any risks (physical or psychological).

All the information provided in the interview will be pseudonymised and remain confidential unless information is disclosed which suggest that an individual is at risk of harm. In such cases, you will be informed by the team member that the information will be shared with the research safeguarding lead who will take the necessary steps to ensure that the person at risk gets help.

If you become distressed or upset at any point during the interview you can stop at any time without giving an explanation. Also, the team member might decide to stop the formal part of the interview and double check that you are fine to continue.

**Confidentiality of the Data**

The recordings and partial transcripts of the interview will be kept in secure password protected server to ensure confidentiality. All interview recordings and partial transcripts will be partially anonymised and only show the unique ID label given to interview participants. Before sharing results of the evaluation, data will be pseudonymised to protect your identity. No individual healthcare practitioner or other staff member will be identifiable in our report, however because the sample size is small, we cannot guarantee that information provided is not traceable back to your service/back-office function.

Your confidentiality will be maintained unless a disclosure is made that indicates that you or someone else is at serious risk of harm.

All data collected as part of the evaluation will be destroyed up to 24 months following the end of the study in accordance with the University’s Data Protection Policy.

**Data Protection statement**

In compliance with the General Data Protection Regulation (GDPR) the University’s lawful basis for the processing of personal data collected, used and retained for research purposes is the ‘public task’ condition, GDPR Article 6 (1) (e). Therefore, the University does not rely on consent to process your personal data. However, the University will seek your consent to participate in this research project. Please see the following link for more information: [Data protection – University of East London (UEL)](https://www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection)

**Location**

The evaluation is coordinated from University of East London, Stratford Campus, Water Lane, E15 4LZ.

**Disclaimer**

Your participation in this study is voluntary, and you are free to withdraw at any time during the research. Should you choose to withdraw from the project you may do so without disadvantage to yourself and without an obligation to give a reason. Please note that your data can be withdrawn up to the point of data analysis – after this point it may not be possible if your data is anonymised.

Ethical approval for the research project has been granted by the Ethics and Integrity Sub-Committee (EISC).

If you have any concerns regarding the conduct of the research in which you are being asked to participate, please contact:

Catherine Hitchens, Ethics, Integrity and Compliance Manager, Office for Postgraduates, Research and Engagement, University of East London, Docklands Campus, London, E16 2RD. Telephone: 020 8223 6683. Email: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk)

For general enquiries about the research, please contact the Principal Investigator

on the contact details at the top of this sheet.

**Consent Form**

**Project title**: Evaluation of the North-East London Primary Care Network Facilitator Service for Cancer

**Names of researchers**:

Dr Darren Sharpe

Nora Morocza

Liliana Paola Galicia Mesa

Please tick as appropriate:

|  |  |  |
| --- | --- | --- |
|  | YES | NO |
| I have read the information leaflet relating to the above research project in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research project have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me. |  |  |
| I understand that my interview will be audio recorded, and I give my consent. |  |  |
| I understand that my involvement in the research project, and particular data from this research, will remain strictly confidential as far as possible. Only the researchers involved in the research project will have access to the data. *(Please see below)* |  |  |
| I understand that maintaining strict confidentiality is subject to the following limitations:  Because the sample size is small, we cannot guarantee that the information provided is not traceable back to your service/back office function.  Confidentiality will be maintained unless a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authority. |  |  |
| I give my consent to use anonymised quotes in publications. |  |  |
| I give my consent to anonymised quotes in reports and journal papers produced as part of the research. |  |  |
| I understand that the data collected for the research project will be anonymised/pseudonymised before it is published. (Pseudonymised data can no longer be attributed to an individual without the use of additional information). |  |  |
| I understand that the University’s lawful basis for processing my personal data collected, used and retained for research purposes is the ‘public task’ condition and the University does not rely on consent to process my personal data. |  |  |
| I understand that the published results of the research project will be accessible in the public domain and may be deposited in an open access data repository. |  |  |
| I understand that the published results of the research project will be accessible in the public domain and may be re-used, republished or reanalysed by others in future research. |  |  |
| I give my permission for the research team to use the data that I have provided in future research projects which may be made publicly available. |  |  |
| I give my permission for the research team to retain my personal contact details and contact me regarding participation in future research projects. |  |  |
| It has been explained to me what will happen once the research project has been completed. |  |  |
| I understand that my participation in this research project is entirely voluntary, and I am free to withdraw at any time during the research without disadvantage to myself and without being obliged to give any reason. I understand that my data can be withdrawn up to the point of data analysis, and that after this point it may not be possible if the data is anonymised. |  |  |
| I hereby freely and fully consent to participate in the research project which has been fully explained to me and for the information obtained to be used in relevant research publications. |  |  |

Participant’s Name (BLOCK CAPITALS) …………………………………………………………………….

Participant’s Signature ………………………………………………………………………………………..

Investigator’s Name (BLOCK CAPITALS) …………………………………………………………………..

Investigator’s Signature ………………………………………………………………………………………

Date: ………………………….

**Annexe 3**

**Ethics and Integrity Sub-Committee Privacy Notice**

The University of East London adheres to Data Protection Act 2018 (DPA) and UK General Data Protection Regulation (GDPR) 2018.

UK GDPR states that personal data is any information that can be used to identify a living person directly or as result of combinations of data relating to or being about a person. As a participant in a research project the University has a responsibility to inform you how we are collecting, using and managing your personal data. Fully anonymised data is not governed by UK GDPR, however data that has had identifiers removed or replaced to pseudonymise the data is classed as personal data for the purposes of UK GDPR.

The Data Protection Act 2018 is based around seven principles which grants a person specific rights in relation to their personal information and places certain obligations on those organisations that are responsible for processing the information. The seven principles govern the collection, use, retention, transfer, disclosure and destruction of personal data. These principles are followed by the University of East London when processing personal data:

* **Lawfulness, Fairness and Transparency** – Personal data shall be processed lawfully, fairly and in a transparent manner;
* **Purpose Limitation** – Personal data shall be collected for specified, explicit and legitimate purposes and not used for other purposes where such use would be incompatible with the initial purpose;
* **Data minimisation** – Personal data shall be adequate, relevant and limited to what is necessary for the purpose it was collected;
* **Accuracy** – Personal data shall be accurate and, where necessary, kept up to data;
* **Storage Limitation** – Personal data shall be kept in a form which permits identification of data subjects for no longer than is necessary;
* **Integrity & Confidentiality** – Personal data shall be processed in a manner that ensures appropriate securing including protection against unauthorised or unlawful processing, and against accidental loss, destruction or damage to that data;
* **Accountability** – The University must be able to demonstrate how we comply with the law by ensuring that we have documented process, procedures and policies in place.

Further guidance on data protection can be found on the University’s website: [Data Protection | University of East London (uel.ac.uk)](https://www.uel.ac.uk/about/governance/data-protection)

**Information Rights**

Every participant in a research project has rights associated with how their personal data is used and managed. Where an individual makes a request related to any of their information rights the University will consider each request in accordance with all applicable laws and regulations.

The Data Protection Act, 2018 gives you more control over your personal data by strengthening your information rights. These are:

* The right to be informed;
* The right of access;
* The right to rectification;
* The right to erasure (aka. The right to be forgotten);
* The right to restrict processing;
* The right to data portability;
* The right to object;
* Rights related to automated decision making and profiling.

Please note, that none of above are absolute rights. More information about each of these rights is provided on the Information Commissioner’s Office website: [A guide to individual rights | ICO](https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/individual-rights/individual-rights/)

You can submit an Information Rights request to the University quickly, easily and free of charge by completing an [Information Rights Request form](https://www.uel.ac.uk/sites/default/files/6342.pdf) and emailing the form to the [dpo@uel.ac.uk](mailto:dpo@uel.ac.uk). A request can also be made directly to the University.

Should you have any concerns about the conduct of the research project or management of your personal data please contact the Ethics, Integrity and Compliance Manager, Catherine Hitchens: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk) or the Data Protection Officer: [dpo@uel.ac.uk](mailto:dpo@uel.ac.uk)

**Appendix**

ICO website: [Home | ICO](https://ico.org.uk/). Accessed on 6th November 2024