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Participant Information Sheet

Service Users – Focus Group Discussions

The title of the research study:

Advancing Skin Cancer Care: Investigating and Co-Creating a Nurse-Led Model of Service Delivery

Invitation to take part

You are being invited to take part in research. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Ask the Chief Investigator (Leila Kattach) if there is anything that is not clear or if you would like more information. The Chief Investigator's email address is at the end of this document. Please take the time to read the following information carefully and discuss it with others if you would like to, and then decide whether or not you wish to take part.

What is the purpose of the project?

This PhD research addresses the increasing prevalence of skin cancer across England and the shortage of dermatologists available to meet rising referral rates. Early detection of skin cancer is crucial, yet the demand for timely, high-quality care presents a challenge for existing healthcare services. To help bridge this gap, this research aims to develop a viable nurse-led model of service delivery for skin cancer care for implementation within the NHS in England. This model, designed collaboratively with both service users and specialist skin cancer clinicians (physicians and nurses), seeks to improve service delivery by making skin cancer care more accessible, efficient, and patient-centred.

Study Design

The study uses a mixed methods approach, conducted in two phases:

- **Phase One**: a questionnaire survey of nurses who provide skin cancer care across the United Kingdom and Crown Dependencies in various healthcare settings.
- **Phase Two**: focus group discussions with:
    - **a. Service Users**: individuals referred into secondary care in England on a suspected skin cancer referral pathway regardless of diagnosis.
    - **b. Specialist Skin Cancer Clinicians**: physicians and nurses who deliver skin cancer care in England.

The focus groups enable complex discussions, gathering insights from patients and clinicians on their experiences, concerns, and recommendations. This collaborative approach helps surface valuable perspectives that may not emerge through surveys alone, ensuring the final model of care is comprehensive and responsive to the needs of all stakeholders (patients, clinicians, and health care organisations) in skin cancer services.

Who is organising/funding the research?

The Chief Investigator, Leila Kattach, is a PhD student and Advanced Nurse Practitioner employed by Bournemouth University (BU) and holds an honorary contract with University Hospitals Dorset NHS Foundation Trust (UHD). This PhD research is funded by BU and UHD. Leila is supported by a practice supervisor and a team of academic supervisors, who comprise the research team and they are:

1. Dr Heidi Singleton. Senior Lecturer. Bournemouth University.
2. Professor Steven Ersser. Professor of Nursing and Dermatology Care. Bournemouth University.
3. Professor Debbie Holley. Professor of Learning Innovation. Bournemouth University.
4. Dr Ian Pearson. Consultant Dermatologist. University Hospitals Dorset NHS Foundation Trust.

For more information, please visit the following links:

- **Nurse-led Model for Skin Cancer Detection Project**
- **Leila Kattach's Staff Profile**

Why have I been invited?

You have been invited because of your lived experience of receiving an assessment for suspected or actual skin cancer in England. Your contribution is crucial to ensure that health research is conducted 'with' you or 'by' you, making it more relevant and impactful.

Can I take part?

You can take part if:

- you were referred by your GP on a fast-track/two-week wait/suspected skin cancer referral pathway because of a skin lesion that might be skin cancer
- you are 18 years or over
- you can read and speak English well enough to join the discussion and give informed consent
- you want to take part and can sign the consent form
- you are happy for the session to be audio and video recorded (only the research team will access recordings)
- your assessment or treatment took place in an NHS dermatology service in England.

It’s helpful (not required) if you have taken part in research before.

You may also choose to give extra consent to share a photo, correspondence, or a named opinion piece. If you choose this, we will ask you to sign an additional consent form.

What we mean by:

- **Fast-track/two-week wait/suspected skin cancer referral pathway:** your GP sends you to a specialist to be seen quickly because of concern about skin cancer.
- **Skin lesion**: a visible change on the skin (for example a new or changing mole, lump, sore, or discolouration).
- **Informed consent**: you decide to take part after you understand the purpose, what's involved, the risks and benefits, and how your data will be used.

Should I avoid taking part?

You should not take part if:

- talking about your diagnosis or care would be too distressing for you or could affect your wellbeing.

If I'm joining online

If you plan to join online, you'll also need:

- a smartphone, laptop, or desktop with internet access
- the basic skills to read emails, join a video call, and use Microsoft Teams (we can guide you)
- a private, quiet room for the session.

Please do not join online if:

- you do not have a suitable device or internet and cannot join even with guidance.
- you cannot find a private space, which makes it hard to protect your privacy.

Not sure if you're eligible?

You don't need to decide on your own. Email the Chief Investigator (Leila Kattach) and she will check your eligibility with you.

What would taking part involve?

Your involvement in this research project could include one or more of the following activities:

1) Participate in an online or face-to-face focus group* discussion (lasting a maximum of 90 minutes), where you will answer questions and offer feedback on topics related to this PhD research. Your input is valuable because of your lived experience of skin cancer or accessing care in England, just like all participants. However, remember that your experience is unique to you, and we want to hear what matters most to you. *The researcher will aim to find a mutually convenient time for the discussion.*
2) Produce written feedback as requested by the Chief Investigator or respond to messages asked by the Chief Investigator on Microsoft Teams.

** A focus group is a gathering of people who come together to discuss a particular topic, product, or idea. These discussions are led by a facilitator (the Chief Investigator) who asks questions to understand participants' opinions, experiences, and feelings. The goal is to gather insights and feedback to help improve or develop something, like a product, project or in this case nurse-led model of service delivery for skin cancer.*

The purpose of involving service users in a focus group is to discuss and contribute to the development of a nurse-led model of service delivery for skin cancer. By sharing your personal experiences and insights, you can help ensure that the proposed service is patient-centred, effective, and meets the needs of those accessing care.

During the session, you will be asked to:

1. Share your thoughts, opinions, and preferences regarding the components of an acceptable and viable nurse-led model of service delivery for skin cancer care.
2. Discuss and evaluate model components (options appraisal) to determine the most effective and feasible approach.

3. Work together to reach a consensus on the final components of an acceptable and viable nurse-led model of service delivery for skin cancer care.

Ground Rules for Focus Group Discussions

To ensure a safe and respectful environment, we ask that you respect others' privacy and do not share what is discussed outside the group.

- **Confidentiality:** Everything shared in the group will be treated as confidential and anonymised. We ask that participants also respect each other's privacy and do not share what is discussed outside the group.
- **Limits to Confidentiality:** In rare cases, confidentiality may need to be broken. This could include situations where you disclose something that suggests a serious risk to yourself or others, a safeguarding concern, or involvement in a serious crime. Where possible, the Chief Investigator will discuss this with you before taking further action.
- **Respect:** Please allow others to speak, avoid interrupting, and respect differing views. Everyone's experience is valid.
- **Right to Withdraw:** You may leave the group at any time, skip any question, or switch off your camera if you feel uncomfortable.

If you have any concerns after the session, you can contact the Chief Investigator using the contact details provided.

Format:

There will be a short introduction at the beginning of each focus group discussion. Discussions will likely be held for a minimum of 1 hour and a maximum of 1.5 hours. The focus group meetings will be conducted either online (via video conferencing using Microsoft Teams) or face-to-face, depending on participant preferences and location. If the meetings are face-to-face, they will be held at either Christchurch, Royal Bournemouth, or Poole Hospital in Dorset. All meetings, whether they are face-to-face or online will be recorded (video and audio) and transcribed by the Chief Investigator whilst adhering to the University Research Data Policy (BU 2022) found at this link: https://libguides.bournemouth.ac.uk/research-data-management and the Code of Good Research Practice (BU 2020) found at this link:

https://intranetsp.bournemouth.ac.uk/policy/BU%20Code%20of%20Good%20Research%20Practice.pdf. Transcriptions will be held by the Chief Investigator on a password-enabled laptop within the Bournemouth University secure server. The Chief Investigators' supervisory team will also have access to the data collected as they are members of the research team. At the end of the study, the video recordings will be deleted, and the transcriptions anonymised and stored.

Frequency:

Participants will each be requested to attend one focus group meeting, and the time, date and location will be discussed and agreed upon collectively.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, please read this information sheet, and sign and keep a copy of your participant agreement form (Document ID: PAFSU01). A copy of all documents will be sent to your email address by the Chief Investigator at the start of the study. We want you to understand what participation involves before you decide on whether or not to participate. Your medical care will not be affected by your decision, and we will not contact your dermatologist or general practitioner (GP) without your permission. However, we will request your GP's contact information in case of any concerns or emergencies. If you or any family member have an on-going relationship with Bournemouth University or the research team, e.g., as a member of staff, as a student or other service user, your decision on whether or not to take part (or continue to take part) will not affect this relationship in any way.

Can I change my mind about taking part?

Yes, you can stop participating in study activities at any time and without giving a reason. To withdraw you can send an email to the Chief Investigator (Leila Kattach) stating that you wish to withdraw. The Chief Investigator's contact details are provided at the end of this document.

Will I be reimbursed for taking part?

You will receive a £25 Lifestyle gift card as a thank you for taking part in one focus group.

- If you are asked to answer extra questions outside of the focus group, you will receive an additional £5 for every set of three questions answered.
- If you attend a face-to-face focus group, you will also receive up to £5 to cover travel expenses.
- For online focus groups, the £25 covers any incidental costs such as electricity.

The gift card will be sent within 6 weeks of your final contribution. Only participants who complete the focus group will receive payment.

What are the advantages and possible disadvantages or risks of taking part?

For taking part, we would like to offer you an honorarium (a “lifestyle” gift card) that will be provided as a token of appreciation for your participation in this research project. Your input will directly influence the direction of our research, making it more relevant and impactful. More specifically, your input will help to improve patient outcomes for people accessing skin cancer services by facilitating their access to information and tailoring services to meet their needs. The research may also influence the care you receive particularly if you receive long-term follow-up. You may also empower yourself and others by actively participating in research that directly impacts your community. You will have the opportunity to connect with like-minded individuals who share an interest in improving skin cancer care.

Participation will involve being asked sensitive questions, which may make you feel emotional during or after each meeting, for example thinking about checking your skin may have advantages or disadvantages for you and the way you feel about it, or you may have experienced a different care pathway to other participants of the focus groups that you feel satisfied or dissatisfied about. For people who have received bad news regarding their diagnosis, a group session may trigger certain thoughts and feelings, which may cause distress. Therefore, it is advised that everyone downloads and keeps a copy of the help and support information, which you can find at the end of this document or by following this link: Study help and support information 31st March 2024.pdf (bournemouth.ac.uk). You can ask the researcher for another copy of this information at any point during the research project. You can decide at any point to leave the study which can include during one of the online meetings. If you do experience distress you can switch off your camera, leave the meeting and direct message or email the researcher to advise as to whether or not you will continue with the meeting. Once the online meeting is complete the Chief Investigator will contact you directly and offer you support accordingly. You can leave the study at any point.

Will I be recorded, and how will the recorded media be used?

We record the focus group discussions, so your views are captured accurately. The meetings will be recorded with video and audio. The reason for video recording is to ensure that the Chief Investigator does not miss important verbal or non-verbal communication. The audio and video recordings of your activities made during this research will be used for analysis and the transcription of the recording(s) may be used for illustration in conferences, presentations, lectures, and publication. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings as these will be stored by the Chief Investigator (Leila Kattach) on a Bournemouth University password-protected server. As these recordings will include other participants of the focus groups, if you were to withdraw, the content of these recordings will still be used. Pictures of you and your personal information will be used only with your written permission otherwise you will remain anonymous throughout except to members of your focus group if you choose to keep your camera on or attend a face to face session and share your real name. All participants will otherwise be given a pseudonym.

How will we use information about you?

We will need to use information from you for this research project.

This will include your:

- Name (known only by the research team).

- Email address (known only by the research team).
- Diagnosis or reason for being referred on the suspected skin cancer pathway in England by providing a clinic letter (checked by the Chief Investigator and known only by the research team).
- NHS Trust or service where you received care (known only by the research team).
- Equality, Diversity and Inclusion (EDI) data (for example age, gender, ethnicity, disability, sexual orientation, religion or belief), which will be known only by the research team. *Providing EDI data is voluntary and will only be used in an anonymised form to ensure the research includes a wide range of perspectives* (known only by the research team).

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead and you can have a pseudonym during the focus group discussions.

Bournemouth University is the sponsor of this research with the support of University Hospital Dorset NHS Foundation Trust.

Bournemouth University is responsible for looking after your information. We will share your information related to this research project with the following types of organisations:

- Only the members of the research team based at University Hospitals Dorset NHS Foundation Trust, an NHS Teaching Hospital, will access your data in an anonymised format.

International transfers

- Your data will not be shared outside the UK.

How will we use information about you after the study ends?

- Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for a maximum of 10 years. At that point, the study data will be fully anonymised and securely archived.

Archiving will involve the study data being transferred into Bournemouth University's Data Repository (BORDaR), which is open to the public. BORDaR (Bournemouth University's Data Repository) can be found by following this link: https://bordar.bournemouth.ac.uk.

We will keep all information about you safe and secure by:

- Storing electronic data on encrypted, password-protected systems.
- Keeping paper records in locked storage.
- Using pseudonyms instead of your real name in research findings.
- Restricting access to personal data to authorised researchers only.
- Collecting only the minimum information needed.
- Following Bournemouth University's data protection and ethics policies.
- Not sharing your information outside the research team unless required by law.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- You have the right to ask us to access, remove, change, or delete data we hold about you for the purposes of the study.
- You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

- No personally identifiable information will be included without your written permission.
- If your picture or information has been included in published documents such as an article published for a journal it cannot be withdrawn once published.

Where can you find out more about how your information is used?

- Read Bournemouth University's Research Participant Privacy Notice: https://www.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy/research-participant-privacy-notice
- Email the Chief Investigator, Leila Kattach: lkattach@bournemouth.ac.uk

When can I receive an update on the findings?

You may request updates on the research project. These updates will be limited and will not be shared publicly unless agreed by the Chief Investigator in writing by email. Data collection is expected to conclude in September 2026, with no additional data collection planned beyond this date. Conference presentations, posters, and publications sharing the findings are likely to be produced after the completion of this PhD research, which is not expected to extend beyond September 2027.

What to do now if you would like to participate

If you meet the eligibility criteria and would like to take part, please email the Chief Investigator, Leila Kattach, at lkattach@bournemouth.ac.uk.

Contact for further information

Primary contact: If you have any questions or would like further information, please contact Leila Kattach (PhD student and Advanced Nurse Practitioner) at: lkattach@bournemouth.ac.uk

This research project is being undertaken under the supervision of Dr Heidi Singleton: hsingleton@bournemouth.ac.uk Senior Lecturer, Lecturer with the Centre for Wellbeing & Long-Term Health (Bournemouth University).

In case of complaints

Any concerns about the study should be directed to Professor Jane Murphy the Deputy Dean for Research & Professional Practice (for the faculty of Health and Social Sciences at Bournemouth University) by email to: researchgovernance@bournemouth.ac.uk

Finally

If you decide to take part, you will receive a copy of this information sheet and your signed consent form to keep.

Thank you once again for your time and interest in supporting this important research.