ACTIOHN
ACTIVITY AS MEDICINE - HEAD AND NECK

Local headed paper

MAIN STUDY CLINICIAN INFORMATION SHEET

Activity as medicine in oncology for head and neck

The ACTIOHN Study

You are being invited to take part in a research study. Please ask us if there is anything that is not clear in this sheet or if you would like more information.

What is the purpose of the study?

We would like to interview health professionals and exercise specialists about the ACTIOHN study so we can learn how to improve studies like this in the future.

Why have I been chosen?

You have been chosen because you have had some involvement in ACTIOHN Interview Study as part of your role. Whether your involvement is direct (e.g. working with ACTIOHN patients) or more indirect (e.g. discussing ACTIOHN with patients or colleagues) your viewpoints are very important to us. In all, we are hoping to interview about 20 health professionals and 2 exercise specialists.

What will happen if I take part?

We'd like to talk to you about your views and experiences of the ACTIOHN exercise programme and the study more generally. The interviews will explore all aspects of ACTIOHN, including any challenges you've encountered with the study or the exercise programme. We're also very interesting in hearing any advice you have on improving the programme and way that the study is carried out in the future.

The ACTIOHN study researcher [Name] will contact you to arrange a telephone or video-conference interview at a time of your convenience. The interview with [Name] will last about one hour. With your permission, we will audio-record the interview.
We will also be interviewing some of the patients who are taking part in ACTIOHN or have been invited to take part.

Do I have to take part?

No – participation is voluntary. If you decide to take part, you will be given this sheet to keep and asked to sign a consent form. You can withdraw from the interviews at any time and without giving a reason.

What about confidentiality?

Information collected during this study will be kept confidential. Apart from the ACTIOHN interview study researchers, no one will know what you have said. Each audio-recording will be typed out by a transcription agency but we will take out identifying details like names and places before analysing the transcripts. The audio-recordings will be marked with a number only, and stored securely. You will not be identified in any reports of the ACTIOHN study. We may include brief quotations from the interviews in our reports, but we will always omit any identifying details.

What are the possible risks and benefits of taking part?

We do not anticipate any major risks. We hope this study will benefit future patients, health professionals and exercise specialists involved in studies like ACTIOHN. We cannot promise that anyone participating will benefit directly, but many people find that taking part in studies like this is useful because they can air their views and reflect on things.

What if there is a problem?

If you have a concern about the study, you should speak to the researchers who will do their best to answer your questions (see contact details below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from your employers.
In the event that something does go wrong and you are harmed during the study due to someone's negligence then you may have grounds for legal action, but you may have to pay your legal costs. There are no special compensation arrangements for non-negligent harm, though the normal NHS complaints mechanisms will still be available to you.

How will the data collected about me be stored and used?

All data collected for this study will be kept safely and securely on computer and on transcribed paper records. Professor Jo Patterson at the University of Liverpool will be custodian of all data for the ACTIOHN. With your permission, transcripts of your interview will be archived and stored for up to 10 years after the end of this study for research review purposes.
The results will be used to inform training and published in scientific journals, but it will not be possible to identify any individuals from these reports. We will send you a summary of the results at the end of the study if you would like one.

How will you use my information?

The University of Liverpool 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. The University of Liverpool will keep identifiable information about you until 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, unless you ask us to delete it. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more

about how we use your information by contacting the Research Assistant Debra Fisher, email: debra.fisher@liverpool.ac.uk

The University of Liverpool will collect information from you for this research study. We will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of Liverpool and regulatory organisations may look at your clinic records to check the accuracy of the research. Your clinic site will pass these details to the University of Liverpool but the only people in the University who will have access to information that identifies you will be people who need to contact you as part of the study or audit the data collection process. 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.

Data Protection Privacy Notice

The University of Liverpool conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.liverpool.ac.uk/legal/data_protection/policy/).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Liverpool is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Liverpool is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Liverpool will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. The University will not do anything with your personal data that you would not reasonably expect.

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.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used? *
You can find out more about how we use your information:-

- by asking one of the research team
- by sending an email to joanne.patterson@liverpool.ac.uk or legal@liverpool.ac.uk or daniel.howarth@liverpool.ac.uk

Who can I contact if I have a complaint?
If you want to complain about how researchers have handled your information, you should contact the research team (debra.fisher@liverpool.ac.uk or joanne.patterson@liverpool.ac.uk). If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

Who is organising and funding the study?

The National Institute for Health Research have provided the funds to carry out this study and the University of Liverpool is the study sponsor.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by the [INSERT NAME] Research Ethics Committee.

Who can I contact for further information?

If you have any questions at all, at any time, please contact: [ACTIOHN researcher contact details] Alternatively, you may prefer to contact Dr [local PI contact details].