

PATIENT INFORMATION SHEET

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PLUS: Pharmacy referral for Lung Symptoms

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Pharmacy referral for Lung Symptoms: a feasibility study to assess the role of pharmacists in lung cancer diagnosis compared to current pathways

*We would like to invite you to take part in a research study – the **Pharmacy referral for lung symptoms (PLUS)** study. The study is about what people think of using pharmacies to refer people with lung symptoms for a chest x-ray. Before you decide if you would like to take part or not, it is important for you to understand why the research is being done and what it will involve for you.*

This sheet will give you more information about what the study is being done (Part 1). It will also tell you what will happen if you take part (part 2). 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.

PLEASE ASK US IF YOU WOULD LIKE THIS PATIENT INFORMATION SHEET TRANSLATED INTO WELSH.

Patient Information Sheet – Part 1

What is the study about?

We would like to know what people think about using pharmacists to refer people with lung symptoms for a chest x-ray. We will see if this could be something that could be used in the future, and what we can do to improve it.

Why me?

You told your pharmacist that you have some lung symptoms e.g. a cough. You also said that you're currently smoke or used to smoke. Your pharmacist thinks you might be able to have a chest x-ray. We would like to know about your experience of this service, and what you think about it.

What will happen to me if I take part?

Your pharmacist will ask you some questions about your health. This will take about 10 minutes and will take place in a private room. If your pharmacist feels you need a chest x-ray they will send you for one.

You will then be referred to the hospital for a chest x-ray (a picture inside the lungs). **It is important you go to the hospital for your chest x-ray after 2 working days.**

The hospital will send you a letter or ring you to let you know your results. You might be asked to go to the hospital for further tests if needed. If you feel unwell or your symptoms get worse in this time please see your GP.

If it is OK with you, the study team will ask the hospital if anything was found on your chest x-ray, and what was found.

The pharmacist will then give you a short questionnaire to fill in when you get home. The questions will be about what you think of the service. It will take about 10 minutes to complete. It will come with a freepost envelope (no stamp needed) for you to send back to the research team.

Some people will be invited to take part in an interview (an informal chat). We will be asking questions to get a better idea of what you thought about the service, why you went to your pharmacist for advice and how we can help other people to access this help in the future. This information will help us to understand your views and experiences of the service so we can improve it in the future. There is no right or wrong answers to any of our questions – we are just interested in what you think.

If you would like to take part, a researcher will visit you at home or in your local hospital – you can decide. The interviews will take about 40 minutes. To say thank you, we will give you a £20 shopping voucher.

If it is OK with you, we will audio-record the interview. After the interview, everything you said will be typed. This means the research team can let other researchers know the results of this study. Anything which can identify you like your name or where you live will never be typed.

If your pharmacist does not think you need a chest x-ray, they may suggest that you see your GP or take some medication.

Do I have to take part?

No. It is up to you if you decide to take part or not. If you do decide to take part you will be asked to sign a consent form. The pharmacist will go through this with you. Your treatment or care will not be affected if you decide to take part or not.

If you decide to take part, you can stop any part of the study at any time and you don't need to give us a reason. If you leave the study part-way through and you have had a chest x-ray, or you did the questionnaire and/or interview, we will ask if it is OK to use that we have collected from you up until that point.

What are the possible disadvantages and risks of taking part?

The symptoms that you have described to your pharmacist mean that a chest x-ray is recommended in guidance from the National Institute for Health and Care Clinical Excellence (NICE). We would recommend you have a chest x-ray even if you chose not to participate in the study.

A chest x-ray is a form of ionising radiation that allows images to be made of your body. Exposure to large amounts of ionising radiation can carry risks to the body, for example, it can cause cell damage that may, over many years and decades, turn cancerous. The amount of radiation that a chest x-ray will expose you to is very small and is the same amount of exposure as 2 days natural radiation from the environment. This has less than 1 in 1 million chance of causing cancer.

What are the possible benefits of taking part?

The results of the research will help us to understand what services can make the most difference to patients. This can help other patients like you in the future. It may also mean that you can get the appropriate treatment for your symptoms.

What if there is a problem?

If you have concerns about this study, you should ask to speak to the researcher who will do their best to answer your questions. You can also ring study manager Mrs Rachel Gemine on 01554 779309. If you wish to speak to someone who is not part of the study team you can contact the Research and Development Department on 01437 773813. If you would like to complain formally, you can do this through the NHS Complaints Procedure. More details can be found at the hospital.

Participant information sheet – Part 2

What will happen to the results of the research study?

The overall findings of the study may be published in a scientific journal so that other researchers can see the results of our study. We may use a direct quote from the answers you gave us in the interview. If we do, we will take out anything that could identify you, so your quote cannot be traced back to you. At the end of the study you will be sent a summary of the findings.

Will my taking part in the study be kept confidential?

No one outside of the study team will know that you have taken part in the study. If you consent to take part in the research any relevant data collected during the study may be checked by the regulatory authorities to check that the study is being carried out correctly.

The data generated from this research will be stored on password protected NHS and Cardiff University computers. Data will be kept for 5-years or up to 1 year after the findings are published in a scientific journal.

Who is organising this study?

The research is sponsored by Hywel Dda University Health Board. The study is being funded by Health & Care Research Wales. The staff conducting the study will receive no personal payment resulting from this study.

Who has reviewed this study?

The Research Governance aspects of this study have been reviewed and approved by the Hywel Dda University Health Board Sponsor Review Panel. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by Local Research Ethics Committee.

Additional Data Protection Information

Hywel Dda University Health Board is the sponsor for this study based in Wales. We will be using information from you and your medical records 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. Hywel Dda University Health Board will keep identifiable information about you for 10 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 at:

<http://www.wales.nhs.uk/sitesplus/862/page/74864>

Hywel Dda University Health Board will collect information from you and your medical records for this research study in accordance with our instructions.

Hywel Dda University Health Board will use your name, address, NHS number 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 sponsor organisation and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The only people in the sponsor organisation who will have access to information that identifies you will be people who need to contact you to complete questionnaires or invite you to interview 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, address, NHS number and contact details

Hywel Dda University Health Board will keep identifiable information about you from this study for 10 years after the study has finished.

If you need any more information or you have any concerns about the study please contact:

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Alternatively if participating in this research has raised any questions in relating to lung cancer, or lung cancer support please visit the following websites for further information:

- www.tenovuscancer.org.uk/
- www.macmillan.org.uk
- www.nhs.uk/Livewell/Lungcancer
- www.roycastle.org