

Oxford Cancer  
University of Oxford  
Churchill Hospital  
Oxford  
OX3 7LE  
mymelanoma@medsci.ox.ac.uk

Dear Sir/Madam,

I am writing because you received an invitation to join the MyMelanoma study even though you don't have a melanoma diagnosis. I'm really sorry that you received the letter, which must have been confusing and distressing.

You were chosen to receive the letter because your NHS record has a melanoma diagnosis code in it. The MyMelanoma study team does not have access to your NHS record, so we are unable to tell you why your NHS record indicates that you have or have had a diagnosis of melanoma. We are not allowed to amend your records, so you will need to discuss correcting any mistakes with your usual doctor(s).

Attached are some frequently asked questions about how you came to be contacted. We are working with NHS England to understand why this mistake has happened and will post updates on the MyMelanoma website as and when more information becomes available.

Once again, my apologies,

Yours sincerely,



Prof. Mark Middleton  
Chief Investigator of MyMelanoma  
Head of Department of Oncology, University of Oxford

**Why was I sent the MyMelanoma invitation letter?**

University of Oxford asked NHS England to invite people aged 18 or over and who live in selected areas of the UK to join the My Melanoma study. NHS England holds this information from records that health and social care providers in the UK keep about the care and treatment they give. You can choose whether the NHS uses your data for research and planning at <https://www.nhs.uk/your-nhs-data-matters>

**Does the University of Oxford have my data?**

No. NHS England arranged for this invitation to be sent using a secure and trusted printing and postage company. Your data has not been shared with the University of Oxford. The printing and postage were paid for by the University of Oxford.

**Who gave permission for me to be sent the MyMelanoma invitation letter?**

NHS England received legal permission to invite people from the Health Research Authority, who themselves received advice from an independent body called the Confidentiality Advisory Group. This permission comes under Regulation 5 of The Health Service (Control of Patient Information) Regulations 2002.

**Why was I contacted?**

Your name was chosen at random from the list of people who reside in England who met the My Melanoma study inclusion criteria. The Health Research Authority (HRA), following advice from the Confidentiality Advisory Group (CAG), provided support which allows NHS England to use your identifiable patient information for the purposes of inviting you to this study.

**Legal and Ethical aspects of the MyMelanoma:**

The My Melanoma trial has both a legal basis and ethical approval to send out invitations to potential participants for this study. There are certain circumstances when confidential patient information can be used for the benefit of research and other important activities where it is not always practical to obtain patient consent. Confidential patient data is used in accordance with section 251 of the NHS act 2006. A study can apply to Confidentiality Advisory Group (CAG) for section 251 support. Please see below link for more information: <https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/>

The common law duty of confidentiality for the patient identifying data to flow for the purpose of My Melanoma inviting the cohort to take part in the study is Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process confidential patient information without consent. This was established by an application to the Confidentiality Advisory Group and gained the approval of the Health Research Authority and Research Ethics Committee.

**Has the National Data opt out (NDOO) been applied?**

Yes, both the National Data opt out and a Programme Specific opt out were applied by NHS England to the data. As part of the section 251 approval, My Melanoma ensured that they did an outreach campaign in all areas where they planned to do a mailing, at least 4 weeks before invitations were sent out. This was to give the public the opportunity to opt out of receiving an invitation. Health records contain confidential patient information, and this data can be used, subject to the appropriate legal basis and controls, to help with research and planning.

Individuals can choose to stop confidential patient information being used for research and planning purposes by applying the national data opt out.