OxTREC ref 554-14
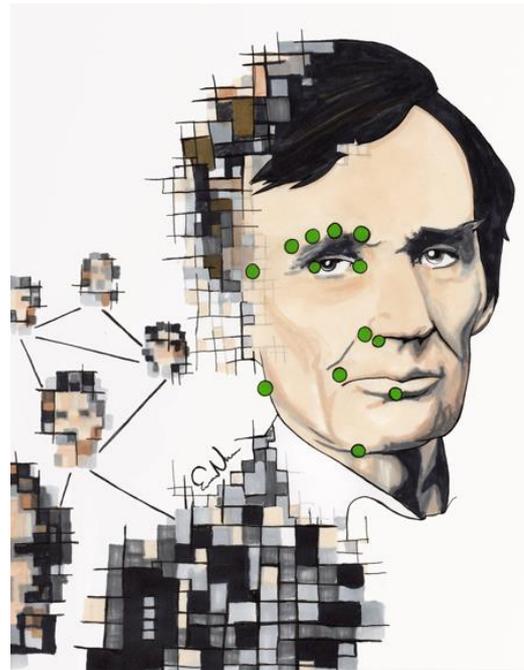
Version 1.02

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Study Invitation

Training computers to diagnose diseases from photographs

We would like to invite you to participate in a study to help teach computers to look at faces for clinical diagnoses. Before you decide whether to take part, it is important to understand what the study and what your participation would involve. This sheet provides information about this study. Please take time to read it carefully. Talk to others about the study if you wish. If anything is unclear or you would like more information, please visit our online portal for contact information.

What is the purpose of the study?

We think that computers can help to diagnosing individual who have particular diseases. To do this we are training computers to look at photographs of peoples' face to try to identify combinations of subtle changes that might together be indicators of a specific disease.

Doctors often use measurements (such as blood pressure, weight, and haemoglobin levels) to help identify any disease you might have. Doctors also assess external physical features (such as changes in the head and face) which can also tell them about underlying diseases.

We are trying to teach computers to use these visible signs to help in making diagnoses. In the future this may become a valuable tool that will be able to spot features that simple observation would miss. The software would be used to suggest a disease condition and prompt further tests such as blood samples, scans or genetic analyses that could be used to confirm a diagnosis.

To determine if this is possible we need to show the computer program pictures of people who are known to have the disease conditions. The more people it is shown, the better the computer will get at understanding human faces.

Why have I been invited?

If you or your child have a diagnosis with one of the specific medical conditions under study then your family could very helpful in training the computer to look at faces.

You have been invited because you might have or be related to someone who has a disease we believe computers will be able to help clinicians identify. To be part of this study you would be asked to answer a short questionnaire and upload, store and analyse photographs of the affected individual and possibly other members of the family, with their permission.

What we will do with your photographs and information?

The way we collect and store your information and photographs

To take part in this study you will need to create a user account on our online web portal (link). This site allows you to control the way you want to participate, answer some short questions and upload the photographs you are willing to share.

We will store and analyse the photos on a secure computer network at the University of Oxford, United Kingdom.

You still own and control your information and photographs

If you would like to be part of this study you will be asked about the ways in which you will allow us to analyse and use your information. If at any point you wish to change your answers or completely withdraw from the study you can easily do so using the online portal. You can opt out of the study at any time and all your stored data will be permanently deleted from our computers.

The way we will be analysing your information and photographs

Your information and photos can be used in several different ways. Using the web portal you will be asked to choose which aspects of the study you want to be part of and you can change these options as the study proceeds. The components are:

1. Using your information to train the computer programs to better find, analyse and model how facial features change with diseases.
2. Linking your data to other members of your family who have also agreed to participate. This will help us teach the computer how faces vary within families.
3. We may wish to use your face as an example case for our computer programs to represent your particular disease condition. This will help us find other people with similar diseases.
4. Communicating the results of the study to other scientists and medical professionals it is often useful to publish images of certain individuals. Agreeing to this aspect is important as once an image is publically published this cannot be undone. Even if you agree to this on the portal, we would contact you to again to confirm that you were still happy for a specific picture to be published.

What are the risks? What do you get?

We will be storing your information in the secure University of Oxford computer servers. In the unlikely event that our data servers were breached it is possible that your data could be stolen and even posted online. This would require an illegal action by the perpetrator.

We will only use the information you provide in accordance with your wishes and we will never share your information with third parties without your consent unless legally obligated. However, please do

still consider your specific circumstances and what would be the consequences if your information or photographs were to be taken by someone. This is the risk that we would like you to think about when deciding if you want to be part of this study.

There are no direct benefits to you but we hope that all who take part will be improving the computer programs which might help others with diseases in future. In participating in this research study you would be helping us bring these computer programs closer to being used by doctors to get patients the right diagnoses. We hope that by being part we will be able to give you a glimpse into the underlying research by showing you what the computer learns from your photographs.

It is not anticipated that the study will be able to contribute any medically relevant information to you at this current stage. If in the future the programs might be useful to you by letting your doctor see your data - the dynamic consent website will add new questions and possibilities for you to decide how you wish to proceed.

Choice is central. You can leave the study whenever you want.

The choice to participate or not in this study is yours to make. You keep control of your information and you can remove or change it at any time, for any reason without telling us. The online dynamic consent website for this project allows you to enter, edit and delete your information and images. Some questions allow you to adjust how we are allowed to use your information, which you can also change your answers to at any time.

There is one specific question which asks if you consent to publication of an image - this can be changed only until your image is at some point published. Once an image has been published in the public domain it will be impossible to undo. This question is particularly highlighted in the consent forms to alert to the extra risk. We would still contact you again to check if you have changed your mind before any picture is published.

Would you like to know more?

Please visit our website for more information about the research and also to sign up to participate.

minervaandme.org

Complaints

If you have any problems, comments, complaints, or would simply like to know more please contact Dr Christoffer Nellaker on 01865 287 851 or christoffer.nellaker@well.ox.ac.uk.

Disclaimer

In the future we might need to form partnerships with industrial partners in order to make the computer programs available to healthcare services across the world. If so, this will not affect your rights or ownership of your data. As before, you will still be able to see, delete and change how your data is being used.