ICBP
International Cancer Benchmarking Partnership

Patient information leaflet

UCL

You are invited to take part in an international survey on time from start of symptoms to treatment involving patients with lung, bowel, breast, and ovarian cancer.

This leaflet explains why the research is being done and what would be involved if you choose to take part. Please feel free to discuss this study and ask us if there is anything that is not clear or if you need further information.

What is the International Cancer Benchmarking Partnership (ICBP)?
The ICBP is a partnership between Australia, Canada, Denmark, England, Northern Ireland, Norway, Sweden and Wales which is co-ordinated by the Department of Health (DH) with support from Cancer Research UK in England. The aim of the partnership is to compare cancer survival rates across the countries and investigate causes for any international differences.

What is the purpose of the current survey?
The partnership has found that there are differences in survival in patients with lung, breast, bowel and ovarian cancer in the various ICBP countries. This survey seeks to explore whether this is due to differences in time to diagnosis and treatment of cancer. We hope to compare information collected from all patients recently diagnosed with these cancers in the participating countries.

Why have I been chosen?
The NHS Cancer Registration System has been notified that you have been recently diagnosed with one of these cancers. It therefore contacted your GP to inform him/her that you are eligible for participation in this survey. You are now receiving this invite as your GP agrees that you may wish to contribute towards this very important study which aims to improve cancer outcomes in the NHS. Please be aware that the ICBP research team is **not aware** of your diagnosis or details unless you decide to take part and return the questionnaire. If you decide to take part, your GP will not receive a copy of your answers.

Do I have to take part?
No, you do not have to take part. Participation is entirely voluntary and whether you participate or not will not affect your medical care. If you decide not to take part, we will not contact you again.

What will happen to me if I take part?
If you agree to take part, (1) you will need to complete the enclosed questionnaire which includes questions about symptoms that you might have experienced before being diagnosed, the time taken to diagnosis and treatment, any tests done and (2) provide consent for the researchers to contact your GP and hospital doctors for further information about your diagnosis and treatment and to receive information from the NHS Cancer Registration System. In order to take part you need to consent to all parts of the study. It will probably take you about 20 minutes to complete.

Will you be contacting me in the future?
We may contact you for clarification if there is something on the returned questionnaire that is unclear. We may also contact you again asking you to fill in the questionnaire for a second time (re-testing). This helps us assess the quality of the questionnaire and how understandable it is.

What are the possible disadvantages and risks of taking part?
The main risk is that you get distressed as you recollect your journey through cancer diagnosis and treatment. The survey questions have been carefully drafted and piloted to try and ensure this does not happen.

What are the possible benefits of the study?
The NHS is committed to improving cancer survival. The study will help us understand any delays that you may have faced as a cancer patient. This will help us improve the way we look after cancer patients.

What if something goes wrong?
As the study only involves completing the questionnaire there is little that could go wrong. If you have any concerns you should contact the local research team in London (details below)

Will my taking part in this study be kept confidential?
Yes. All the information gathered will be treated in the strictest confidence. Your personal data will be held for 15 years in accordance with the Data Protection Act 1998 by the research team at University College London. Only this research team will know your personal details. No personal information will ever be made available to anyone outside the study and no individually identifiable information will be published. You can withdraw the information you give in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

What will happen to the results of the research study?
The results will be reviewed by the ICBP international Programme Board and published in the medical press. If the results are significant, it is expected that they will be reported widely in the lay press.

Who is organising and funding the research?
The overall study is being organised by the ICBP with the help of Cancer Research UK. This international survey is led by Professor Peter Vedsted, Aarhus University Denmark, Professor David Weller, Edinburgh University and Professor Usha Menon, University College London. The study in England is coordinated by the University College London team at the Institute for Women's Health.

The study is funded by a mixture of government bodies and cancer charities with the England study further supported by the Department of Health/National Cancer Action Team and the charity Eve Appeal.

What next?
We hope that you will join the research study and complete and return the attached questionnaire. With your help we believe that we can make a significant contribution towards improving cancer survival.

Contact for further information
If there is anything that is not clear, or if you would like more information, please contact:

Name: Dr Evangelia Ourania Fourkala / Professor Usha Menon
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For more information on the NHS Cancer Registration System, please visit the website of the UK Association of Cancer Registries: http://www.ukacr.org/content/patient-information

Thank you for reading this.

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