



COMPUTATIONAL ONCOLOGY LABORATORY

[Home](#) [Clinical trials](#) [Big data](#) [Patient focus](#) [Quality of life](#) [Near-patient sensing](#) [Consulting](#) [Publications](#) [Working with us](#) [Blog](#)



WELCOME

This is the Indigo cancer survey participant information sheet. It will tell you about the survey and it should answer any questions you have so that you can decide if you want to take part in the research.

Before you decide to complete the survey, it is important for you to understand why the research is being done and what it will involve.

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Do I have to help?

It is up to you to decide whether or not to take part. This research will not make any changes to any treatment you are having. If you decide to take part on the next page you will be asked to give your consent (agreement) to take part in this study. If you agree to take part, you are still free to withdraw at any time and without giving a reason and this won't affect your care or treatment.

How can I help?

We have created a survey to help learn more about the impact of cancer and its treatment on people's lives. This survey asks questions about you and your cancer treatment. It also asks about your health now and any effects your cancer or its treatment might be having on your life. Most people are able to complete the survey in about half an hour.

Who can help?

If you were over 16 years old when you were diagnosed with cancer you can take part. We want to hear from people from all backgrounds who have had any type of cancer and any type of treatment.

It's best if you have finished your first treatment before taking part. If you are on long-term treatment, like hormone therapy, you can still take part. If your cancer came back and you had more treatment, you can take part. If your cancer is still present, you can take part. If more people take part, we can make more of a difference to everyone affected by cancer in the future.

What would I have to do if I take part?

You will need to complete the survey. We hope you will answer all the questions, but you can skip any questions you don't want to answer.

Most people are able to complete the survey in about half an hour. It's great if you can finish it in one go, but you can take breaks. You have 7 days to complete it from when you start. You can leave the survey and return later using the same link, but **you must be on the same device**. You cannot start on one device and finish on a different one.

You can do this survey on a smartphone, tablet or computer. If it helps, you can have someone assist you to make it easier or help you remember things. Each answer you give is saved automatically, so you don't need to worry about saving your answers. You can change your answers if you need to.

Will it affect my current care?

No. This research will not make any changes to your current healthcare. You can have a copy of your answers and share them if you wish.



What are the possible benefits of taking part?

Taking part may not benefit you directly. By sharing your experience, you can help to improve care and support for those who get cancer in the future by completing a short confidential survey. Cancer now affects 1 in 2 people in their lifetime so you could help someone you know.

Are there any possible disadvantages of taking part?

Patients can complete the survey with or without providing any of their personal details. It is very unlikely that taking part in this research will cause you any problems. All data is held securely and remains confidential.

Do I have to answer every question?

No. It helps us more if everyone answers all the questions, but you can skip any questions you don't want to answer. There are extra questions in the study that ask you for information which can be used to identify you. You will be asked very clearly whether you agree to answer those questions or not.

Is everyone asked the same questions?

Most of the questions in the survey are the same for everyone. But in one section you will be shown one out of three different sets of questions. A computer will randomly choose which set of questions you are shown.

Do I have to complete the whole survey in one go?

It's great if you can finish it in one go, but you can take breaks. You have 7 days to complete it from when you start.

You can leave the survey and return later using the same link, but **you must be on the same device**. You cannot start on one device and finish on a different one.



How accurate do my answers need to be?

You do not need to give us perfect answers. Just answer as best as you can remember. Please don't worry about looking through letters or calendars for exact details. When we ask questions about how you feel and how your life is today, it's best to answer without thinking too much. Your first instinct is often the best answer.

Will my answers be kept confidential?

Yes

What if the survey makes me upset or triggers unhappy thoughts?

Usually, people who complete surveys like this are not upset by the experience. However, some people may be affected. If that happens to you then talking to friends or family may be a good place to start. Or if you would prefer you can use the free Tenovus Cancer Care Support Line (0808 808 1010 or [use this link](#)), which is available 7 days a week to support you with questions or concerns about your cancer diagnosis, treatment or side-effects. Tenovus Cancer Care are not involved in this research so you can be open and honest with them. What you discuss with them is completely confidential.

Who is organising and funding the research?

[Imperial College London](#) is the sponsor of the study. The trial has received funding from [Macmillan Cancer Support](#), [Imperial Health Charity](#) and the [Brain Tumour Research Campaign](#).



What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator (Dr M Williams, [send an email](#) to imperial.patients.indigo.trial@nhs.net).



The normal National Health Service complaints mechanisms are also available to you. If you are still not satisfied with the response, you may contact the Imperial AHSC Research Governance and Integrity Team ([send an email](mailto:rgit@imperial.ac.uk) to rgit@imperial.ac.uk).

My question has not been answered, what can I do?

If you feel you still have questions about the study, please contact us directly ([send email](#)).

You can read more on [our transparency notice](#). The London Surrey Research Ethics Committee has reviewed and

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