**TIC-TOC Study**

**Study Title: TIC-TOC (Targeted Intensive Community-based campaign To Optimise Cancer awareness): feasibility of a symptom awareness campaign to support the Multidisciplinary/Rapid Diagnostic Centre referral pathway in a socioeconomically deprived area**

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**Participant QUESTIONNAIRE INFORMATION SHEET**

The TIC-TOC study is testing if we can deliver a public awareness campaign to help people recognise vague cancer symptoms and get advice from their GP. We also want to find out public perceptions about the campaign, and whether the campaign reached people in the local community. We also need to find out whether we can collect the data needed for a future trial to test if the campaign works.

We would like to invite you to take part in this study. Before you decide if you would like to take part, you need to understand why this research is being done and what it would involve for you. Please take time to read this information carefully.

**Why have I been invited?**

You have been invited because you have been referred by your GP to attend the Multidisciplinary/Rapid Diagnostic Centre (M/RDC) clinic.

**Do I have to take part?**

No, you do not have to take part. You can talk to your family, friends or your doctor about this study. They might be able to help you decide if you want to take part or not. Your medical care will not change or be affected in any way if you decide to take part in the study or not. If you decide to take part you can still stop at any time and you don’t have to give us a giving a reason.

**What does being in the study involve?**

We will ask you to complete a questionnaire over the telephone with a member of our research team based at Cardiff University which will take about 30 minutes. The questions will focus on your experience of going to your GP about your symptoms, what your symptoms were, your general health, if you have been to the doctor with similar symptoms before, and if you have been aware of any adverts, publicity or other types of information in the last 6 months which focused on the subject of cancer*.* We will also ask some general information about you such as your gender and postcode.

**Will I get paid for taking part?**

As a thank you for taking part we will give you a £10 shopping voucher. This will be sent to you in the post or via email (you can choose what you prefer).

**What are the possible benefits of taking part?**

Your valuable input will allow us to understand if we can deliver a public awareness campaign to help people recognise vague cancer symptoms and get advice from their GP. This may benefit others in the future.

**What are the possible disadvantages and risks of taking part?**

It is possible that some people may find it upsetting answering questions about being referred to the Multidisciplinary/Rapid Diagnostic Centre (M/RDC) clinic and their symptoms. Another possible disadvantage is that we will be asking you to give up about 30 minutes of your time.

**How will we use information about you?**

We will need to use information from you for this research project.

This information will include your initials and partial date of birth. People will use this information to do the research to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason. If you withdraw from the study, you will have a choice whether we will keep the information that we already have about you and if it will be used in the final analysis. We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

* by asking one of the research team
* by sending an email to **tic-tocstudy@cardiff.ac.uk**
* at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>
* by contacting the University’s Data Protection Officer: inforequest@cardiff.ac.uk/ or in writing to: Data Protection Officer, Compliance and Risk, University Secretary's Office, Cardiff University, McKenzie House, 30-36 Newport Road, Cardiff, CF24 0DE.

**What will happen to my data?**

Cardiff University is the data controller and is responsible for looking after your

information and using it properly in accordance with the General Data Protection Regulations (GDPR). Cardiff University will keep identifiable information about you for 15 years after the study has finished. Study data will be stored securely and only authorised staff on the research team will be given access to your personal data.

**Will my taking part in this study be kept confidential?**

*Yes, we will follow ethical and legal practice. All information about you will be handled in confidence.* All information which is collected about you during the research will only be seen by members of the research team.Only members of the research team will have access to view identifiable data. However, sometimes official people from regulatory authorities may need to access data, for example the Centre for Trials Research may be inspected and/or audited internally by Cardiff University. This is to check the quality of the research **only**. All members of the research team and regulatory bodies are trained in data protection issues. They are also bound by the terms of the General Data Protection Regulation (GDPR) and any future legislation.

**What will happen if I don’t want to carry on with the study?**

You can stop doing the study at any time, without giving a reason. We may ask you why you have decided to stop, but you don’t have to give any reasons.

**What if there is a problem?**

If you have a concern about any part of this study, you can speak to the researchers at Cardiff University. They will do their best to answer your questions. The contact details are on the last page.If at any point, you are unhappy about the study and wish to speak to someone independent of the study team or make a complaint, you can contact Kerry Hood, Director of the Centre for Trials Research on 02920 687163.

**What will happen to the results of the research study?**

At the end of the study the results will be available on our website: https://www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/tic-toc. We will also write up the results in scientific journals and present them at scientific meetings. You will not be identified in any report, publication or presentation. This is because no personal information or unique information about you will be included.

**What happens next?**

 1. Consent:

If you agree to take part we will need to take consent from you. We will read out statements to you and you can tell us if you agree to these statements.

2. Interview:

Once you have completed your Consent Form, you can complete the questionnaire.

 3. Voucher:

After the questionnaire we will send out your £10 shopping voucher. This is to thank you for your time.

**Who is organising and paying for the research?**

This study is being organised by the Centre for Trials Research at Cardiff University. To run this study we have been given money by Cancer Research Wales.

**Who has reviewed the study?**

This study has been reviewed and approved by London - West London & GTAC Research Ethics Committee NHS Research Ethics Committee (reference:

21/LO/0402), who are there to safeguard your interests.

**How do I take part?**

A member of the TIC-TOC team will call you after you have been given a date to attend the M/RDC clinic. They will arrange a time that is convenient for you to phone you back to complete the questionnaire. The questionnaire will be completed over the telephone.

**Further Support**

If you have become upset about anything as a result of taking part and would like to speak to someone else for further support you can contact:

**Tenovus Cancer Care:**

Freephone support service 365 days/year,

8am—8pm on: **0808 808 1010**

**Cancer Research UK:**

Freephone support service Monday—Friday,

9am—5pm on: **0808 800 4040**

**Please contact your GP for further support.**

**What do I do if I have a question?**

If you have any questions about the study you can contact:

**Gwenllian Moody**

Study Manager

Centre for Trials Research,

Cardiff University

7th Floor Neuadd Meirionnydd,

Heath Park

Cardiff

CF14 4YS

E-mail: **tic-tocstudy@cardiff.ac.uk**

**Thank you for THINKING ABOUT taking part in THE STUDY.**