

## Participant Information Sheet

<b>Study title:</b>	Cancer Loyalty Card Study-2. <b>Short title</b>
	CLOCS-2
<b>Protocol version:</b>	<b>5.0 Dated 19/03/2025</b>
<b>IRAS Number:</b>	324742
<b>Chief and Principal Investigator:</b>	James Flanagan
<b>Sponsor:</b>	The study is sponsored by Imperial College London
<b>Funder:</b>	This research is being funded by a Cancer Research UK Early Detection Primer Award EDDPMA-May22\100019 and Project Grant
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### Summary of this participant information sheet and the privacy notice

This document (and the privacy notice) provides all the information you need to make an informed choice about participating in our study. Importantly, you will find details on how we will keep your data secure and how long we will keep it for. If you choose to take part, you will be asked to:

1. **Give your consent to participate** by signing a form and answering a few more screening questions to check if you are eligible.
2. If eligible, **provide your contact details, GP address, and loyalty card details** (name and number on card)
3. **Answer some questions about your health** by completing the CLOCS-2 survey
4. **Give permission** for the high street retailer to share your loyalty card purchase history with us – up to six years' worth, depending on how long you've had the card for.

### Invitation to the Cancer Loyalty Card Study-2 (CLOCS-2)

You are invited to participate in a research study. Before making your decision, it is important to understand the purpose of the research and what is involved. In addition to this

information sheet, we have provided a privacy notice [[CLOCS-2-Privacy-Notice-V7-14.07.2025-English.pdf](#)] that explains the information we are collecting, and how it will be used and stored. Please take your time to read both documents carefully and discuss with others if you wish. You can also contact us if anything is not clear, or if you would like more information.

### **1. What is the purpose of the study?**

Some cancers are diagnosed at an advanced stage, making treatment more challenging. Researchers and medical professionals are keen to find methods to aid earlier diagnosis in order to improve health outcomes. Individuals with undiagnosed cancer might use over-the-counter medications, such as painkillers, digestive aids, or herbal remedies, to alleviate symptoms that mimic other common conditions. Store loyalty cards, which record items bought when presented at purchase, provide a valuable source of purchasing data for investigation. Our initial Cancer Loyalty Card Study (CLOCS-1) revealed that women with ovarian cancer significantly increased their purchases of pain and indigestion medications up to 8 months before diagnosis, compared to women without ovarian cancer. However, there is limited knowledge about whether early symptom management for other cancer types can also be identified through purchasing data.

CLOCS-2 will look at whether store loyalty card purchase data can detect differences in the shopping habits of cancer patients before they are diagnosed for the following ten cancers: bladder, colorectal (bowel), endometrial, liver, oesophageal, ovarian, pancreatic, stomach (gastric), uterine, and vulval. We plan to recruit 1,450 people with cancer (Cases) and 1,450 people without cancer (Controls) who have a Boots and/or Tesco loyalty card. These retailers will send us up to six years of backdated purchase data, taken from the date of consent. We will compare the data between the two participant groups to see which types of products were bought, in what quantities, and how often, and look for any differences which could indicate an undiagnosed cancer. We will also determine if the results suggest the best time for an intervention to encourage earlier medical help. If so, then this could not only lead to earlier cancer diagnosis but also improve health outcomes.

### **2. Why have I been invited?**

You may have been invited to the study either by a text message from your GP or cancer clinic, an email invite from Be Part of Research, or from someone else in your household.

We aim to recruit 2900 adults in the United Kingdom to take part in CLOCS-2, made up of the following two participant groups:

- Group 1 (Cases): 1,450 individuals who have received a cancer diagnosis within the last 24 months of one of the following: bladder, colorectal (bowel), endometrial, liver, oesophageal, ovarian, pancreatic, stomach (gastric), uterine and vulva.
- Group 2 (Controls): 1,450 individuals who have not received a cancer diagnosis in the last 6 years, except where the diagnosis was non-melanoma skin cancer.

### **3. Do I have to take part?**

No, it is entirely up to you to decide if you take part or not. If you do decide to take part, you are still free to withdraw at any time and without giving a reason by emailing the study team at [clocs@imperial.ac.uk](mailto:clocs@imperial.ac.uk). However, providing a reason for your withdrawal can be really helpful to us, in case there is anything we can do to improve the experience of future study participants. If you withdraw from the study, we will still use the data we have collected. A decision to withdraw at any time, or a decision not to take part, will not affect your standard of medical treatment, care, or legal rights in any way.

### **4. What will happen to me if I take part?**

There are three stages to your participation in the study as summarised in **Figure 1** below.

**Figure 1 Three stages of participation**



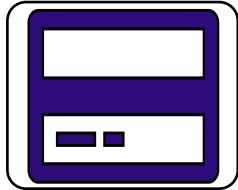
## Stage 1

- Set 1 of screening questions (already completed)
- Read Participant Information Sheet and Privacy Notice



## Stage 2

- Sign Informed Consent Form
- Answer 2nd set of screening questions



## Stage 3

- Enter contact details
- Provide details of your GP Practice
- Enter Loyalty Card details
- Complete CLOCS-2 survey

Further details on each of the stages presented in Figure 1 are provided below.

### **Stage 1 – Reading the participant information sheet and privacy notice**

Before deciding whether to take part, please read this participant information sheet and the privacy notice thoroughly and take the time you need to decide whether you would like to participate. If you have any questions or find anything unclear while reading these documents, please contact a member of the research team before making your decision. You can reach us by calling 07353923305 or emailing [clocs@imperial.ac.uk](mailto:clocs@imperial.ac.uk). We aim to respond within 24 hours for enquiries received between Monday and Thursday. Please wait for our response before signing up.

### **Stage 2 – Informed consent and second set of screening questions**

If you decide to participate, you will need to sign the consent form. The consent form is divided into consents which are required for participating in the study, and those which are not i.e., optional consents. You will not be able to participate in CLOCS-2 if you do not agree to all of the required consents. If you are the primary registered loyalty cardholder, you are required to answer yes for the box relevant to you on the consent form before selecting the relevant high street loyalty card for the purchase data you want to share for this study. If you are not the primary registered loyalty cardholder, then you are required to select yes for the box relevant to you. If you are sharing your loyalty card purchase data for both cards (i.e.,

Tesco Clubcard and Boots Advantage Card), but are only the primary registered cardholder for one of these, then you will need to say yes to both consents.

After signing the consent form, you will be presented with the second set of screening questions (you answered the first set before being presented with the PIS). We require your consent at this stage because we need to ask you questions about your cancer status. As this information is health data (or special category data) it requires your explicit consent for us to view and use it. By the end of these questions, we will know whether you qualify as a case participant (Group 1), a control participant (Group 2), or if you are not eligible to continue. We hope this process will reduce any unnecessary effort on your part. If you are not eligible, we will retain your consent form in accordance with our data retention policy as detailed in the privacy notice, along with any responses you have provided up to that point. This helps us meet our obligations to report on our recruitment efforts. However, your responses will be deleted once recruitment has closed. Please note that at this stage, we will not have collected any personally identifiable information from you, except for your name as contained in the consent form.

### Stage 3 Sharing your details, and completing the CLOCS-2 survey

#### Contact details

The CLOCS team may need to reach out to you using your name and contact details to address any questions we have after you complete the survey, or if the high street retailer has trouble matching your loyalty card details with an account. If you decide to participate in CLOCS-2, we will ask you to provide a contact email address and/or a phone number, as well as your home address. We will use the postcode from your home address to generate an Index of Multiple Deprivation (IMD) decile. This non-identifying IMD decile, rather than your postcode, will be used in our analysis to help us explore the relationship between health inequalities and purchasing behaviour.

#### GP Practice details

You must be registered with a GP practice to participate in this study therefore you will be asked to enter the name and address of your GP practice after completing the second set of screening questions. While some GP practices may already be listed, yours may not be. Instead, you will be asked to enter it manually. Please note that we will not share any of your details with your GP, nor will we request any information about you from them. However, we may contact newly entered GP practices to see if they would like to join the study and start recruiting participants directly. We will also use the compiled list of GP practices from all participants to inform our broader recruitment efforts.

#### Sharing your Loyalty card details and purchase data

##### Read this if you are NOT the primary loyalty cardholder

A loyalty card for a high street retailer is usually registered under one person's name i.e., the primary registered loyalty cardholder. However, often the cardholder will make purchases for or on behalf of other members of their household or will give them a copy of the card so they can make their own purchases. We want to give the opportunity for people to join the study who are not the primary registered loyalty cardholder, but who share the use of a loyalty card, or live in a household where the primary loyalty cardholder makes purchases for them. We are not able to request shared household loyalty card purchase data from the high street retailer from non-primary loyalty cardholders. Therefore, if you wish to take part in the study, the primary loyalty cardholder will also need to enrol as a participant. Please refer this information sheet to the primary cardholder and ask them if they would be willing to participate in the study (and share their loyalty card purchase data) before continuing further.

If you enrol and complete the study as the non-primary loyalty cardholder and we notice towards the end of recruitment that the primary registered loyalty cardholder has not joined the study, we may reach out to you to find out what their plans are. If we do not hear back from you, or if you tell us that they will not be participating, we may still be able to use your health data to create risk profiles.

**Figure 2 Understanding joining requirements for non-primary cardholders**

**If you are not the primary registered cardholder(s)\***



Before joining you should consider the likelihood of the primary registered cardholder consenting to joining the study and completing the study requirements.



You must have the exact loyalty card details of the primary registered cardholder, as you will need to enter these details during the enrollment process.



We will not be able to obtain your shared household loyalty card data if the primary registered cardholder in your household does not join the study.

If you have any questions about joining the study as the non-primary registered loyalty cardholder, then please call us at 07353923305 or email us at [clocs@imperial.ac.uk](mailto:clocs@imperial.ac.uk). We aim to respond within 24 hours for enquiries received between Monday and Thursday. Please wait for our response before signing up.

**Read this if you are the primary loyalty cardholder**

To allow us to request your purchase data from your Tesco Clubcard or Boots Advantage Card, you will need to provide your loyalty card number(s). This is the long number found on the front of the card. If you do not have a physical card, you can find this information by logging into your online loyalty card account(s) or the respective app(s). It is important to provide the exact details from your loyalty card to avoid any delays and ensure that the home address you provide matches the one linked to your card. Boots will verify your card details by checking your loyalty card number, your name, and your home address. Tesco

may also use this process. However, it is likely that you will be asked to consent to sharing your Tesco loyalty card purchase data directly with Tesco via OpenID Connect. This procedure will commence once you have reached the end of the survey.

The high street retailers will only send us your loyalty card purchase data once. The data provided by the high street retailer will be historic data, backdated for up to six years from the date of your consent i.e., we will not receive details of any future or ongoing purchases. The data sent to us will include details about the items you have purchased when you presented your loyalty card. For example, if you bought paracetamol, we would know the product name and brand, the purchase date, and the store location (identified by the store's postcode). You can choose which card(s) to share, but the more data we have on shopping behaviours, the better we can identify patterns that might help lead to earlier diagnoses for others. Please note that sharing your loyalty card purchase data does not grant us access to any details about your NHS prescriptions.

#### **When we might ask you to provide two forms of identification**

If the high street retailer is unable to match you on their system using the loyalty card details you have provided to us, we will be told first and then we will follow up with you. In these cases, we may be required to verify your identity. Our identity verification process involves matching your name and address against a utility bill in your name (e.g., council tax bill, gas/electricity bill) and against photographic identification (e.g., passport or driving licence). Once you have uploaded your documents, a member of the CLOCS-2 research team will review them to confirm that your name, address, and photo ID matches the contact details you have provided and the name on your consent form. We will not send your identity documents to the high street retailer(s). We will permanently delete your uploaded ID documents once we have received your loyalty card purchase data from the high street retailer(s). This process aligns with your data portability rights under the General Data Protection Regulation (GDPR) and ensures your data is protected. **Please note, identity verification is only required if you are the primary registered loyalty cardholder, AND the high street retailer has not been able to match your loyalty card details from the information you have provided.**

#### **Completing the CLOCS-2 survey**

The CLOCS-2 survey will ask about your age, gender, ethnicity, educational status, relationship status, medical history (including reproductive history for female sex), family medical history, lifestyle, and details about other loyalty cards you use. The time required to

complete the various parts of the CLOCS-2 survey will differ for each participant, as it is designed to present only the questions relevant to you. We estimate that the survey will take between **35 to 55 minutes** to complete. However, you do not need to finish it all at once. If you wish to pause the survey at any time, you can save your progress by pressing 'Save and submit.' This will generate a unique reference number that you can use to resume the survey later. The questions will also vary depending on whether you are participating as a 'Case' (Group 1) or 'Control' (Group 2) and if you indicate you are of female sex. Case participants will be asked about their cancer diagnosis, while Control participants will not. Female sex participants will be asked about their reproductive history. Once you complete Stage 3, a digital copy of your written information and signed consent form will be immediately available for download. If you would like an electronic copy of your signed consent form after your access to the electronic database has closed, you can request one from us. A permanent link to the participant information sheet is provided here: [\[CLOCS-2-Privacy-Notice-V7-14.07.2025-English.pdf\]](#), and a permanent link to the privacy notice is provided here [\[CLOCS-2-Privacy-Notice-V7-14.07.2025-English.pdf\]](#). If you have any questions about the survey either before or after completing it, please feel free to email the CLOCS-2 team at [CLOCS@imperial.ac.uk](mailto:CLOCS@imperial.ac.uk).

**Please note that we will not verify any of the data you provide with your NHS records, nor will we ask your GP to share your medical notes with us.** Therefore, it is crucial that you complete this survey as thoroughly and as accurately as possible. However, if you were referred to the study by your GP or your cancer clinic i.e., you received a text message from your GP practice or cancer clinic with a link to this study, they may need to re-access your medical records at a later date to meet any obligations in the event of an audit.

## 5. How long will I be involved in the study?

Your active participation in the study will be complete once we have received your shared loyalty card data from the high street retailer, and all follow-up questions have been resolved. However, we will retain your contact details for the duration of the recruitment period. Once recruitment has closed and all data checks are finalised, we will delete your contact details unless you have agreed to let us retain them for follow-up studies or to receive the study results once published. For more information, please refer to the privacy notice [\[CLOCS-2-Privacy-Notice-V7-14.07.2025-English.pdf\]](#). Except in the case of Tesco OpenID Connect, individual requests for data will not be made to the high street retailer(s) each time a new person enrols in the study. Instead, we will make bulk requests every 3-4 weeks. While we aim to request and receive your loyalty card purchase data within a 6-week

period, including resolving any queries regarding matching your details, it may take longer depending on the resources available on both sides. This means **you might receive an enquiry from us some time after enrolling in the study and completing all other aspects**. We will contact you up to three times to resolve any issues with matching your loyalty card details. If there is no response after the third contact, we may still be able to use your health data to create risk profiles. However, the high street retailer will not be able to send us your loyalty card data.

## 6. Follow on qualitative study

While the design of our follow-on qualitative study is still in progress and will require separate ethics approval, we aim to select around eighty participants from CLOCS-2 for an interview study exploring self-care purchasing behaviours. To facilitate this, we have included an optional consent on this in the consent form, asking if you agree to be contacted about this future study. Please note that selecting this option does not commit you to take part.

## 7. How will my information be kept confidential?

Your health data and personally identifiable information will be collected and stored separately to your loyalty card purchase data. When you access REDCap from the link you received, a unique Participant Identification Number (PIN) is automatically generated. Only researchers at Imperial College London directly involved in the study will know that this number is linked to you. Your personal identifiable information (such as your name and contact details) will be securely stored and destroyed according to the privacy policy. Imperial College London will manage access to this information and limit it to authorised personnel. Your contact information will be used solely to verify the information you have provided, to reach out to you about future studies, or to inform you of the study results, where you have consented to one or more of these options.

If you are the primary registered loyalty cardholder, your purchase data will be stored in the secure enclaves at Imperial College London. If your data is coming from Boots (and in some cases from Tesco) then before requesting we will create a barcode which will function as a pseudonym (a non-personally identifying ID) for your loyalty card purchase data. When the high street retailer returns your data, this will be included instead of any personally identifiable data. While we will have the ability to link this barcode back to you, only the study's Chief Investigator will be able to do this and will only do so if absolutely necessary. For Tesco, we expect the majority of data transfer requests to be done by you through their

OpenID Connect platform. The data that is sent from Tesco will not contain your personally identifiable data.

Further information about how we use your information and how it is stored can be found on the CLOCS-2 privacy notice: [\[CLOCS-2-Privacy-Notice-V7-14.07.2025-English.pdf\]](#), or by contacting Imperial College London using [CLOCS@imperial.ac.uk](mailto:CLOCS@imperial.ac.uk).

### **8. How long will my data be kept for?**

Any uploaded copies of identity documents will be permanently deleted as soon as we have received your purchase data from the high street retailer. If the retailer is unable to match your provided loyalty card details with an account and we are unable to resolve this through our communications with you, we will permanently delete any uploaded identity documents at the earliest opportunity. Consent forms will be kept for 10 years after the end of the study. Past purchase data and your health data will be kept pseudonymised until the results are published or for five years after the study has completed, whichever comes first. Then all past purchase data and health data will be fully anonymised, and any link to identifiable data deleted.

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

There are no clear risks in taking part in this study. However, we understand that it may be emotional or distressing to think about cancer. We have designed the survey questions in the most sensible and sensitive way to minimise the negative effects of this study on participants' well-being. If you are currently concerned, or become concerned later about symptoms you are experiencing, please seek help and advice from health professionals.

### **10. What are the possible benefits of taking part?**

The study will not provide any direct benefits to you. However, the study is a unique project which could benefit public health in the future. For example, if the study is successful, this could be instrumental in raising cancer symptom awareness in commercial settings.

### **11. Who is organising and funding the research?**

The study is being organised by the CLOCS-2 study team who are based at the Department of Surgery and Cancer, Imperial College London. This research is being funded by a Cancer Research UK Early Detection Primer Award EDDPMA-May22\100019 and Project Grant.

### **12. Who has reviewed the study?**

The study was first reviewed by patient representatives and edited accordingly. The project grant was reviewed and funded by the Cancer Research UK Early Detection committee. The original protocol received ethical approval by the East Midlands - Leicester South Research Ethics Committee REF: 23/EM/0224; IRAS Project ID: 324742.

**13. Who can I contact if I want further information or if I have any questions?**

If you would like further information about the study or have any questions, please do not hesitate to email the CLOCS study team [CLOCS@imperial.ac.uk](mailto:CLOCS@imperial.ac.uk) or the study's Chief and Principal Investigator: Prof James Flanagan [j.flanagan@imperial.ac.uk](mailto:j.flanagan@imperial.ac.uk).

You can also contact the Cancer Research UK nurse helpline on 0808 800 40 40 for information on any of the cancer types listed in this information sheet, or visit their website: <https://www.cancerresearchuk.org/information-and-support>.

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

We plan to share our findings through peer-reviewed academic journals and also make them available on our website and on social media platforms. We will also host webinars or in-person events, so that as many people as possible can hear about the results. All information presented or published will be fully anonymised. We will ask you, as part of the consent process, whether you would like us to keep your email address, so that we can email you when we have published the results. From time to time, we will also provide updates about this study on our website, including any dates for future webinars, see [www.clocsproject.org.uk](http://www.clocsproject.org.uk).

**15. 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 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 Prof James Flanagan [j.flanagan@imperial.ac.uk](mailto:j.flanagan@imperial.ac.uk).

**16. How do I make a complaint?**

If you are not happy with any aspect of your participation in this research project you should raise this in the first instance with the Chief and Principal Investigator of the study, Prof James Flanagan [j.flanagan@imperial.ac.uk](mailto:j.flanagan@imperial.ac.uk). You can also contact the Research Governance and Integrity Team (RGIT) at Imperial College London if you are not happy with your response.

Thank you for taking the time to read this participant information sheet. We really appreciate your interest in this study.

## Privacy notice for project: The Cancer Loyalty Card Study-2 (CLOCS-2)

### I have questions about this privacy notice, who do I talk to?

If you have any questions or concerns about how your data will be processed within this project, then please contact a member of the CLOCS-2 team in the first instance by emailing [clocs@imperial.ac.uk](mailto:clocs@imperial.ac.uk).

### What is this project about?

Some cancers are diagnosed at an advanced stage, making treatment more challenging. Researchers and medical professionals are keen to find methods for earlier detection to improve health outcomes. Individuals with undiagnosed cancer might use over-the-counter medications, such as painkillers, digestive aids, or herbal remedies, to alleviate symptoms that mimic other common conditions. Store loyalty cards, which record items bought when presented at purchase, provide a valuable source of purchasing data for investigation. Our initial Cancer Loyalty Card Study (CLOCS-1) revealed that women significantly increased their purchases of indigestion medications up to nine months before being diagnosed with ovarian cancer. However, there is limited knowledge about whether early symptom management for other cancer types can also be identified through purchasing data.

CLOCS-2 will look at whether store loyalty card purchase data can detect differences in the shopping habits of cancer patients before they are diagnosed for the following ten cancers: bladder, colorectal (bowel), endometrial, liver, oesophageal, ovarian, pancreatic, stomach (gastric), uterine, and vulval. We plan to recruit 1,450 people with cancer (Cases) and 1,450 people without cancer (Controls) who have a Boots and/or Tesco loyalty card. These retailers will send us up to six years of backdated purchase data, taken from the date of consent. We will compare the data between the two participant groups to see which types of products were bought, in what quantities, and how often, and look for any differences which could indicate an undiagnosed cancer. We will also determine if the results suggest the best time for an intervention to encourage earlier medical help. If so, then this could not only lead to earlier cancer detection but also improve health outcomes.

## What data are you using?

### All participants i.e., Group 1 (Case) and Group 2 (Controls)

The Cancer Loyalty Card Study-2 conducted by Imperial College London, will collect information from you when you provide it to us online. The majority of the information we are collecting will be the same across both participant groups i.e., Group 1 (Cases) and Group 2 (Controls). If you agree to take part in the study, the information we will collect from you will include health data, demographic data and contact details. We will also request on your behalf, your loyalty card purchase data, but only from the high street retailer(s) you authorise us from which to request this data.

If you participate in CLOCS-2, we will collect the following information:

#### CONTACT AND COMMUNICATION INFORMATION, INCLUDING:

- Contact email address and/or phone number, whichever you have provided
- Home address\*
- We will also make records of communications and interactions we have had with you.

The CLOCS-2 team may contact you using your name and contact details to ask any questions we may have once you have completed the survey, or if there are any issues with trying to match your loyalty card details.

\*As detailed in the participant information sheet, we will also use your postcode from your home address to create an Index of Multiple Deprivation (IMD) decile (see <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019> for further information). This decile will serve as a marker of income and wealth and will help us to explore the relationship between health inequalities and purchasing behaviour. The non-identifying IMD decile, rather than your postcode, will be used in the analysis.

#### DEMOGRAPHIC INFORMATION, INCLUDING:

- Your full name, gender, ethnicity, number of people in your household, and age (confirmed by date of birth). Age rather than date of birth will be used in the analysis.

#### LOYALTY CARD DETAILS FROM PARTICIPATING HIGH STREET RETAILERS,

#### INCLUDING:

- The name as written on your loyalty card

- Your loyalty card number(s)

### SPECIAL CATEGORIES OF INFORMATION

We will also collect some 'special categories' of information:

- **Health data:** (Group 1 or 'Case' participants) Cancer diagnosed with, date of diagnosis, and stage of cancer.
- **Health data:** (All participants): Cancer history (if any) and other medical history
- **Health data:** (Women only): Reproductive history
- Relationship status<sup>^</sup>

<sup>^</sup>Although relationship (or marital status) is not considered special category data, as detailed in the informed consent form, sexual orientation is. For those that are joining the study from the same house, it could be possible to derive your sexuality using your gender and your relationship status. It is important that we clarify that this study does not require use of this information so we will not make this connection.

### COPIES OF IDENTITY DOCUMENTS

We may need to ask you to provide two forms of identity if the high street retailer is unable to match the loyalty card details you have provided with an account<sup>1</sup>. In these cases, you will need to upload a copy of one of each type of document listed below:

- one photo ID e.g. driving licence, passport
- one utility bill e.g. council tax bill, gas/electricity bill.

### INFORMATION REQUESTED FROM HIGH STREET RETAILERS

If you are a primary registered loyalty cardholder and have fully enrolled into the study, this means you have consented for us to request your data on your behalf for the loyalty card(s) you provided details for. We are requesting your loyalty card purchase data on your behalf under your right to data portability. The right to data portability allows individuals to obtain and reuse their personal data<sup>2</sup> for their own purposes across different services. It allows

<sup>1</sup> Only primary registered cardholders that the high street retailer is unable to match an account with the details provided may be asked to provide two forms of identity.

<sup>2</sup> The UK GDPR describes personal data as... "any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person".

them to move, copy or transfer personal data easily from one IT environment to another in a safe and secure way, without hindrance to usability.

The right to data portability only applies:

1. To personal data an individual has provided to a controller.
2. Where the processing is based on the individual's consent or for the performance of a contract, and
3. When processing is carried out by automated means.

High street retailers named on the consent form will recall data from your existing records for this research study in accordance with the instructions outlined in our data sharing agreements, and in line with the retailers' data protection policies. When we request your data from the high street retailer, we will send a file which contains your name, loyalty card number, and your home address. We will also send a specially generated unique barcode, which will be linked to your record. We will create this barcode when we request your loyalty card data from the retailer(s). When the retailer(s) sends us the purchase data, they will remove the personally identifiable information. This will leave just the specially generated barcode as a way for us to identify you. The high street retailer will not receive any other details about you, nor have any way to link your barcode with your participant identification number, or your other data. Only key members of the research team will be able to link your purchase data with your health data or link your purchase data with your identity.

The loyalty card purchase data we will receive from the retailers will include the following:

- Detail about products you have purchased including category, product, brand, and date of purchase
- The postcode of the store that you purchased each product from

## OTHER INFORMATION

We will also ask you about the loyalty cards you hold and the frequency which you use these. As detailed in the participant information sheet we will ask you to provide the address of your GP Practice. Please note that we will not provide any details about you to your GP, and we will not request any details about you from them. However, we may contact newly entered GP Practices, to see if they would like to enrol into the study and start recruiting. We will also use the list of GP Practices collated from across all participants to help inform recruitment.

## Legal basis for processing information

Imperial College London, based in the United Kingdom (and who is also the study sponsor) will act as the data controller for the information you provide through the Research Electronic Data Capture (REDCap) platform, and as an independent data controller for your loyalty purchase card data, once we receive it from the high street retailer(s). This means that we are responsible for looking after your information and using it properly. Processing will be limited to accessing your contact details only for the purposes outlined in the participant information sheet and for any additional purposes you have consented to on your signed consent form. Imperial College London is the data controller of the information it collects and processes as described in this Notice. This means that it has the core legal responsibility to safeguard the information and ensure it is processed lawfully. The law is set out in the EU General Data Protection Regulation (called “GDPR”) and a new UK law, the Data Protection Act 2018. In particular Imperial College London must:

- Take steps to ensure that the data it processes is accurate and up to date;
- Give you clear information about its processing of your data, in one or more privacy notices like this one and the respective participant information sheet (referred to together in this section as a “Privacy Notice”);
- Only process your data for specific purposes described to you in a Privacy Notice, and only share your data with third parties as provided for in a Privacy Notice; and
- Keep your data secure.

As a university we use personally-identifiable information to conduct research to improve health care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. The law states that we can only process your personal data if the processing meets one of the conditions of processing in Article 6 GDPR. As we are processing your special category data, we also must meet one of the conditions in Article 9 GDPR. Special Category data includes personal data which relates to your ethnicity, sex life or sexual orientation, health, or disability, biometric or genetic data, religious or philosophical beliefs, political opinions, or trade union membership. Under the data protection legislation, we need to explain the legal basis for holding your data, i.e. which of these conditions apply. Our legal basis for using

your information under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:

- Article 6.1(e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that Imperial College London performs in the public interest, as part of our core function as a university
- Article 9.2(j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purposes. This condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests.

More information on legal basis on processing information can be found on Information Commissioners Office website (<https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/>)

#### WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED?

You can find out more about how we use your information:

- by reading this study specific privacy notice available online from [\[CLOCS-2-Privacy-Notice-V7-14.07.2025-English.pdf\]](#)
- by sending an email to the research team at [clocs@imperial.ac.uk](mailto:clocs@imperial.ac.uk), or
- by ringing us on 07353923305.

#### WHO WILL HAVE ACCESS TO YOUR DATA?

In this research study we will use information that you have provided through REDCap as well as your loyalty card purchase data, received from the high street retailer(s). We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study. People within the College and study team (see section titled 'Sharing your information with others') will use this information to do the research or to check your records, to make sure that the research is being done properly and the information held (such as contact details) are accurate. 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 participant identification number (PIN) instead, and a barcode (for those who are the primary registered loyalty cardholder). 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 up the results in a way that no-one can work out that you took part in the study.

## HOW WILL YOU LOOK AFTER MY DATA?

Your initial data will be captured through REDCap. This is a data collection tool with a simple secure web-based interface designed for clinical researchers to manage their study collection needs. Imperial College London is registered as a REDCap partner with the REDCap consortium. Under the terms of this licence, a central instance of the software has been installed on Information and Communication Technologies run College infrastructure which can support multiple concurrent projects. The software is provided for the purposes of non-commercial research only when the research activity is led by an Imperial College Chief Investigator (CI). Imperial College provides a secure hosting environment for the REDCap software. Data will be transferred periodically for processing into Imperial College London's ISO27001 certified secure environment, called the "Secure Enclave".<sup>3</sup> This fully managed infrastructure and secure environment provides high availability, resilience, and business continuity through multiple servers, back-ups, and disaster recovery measures. The Secure Enclave is an isolated environment within the Imperial College network. It is split into two main sections, one for holding identifiable data and the other for de-identified research data. It was created to assure Imperial College that groups holding personal health data complied with all their processing requirements. All access into the enclaves is controlled and audited by the Security Manager and Quality Assurance Officer. The environment is Data Security and Protection Toolkit compliant and ISO27001 certified.

A robust data security model has been designed to protect sensitive personal and medical data from the potential risk of unauthorised access or distribution. All information input, viewed or extracted, is protected so that only users with the proper authority and access can create, view, amend or delete information. Access to the system will be governed by authentication and authorisation privileges that will check whether:

- Access is by an authorised person, and the user is whom they say they are. With entry to the enclave controlled by username, and a complex password requirement.
- The user accessing the system is authorised to do what they are attempting to do. That includes searching, updating, deleting, and uploading information at the appropriate authorised level for the database(s) or table(s).

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<sup>3</sup> However, until recruitment has closed, your data will also remain securely on REDCap for the purposes of project management and facilitation. Once recruitment has closed, your data will be fully deleted from REDCap and only held in the secure enclaves.

In summary, the security architecture provides the optimal level of protection available through implementing best practice network, hardware, software, and data security measures.

#### HOW LONG WILL YOU KEEP IT FOR?

Consent forms will be kept for 10 years after the end of the study. After this period, all paper documents and electronically stored identifiable data will be destroyed or deleted according to Imperial College London's data deletion and retention policies. Contact details will be maintained solely for project management and facilitation while the project is actively recruiting, and data is stored on REDCap. Once data is fully transferred from REDCap to secure enclaves, contact details will be permanently deleted, unless you have given permission for us to retain them for follow-up research, or to receive the study results once published.

Past purchase data will remain pseudonymised until either the results are published, or five years after the study has completed, whichever occurs first. After five years, all past purchase and health data will be fully anonymised, and any links to identifiable information will be deleted.

Any identification documents uploaded to REDCap, such as copies of photo IDs and utility bills, are collected solely for identity verification in accordance with high street retailers' data portability policies for sharing data with third party organisations. These documents are collected for our own data checks and will not be shared with the retailer(s). These documents will be permanently deleted once we receive your purchase loyalty card data from the retailer. If the retailer still cannot match your details with an account and the CLOCS-2 research team cannot resolve this, your identity documents will be permanently deleted at the earliest opportunity.

In summary, Imperial College London will keep your personally identifiable data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 5 years after the study has completed in relation to your health data and loyalty card purchase data (at which point your data will be fully anonymised).

- Your uploaded identity documents will be kept only until we receive the loyalty card purchase data, or until all efforts to match the loyalty card details with an account through the high street retailer(s) have been exhausted.
- Your contact details will be retained for the duration of the recruitment period. Once the data on REDCap is deleted, your contact details will also be permanently deleted, unless you have authorised us to retain them for follow-up studies or to receive the study results.

The study is expected to finish on 30<sup>th</sup> April 2027.

Further information on Imperial College London's retention periods may be found at <https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf>.

## How will we use information about you?

We will need to use your personally identifiable information to request your purchase data, on your behalf, from the high street retailer(s) i.e., Tesco and/or Boots. We will use the information you have provided to identify you only to the high street retailer that you have authorised us to request your purchase data from, as indicated on your signed consent form. This information will include your:

- Name
- Contact details e.g., email and/or telephone number
- Home address
- Name on your loyalty card, and loyalty card number

## WHAT INFORMATION WILL THE HIGH STREET RETAILER(S) HAVE ABOUT ME?

- Your full name
- Your loyalty card details e.g., the name associated with your loyalty card and your loyalty card number
- Your home address

The data listed above will already be known to the high street retailer. These details will have been supplied by you when you first registered for your loyalty card. They will not be

receiving any information about you that they did not know already, except in the case where you supply a new home address which you have not yet linked to your loyalty card. It is important therefore that the home address you provide us is the one connected with your loyalty card account. If you need to update your contact details (including your address) with the high street retailer, you should do so before enrolling into this study.

#### WHAT INFORMATION WILL THE HIGH STREET RETAILER(S) NOT HAVE ABOUT ME

The participating high street retailers will not have access to any of the information listed below:

- Any of the data collected about you as part of the CLOCS-2 survey
- Whether you have cancer or not.

We will use the combined information provided by the high street retailers and the information collected from the CLOCS-2 survey for the purpose of identifying differences in purchase behaviour between case participants (Group 1) and control participants (Group 2) in the time leading up to cancer referral and/or diagnosis.

#### 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, but we will keep information about you that we already have, because some research using your data may have already taken place and this cannot be undone. However, we will remove you from the dataset for any future studies requesting use of this data.

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 if this could affect the wider study, or the accuracy of data collected.

#### SHARING YOUR INFORMATION WITH OTHERS

We will only share your personal data with certain third parties for the purposes referred to in this privacy notice and by relying on the legal basis for processing your data as set out above. We may share your personal data with:

- Other Imperial College London employees (including staff involved directly with the research study or as part of certain secondary activities which may include support functions, internal audits, ensuring accuracy of contact details etc.), Imperial College London agents, contractors and service providers (for example, suppliers of printing

and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third-party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

- Tesco Stores Ltd., Welwyn Garden City, United Kingdom, AL7 1GA and Boots UK Ltd. (Nottingham, NG2 3AA); only if you have consented us to request your loyalty purchase data from one or more of these companies. We will make a request sending the loyalty card details you have provided, your full name, and your address. The next two sections outline what information the high street retailer(s) will have or will not have about you.

#### POTENTIAL USE OF STUDY DATA FOR FUTURE RESEARCH

When you agree to take part in a research study, the information collected either as part of the study or in preparation for the study, may if you consent to this, be provided to researchers running other research studies at Imperial College London and in other organisations. These third-party universities or organisations may be involved in research either in this country, or abroad. Your information will only be used to conduct research in accordance with legislation including the GDPR and the [UK Policy Framework for Health and Social Care Research](#). This information will not identify you and will not be combined with other information in a way that could identify you, be used against you, or used to make decisions about you. Your information will only be used by organisations and researchers to conduct research in accordance with recognised national or international good practice guidelines and in accordance with research ethics. For the CLOCS-2 study, this means we will only share anonymised information collected by us and information that we are a data controller for. Any data access requests are subject to strict approval processes and restrictions. If you have not agreed to sharing your anonymised data for other research studies, or if you withdraw from this study, then your data will be excluded from any future granted data access requests.

#### INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the United Kingdom (for example, to a research partner, either within the European Economic Area (EEA) or to other countries outside the EEA. Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation.

If the data is transferred to a country which is not subject to a UK adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient research partner that incorporates UK approved standard contractual clauses or utilise another transfer mechanism that safeguards how your personal data is processed.

### COMMERCIALISATION

Data from the study may, if you consent to this, also be provided to organisations not named in this privacy notice, e.g. commercial organisations or non-commercial organisations for the purposes of undertaking the current study, future research studies or commercial purposes such as development by a company of a new test, product, or treatment. We will ensure your name, and any identifying details will NOT be given to these third parties, instead you will be identified by a unique study number with any sample having the potential to generate 'personal data.'

Aggregated (combined) or anonymised data sets (all identifying information is removed) may also be created using your data (in a way which does not identify you individually) and be used for such research or commercial purposes where the purposes align to relevant legislation (including the GDPR) and wider aims of the study. Your data will not be shared with a commercial organisation for marketing purposes.

### Your rights as a data subject

Under the data protection laws, you have a number of rights in relation to the processing of your data. These are limited by the lawful basis under which we hold your data. Your rights are:

- Right to request access to your data as processed by Imperial College London and information about that processing
- Right to rectify any inaccuracies in your data
- Right to place restrictions on our processing of your data.

If you would like to exercise any of your rights as outlined above, you can contact Imperial College London's Data Protection Officer via email at [dpo@imperial.ac.uk](mailto:dpo@imperial.ac.uk), via telephone on 020 7594 3502 or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

Under your right to data portability, you will be able to request your purchase data from the high street retailer(s) using a subject access request (SAR). However, we advise you send requests of this nature directly to them, as we will refer all requests we receive of this nature to them in any case.

You can find Imperial College London's data protection webpage at this link:

<https://www.imperial.ac.uk/admin-services/legal-services-office/data-protection/>. However, this document is the primary notice relevant to the information we collect from participants of the Cancer Loyalty Card Study-2 and takes precedence for all purposes described here.

## **COMPLAINTS**

If you wish to raise a complaint about how we have handled your personal data, please contact the research team first by sending an email to the Chief and Principal Investigator of the study, Prof James Flanagan [j.flanagan@imperial.ac.uk](mailto:j.flanagan@imperial.ac.uk), or by ringing us on 07353923305.

Following our response, if you are not satisfied please contact Imperial College London's Data Protection Officer via email at [dpo@imperial.ac.uk](mailto:dpo@imperial.ac.uk) or via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you remain unsatisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO)-via [www.ico.org.uk](http://www.ico.org.uk). Please note the ICO does recommend that you seek to resolve matters with the data controller (us) first before involving them.