

## **PARTICIPANT INFORMATION SHEET**

**Title of Study: Physical Activity in people with Chronic Lymphocytic Leukaemia (CLL): Exercise advice received and preferences of exercise programs. (PatientQ-CLL)**

**University of Surrey Ref: FHMS 21-22 261 EGA**

**PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS**

### **Section: Taking Part**

#### **Invitation Paragraph**

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to participate will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. If you have any questions, you can contact us using the contact details at the end of this information sheet.

The research is being undertaken by Dr David Bartlett and his PhD student Ellie Miles from the School of Biosciences and Medicine at the University of Surrey. The study is part of a larger research initiative to increase physical activity awareness and participation for people with chronic lymphocytic leukaemia. The purpose of this information sheet is to familiarise you with the study, to let you know what your role is as a participant in the study and to familiarise you with how your data will be collected and stored.

Your participation in the study is entirely voluntary. You can withdraw from the study at any time without giving a reason. Please contact us if you wish to withdraw from the study, and we will act accordingly. You can discuss the study with others if you wish. If you have any questions, please let one of the team members know directly or contact us using the contact details at the end of this information sheet.

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

This study aims to gather information on the physical activity levels of individuals with CLL and compare them to varying levels of treatment (i.e., no treatment, targeted therapy, chemotherapy, post-treatment) and demographics. Understanding the physical activity behaviours and beliefs of people with CLL will allow better advice to be provided to improve their health status.

To do this, we ask you to complete a 240-part online questionnaire in your own time with no time restrictions. Questions will cover your personal information, clinical status, general health, physical activity levels, exercise advice received by practitioners and preferences on exercise programmes.

### **Who is responsible for this study?**

This study is the responsibility of Ellie Miles, supervised by Dr David Bartlett, at the University of Surrey and involves collaborators at the CLL Support Association.

### **Why have I been invited to take part?**

You are invited to participate in this study because you are a member of the Chronic Lymphocytic Leukaemia (CLL) Support Association and have CLL, either as treatment naïve, have been treated or are currently on treatment. As this is a questionnaire, you are only eligible to complete the study if you fulfil the below inclusion criteria. If you do not fulfil each of these criteria, you are ineligible to complete the survey and will be excluded from the study.

#### Inclusion criteria

- Have a confirmed diagnosis of CLL.
- Aged >18 years.
- Have access to a computer/laptop.
- A good understanding of the written English language is essential.
- Able to provide written informed consent.

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

Participation is voluntary, and you do not have to take part. We will describe the study in this information sheet. Once you have read the information sheet, you will be provided with the option to complete the online questionnaire. Please ensure you read this information sheet fully and if you have any questions, please contact us before you begin the questionnaire. We advise you to process the information overnight before starting to fill in the questionnaire. Please contact us if there is anything that is not clear during the questionnaire or if you have any questions or need more information.

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

If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form to confirm your agreement to participate. After that, you will be taken through a series of questions separated into specific sections: Personal Information; Self-reported health- and disease-related characteristics; Quality of Life questionnaire; Physical activity levels; Interest and advice on physical activity. The questionnaire will take approximately 1 hour to complete. You can complete the questionnaire in your own time with no time restrictions and if needed you can come back to the questionnaire multiple times before submission. Once the questionnaire has been completed, you will get given a copy of your consent form and questionnaire to keep.

### **What happens if I do not want to take part or if I change my mind?**

You are free to withdraw from the study anytime during the questionnaire or after the completion of the questionnaire, without giving a reason. To withdraw from the study while completing the questionnaire, simply stop filling in the questionnaire. To withdraw after submission of a completed questionnaire please email a member of the research team and we will act accordingly.

### **What happens to my data if I want to withdraw?**

Anonymised data already collected cannot be removed from the study and will be usable by the research team, however, any personal information and details will be removed from our database if withdrawal occurs after completing the questionnaire.

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

The data generated from this study will help develop a greater understanding of the factors influencing physical activity participation in CLL. In turn, this study will help to create effective strategies to increase physical activity and thus increase the quality of life of people with CLL.

### **Are there any potential risks involved?**

A possible disadvantage to participating in the study is that within the questionnaire, you will be asked about your health which could cause distress. To reduce this risk, we will ensure the questions are more general for the CLL population than specific personal experiences to alleviate the risk. If such an incident occurs, we may direct you to your clinical care team for support.

### **How is the project being funded?**

This research is a student project as part of a Postgraduate Research Degree (PhD).

### **Will my participation be kept confidential?**

We are responsible for ensuring your participation is kept strictly confidential, and any data is kept secure and used only in the way described in this information sheet.

The University of Surrey and/or regulators may review your information for monitoring and audit purposes who will treat your data in confidence. You will not be able to be identified in any subsequent reports or publications.

### **Will my data be shared or used in future research studies?**

We would like your permission to share your findings from the Questionnaire to aid with understanding potential factors, such as CLL symptoms, treatment stage and treatment-related side effects, which could impact physical activity participation. Deidentified data may be used for publication to inform the scientific community of the results.

We would also like your permission to keep non-identifiable study data and personal data for potential use in future studies.

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

We will produce a final report summarising the main findings. This research may be published in and disseminated to the scientific community via peer-reviewed journals and international conferences. The general public will be engaged via the release of results to the local and national media, relevant charities, community networks and invited talks at the University when appropriate. All participant data will be anonymised.

You can also contact the study team to find out the results of the research.

### **Who has reviewed this study?**

This research has been reviewed by an independent group of people, called an Ethics Committee. This study was reviewed and given a favourable ethical opinion by the University of Surrey Ethics Committee.

## **Section: Your personal data**

### **What is personal data?**

'Personal Data' means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to completing the study and this section describes what that means.

The information that we will collect will include your name, contact details and date of birth, which is regarded as 'personal data' and ethnic origin, family information, level of education and health, which is regarded as a 'special category personal data'. We will use this information as explained in the 'What is the purpose of the study' section above.

## **Who is handling my personal data?**

The University of Surrey, who has the legal responsibility for managing the personal data in this study, will act as the 'Data Controller' for this study. The research team will process your personal data on behalf of the controller and is responsible for looking after your information and using it properly.

## **What will happen to my personal data?**

As a publicly-funded organisation, we must only use **identifiable personal** information from people who have agreed to participate in research and process this data fairly and lawfully. The University of Surrey processes personal data to carry out research in the **public interest**, and special category data is processed on an additional condition necessary for **research purposes**. This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

Your personal data will be held and processed in the strictest confidence and in accordance with current data protection regulations. When acting as the data controller, the University will keep identifiable information about you for **six** years after the study has finished, after which time any identifiers will be removed from the aggregated research data.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you decide to withdraw from the study, we may not be able to withdraw your data. We will keep and use the minimum amount of your personally identifiable information that we have already collected to complete the study.

If you wish to complain about how we have handled your personal data, you can contact our Data Protection Officer, who will investigate the matter ([dataprotection@surrey.ac.uk](mailto:dataprotection@surrey.ac.uk)). If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can contact the Information Commissioner's Office (ICO) (<https://ico.org.uk/>).

You can learn more about how we use your information <https://www.surrey.ac.uk/information-management/data-protection> and/or by contacting [dataprotection@surrey.ac.uk](mailto:dataprotection@surrey.ac.uk) .

## Section: Further information

### **What if you have a query or something goes wrong?**

If you are unsure about something, you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO)  
Research and Innovation Services  
University of Surrey  
Senate House, Guildford, Surrey, GU2 7XH  
Email: [rigo@surrey.ac.uk](mailto:rigo@surrey.ac.uk)

The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have concerns about how you have been treated during the course of this study, then you should follow the instructions given above.

### **Who should I contact for further information?**

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Ellie Miles (PGR)  
Department of Nutritional Sciences  
Faculty of Health & Medical Sciences,  
The University of Surrey,  
Guildford, Surrey GU2 7WG  
Email: [e.e.miles@surrey.ac.uk](mailto:e.e.miles@surrey.ac.uk)

Dr David Bartlett  
Department of Nutritional Sciences  
Faculty of Health & Medical Sciences,  
The University of Surrey,  
Guildford, Surrey GU2 7WG  
Telephone: 01483 683995  
Email: [d.bartlett@surrey.ac.uk](mailto:d.bartlett@surrey.ac.uk)

### **Sources of support**

If you require any additional support during or after the study, we will direct you to your clinical care team.

**Thank you for reading this information sheet and considering participating in this research. Now that you've read the participant information sheet, we advise you to process the information overnight before starting the questionnaire.**