CLL SUPPORT

# Participant Information Leaflet – Online Survey on Fatigue

## Title of the Study

"Understanding Fatigue in People Living with Chronic Lymphocytic Leukaemia

## Invitation to Take Part

You are invited to take part in a research study. The study is about fatigue in people living with CLL or SLL To do this we also need to know about fatigue symptoms in people who do not have these diseases.

Before you decide whether or not to participate, please take time to read the following information carefully. It explains why the research is being done and what it involves.

## What is the purpose of the study?

The aim of this study is to better understand the experiences of fatigue in people living with CLL. Fatigue is one of the most common and distressing symptoms reported by people living with CLL, but we still know relatively little about how it affects daily life. The results will help us design better ways to assess fatigue and support people living with CLL in the future.

## Why have I been invited?

You have been invited as a person who does not have CLL or SLL. It does not matter whether you personally suffer fatigue since we just need a group of people without CLL or SLL who can form a comparison group when we look at our results.

## Do I have to take part?

No. Participation is entirely voluntary. If you do take part, you may stop at any point before submitting your answers, without giving a reason.

## What will happen if I take part?

- You will be asked to complete an online questionnaire.
- It should take about 10-15 minutes to complete.
- The questionnaire will ask about:
  - your experiences of fatigue (or not)
  - any impact fatigue might have on your daily activities, mood, and quality of life
  - some background information (such as age and general health).

## Are there any possible benefits of taking part?

There may be no direct benefit to you personally. However, your contribution will help improve understanding of fatigue in CLL and may lead to better support and resources for patients in the future. We hope that as things move on the “fatigue scale” we develop may be used by patients and doctors to improve how fatigue is recognised and treated in CLL.

## Are there any risks of taking part?

Questions may touch on personal experiences of fatigue. If you feel upset at any point, you can stop the survey. Details of support organisations are detailed below.

## How will my data be kept confidential?

- Your responses will be fully anonymous and will not identify you personally in any way.
- Data will be stored securely on password-protected systems
- Only members of the research team will have access to the anonymous data.
- Results will be presented in reports and publications in a way that does not identify any individual.

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

The results will be used for research publications, presentations at conferences, and reports to patient organisations. A summary of the findings will be made available to participants who wish to receive it.

## Who is organising and funding the research?

This research is being carried out by CLL Support in collaboration with academics and clinicians.

## Who has reviewed the study?

The study has been reviewed and approved by a Research Ethics Committee at the University of Plymouth to ensure it is ethically sound and safe for participants. For further information about this ethical review please contact research.ethics@plymouth.ac.uk

## What if I have questions or concerns?

At any time you can stop completing the survey and your results will not be considered. Once submitted all results are anonymous so unfortunately, we cannot delete any submitted results from individuals as we cannot identify you.

If you have any questions about the study, please contact:
CLL Support ; Email: info@cllsupport.org.uk. Helpline: 08009774396
If taking part raises any concerns or distress, you may wish to contact your GP.