Texting for Wellness (Lung Support)

PARTICIPANT INFORMATION STATEMENT

What is this study about and who can participate?
You are invited to take part in a research study that aims to help researchers understand if receiving a text message support program during the COVID-19 pandemic is useful and supports people with chronic lung disease.

You are eligible to participate if you are over 18 years of age, own a mobile phone with an Australian mobile number, are living with chronic lung disease and are willing to provide informed consent to participate. To receive text messages, you will need a working mobile phone, with sufficient charge, memory and reception.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don’t understand or want to know more about.

Participation in this research study is voluntary. By giving your consent to take part in this study you are telling us that you:
- Understand what you have read.
- Agree to take part in the research study as outlined below.
- Agree to the use of your personal information as described.

Who is running the study?
The study is being carried out by a team of researchers based at Westmead Applied Research Centre at the University of Sydney. Their names are Professor Julie Redfern, Dr Stephanie Partridge, Ms Rebecca Raeside, Dr Karice Hyun and Ms Anna Singleton.

What will the study involve for me and how much time will it take?
If you agree to participate you will receive a free weekly (4-5 text messages per week) text message program for 6 months to your mobile phone related to your health condition, tips on living healthily (diet, physical activity and general health), certain basic government advice about COVID-19 and the value of medication adherence. You will also be asked to complete a brief online survey at the end of the program. Completing the approximately 3-minute survey will allow the researchers to evaluate if the program is useful and helpful for participants and to gain suggestions for improvement.

If you lose your phone, are about to travel overseas or want to change your phone number, please send a text message or email (Rebecca Raeside: rebecca.raeside@sydney.edu.au) and we will pause the Study or help you re-register with your new number.

What if I need medical advice?
The study provides short and general information by way of text messages written in simple English of approximately 160 characters or less. It does not provide comprehensive or detailed information. The
messages that you will receive have been designed for people with chronic lung disease. However, it is important to appreciate that these messages are not tailored to meet any unique features of your diagnosis and/or lifestyle. We have not, and will not, verify the information that you provide to us (including that we will not conduct any examination or assessment of you).

The study is designed to provide you with general information, primarily in the form of one-way communication from us to you. We do not monitor the study daily. If you send us a message that requires a response, please expect a delay of approximately 2 – 3 days. The study should never be used as a substitute for seeking professional advice or help. In particular, the study is not intended for and should not be used for any therapeutic purpose, including the diagnosis, prevention, monitoring, treatment or alleviation of any disease.

If you require or desire medical advice, please contact a qualified healthcare professional (e.g. your general practitioner or specialist). Similarly, for advice on diet or nutrition, please contact a suitably qualified professional (e.g. a general practitioner or accredited practising dietitian). We are not able to provide you with such advice.

If any of the information in our messages contradicts recommendations or advice that you have received from the Australian Government (e.g. in respect to COVID-19 restrictions, which are in a constant state of change), a qualified healthcare professional (e.g. your doctor) or the like, their advice should take precedence to the general information that we provide.

In life threatening or emergency situations, please call Triple Zero (000) for Police, Fire or Ambulance. The study is not suitable for use in such situations.

Do I have to be in the study? Can I withdraw from the study once I've started?
Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by replying ‘STOP’ to any of the messages and one of the research team will cease the messages at their earliest capacity. If you decide to withdraw from the study, we will not collect any more information from you. Any information that we have already collected, however, will be kept in our study records and may be included in the study results.

Are there any risks or costs associated with being in the study?
We do not charge you for taking part in this study and you will not receive any payment for your involvement. You are responsible for the payment of personal fees with your mobile phone carrier, including monthly subscription fees and fees for any messages that you send to us. In Australia, the majority of mobile phone subscription plans do not charge their customers for receiving standard in-coming text messages. If you are unsure, please clarify with your provider before signing up for the study.

Aside from giving up your time, we do not expect that there will be any significant risks associated with you taking part in this study. There is a very low risk that another person could access on health information via your mobile phone. This can be minimised by ensuring your phone or hand-held device has a secure passcode lock and message preview function is disabled.

Are there any benefits associated with being in the study?
We hope that participants will benefit from the information they receive though the text messages. It is possible that participation in this study may reduce your risk factors for your health condition. There are also potential benefits to others because if the messages are useful then they may be made more widely available to more people.

What will happen to information about me that is collected during the study?
By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. All information will be treated confidentially and stored securely accordingly to ethical, legal and government regulations. Any identifiable information that is collected about you in connection with this study will remain confidential, will only be used for the purpose of this research project and will only be disclosed with your permission, or except as required by law.

As noted on the registration page, to help us to provide the Program, we have engaged an Australian company, Known Pty Ltd (ABN 40 116 431 700) trading as ‘Burst SMS’ (“Burst SMS”). All of the text messages that we will send you will be sent through Burst SMS’s platform. Any replies that you send will also come through this system. To participate in the study, you will need to directly provide Burst SMS with your mobile number and name, which you can do through the link at the end of the registration page. Please read our Privacy Statement and that of Burst SMS, for we will collect, store and use your information in accordance with our Privacy Statement and that Burst SMS can do so in accordance with their statement.

We will store your personal information securely on the University of Sydney research portal for 5 years after completion of the study then destroyed. As for Burst SMS, please refer its Privacy Statement.

Study findings may be published, but you will not be individually identifiable in these publications. We will keep the information we collect for this study, and we may use it in future projects. By providing your consent you are allowing us to use your information in future projects. We don’t know at this stage what these other projects will involve. We will seek ethical approval before using the information in these future projects.

The Study also involves a very similar program being offered to adults who have completed active breast cancer treatment. By providing your consent, you are agreeing to the findings from this part of the study being published separately and/or in combination with the other part.

Can I tell other people about the study?
Yes, you are welcome to tell other people about the study. If they also are also eligible, they can also volunteer to participate.

What if I would like further information about the study?
When you have read this information, Rebecca Raeside, or a nominated research team member, will be available during business hours to answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact rebecca.raeside@sydney.edu.au. At the end of the study, you have a right to receive feedback about the overall results of this study. You can also tell us that you wish to receive feedback by contacting rebecca.raeside@sydney.edu.au.

What if I have a complaint or any concerns about the study?
Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [2020/181]. As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:
- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

*This information sheet is for you to keep*