

## PARTICIPANT INFORMATION STATEMENT

### From Symptoms to Surgery - The Journey of Young-Onset Colorectal Cancer in Rural Australia: A Qualitative Study

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<b>Chief Investigator</b>	<b>Dr Rob Knox</b> FRACS, MBBS Director of Surgery, Orange Hospital, Western NSW Local Health District (WNSWLHD) General surgery, Colorectal surgery
<b>Associate Investigator</b>	<b>Dr Indra Choudhury</b> MBBS, MSc (Orth & Rehab), MMST (Silver Medalist), PhD, AFHEA (UK) Year 5 Convenor / Lecturer in Medicine Charles Sturt University, School of Rural Medicine
<b>Associate Investigator</b>	<b>Ms Leanne Sargeant</b> McGrath Colorectal Cancer Specialist Nurse, Daffodil Cottage Cancer Centre Bathurst Health Service, WNSWLHD

## INVITATION

You are invited to participate in a research study on the journey of young-onset colorectal cancer in rural Australia.

The study is being conducted by a medical student researcher from the School of Rural Medicine at Charles Sturt University, under the supervision of experienced clinicians and researchers. Charles Sturt University is an Australian University, TEQSA Provider Identification: PRV12018. Charles Sturt University CRICOS Provider: 00005F

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with family members, friends, or your GP or treating team.

### What is the purpose of this study?

Bowel cancer in people under 50 is becoming more common and is often diagnosed later than ideal. Many patients describe delays, multiple healthcare visits, or difficulties accessing investigations before diagnosis.

This study aims to understand:

- patient experiences before diagnosis

- barriers to timely diagnosis in rural areas
- how diagnostic delay may affect treatment and surgery

## Why have I been invited to participate in this study?

We are seeking adults aged 18--49 who were diagnosed with colorectal (bowel) cancer under the age of 50 who lived in a rural or regional area at the time of diagnosis.

## What does this study involve?

If you agree to participate, you will be asked to:

- Fill out a small questionnaire about your cancer journey
- Participate in an online **interview** lasting approximately **40–60 minutes**
- The interview will be audio recorded to allow for transcription. You will be provided with a copy of the transcript and have the opportunity to edit it
- You will be asked about symptoms, healthcare visits, diagnosis, treatment, and challenges you experienced

You may choose not to answer any question and can stop the interview at any time.

## Are there risks and benefits to me in taking part in this study?

We recognise that discussing your cancer journey may be distressing and may bring up emotional or distressing memories for you. If you appear uncomfortable or distressed at any time during the interview, the interviewer may pause or stop the interview, even if you do not explicitly request to. You are also free to voluntarily pause or stop the interview at any point.

Should you experience distress during or after the interview, we suggest you contact one of the following support resources:

1. Your General Practitioner or bowel care nurse
2. Bowel Cancer Australia on 1800 727 336 | <https://www.bowelcanceraustralia.org>
3. The Cancer Council (support line) 13 11 20
4. CanTeen (Young People Living With Cancer) Phone: 1800 835 932 <https://www.canteen.org.au>
5. McGrath Foundation – Cancer Support <https://www.mcgrathfoundation.com.au>
6. Redkite (for young adults with cancer and families) <https://www.redkite.org.au>
7. Lifeline – 24 hrs, 7 days per week – 13 11 44 or text 0477 13 11 14 or [www.lifeline.org.au](http://www.lifeline.org.au) for online chat
8. Beyond Blue – 24/7 - 1300 22 4636 for brief counselling or <https://www.beyondblue.org.au/get-support/talk-to-a-counsellor> for web chat.

A qualified colorectal cancer specialist nurse experienced in cancer care will be present in the interview along with the student researcher.

While there may be no direct benefit to you, and you will not be paid, your participation may help improve:

- early recognition of bowel cancer in younger people
- rural access to diagnostic services
- future patient care pathways

## How is this study being paid for?

This study is being conducted as part of the requirements of the medical student researcher's degree and does not therefore require funding. Academic supervision is provided by the School of Rural Medicine, and clinical supervision and oversight is being provided by a General and Colorectal Surgeon experienced in colorectal cancer.

## Will taking part in this study cost me anything, and will I be paid?

There is no reimbursement or payments to participants. You have the right to withdraw partway through the study without penalty.

## What if I don't want to take part in this study?

Participation in this research is entirely your choice. Whether or not you decide to participate, is your decision and will not disadvantage you. Choosing not to take part will not affect your medical care or relationship with any healthcare provider. Only those who give their informed, written consent will be included in the project.

## What if I participate and want to withdraw later?

If you wish to withdraw your consent you can do so by contacting Coordinating Principal Investigator, Dr Catherine Keniry (ckeniry@csu.edu.au). There is no penalty for withdrawing consent and measures will be taken to destroy your information where practicable. A copy of the transcript from your interview will be sent to you and you will be given a 14-day period to review this before it is de-identified. Withdrawal of consent will result in your interview recording and transcript being deleted if withdrawal occurs before it is de-identified for thematic analysis. De-identified data however cannot be destroyed.

## How will my confidentiality be protected?

Data will be collected on a password protected server which will only be accessible by the data collector (NB) and direct supervisors (CK and RK). This ensures that data access is strictly controlled and limited to authorised research team members. To enhance security, interview transcripts will be de-identified - names will be replaced with pseudonyms (codes) which will only be known by the interviewing researcher. Information referring to third parties which might reveal identity will be redacted. All data will be retained for a minimum of five years after the project's completion, and stored securely according to CSU's data management policies. Interviews and the associated records of them are strictly confidential and will not be disclosed to persons outside the research team. No identifying information will be included in publications or presentations

## What will happen to the information that I give you?

This study is part of a student-led research project required for completion of the Doctor of Medicine with Charles Sturt University. Deidentified data will be included in the final report submitted to the University as part of this requirement. Additionally, the research may be submitted to be published in academic journals or presented at conferences. Any data collected from the study will not be presented in a way that includes identifying information. At times, direct quotes from the interviews may be included in the report. All other information will be presented in a generalised way.

Interviews conducted as part of this research will be audio recorded and transcribed verbatim. You will be given the opportunity to review your transcript once completed in order to edit or erase your contribution.

1. During the study:  
Please be advised that interviews will be audio recorded and transcribed for analysis. You will be offered the opportunity to choose a pseudonym to be used in the research report and publications. Alternatively, the researchers will identify a pseudonym. You will be offered the opportunity to review the transcript of the interview which will be emailed within one week of the interview. Participants will be advised that they must respond with any edits / amendments to their transcript within two weeks from receipt. After this time, the transcript will be de-identified and withdrawal of individual participant data will not be possible.
2. After the study:  
If participants wish to receive a copy of the report, they can contact [srm-research@csu.edu.au](mailto:srm-research@csu.edu.au). If the findings are published, the publication will be shared on the CSU School of Rural Medicine website (<https://science-health.csu.edu.au/schools/medicine/research>).
3. Dissemination and Publication:  
Results will be submitted to peer-reviewed journals focusing on cancer and rural health to reach a wide audience of academics and practitioners. Findings may also be presented at relevant

conferences (e.g., cancer, rural health) to engage with stakeholders and disseminate knowledge to a broader audience.

4. Future research:

Data collected during the study will be deposited in an open-access repository to ensure that it is publicly accessible for researchers, policymakers, and practitioners interested in yCRC in Australia. All data will be anonymised to protect the identities of participants and ensure compliance with ethical standards and data protection regulations.

5. Feedback:

Feedback from the participants regarding the study is always welcome.

### **What should I do if I want to discuss this study further before deciding?**

If you would like further information, please contact Dr Catherine Keniry at: [ckeniry@csu.edu.au](mailto:ckeniry@csu.edu.au).

### **Who should I contact if I have concerns about the conduct of this study?**

Charles Sturt University's Human Research Ethics Committee has approved this project (Ethics#:XXXXX ). If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Research Integrity Unit via the following contact details:

The Presiding Officer  
Human Research Ethics Committee  
Research Integrity Unit  
Locked Bag 588  
Wagga Wagga NSW 2678  
Phone: (02) 6933 4213  
Email: [ethics@csu.edu.au](mailto:ethics@csu.edu.au)

Any issues you raise will be treated in confidence and investigated thoroughly, and you will be informed of the outcome.

### **Conclusion**

Thank you for considering this invitation. This information sheet is for you to keep.