

**BRIDGING THE GAP:
A PALLIATIVE APPROACH TO CARE FOR YOUNG ADULTS**

LETTER OF INFORMATION

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Purpose of the Study

We are conducting a study to develop a strategy to inform a palliative approach to care for young adults (18 – 35 years) with life-threatening conditions. In a palliative approach, young adults, their parents and caregivers, professionals, community providers and volunteers come together to ensure the well being of young adults.

This research is being conducted because there are no coordinated health and community services that anticipate and manage young adult palliative conditions, coordinate social services, and support their pursuit of meaningful activities.

What will happen during the study?

We invite you to contribute to the development of the strategic plan. There are three phases of this study that you can be involved in: 1) brainstorming; 2) sorting and rating; and 3) participation in a face-to-face workshop. You do not have to commit to participate in all three phases.

We are using a concept mapping process. This process brings together diverse groups of people (e.g., young adults, their parents and service providers) to organize ideas to form a common plan. Phase 1 and 2 are completed online using a secure platform. You can enter the online site as many times as needed. Phase 3 is a half-day face-to-face workshop. The result will be a strategy to develop health, social service, community, and volunteer strategies, collaborations, and programs appropriate to the needs and goals of young adults with life-threatening conditions.

We hope that you will be able to participate in all three phases of the study. However, if you are unable to do so, the data you provide in Phases 1 and 2 will continue to be valuable in Phase 3.

Prior to starting the concept mapping process, you will be asked for some background information. For example, if you are a young adult, you will be asked some questions about your age, and how long you have lived with your condition. If you are a health care professional, community provider or volunteer you will be asked your job title and profession, your work setting and how long you have worked there.

Are there are any risks to the study?

It is not likely that you will experience any discomfort associated with answering the online questions in Phase 1 and 2, or participating in the collaborative process in Phase 3. The questions will be focused on new ideas for developing a palliative approach to care for young adults with life threatening conditions. For anyone who experiences any discomfort or uncertainty participating in this study, a professional counsellor will be available for support by phone or in person. To obtain this support please email Dr. Karen Cook at kcook@athabascau.ca. Finally, you may decline participation at any time; in Phase 1 and 2 by exiting the online system and in Phase 3 by leaving the workshop.

Are there any benefits to participating in this study?

What is learned from this study will set a strategic direction for the development of a palliative approach to care for young adults with life threatening conditions. It is hoped that the recommendations in the strategic direction will enhance care and support for young adults, and forge new partnerships and awareness among professionals and community members to create a palliative approach to care.

Confidentiality

In phases 1 and 2 the information that you provide is confidential as no identifying factors such as your name will be asked. In Phase 3, participants will be asked not to divulge confidential information. Confidentiality of who attends the workshop cannot be secured; however, participants will be advised to only share what they are publically comfortable sharing, and if they talk about the workshop after the event, they will be asked to discuss concepts/ideas presented and not identify what specific people shared.

You will not be identified in any way if the results are published and nothing will connect you to your responses. All data will be stored in a secure computer file. The data will be accessible only to Dr.'s Karen Cook and Kim Bergeron. Once the study has been completed, the data will be destroyed.

What if I change my mind about being in the study?

Your participation in the study is voluntary, and you can withdraw from the study at any time. If you withdraw, there are no consequences to you, and your anonymous data will remain in the study. You do not have to answer all of the questions to remain in the study.

How will I find out what was learned in this study?

A report of the key findings of this study will be written and notification will be shared with those invited to participate in this study.

Has ethical approval been secured?

The Athabasca University Research Ethics Board, Canuck Place Research Committee, and the BC Ethics Harmonization Initiative have reviewed and approved this study. If you have any comments or concerns regarding your treatment as a participant in this study, please contact:

Athabasca University Office of Research Ethics by telephone at 1-780-675-6718 or by e-mail at rebsec@athabascau.ca;

Fraser Health Authority Research Ethics by telephone at 604-587-4436;

Vancouver Coastal Health Authority Research Ethics by telephone at 604-822-8598 or by e-mail to RSIL@ors.ubc.ca.

Questions about the study:

If you have questions, or need more information about the study, please contact:

Dr. Karen Cook

Assistant Professor, Faculty of Health Disciplines, Athabasca University

kcook@athabascau.ca Tel. 604 559 0165

LETTER OF INFORMATION AND CONSENT FORM FOR ONLINE BRAINSTORMING

Opening Screen for Phase 1 Brainstorming

Thank you for your interest to participate in this research study to develop a strategy for a palliative approach to care for young adults with life threatening conditions.

This research study is being conducted by Dr Karen Cook, Athabasca University and Dr. Kim Bergeron, Queen's University. This study has been granted ethical approval by the Athabasca University Research Ethics Board and other Health Authorities' Research Ethics Boards.

Purpose of the Study

We are conducting a study to develop a strategic plan for a *palliative approach to care* for young adults (18 – 35 years) with life-threatening conditions. A palliative approach to care aims to develop collaborative partnerships across community and professional agencies to ensure the availability of timely and seamless resources. In a palliative approach, young adults, their parents and caregivers, professionals and community organizations come together to ensure the well being of young adults.

This research is being conducted because there are no coordinated health and community services that anticipate and manage young adult palliative conditions, coordinate social services, and support their pursuit of meaningful activities.

Eligibility

You are eligible to participate in this study if you reside in British Columbia and are:

- A young adult between the ages of 18 and 35 with a palliative condition; or
- A parent or guardian of a young adult with a palliative condition, or a parent or guardian whose young adult has died from a palliative condition; or
- A health care professional, community service provider or volunteer;
- Have access to the internet; and
- Understand written and verbal English.

Risks and Confidentiality

There is no financial remuneration provided for participating in this study. There are no known risks associated with participating in this study. Your participation is voluntary. You are free to withdrawal at any time for whatever reason by exiting the survey at any time. In cases of withdrawal, any data you have provided will be destroyed upon your

request. You are not obliged to answer any questions you do not wish to answer. No personal data will be collected; therefore, you will not be identified in any way if the results of this phase of the study are published and nothing will connect you to your responses. All data will be stored in a secure computer file. The data will be accessible only to Dr.'s Karen Cook and Kim Bergeron. Once the study has been completed, the data will be destroyed.

Questions about the study:

If you have questions, or need more information about the study, please contact:
Dr. Karen Cook, Athabasca University by email at kcook@athabascau.ca or by phone at 604-559- 0165.

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I have read the letter of information and the information provided on this site and I consent to participate in the research study described above

If you choose to participate, clicking on 'yes' will provide you with a direct link to the survey. [Yes](#)