



Information sheet

Project title: Understanding the impact of COVID-19 on psycho-oncology services and research in the UK

Project leads: Dr Trish Holch, Dr Stephanie Archer, Dr Kate Absolom, Dr Lynn Calman, Dr Jo Armes, Professor Claire Foster & Dr Sarah Gelcich on behalf of the British Psychosocial Oncology Society

Invitation to participate

We are inviting UK based professionals who work in a psychosocial oncology related role to complete an online survey. This includes people who work in:

- health professional roles (e.g. from nursing, allied health, clinical/medical oncology, clinical psychology, psychiatry)
- A third sector/charity organisation
- An academic/researcher position
- Or other relevant roles

Taking part is voluntary and up to you to decide whether or not to take part. To understand the research and what it will involve, please take time to read the following information. If anything is not clear to you or you would like more information, please ask (see contact details below).

What is the project about?

The COVID-19 pandemic has had a profound impact on all aspects of life in the UK. The re-prioritisation of health services and social distancing measures have led to many changes in the standard care and treatment of many patient groups. People living with and beyond cancer have been particularly affected, cancer screening and treatment pathways have been suspended in many cases, routine clinical follow-up appointments have been limited or moved to telephone rather than face-to-face consultations. In addition, many people living with cancer have been advised to shield and may be socially isolated.

Local and national cancer charities who provide information and psychological support have had to stop or limit activity as a consequence of social distancing and financial implications. Collectively these changes will be having a significant impact on the psycho-social care of cancer patients and their families at a time when many unique concerns and challenges are being encountered. The British Psychosocial Oncology Society (BPOS) is undertaking an online survey of professionals working across the field to create a comprehensive picture on how psycho-oncology activity around the UK has been affected.

What will I be asked to do?

You are invited to take part in an online survey where you will answer questions by providing comments in text boxes. The survey will ask for feedback and views on how psycho-oncology practices and research activity have been changed by COVID-19. Psycho-oncology is a multi-disciplinary activity therefore we will be seeking the views of professionals working across the field. In addition, we will explore professionals' general concerns for the ongoing psycho-social care of cancer patients and their families in the coming months. Information on any perceived benefits to changes in practice, education or research procedures as a result of COVID-19 will also be explored. We will ask for your professional role and which geographic region you are working within to build a picture of the COVID-19 impact across the UK. We will not ask for your name or personal contact details, unless you wish to receive an anonymised summary of our findings. It is expected that this survey should take up to 30 minutes however feel free to withdraw at any point by exiting your browser.

What are the advantages and disadvantages of taking part?

Research has previously found that sharing your experiences can be cathartic. This may provide you with an opportunity to reflect upon the very good work that you do to support patient care. Further, you may benefit from knowing that your thoughts and responses may help others in the future.

However, we recognise that by reflecting on your practice this may be stressful and you can stop the survey at any time. If you do experience distress we will provide contact details of organisations who can offer free and confidential sources of support. Examples of these can be found at:

- Samaritans: they can be reached via www.samaritans.org or via their helpline on 116 123 / email: jo@samaritans.org
- NHS UK. Understanding stress <https://www.nhs.uk/conditions/stress-anxiety-depression/understanding-stress/>

How will my information be used?

We will produce a summary of the collective findings from the survey and will use anonymised extracts from free text comments to write a report. This report may be published in academic journals, presented at academic conferences, or used for teaching purposes. Furthermore, we will use anonymised information to provide a report for BPOS. Although the information may be used for these purposes, you will not be identifiable in any way through these outputs. You will be asked to create a memorable ID number, and this will be used instead of your name.

Will my information be confidential?

All the information you provide will be treated in confidence. This means that your name will not be passed on to anyone else should you give it and your information will be used solely for the research or teaching purposes of the university and summarised dissemination to the charity BPOS. In line with GDPR rules, all of your information will be stored securely (i.e. password protected) and the only time that any of the project team would reveal anything to an appropriate authority would be if you divulge information that we feel could potentially put you or another person at risk of harm. This decision would only be taken following full consultation with the project lead and we ask that you do not disclose such information as it is not relevant to this topic of research.

Can I change my mind?

Yes, of course. For any reason, you can choose to terminate the survey whilst you are completing it by exiting your browser. Furthermore, once you have ended the survey you will be able to withdraw up to June 6th. You do not have to provide a reason for this, but you will need to email one of the researchers with your memorable ID number which you will generate at the time of the survey. We advise you to keep a note of the researchers' contact details below and your unique number.

Who can I contact for further information?

Any member of the project leads:

- **Dr Trish Holch:** t.holch@leedsbeckett.ac.uk 0113 812 4950.

Trish has expertise in developing health interventions exploring patient understanding and is an executive member of the British Psychosocial Oncology Society and UK & Ireland Chair of the International Society for Quality of Life Research Special Interest Group.

- **Dr Stephanie Archer** saa71@medschl.cam.ac.uk

Steph is a Chartered and Registered Health Psychologist working on the CanRisk project funded by Cancer Research UK. Steph led a programme of work looking at patient safety in mental health and was also the academic lead for patient and public involvement and engagement, also improving care for women with breast and gynaecological cancers.

- **Dr Kate Absolom:** k.i.absolom@leeds.ac.uk

Kate is an academic researcher with expertise in health services research, particularly in the area of psychosocial oncology and collecting patient reported data. Kate is the current Chair of the British Psychosocial Oncology Society (BPOS).

If, however, you wish to talk to an independent representative within the university and someone who is outside of this research study, please contact Dr Sophia Price, School Representative, on 0113 812 4879 or via sophia.price@leedsbeckett.ac.uk