



The Official Launch of the Australian Research Centre for Cancer Survivorship

Research Priorities: Ideas from Cancer Survivors and Carers

Ms Julie McCrossin AM

Broadcaster, Podcaster, MC

Survivor Stage 4, HPV-related Oropharyngeal Cancer

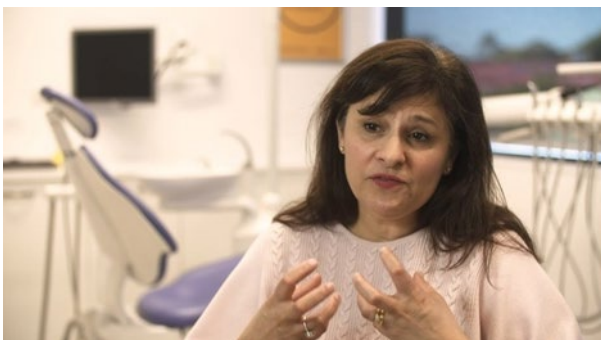
Head & Neck Cancer Advocate

Julie McCrossin gets people talking. After 20 years as a presenter with ABC Radio National, ABC TV and Network Ten, she is now a freelance broadcaster, podcaster and MC. Julie was treated for stage four, HPV-related oropharyngeal cancer (tonsils, tongue and throat) in 2013. Julie is a member of the advocacy group, Cancer Voices SA. Julie hosts the podcast series, *The Thing About Cancer* and *The Thing About Advanced Cancer* for Cancer Council NSW.

Julie has co-produced and presented a range of educational videos in partnership with cancer clinicians and advocates. Julie's video series include *Talking To Doctors* for Cancer Voices SA; the *Head and Neck Cancer Video Series 2020/2021* with St Vincent's Hospital Sydney, St Vincent's Private Hospital and the Kinghorn Cancer Centre; and *How Can We Improve the Patient and Family Experience of Radiation Therapy?* in 2020/2021 with SAHMRI, the South Australian Health and Medical Research Institute. Julie has qualifications in the arts, education and law.

In 2019, Julie was awarded a Member of the Order of Australia for significant service to the community, particularly through LGBTIQ advocacy roles and to the broadcast media. www.juliemccrossin.com

Areas of Survivorship Research that have been overlooked or received too little attention.



[Head & Neck Cancer - Innovations in dental care with A/Prof Sharon Liberali](https://youtu.be/Head&NeckCancer-InnovationsindentalcarewithA/ProfSharonLiberali)
[youtu.be](https://youtu.be/Head&NeckCancer-InnovationsindentalcarewithA/ProfSharonLiberali)

The dental care needs of Head and Neck Cancer patients at every stage of their cancer journey: diagnosis, pre-treatment dental work, recovery and long-term late effects.

Prof Sharon Liberali is a Special Needs Dentist in Adelaide with extensive experience in treating Head and Neck Patients. I interviewed her about her patients in 2021. Limited access to public dentistry has a catastrophic impact on these cancer survivors.



Improve Access to Dental & Mental Health Services: Medicare Should Be Changed [youtu.be](https://youtu.be/...)

Dr Richard Gallagher, ENT Surgeon, St Vincent's Hospital Sydney discusses his Head and Neck cancer patients and the impact of limited dental care access.



Presentation "Sexual Intimacy After Cancer" by Julie McCrossin, ASTRO 2023, San Diego California [youtu.be](https://youtu.be/...)

The sexual intimacy needs of cancer survivors are neglected.

I gave this presentation on "Sexual Intimacy after Cancer" at ASTRO 2023 in San Diego California. ASTRO is the American Society for Radiation Oncology.



Sexual Intimacy After Cancer - Dr Isabel White, Psychosexual Therapist [youtu.be](https://youtu.be/...)

In 2024 I interviewed Dr Isabel White about sexual intimacy after cancer. Dr Isabel White is accredited by the College of Sexual & Relationship Therapists (COSRT) and also a registered general nurse with the Nursing and Midwifery Council (NMC). Dr Isabel White established the first psychosexual therapy clinic at the Royal Marsden Hospital, London (in 2010) dedicated to the support and management of people whose sexual lives and intimate relationships had been adversely affected by cancer and its treatment.

Alongside working in private practice, she practices as a psychosexual therapist and senior cancer nurse in both the NHS and charitable sectors and continue to raise professional awareness of the importance of sexual rehabilitation for those living with the impact of long-term conditions.

The Official Launch of the Australian Research Centre for Cancer Survivorship

Research Priorities: Ideas from Cancer Survivors and Carers

Dr Ben Bravery

Bowel Cancer Survivor, Psychiatrist, Author.
The Patient Doctor, Hachette Australia 2022

In 2011, while living in Beijing, China and building his own science communication business, Ben was diagnosed with colorectal cancer. He was 28 years old. He returned to Australia and underwent 18 months of treatment, which included radiotherapy, chemotherapy and surgery. After treatment, Ben needed a change. He decided to become a doctor. He completed a MBBS with Honours from the University of Notre Dame Australia in 2018 and is now undertaking speciality training in Psychiatry.

Ben volunteers, advocates, writes and speaks about colorectal cancer, living with cancer, cancer in young adults, medicine and medical education. He has written for the ABC, Huffington Post, Cosmos and the China Daily. He's appeared on ABC Radio, Sunrise, 9 News, 7 News and China Radio International.

In his previous life as a zoologist and science communicator, Ben worked for the Commonwealth government, Chinese government, a medical research facility and an environmental NGO. He's lived and worked in Canberra, Darwin and Sydney, as well as in Hainan and Beijing in China.

Ben grew up in Queensland, Australia. In addition to his medical degree, he has a Bachelor of Science with Honours from the University of Queensland (majoring in zoology and animal behaviour) and a Graduate Diploma in Science Communication from the Australian National University.

Ben's memoir, The Patient Doctor, was published in 2022 by Hachette Australia.

Key Messages

Here are three areas of research about survivorship that have been overlooked or received too little attention.

1. What are the best methods to capture the experience of patients during treatment in order to prevent problems after care? How can we do this better? There are simple things we are missing.
2. We need to pay more attention to the chronicity of surveillance and the impact on patients: the time, financial burden and psychological challenges. We need to research the art and practice of surveillance. Surveillance is "a bitter, double-edged sword."

Definition of Surveillance: National Cancer Institute. USA.

"In medicine, closely watching a patient's condition but not treating it unless there are changes in test results. Surveillance is also used to find early signs that a disease has come back. It may also be used for a person who has an increased risk of a disease, such as cancer. During surveillance, certain exams and tests are done on a regular schedule. In public health, surveillance may also refer to the ongoing collection of information about a disease, such as cancer, in a certain group of people. The information collected may include where the disease occurs in a population and whether it affects people of a certain gender, age, or ethnic group."

3. The further I get from my cancer treatment, the more I have forgotten. As patients, we need methods of capturing the experience of treatment so we can carry it with us. We need a mechanism for patients to do this.

The Official Launch of the Australian Research Centre for Cancer Survivorship

Research Priorities: Ideas from Cancer Survivors and Carers

Mrs Nyan Thit Tieu

Breast Cancer Survivor

Retired Operations Manager, NSW Adult Migrant English Service, DET.

Founder, & Chair of Sisters Cancer Support Group Inc. Illawarra NSW

M.A. (Applied Linguistics); B. Ed (Science); Dip TEFL;

Grad. Dip. Public Sector Management.

Cert IV Training and Assessment.

🏆 2022 NSW Health - Consumer / Community Representative of the Year.

🏆 2023 Wollongong Senior Citizen of the Year.

🏆 2023 Wollongong Community Service Award – Leadership in Small Community Organisation

🏆 2024 Keira Local Woman of the Year.

🏆 2025 Recognition of Honour – Burmese Muslim Association



Sisters Cancer Support Group Inc. www.scsge.org.au

Thit's personal cancer experience and why she established the Sisters' Cancer Support Group Inc. (SCSG) in 2014.

Thit's breast cancer came as a complete surprise—it was picked up during a routine screening. The treatments and recovery were difficult, and she felt lost without clear guidance or emotional support. She realized that if she faced these challenges, people from culturally and linguistically diverse communities (CALD), with language and literacy barriers, must struggle even more. Research confirms this gap - lack of health literacy and cultural stigma only makes it worse. That's why she created a support structure "SCSG Inc." with the vision to *improve the quality of life of women from multicultural communities who are affected by cancer*. Its mission is to support each other and ensure no one feels alone on their cancer journey.

SCSG also leads initiatives that empower (CALD) communities in the cancer space. It provides trained peer support, education, and advocacy for survivors and carers including the most vulnerable refugees and new immigrants. SCSG also runs "Social Women Intercultural Friendship Tricycling/Cycling - SWIFT Club, a intercultural cycling group that promotes physical and mental wellbeing for CALD women.

Beyond direct support, Thit collaborates with health professionals and researchers to highlight gaps in survivorship care, especially for communities with low health & language literacy—and advocate culturally appropriate strategies to improve outcomes. Currently, SCSG is developing a project "Culturally Appropriate Cancer Health Improvement" (CACHI) program for Refugees from Burma-Thai border which consist of Karen, Kareni and Chin ethnic groups and Arabic speaking new immigrants settled in Wollongong. This project which is for both men and women is funded by Cancer Australia. The project is administered in partnership with ISLHD (Illawarra Shoalhaven Local Health District), MCCI (Multicultural Community Council of Illawarra) and UOW (University of Wollongong).

Lessons Thit learnt from 11 years with SCSG and the CACHI program

Challenges our participants face:

- Many struggles with English—some seniors can't speak or understand it at all.
- Reading and writing are difficult, even in their own language, and health literacy is very low.
- Those from refugee camps often have no formal education.
- Flyers in different languages don't always work. What truly makes a difference is trusted voices—people they know, ideally from the same cultural background. (We use Community Navigators.)
- They want and need Information to be oral, visual, and hands-on, delivered in a safe, welcoming space. (Our Monthly Morning Tea Meetings are a great example: specialists share health information over tea, using pictures to explain and discuss complex topics like radiation or lymphedema. These sessions are well received and understood.)
- Finally, the biggest lesson: information alone isn't enough—we need strategies that turn knowledge into action and real behaviour change.

Key Messages

1. Equitable care and support for all communities

We have achieved so much in cancer care and that deserves recognition. However, we all know many people from CALD communities, First Nation People and LGBTQ+ individuals and others are still left behind. Their voices are often silent because of systemic barriers we have not yet removed.

Equity in cancer care and support” must be real action at the grassroots level where marginalized people live and struggle. That means listening carefully to them & co-designing services with communities, embedding cultural safety, and holding ourselves accountable for outcomes.

Keynote: Equity isn't achieved by good intentions alone. It takes structural change, adequate funding, genuine partnership, and measurable action.

2. Translate research into Real-world programs that reach grassroots level

The real challenge isn't producing research; it's making sure it reaches the people who need it most. We have so much high-quality research, yet its impact is often invisible at the grassroots level. Communities, especially the most vulnerable, don't see these findings in their daily lives.

Researchers need to go beyond publishing papers. We need them to translate the research outcomes into clear easy end points, engage with communities, co-design solutions, and advocate for implementation. Evidence-based ideas only matter when they become practical, culturally relevant programs that people can understand, trust and use.

Keynote: Research only makes a difference when it becomes action that people can understand, trust, and use.

3. Collaborative programs with community-based organisations

Cancer funding is abundant, yet very little of it reaches the grassroots, where the most vulnerable people need support the most. This gap affects every stage of the cancer journey, prevention, screening, treatment, and survivorship.

Community organisations are already doing vital work, supporting survivors and carers, especially those whose voices are rarely heard. These groups know their communities, they build trust, and they make care accessible in ways that big systems often can't. We need to move away from top-down

funding models and invest in community-driven solutions that are culturally safe, practical, and truly inclusive. Research should also help us find sustainable ways for health systems and grassroots organisations to work together—because collaboration amplifies impact and can even reduce costs for government.

Keynote: Funding must flow where it matters most—into grassroots programs that break barriers and deliver real impact across the cancer journey.

4. Prevention is our first line of defence

While screening and treatment have advanced significantly, prevention remains the most under-addressed area in the fight against cancer. We need urgent action to reduce risk factors, especially those linked to food, diet, and lifestyle. Why are cancer rates rising among young people, and what practical steps can we take to reverse this trend?

How do we translate research on diet and lifestyle into accessible, culturally relevant programs for the most vulnerable communities? Prevention must become a priority, even before screening, not an afterthought."

Keynote: Prevention is the first line of defence- healthy lifestyle choices and accessible programs must come before screening, not after.

5. Supporting Survivors: Holistic Wellbeing Beyond Treatment

When we talk about cancer, most of the focus is on detection and treatment—and that's important. But what happens after treatment? Survivorship isn't just about living, it's about thriving.

Life after cancer brings new challenges. Survivors need support for nutrition, mental health, emotional resilience, and lifestyle changes to prevent recurrence and improve quality of life. The same healthy habits that help prevent cancer—balanced diet, physical activity, stress management—are just as critical for survivors.

We need to create holistic, culturally relevant programs that help people not only survive but truly live well beyond treatment.

Keynote: Survivorship care must go beyond treatment—it should empower individuals to live well, thrive, and prevent recurrence through holistic support.

The Official Launch of the Australian Research Centre for Cancer Survivorship

Research Priorities: Ideas from Cancer Survivors and Carers

Prof Phoebe Phillips AM

School of Biomedical Sciences, UNSW

Pancreatic Cancer Researcher, Uterine Cancer Survivor

Carer for late husband, A/Prof Joshua McCarroll, childhood cancer survivor & cancer researcher. Late effect diagnosis of advanced liver cancer after childhood radiation.

Research Areas:

Professor Phoebe Phillips is a leading pancreatic cancer researcher at UNSW with over 25 years of experience. Her work focuses on innovative treatments for pancreatic cancer and has led to several clinical trials, including current personalised medicine trials she leads.

Beyond her research, Phoebe is passionate about community engagement, organising outreach events and advocating for the inclusion of lived experience in research programmes. In recognition of her contributions to pancreatic cancer research and health policy change, she was appointed a Member of the Order of Australia (AM) in 2022. She also serves as a Board Member for Cancer Council NSW and was awarded an International Eisenhower Fellowship in 2019 for her leadership in research and health policy.

Phoebe brings a truly unique perspective to this discussion—she has lived the cancer journey as a patient, supported her late husband as a carer, and continues to lead as a researcher.

In 2022, Phoebe had uterine cancer surgically removed. Her late husband, Associate Professor Joshua McCarroll, was a childhood cancer survivor and a dedicated cancer researcher. In 2023, Joshua faced a devastating diagnosis of advanced liver cancer caused by the radiation that saved his life as a child. It spread to his peritoneum and lungs.

Key Messages.

There have been significant improvements in research to treat and kill the cancer, but we inadvertently kill the spirit of the patient and carer. We need to support patients and carers to live well wherever they are on the patient journey. It's about what happens outside the hospital as well. How do we provide holistic support at all phases of the journey?

We need to put trauma on the radar of clinicians and researchers. As a carer I was dealing with trauma on a daily basis. We need skills to handle the psychological impact of cancer treatment. We need holistic skills to handle the trauma. How can we upskill patients, carers and clinicians to deal with trauma across the whole survivorship journey?

We need research into the impact of cancer on sexual intimacy. How can we support patients and partners across the whole survivorship journey to deal with the impact of cancer and or treatment on sexual intimacy?

Survivorship from diagnosis to palliative care and end of life is a “team sport” but everyone is working in silos. The person receiving treatment and the carer are members of the team. How do we work better together? How can the patient and family be effective participants in the team?

We need research on the impact of treatment toxicity on the body of the person in long-term survivorship. We need this research for people treated as children, young people and adults as well.

What are the unmet needs of these survivors? How can we offer effective support, including beyond five years?

Our goal should be to rehumanise cancer care – and prioritise wellbeing alongside survival and killing the cancer. Finally, if you could issue one call to action to the cancer research and care community, what would it be?

Example of Action

Prof Phoebe Phillips is working in partnership with Petrea King from Quest for Life to provide holistic wellbeing support to for patients and carers, based on Phoebe's experience. To ensure cancer survivors and carers live well and have compassionate, comprehensive support beyond the hospital walls. The program is designed to reduce psychological distress and anxiety, improved quality of life and coping, validation of lived experience and connection, increased sleep quality and tools for relaxation, increased self-worth and emotional resilience.

1. Prioritise Human Connection

- Move beyond technical precision to include emotional presence.
- Empathy is not about time spent, but about being fully present and listening.

2. Embed Holistic Care

- Integrate psychosocial wellbeing and caregiver burden as quality indicators in routine care.
- Use patient-reported outcomes as conversation tools, not just compliance metrics.

3. Trauma Awareness

- Recognise trauma as a daily reality for patients and carers.
- Seek training in trauma-informed care and psychological first aid.
- Refer early to supportive care services for coping strategies.

4. Communication Skills

- Advocate for formal training in communication and emotional care.
- Normalise conversations about intimacy, fear, grief, and identity.

5. Referral Pathways

- Establish clear, proactive referral pathways to:
 - Psychotherapy and behavioural therapy
 - Mindfulness-based stress reduction
 - Supportive expressive group therapy
 - Community-based wellbeing programmes

6. End-of-Life Care

- Ensure palliative care is integrated early, not just at crisis points.
- Focus on dignity, presence, and patient/carer wishes (e.g., being alert vs sedated).

7. Co-Design Care

- Involve patients and carers in care planning and survivorship research.
- Treat survivorship as a “team sport” where patients and carers are active members.

8. Advocate for System Change

- Push for institutional cultures that value compassion and wellbeing.
- Support funding for survivorship research and holistic care models.

The Official Launch of the Australian Research Centre for Cancer Survivorship

Research Priorities: Ideas from Cancer Survivors and Carers

Mr Peter Spolc

PhD candidate, UTS

Consumer Panel, Thoracic Oncology Group Australasia (TOGA)

2021 Diagnosis Stage IV, Non-Small Cell Lung Cancer

Making research lemonade from the cancer lemon

Peter Spolc is a retired university administrator from the NSW Blue Mountains. He was diagnosed in March 2021 with stage IV, ALK+ NSCLC (Anaplastic Lymphose Kinase positive non-small cell lung cancer) and has since actively pursued opportunities to better understand his cancer and its treatments and engage with the clinical and research environments. He contributed to the 2022 review of both the Understanding Lung Cancer and Living with Advanced Cancer publications of Cancer Council Australia. He is a Consumer Representative at the Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) unit at UTS. Peter was selected for the International Association of the Study of Lung Cancer STARS program for Patient Research Advocacy in 2024 and the STARS Scholar program in 2025. Peter attended and presented at the 2023 and 2025 Australian Lung Cancer Conferences (biannual) and has attended most Thoracic Oncology Group of Australia Annual Scientific Meetings since his diagnosis.

Key Messages

1. Consumer involvement in research:

Only a relatively small number of people who have had cancer are active in engaging with researchers to shape research. We need to offer constructive opportunities to involve people in survivorship research who may not (yet) know the language, feel they are not informed enough, or even just not aware that there is an opportunity open to them to play a role. We need to include these people if our research is to be effective. So far, I have not seen this done all that well. It requires dedicated listening, a sustained effort, and a well-crafted plan.

2. “Super Patients” and the challenge of representation and representativeness.

In the cancer context, there are three key groups of players in effective research: Researchers, Patients+ (i.e. including their supporters and carers) and Clinicians. Some clinicians are researchers as well. For the purposes of informing research, researchers quite often engage with ‘patients+’ who are recommended to them, partly because they are known, have a track record of involvement and are more likely to be familiar with the concepts, terminology and processes of research. These people tend to be experienced ‘patient+’ advocates with whom researchers are professionally comfortable. They have been called “Super Patients” or “Professionalised consumers”. We need to ask, “Who is most going to benefit from this research?” and then create welcoming initiatives to include a cross section of those people in the research processes as much as possible. In this way, we can add to the role of the “Super Patient”. “Super Patients” can be wonderful interlocutors to help find and involve a greater number of representative patients. This is a challenge to all in research.

Another challenge is that the most vulnerable patients are too sick to participate and may die soon after diagnosis. The most deadly cancers mean people have shorter lives and are least able to contribute to the most needed research. How to better involve them?

3. Representation of cancer patients in proactive health engagement.

In November 2024, I started my PhD study and aimed to include cancer patients' experience and motivation for proactive health engagement. I care deeply about this topic and felt that by doing a PhD, I could contribute to what I believed is so important: - supporting the involvement of a whole, representative cohort of patients and the public in health, and especially, cancer research.

4. The purpose of my PhD research.

A question we need to ask when planning research is, “What difference do you want to make?” I benefited enormously from dedicated and sophisticated research and felt I had to do something to support this research process to continue and improve. I am not seeking to prove an academic point. I want to make a practical point in order to support the value of our research.

5. The value of the patient contribution.

Researchers need to understand the value of the patient contribution, including to reveal what may not be known to the research effort. This involves “deep listening” with an attitude of willingness. It involves the need to accept the limits of our knowledge in order to be open to learning because patients know things researchers don’t know (and vice versa, of course). It is also important for patients to recognise that their own health experience can be instructive to the efforts to heal those that follow.

6. The challenge of talking about “survivorship”.

It is hard to talk succinctly about “survivorship”. This is a problem. If you try to be brief about this, you may be left with a brutally simplified version of the thing. It is not always clear what it means. For some, identifying as a “survivor” is a powerful identity as someone who beat the odds. For others it may be something quite different. Is it just about being alive? Is it necessary to be “cured” to be a survivor? If you are not cured - and may never be - are you more of a survivor? If you have had a cancer diagnosis, are you ever not a survivor?

A 2025 COSA Pre-Conference Workshop on Patient Involvement in Cancer Research was a great opportunity to contribute. There was enough time. A full day. A bunch of Super Patients got together and created a curriculum which (humbly acknowledging I was part of that group) delivered a highly valued program.

7. My 'Dr Who' experience

Getting cancer was a door opening for me and an unrequested opportunity to enter the TARDIS of the cancer world. I retired four years after getting my diagnosis, and soon after, started my PhD. My wife says I have never been happier. You just have to get a killer disease to experience this joy. 😊 I believe I am a better person due to having cancer. I have been welcomed by academia. I have terrific supervisors. I have the time to participate in advocacy. Why is all this possible? Because, due to the dedicated efforts of researchers I have never met, my treatment is working, I am living well and I have had the good fortune to be able to become involved.