

Shared Lives: Cancer

Developing an online resource to support people affected by cancer through making academic research publicly accessible

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What is Shared Lives Cancer?

Shared Lives: Cancer, is a new and innovative approach to making academic research data publicly available.

Developed collaboratively by a research team from the University of Lincoln, Lincolnshire Clinical Commissioning Group and Macmillan Cancer Support.

Presented as a dynamic searchable database driven website of quotes and stories derived from independent research studies undertaken with people living with and affected by cancer conducted 2017-2019.

Why is Shared Lives: Cancer Needed?

- ☑ Aims to support people living with and affected by cancer by engaging a public audience with patient voice data.
- ☑ Supports recovery and engagement with self-management. Users are linked to a flexible and adaptable repository of credible sources of support that include the HOPE and iHOPE self-management programmes, and Macmillan's online resources.
- ☑ It is more important than ever, in supporting to relieve feelings of loneliness and isolation. Particularly when many people living with cancer remain vulnerable and may currently be confined to their homes, as a consequence of COVID-19.
- ☑ Has the potential to help professionals and researchers better understand the cancer experience which as a result, could help to improve care outcomes.

How Did You Populate Shared lives: Cancer?

All studies were subject to the appropriate ethical and research governance approvals.

Data collected across a range of ages, genders, cancer types, treatment type, as well as, from carers and people who support those with cancer.

217 participant contributions, were consolidated and thematically coded (Braun and Clarke, 2006, 2013) as a single data-set.

870 unique contributions coded to over 3000 quotes searchable by 40 broad themes and over 70 keywords that can be filtered by age, gender, cancer type, and treatment type.

Ten patient stories developed from interview transcripts, that are linked to selected quotes, aim to deepen the shared life connection.

How Do I Search Shared lives: Cancer?

To facilitate ease of use, Shared Lives: Cancer, has multiple search functionality incorporating theme word cloud, free text search and drop down box theme search.

Each search strategy retrieves and presents quotes associated with search terms. Filter options enable users to further refine the quotes presented.

How Will You Know If User Needs Are Being Met?

We will routinely use Google Analytics to help us to understand usage trends.

Evaluate search strategies and identify frequencies of keywords/themes searches.

Identify pages most often visited and the time spent interacting with Shared Lives: Cancer.

Evaluation will inform existing and new data coding strategies and ensure evolution in line with user's needs.

Identify click throughs from Shared Lives: Cancer to collaborative partners and click in from partner resources and social media platform, search engines and collaborative partners.

Ongoing evaluation will enable us to better identify marketing and sustainability strategies.

Users of Shared Lives: Cancer will be asked for feedback via anonymous, moderated, character restricted website comments.

Can I Share MY Research Through Shared Lives: Cancer?

YES!

We are seeking collaborative partnership with researchers interested in engaging a public audience with their research exploring the lives of people living with and affected by cancer through Shared Lives: Cancer. As part of this partnership we will promote you as a collaborative partner and include links to your associated research outputs within Shared Lives: Cancer.

An ongoing research project (ethical approval pending) enables world-wide users to share their stories either by completing a survey or taking part in an interview in English via video chat.

Search terms
Emotional Impact
Support Groups
Practical Support – Tips
Emotional Impact
Loneliness & Isolation

Search Terms
Emotional Impact
Loneliness & Isolation
Support Groups
Peer Support (shared experience)
Practical Support – Tips

"Personally, I have found understanding other people's journeys and experiences of cancer helpful in enabling me to come to terms with my own situation. I found it helpful to talk to others who have been in a similar situation to myself. I think this is because during the cancer journey one can feel very isolated".
Man 35-44 Head and Neck Cancer

"Coping with the treatment and it's side effects, is hard, it's how to cope when treatment, such as chemotherapy ends and you have to endure a void of 3 months or so, when you are totally alone with no contact from your cancer team to see how you are. Mentally, this can be very difficult, after being so well cared for, for months, suddenly you are shown the door and told to return in 3 months! It is disconcerting, to say the least."
Man 55-64 Prostate Cancer

"You want to hear the magic words you're cured, but you don't get that. Looking back, of course not, nobody knows. To me, that felt like stepping off a cliff and hoping the parachute will open. That was difficult and I became depressed."
Man 65-74 Cancer of the Stomach

Search Terms
Recovery
Depression
Emotional Impact
Healthcare Professional Support
Emotional Support

Search Terms
Physical Impact
Eating
Side Effects

"You had to find your own way around eating. At first my taste was affected. I couldn't eat certain foods like tomato. Some things still leave a terrible taste. I never enjoy coffee now. At first it was really awful. I lost a lot of weight. I just couldn't eat certain things. Bread or cake is the worst. I've had to find different things that I can eat."
Woman 65-74 Mouth Cancer

Image by Coffee Bean, CCO public domain via Pixabay

What Are The Benefits of Shared Lives Cancer?

- ☑ Unique approach which makes research findings and patient experiences more accessible across a broader audience.
- ☑ Brings academically derived, real life experiences into the public domain in a free to access user friendly format.
- ☑ Offers alternative approaches for people living with cancer to seek information which might support them whilst dealing with their own circumstances, e.g. helping them in feeling 'they are not alone', or knowing that others have gone through similar experiences.
- ☑ Users not obliged to become active participants in the same way as online communities require.
- ☑ Available online at a time when face-to-face contact is significantly reduced due to COVID-19 and people living with cancer might benefit more from digital information and support in different formats.
- ☑ Provides a platform to help cancer professionals develop their awareness and understanding of how people living with cancer might be feeling, or might cope with their condition.
- ☑ **Academic collaborative partnership**, bringing together like minded researchers to build relationships that increase opportunities for meaningful research impact.

With Special Thanks To

East Midlands Cancer Alliance, Lincolnshire CCG and Macmillan for funding Shared Lives: Cancer. Wendy Munro and Andy Rowston for their continued support developing Shared Lives: Cancer.

Contact and Enquires

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