



Supporting people to live well in the face of death

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<https://youtu.be/uQtz53dAD0o>



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Experience based co-design

- Why do it?
- What is it?
- Key principles

https://www.kingsfund.org.uk/sites/files/kf/field/publication_file/patient-centred-care-project-evaluation-aug11.pdf



Why do it?



An **Evidence Check**
rapid review brokered
by the **Sax Institute**
for the
Australian
Commission on
Safety and Quality in
Health Care.
December 2015

Background

Patients are uniquely positioned to provide insightful comments about their care.

Method

A synthesis of evidence from qualitative studies of patients' reported experiences in hospital and day procedure between January 1995 to July 2015

Results

Thirty-nine publications were included; 33 articles from database searches and six from the grey literature

Conclusion

Tangible opportunities to enhance the patient experience are apparent.

Small changes to the way that the health system operates, is resourced, and the way that health professionals engage with patients, could substantially improve care.



What is it?

Co-design is a way of improving healthcare services **with** patients and families

Co-design focuses on **understanding** consumers' experiences of services as well as the services themselves

Its about **designing and improving** experiences



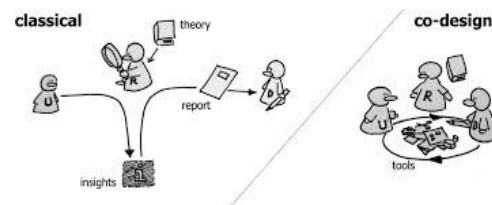
<http://www.healthcodesign.org.nz/about.html>

https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/patient-centred-care-project-evaluation-aug11.pdf



“Doing” service and care redesign

1. We don't listen very much to our users and we do the designing
2. We listen to our users then go off and do the designing
3. We listen to our users and then go off with them to do the designing



- Values patients, carers and staffs' experiences
- Stories not surveys
- 'Deep dives' and direct observation
- 'Touchpoints' and emotional mapping
- Direct participation in the improvement process




<http://www.healthcodesign.org.nz/about.html>

1. Building on people's existing capabilities
2. Promoting mutuality and reciprocity
3. Developing peer support networks
4. Breaking down boundaries
5. Facilitating as well as delivering
6. Recognising people and their experiences as assets




<https://www.scie.org.uk/publications/guides/guide51/references.asp>





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The Signpost Study



Development of a Tailored Supportive Care Intervention for Women Living with Metastatic Breast Cancer






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MELBOURNE**


Background

Women living with metastatic breast cancer (MBC) report many unmet supportive care needs that impact quality of life and disease outcomes.



Living with secondary breast cancer: coping with an uncertain future with unmet needs
S.R.D. JOHNSTON MA, PhD, FRCP (C)
First published: 13 August 2019 | Full publication history
DOI: 10.1111/1365-2294.13810
Cited by (CrossRef): 3 articles | Check for updates | Download icon


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Contents lists available at ScienceDirect
The Breast
Journal homepage: www.elsevier.com/locate/brst


Original article
Evolving psychosocial, emotional, functional, and support needs of women with advanced breast cancer: Results from the Count Us, Know Us, Join Us and Here & Now surveys^{a,c}
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^c Metastatic Breast Cancer Network, New York, NY, USA
^d Breast Care Support Group, Europa Centre Mall, Moorj, Maldives



Mapping the quality of life and unmet needs of urban women with metastatic breast cancer
S. JOHNSON PhD (C), P. SCHIFFRINO PhD (PhD), L. LEBERER PhD (MSc), P. WATTS PhD,
D. MURPHY PhD (PhD), R. SAUNDERS PhD (PhD), M. WOODS PhD (PhD)
First published: 13 May 2019 | Full publication history
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Cited by (CrossRef): 28 articles | Check for updates | Download icon

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BJC British Journal of Cancer (2019) 119, 1543–1548 | doi: 10.1038/s41416-019-4922-4
Keywords: breast cancer; metastatic; advanced; quality of life; questionnaire

'Being there' for women with metastatic breast cancer: a pan-European patient survey
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The Team

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- Pamela Salamanca – Consumer
- Roslyn Lam – Consumer

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- Nadine Borschmann
- Andrea Cannon – Think Pink
- Fiona McRae - Counterpart
- Danielle Spence – BCNA
- Jenny McIndoe – McGrath Foundation
- Lisa Sheeran -Peter MacCallum Cancer Centre
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- Prue Francis - Peter MacCallum Cancer Centre
- Karla Gough- Peter MacCallum Cancer Centre
- Jo Phipps-Nelson - Peter MacCallum Cancer Centre
- Katherine Lane & Anna Boltong – Cancer Council Victoria



Study Aims

- 1) To develop an evidence-based, *co-designed* supportive care intervention for women living with metastatic breast cancer

- 2) To generate a solution and test the relevance of the content with women living with metastatic breast cancer

- 3) To test the feasibility and acceptability in real world settings



Phase 1: An exploratory, mixed methods study*

Phase 2: A consumer-led co-design study

Phase 3: A pilot feasibility study

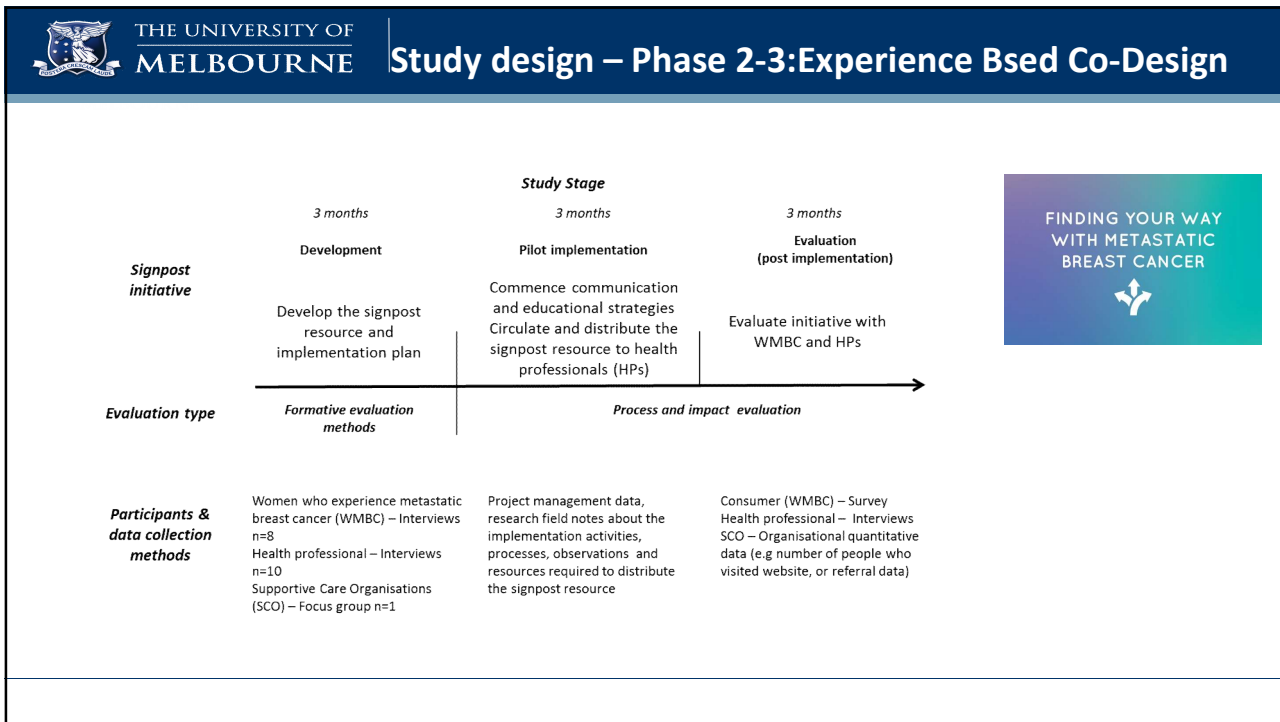
* Blaschke SM, Gough KC, Chua BH, Francis PA, Cockerell R, Drosdowsky AF, Sheeran L, **Krishnasamy M.** Clin Breast Cancer. 2019 Apr;19(2):e327-e336.



*Knowledge
that life is
limited -
living with
uncertainty
and
fluctuating
health*



- Knowledge about what supportive care resources exist and how to find reputable resources
- Variability in timing of when and how women get information and the amount of information provided – reliance on others
- Finding resources and people with metastatic breast cancer expertise is complex
- Current medical system focuses on disease progression and treatment modifications
- Lack of information and support for women, families and the community more broadly



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www.unimelb.edu.au/signpost

McGrath Foundation
Breast Cancer Network Australia
Cancer Council
COUNTERPART
thinkpink

FINDING YOUR WAY WITH METASTATIC BREAST CANCER

If you or someone you care about has metastatic breast cancer and would like to know about resources and services such as:

- Information and education
- Counselling
- Talking with others with metastatic breast cancer
- Support from a Breast Care Nurse
- Finances and superannuation
- Exercise, nutrition and wellbeing
- Support for those close to you

FEEL FREE TO CONTACT

Breast Cancer Network Australia w bcna.org.au ph 1800 500 258	Counterpart w counterpart.org.au ph 1300 781 500
Cancer Council Victoria w cancerciv.org.au ph 13 11 20	McGrath Foundation w mcgrathfoundation.com.au ph 1800 183 338
	Think Pink w thinkpink.org.au ph 03 9820 2888



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www.unimelb.edu.au/signpost

Finding your way with metastatic breast cancer



DOWNLOAD THE RESOURCE →

The [Signpost resource](#) provides people with metastatic breast cancer with links to useful, accessible and reliable information and support services in Australia.



Many services and resources are available for people with metastatic breast cancer, including counselling, financial and legal support, peer support, and support for those close to you.

If you or someone you care about has metastatic breast cancer and would like to know about resources and services, please [download](#) and use the Signpost resource below for details.

“*Reading the stories of other women with metastatic breast cancer, I felt immediately uplifted. I thought, if they can do it, this is something that I can manage in a positive way as well.*”

— Ros, participant and co-designer



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The power of consumer voice – working in
partnership to *influence change*

Video for health professionals



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The PanSupport project

Co-designing an online resource with and for people with pancreatic cancer - to support them to live as well as possible

A/Prof Soumitri Varadarajan

Catherine Devereux



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PanSupport

A place for people with pancreatic cancer



PanSupport is a Cancer Australia *Supporting people with cancer* Grant initiative, funded by the Australian Government.



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Palliative and Supportive Care (2018), **16**, 534–543.
 © Cambridge University Press, 2017 1478-9515/17
 doi:10.1017/S1478951517000608

Association between pancreatic cancer patients' perception of their care coordination and patient-reported and survival outcomes

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 AND RACHEL E. NEALE, PH.D.¹

Improvements in emotional support, referral to specialist services and self management education needed to improve patient reported outcomes

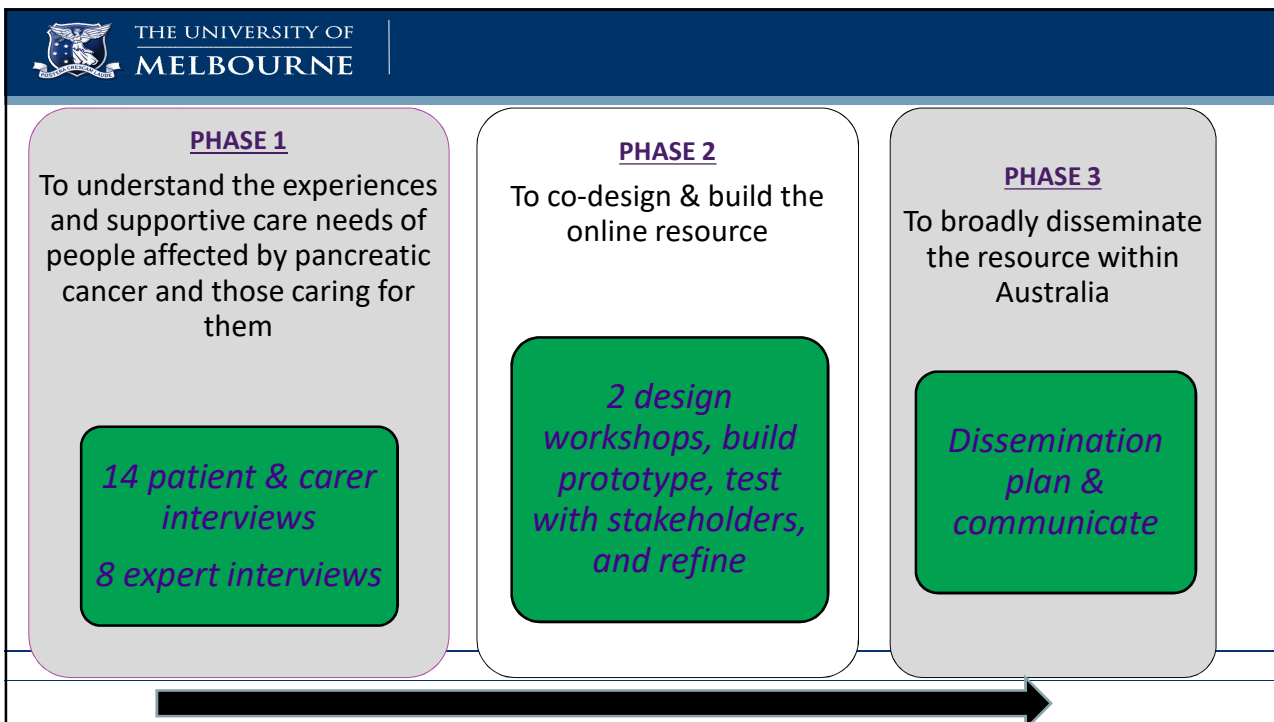
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Aim

To design, develop and implement a supportive care online resource with and for people affected by pancreatic cancer to enhance their self-management and wellbeing – *wherever they live*

Experienced Based Co-Design



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**Phase 2
Co-design workshops**

PanSupport co-design workshop paper prototype

Cards
– generated from interviews
– determine what was included

“I felt important being asked what I thought would benefit others”



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- *“Look and feel”*
- *Wanted a positive, safer place*
- *Treated like an individual and not a person with a disease*

Build very detailed – navigation & layout

Used patients advice, quotes, language

Uncluttered – key Australian resources

Draft reviewed by 15 consumers and experts early 2019 & updated



Information, ideas and resources to help you to live as well as possible...

www.pansupport.org.au

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MY CARE

A diagnosis of pancreatic cancer can be difficult to hear and to come to terms with.

Pancreatic Cancer

Pancreatic cancer is a complex disease that is not well understood by many people. Because it is often not experienced until the cancer is quite advanced, it is a very hard diagnosis to hear, learn about, and be frightened.

Cancer can turn your world upside down.

- HOME
- MY CARE
 - [Pancreatic Cancer](#)
 - Talking To My Team
 - Clinical Trials
 - Public Or Private
 - Palliative Care
- FEELING BETTER
- LIVING WELL
- MY PEOPLE
- PRACTICAL INFO
- LOOKING AHEAD
- FEEDBACK

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People who receive palliative care early tend to do better. Recent studies show that people who have early palliative care tend to live longer, with fewer symptoms and had better quality of life than patients who did not have palliative care.

Palliative Care

Experts explain Palliative Care and its benefits.

” I am sorry I didn't know earlier how Palliative Care could have helped our family as dad was getting more unwell. I did not understand that this care was available alongside his other treatments.” This care was amazing and the follow up for the family continued even after he passed away

Irene, carer of her dad with pancreatic cancer

FEELING BETTER

Do not let what you cannot do interfere with what you can do *John Wooden*


Fatigue


Fatigue is extreme tiredness. It is a common symptom for people with pancreatic cancer. It may be caused by the cancer, its symptoms or your treatment. It can be constant or start and stop and may not be improved by resting.

If you are fatigued your treating team may want do some blood tests to check there is not a treatable cause for your fatigue.


Managing fatigue will impact on how you feel. Some ideas that might help are:

- Prioritise things you want to get done
- Pace yourself, you might find you can do more at certain times in the day
- Accept offers of help and ask for help if you need it. [Gather My Crew](#) helps organise daily tasks by emailing your friends and inviting them to help out
- Its fine to say no to calls and visitors – if you don't feel up to it.

 *It's okay to not be okay all the time.*



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LIVING WELL


Spiritual practices can help in coping with difficult experiences

Spirituality


Spirituality is a broad concept which has many perspectives. Generally it includes a sense of connecting to something bigger than ourselves, and can involve looking for meaning in life. It is a universal human experience—something that touches us all.


Some people find their spiritual life is linked to a church, temple, a higher being, prayer, the practice of [yoga](#) or [meditation](#).





- HOME
- MY CARE
- FEELING BETTER
- LIVING WELL
 - Exercise
 - Massage
 - Keeping A Strong Mind
 - Finding The Positives
 - [Spirituality](#)
 - Meditation & Mindfulness
- MY PEOPLE
- PRACTICAL INFO
- LOOKING AHEAD
- FEEDBACK





LIVING WELL


Yesterday is not ours to recover, but tomorrow is ours to win or lose *Lyndon Johnson*


[Keeping A Strong Mind](#) [Gardens & Nature](#) [Music](#) [Art & Creativity](#)

Keeping a strong mind

We talked to people living with pancreatic cancer about the things that help them cope with the more challenging aspects of living with their illness.

”
I'm not thinking too much about what will happen next year, I'm taking one step at a time and being hopeful. Stress is the most important thing to manage. If your stress is down I am sure you recover faster, that's what I think.
 Navin, 44yrs with pancreatic cancer





LOOKING AHEAD

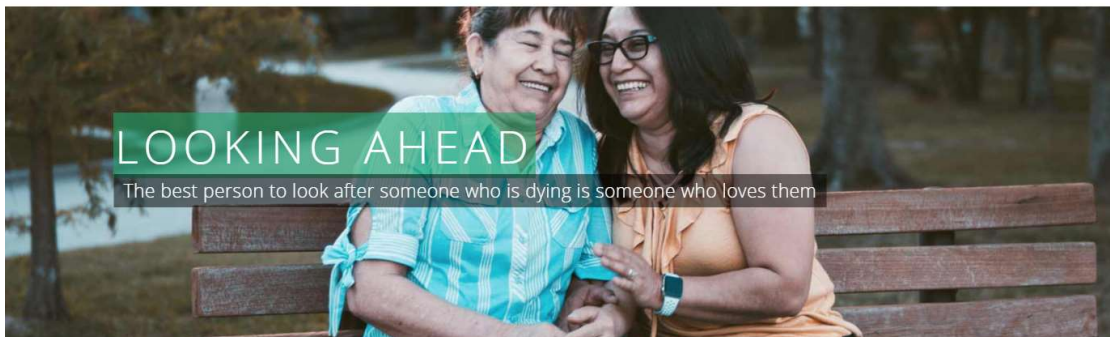
Living happens to all of us. Dying happens to all of us. *Zen hospice project*

Talking about death

Fear or anxiety about dying can impact how we live in the day to day, and on the quality of life. Like many things that worry us, talking about and sharing those fears can help reduce them.

”
 Most of us have thought about death, but it's hard to talk about. Many people want to talk about death because they do not want to burden family members. Often find that family members share similar fears but don't talk about them. It's important to protect the person with cancer. Talking about death and sharing fears can help make it more manageable.

- HOME
- MY CARE
- FEELING BETTER
- LIVING WELL
- MY PEOPLE
- PRACTICAL INFO
- LOOKING AHEAD
 - Death Is Hard
 - Talking About Death
 - End Of Life Care
 - Nearing Death
 - Bereavement
- FEEDBACK



LOOKING AHEAD

The best person to look after someone who is dying is someone who loves them

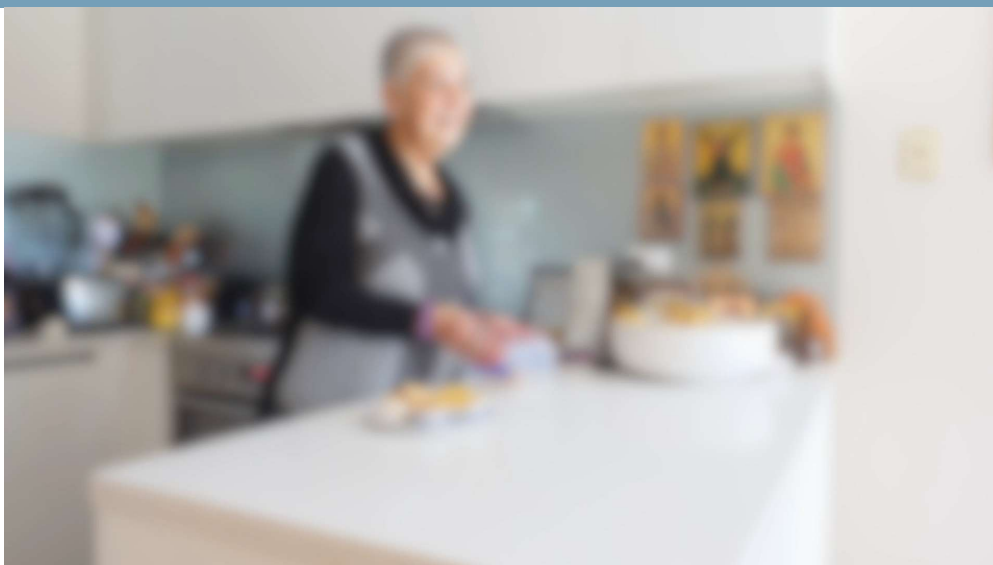
End of life care

Patients and their carers told us that they worry about having a painful death.

”

I don't want him to suffer. I'm not scared of him dying, I just don't ... I want this time to be less suffering, less painful.

Irene, carer of her dad with pancreatic cancer





Thank you to all of the patients, families and carers
who contributed to the PanSupport project

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A place for people with pancreatic cancer