Annual Forum 2018/19

A year in review



Annual Forum

Western & Central Melbourne Integrated Cancer Service

Event concludes - light refreshments and networking

21 November 2019, 4pm to 6pm

6:00pm

4:00pm	Acknowledgement of Country Words from our Chair
4:15pm	Rhonda's story: A metro-regional collaboration Loddon Mallee Integrated Cancer Service Western & Central Melbourne Integrated Cancer Service
4:30pm	Creating a personalised survivorship care plan: mycareplan.org.au Australian Cancer Survivorship Centre
4:45pm	Co-PreP: Co-designing a Prehabilitation Program for patients with prostate cancer at Western Health Western Health
5:00pm	Road to Recovery: Supporting patients undergoing curative Upper GI cancer surgery with an optimal nutrition care pathway Western Health St Vincent's Hospital Melbourne Peter MacCallum Cancer Centre Royal Melbourne Hospital
5:15pm	Pregnancy and cancer: Do our cancer services meet the mental health and supportive care needs of women with gestational cancer? The Women's
5:30pm 5:45pm	Cultural adaptation of the Malnutrition Screening Tool and associated education resources Victorian Cancer Malnutrition Collaborative Peter MacCallum Cancer Centre Launch of pancreatic patient resource videos WCMICS Pancare Foundation
	Victorian Cancer Malnutrition Collaborative Peter MacCallum Cancer Centre Launch of pancreatic patient resource videos WCMICS

Rhonda's story: A metro-regional collaboration

Patricia Calder & Chris Caudle Metropolitan/Regional Engagement Managers

Loddon Mallee Integrated Cancer Service Western & Central Melbourne Integrated Cancer Service





Metropolitan/Regional Engagement: Working towards sustainable professional networks

The project identified 'transition' and 'communication' as significant themes for regional cancer patients who travel to the city for their treatment.

Metropolitan cancer network. 5 large health services. 25% of patients are from Regional Victoria.

Metropolitan Regional Engagement Project Regional cancer network. 19 health services. 31%* of residents treated with chemotherapy and 41%* with surgery over 2017/18 had their first treatment in Melbourne.



Resource pack created to help patients & carers navigate metropolitan health services.



Regional service directory created to help facilitate referrals back to local services.

Conclusion:

Using shared Project Managers between clinical networks can be an effective way to bridge some of the barriers between Melbourne and Regional clinicians and deliver benefits to patients and carers.



The Rhonda Story video portrays the challenges faced by a remote regional family accessing a clinical trial in Melbourne.

Creating a personalised survivorship care plan:



Helana Kelly - Manager

Australian Cancer Survivorship Centre Peter MacCallum Cancer Centre









AUSTRALIAN CANCER SURVIVORSHIP CENTRE



OPTIMAL OUTCOMES for CANCER SURVIVORS & their CARERS

Who is a cancer survivor?

- A person is considered to be a **cancer survivor** from the time of diagnosis, throughout the balance of their life.
- **Survivorship** provides a focus on the health and wellbeing of a person living with and beyond cancer in the time *after* active treatment.
- Recognise the term 'survivor' isn't right for everyone

Principles of Cancer Survivorship, Cancer Australia 2017

What is a survivorship care plan?

- Formal, written document created by the patient's care team with the patient.
- Includes information about the patient's cancer treatment, their recommended follow-up, and what they can do to look after themselves.
- Help the patient transition from 'active treatment' to 'after treatment'.
- Assist other healthcare professionals to organise the patient's care.
- ACSC Fact Sheet: "Survivorship Care Plans: What they are and how to use them"

Why are survivorship care plans useful?

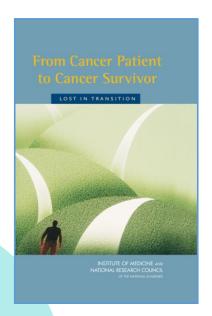
Survivors:

- are often unprepared for the post-treatment phase
- may be unaware of health risks and things that can reduce their risks
- often have symptoms and other issues that are under-recognised / under-treated
- often have too many, poorly-coordinated review appointments
- may travel long distances for reviews

Community health professionals e.g. GPs:

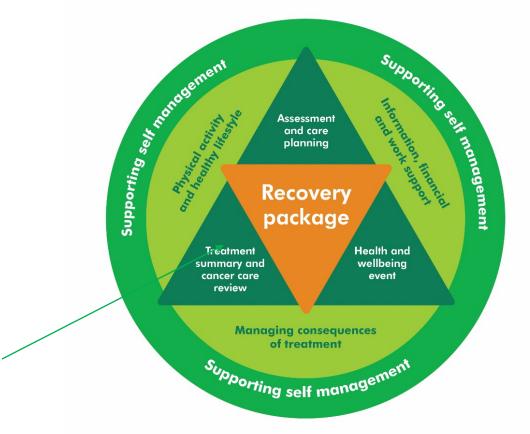
- may not be adequately engaged in the care of survivors
- may not have the information and support they need

Are survivorship care plans endorsed?





Recommendation 2: Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This "Survivorship Care Plan" should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payors of health care.



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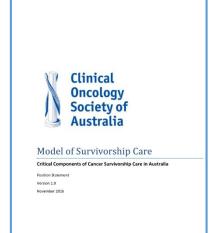
Model of Survivorship Care: Appendix 1

Cancer Survivorship: Living well with and beyond a cancer diagnosis

PRINCIPLES OF CARE

- Survivor centred (enabling, engaging, empowering)
- Integrated care across all service levels at every time point
- Coordinated care
- Accessible and equitable





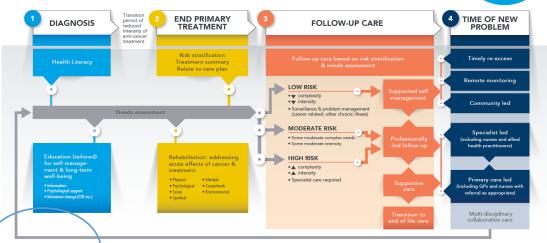


Figure 1. Model for wellness in cancer survivorship

Level of risk associated with

- cancer type
- Needs assessment

- Patient ability & motivation
- to self-manage
- Level of professional

- Patient action - Rehabilitation

· Aims to document main concerns

of survivor & health professional

& agreed actions for:

- Management

on referral

- Clinical team follow-up, sign posting

- a Places supriver & their pends at centre of healthcare & wellness interactions Facilitates communication between all
- health professionals Gets survivors to the right services at the
- Ensures regular review of survivorship care
- plan and survivor needs
 Ensures appropriate follow-up for cancer

recurrence and late effects of treatment and meaningful

- Survivors engage with services they need when they need them Survivor priorities & needs are addressed from most
- to least urgent

 Survivor time in healthcare environments is minimised
- to that required to maintain health & well-being . Survivors have rapid access to healthcare support
- when required for cancer & treatment related events . Resource use is minimised to the level that is effective

- Needs assessment tools
- Directory of services
 Referral pathways
- Motivational interviewing
- Information & support services

Optimal care pathway for people with colorectal cancer



Summary	
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Summary – optimal timeframes	3
Intent of the optimal cancer care pathway - key principles	4
Optimal cancer care pathway	g
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Step 5

Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

Treatment summary (provided to the patient, carer and general practitioner) outlining:

- diagnostic tests performed and results
- · tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided.

Follow-up care plan provide a copy to patient/carer and general practitioner) outlining:

 medical follow-up required (tests, ongoing surveillance)

- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication - lead clinician to:

- explain the treatment summary and followup care plan to the patient/carer
- inform the patient/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the patient's general practitioner.

How will cancer survivors use survivorship care plans?

Nicole A. Kinnane, Amanda J. Piper & Michael Jefford

To cite this article: Nicole A. Kinnane, Amanda J. Piper & Michael Jefford (2017) How will cancer survivors use survivorship dare plans?244aofn219g(98%):2vishedstonceceive a SCP 10.1080/0284186X.2016.1266082

To link to this article: https://doi.org/10.1080/0284186X.2016.1266082

What is mycareplan.org.au?

Free, online survivorship care plan generator.

Allows users to create a care plan including:

- ✓ Diagnosis
- ✓ Treatment
- ✓ Current side-effects of treatment
- ✓ Long-term and late effects, including psychosocial effects
- ✓ Concerning symptoms
- √ Follow-up schedules
- √ Wellbeing recommendations
- ✓ Support services.

my CarePlan.org.au

online cancer survivorship care plan generator



since March 2019









my CarePlan.org.au

									Cumulative
MyCarePlan	Mar-19	Apr-19	May-19	Jun-19	Jul-19	Aug-19	Sep-19	Oct-19	Total
Total Users	292	202	158	82	93	103	119	145	1194
Total plans created	119	53	54	19	21	24	15	22	327
Users who completed at least one component	95	49	51	17	20	21	14	22	289
Number of Plans downloaded	68	30	26	9	12	19	9	6	179
Number of plans emailed	24	9	5	1	2	1	2	2	46
User: Doctor/HP (%)	50.00%	59.30%	60.00%	54.30%	47.10%	48.80%	50.00%	51.40%	52.61%
User: Patients (%)	50.00%	40.70%	40.00%	45.70%	52.90%	51.20%	50.00%	48.60%	47.39%

Plan your future after cancer Create a personalised survivorship care plan, giving you a better understanding of life after cancer treatment. Get started →



Step 1: Prepare

Before starting, you'll need a list of all treatments you've undergone including surgery, chemo, radiotherapy, and hormone therapies.



Step 2: Create

After answering a series of questions, your personalised care plan will be created instantly, ready to be viewed online or downloaded.



Step 3: Review

Review your care plan with your treating team, ensuring you're all on the same page. Come back and update your plan when you need to.

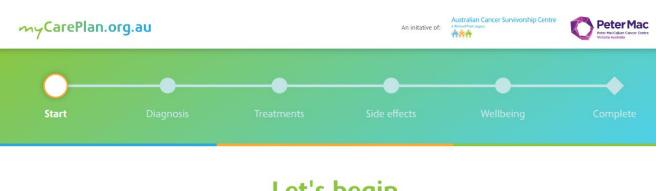


66

My care plan is my physical record. It came along with me during my journey and acted as a valuable communication tool as I moved between healthcare professionals.

- Cancer survivor

"









Next -



Diagnosis

What type of cancer has affected you?

- Early stage breast cancer
- Early stage bowel cancer
- Localised prostate cancer

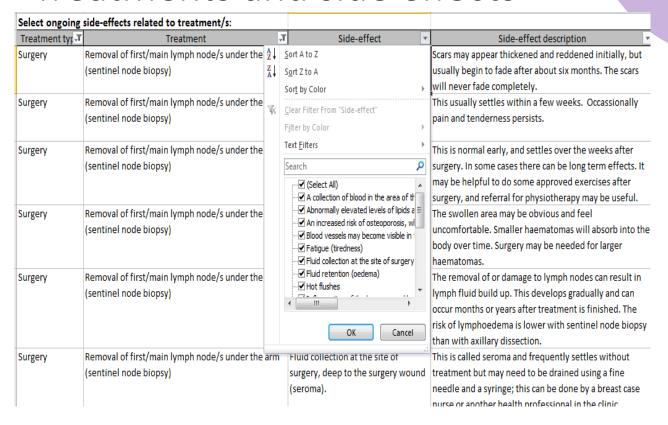


Treatments

What treatments did you have? Please select all.

Surgery (1 selected)
Removal of first/main lymph node/s under the arm (sentinel node biopsy)
Removal of lymph nodes (glands) under the arm (axillary dissection)
Breast conserving surgery (lumpectomy, wide local excision, partial mastectomy - removal of just the cancer with some surrounding normal tissue)
✓ Mastectomy (removal of the entire breast)
Breast reconstruction
Removal of ovaries and tubes (oophorectomy and salpingectomy)
Other or don't know surgery type
Chemotherapy (1 selected)
Chemotherapy (i selected)
Neoadjuvant chemotherapy is before the main treatment (usually surgery). Adjuvant chemotherapy is after or in addition to the main treatment.
Adjuvant AC (adriamycin and cyclophosphamide)
✓ Adjuvant AC (adriamycin and cyclophosphamide) followed by paclitaxel

Treatments and side effects



Current side effects

Based on the treatments you've selected, you may have experienced or may still experience some of the following side-effects. Please note that this is not a complete list of all possible side-effects, and not everyone who has cancer treatment will have these side-effects. Often people who have had the same type of treatment won't experience the same side-effects. Potential longer term side effects of your treatments will be shown in your care plan.

Are you currently experiencing any of the following symptoms?

A collection of blood in the area of the surgical wound (haematoma).	V
Bleeding and bruising problems	v
Changes to periods and other menopausal symptoms	~
Diarrhoea or constipation	v
✓ Fatigue (tiredness)	~
Fluid collection at the site of surgery, deep to the surgery wound (seroma).	~
✓ Hair loss from chemotherapy	~









Wellbeing

After treatment is a great time to make some changes and commit to staying healthy. General healthy living recommendations are for all people who have had a diagnosis of cancer. Simple measures reduce many of the physical and emotional effects of cancer treatment. Speak to your treating team or GP about making healthy living changes.

Which topics would you like more information on?

Quit smoking and avoid second-hand smoke	~
Be physically active	~
Have a healthy diet	~
Sun safety	~









Your survivorship care plan is ready



Download and print

Download a printable PDF version of your care plan.

Download



Send via email

Email your care plan to yourself, a loved one, or your doctor.

Email



Review plan

Step through your personalised care plan below.

Review







Name: Helana Test Date: Jun 25 2019

Here is Helana's survivorship care plan

To view the online version of this plan, visit: https://www.mycareplan.org.au/care-plan/mvcuq9e4/

How to use your care plan

This care plan contains information about the health risks you may face as a result of your cancer and therapies. Your level of risk will vary depending on the type and combination of treatments you have received.

As your circumstances change, and as this is a growing area, you may wish to review your plan periodically.

Always discuss with your doctors

You should discuss this content with your treatment team to better understand your personal risks. These results can be concerning, but not every survivor experiences every side-effect, and some survivors do not experience any long-term effects.

How can I be involved?

"Survivorship care plans are simple but very important" -Cancer survivor

- Cancer survivors: consider making a survivorship care plan
- Health professionals: assist survivors to make a survivorship care plan

Key message

Cancer treatment is different for everyone.

Having a personalised care plan to share with health professionals can make things easier.



Acknowledgements

- WCMICS mycareplan.org.au funding, and invitation to share at this event
- ACSC team, including Sandra Picken, Project Officer
- DHHS- funding for the database that supports mycareplan.org.au, and ACSC
- All the users of mycareplan.org.au

Thank you! Questions?



www.mycareplan.org.au www.petermac.org.au/cancersurvivorship helana.kelly@petermac.org



3rd Victorian

CANCER SURVIVORSHIP CONFERENCE

A 2020 VISION

Building on learnings ... partnering for success

12-13 MARCH 2020

Crown Convention Centre, Melbourne



Australian Cancer Survivorship Centre
A Richard Pratt Legacy

www.survivorshipconference.com.au

Co-designing a Prehabilitation program for patients with prostate cancer (Co-PreP)

Dr Clarice Tang (PhD)
Western Health







Background

Prostate cancer is the most commonly diagnosed cancer among males

in Australia [Australian Institute of Health and Welfare, 2013]

Treatment results in:

Physical health Psychological health Quality of life

Difficulty with patient engagement

[Granger et al., 2016]

Prehabilitation: (Diagnosis → Acute treatment) [Silver et al.,2013, Santa Mina et al.,2018]



Physical health



Psychological distress

Post-surgical complications

Lack of a voice

Experience Based Co-Design (EBCD)



1. Set the plan



4. Understand experiences



2. Engage with people



5. Improve through codesign



3. Capture experiences and ideas



6. Measure

aims:

Using Experience Based Co-design (EBCD)

1. Design a prehabilitation program for patients with prostate cancer

 Identify both positive experiences and challenges prostate cancer survivors faced, as well as opportunities for improvement

STEP 1: Set the scene

Short video clip that will be played at commencement of each workshop

Purpose:

Facilitate workshop discussion and identification of key themes



Step 2: Workshops

Patients and caregivers

CALD patients

Health Professionals



<u>Combined - Patients, Caregivers and Health Professionals</u>
Working together to improve the experience

Results

- Eight patients, one support person and 11 health professionals attended Stage 2 workshops.
- Two patients were from a Vietnamese background
- Multidisciplinary team members recruited:
 - 4 Medical/surgical doctors
 - 2 Nurses
 - 5 Allied Health professionals

Results- The positives

Positive experiences with care

"I honestly believe that our patients get very good care from our hospitals. Not many hospitals where run urology and oncology together." (HP5)

"I am extremely grateful for the help that I received throughout my journey" (P2)

Timely access

"I had been asked to exercise in preparation for surgery but had no idea how to do this. One session with the physiotherapist made a whole lot of difference" (P5)

Results- Challenges

"The scary part about cancer is when you go to sleep and...the house is dead stone cold. That's when its scary" (P8)

Not everyone received the same service

Men feeling lonely, anxious and frustrated

Pressure on clinicians to capture everyone

Discrepancy in the information provided/received

"I worry. I got to think about my wife, my daughter and my kids. I worry about the family if things do not work out"(P2)

". Wards now don't discharge on weekends as X is not there. X reviews before they go home. Been in place last 18 months. But that is not a sustainable solution – if X is not there." (HP5)

"Cancer is all that is on their mind. They just want it out and then to deal with other things later" (HP3)

Solutions

Development of Prehabilitation program: **CO-PREP**

Week 1



+



Week 2



Discussion topic	Sub-topic	Nun				
Priority		*1	2	3	4	5
Diagnosis	What is prostate cancer?				6	6
	What is my outlook/prognosis?				3	9
	What feelings might I have?			2	8	2
	How to tell my family/friends?	2	1	2	5	2
	What about work?	4	3	3		2
Side effects of treatment	Sexual dysfunction	4		2	3	3
	Incontinence				6	6
	Fatigue	2	1	1	5	3
	Anxiety and depression	2	0	1	4	5

Discussion topics	Sub-topic	Number of people					
Wellbeing	Physical				4	4	
	Emotional				4	4	
	Carer's support				3	5	
Lifestyle modifications	Exercise			1	3	2	
	Diet		1	4	3	2	
	Alcohol			4	1	2	
	Smoking	1		3	2	2	

Discussion

- Highlights the benefits of using EBCD to develop health programs
- Feasible to use EBCD for men with prostate cancer including men from CALD backgrounds
- Currently piloting the model with aim to further refine the program
 - Quicker access
 - Develop peer support
 - Other types of treatment
 - ? Other cancer types

Acknowledgement

- Patients and caregivers
- WCMICS
- Sunshine Hospital Radiation Therapy Centre (Peter MacCallum Cancer Centre)
- WH Physiotherapy department
- WH Cancer services
- Interpreters



Project team:

Dr Clarice Tang, Ms Monica Turczyniak, Ms Alesha Sayner, Ms Sally Butzkueven, Dr Kimberley Haines, Prof Helen O'Connell, Dr John Violet, Ms Priya Rangarajan, Dr Shirley Wong



Email:

Clarice.tang@wh.org.au

Or

Clarice.tang@westernsydney.edu.au

Twitter: @TangClarice

References

- 1. Prostate Cancer in Australia, in Cancer Series, A.I.o.H.a. Welfare, Editor. 2013, Australian Institue of Health and Welfare: Canberra.
- 2. Silver, J.K. and J. Baima, Cancer Prehabilitation: An Opportunity to Decrease Treatment-Related Morbidity, Increase Cancer Treatment Options, and Improve Physical and Psychological Health Outcomes. American Journal of Physical Medicine & Rehabilitation, 2013. **92**(8): p. 715-727.
- 3. Santa Mina, D., Hilton, W. J., Matthew, A. G., Awasthi, R., Bousquet-Dion, G., Alibhai, S. M. H., . . . Carli, F. (2018). Prehabilitation for radical prostatectomy: A multicentre randomized controlled trial. *Surgical Oncology*, *27*(2), 289-298. doi:https://doi.org/10.1016/j.suronc.2018.05.010
- 4. Granger, C. L. (2016). Physiotherapy management of lung cancer. *Journal of physiotherapy,* 62(2), 60-67.

Road to Recovery

Supporting patients undergoing curative Upper GI surgery with an Optimal Nutrition Care Pathway

Irene Deftereos Senior Dietitian and Project Lead Western Health











Upper GI cancers can affect the esophagus, stomach or pancreas 1 in 2 patients with Upper GI cancer in Victoria are malnourished

The problem

- Lack of funding for proactive outpatient services
- Patients often only seen during inpatient admission
- Lack of standardised processes and pathways

= Inadequacies and variations in nutritional care across health services

Project Design and Aims

- Pilot feasibility project
- Western Health, St Vincent's Hospital, Melbourne Health (+Peter Mac)
- 6 months pilot period Sept 2018 March 2019

AIMS

- 1. To develop and implement a standardised pre-operative Nutrition Care Pathway (NCP) for Upper GI cancer patients undergoing curative resection at all participating sites
- To investigate feasibility and implementation outcomes (including patient and staff experiences)
- To evaluate impact on nutritional and clinical outcomes using retrospective comparison group

Supported Implementation Process

Stakeholder Engagement

Dietitian Managers, Executive, Surgeons, Oncologists, Clinic NUMS

Context Analysis

Mapping of site specific processes, Barriers and enablers

Nutrition Care Pathway Development

Literature Review, Expert consultation, Stakeholder feedback

Facilitated Implementation

Systems and Processes, Training, Site visits, Pathway Promotion

6 month Pilot Period

Group debrief sessions, Site Visits, Fortnightly correspondence
Patient and Implementation data collection

Evaluation and Results analysis Recommendations and Sustainability

OPTIMAL NUTRITION CARE PATHWAY

SCREENING

Dietitian attends Multi-Disciplinary Team Meeting

DIAGNOSIS/PLANNING CLINIC

nitial Assessment aim within 1 week post MDM

Nutrition optimisation

Pre-treatment education

NEOADJUVANT CHEMO/RADIOTHERAPY

Initial Assessment aim within 1 week
Ongoing monitoring

PRE SURGERY CLINIC

Aim review within 2 weeks post neoadjuvant Continue pre-surgical optimisation Pre-surgery Education

SURGICAL INPATIENT ADMISSION

Assessment Day 1 post surgery Inpatient optimisation Education for discharge

KEY ELEMENTS

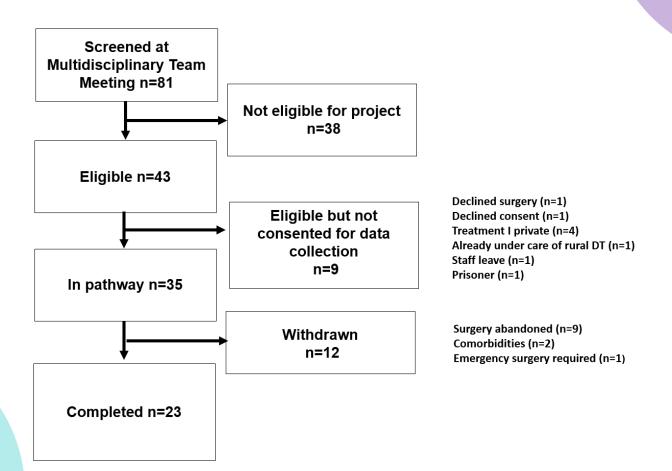
Outpatient Service Setup

RISK STRATIFICATION
Intervention and Reviews

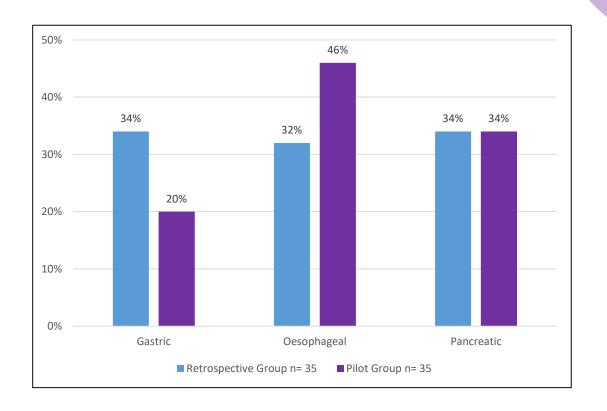
Patient Journey Tracking Management at key stages

MDT Communication

Project Participation



Cancer Types at enrolment n=70

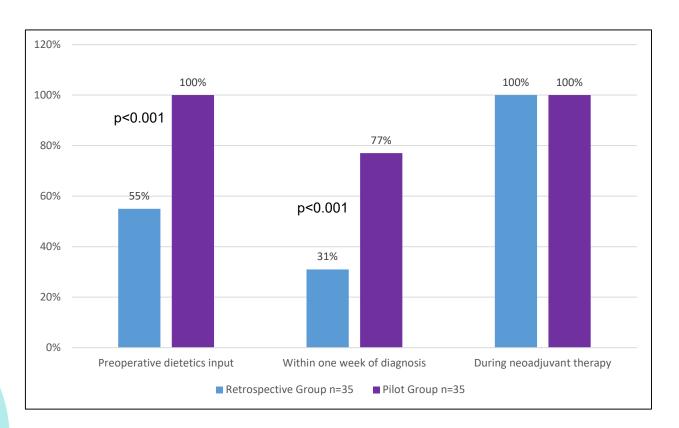


^{*}No differences in terms of age, sex, tumour characteristics or baseline weight loss

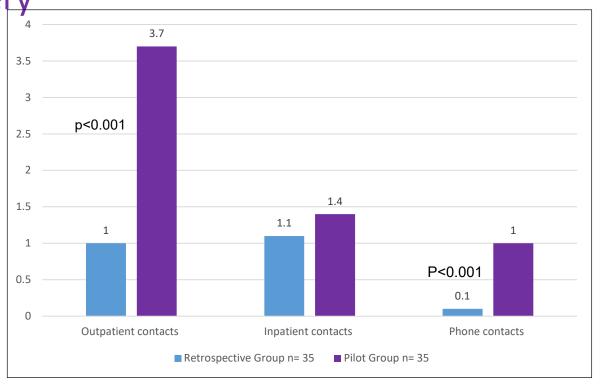
Impact of the project

- Service delivery impact
- Clinical impact
- Qualitative patient and clinician feedback

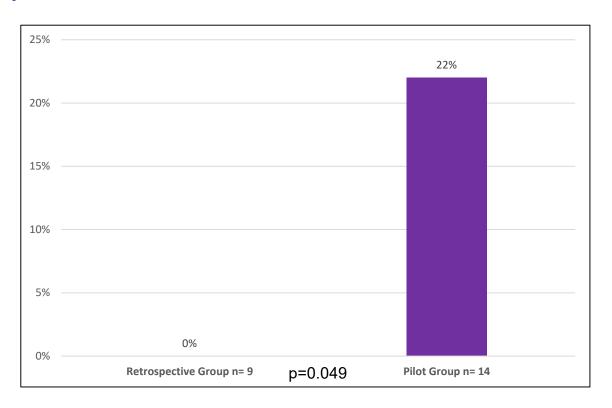
Significant improvements in number of patients accessing dietetics care, at an earlier time



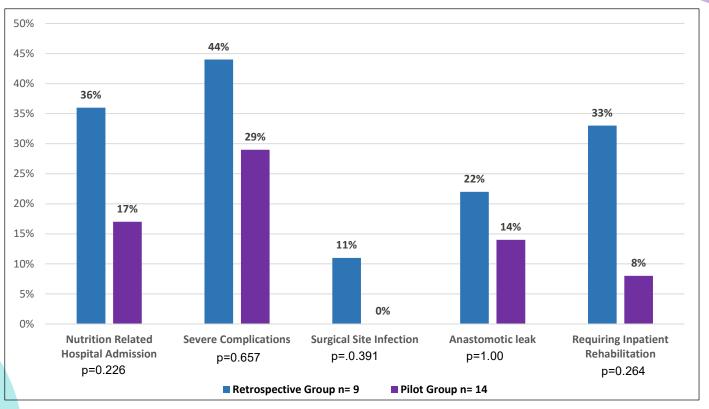
Proactive, increased dietetics outpatient service delivery



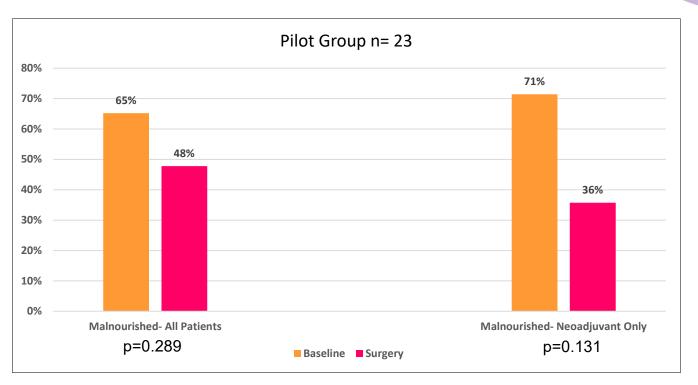
Proactive feeding tube insertions during neoadjuvant therapy



Neoadjuvant therapy: potentially clinically important improvements in surgical oncology outcomes



Neoadjuvant therapy: potentially clinically important improvements in nutritional status



Patients loved the service!



Improved my general health 4.25/5

Helped my body to heal 4.5/5 Helped me to recover faster 4.4/5

Improved the results of my medical treatment 4.25/5

Been helpful 4.5/5

Met my expectations 4.4/5

So did the Surgeons and Oncologists...

Very happy with now having Dietitians in the clinic

Dietitians are seeing high-risk patients earlier

Overall the model of care is significantly improved

Patients often remarked on the dietetic service positively

I believe that increased dietetic care will lead to improved surgical outcomes

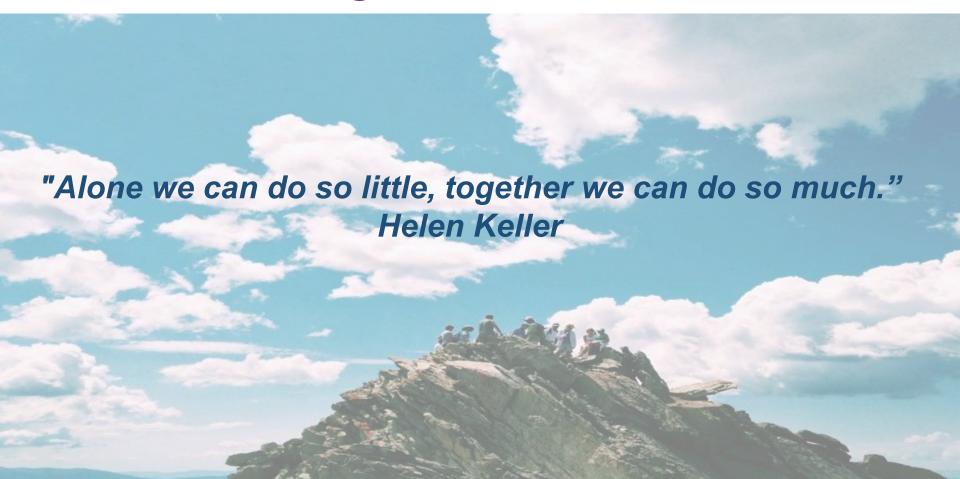
The Dietitians found the process feasible and highly beneficial, but challenging at times..

Improved clinical Improved MDT knowledge relationships Can see the benefits for patients **Improved** patient tracking Patients plans and handover often change A lot of time spent coordinating

Next Steps

- 1. Continue to evaluate feasibility, costs and impact
- 2. Publish results and share with others
- 3. Use pilot and feasibility data for larger prospective project grant applications

Take Home Message



THANK YOU!

Our participants

WCMICS

Project Officer:

Sally Butzkueven

Project Dietitians:

WH: Aurora Ottaway, Jacqui McNamara, Hollie Bevans, Yvette Boxhall

STVHM: Kate Fox, Nadia Hendricks, Orla Doran

RMH: Jessie Varghese, Emma Bidgood

Peter Mac: Kate Graham, Rose Rocca, Kirsty Rowan

Dietetics Managers and senior staff:

WH: Kathryn Pierce, Vanessa Carter and Allison Lauder

SVHM: Natalie Simmance

RMH: Kate Fetterplace, Michele Hughes

Peter Mac: Belinda Steer

Surgical and Oncology Colleagues at each site

Outpatient Clinic and Preadmission Clinic NUMS and staff at each site





Pregnancy and cancer:

Do our cancer services meet the mental health and supportive care needs of women with gestational cancer?

- Associate Professor Lesley Stafford & Ms Michelle Sinclair
- Centre for Women's Mental Health, The Royal Women's Hospital



Cancer in pregnancy



- 1 in 1500 pregnancies¹
- Limited empirical evidence² but together with clinical experience suggest substantial distress
- A time of difficult choices and time-sensitive decisions
- Maternity units and oncology units are very different places
- Care needs are complex and require a co-ordinated multidisciplinary team

Key questions



- What are the supportive care and mental health needs of women diagnosed with cancer during pregnancy?
- What are their partners' needs?
 - Are we meeting these needs in our delivery of care?
 - What are the characteristics of a positive healthcare experience for this population?
- What is the impact of gestational cancer on parenting and family?
 - Are we providing family-focused cancer care?
- What are the experiences of clinicians who care for these women?
 - Do current guidelines meet clinicians' professional needs?
 - What is the psychological impact of caring for this population?

Expected project output



- Recommendations for
- Development of consistent, well-coordinated and evidence-based model of care that is suitable for use in our cancer services
- Providing family-focused cancer care that includes recognition of the impact of cancer during pregnancy on the partner and broader family unit
- Taking steps to ensure that clinicians are well supported to care for these women
- Clarifying areas that require further research
- Providing specific information that can be used to refine existing **mother-infant therapy** programs for use in this population

What have we done?

14 partners

1 cervical ca, 10 breast ca, 2 blood ca, 1 lung ca

27 clinicians

3 psychologists, 1 psychiatrist, 2 social workers, 1 midwife, 6 nurses, 5 oncologists, 3 surgeons, 6 obstetricians

Interview data analysed thematically

Australia

Recruited from across

17 live births, 6 pregnant, 2 terminations

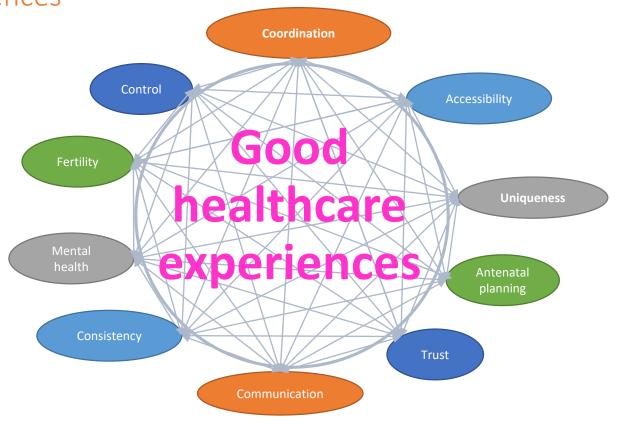
25 women

1 cervical ca, 16 breast ca, 5 blood ca, 1 bowel ca, 2 lung ca

3337 minutes of interviews

A sneak peak of findings related to women's healthcare experiences







"I turned up to the appointment, nervous, and anxious, and worried. And there was no oncology results. Because they hadn't sent them across.... It's been a little infuriating. ... when information goes missing...or scans hadn't turned up, it's not a reassuring feeling at all... I had a joke, before I went into surgery, like what if they do the wrong breast."

"I would see the same oncologist every time for the appointment. I wouldn't have to repeat my story over and over. So I'd have the continuity of care, which, when I'm feeling extremely vulnerable at that time, it definitely felt very reassuring, to be able to say, I meet this one quy, and he will see me right through to end of treatment..."



"There were NICU people from upstairs, IVF people, obstetricians, radiologist, the oncologist, nurses, an anaesthetist, administrative staff. It was a bit insane... I felt like a little bit of a rock star, like a really special case... then of course trying to squeeze my husband in next to me..."

"they're the ones with the real knowledge and I'm going to be guided by their decisions ...but I like to be able to really understand it wholeheartedly. So she would, everything from sharing research papers with me to talking through each of the different options and the pros and cons of chemo pre surgery and vice versa and keeping me up to date with things like when they were making the decisions around my treatment and including me in that process."



The INTEGRATE team

Lead Researcher

A/Prof Lesley Stafford

Research Team

- Ms Michelle Sinclair
- Dr Leah Collins
- Prof Louise Newman
- A/Prof Kylie Mason
- Dr Emma Symes
- Dr Jocelyn Lippey
- Ms Julia Cannell
- Dr Lisa Briggs
- Ms Monique Baldacchino

- A/Prof Ryan Hodges
- Prof Mark Umstad
- Dr Angela Ives
- Dr Michelle Peate
- Prof Christobel Saunders
- Dr Rebecca Szabo
- Dr Catherine Oakman
- Ms Kerry Shanahan
- Mr. Michael Barton





Cultural adaptation of the Malnutrition Screening Tool and associated education resources

Jane Stewart & Emma McKie Clinical Dietitians

Peter MacCallum Cancer Centre, Melbourne







Background



Malnutrition and cancer

- Cancer malnutrition highly prevalent 15% overall prevalence, 29% inpatient setting (Steer et al 2018 unpublished)
- Associated with poor clinical, functional and healthcare outcomes
- (Arends et al 2017; Pressior et al 2010; Friejer et al 2013; Marshall et al 2018)



Nutrition risk screening

- All patients with cancer, irrespective of weight history or BMI, should be screened for risk or presence of malnutrition (Arends et al 2017, Thompson et al 2017)
- Screening should occur at cancer diagnosis and regularly thereafter (Arends et al 2017)

Background



Identification of malnutrition in CALD patients

- Victoria is Australia's most culturally diverse state
- MST only available in English
- MVCS project in 2016/2017 showed suboptimal screening practices for CALD patients in Victoria:
 - Malnutrition screening completed routinely in only 1/3 of CALD patients
 - For those screened, an interpreter was utilised for < 1/4 of all patients
 - Family members commonly used to assist with malnutrition screening (85%)

Aim



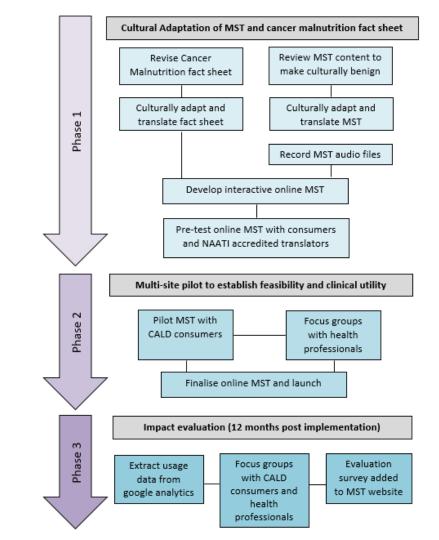
Aim of cultural adaptation of MST project

Culturally adapt the MST and associated malnutrition education resources into Victoria's top 10 languages other than English, to reduce unwarranted variation of practice in the CALD population and promote best practice in nutrition risk screening

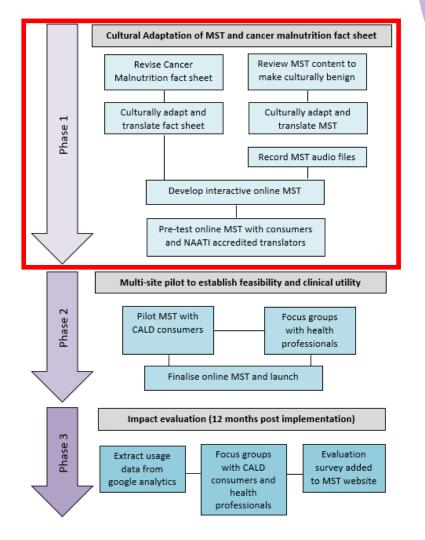


Funders

- Funded by WCMICS
- 14 month project
- (+ 4 month impact evaluation)



Overview



Phase 1 — Cultural adaptation of MST and fact sheet



Language Profile

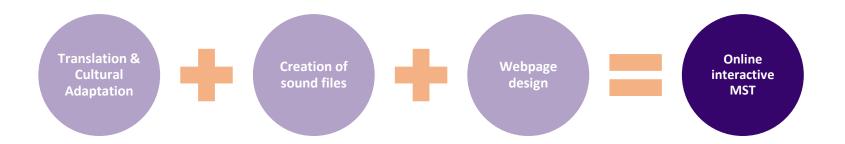
- Top 10 languages (2013-2017):
 - 1. Greek
 - 2. Italian
 - 3. Mandarin
 - 4. Arabic
 - 5. Vietnamese

- 6. Cantonese
- 7. Macedonian
- 8. Turkish
- 9. Croatian
- 10. Spanish





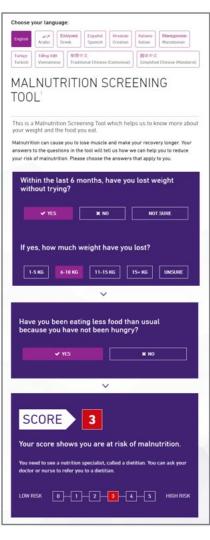
Develop online interactive MST



Access the online interactive MST:

https://www.petermac.org/MST

MST score calculated automatically and displayed



Recommendations generated based on MST score



Pre-test online interactive MST

- Feedback from consumer representatives (n=4), bilingual health professionals (n=4)
 - = 100% answer/question options & audio files easy to comprehend
- NAATI accredited translators (n=10)
 - = 100% very satisfied with dialects and overall clarity

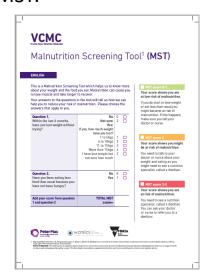


Revise/develop resources

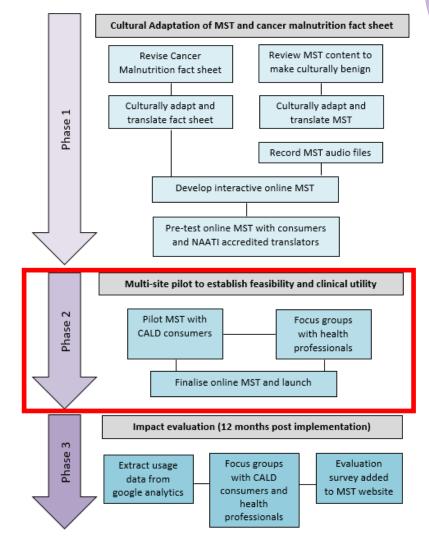
Cancer malnutrition fact sheet:



Printable MST:



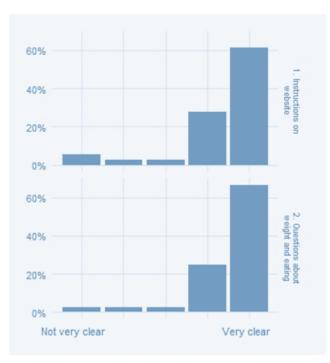
Available for download on Peter Mac website https://www.petermac.org/nutritioninfo-clinicians

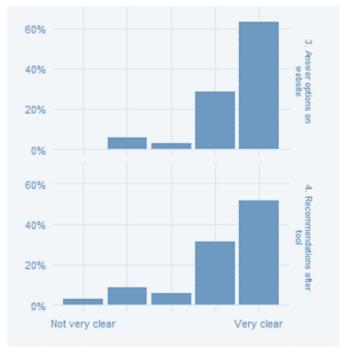


Phase 2 – Multi-site pilot

3

Pilot online MST with CALD patients (preliminary results)





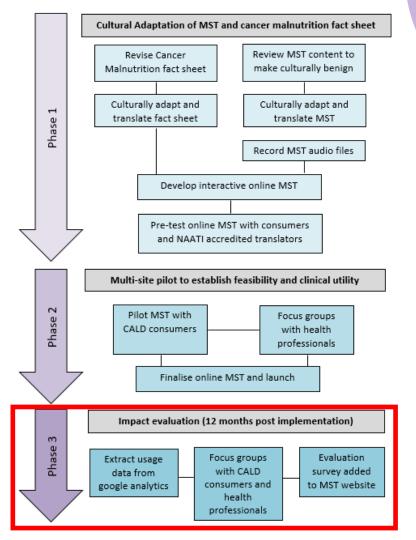




Focus groups with health professionals (preliminary results)

Acceptability Perception that MST includes appropriate content, is easy to use & functions well	Appropriateness Perceived usefulness of MST
 User friendly & content flowed well. The online platform posed a challenge for some of the elderly patients. Best device to use – iPad. 	 Patients appreciated having the tool in their language Fills a gap in service delivery – ensures CALD patients aren't disadvantaged. Appropriateness for elderly patients in question – some responded verbally and had the staff, interpreter or a family member fill it out online.
Adoption Uptake of MST	Feasibility Suitability of MST for everyday use

Phase 3



Phase 3 - Impact Evaluation

Aim:

Utilise principles of implementation research to understand how the online interactive MST is utilised by patients and health professionals, and its effectiveness.

What will be investigated?

- Factors effecting implementation
- Process of implementation
- Results of implementation

What does this mean?

- Improved equity of care for CALD patients
- Broad scope of impact
 - Victoria, Australia and abroad
 - Various health service settings (acute, community, primary care)
 - Anyone can use it- health professionals, family/carers, patients



Acknowledgements



Project Team

Emma McKie, Project Officer
Jane Stewart, Project Manager
Jenelle Loeliger, VCMC program oversight
Karla Gough, Senior Research Fellow,
Dept of Cancer Experience and Research, Peter Mac
Nicole Kiss, Institute for Physical Activity and Nutrition (IPAN),
Deakin University
Tanya McKenzie, Health Literacy Manager, Peter Mac



<u>Suppliers</u>

Sylaba, Translation services Liefbouy, Multimedia agency Icon, Web design Green Scribble, Graphic design



Project Steering Committee

Kathy Quade, Program Manager Quality & Cancer Outcomes, WCMICS

Prof Liz Isenring, Bond University

Wendy Swan, Nutrition & Dietetics Manager, Goulburn Valley Health

Kathryn Pierce, Manager of Nutrition, Western Health

June Savva, Senior Dietitian, Monash Health

Jennifer Kent, ACSC, Peter Mac

Courtney Pocock, Senior Speech Pathologist, Western Health

Philippa Gayler, Publications Manager Strategy & Support, CCV

Cinzia Bonciani, Cultural Diversity Coordinator, Alfred Health

Shu-Yi Soong, Consumer Representative

Jane.Stewart@petermac.org

Emma.Mckie@petermac.org

Optimal Care Pathway Pancreatic Cancer

Dilu Rupassara – OCP Project Lead

Western & Central Melbourne Integrated Cancer Service



background

 Western and Central Melbourne Integrated Cancer Service (WCMICS) is funded by the Victorian Department of Health and Human Services (DHHS), established in response to a State-wide commitment to cancer reform

- Our role is to work with hospitals to improve patient experiences and outcomes by connecting cancer care and driving best practice
- Optimal Cancer Care Pathways (OCPs) are national guides to the best cancer care for specific tumour types. Primary purpose is to improve patient outcomes by facilitating consistent cancer care based on standardised pathways



Pancreatic videos

Aim:

Facilitate access to self-care information for patients and carers affected by pancreatic cancer.

Objective:

Easily accessible and complementary to existing services and resources

Deliverables:

- Thoughts Matter
- Keeping Active
- Strength through Nutrition



Source: www.worldpancreaticcancerday.org

Thoughts Matter

Coping with stress and anxiety







https://youtu.be/06VCAxmbz2k



Strength through Nutrition

Managing what you eat and drink







https://youtu.be/sDUxbKTJGY4



Keeping Active

The importance of exercise







https://youtu.be/1iP9htz4yaY



Scan the QR codes using your phone camera



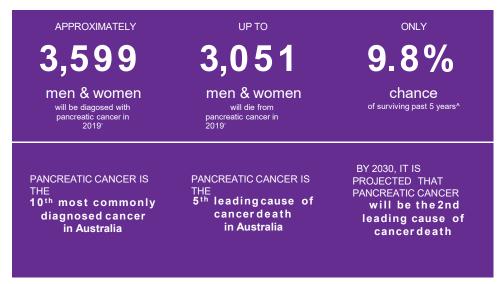


Rewrite
the story of
pancreatic cancer
with us

The five-year survival rate for pancreatic cancer is just 9.8%

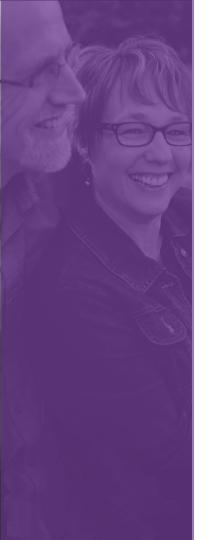
It has remained relatively unchanged for over 40 years. In contrast, other cancers, such as breast and prostate cancer, have achieved a five-year survival rate of over 90%, largely credited to progress made in early detection and treatment options.

THE HARSH REALITIES



^{*} Australian Government: Australian Institute of Health and Welfare: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/summary

^ Australian Government: Australian Institute of Health and Welfare "Cancer in Australia: 2019" https://www.aihw.gov.au/getmedia/8c9fc/f52-0055-41a0-96d9-f81b0feb98cf/aihw-can-123.pdf



Our plan for the future to demand better for pancreatic and upper gastrointestinal cancers

We're committed to delivering patient support services and research investment into services and programs that will have a direct impact on increasing survival rates for pancreatic and upper GI cancers.



PATIENT SUPPORT PROGRAMS

Access to a Nurse Specialist

Financial assistance program Living with pancreatic cancer Patient

Support Days

Patient and carer support services

Telephone and face-to-face support groups



AWARENESS AND EDUCATION

Patient and dietary handbooks

Health professional education for GPs, nurses and practice managers

Fact sheets on signs and symptoms

Video resources about the importance of nutrition, exercise, psychology



RESEARCH

Discovering new treatments

Early detection screening program National cancer registries

Supporting pancreatic cancer clinical trials

Providing scholarships for young researchers

Patient support programs

Pancreatic Cancer Nurse Specialist

It's critical for pancreatic cancer patients and their carers to receive the right information and resources to support them. Through our dedicated service, our pancreatic cancer nurse can help patients understand a recent diagnosis, treatment options, learn practical ways to manage symptoms, connect them to supportive services and make informed choices on how they can live with pancreatic cancer.

Pancreatic Cancer Nurse Network

The Nurse Specialist will be developing a Pancreatic Cancer Nurse Network across Australia. The network will provide professional development but also link nurse with pancreatic cancer patients. This will be the first national network for pancreatic cancer nurses.

Living with Pancreatic Cancer Patient Support Days

An informative series that brings together a team of dedicated health professionals to guide patients from diagnosis through to treatment and management of the disease. Each session provides information on managing symptoms, diet and exercise, mindfulness and more. These days are the first of their kind offered for people with pancreatic cancer.

Financial Assistance Program

Support for families who are experiencing hardship due to the burden of living with pancreatic cancer by providing funds to pay for to medical appointments or scans, access complimentary therapies, purchase medical and mobility equipment and pay for household bills. We also provide funds for accommodation and travel for patients coming from regional or rural areas for treatment or appointments.

Patient & Carer Support

A network of face-to-face and telephone support groups for both patients and carers that connect people living with pancreatic cancer to exchange experiences in a caring environment. We will also be developing further carer services now the Carers Feasibility project is complete.







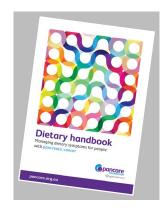
Awareness and education

OUR INITIATIVES

Patient Education

We develop and produce key patient information handbooks, factsheets and digital assets so patients and their carers can better understand their disease, diagnosis and treatment options to help raise awareness and education on these deadly cancers.

- Pancreatic Cancer Patient Handbook
- Pancreatic Cancer Dietary Handbook
- Cancer factsheets: signs and symptoms
- Digital assets: videos, animations and infographics to spread awareness on each cancer



Health Professional Education

In conjunction with Pancreatic, Liver and Biliary Cancer specialists we conduct Education evenings for GPs, nurses, practice managers and other interested parties on the management of pancreatic, liver and biliary cancers. We also work in conjunction with nurses to deliver pancreatic cancer Nurse Seminars for professional development.



Research

OUR INITIATIVES

University of Melbourne & Austin Health Department of Surgery

Accelerating research into the treatment of pancreatic cancer by use of Novel Agents. The team are investigating therapies for the most common and most deadly form of pancreatic cancer, pancreatic ductal adenocarcinoma - known as PDAC. Research leads: Prof. Graham Baldwin and Assoc/Prof. Dr Mehrdad Nikfarjam.

University of Wollongong

Localised drug delivery for non-resectable pancreatic cancer at the University of Wollongong with principal investigator Dr Kara Vine-Perrow. This project is in partnership with Cancer Australia and funded by Pancare. While surgical removal of the tumour remains the only curative option, over 80% of patients present with inoperable disease. This project will test a novel drug delivery system that is capable of locally delivering 2 chemotherapeutic drugs directly to the site of the tumour with the overall goal of reducing tumour size so that patients can undergo life-saving surgery.

Scholarship PhD Researcher - University of Melbourne

Support a PhD Researcher in the field of pancreatic cancer for three years. Aligned with one of the leading cancer research facilities in Melbourne. Researchers also publish and can present at conferences their work.

Upper GI Cancer Registry - Monash University

The Upper GI Cancer Registry (UGI-CR) is a clinical quality registry designed to describe patterns of care following diagnosis of pancreatic, oesophageal, stomach, liver and biliary cancers. The aim of the registry is to identify variation in treatment and outcomes of patients that will lead to an improvement in patient outcomes and quality of care. Currently, a network of 27 cancer centres across Australia, New Zealand and Singapore with longitudinal data on in excess of 850 pancreatic cancer patients, which is set to grow. Research lead: Professor John Zalcberg.





Thank you for helping us rewrite the story of pancreatic cancer





www.wcmics.org
contactus@wcmics.org