

The gap between theory and practice: quantity and quality of care plans and treatment summaries across survivorship care pilot sites in South Australia

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**Government
of South Australia**

SA Health

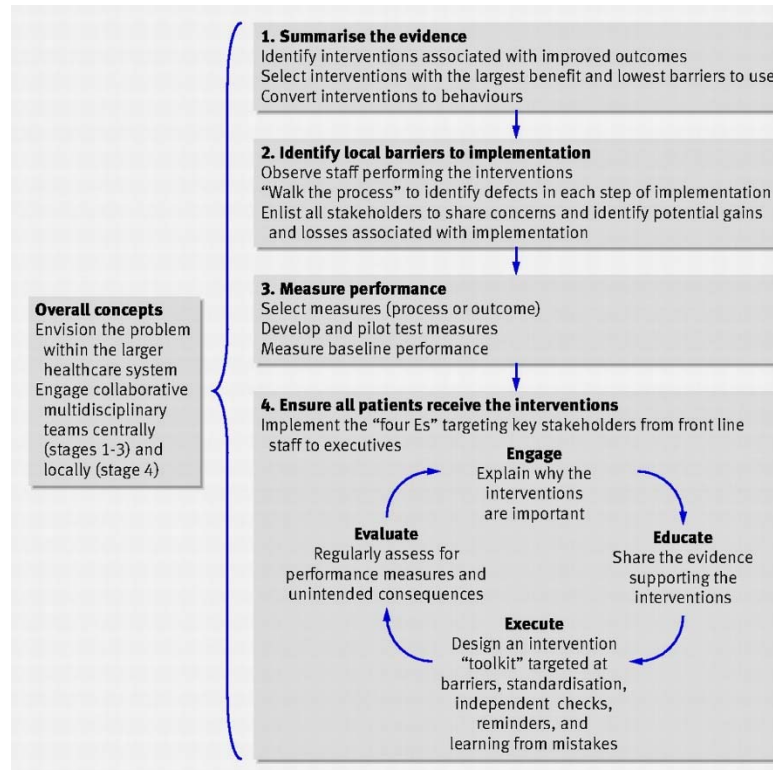
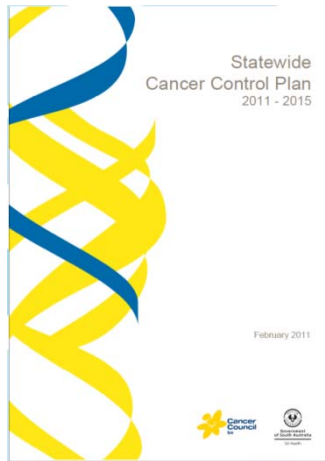
Background

- > Survivorship care plans and treatment summaries are considered the key component of survivorship care
 - Even though there is conflicting evidence of their utility in clinical trial setting
- > South Australia is taking a state-wide approach to health transformation
- > South Australian Cancer Service has been asked by the National Cancer Experts Reference Group to develop and pilot a state-wide survivorship framework that may help informing survivorship care initiatives nationally

Aims

- > To design, pilot and evaluate a state-wide strategy to deliver survivorship care to adults and children treated for cancer with curative intent in South Australia.

Strategy for translating evidence into practice.



Peter J Pronovost et al. BMJ 2008;337:bmj.a1714

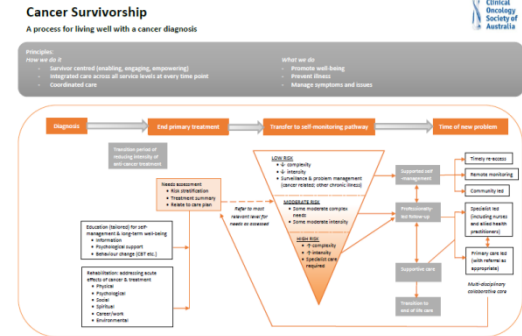
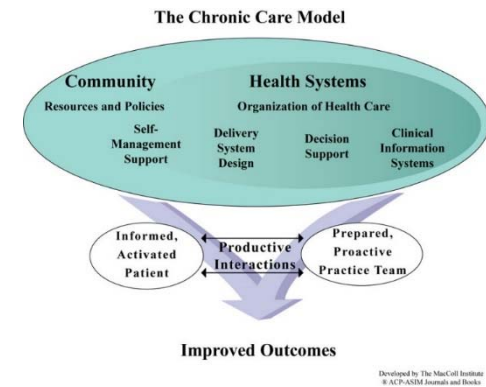
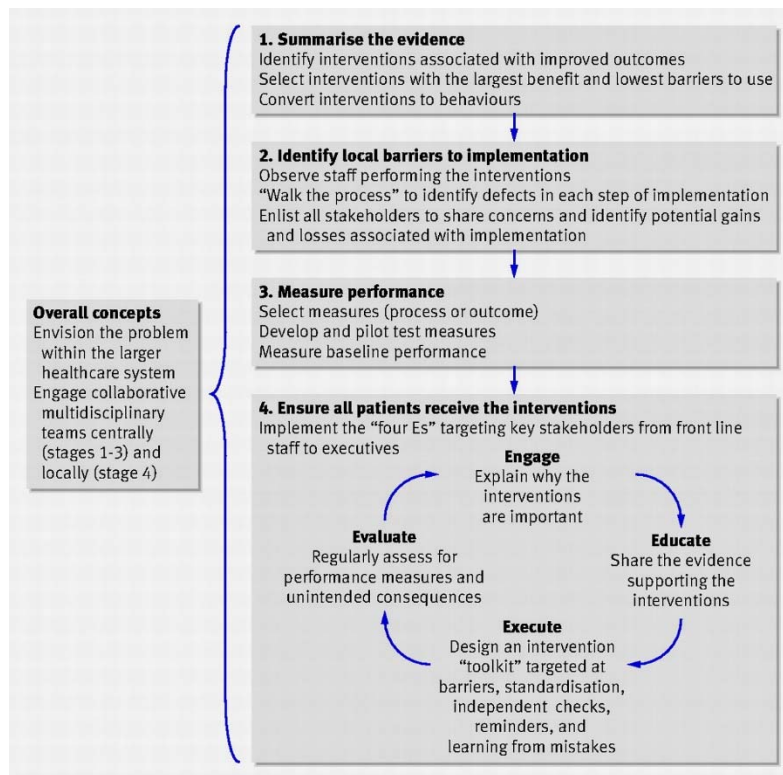


Figure 1. Model for wellness in cancer survivorship



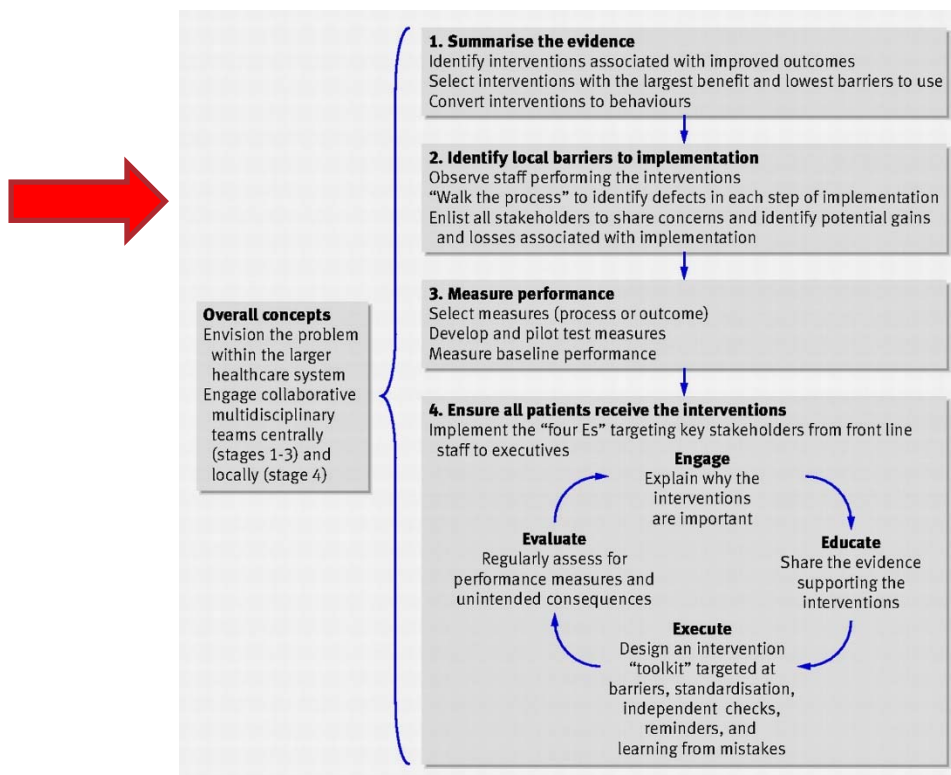
Strategy for translating evidence into practice.



- 1. Magnitude of the problem**
Survivors perceptions and needs
Providers perceptions and needs
Data on incidence, prevalence, patterns of care
- 2. Solutions**
Existing models of care

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Strategy for translating evidence into practice.



3. Strategy development

Stakeholder feedback

Process/system mapping

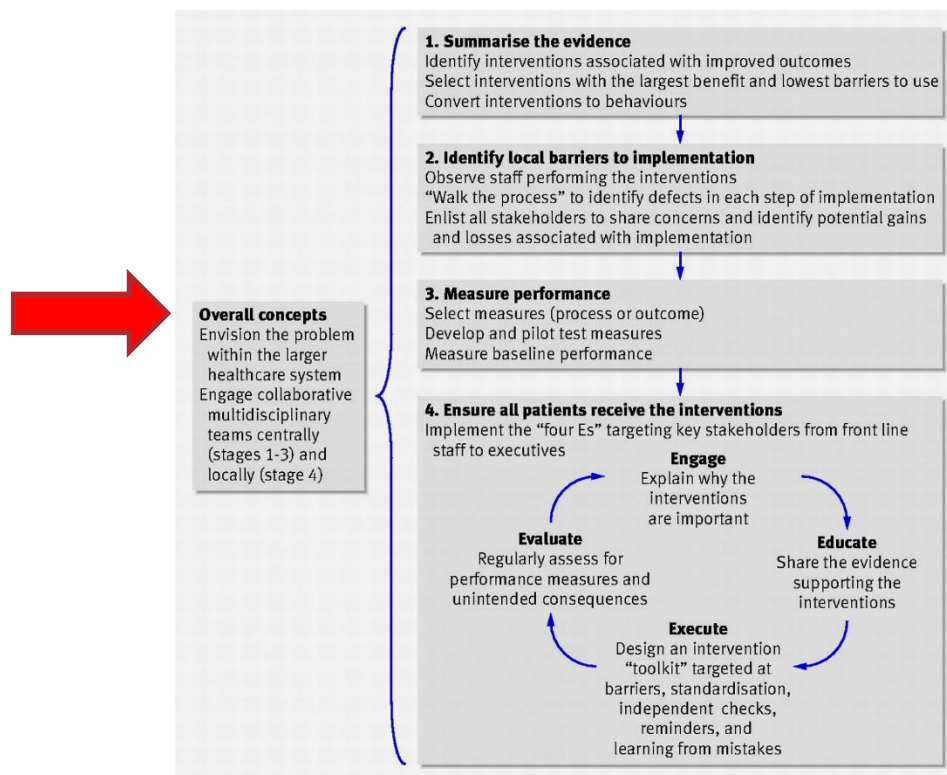
Consensus meeting re solutions

Work on tools strategies

Ongoing stakeholder feedback

Peter J Pronovost et al. BMJ 2008;337:bmj.a1714

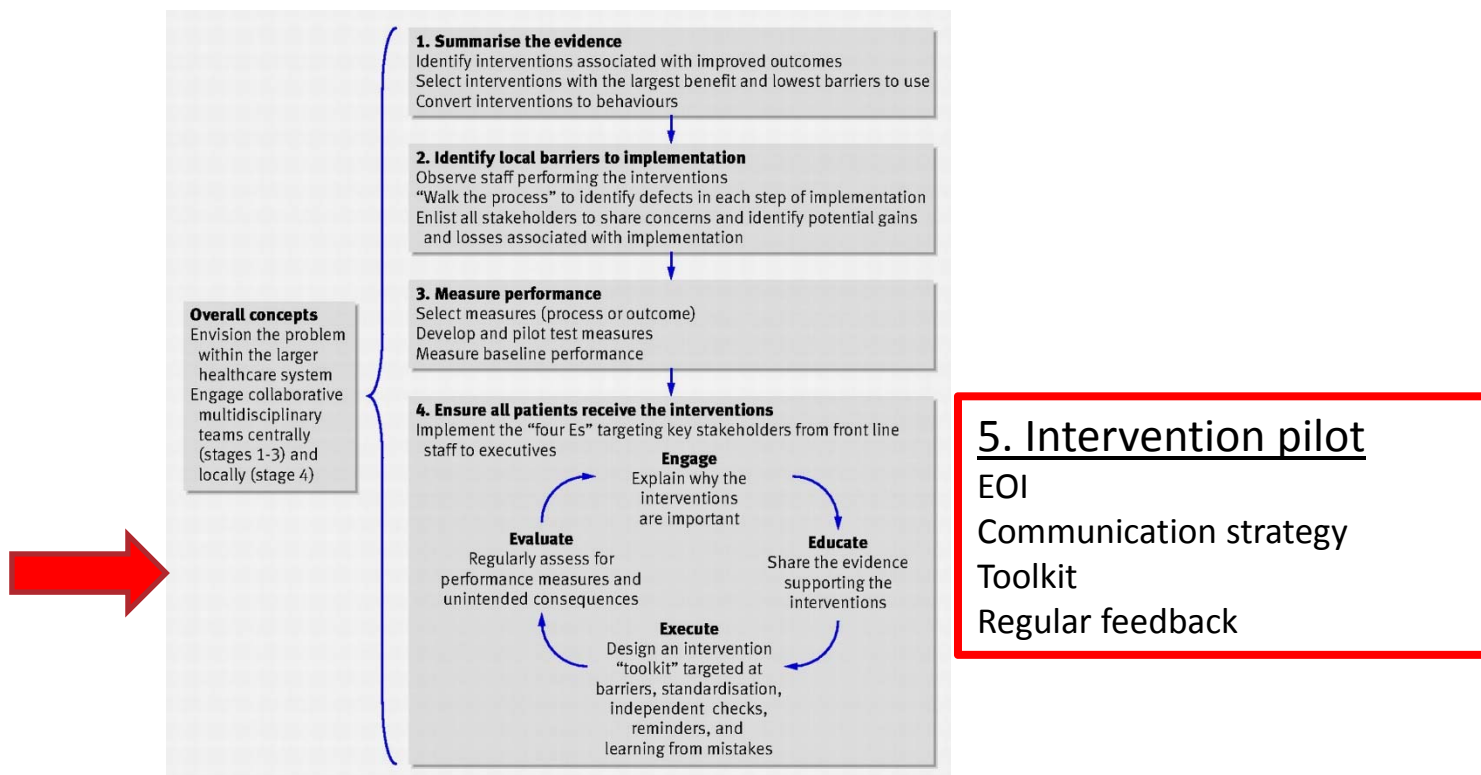
Strategy for translating evidence into practice.



4. Measures development
Process and outcome
HE measures
Framework of measures

Peter J Pronovost et al. BMJ 2008;337:bmj.a1714

Strategy for translating evidence into practice.



Peter J Pronovost et al. BMJ 2008;337:bmj.a1714

Implementation Principles

- Multi-disciplinary, multi-sectoral and comprehensive (survivor, family and community)
- Evidence-based
- Data driven
- Technology enabled

Overarching Principles

1. Holistic and patient-centred
2. Safe
3. Accessible
4. Effective
5. Efficient
6. Equitable



- KPIs
- Health economic measures

Methodology

- > 4 champion teams recruited after EOI
 - Nurse/med onc
 - Inner metro (2), outer metro (1), rural (1)
 - 1 well established survivorship service
- > 3 month recruitment of patients
 - Established templates and procedures
 - Regular debrief, action and outcome logs
- > Ethics approval for evaluation
 - TS and CP content, demographics
 - Feedback from champions
 - Patient/survivor survey



Affix patient label here

Cancer Treatment Summary for Patients Name

Type of Cancer:
Date and details of diagnosis:
Stage:
Pathology findings and pathology service:

| Treatment | Type/findings | Doctor/Hospital/Dates | Complications/changes to treatment |
|-------------------------------|---------------|-----------------------|------------------------------------|
| Surgery | | | |
| Chemotherapy | | | |
| Hormonal treatment | | | |
| Radiation therapy | | | |
| Supportive and other services | | | |

This is a brief record of the major aspects of your cancer treatment. This document is not intended to be a detailed or comprehensive record of your care. If however, you would like a more detailed account of your treatment please contact your cancer specialist.

Summary completed by:

Date:



Affix patient label here

Distress Thermometer and Checklist

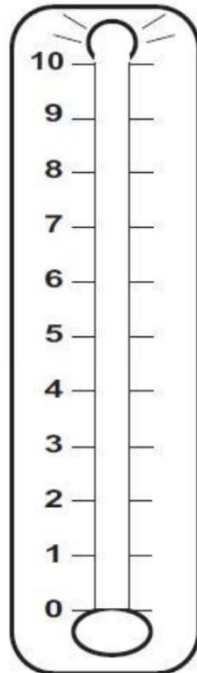
Distress is often unpleasant feelings or emotions that can impact on the way you think, feel and act. It can include feelings like sadness, worry, anger, helplessness and guilt. It's common for someone who has been diagnosed with cancer to experience some level of distress at some point in time (anywhere from diagnosis and beyond). Your level of distress may only be minor or could be more serious where you find that you're not able to do the things you used to do. It's important for your Treatment/Medical Team to know how you're feeling. By completing the following tool your team will work with you and help link you with other supportive services (for example counsellors, social workers, dietitians) when you need or want to.

Instructions:

1) please circle the number 0 – 10 that best describes how much distress you have been experiencing in the past week including today

2) please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each

Extreme distress



No distress

- | | | | | | |
|--------------------------|--------------------------|--|--------------------------|--------------------------|----------------------------|
| YES | NO | Practical Problems | YES | NO | Physical Problems |
| <input type="checkbox"/> | <input type="checkbox"/> | Child care | <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing | <input type="checkbox"/> | <input type="checkbox"/> | Bathing / dressing |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance / financial | <input type="checkbox"/> | <input type="checkbox"/> | Breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation | <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Work / school | <input type="checkbox"/> | <input type="checkbox"/> | Constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions | <input type="checkbox"/> | <input type="checkbox"/> | Diarrhoea |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Eating |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Fatigue |
| YES | NO | Family Problems | <input type="checkbox"/> | <input type="checkbox"/> | Feeling swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children | <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner | <input type="checkbox"/> | <input type="checkbox"/> | Getting around |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children | <input type="checkbox"/> | <input type="checkbox"/> | Indigestion |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues | <input type="checkbox"/> | <input type="checkbox"/> | Memory / concentration |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| YES | NO | Emotional Problems | <input type="checkbox"/> | <input type="checkbox"/> | Nausea |
| <input type="checkbox"/> | <input type="checkbox"/> | Depression | <input type="checkbox"/> | <input type="checkbox"/> | Nose dry / congested |
| <input type="checkbox"/> | <input type="checkbox"/> | Fears | <input type="checkbox"/> | <input type="checkbox"/> | Pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness | <input type="checkbox"/> | <input type="checkbox"/> | Sexual |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness | <input type="checkbox"/> | <input type="checkbox"/> | Skin dry / itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | Worry | <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| <input type="checkbox"/> | <input type="checkbox"/> | Loss of interest in usual activities | <input type="checkbox"/> | <input type="checkbox"/> | Substance abuse |
| <input type="checkbox"/> | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands and feet |
| YES | NO | Spiritual / religious / cultural concerns | <input type="checkbox"/> | <input type="checkbox"/> | |
| <input type="checkbox"/> | <input type="checkbox"/> | | | | |

Other Problems: _____

Adapted from the National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines and Distress Thermometer for Patients



Affix patient label here

Care Plan for Patient's Name

This care plan aims to assist in identifying and developing your health goals as a cancer survivor and steps you can take to reach these. You're encouraged to discuss and share your care plan with your GP, family or others you feel can support you and continue to build as you achieve your goals or have other needs arise in the future.

| Current issues, problems or concerns | Level of importance to you 1-very 2- somewhat 3- not important | Goal moving forward What do you want to achieve? | Strategy How do you want to achieve it? | Who should assist you in achieving it GP, specialist, allied health, friends, others? | GP Involvement | Other providers involved (ie: specialist) |
|---|--|--|---|---|-----------------------|--|
| Cancer Surveillance | | | | | | |
| | | | | | | |
| Side effect management | | | | | | |
| | | | | | | |
| Other health problems | | | | | | |
| | | | | | | |
| Wellness & health promotion | | | | | | |
| | | | | | | |
| Other | | | | | | |
| | | | | | | |

Data collected

- > Demographics
- > Process measures
- > Content: completeness and quality
- > Providers and survivors' feedback

Results

| Demographic Data | Total | Site A | Site B | Site C | Site D |
|----------------------|-----------------|----------|----------|----------|--------|
| Cohort (#) | 43 | 34 | 6 | 3 | 0 |
| Age range (years) | 32 - 80 | 39 - 80 | 32 - 75 | 53 - 71 | 0 |
| Median age (years) | 59 | 59 | 58.5 | 59 | 0 |
| Gender | | | | | |
| - Male | 7 (16%) | 6 (18%) | 1 (17%) | 0 | 0 |
| - Female | 36 (84%) | 28 (82%) | 5 (83%) | 3 (100%) | 0 |
| Tumour type | | | | | |
| - Breast | 32 (74%) | 23 (67%) | 6 (100%) | 3 (100%) | 0 |
| - Colorectal | 7 (16%) | 7 (21%) | 0 | 0 | 0 |
| - Ovarian | 1 (2%) | 1 (3%) | 0 | 0 | 0 |
| - Tonsil SCC | 1 (2%) | 1 (3%) | 0 | 0 | 0 |
| - Testicular | 1 (2%) | 1 (3%) | 0 | 0 | 0 |
| - Cholangiocarcinoma | 1 (2%) | 1 (3%) | 0 | 0 | 0 |

Results

| Preparation | Appointment | Follow-up/Finalising |
|--|----------------------------|----------------------------|
| 20 – 90 mins (avg 51mins) | 45 – 90 mins (avg 57 mins) | 30 – 75 mins (avg 46 mins) |
| Total: average of 154 minutes per person | | |

Challenges identified:

1. Location of medical records and files (in some instances across multiple sites)
2. Accessing original documentation (eg. pathology reports)
3. Compiling information of treatment, particularly if survivors received services in both the public and private sectors

Results –Treatment Summary

TS complete with regards to:

- > Date of diagnosis (98% included)
- > Diagnosis (100% included)
- > Stage (90% included)
- > Pathology findings (98% included) and service providers (95% included)
- > Treatment received (100% included)

Details relating to complications were more likely to be missing:

- Time of when complications developed
- Level of severity of complications
- Actions taken
- When or if the complications were resolved

Results Care Plan

| Problem | Total # CP reported on | % CP | Avg level of importance | Avg Strategy Score | Average Provider Score |
|--|------------------------|------|-------------------------|--------------------|------------------------|
| Cancer Surveillance | 43 | 100% | 1.2 | 2/5 | 1.2/3 |
| Heart health (hypertension, cholesterol management, risk of cardiac toxicities, atrial fibrillation, heart failure) | 23 | 53% | 2.1 | 2/5 | 1.1/3 |
| - Management of existing condition | 10 | 44% | 2.1 | 2/5 | |
| - Prevention | 13 | 57% | 2.1 | 2/5 | |
| Lifestyle (weight management, PA, HE, alcohol intake, smoking) | 20 | 47% | 1.7 | 2/5 | 1.6/3 |
| Cancer Screening (bowel, cervical, breast where applicable) | 18 | 42% | 2.1 | 2.1/5 | 1.4/3 |
| Bone health (osteoporosis, osteopenia, bone health) | 16 | 37% | 1.7 | 2/5 | 1.8/3 |
| Anxiety & Depression (include fear recurrence) | 12 | 28% | 1.3 | 2/5 | 1.8/3 |
| Peripheral Neuropathy | 12 | 28% | 2.3 | 1.7/5 | 3/3 (only on 1/12) |
| Fatigue | 10 | 23% | 1.6 | 2.1/5 | 1.6/3 |
| Lymphoedema | 7 | 16% | 2 | 2/5 | 1.8/3 |
| Bowel problems (diarrhoea, constipation; both; IBS) | 7 | 16% | 1.8 | 1.9/5 | 1.5/3 |

Results – champions' feedback

- > “Different model of care”
 - Templates useful
 - Delivery improved with confidence and skill
 - Team support valued
 - Specialist endorsement important
 - Patient preparation important

Results – survivor feedback

- Response rate 35% (15/43)
- 93% reported value in attending a survivorship appointment

Treatment Summary:

- 87% reported having a personalised copy as being useful

Care Plan:

- 73% found the CP useful, 20% unsure
- 67% had used their CP and shared with GP
- 47% reported acting on a goal

Time of appointment:

- 53% reported time SCP developed was “just right”, usually between 2 weeks to 6 months post-treatment

100% recommended all survivors in future receive individualised TS & CP

Strenghts and limitations

- > Real life setting, real life resources
- > Consumer engagement and feedback

- > Small numbers
- > Mostly breast cancer
- > Self selected champions
- > No measure of impact on outcomes

Conclusions

- > The initial pilots of the state wide model indicate significant variability in uptake and quality of service
- > Future work needed on
 - Strategies needed to insure quality of TS and CP
 - Engagement with providers that goes beyond initial champions
 - Move from the illness to wellness model
 - Preparation of providers and survivors
 - Defining the demand and capacity for service
 - Engagement of GPs
 - Long term impact and sustainability

Survivorship Steering Group

Professor Bogda Koczwara (Chair): Senior Staff Specialist in Medical Oncology FCIC

Ms Tracey Doherty (Co-chair): A/ Service Director, SA Cancer Service

Ms Chantelle Hislop: Senior Project Officer, SA Cancer Service

Dr Kate Cameron: Nursing Director, WCH

Professor Marion Eckert: Director Rosemary Bryant AO Research Centre, UniSA

Ms Julie Marker: Consumer & Chairperson, Cancer Voices SA

Ms Chris Christensen: Consumer & Deputy Chairperson, Cancer Voices SA

Ms Karen van Gorp: Consumer, Melanoma Patients SA Facilitator & Cancer Voices SA

Mr Michael Fitzgerald: Nurse Practitioner Candidate (Medical Oncology), SALHN

Ms Nicole Loft: Nurse Practitioner (Haematology), CALHN

Dr Dagmara Poprawski: Medical Oncologist, CHSA

Ms Kate Turpin: Nurse Practitioner (Haematology/Oncology), WCH

Dr Michael Osborn: Lead Clinician, Consultant Haematologist Oncologist, Youth Cancer Service SA/NT

Ms Janet Stajic: Senior Project Officer, SA Cancer Service

Clinical A/Professor Taryn Bessen: Senior Staff Radiologist, CALHN

Dr Nadia Corsini: Senior Research Officer, Cancer Council SA

Pilot Champion Teams

Mr Michael Fitzgerald & Professor Bogda Koczwara: SALHN

Ms Julie Campbell & Dr Dagmara Poprawski: CHSA

Ms Shirley Roberts & Dr Rohit Joshi: NALHN

Ms Janette Prouse & Dr Sid Selva: CALHN

Thank you to all stakeholders who have contributed to the development of the SA Survivorship Framework over the past 2 years