Epworth & the ECS system

Paul Fenton
Director of Operations, Epworth Radiation Oncology

3rd June, 2017
Introduction

• Background
• Supportive Care and Survivorship
• Survivorship Models
• Epworth Nurse Led Model
• Building a Survivorship Application
• Patient experience with the application
• Benefits for Patients
• Next steps
Background - how did we get here?

- Study tours of US facilities
- Scholarship recipients implementing findings within some Epworth cancer services
- Awarding of State contract in Warrnambool
- Introduction of wellness model
- Growing interest from physicians and clinicians to develop supportive care and survivorship services
Survivorship Rates – Cancer becomes chronic condition

If survival continues to increase at the current rate, by 2015 the 5-year survival for Victorians with cancer will be 67%.

If a further 10% improvement in survival can be achieved by implementing the actions in the plan, by 2015 the 5-year survival for Victorians with cancer will be 74%.

Victorian Cancer Action Plan, 2012
Supportive Care and Survivorship

- Excellent acute treatments and care already in place
- Varied Allied Health support in prehab, acute, post treatment phases
- Known spike in anxiety and distress post acute phase
- Complements existing services

Screening Points
Definitions – Supportive Care

An overarching term describing services required by those affected by cancer.

Includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care.

Supportive care in cancer refers to the following five domains:

- Physical needs
- Psychological needs
- Social needs
- Information needs
- Spiritual needs

(NICE, 2004)
Definitions – Survivorship

A survivor is defined as those individuals who have completed curative treatment or who have transitioned to maintenance or prophylactic therapy.

Survivorship

Can be defined as the process of living with, through and beyond cancer and incorporates physical, psychosocial and economic issues from diagnosis until the end of life and is now recognised as a distinct phase in the cancer care continuum.

(Institute of Medicine, 2005)
# Models for Survivorship Delivering

<table>
<thead>
<tr>
<th>Model</th>
<th>Definition</th>
<th>Advantages</th>
<th>Disadvantages</th>
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<tbody>
<tr>
<td>Nurse-Led Program</td>
<td>RN prepares treatment summary and care plan; presents to patient during teaching visit</td>
<td>• Staffing costs lower than for other models</td>
<td>• Cannot bill for service</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Onus on patient to complete recommended care</td>
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</tr>
<tr>
<td>NP-Led Survivorship Clinic</td>
<td>NP conducts H&amp;P, makes referrals for supportive care and screenings, educates patient, prepares treatment summary and care plan, coordinates with PCPs and oncologists</td>
<td>• Clinic visits may be reimbursed</td>
<td>• Difficult to make financially self-sustaining</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Facilitates transition back to primary care</td>
<td>• Requires clinic space</td>
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<tr>
<td>Multi-disciplinary Survivorship Clinic</td>
<td>Multidisciplinary team, including MD/NP, SW, RD, PT and pharmacist meet individually with patient to provide care and referrals; collectively develop treatment summary and care plan, which is later presented to patient</td>
<td>• Very comprehensive approach to care</td>
<td>• Resource intense</td>
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<tr>
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<td>• Clinic visits may be reimbursed</td>
<td>• Difficult to make financially self-sustaining</td>
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<td>• Requires clinic space</td>
<td>• Requires clinic space</td>
</tr>
<tr>
<td>PCP-Led Survivorship Care</td>
<td>APN prepares treatment summary and care plan; meets with patient to present care plan and provide in-depth education about late- and long-term effects, screenings for recurrence and secondary cancers; ongoing group education sessions available; goal to make patient “conduit of information” for other healthcare professionals involved in care</td>
<td>• Staffing costs lower than for other models</td>
<td>• Cannot bill for service</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Facilitates transition back to primary care</td>
<td>• Assumes patient has access to full spectrum of health services</td>
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<td>• Onus on patient to complete recommended care</td>
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</table>
Supporting cancer survivors in Victoria: summary report
Learning from the Victorian Cancer Survivorship Program pilot projects 2011–2014
## Local models of care

### Breast cancer Survivorship program
- Risk stratified to shared care follow-up with GPs at MDM. Offered face-to-face or telephone-delivered nurse-led clinic. Develop SCP and facilitated shared care with nominated GPs.
- RMH, RWH, Western, BreaCan, Inner NW Medicare Local

### Barwon: Improving outcomes for survivors of cancer
- SCPs and 1 page tumour specific surveillance schedules for GPs across 8 tumour streams. Nurse-led clinics, delivering two consults to develop SCP, screening, care coordination and transition to shared care with nominated GPs.
- BH, Deakin, BSWRICS, WDHS, Barwon & Great South Coasts ML

### Melanoma shared care: tripartite approach for survival
- Low risk patients discharged to GPs. Surveillance plan developed by specialists, diary resource summarising treatment and surveillance plan, generating electronic reminders.
- Alfred, Gippsland RICS, SMICS, Peninsula GP network, Melanoma Patients Australia

### A model of youth-friendly survivorship care
- Specialists supported coordinators to deliver developmentally appropriate screening, assessment and intervention for AYA survivors. Supplemented routine follow up. Encouraged to engage GP with SCPs.
- ONTrac at Peter Mac, RMH, Bendigo, CanTeen, Melb Uni, Youth Cancer Advisory Board.

### Moving forward with confidence: capacity for self-management in cancer survivors
- Nurse supported survivors to develop well-being focused SCPs and in self-management. CCV nurse helpline provided follow-up 3 times over 8 months.
- NEMICS, Austin, Eastern, Northern, CCV, QUT

### Positive change for life: Health and Wellbeing for blood cancer survivors
- 12 month community based individualised program based on physical activity, nutrition, group activities and motivational support. Participants received face-to-face and phone dietetic support, tailored physical activity plan, cost-neutral gym membership.
- Alfred, SMICS, Leukeamia Foundation
Shared care with GPs or discharge to GP follow-up

- Three projects piloted this model
- High level of acceptance and satisfaction
- GP engagement presented challenges across the projects
- Most included primary care representative on steer co
- Opt-out approach to obtain GP consent to participate in shared

Nurse-led clinics and care coordination approaches

- Two of six projects established NLCs following active treatment
- NLCs facilitated supportive care screening, tailored information provision, linkage with services and transition to GP follow-up
Organisation/System

• Strong clinical leadership and project management principles are critical for effective implementation.
• Information management systems can support or impede the process of identifying patients at the end of their treatment.
• They can also help generate SCPs and with communication with general practice.
• Important to consider principles of service and workforce design when initiating new models of care.
• Re-orientating health services to support self-management and wellness requires major cultural change.
Engaging primary care

• Most GPs are willing to provide cancer surveillance for low-risk survivors.

• Establishing and communicating clear roles and responsibilities in survivorship care is essential.

Survivors

• It is important to prepare survivors during treatment for the potential impacts of cancer.

• Empowering survivors to seek post-treatment information and support is important.

• Preparing survivors early for GP follow-up helps them to accept shared care.
Survivorship at Epworth

Model of Care

• Nurse led model following referral, we engage with patient while on treatment
• Introduce our service and orientation to the online patient portal
• Program underpinned by IT application for consistency, efficiency and sustainability
• Survivorship clinic held at 3 - 6 months and 12 months post treatment completion
• A range of questionnaires identify unmet needs and to tailor appointments
Survivorship Model of Care

Survivorship clinic

• Address unmet needs and make referrals accordingly
• Survivorship care plan, follow up plan and monitoring
• Self care education
• Provide information on support groups
• Monitoring of side effects

Survivorship Care Plan

• Patient leaves with hard copy
• Care plan to GP
• Also accessible through the portal

Transition to GP care after 12 month appointment
Our Vision

Program aims:

• Early identification and intervention of unmet need
• Decrease anxiety by providing a clear history and future plan
• Empower patient to be an active member of their care team
• Increase compliance in follow up care
• Data collection to quantify cancer patient unmet needs
• Inform regional service planning for cancer survivors
• To set the benchmark for regional survivorship care
Equicare™

- Equicare™ is a Canadian based company
- Vendor neutral system offering patient portal and/or survivorship module
- Equicare™ interfaces with oncology information system – ARIA
- Patient portal deployment in NSW
- Epworth is the first fully integrated system in Australia
- Web based platform for patients
- Patient may choose for their family and/or GP to access their information
Equicare™

Web based access with interfaces to clinical systems – consideration for security risk

Option 1 Using Three VMs and Reverse Proxy

Building a Survivorship Application

- Building and testing of survivorship module content
- Installation and configuration commenced February 2017
- Initially for major cancer groups
  - Breast, prostate, lung and colorectal cancers
- Patients and care providers access to information including:
  - Treatment history, test results, appointment times
  - Follow up plans, questionnaires, useful links, care team details
- Final testing and training over the last 2 weeks
Survivorship Care Plan

*Automation Streamlines Care Plan Creation*

- Radiation Oncology
- Medical Oncology
- Imaging
- Pathology
- Surgery
- Late and long-term effects
- Care team contact info
- Community resources
- Diet, exercise
- Screenings

**EQUICARE CS™**

- Treatment Summary
- Care Plan

40+ page treatment summary and care plan
Building the Survivorship application

South West Regional Cancer Centre

Education Library

- All

Library
- Introduction (32)
- Surgery (2)
- Drug Therapy (6)
- Radiation Therapy (18)
- Short Term Side Effects (2)
- Long Term Side Effects (11)
- Support Resources (13)
- Survivorship (10)

To find education articles, select a library category on the left or use the Search Library feature above.
Building the Survivorship application

South West Regional Cancer Centre

Education Library

Library

Introduction (32)
Surgery (2)
Drug Therapy (6)
Radiation Therapy (18)
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Long Term Side Effects (11)
Support Resources (13)
Survivorship (10)

Introduction
Bowel cancer screening
Cancer prevention plan for Women
Centrelink
Follow up of survivors of breast cancer
Genetic Testing for Breast Cancer- FACT SHEET
Get checked- a cancer prevention plan FOR MEN
Get checked- a cancer prevention plan FOR WOMEN
Healthy eating to reduce cancer risk- FACT SHEET
Limit alcohol
Living well after Cancer
Living with advanced cancer
Maintain a healthy Weight
Managing your Bowel Cancer risk: Lifestyle Factors
Managing your bowel cancer risk: screening
Money help
Move your body
Nutrition and cancer
On the road to recovery- A guide for those who have finished their cancer treatment
Overcoming cancer pain
Questions you may wish to ask about the time after treatment
Quit smoking
Quit smokingQUIT smoking
Secondary lung cancer
Sexuality, intimacy and cancer
Stay in shape
Sun smart
Building the Survivorship application

South West Regional Cancer Centre

Frequently Asked Questions

What is Survivorship?

What is Navigation?

What kinds of medical information can the patient portal provide to me?

When can I see the results of my medical tests on the patient portal?

Why are some of my medical tests not available on the patient portal?

If some of the information on the patient portal is not correct, what should I do?

What is a Survivorship care plan and why do I need one?

What is a treatment summary and why do I need one?

Who decides which education information I see on the patient portal?

If I want to find more information that might be related to my disease, is there a way to do that?

What are questionnaires used for?

Is the patient portal secure?

What is the privacy policy related to the patient portal?

Computer/Browser requirements for the patient portal
Building the Survivorship application

South West Regional Cancer Centre

Useful Links

Breast, Prostate, Lung and Colorectal Cancer

- Australian Cancer Survivorship Centre
- Beyond Blue
- Cancer Australia- Australian Government
- Cancer Council Australia
- Cancer Council Victoria
- CanTeen
- Care Search: Palliative Care Knowledge Network
- Better health Channel-(Produced with Cancer Council)
- Health Direct Australia (Australian Government)
- Evig- For information about cancer treatment and related procedures
- Epworth Health care/cancer services/Radiation oncology
- Look Good, Feel Better
- About Herbs-Expert advice and information on supplements, integrative medicine treatments, and more.

Breast Cancer

- Breast Cancer Network Australia
- Think Pink Centre
**Building the Survivorship application**

South West Regional Cancer Centre

**Questionnaire Templates**

<table>
<thead>
<tr>
<th>Title</th>
<th>Internal Description</th>
<th>Disease Sites</th>
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<tr>
<td>Cancer Survivors' Unmet Needs (CaSUN)</td>
<td>Hodgkinson et al. 2007</td>
<td>All Disease Sites</td>
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<td>Cancer Survivors' Unmet Needs (CaSUN) rev 1</td>
<td>Hodgkinson et al. 2007</td>
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<td>EORTC QLQ-BR23</td>
<td>EORTC QLQ-BR23 for the assessment of quality of life in patients with breast cancer.</td>
<td>Breast</td>
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<td>EORTC QLQ-CR20</td>
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<td>EORTC QLQ-LC13 for the assessment of quality of life in patients with lung cancer.</td>
<td>Lung (Non-Small Cell), Lung (Small Cell)</td>
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<tr>
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</tr>
<tr>
<td>EORTC QLQ-PR25</td>
<td>EORTC QLQ-PR25 for the assessment of quality of life in patients with prostate cancer.</td>
<td>Prostate</td>
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<tr>
<td>Form - History</td>
<td>Used to gather information on Medical, Family, and Social History.</td>
<td>All Disease Sites</td>
</tr>
<tr>
<td>Form - Medications and Allergies</td>
<td>Used to gather information on medications and allergies</td>
<td>All Disease Sites</td>
</tr>
<tr>
<td>Form - Registration</td>
<td>Used to gather basic information from a patient prior to first appointment at clinic.</td>
<td>All Disease Sites</td>
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</table>
Building the Survivorship application

- 80 plus spreadsheet tabs for diagnosis and stage
- NCCN guidelines for follow up
- Review and approval by Specialists

<table>
<thead>
<tr>
<th>Year</th>
<th>Month</th>
<th>Provider</th>
<th>Notepad</th>
<th>Breast Self-exam Education</th>
<th>Genetic Counseling</th>
<th>Clinical Breast Exam</th>
<th>Mammogram Followup</th>
<th>Breast MRI Followup</th>
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</tbody>
</table>
Equiricare™ – Active Patient Portal

Patient Management – Register Patient, assign care team and questionnaires
Equicare™ – Active Patient Portal

Questionnaires

Present questionnaires to patient

– National Comprehensive Cancer Network (NCCN) Distress thermometer
– Malnutrition Screening Tool (MST)
– Satisfaction Survey post radiotherapy treatment completion

Results written back to ARIA

Prospective electronic data collection of all assessments
**Equicare™ – Active Patient Portal**

**Education material**

**Online educational resources**

*Education Library*

- **Library**
  - Introduction (6)
  - Diagnosis and Work-up (24)
  - Surgery (11)
  - Drug Therapy (9)
  - Radiation Therapy (15)
  - Drug Fact Sheets (42)
  - Short Term Side Effects (57)
  - Long Term Side Effects (25)
  - Health Emergency (5)
  - Support Resources (20)
  - Survivorship (20)

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**Useful Links**

**Breast, Prostate, Lung and Colorectal Cancer**

- Cancer Australia. Australian Government
- Cancer Council Australia
- Cancer Council Victoria
- Better Health Channel (Produced with Cancer Council)
- Health Direct Australia (Australian Government)
- Ezi
- Epworth health care/cancer services/Radiation oncology

**Breast Cancer**

- Breast Cancer Network Australia
- Think Pink Centre
- Breast Cancer Care Western Australia
- National Breast Cancer

**Prostate Cancer**

- Prostate Cancer Foundation of Australia
- Prostate Cancer Institute
- Australian Prostate
- Presentation 453: this is a test's health website

**Lung Cancer**

- Lung Foundation of Australia

**Colorectal Cancer**

- Breast Cancer Australia
Equicare™ – Active Patient Portal

Appointments - List can be viewed or printed

Upcoming Appointments

<table>
<thead>
<tr>
<th>Date</th>
<th>Type</th>
<th>Provider</th>
<th>Location</th>
<th>Status</th>
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<tbody>
<tr>
<td>5/01/2017 9:00 AM</td>
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</tr>
</tbody>
</table>
Equicare™ – Active Patient Portal

- Clinical staff receive status alerts for completed questionnaires
- Patient receive notifications of appointments or questionnaires via text or email
Initial experience – Patient Portal

- Built portal content across July – August 2016 with September training staff
- Commenced portal access to patients in October 2016
- DT and MST screening via questionnaires
- 135 patients treated in 6 months, 131 patients screened – 94% (50% State target)
  - 1 x Missed
  - 3 x inappropriate due to mental state
Support service referrals – 6 months data

Social Work

- 19 referrals, 15 (79%) from positive responses in the distress thermometer
- Some referrals required despite low distress levels reported on DT

Dietitian

- 41 referrals, 24 (59%) from positive responses on the MST
- Remainder were due to standing orders:
  - by tumour stream or
  - on-treatment deterioration
Initial experience – Patient Portal

• Uptake of portal is promoted at initial nursing consultation
• Provides real-time 1:1 assistance to access, orientate and complete questionnaires
• Patient requires an email address to log in
  – 41 (30%) patients – had/knew their email address
  – 36 (88%) logged into the portal outside of nursing consult
• Not all patients engage with the system post orientation
• But those that do, continue to do so through their care
Patient experience - appointments

“"I know, I logged on and saw it had moved"
Patient experience – SCP

• Cover Page
• Table of Contents
• Explanation/welcome letter
• Treatment Summary
• Follow Up plan
• List members of Care Team with contact details
• Questionnaires, description and due date
• Education material and online links
• Blank “notes” page for patient to record thoughts
• Circa 40 page resource document
Patient experience – SCP

- Patient can access electronic version of SCP on portal
- Hardcopy provided at Survivorship Clinic Initial Consultation
Your care team has customized a follow up plan specifically for you. The following schedule shows all appointments and planned appointments as at this time. Specific dates and times will be assigned as the appointment approaches.

<table>
<thead>
<tr>
<th>Follow-Up</th>
<th>Target</th>
<th>Scheduled</th>
<th>Status</th>
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Benefits to Patients

Positive impact on experiences
- reducing anxiety and depression
- managing physical symptoms
- increasing knowledge of disease and treatment

Improved medical outcomes
- better adherence to treatment
- faster recovery
- fewer post-hospital complications
- enhanced self management strategies
- greater ability to cope with difficult treatments

Enhanced decision-making, active participation in care and satisfaction with care.
Funding Structure

How do we fund this program?

Survivorship

- Nurse Practitioner
- Patient Co-payment
- Philanthropic approach
- Internal cost - Downstream benefits
Benefaction

Major Donor
Epworth Medical Foundation

Local Trusts and Foundations
Peter’s Project
Overcoming Barriers to Success

- Prepare patients early for the Survivorship transition
- Care plan is best means of provider education
- Keep Care plans targeted and brief
- Educate patients about how to use Care Plans
- Collaboration the foundation of Physician Engagement
- Quantify the impact
Applying the lessons learnt

Success reliant on an efficient and sustainable model

The Survivorship Patient Portal
- IT application - first in Australia
- Overcome limitations identified in previously trialed models
- Interfaces with our oncology information system ARIA
- Electronic data collection - ease of auditing, analysis, sharing

Shared Care
- Survivorship care plan is sent to GP
- GP’s are given access to the portal with read only rights
- Transition to GP after 12 month appointment
- Supplementing Medical Care, not replacing it
What’s next….

- Appointed a Survivorship Nurse
- Final testing and user training
- Engaging key stakeholders - inform and promote service
  - PHN
  - Cancer Nurses
  - Medical Staff
- Workflow finalisation
- Referrals
- Commence service
- Longer term deploy model across rest of Epworth Group
Conclusion

- Successful implementation of a secure Patient Portal integrated with our OIS
- System readily captures patient specific information through questionnaires
- Supplement the nursing education and material with online resources
- Patients that are “IT savvy” continue to be engaged with the platform
- Embedded into our workflow at patient education
- Developed a Survivorship model supported by an Australian first IT application
- Applying the lessons learnt for evidence based, sustainable & efficient model
- Informs and improves the care provided to and benefiting our patients