Re-engaging ‘dis-engaged’ childhood cancer survivors: Overcoming barriers to long term follow-up care with innovative models of survivorship care

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This project is supported by Kids Cancer Alliance, ANZCHOG, The Kids Cancer Project and CCNSW(PG16-02, with the support of the Estate of the Late Harry McPaul)
Background

• Over 80% cure rate

• More than 400,000 young people (20-39 years) alive are survivors worldwide = 1 in every 530

• Therefore increasing recognition of the need for life-long follow-up care
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• More than 400,000 young people (20-39 years) alive are survivors worldwide = 1 in every 530

• Therefore increasing recognition of the need for life-long follow-up care

• Treatment-related late effects present many years later:
  - 75% severe/chronic illness
  - 37% life threatening conditions

Despite the risk of life threatening conditions post-treatment, many childhood cancer survivors are disengaged with cancer-specific follow-up care.

Robison et al 2014 Nat Rev Cancer
ANZCHOG Survivorship Study

Aim: to develop a model of care for the long term follow-up of childhood cancer survivors

Stage 1: Understanding what survivors want

What are the preferences and needs of childhood cancer survivors, and their parents?

Stage 2: Clinic audit

What follow-up care is provided in paediatric oncology in ANZ and how are survivors transitioned?

Stage 3: Resources to support transition

Are GPs prepared to manage the integrated care of long term survivors of childhood cancer?
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Are GPs prepared to manage the integrated care of long term survivors of childhood cancer?

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<thead>
<tr>
<th>Method</th>
<th>Participants</th>
<th>N</th>
<th>Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Questionnaire</td>
<td>Survivors &amp; parents</td>
<td>594</td>
<td>Ongoing</td>
</tr>
<tr>
<td>Interview</td>
<td>Survivors &amp; parents</td>
<td>90</td>
<td>Ongoing</td>
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</table>
Results

### Stage 1

**Section D: Health Issues**

**Why are we asking this?** We would like to know what late effects you have been experiencing (side effects related to cancer or its treatment that appear after treatment completion), so that we can develop tailored services.

1. **Please tick all issues you believe to be associated with your cancer/treatment which have occurred since finishing treatment (Past) or which you believe you may be at risk of experiencing in the future (Future), or both.**

   - Pain
   - Thyroid issues
   - Metastasis
   - Sexual issues

#### Late effects

<table>
<thead>
<tr>
<th>Percentage</th>
<th>One or more events</th>
<th>Two or more events</th>
<th>Three or more events</th>
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<tbody>
<tr>
<td>81.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>64.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55</td>
<td></td>
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</table>

48% non-attendees

89% of disengaged survivors were dissatisfied with their care.
Barriers to LTFU

- Out of my control
- Costs too much to attend
- Too far away
- Don't like having tests done
- Lack of prompts/reminders
- Want to get on with life
- No need for specialist care
- GP is best for follow-up
- Unaware of clinic

Results

<table>
<thead>
<tr>
<th>Barriers to LTFU</th>
<th>Attendees</th>
<th>Non-attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out of my control</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Costs too much to attend</td>
<td>**</td>
<td></td>
</tr>
<tr>
<td>Too far away</td>
<td>**</td>
<td></td>
</tr>
<tr>
<td>Don't like having tests done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of prompts/reminders</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Want to get on with life</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>No need for specialist care</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>GP is best for follow-up</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Unaware of clinic</td>
<td>*</td>
<td></td>
</tr>
</tbody>
</table>

* * p<0.001
** ** p<0.05
Results

33% reported 3+ barriers

60% beliefs (get on with life, GP best for FU, out of my control)

58% logistics (unaware, inflexible times)

26% costs (distance, loss of wages, childcare)
Results

Unmet information needs

- possible late side-effects
- possible development of second cancers
- any follow-up care I should receive
- how often I should have check-ups
- potential fertility issues
- genetic information related to my cancer
- genetic risk of cancer for family members
- cancer treatments I received
- psychological support
- managing Vitamin D levels
- genetic information about (future) children
- possible development of skin cancers
- managing fatigue
- Diet
- exercise needs
- potential sexual issues
- sun protection behaviours
- contraception choices
- managing pain
- support for family members
- education advice (returning to school)
- relationship issues
- financial/employment advice
- future health behaviours (smoking, alcohol)
- community support services

% of disengaged survivors
Stage 1: Understanding what survivors want

What are the preferences and needs of childhood cancer survivors, and their parents?

Stage 2: Clinic audit

What follow-up care is provided in Paediatric Oncology in ANZ and how are survivors transitioned?

Stage 3: Resources to support transition

Are GPs prepared to manage the integrated care of long term survivors of childhood cancer?

Method | Participants | N | Stage
--- | --- | --- | ---
2. Interview (clinic audit) | LTFU clinic Director & CNC | 19 (from 11 hospitals) | Completed
Participating hospitals

- PMH, Perth
- WCH, Adelaide
- TRCH, Melbourne
- LCCH, Brisbane
- JHH, Newcastle
- SCH, Sydney
- CHW, Sydney
- Starship, Auckland
- Wellington
- Christchurch
## Transition practices

<table>
<thead>
<tr>
<th>Model</th>
<th>SCH</th>
<th>CHW</th>
<th>JHH</th>
<th>WCH (A)</th>
<th>TRCH</th>
<th>Monash</th>
<th>LCCH</th>
<th>Perth</th>
<th>Auckland</th>
<th>Christchurch</th>
<th>Wellington</th>
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<tbody>
<tr>
<td>Age at discharge from paediatric Clinic (years)</td>
<td>no</td>
<td>18-24</td>
<td>18-24</td>
<td>18</td>
<td>18</td>
<td>18</td>
<td>14-18</td>
<td>18</td>
<td>18</td>
<td>18</td>
<td>18</td>
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<tr>
<td>Young adult transition: Adult Oncology directed care ± paediatric input</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓*</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓*</td>
<td>✓*</td>
<td>✓*</td>
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<tr>
<td>Community based care: PCP or paediatrician with continued contact with LTFU clinic (shared care)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
</tr>
<tr>
<td>Community based care: PCP or paediatrician without LTFU clinic contact</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
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<tr>
<td>Referral to “non LE” specialist (cardiology, endocrine)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
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<tr>
<td>Referral to risk-based specialists: BMT</td>
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<td>✓</td>
<td>✓</td>
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<tr>
<td>Referral to risk-based specialist: Radiation Oncology</td>
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<td>✓</td>
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<tr>
<td>Referral to risk-based specialist: Sarcoma surgeon</td>
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<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
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<td>✓</td>
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</tbody>
</table>

*Youth cancer Service
Audit results

Transition practices

- 9 of 11 clinics transition survivors to adult care between 18-24 years
- Varying transition practices: preparation, education and pathways (see Kenney et al 2016)
- Limited transition options

Screening/education

- Recognised/diagnosed chronic conditions well managed by sub-specialists (e.g. cardiology)
- Poor education about late-onset complications; delayed dx
- Deficient ongoing lifestyle education

Parent → survivor knowledge transfer

- Many parents well-informed, but not transferred to survivor
- OR become disengaged prematurely (e.g. due to ‘empty episodes of care’)
Audit results

- No accepted MOC
  - Guidelines
  - SCPs
  - Transition
- Varying practices between and within clinics
- Duplication of resources
- Need for better guidelines and further funding

“Some of my patients who I have looked after since they were 2 or 3 who are very safe and share absolutely everything with me which is amazing...but then it is severely difficult to get them to transition out” (Oncologist)

“We’ve got significant increases in the number of kids being referred into the service and we don’t have the capacity to run anymore clinics on the budget that we have...we’re trying to increase our output without increasing our expenditure” (CNC)

Most LTFU clinics do not have the capacity to provide lifelong care, forming an urgent need for improved discharge pathways.
**Stage 1:** Understanding what survivors want

What follow-up care is provided in Paediatric Oncology in ANZ and how are survivors transitioned?

**Stage 2:** Clinic audit

What are the preferences and needs of childhood cancer survivors, and their parents?

**Stage 3:** Resources to support transition

Are GPs prepared to manage the integrated care of long term survivors of childhood cancer?

**Method** | **Participants** | **N** | **Stage**
--- | --- | --- | ---
3. Interview | GPs | 50 | Ongoing
Are GPs prepared to manage the integrated care of long term survivors of childhood cancer?

### Aim and participants

<table>
<thead>
<tr>
<th>50 GP interviews</th>
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</thead>
<tbody>
<tr>
<td>47% male</td>
</tr>
<tr>
<td>28.4 years experience</td>
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<tr>
<td>2.1 CCS average in career</td>
</tr>
</tbody>
</table>
Results

Survivors

34% survivors do not have a regular GP

35% unwilling to see GP for follow-up

22% feel their GP is best placed to meet their follow-up needs
Survivors

- **34%** survivors do not have a regular GP
- **35%** unwilling to see GP for follow-up
- **22%** feel their GP is best placed to meet their follow-up needs

"haven't liked the GPs I've seen, they’re not informed enough"
Results

Survivors

- **34%** survivors do not have a regular GP
- **35%** unwilling to see GP for follow-up
- **22%** feel their GP is best placed to meet their follow-up needs

GP

- **16%** recalled receiving a tx summary or SCP
- **50%** confident caring for CCS
- **92%** have unmet information needs

“GPs like things in black and white... it distils the requirement into an action plan and we can easily then set up reminders in our system to say this is what's needed.”
Results

Survivors

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- 35% unwilling to see GP for follow-up
- 22% feel their GP is best placed to meet their follow-up needs

GP

- 16% recalled receiving a tx summary or SCP
- 50% confident caring for CCS
- 92% have unmet information needs

Survivors are not confident in their GPs  
GPs willing/able, but lack confidence caring for CCS  
Improved communication is key
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<tr>
<td>4. RCT</td>
<td>Survivors &amp; parents</td>
<td>-</td>
<td>Pilot</td>
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</table>
Aims

Re-engage

: online (live) nurse-led intervention for disengaged survivors

**Aim**

- To re-engage young ‘disengaged’ survivors who currently access no cancer follow up care a novel, free and low-burden intervention

**Eligibility**

- CCS >16 years, or parents (of CCS <16)
- No cancer-related LTFU care in the past 2 years

**Primary outcome**

- Adherence to the medical follow-up schedule recommended for each survivor’s cancer and treatment profile.

- Self-efficacy
- Health behaviours
- LE knowledge
- Risk perception
Method

Eligible survivors identified via medical records cross-checked with LTFU attendance records

Eligible participants mailed an invitation package

Interested participants opt in to the study

Participants complete Questionnaire 1

Participants randomised to control or intervention

Allocated to intervention group

Allocated to waitlist control group

Disinterested participants opt-out: study ends

Non-responders followed up by telephone and email
Method

First online session with CNC: history taking and risk assessment

Medical review panel risk-stratify patients & determine appropriate follow-up pathway

Second online session with CNC: review feedback, referral and connection to e-tool

Participants complete post-consultation Questionnaire 2

Participants complete follow-up Questionnaires 3 and 4

Control group offered intervention
Method

Consultation 1
- Live online consultation with a survivorship CNC
- Collection of medical/lifestyle history, and risk assessment

Medical review
- Medical case review
- Board consists of paediatric and adult oncologists, psychologist, social worker, and GP to review survivors’ case and make recommendations

Consultation 2
- Second live online consultation with CNC for medical review feedback, intro to/creation of SCP, and referral to appropriate services.

Connection to e-tool
- To help survivors manage their follow-up independently
- App features: schedule essential surveillance, communicate with their healthcare providers and connect with other young survivors
Thank you!

Christina Signorelli
c.signorelli@student.unsw.edu.au

### Participating hospitals

<table>
<thead>
<tr>
<th>Name</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof Richard Cohn, Dr Jordana McLoone, A/Prof Claire Wakefield, Ms Christina Signorelli, Dr Joanna Fardell, Ms Karen Johnston, Ms Tali Foreman, Ms Emma Doolan, Ms Sarah Ellis</td>
<td></td>
</tr>
<tr>
<td>Dr Melissa Gabriel, Ms Sinead Molloy</td>
<td></td>
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<tr>
<td>Dr Heather Tapp, Dr Michael Osborn, Ms Kate Turpin</td>
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<tr>
<td>Dr Frank Alvaro, Ms Jaime Chase</td>
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</tr>
<tr>
<td>Dr Thomas Walwyn, Ms Kerrie Graham</td>
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</tr>
<tr>
<td>Dr Peter Downie, Dr Maria McCarthy, Ms Jane Williamson, Ms Karen Egan</td>
<td></td>
</tr>
<tr>
<td>Dr Rob Corbett, Ms Rosemary Simpson, Ms Liz Sommers</td>
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<tr>
<td>Dr Rob Corbett, Ms Jo Truscott</td>
<td></td>
</tr>
<tr>
<td>Dr Jane Skeen, Ms Kathy Yallop</td>
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</tr>
<tr>
<td>Dr Liane Lockwood, Ms Tracy Till</td>
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### Funding bodies

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