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PROMPT-Care eHealth system to support patient-centred care: The long road to transition to business as usual

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ISLHD Team: Anthony Arnold, Andrew Miller, Tiffany Sandell, Martin Carolan, Ken Masters, Ashley Maher (Didymo Designs)

Funding: Cancer Institute NSW, Bupa Health Foundation, SWSLHD, Wollondilly Health Alliance

Our motivator for change: Cancer service challenges

- Growing population of cancer survivors => specialist cancer follow-up not sustainable
- Much of cancer follow-up is unnecessary, anxiety-provoking, non-uniform
- Specialists not necessarily best placed to manage some long-term toxicities, which may not be oncology-specific

Need to rethink models of follow-up care

**PRO systems can help tailor shared care:
self-management | +/- specialist | +/- GP**

Initial project aim: Proof of concept

1. Identify or build an eHealth system that facilitates:
 - a) ePRO data capture (including remote data inputs)
 - b) data linkage and retrieval (via EMR), to support clinical decisions and patient self-management, based on decision-support algorithms
 - c) data retrieval for evaluation and innovative research
2. Test the feasibility and acceptability of the system

Funding: Cancer Institute NSW
Partners: SWSLHD, ISLHD

Phase 1: Proof of concept (2013+)

Phase 1

- Development
- Testing acceptability & feasibility
- 2 cancer centres (35 pts, 5 onc staff)

PROMPT-Care, first Australian fully integrated eHealth platform using systematically collected PROs to inform cancer survivors' real-time clinical care and self-management

JMIR RESEARCH PROTOCOLS

Girgis et al

Protocol

Development and Feasibility Testing of PROMPT-Care, an eHealth System for Collection and Use of Patient-Reported Outcome Measures for Personalized Treatment and Care: A Study Protocol

Afaf Girgis^{1,2}, BSc (Hons), PhD; Geoff P Delaney^{1,2,3}, MBBS, PhD, MD; Anthony Arnold^{1,4}, BAppSc(MRS)RT; Alexis Andrew Miller^{4,5}, BSc, BMed, MInfCommTech (Res); Janelle V Levesque^{1,2}, BPsych (Hons), PhD; Nasreen Kaadan^{1,3}, BAppSc; Martin G Carolan^{1,4,6}, BSc (Hons), PhD; Nicole Cook⁷, BPsych, MPsych (Clin), PGDip (Psych); Kenneth Masters⁴, AdvDipBus; Thomas T Tran^{1,3}, BAppSc(MRS)RT; Tiffany Sandell⁴, BSc, MPH, MSc (Health Management); Ivana Durcinoska¹, BBiotech, MIPH; Martha Gerges¹, BA (Psych); Sandra Avery^{1,3}, GradCert Business Technology; Weng Ng^{1,3}, BSc (Med), MBBS (Hons), PhD; Stephen Della-Fiorentina⁸, MBBS; Haryana M Dhillon⁹, BSc, PhD; Ashley Maher¹⁰, BSc, MCS

JOURNAL OF MEDICAL INTERNET RESEARCH

Girgis et al

Original Paper

eHealth System for Collecting and Utilizing Patient Reported Outcome Measures for Personalized Treatment and Care (PROMPT-Care) Among Cancer Patients: Mixed Methods Approach to Evaluate Feasibility and Acceptability

Afaf Girgis^{1,2}, BSc (Hons), PhD; Ivana Durcinoska¹, BBiotech, MIPH; Janelle V Levesque^{1,2}, BPsych (Hons), PhD; Martha Gerges^{1,2}, BA (Psych); Tiffany Sandell³, BSc, MPH, MSc (Health Management); Anthony Arnold^{1,3}, BAppSc(MRS)RT; Geoff P Delaney^{1,2,4}, MBBS, MD, PhD; The PROMPT-Care Program Group¹

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ORIGINAL REPORT

Development of Health Pathways to Standardize Cancer Care Pathways Informed by Patient-Reported Outcomes and Clinical Practice Guidelines

Afaf Girgis , Ivana Durcinoska, Eng-Siew Koh, Weng Ng, Anthony Arnold, Geoff P. Delaney, and PROMPT-Care Pathways Working Group

Afaf Girgis, Ivana Durcinoska, and Geoff P. Delaney, The University of New South Wales, Sydney; Eng-Siew Koh, Weng Ng, and Geoff P. Delaney, Liverpool Hospital, Liverpool; and Anthony Arnold, Wollongong Hospital, Wollongong, NSW, Australia.

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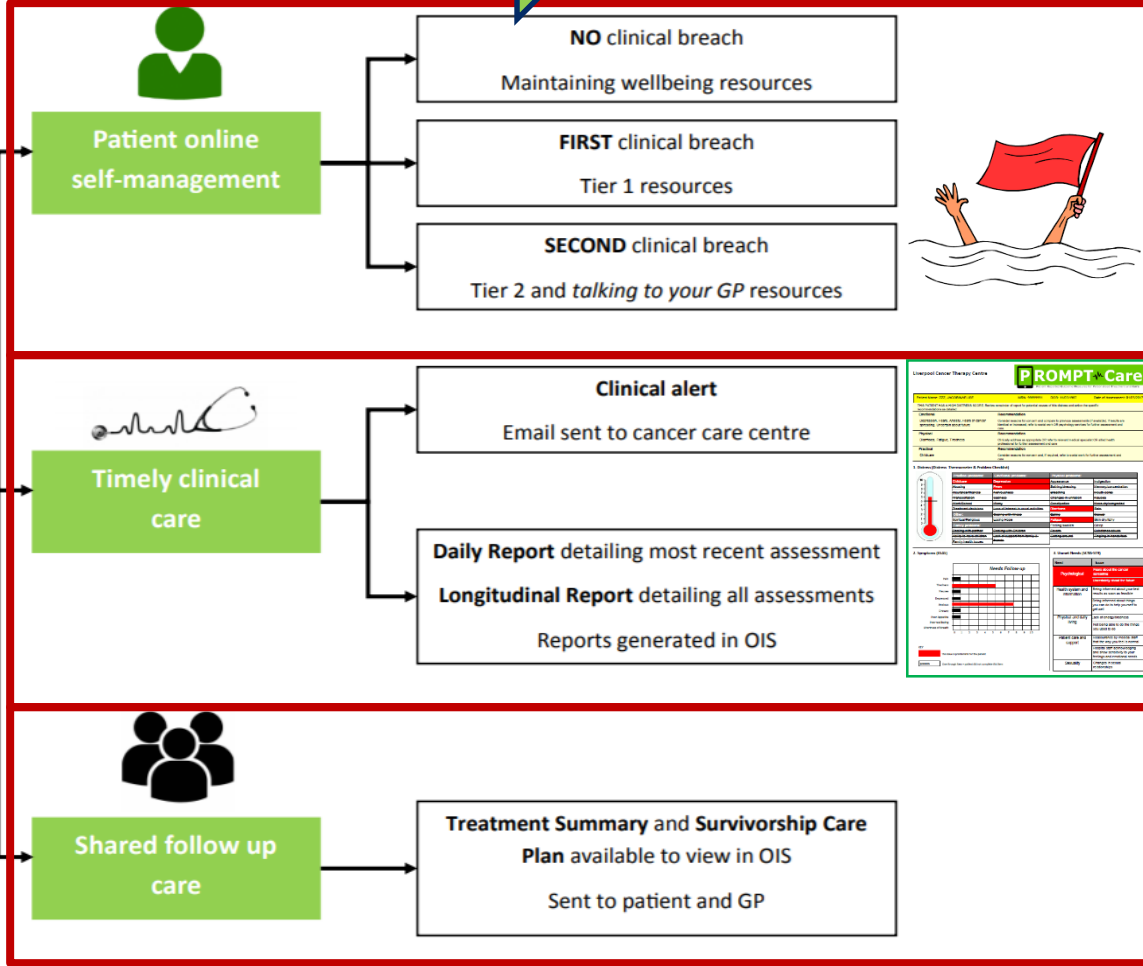
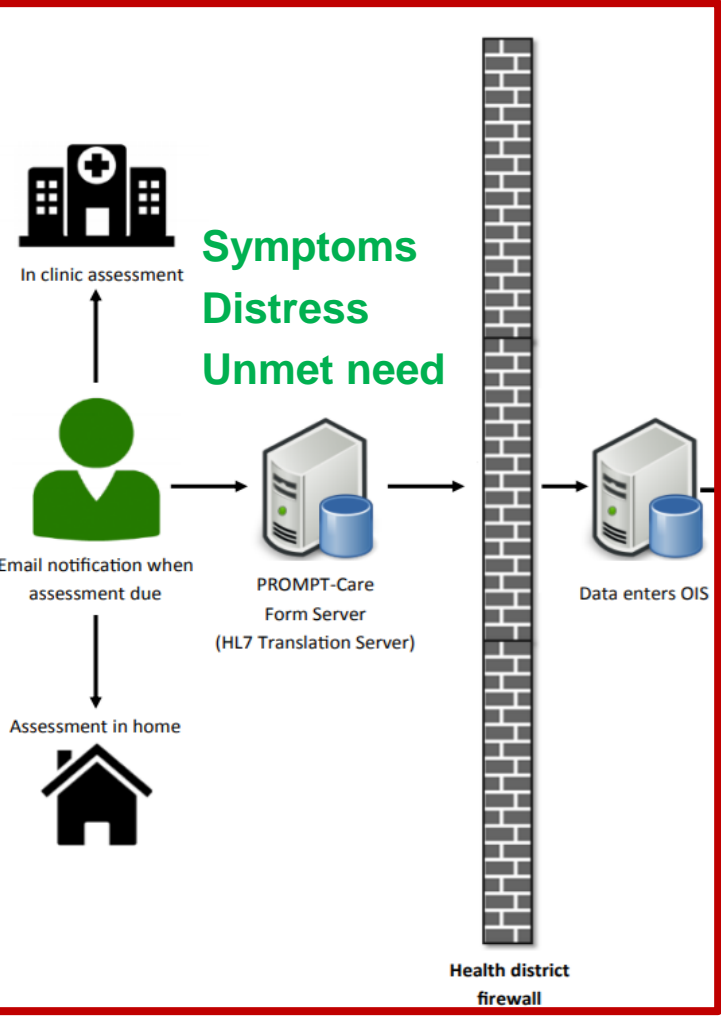
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PROs => EMR in real-time, care pathways to standardise care



PROMPT-Care

Longitudinal Report detailing all assessments

Assessment	1	2	3	4	5	6	7	8	9	10
Need Follow-up										

Phase 2: Test implementation

Phase 1

- Development
- Pilot testing

Phase 2

- Modifications
- Implementation in 4 cancer centres (2 LHDs)
- Impact on ED presentations, health service use

Modifications from Phase 1 pilot testing:

- Clearer survey **instructions** – in reference to CANCER
- More **pragmatic** approach:
 - ✓ Survey link sent via email more acceptable than tablets in clinic (include MRN #)
 - ✓ Trigger for reviewing PROMPT-Care report - clinical alert emailed to care coordinators [adapted model of care]
- Engaging **GPs**: Treatment Summary/Care Plan developed with GP input, auto-populated from EMR



Girgis et al. *BMC Cancer* (2018) 18:845
<https://doi.org/10.1186/s12885-018-4729-3>

BMC Cancer

STUDY PROTOCOL Open Access

Study protocol for a controlled trial of an eHealth system utilising patient reported outcome measures for personalised treatment and care: PROMPT-Care 2.0 

Afaf Girgis^{1,2*}, Ivana Durcinoska^{1,2}, Martha Gerges^{1,2}, Nasreen Kaadan^{1,2,3}, Anthony Arnold^{1,4}, Joseph Descallar^{1,2,5}, Geoff P. Delaney^{1,2,3} and on behalf of the PROMPT-Care Program Group

Phase 2 status – wrap up

- Informed care for 439 patients across 4 cancer centres
- 2,995+ assessments completed to date (200,000+ data items)
- Multi-dimensional outcomes (health system, patient, clinician level) (n=352 intervention, 1408 control):
 - ✓ **ED presentations (primary outcome)**, chemotherapy adherence, referral to health services
 - ✓ Impact on resource utilisation (specialist, allied health, GPs)
 - ✓ System uptake (patients, cancer team)
 - ✓ Usability & acceptability (patients, cancer team, GPs)

Phase 3: BAU, closing the gaps

Phase 1

- Development
- Pilot testing

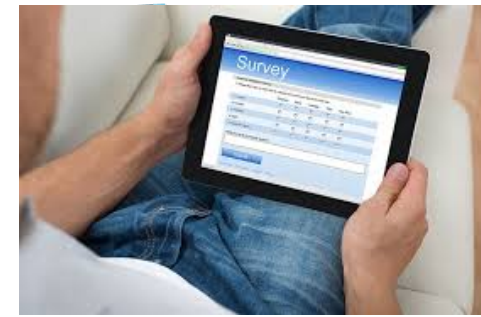
Phase 2

- Implementation
- Impact

Phase 3

- BAU - “Business as usual”
- All SWSLHD cancer centres
- “Excluded” populations

Considerations as we progress to BAU



Which PROs?

- Balancing patient burden vs comprehensive assessment
BUT let's not assume burden
 - ✓ 100% of patients (n=35) time to complete assessments “about right” (average 15 minutes, range 2-69 minutes)
 - ✓ 96% - online assessment “easier/ same as” paper-pencil assessments
 - ✓ Some patients completed 20+ assessments
- Deciding on assessment frequency – data will inform BAU
 - ✓ Patients on-treatment vs in follow-up
 - ✓ Different tumour groups

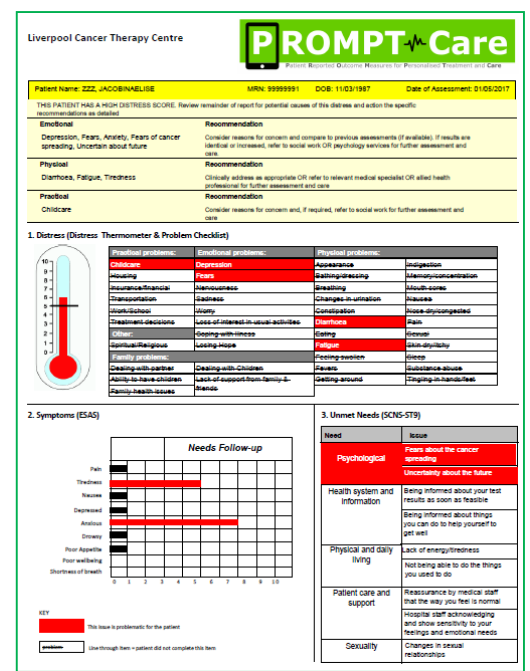


Who are we missing?

- Approximately 1/3 pts screened were ineligible for PROMPT-Care
 - ✓ Non-English speaking: 50% of ineligible Liverpool pts
 - ✓ Computer access/literacy: 10% of ineligible Liverpool pts
 - ✓ Literacy - ???
- Is an App part of the answer?
 - ✓ Overcomes the language barrier – patient selects preferred language
 - ✓ Overcomes poor literacy barrier - voice-prompt/recognition capabilities

What's the right model of care?

- PROMPT-Care reports mostly reviewed by nursing staff
- 43% of clinical alerts had 1+ recorded action
 - ✓ Does it matter who actions, as long as someone does?
 - ✓ Are there too many alerts? Rethink thresholds, available capacity, balance b/w false positives vs false negatives?
 - ✓ Improve report accessibility – push not pull?
 - ✓ Ongoing training - for whom, when? Registrar turnover, patients?



Liverpool Cancer Therapy Centre **PROMPT-Care**
Patient Reported Outcome Measures for Personalised Treatment and Care

Patient Name: ZZZ JACOBENLISE M/N: 9999991 DOB: 11/03/1987 Date of Assessment: 01/06/2011

THIS PATIENT HAS A HIGH DISTRESS SCORE. Review remainder of report for potential issues of this distress and action the specific recommendations as detailed.

Distress	Recommendation
Emotional	Depression, Fears, Anxiety, Fears of cancer spreading, Uncertain about future Consider reasons for concern and compare to previous assessments (if available). If results are identical or increased, refer to social work OR psychology services for further assessment and care.
Physical	Diarhoea, Fatigue, Tiredness Clinically address as appropriate OR refer to relevant medical specialist OR allied health professional for further assessment and care.
Practical	Chillcare Consider reasons for concern and, if required, refer to social work for further assessment and care.

1. Distress (Distress Thermometer & Problem Checklist)

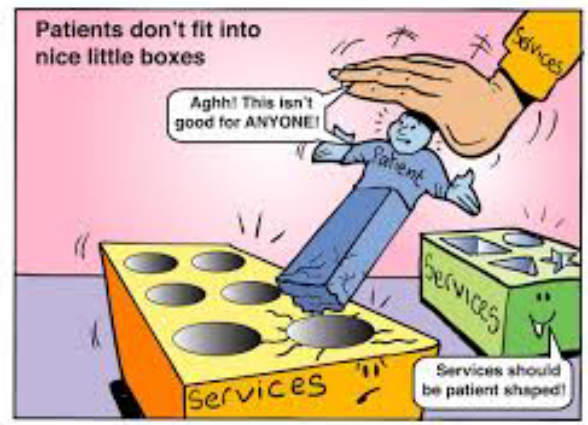
Distress thermometer	Clinical problems	Physical problems	Psychological problems
10	Chillcare	Depression	Appearance
9	Worrying	Fears	Memory/concentration
8	Worrying/fatigue	Neuroticism	Nausea/vomiting
7	Change in appetite	Diarrhoea	Change in medication
6	Work/school	Stuffy	Constipation
5	Treatment decisions	Loss of interest in usual activities	Diarrhoea
4	Worrying	Feeling unwell	Fatigue
3	Worrying/religious	Looking unwell	Fatigue
2	Family problems	Feeling unwell	Feeling unwell
1	Caring with partner	Caring with children	Fears
0	Worrying about future	Lack of support from family & friends	Change in mood
	Worrying about future	Stuffy	Change in medication

2. Symptoms (ESAS)

Symptom	Needs Follow-up
Pain	1
Tiredness	3
Nausea	1
Diarrhoea	1
Anxiety	3
Dizziness	1
Poor Appetite	1
Poor walking	1
Shortness of breath	1

3. Unmet Needs (SCRG-STP)

Need	Issue
Psychological	Fears about the cancer spreading Uncertainty about the future
Health system and information	Being informed about your test results as soon as feasible Being informed about things you can do to help yourself to get well
Physical and daily living	Lack of energy/tiredness Not being able to do the things you used to do
Patient care and support	Reassurance by medical staff that the way you feel is normal Hospital staff acknowledging and show sensitivity to your feelings and emotional needs
Sexuality	Changes in sexual relationship



Engaging GPs in shared care?

- Ongoing CISCO project – Prof Eng-Siew Koh – *WATCH THIS SPACE*

Treatment Summary		HOSP ID	MRN	
INSERT SITE SPECIFIC LOGO HERE		SURNAME		
		OTHER NAMES		
		DOB	SEX	AMO
		MRN BAR CODE		
Diagnosis: _____				
Date Diagnosed: _____				
Chemotherapy: Yes <input type="checkbox"/> No <input type="checkbox"/>	Regimen:.....			
Clinical Trial: Yes <input type="checkbox"/> No <input type="checkbox"/>	Name:.....			
Prescribed by:		Medical Oncologist <input type="checkbox"/> Haematologist <input type="checkbox"/>		
Date commenced:		Date Completed:.....		
Ongoing medications (e.g. Tamoxifen).....				
Complications of treatment.....				
Referrals to other specialist(s).....				
.....				
Radiotherapy: Yes <input type="checkbox"/> No <input type="checkbox"/>	Dose:.....			
Radiation Oncologist:.....		Site Treated:.....		
Date commenced:.....		Date Completed:.....		
For detailed information regarding treatment including common side effects go to www.evig.org.au				
Support Services:				
This includes a list of allied health workers your patient has been referred to during the course of their treatment				
Dietician <input type="checkbox"/>	Speech Pathologist <input type="checkbox"/>			
Social Work <input type="checkbox"/>	Occupational Therapist <input type="checkbox"/>			
Physiotherapist <input type="checkbox"/>	Psychologist <input type="checkbox"/>			
Exercise Physiologist <input type="checkbox"/>	Care Coordinator <input type="checkbox"/>			
Community Palliative Care <input type="checkbox"/>	Community Nursing <input type="checkbox"/>			
For any enquiries regarding your patient please contact: INSERT PHONE NUMBER				



Sustainability after research funding ends?

Planned transition to BAU – consultation with relevant departments (admin, nursing, allied health, oncology, IT etc)

- System redesign: RATHER THAN “How can we possibly do more?”, ASK “What can we do differently?”
- What human resources are needed at front/back end?
- Which components of PROMPT-Care are essential to keep?
- Ongoing IT support – competing priorities

Thank you

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