



PRO programs in practice: examples and lessons learned

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Overview

- No shortage of PRO systems
- Examples of systems in Australia and internationally NB: have focused on electronic collection systems only
- Some of the challenges experienced
- Can we build an ideal system? What would it include?





Jensen RE, Snyder CF, Abernethy AP, et al. Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care. *Journal of Oncology Practice*. 2014;10(4):e215-e222. doi:10.1200/JOP.2013.001067.

Identified e-PRO Systems

System	Institution		In Use	Focus
Advanced Symptom Management System in Palliative Care (ASyMSp)	University of Stirling, Stirling, Scotland		No	Patient
BrightOutcome (clinic-based system)	BrightOutcome, Buffalo Grove,		Yes	Patient
BrightOutcome (Web-based system)	BrightOutcome		Yes	Patient
Comprehensive Health Enhancement Support System (CHESS)	University of Wisconsin		Yes	Patient
Computer-based Health Evaluation System (CHES)	Medical University of Inns ion So	oftware Development), Innsbruck, Austria	Yes	Patient
Dynamic Clinical Systems	Dynamic Clinical System		Yes	Patient
Electronic Patient-reported Outcomes from Cancer Survivors (ePOCS)	Clinical Centre in Leed v I	Hospital, University of Leeds, Leeds, United Kingdom	Yes	Patient
Electronic Patient Self-Assessment and Management (SAM)	Memorial Sloan-Kett	niversity of California, San Francisco	Yes	Patient
Electronic Self Report Assessment-Cancer (ESRA-C)	University of Washi	er Institute	Yes	Patient
EPIC-AC			Yes	Patient
Navigating Cancer (Web-based system)	33		Yes	Treatment
Ontario Symptom Management Collaborative (OSMC)	systems		Yes	Patient
Patient Assessment, Care and Education (PACE)	Systems		Yes	Patient
Patient Viewpoint	Johns h reported		Yes	Patient
Quality of Life In Childhood Oncology (QLIC-ON)	Academi	erdam, the Netherlands	No	Patient
Symptom Monitoring and Management SyMON-1	Northy III 2014		Yes	Treatment
Symptom Tracking and Reporting (STAR)	Mem		Yes	Treatment
Support Screen	Cit Cente.		Yes	Treatment
Tell Us	Jo ny; the Medical Decis.		No	Patient
The Personal Well-Being Checklist (PWBC)	cer Centre, Calgary, Alberta, Ca	nada	No	Treatment
Un-named	imic		No	Treatment
Un-named	oregon Health & Science University		No	Treatment
Un-named Indiana QOL	School of Nursing, Indiana University		No	Patient
VisionTree	VisionTree Software		Yes	Patient
WebChoice	Rikshospitalet Medical Center, Oslo, Norway		Yes	Patient
WebCore	Memorial Sloan-Kettering Cancer Center		Yes	Patient
Wireless Health Outcomes Monitoring System (WHOMS)	Istituto Nazionale Tumori, Milan, Italy		No	Treatment







A PRO-cision Medicine Toolkit to Address the Challenges of **Personalizing Cancer Care Using Patient-Reported Outcomes**



Project Leaders and Steering Group



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Johns Hopkins Bloomberg School of Public Health



Yonaira Rivera, MPH, PhD(c) Johns Hopkins Bloomberg School of Public Health



Paper series to be published in early 2019. Three sets of papers:

- Papers addressing 1. methods to aid score interpretation
- 2. Papers addressing the applicability (or not) of group-level metrics to individual patient scores

Examples of methods used in various PRO systems



Ethan Basch, MD, MSc University of North Carolina Lineberger Cancer Center



Karon Cook, PhD Northwestern University Feinberg School of Medicine







Dennis Revicki, PhD

Jeff Sloan, PhD



3.

Carrier Stricker, PhD, RN Carevive





Systems not integrated in EMRs







Cancer Care Ontario (CCO) (Canada, Lisa Barbera) Since 2007

Not integrated in EMR

Ontario's cancer symptom screening program using ESAS

The only population-based cancer symptom-screening program in North America

14 regional cancer centres 49 hospitals 261,991 unique patients screened in 2015

30,000 unique patients screened per month Created the largest cancer symptom database in the world. **3.4 million** ESAS screens collected since 2007





CCO – PRO implementation 2017

Applied Medical Research



ESAS-r = Edmonton Symptom Assessment System, revised version.

Data source: Patient-Reported Outcome Initiative partners





CCO – clinical support tools



Managing Symptoms, Side Effects & Well-Being

Many people living with cancer experience nausea, diarrhea, and other symptoms and side effects from their treatment or disease. For healthcare providers, we offer tools for assessing and managing patients' symptoms and side effects. For patients, we provide information about maintaining your well-being as well as information on how to recognize symptoms and side effects, what you can do to manage them at home and when to call your doctor.

Symptom Assessment Tools



Ingham Institute

Symptom Management Guides



CCO – clinical support tools

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Centre for Oncology Education & Research Translation



٥	Symptom Management Guides	SAS: 7		
G Symptoms	Q Assessment	() Intervention		
Pain - Intervention				
Considerations for All Patients		0		
Adverse effects of opioids		0		
Mild Pain		÷		
Moderate Pain	\odot	Symptom Ma	nagement Guides	
Severe Pain	Θ	- A	0	0
Conversion Ratios		5 435	essment	Interver
Titration Guide	Pain - Interventi	ion		
Conversion Guide	Considerations for All I	Patients		
Follow-Up and ongoing Monitoring	Adverse effects of onic	ide		
	Mild Pain			
	Moderate Pain			
	Severe Pain			
		Sovoro Pair	Intervention	
		Severe Fail		
	(ESAS 7-10)			
	Pharmacologic	al		
	Treatment with s	trong opioids		
	Severe Dain Cris	is		
CONCERT				



CCO – clinical and pt guides



Interventions for all patients, as appropriate

NON-PHARMACOLOGICAL

- · Psycho-social-spiritual interventions (patient education, counseling, recreational activities, relaxation therapy imagery, social interaction, spiritual counselling).
- Other therapies (physiotherapy, occupational therapy, massage, aromatherapy, music therapy, acupuncture, transcutaneous electrical nerve stimulation, reflexology, Reiki, hypnotherapy).
- Other interventions such as radiation therapy, vertebroplasty, surgery and anesthetic interventions should be considered in patients with difficult to control pain. Patient Education
- Taking routine and breakthrough analgesics, adverse effect management, non pharmacologic measures that can be used in conjunction with pharmacologic treatment.

How to Manage Your



This patient guide will help you understand:

What is cancer-related pain?	pg 2
What causes cancer-related pain?	pg 3
What can I do to manage my pain?	pg 4
When should I talk to my health care team?	pg 12
Where can I get more information?	pg 14







CCO – Lisa Barbera feedback

- Variable use of the PROs in provinces
- 1-page clinical algorithms most popular
- Difficult to keep clinical and patient information up to date
- Lack of integration into EMR problematic









Children with chronic disease & their parents, The Netherlands (Lotte Haverman) First KLIK publication in 2011

Not integrated in EMR









KLIK

- Web-based, systematic monitoring of QOL of children being treated in a (child) hospital and their parents
- KLIK project is implemented per patient group (e.g. diabetes, oncology), on request of the MDT





KLIK



- Eligible patients and parents receive a letter introducing KLIK as **new standard of care** at the outpatient clinic
- Patients/parents **register** themselves, and receive an automatic email containing a password
- Two weeks to three days (depending on team preference) before the outpatient consultation, patients/parents receive an **automatic email** to inform them that the PROMs are available online
- If necessary, automatic email reminders are sent
- Care team PRO feedback literal PRO scores, summary scores, graphic representation







KLIK ~ 200 PROMs available

Categories of PROMs:

- Generic HRQOL (e.g. PedsQL)
- Disease-specific HRQOL (e.g. PedsQL transplant module)
- Daily functioning (e.g. CHAQ)
- Cognitive functioning (e.g. Behavior Rating Inventory of Executive Functioning (BRIEF))
- Symptoms (e.g. Pediatric Ulcerative Colitis Activity Index (PUCAI))
- Psychological screening (e.g. Strengths and Difficulties Questionnaire (SDQ), HADS)
- Transition (e.g. Skills for Growing Up Nephrology (SGU-N) tool)





KLIK – current status



- In the Netherlands:
 - >750 HCPs (paediatricians, nurses, physiotherapists, dieticians, social workers, psychologists)
 - > >11,000 patients (from >100 different patient groups)
 - >20 centres
 - Training compulsory for all HCPs using KLIK
- In 2018, some hospitals in the UK will start using KLIK
- Adapted for adult patient groups
- Identified problems: lack of EMR integration; reporting by 2 parents if not consistent







Symptom Care at Home (SCH) University of Utah and Huntsman Cancer Institute (USA, Kathi Mooney) Since 2000

Not integrated in EMR





Symptom Care at Home



- Patients in active treatment, pts & carers at end of life
- Patients call the automated monitoring system (phone-based IVR system) daily to report severity of 11 symptoms (0-10 scale)
- Patients receive automated **self-management** coaching
- Alerts to nurse practitioner if symptoms uncontrolled, a guideline-based decision support system via dashboard
- Nurse practitioners **telephone patients** to follow-up poorly controlled symptoms
- Currently phone-based IVR system, in process of developing web-based and app versions to extend access
- Plans for EMR integration to enhance compatibility with workflow









ADAPT Cancer services in NSW (Australia, Phyllis Butow) Since 2015

Not integrated in EMR





The Australian Clinical Pathway for the Identification and Management of Anxiety and Depression in Adult Cancer Patients

- Uses best available evidence to recommend clear treatment pathways (screening, referral and management, timing and staff responsibilities)
- Recommends care based on symptom severity, using a stepped-care model
- Tailored to reflect local referral networks, resources and preferences



More intensive interventions reserved for patients who require specialist mental health treatment



ADAPT Portal: Two Phase Online Screening



ADAPT Portal Alerts

- Identifies patients of concern (psychologically or physically)
- A 'traffic light' approach used



Step 4/5 Severe/Very Severe Step 3 Moderate Step 2 Mild

Goes to staff responsible via Portal alert/email/SMS



	Action required	🛓 Patient list 🛛 🔒 Pathway 🛛	Messages 🔗 Configuration	Resources	User, Role or ID Search	c
anxiety path	dap & depression way program	t		🔳 Dain Hosp Da	Log shboard 🌣 Profile 🥑	gged in as Lindy Ma O Support req Portal support (C Lo
ctic	on require	ed			Dashboard >	Action required > All a
My al	erts All aler	ts Completed	Low		Filter	٩
0	URN/MRN	Patient name	Alert Type	Allocated to	Alert date	Due date
•	URN/MRN 65214529 3215441	Patient name Gemma Raines Savina Weights	Alert Type Screening score (Severe/Very Severe) Screening due (Clinic)	Allocated to Mrs Heidi On Dr Kit M Mr Ken Pom Mrs Susan Kaliku	Alert date 25/06/2018 23/06/2018	Due date 26/06/2018 7/07/2018
•	URN/MRN 65214529 3215441 3698521	Patient name Gemma Raines Savina Weighls Fran Fine	Alert Type Screening score (Severe/Very Severe) Screening due (Clinic) Screening due (Clinic)	Allocated to Mrs Heidi On Dr Kit M Mr Ken Pom Mrs Susan Kaliku Dr Kit M Mr Ken Pom Mrs Susan Kaliku	Alert date 25/06/2018 23/06/2018 23/06/2018	Due date 26/06/2018 7/07/2018 7/07/2018
0	URN/MRN 65214529 3215441 3698521 74521	Patient name Gemma Raines Savina Weights Fran Fine Annika Vamiska	Alert Type Screening score (Severe/Very Severe) Screening due (Clinic) Screening due (Clinic) Screening due (Clinic)	Allocated to Mrs Heidi On Dr Kit M Mr Ken Pom Mrs Susan Kaliku Dr Kit M Mr Ken Pom Mrs Susan Kaliku Dr Kit M	Alert date 25/06/2018 23/06/2018 23/06/2018 23/06/2018	Due date 26/06/2018 7/07/2018 7/07/2018 7/07/2018
	URN/MRN 65214529 3215441 3698521 74521 632549	Patient name Gemma Raines Savina Weights Fran Fine Annika Vamiska Angela Phillips	Alert Type Screening score (Severe/Very Severe) Screening due (Clinic) Screening due (Clinic) Screening due (Clinic) Screening score (Severe/Very Severe)	Allocated to Mrs Heidi On Dr Kit M Mr Ken Pom Mrs Susan Kaliku Dr Kit M Mr Ken Pom Mrs Susan Kaliku Dr Kit M Mr Ken Pom Mrs Susan Kaliku Mrs Heidi On	Alert date 25/06/2018 23/06/2018 23/06/2018 23/06/2018 21/06/2018	Due date 26/06/2018 7/07/2018 7/07/2018 7/07/2018 22/06/2018

ADAPT Portal: Referral recommendations & networks

The Portal will display the referral options below. Add any additional referral options health professionals at Gabrielle's Wing can refer to.	
Referral options	
🚓 "At Risk" policy / procedure activated OR Acute Mental Health Team	
🛱 Community based support – Health Professional led support group	Deserves en al sal
🚓 Community based support (i.e. peer support groups, helplines, etc.)	Recommended
🚓 Consultation Liaison Psychiatry Service	
🚓 Formal psychological assessment	reterral options as
nh GP	
🚓 Online program: iCanAdapt – Advanced	indicated by
🚓 Online program: iCanAdapt – Early	
ភ្នំ Online program: Other	Clinical Pathway
តំ Psychiatric services	Chinearranway
🚓 Refused treatment	Stop and online
$\mathfrak{A}_{\mathfrak{h}}$ Return to a mental health specialist's care (patient has pre-existing relationship)	Step and online
Add new referral option	referral capacity
Referral option	
Is this referral option to an individual Ves health professional? No	

Referral networks

Management of locally available referral options



ø	Referral Networks		
•	Who is responsible for ensuring referral information and system preferences are up to date?	$\odot \bigcirc$	
•	Who is responsible for verifying if patients take up referrals?	$\bigcirc \bigcirc$	
•	Who is responsible for ensuring patient Progress Reviews occur and Discharge Treatment For	ms are updated in the system?	
•	Where there are multiple psychology health professionals in the same role, indicate the order of	f priority for referrals	
•	What additional referral options are available to the health professionals at this facility?	$\overline{\mathbb{O}}$	

Dashboard > Health facility configuration > Setup > Referral networks



STAR Trial 2007-2011 (Symptom Tracking & Reporting)

PRO-TECT Trial 2017-(Patient Reported Outcomes to Enhance Cancer Treatment)

MSK & Uni of North Carolina (USA, Ethan Basch, Angela Stover)

Not integrated in EMR







Symptom reporting

- Patients with advanced, metastatic cancer
- Weekly reporting of symptoms, in RCT context
- Web-based (STAR), web or IVR (PRO-TECT)
- Email alerts to nurses when PRO above threshold
- **Report** tracking symptoms printed at each clinic visit for nurse and treating oncologist
- STAR: no specific guidance about actions in response to alerts or printed symptom profiles
- PRO-TECT: email alert included decision support tools tailored to PROs
- Lack of EMR integration identified as problematic







Systems integrated in EMRs







PatientViewpoint Johns Hopkins Cancer Centre (USA, Claire Snyder) Since 2005

Integrated in EMR

PatientViewpoint [°]	Online Patient Survey	
Welcome PatientViewpoint lets patients giv This information will help your do time.	ve their doctors information about how they are feeling and functioning. octors understand how you are doing and to track your progress over	Please Login Username: Password: Login Forgot Your Password
		Username is NOT case sensitive. Password is case







PatientViewpoint

- Designed as an online **questionnaire delivery device**
- Clinicians can "order" from repository of questionnaires, decide which patients complete which questionnaires, at what intervals
- Built-in calendar function, automatically generates emails to patients to alert them when it's time to complete a questionnaire
- Collected PROs are linked with the **EMR**
- To date, only acceptability and feasibility testing with breast & prostate cancer pts on-treatment





PatientViewpoint

- PRO scores reported as line graphs over time
- Possibly concerning scores highlighted in yellow
- "What can I do" link for clinicians to access recommendations for acting on PRO scores
- Recommendations focused on local resources, hence not generalisable

Snyder CF, Jensen R, Courtin SO, and the Website for Outpatient QOL Assessment Research Network AW. PatientViewpoint: A Website for Patient-Reported Outcomes Assessment. *Quality of life research*. 2009;18(7):793-800. doi:10.1007/s11136-009-9497-8.









eRAPID

Uni of Leeds (UK, Galina Velikova) Development publication in 2017

Integrated in EMR



Welcome to the login page of the eRAPID research project

eRAPID stands for "Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice".

Patient Login		
Username	÷	
		LOGIN

Please enter your unique username and this will take you to the eRAPID homepage. On the homepage you will be able to access your symptom reports and view selfmanagement advice.





eRAPID

- Ingham Institute
- Online symptom reporting (adverse events), chemotherapy pts
- Immediate feedback to pts, severity-tailored advice: self-management vs contacting the hospital if symptoms severe+current (extra branch added re currency of symptoms after piloting)
- Nurse-led phone triage when pt calls re severe adverse events
- Electronic reporting graphic representation of each symptom's scores over time
- Acceptability tested, RCT nearing completion









PROMPT-Care Cancer centres in SWSLHD & ISLHD (Australia, Afaf Girgis)

Since 2013

Integrated in EMR









- PROs: Symptoms, distress, unmet needs
- Web-based monthly assessment, at clinic or remote (via survey link emailed to pts)
- All cancer patients, any tumour/stage
- Monthly, ongoing from start of treatment



PROMPT-Care

Please note that the following questions ask you to consider how you are feeling today, in relation to your cancer.

A score of 0 would mean that you are not experiencing that symptom and a score of 10 would mean that symptom is as severe as possible.

Edmonton Symptom Assessment Scale

Please select the number that best describes:



Please select the number that best describes:



Please select the number that best describes:













Liverpool Cancer Therapy Centre

ine through item + patient did not complete this item

- Ingham Institute Applied Medical Research
- Clinical reports available in "real-time"
- Email alert sent to cancer centre if issues unresolved
- Problems highlighted in red
- **Recommendations** re care and/or referrals [based on developed algorithms]







Sexuality

Changes in sexual

elationships

Self-management (eviQ)



Patients emailed selfmanagement links -114 resources, available via 6 pages, tailored to their PRO responses:

- Physical wellbeing 1.
- Emotional wellbeing 2.
- Practical support 3.
- Social/family wellbeing 4.
- 5. Maintain wellbeing
- 6. Talking to your GP



Thank you for recently completing the PROMPT-Care survey.

While the responses you provided suggested that you are not currently experiencing any specific concerns, you may find the following information about maintaining general wellbeing interesting.

- ENRICH Cancer Council NSW exercise and nutrition program
- Exercise for people living with cancer
- iCanOuit
- Learning to relax Nutrition & cancer
- Staying healthy after treatment

Cancer Council NSW Cancer Support Services

- Supportalk is a community of people affected by cancer you can connect with online, by phone or in person.
- Cancer Information and Support 13 11 20 is a confidential service where you can speak to a specialist cancer professional about anything to do with cancer.
- Find out about programs, resources and support services after cancer treatment, see Coping with cancer.

If you require immediate assistance, please call Emergency Assistance on 000

For crisis support chat, please call Lifeline on 13 11 14



PROMPT-Care is a collaborative project being conducted by Ingham Institute researchers and clinicians from South Western Sydney and Illawarra Shoalhaven Local Health Districts, with funding from the Cancer Institute NSW and BUPA Health Foundation.

We acknowledge the traditional custodians of the land on which we work and live, and pay our respects to Elders past, present and future.









Publications to date

- 1. Girgis A, Delaney GP, Miller AA. Utilising eHealth to support survivorship care. Cancer Forum: July 2015, 39 (Issue No 2): 86-89.
- Girgis A, Delaney GP, Arnold A, Miller AA, Levesque JV, Kaadan N, Carolan MG, Cook N, Masters K, Tran TT, Sandell T, Durcinoska I, Gerges M, Avery S, Ng W, Della-Fiorentina S, Dhillon HM, Maher A. 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. JMIR Research Protocols 2016;5(4):e227
- 3. Girgis A, Durcinoska I, Levesque JV, Gerges M, Sandell T, Arnold A, Delaney GP, PROMPT-Care Program Group (Avery S, Carolan M, Della-Fiorentina S, Kaadan N, Masters K, Miller A, Ng W, Tran TT). 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. Journal of Medical Internet Research 2017; 19(10), e330.
- 4. Girgis A, Durcinoska I, Koh E-S, Ng W, Arnold, A, Avery S, Carolan M, Della-Fiorentina S, Kaadan N, Vardy J, Dhillon H, Miller A, Delaney GP. Development of health pathways to standardise cancer care pathways informed by patient-reported outcomes and clinical practice guidelines. JCO Clinical Cancer Informatics 2018, DOI: 10.1200/CCI.18.00024, published online July 13, 2018
- 5. Girgis A, Durcinoska I, Gerges M, Kaadan N, Arnold A, Descallar J,, Delaney GP. Study protocol for a controlled trial of an eHealth system utilising Patient Reported Outcome Measures for Personalised Treatment and Care: PROMPT-Care 2.0. BMC Cancer (In press)







Barriers and challenges







Barriers & challenges

- Patient barriers (eg CALD, computer access, literacy)
- Departmental barriers (eg IT, human resources at the front and back end)
- Technology/EMR "downs"
- Selection of measures (importance vs patient burden)
- Getting the model of care right who reviews reports, when, action?
- Implementation across different EMR systems
- Sustainability funding implementation beyond the research





An ideal system?



PRO capture

- Minimum agreed PRO set
 depends on purpose
- Automated prompts for patients to complete assessments
- Automated reminders when assessment missed
- Variable assessment schedules & PRO sets tailored to tumour type, point on pathway

PRO reporting and use

- Automated PRO scoring
- Evidence-based care recommendations – based on score thresholds + algorithms
- Designated point for review/action in response to PROs
- PROs integrated into EMR for real-time clinical use
- Patient feedback to reinforce the value of PRO reporting

Pragmatic issues

- Patient identified without jumping though too many hoops
- Smart systems to accommodate PRO completion by different cohorts:
- ✓ In first language, for CALD patients
- Cultural adaptation for Indigenous patients
- Using spoken prompts, speech recognition for low literacy patients
- ✓ Caregivers?







Thank you ③ afaf.girgis@unsw.edu.au @Afaf_Girgis



