



Faculty of Design

2017

Synthesis maps: Visual knowledge translation for the CanIMPACT clinical system and patient cancer journeys

Jones, Peter, Shakhder, S. and Singh, P.

Suggested citation:

Jones, Peter, Shakhder, S. and Singh, P. (2017) Synthesis maps: Visual knowledge translation for the CanIMPACT clinical system and patient cancer journeys. *Current Oncology*, 24 (2). pp. 129-134. ISSN 1718-7729 Available at <http://openresearch.ocadu.ca/id/eprint/1575/>

Open Research is a publicly accessible, curated repository for the preservation and dissemination of scholarly and creative output of the OCAD University community. Material in Open Research is open access and made available via the consent of the author and/or rights holder on a non-exclusive basis.

The OCAD University Library is committed to accessibility as outlined in the [Ontario Human Rights Code](#) and the [Accessibility for Ontarians with Disabilities Act \(AODA\)](#) and is working to improve accessibility of the Open Research Repository collection. If you require an accessible version of a repository item contact us at repository@ocadu.ca.

Synthesis maps: visual knowledge translation for the CanIMPACT clinical system and patient cancer journeys

P.H. Jones PhD,* S. Shakhder MD^{Des},* and P. Singh*

ABSTRACT

Salient findings and interpretations from the canIMPACT clinical cancer research study are visually represented in two synthesis maps for the purpose of communicating an integrated presentation of the study to clinical cancer researchers and policymakers. Synthesis maps integrate evidence and expertise into a visual narrative for knowledge translation and communication. A clinical system synthesis map represents the current Canadian primary care and cancer practice systems, proposed as a visual knowledge translation from the mixed-methods canIMPACT study to inform Canadian clinical research, policy, and practice discourses. Two synthesis maps, drawn together from multiple canIMPACT investigations and sources, were required to articulate critical differences between the clinical system and patient perspectives. The synthesis map of Canada-wide clinical cancer systems illustrates the relationships between primary care and the full cancer continuum. A patient-centred map was developed to represent the cancer (and primary care) journeys as experienced by breast and colorectal cancer patients.

Key Words Clinical system analyses, patient experiences, complexity, visualizations

Curr Oncol. 2017 Apr;24(2):129-134

www.current-oncology.com

INTRODUCTION

The canIMPACT initiative (Canadian Team to Improve Community-Based Cancer Care along the Continuum) is a comprehensive research program to improve cancer care by identifying and supporting interventions and support for cancer patients in primary care. The objectives and activities of canIMPACT are described in detail elsewhere¹.

The Strategic Innovation Lab at OCAD University developed synthesis maps to represent canIMPACT's research findings and proposed interventions as a visual knowledge translation tool to communicate salient and systemic issues in the Canadian cancer system to clinical cancer researchers. Early in development, we recognized that a single clinically-oriented system map representing cancer care for the breast and colorectal sites would not sufficiently represent a patient orientation to cancer care and survivorship. Two synthesis maps were therefore developed: a clinical map visualizing the canIMPACT study, models, and interventions; and a patient map

developed in consultation with the patient advisory committee (PAC), who as cancer survivors and patient or family representatives, provided lived-experience perspectives to the study.

METHODS

The synthesis maps were developed using a qualitative design research methodology, informed by an interpretivist (critical) approach to analysis and information design. Synthesis mapping, based on Sevaldson's Gigamap² design method, has been uniquely developed by OCAD University as a technique for the visual interpretation of research evidence, useful in knowledge translation to frame critical issues in health care and scientific domains. Those domains require visualizations that meaningfully present multiple perspectives of the evidence in coherent graphical narratives, enabling understanding and discourse between stakeholders in a field.

Over 6 months, a team of three health care design researchers developed 2 synthesis maps with advice from

Correspondence to: Peter H. Jones, OCAD University, 100 McCaul Street, Toronto, Ontario M5T 1W1.
E-mail: pjones@ocadu.ca ■ DOI: <https://doi.org/10.3747/co.24.3452>

the canIMPACT research team and the PAC. The method consisted of 5 stages:

- *Domain and Literature Review* A scoping review of the canIMPACT study and its references was conducted. Continuous searches informed emergent questions for representing mapping decisions.
- *Expert Interviews and Content Analysis, with Visual Notetaking*³ The canIMPACT qualitative study, the casebook survey of cancer initiatives, and administrative data substudy reports were analyzed, guided by interviews with study area leads.
- *Knowledge Synthesis to Design Maps in Stages* In collaborative sessions, maps were hand-sketched to represent salient findings drawn from content analyses.
- *Peer Critique of Electronic and Print Maps* Structured critiques of the maps were held with the canIMPACT and PAC experts at key stages of map development.
- *Iterative Map Design* The clinical map was developed first, in stages that adhered to the method. The necessity for a patient-centred map was discovered during the peer critique step.

Expert interviews were conducted, recorded, and documented during remote and in-person sessions with seven canIMPACT research leads. The interviews covered the relevant canIMPACT findings, clinical contexts, and specialist insights. Interviews were staged additively, starting with the qualitative study and finishing with specialist interviews to guide continuous map design. Content was analyzed by coding interviews according to canIMPACT study categories and by making cross-comparisons across transcripts. We determined that, to congruently represent a patient-oriented context and experience, a patient-centred map was necessary to complement the clinical map. Based on PAC feedback, we adopted a humanistic visual style, vernacular language, and nonlinear patient narratives to encompass a range of complex relationships and variables indicative of cancer experiences. The iterative mapping process supported continuous feedback for progressive model-formation and agreement between the canIMPACT stakeholders.

Synthesis maps are portable; typically, they consist of printed posters and digital documents that provide accessible entry points for discussion and analytical inquiry with stakeholders of research knowledge, including primary care physicians, cancer clinical specialists, and clinical service professionals (for example, service designers, functional programmers). Synthesis mapping supports the Canadian Institutes of Health Research definition of knowledge translation as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system”⁴. The use intent of the synthesis map supports knowledge creation functions, involving inquiry, synthesis, and the creation of knowledge products⁵. As knowledge products, the synthesis maps serve

all phases of the knowledge-to-action cycle, being visual references across the body of review and research and an index to salient issues identified by the researchers.

RESULTS

The canIMPACT research findings are in press¹ and have been presented at conferences, but are not elaborated here. The synthesis map contributions are summarized next.

Clinical Synthesis Map: Cancer Care Pathways in Canadian Health Care

The clinical map (Figure 1) visually represents breast and colorectal cancer care processes for all Canadian provincial and territorial systems. A roadmap metaphor illustrates a system-wide view of patient flow through the stages of cancer care. Green “road signs” identify clinical cancer stages in the roadmap: Pre-Diagnosis, Peri-Diagnosis, Diagnostic Interval, Diagnosis, Treatment, Rehabilitation, Aftercare, and Survivorship (with Palliative Care expressed as an endpoint). The visual metaphor of seasonal trees visually connects those stages to the patient’s cancer journey from pre-diagnosis (summer) through treatment (winter), followed by new growth (spring) in survivorship.

The levels of primary, secondary, and tertiary care guide the vertical dimension. Information and communications technology span levels and stages, but are shown disconnected from primary care. The road-like pathways are colour-coded where the experts differentiated the breast cancer (pink) and colorectal (blue) care pathways. Where not distinguished (white), the pathways indicate current practices shared by all cancer journeys.

Yellow navigation signs indicate cancer events spanning the primary care pathways. Starting with Prevention and ending with Long-Term Care, the events mark points for primary care continuity during cancer treatment. A parallel path below the stages indicates where some patients might also use complementary or alternative therapies.

The Peri-Diagnosis and Diagnostic Interval pathways reveal significant areas of complexity generalized across cancer care. A patient might be screen-detected (and then present to a family physician, shown in the breast cancer pathway) or might initially be diagnosed in primary care (white pathway). The circular pathways in the diagnostic cycle suggest multiple possible tests within primary care. With a primary care diagnosis, patients are referred and flow to secondary or tertiary cancer care. The stages of intake—biopsy, pathology, and confirmed diagnosis—are shown, and the complex pathways of cancer treatment are shown on the map in a typical—though not definitive—order of surgery, radiation, and chemotherapy, and continuing treatment to assessment of outcome.

The discharge cycle reveals another function in which decision complexity emerges, involving continuity of care planning, transfer to primary care, or re-entry to cancer therapy upon recurrence. The end pathways show long-term care, palliative care, and end-of-life care, representing other consequential transitions from survivorship.

Two inset figures describe anticipated systemic problems arising in the stages. In Diagnosis, an archetypal pattern known as “shifting the burden” appears with a

CanImpact
Improving Cancer Care Together
RESEARCH SYNTHESIS MAP

The Mission: Enhance the capacity of community-based primary healthcare clinicians to provide care to cancer patients and to improve the links between primary care and specialty providers.

CANCER CARE PATHWAYS IN CANADIAN HEALTHCARE

The Clinical Map is a synthesis of findings across the modes of CanIMPACT research. It visually models the complex systems of care for breast and colorectal cancers, portraying the general processes of Canadian cancer care. The system map reveals salient clinical issues while aiming to express a sense of the system's actual complexity.

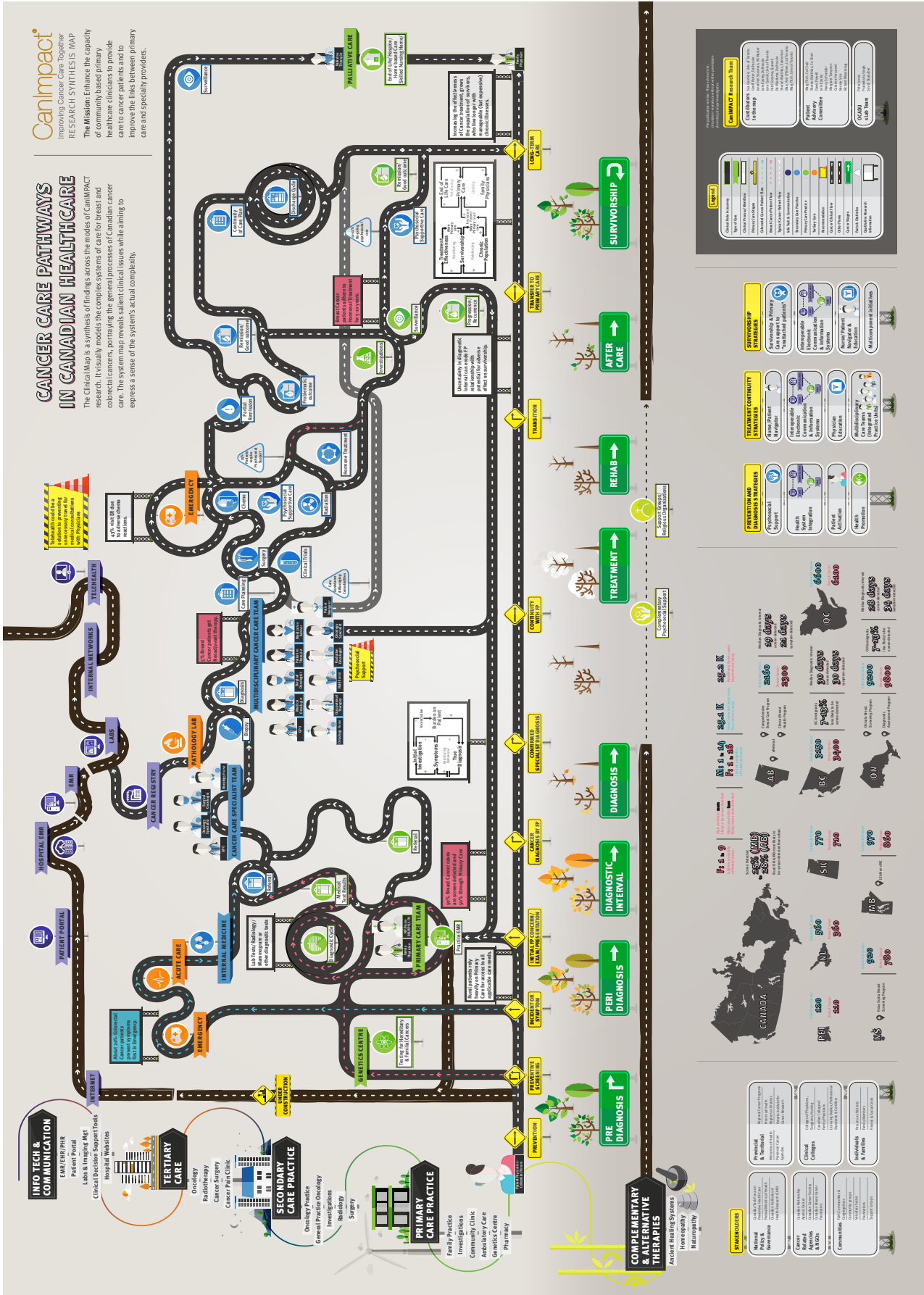


FIGURE 1 Cancer care pathways in Canadian health care. Copyright: Strategic Innovation Lab, OCAD University, 2016; used with permission.

Diagnostic Delay, wherein delays in diagnosis might erode patient trust in the physician. The delay is experienced by patients as physician-caused, because they have no insight into the causes of the perceived delay. The absence of physician communication during this period might diminish self-care, because patients lack guidance during the interval. On the right side, another inset shows Survivorship Population Effects. In this proposed systemic effect, increasingly effective treatment over time increases the survivor population, significantly increasing the patient load in primary care for patients with multiple comorbid chronic needs, consistent with many aging cancer survivors. Summary statistics at the bottom of the map show variations in the key variables across provinces. Stakeholders of the entire system are defined at the left; and tables of preventive, diagnostic, and treatment and survivorship strategies (from canIMPACT studies) are illustrated at the right.

Patient Synthesis Map: The Patient As Person in Relationship-Centred Care

The patient map (Figure 2) is a visual translation of complex human concerns in the cancer journey, as informed by the canIMPACT PAC. Taking a relationship-centred perspective⁶, it illustrates commonly-identified patient experiences of lifestyle, social, and health practices in primary and cancer care. Hand-sketched illustrations in this map are more suggestive of the emotional narratives of patients. Statements indicative of patient concerns are associated with each clinical stage.

The map integrates multiple patient perspectives from across canIMPACT's research with vignettes associated with two personas and their cancers: Beth (breast cancer) and Colin (colorectal cancer). Although no single map can adequately represent the range of real patient concerns and experiences across Canada, this map illustrates a range of lived experiences in cancer journeys as derived from the PAC and qualitative research.

Relationships are indicated from the centre (Patient and Family), to Friends and Workplace, and Health Care Providers. The circular bands encompass a socio-ecological system model⁷ to portray the inherent complexity in the cancer journey as a nonlinear flow between relationships within each cancer narrative. The cancer stages in the patient map can be viewed concurrently with the clinical map. The clinical map as context is suggested by the patient map's outer band.

Given the uniquely personal and varied reactions of people, and considering the existential concern of the cancer journey, the map's emotional representations are not intended to be representative of typical experiences, but indicative of situations that the two fictional personas might encounter. The legend shows a "bundle of emotions" image that portrays the many emotional states experienced by cancer patients, shown where emotional intensity is expected. The bundle was originally based on the Kubler-Ross stages⁸ of grief in dying. Critiques of the stage theory⁹ and internal discussions led to the current icon showing the emotional state as a blended and variable mix. Evidence for the emotional states drawn from the literature¹⁰⁻¹² support experiential claims raised in interviews with PAC members.

SUMMARY

The aim of canIMPACT is to define gaps in care practices and to propose strategies that will enhance primary care capacities for cancer patients and improve integration and coordination. The maps provide an integrated representation of the canIMPACT study, to engage clinicians and researchers in discussion, and to communicate system-wide issues with health care policymakers. The synthesis maps were designed to support formative knowledge translation that will communicate the initial findings of the study and that can identify intervention options and gaps in knowledge. They have been used in knowledge mobilization to complement presentations of the study findings at conferences. Synthesis maps have been developed by the Strategic Innovation Lab for other clinical, health, and social policy problems, and for stakeholder applications and teaching. Perhaps the most significant value in a mapping exercise would be found in extending its disciplined methodology to the representation of clinical pathways and detailed service models for diagnosis, treatment, or full patient lifecycles.

ACKNOWLEDGMENTS

The authors acknowledge Dr. Eva Grunfeld, Vice-Chair (Research) of the Department of Family and Community Medicine at University of Toronto, principal investigator of canIMPACT. The canIMPACT study is supported by the Canadian Institutes of Health Research, 2013–2018 (grant no. 128272).

We acknowledge the following researchers for their substantive contributions: Dr. Geoff Porter (Dalhousie University), Dr. Jonathan Sussman (McMaster University), Julie Easley (Dalhousie University), Dr. June Carroll (University of Toronto), Dr. Patti Groome (Queen's University), Dr. Baukje Miedema (Dalhousie University), Dr. Margaret Fitch, (University of Toronto), and Dr. Mary Ann O'Brien (University of Toronto). We further acknowledge the PAC members, including Sharon Matthias, Dawn Powell, Nancy Schneider, Margaret Tompson, Catarina Versaevell, Bonnie Vick, and Richard Wassersug, who contributed significantly to the research, and whose advocacy resulted in the production of the second, patient-centred map associated with this study. Thanks also to Bojana Petrovic for study support and manuscript review.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

AUTHOR AFFILIATIONS

*Strategic Innovation Lab, OCAD University, Strategic Innovation Lab, Toronto, ON.

REFERENCES

1. Grunfeld E, Petrovic B. Consultative workshop proceedings of the Canadian Team to Improve Community-Based Cancer Care Along the Continuum. *Curr Oncol* 2017;24:135-40.
2. Sevaldson B. GIGA-mapping: visualisation for complexity and systems thinking in design. In: Aalto University. Proceedings of the 4th Nordic Design Research Conference; Helsinki, Finland; 29–31 May 2011: 137–156.
3. Bauer R, Eagen W. Design thinking: epistemic plurality in management and organization. *Aesthesis* 2008;2:568–96.
4. Government of Canada, Canadian Institutes of Health Research. Collaboration > Knowledge translation – Definition

THE PATIENT AS PERSON IN RELATIONSHIP-CENTRED CARE

The map is presented as a visual knowledge translation of both systemic and human issues informed by the CanImpact team's Patient Advisory Council (PAC), taking a relationship-centred view of patient-centred care. It presents a balance to the clinical system represented in the CanImpact clinical map (Cancer Care Pathways).

The synthesis map integrates multiple patient perspectives from across CanImpact research with vignettes associated with two persons, Beth and Colin. Their moments as visualized signify lived experiences drawn from breast cancer and colon cancer narratives. While no single mapping can represent the depth of real patient concerns or the range of experiences across all of Canada, the synthesis map captures a range of known concerns in the lived experience of cancer journeyers. The map illustrates our aim of showing the links of choices, options and difficulties in the current system faced by people with cancer today.

References: Beach, M.C., Iida, et al. (2010). Relationship-centred Care: A Constructive Reframing. *Journal of General Internal Medicine*, 35(5):4.

CanImpact

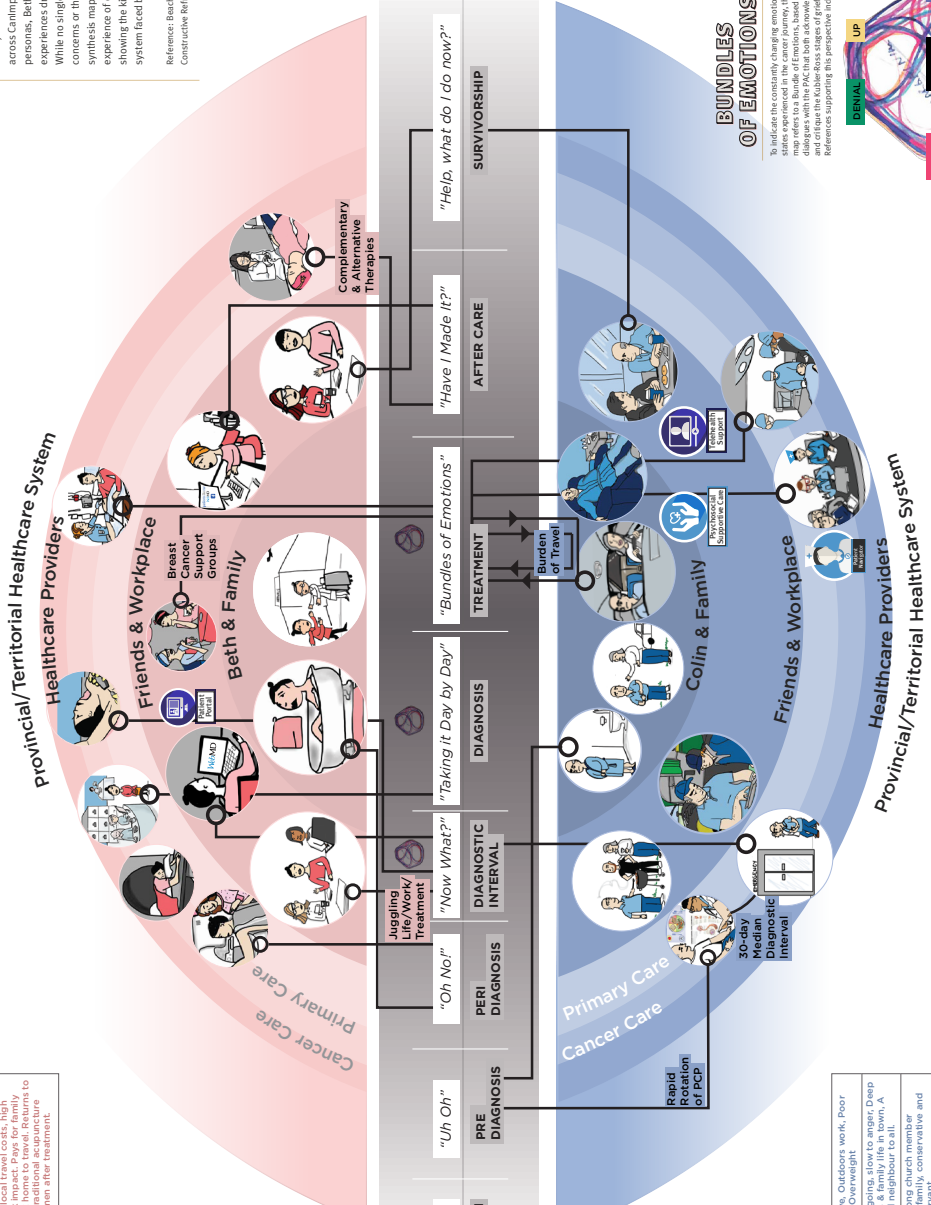
Improving Cancer Care Together
RESEARCH SYNTHESIS MAP

The Mission: Enhance the capacity of community-based primary healthcare clinicians to provide care to cancer patients and to improve the links between primary care and specialty providers.



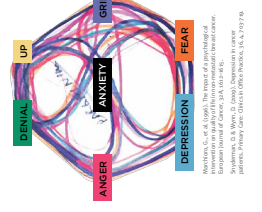
Beth Chen
Cancer Type: BRCA1
Habitation: Urban, Single
Age: 33
Health: Good CV & Health, High veg diet
Occupation: Financial services

Physical	Actively healthy, thin, flexible, yoga, & regular exercise.
Psychosocial	Emotionally resilient but struggles with anxiety. Left a relationship back home.
Spiritual	Not religious, but meditates. Deeply into arts & culture.
Information	Digital native, multi-device, internet expert.
Household	High income, near, good internet.
Personal & Family	Low local travel costs, high work impact. Pays for family care but dines out often. Her traditional acupuncture regimen after treatment.




BUNDLES OF EMOTIONS

To indicate the constantly changing emotional states experienced in the cancer journey, the synthesis map uses a series of icons to represent and critique the Kuber-Ross stages of grief. References supporting this perspective include:



References supporting this perspective include:
 - Elisabeth Kubler-Ross, *On Death and Dying* (1969)
 - Elisabeth Kubler-Ross & Elizabeth Kubler-Ross, *On Grief and Griefwork* (1981)
 - Elisabeth Kubler-Ross & Elizabeth Kubler-Ross, *On Life and Death* (1969)



Colin McCain
Cancer Type: Colorectal
Habitation: Rural, Married, 4 children
Age: 60
Health: Metabolic syndrome, CV disease with hypertension, from farm in Saskatchewan

Physical	Active, outdoors work, poor diet, overweight
Psychosocial	Easygoing, slow to anger, Deep roots & family life in town, A good neighbour to all.
Spiritual	Highly spiritual, meditative and observant.
Information	Prefers paper. Learned computer skills for family farm.
Household	Large family home attached to farmland in rural area, 80 km from town. Variable income, farmed up for 40 years.
Personal & Family	High family caregiving & travel burden. Town 180km Round Chemo & Surgery 500km RT

FIGURE 2 The patient as person in relationship-centred care. Copyright: Strategic Innovation Lab, OCAD University, 2016; used with permission.

- [Web resource]. 2016. [Available at: <http://www.cihr-irsc.gc.ca/e/29418.html>; cited 13 December 2016]
5. Straus SE, Tetroe J, Graham ID, eds. *Knowledge Translation in Health Care: Moving From Evidence to Practice*. 2nd ed. Hoboken, NJ: John Wiley and Sons; 2013.
 6. Beach MC, Inui T on behalf of the Relationship-Centred Care Network. Relationship-centred care. A constructive reframing. *J Gen Int Med* 2006;21(suppl 1):S3–8.
 7. Bronfenbrenner U. *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press; 1979.
 8. Kübler-Ross E. *On Death and Dying*. New York, NY: Macmillan Publishing Company; 1969.
 9. Bugen LA. Human grief: a model for prediction and intervention. *Am J Orthopsychiatry* 1977;47:196–206.
 10. Snyderman D, Wynn D. Depression in cancer patients. *Prim Care* 2009;36:703–19.
 11. Marchioro G, Azzarello G, Checchin F, *et al.* The impact of a psychological intervention on quality of life in non-metastatic breast cancer. *Eur J Cancer* 1996;32A:1612–15.