



Implementing Cancer Survivorship Care Plans: State of the Science

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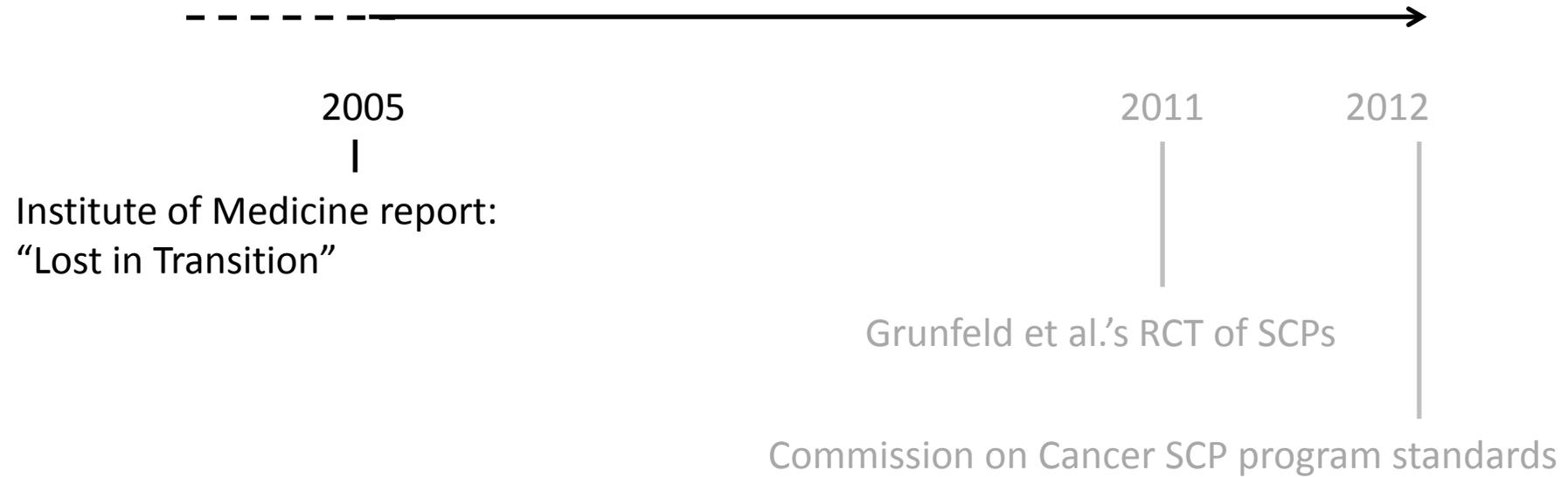
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University of North Carolina at Chapel Hill



WHEN LIFE IS SEWN BACK TOGETHER,
IT HAS CHANGED

A brief history of SCPs



Goal of SCPs

 **Cancer Survivorship Care Plan**

This Survivorship Care Plan will facilitate cancer care following active treatment. It may include important contact information, a treatment summary, recommendations for follow-up care testing, a directory of support services and resources, and other information. [1]

Survivorship Care Plan for Breast Cancer
Prepared by: NearSpace, Inc. on 9/4/2008

General Information

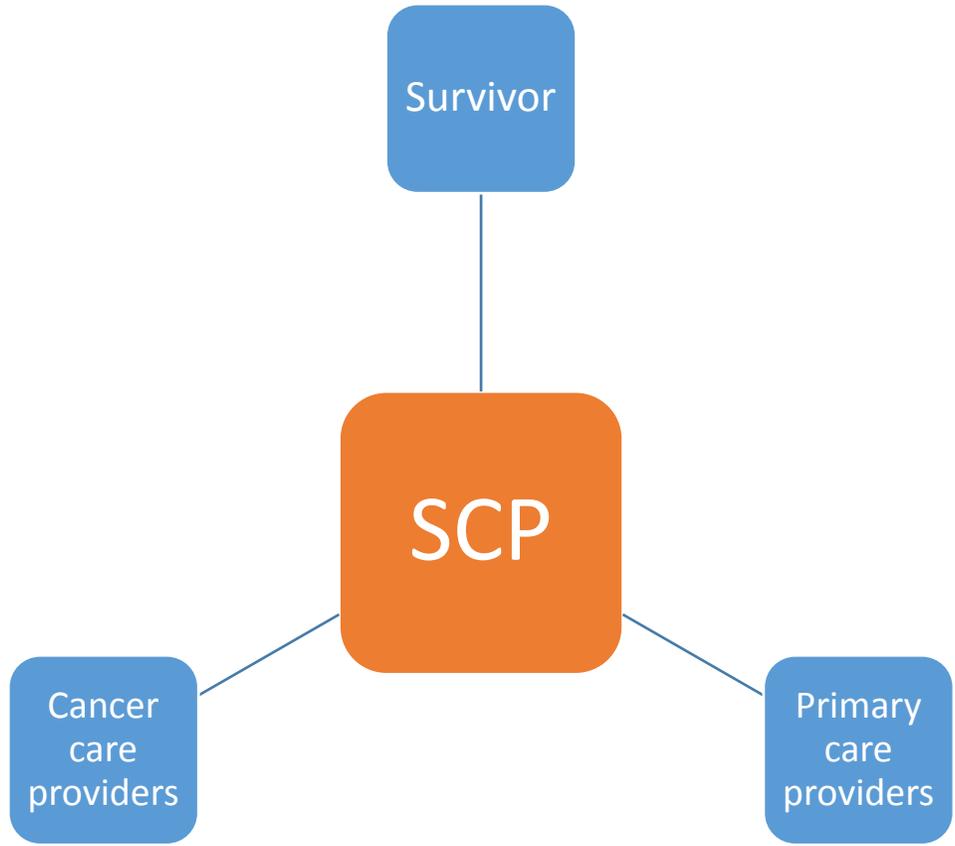
Patient Name	Jane Doe
Patient ID	#121365
Phone	707-555-1211
Date of birth	9/10/1963
Age at diagnosis	45
Support contact	John Doe, 707-555-1212

Care team

Medical oncologist	Dr. Patricia Ganz, 707-555-1210
General/breast surgeon	Dr. McDermon, 707-555-1213
Radiation therapist	Dr. Vascedio, 707-555-1214
Plastic surgeon	Dr. Roman, 707-555-1215
Primary care physician	Dr. Vorgis, 707-555-1216
OB-GYN	Dr. Drexel, 707-555-1217
Nurse/nurse practitioner	Faith Berghat, 707-555-1218
Mental health/social worker	Mary Kratz, 707-555-1219
Other	

v1.0.96
Printed 10/29/2008

www.JourneyForward.org





SCP Core Elements

1. Summary of the cancer type, treatment, and potential treatment-related late complications
2. Recommendations for follow-up
3. Information on secondary cancer prevention and health promotion
4. Guidance on protection of employment and insurance coverage
5. Content and local availability of psychosocial resources

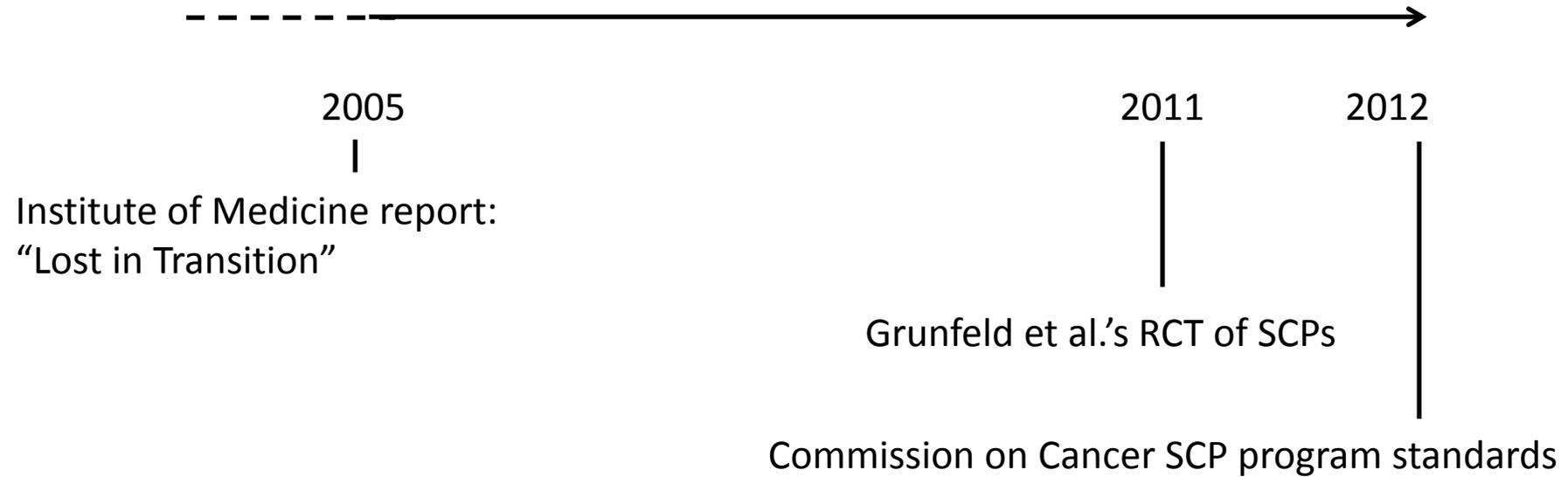
A brief history of SCPs



RCTs of SCPs' effectiveness

Author (Year)	Survivor group	Country	Outcomes Assessed	Intervention
Grunflod (2011); Boekhout (2016)	Early-stage breast cancer	Canada	<ol style="list-style-type: none"> 1) Cancer-related distress at 12 months 2) Quality of life 3) Patient satisfaction 4) Continuity/coordination of care 	SCP + RN educational session (vs. standard discharge)
Brothers (2013)	Gynecologic cancers, one year post treatment	United States	<ol style="list-style-type: none"> 1) Patient assessment of administrative, clinical, and educational health services 2) Helpfulness of written materials 3) Quality of care 	Physician provision of SCP (vs. standard physician care)
Hershman (2013)	Early-stage breast cancer	United States	<ol style="list-style-type: none"> 1) Impact of cancer 2) Patient satisfaction 3) Assessment of survivor concerns 	SCP + provider visit + "Facing Forward: Life After Cancer Treatment" (vs. "Facing Forward: Life After Cancer Treatment" only)
van de Poll-Franse (2011); Nicolaije (2015)	Endometrial and ovarian cancer	The Netherlands	<ol style="list-style-type: none"> 1) Patient satisfaction with information and care 2) Illness perceptions and healthcare use 3) Health-related QOL 4) Prevalence, course and referral rate of survivors in distress 5) providers' evaluation of care 	SCP generated by a Web-based EHR system (vs. standard care)

A brief history of SCPs



Parachute use to prevent death and major trauma related to gravitational challenge: systematic review of randomised controlled trials

Gordon C S Smith, Jill P Pell

Abstract

Objectives To determine whether parachutes are effective in preventing major trauma related to gravitational challenge.

Design Systematic review of randomised controlled trials.

Data sources: Medline, Web of Science, Embase, and the Cochrane Library databases; appropriate internet sites and citation lists.

Study selection: Studies showing the effects of using a parachute during free fall.

Main outcome measure Death or major trauma, defined as an injury severity score > 15 .

Results We were unable to identify any randomised controlled trials of parachute intervention.

Conclusions As with many interventions intended to prevent ill health, the effectiveness of parachutes has not been subjected to rigorous evaluation by using randomised controlled trials. Advocates of evidence based medicine have criticised the adoption of

accepted intervention was a fabric device, secured by strings to a harness worn by the participant and released (either automatically or manually) during free fall with the purpose of limiting the rate of descent. We excluded studies that had no control group.

Definition of outcomes

The major outcomes studied were death or major trauma, defined as an injury severity score greater than 15.⁶

Meta-analysis

Our statistical approach was to assess outcomes in parachute and control groups by odds ratios and quantified the precision of estimates by 95% confidence intervals. We chose the Mantel-Haenszel test to assess heterogeneity, and sensitivity and subgroup analyses and fixed effects weighted regression techniques to explore causes of heterogeneity. We selected a funnel plot to assess publication bias visually and Egger's and Begg's tests to test it quantitatively. Stata software, version 7.0,

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BMJ 2003;327:1459-61

Using Implementation Science to Examine the Impact of Cancer Survivorship Care Plans

Rebecca Selove, *Tennessee State University, Nashville, TN*

Sarah A. Birken, *The University of North Carolina at Chapel Hill, Chapel Hill, NC*

Ted A. Skolarus, *University of Michigan; Veterans Affairs Health Services Research and Development Center for Clinical Management Research; and Veterans Affairs Ann Arbor Healthcare System, Ann Arbor, MI*

Erin E. Hahn, *Kaiser Permanente Southern California, Pasadena, CA*

Anne Sales, *University of Michigan, Ann Arbor, MI*

Enola K. Proctor, *Washington University in St Louis, St Louis, MO*

“We contend that the effectiveness of SCPs is determined, in part, by context and delivery.”

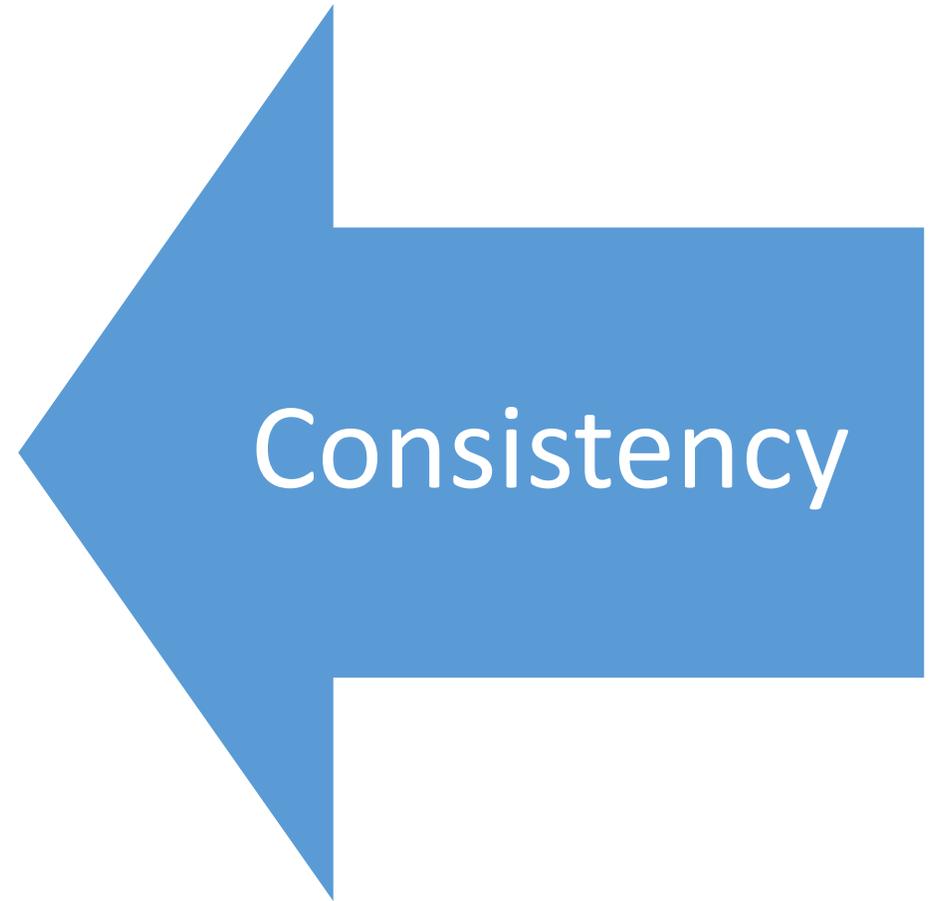
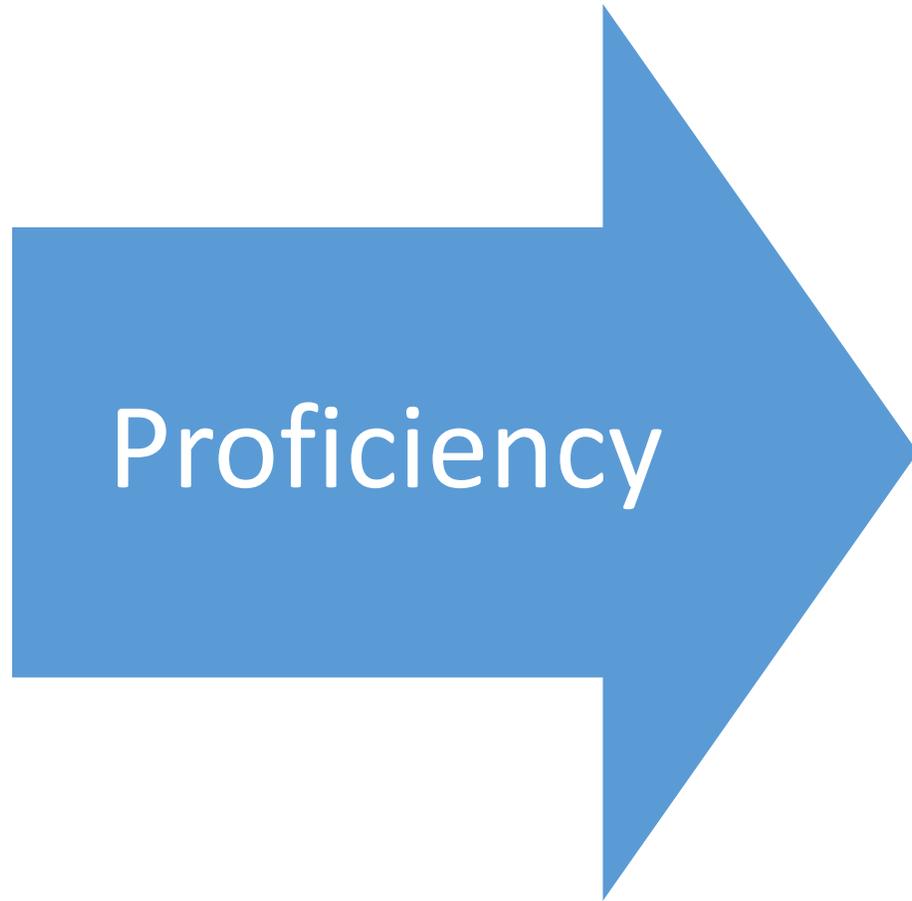
Avoiding Implementation Errors in Cancer Survivorship Care Plan Effectiveness Studies

Deborah K. Mayer, *Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, NC*
Sarah A. Birken, *Gillings School of Global Public Health, University of North Carolina, Chapel Hill, NC*
Ronald C. Chen, *Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, NC*

“ROGY studies omit important details regarding [SCPs’] implementation... [F]uture studies should consider how the SCP is implemented and how implementation may influence SCP effectiveness.”



Implementation





Implementation



None of the NCI-designated cancer centers included in the study delivered SCPs with all **IOM-recommended components**

Salz T, Oeffinger KC, McCabe MS, Layne TM, Bach PB. Survivorship care plans in research and practice. CA Cancer J Clin. 2012 Jan 12.



Implementation

Consistent SCP use involves developing and delivering SCPs to **all cancer survivors and their primary care providers.**

Proficiency

Less than 3% of included cancer programs developed and delivered SCPs to survivors and their primary care providers for at least 75% of their survivors.

Consistency

Birken SA, Deal AM, Mayer DK, Weiner BJ. Following through: The consistency of survivorship care plan use in United States cancer programs. *The Journal of Cancer Education*. 2014;29(4):689-697.



What influences SCP implementation?

Study	Determinants identified	Unit of analysis
Hewitt et al. (2007)	Electronic medical records, insurers' reporting requirements, patient advocacy, survivorship training	Cancer program
Merport et al. (2012)	Lack of training, reimbursement, and templates as barriers to preparing care plans	Oncologist
Forsythe et al. (2013)*	Training in late- and long-term effects of cancer, use of electronic medical records	Oncologist

*Statistical tests of variables' influence on SCP implementation were conducted; all other studies listed were descriptive

What influences SCP implementation?, cont.

Study	Determinants identified	Unit of analysis
Birken, Mayer & Weiner (2013a)	Insufficient organizational resources and systems for SCP use	Cancer program
Birken, Mayer & Weiner (2013b)*	Geographic location, program type (e.g., teaching hospitals), professional organization affiliation (e.g., American Hospital Association)	Cancer program
Birken et al. (2014)*	Geographic location, initiating SCP use in response to survivors' requests, membership in the National Cancer Institute's National Community Cancer Centers Program	Cancer program

*Statistical tests of variables' influence on SCP implementation were conducted; all other studies listed were descriptive

What influences SCP implementation?, cont.

Study	Determinants identified	Unit of analysis
Birken et al. (2014)	beliefs about the consequences of SCP use, motivation and goals regarding SCP use, environmental context and resources, social influences	Oncologist

Birken et al. *Implementation Science* 2014, **9**:167
<http://www.implementationscience.com/content/9/1/167>



RESEARCH

Open Access

Potential determinants of health-care professionals' use of survivorship care plans: a qualitative study using the theoretical domains framework

Sarah A Birken^{1*}, Justin Presseau², Shellie D Ellis³, Adrian A Gerstel⁴ and Deborah K Mayer⁴

What influences SCP implementation?, cont.

Study	Determinants identified	Unit of analysis
Birken et al. (2015)	Quality of guidelines for SCP use	Oncologist

Birken et al. *Implementation Science* (2015) 10:63
DOI 10.1186/s13012-015-0254-9



RESEARCH

Open Access

Guidelines for the use of survivorship care plans: a systematic quality appraisal using the AGREE II instrument

Sarah A Birken^{1*}, Shellie D Ellis², Jennifer S Walker³, Lisa D DiMartino¹, Devon K Check¹, Adrian A Gerstel⁴ and Deborah K Mayer⁴



Stakeholders' Perspectives on SCP Implementation and Outcomes (CRN)

- Setting
 - UNC (Sarah Birken, PI)
 - Kaiser Permanente Southern California (Erin Hahn, site PI)
 - Beatrice Hunter Cancer Institute (Robin Urquhart, site PI)
- Interviews (n=26 to date)
 - Cancer program administrators
 - Cancer care providers (MDs, NPs, RNs)
 - Primary care providers
 - Survivors
 - Caregivers
- Topics:
 - Implementation processes/strategies
 - SCP outcomes (realized vs. ideal)



SCP Implementation

- Wide variation in SCP content and delivery
- Workflow for SCP implementation
 - Not systematic
 - Driven by accreditation requirements, not patient-centered care
- Implementation “strategies”:
 - “Catch as catch can”
 - Reliance on one or two dedicated staff; ambiguous responsibility for developing and delivering SCPs at clinic level → inconsistent SCP implementation



SCP outcomes

- *Ideal* outcomes:

- **Cancer care providers**: Communicate to follow-up care providers and survivors symptoms to watch for, procedures they should perform and when

- **PCP**: tx summary = “backward glance” and “forward glance” = road map for what/when procedures are needed in surveillance/survivorship

- **Survivors**: Assuage fear of recurrence; minimize anxiety

- *Actual* outcomes:

- Cancer care providers lack the impetus and resources to use SCPs

- Survivors and PCPs like SCPs but receive SCPs at suboptimal time; information gets lost in the shuffle.

Strategies for Successful SCP Implementation (NC TraCS)

- Birken (UNC)/Jacobs (RTI), co-PIs
- Interviews with Quality Oncology Practice Initiative cancer program employees:

		TS development	
		High	Low
TS delivery	High	n=5	n=5
	Low	n=5	n=5

- Qualitative Comparative Analysis (within-case analysis and logic-based cross-case analysis)



Strategies for Successful SCP Implementation (NC TraCS)

- Two basic models
 - Devoted champion
 - Person to whom task has been delegated, willing or not
- Strategies:
 - Automatic processes
 - Reflective processes



Stakeholder-centered System Design for SCP Implementation (K01)

- Industrial engineering



- Human factors engineering



- Human-centered design → SCSD: multilevel approach to designing systems that meet user needs instead of asking users to accommodate system designs

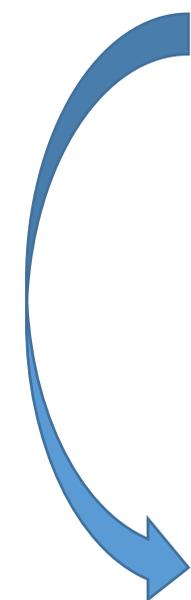
Aim 1: Design SCP implementation systems that accommodate the needs of survivors and cancer care providers.

1. Engage stakeholders:

- Stakeholder assessment
- Promotional materials
- Participation agreements

2. Describe existing SCP implementation system:

- Data collection
- Plus/delta evaluation
- NASA task load index
- Smart database
- Process summary



3. Redesign SCP implementation system:

- SCP implementation drawing board
- Roles assignment

4. Implement redesigned system:

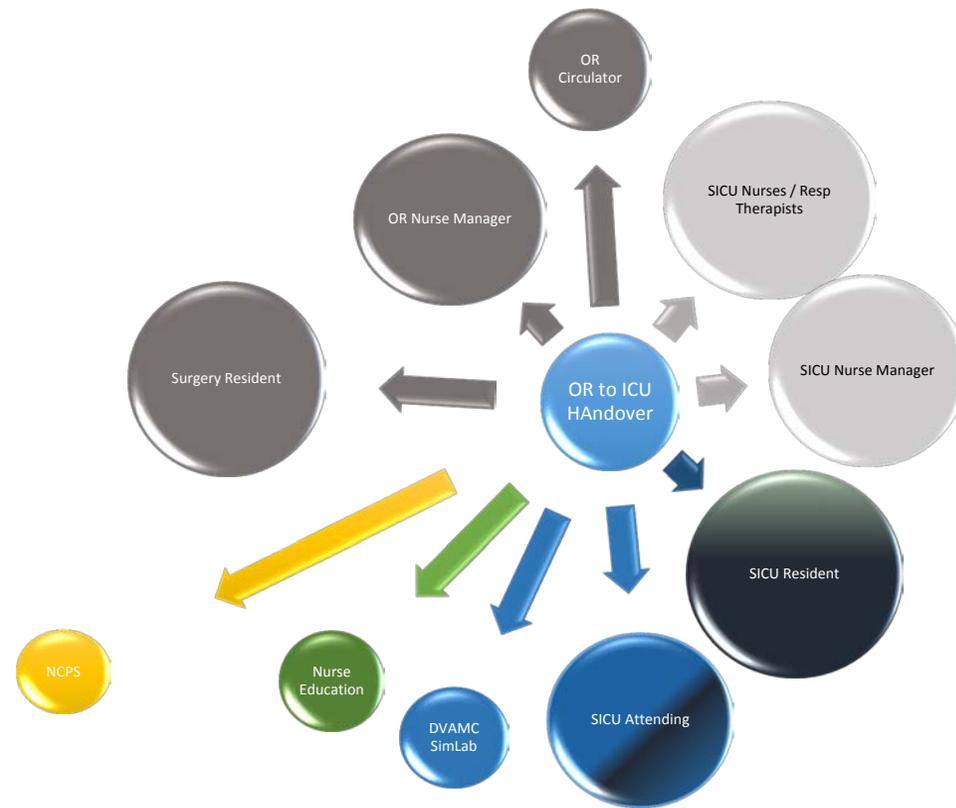
- Implementation checklist
- Protocols

5. Evaluate redesigned system

- [Describing existing SCP implementation system tools]



Aim 1: Design SCP implementation systems that accommodate the needs of survivors and cancer care providers.





Aim 2: Develop StaRS (Stakeholder Responsive Survivorship), a toolkit for designing systems that facilitate SCP implementation.

OR TO ICU HANDOVER IMPROVEMENT DIY TOOLKIT

National Center for Patient Safety

User's Manual

Aim 3: Pilot test the implementation and effectiveness of StaRS.

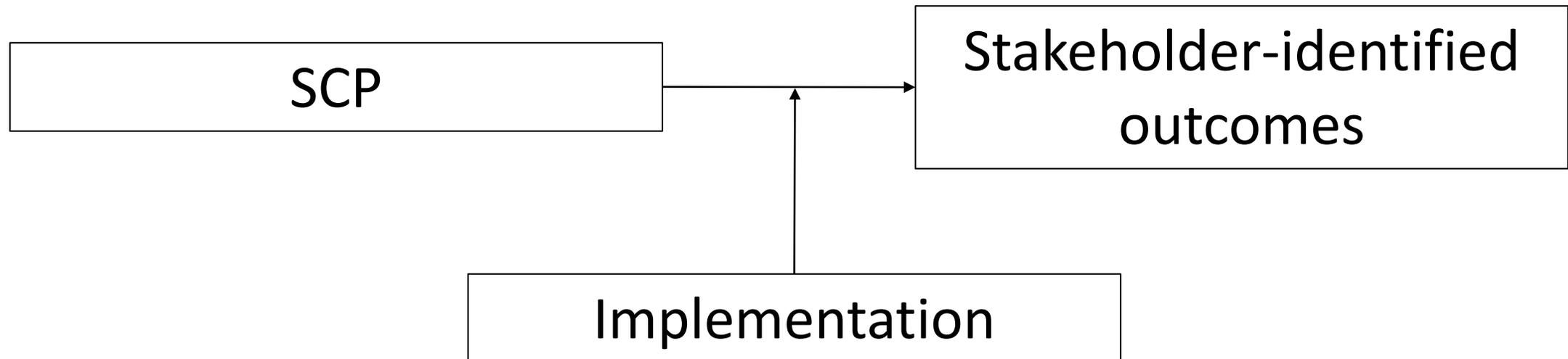
- Assess the feasibility, acceptability, and cost of implementing StaRS
- Evaluate the effectiveness of StaRS in improving SCP development and delivery

Stakeholder-tailored content

- Can cancer care providers develop SCPs tailored to the divergent needs of each stakeholder group?
- An R21 to be written during K01 funding period

Hybrid study of SCP implementation and effectiveness

- Aim 1: Assess SCP implementation.
- Aim 2: Assess the influence SCPs on stakeholder-identified outcomes.
- Aim 3: Assess the influence of SCP implementation on SCP effectiveness.



Finding the forest (Parry 2013)

- SCP vs. survivorship care
- SCPs can't be expected to do the work of what should be a comprehensive survivorship care *program*
SCPs as a convenient (if not ideal) opportunity to begin to understand survivorship care and its goals
- Survivorship care as an opportunity to begin to understand coordination of care more broadly

Acknowledgements

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