Implementation Science Approaches to Integrating Cancer Survivorship Research into Practice and Policy: Models, Methods, and Measures

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To achieve the rapid integration of scientific evidence, practice, and policy, with the ultimate goal of improving the impact of research on cancer outcomes and promoting health across individual, organizational and community levels.
## Models, Methods and Measures for Survivorship from Implementation Science

<table>
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<th>Models</th>
<th>Methods</th>
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<th>Discussion</th>
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**Models:** T0-T4 and Key Lessons Learned

**Methods:**
- Types of Evidence Needed
- RE-AIM Framework

**Measures:**
- Care Planning
- D and I measures (context, implementation, costs)
“Dissemination is the targeted distribution of information and intervention materials to a specific public health or clinical practice audience. The intent is to spread knowledge and the associated evidence-based interventions.” (scale-up)

“Implementation is the use of strategies to adopt and integrate evidence-based health interventions and change practice patterns within specific...settings”
**Dissemination and Implementation Research Characteristics**

- Contextual
- Complex
- Multi-component programs and policies
- Non-linear
- Transdisciplinary
- Multi-level and multi-method
- Addresses “wicked”, messy, important problems

The Translational Science Process for Survivorship

Scientific Discovery
(preclinical, epidemiology mechanism studies)

T1

Tests of promising Interventions
(Phase I, II, & III trials)

Knowledge Integration
(Management, Synthesis and Stakeholder & Survivor Engagement)

T0
Survivor Population Health; Disease Burden; Public health impact (Surveillance indicators)

T2
Evidence based Recommendations & policies (Guidelines)

T3
Implementation into Practice, Organizations, and Communities

T4

Modified from Khoury MJ et al; Am J Epidemiol 2010; 172:517-524
Implications of T0-T4 model

- Progress is not linear
- Knowledge integration involves “knowing where we are going”; not getting stuck at T0-T2
- There is “basic” research at each level of T0-T4
- Need respect and convergence across methods, disciplines, and “stages” of research
- Stakeholder involvement is essential—throughout
Most Common Type of Research?
Bench to Bookshelf
Abundance of D&I Models—61 at Least; But There are Key Common Points:

- Context is critical
- Begin with stakeholders—take their perspective
- Design for dissemination—from beginning—cannot wait until the end
- Need balance between fidelity to evidence-based program and adaptation to local setting
Key Common Points (cont.)

- There is more than evidence needed for successful adoption, implementation and sustainability

- D&I Science is a multi-level affair

- Select the DESIGN and the MODEL that best fits your question—less important WHICH model than that you use it well

- Need to focus on replication, relevance, transparency, and costs
Types of D & I Methods and Evidence Needed: 2R’s and “RCT”

- Relevant
- Rigorous and
- Rapid
- Cost informative
- Transparent

Relevant (Contextual and Practical)

- Relevant to *stakeholders* (patients/family, clinicians, administrators, policy makers)
- Relevant *samples*—representative of real-world, including patients with co-morbid conditions
- Relevant *settings*—similar to those in practice (not just the most advanced and well resourced)
- Relevant *staff*—including those who have other duties and competing demands
# Why is D&I Relevant to Survivorship?

## Ultimate Impact of “Evidence Based Intervention X”

<table>
<thead>
<tr>
<th>Dissemination</th>
<th>Concept</th>
<th>% Impacted</th>
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<tbody>
<tr>
<td>50% of Clinics Use</td>
<td>Adoption</td>
<td>50%</td>
</tr>
<tr>
<td>50% of Practitioners Recommend</td>
<td>Adoption</td>
<td>25%</td>
</tr>
<tr>
<td>50% of Patients Accept Recommendation/Attempt Change</td>
<td>Reach</td>
<td>12.5%</td>
</tr>
<tr>
<td>50% Follow Regimen Correctly</td>
<td>Implementation</td>
<td>6.2 %</td>
</tr>
<tr>
<td><strong>50% of Those Implementing Correctly have Substantial Benefit</strong></td>
<td>Effectiveness</td>
<td>3.1%</td>
</tr>
<tr>
<td>50% Continue to Adhere/Benefit After 6 Months</td>
<td>Maintenance</td>
<td>1.6%</td>
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Moral of the Story?

1. “Focus on the **Denominator**” (not just the numerator)

2. Each step of the dissemination sequence or each “RE-AIM” dimension is important

- [www.re-aim.org](http://www.re-aim.org)
RE-AIM Realist* Question:

- What percent and types of patients are Reached;
- For whom among them is the intervention Effective; in improving what outcomes;
- In what percent and types of settings and staff is this approach Adopted;
- How consistently are different parts of it Implemented at what cost to different parties;
- And how well are the intervention components and their effects Maintained?


RE-AIM Survivorship Care Plan (SCP) Example:

- In what percent and types of patients are SCPs Received;
- For whom among them is the intervention Effective; in improving what outcomes; what broader effects and negative consequences?
- Among what percent and types of settings and practitioners are SCPs Adopted;
- How consistently are different parts of SCPs Implemented across different settings, clinicians, and patient subgroups, and at what cost;
- And how well is the SCP program and its effects Maintained?
Rigorous....and a Word about RCTs

- Address most likely challenges to validity and conclusions for THAT question
- Both external and internal validity are important
- Design should fit the question—NOT vice-versa
- An RCT is not an RCT is not an RCT
- CONSORT delineation of pragmatic trials is an important advance
- RCT is not the only design that is experimental—and it does NOT guarantee causality

Rapid Evidence

- Need rapid learning research—especially for pressing issues such as obesity, HIV, explosion of health care spending, health inequities, and cancer survivorship

- EMRs, and their potential enhancements, make possible “rapid learning health care systems”*
  - Real-time data on millions of real-world patients in real-world health care settings, treated under usual conditions

How to Evaluate Technologies that Outpace Research?

2005
Grant Submit and Award

2006
Development and Pilot Testing

2007
Recruit and Randomize

2008
Follow-ups

2009

2010

2011
Analyze and Publish

YouTube

iPhone

Android

iPad
Cost Evidence

- Replication costs and scalability costs are arguably most needed
- Perspective— that of patient and adopting setting
- Costs should be comprehensive and transparent
- “One persons costs are another’s profits”
- Should be harmonized and include costs frequently not counted that need to be—e.g., recruitment, overhead, training, preparation and supervision¹
- Cost collection and cost-effectiveness analyses need not be overwhelming*--cost per incremental unit change

Transparent Evidence on…..

- Info needed to *replicate* or implement
- *Resources required*—costs for patients and delivery setting perspectives
- How were settings, clinicians, and patients selected—(*who was excluded and why*)
- *Adaptation*—changes made to protocol, to intervention, to recruitment, etc.
- *Differences across settings*
Future Evidence Needs and Opportunities—Keys to Advance Translation

- Context—key factors that may moderate results
- Scalability—potential to impact large numbers
- Sustainability
- Health equity impacts
- Patient/citizen/consumer and community perspective and engagement throughout
- Multi-level interactions, especially between policy and practice
All Models (and Methods) are Wrong...

....Some are useful

“To every complex question, there is a simple answer... and it is wrong.”

H. L. Mencken
Need for Better and Harmonized Measures in D&I and Survivorship Research

- Most studies use their own measures, often unknown characteristics, and quite different measures same construct.
- Without standard or more harmonized measures, difficult to do reviews, syntheses, compare across studies.
- Are different purposes of measurement—e.g.:
  - “Gold standard”—when this is primary focus for grant, need “best possible measure”, have staff to ensure quality.
  - “Practical measure”—for use in busy, low-resource settings; when one of a large set of measures; has to be brief and feasible.
### Care Planning and D&I Measures Initiatives

#### GEM-Dissemination and Implementation Initiative (GEM-D&I)
Healthcare policy and health information environment variables relevant to dissemination and implementation research and practice are dynamic and change rapidly. This creates both enormous opportunities and specific challenges as the D&I community works to identify the outcomes and associated measures evidence base to inform D&I research and practice.

The GEM-Dissemination and Implementation Initiative (GEM-D&I) is a project initiated and co-developed by the Cancer Re...

#### Useful Links & Documentation

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<td>GEM D&amp;I: Acknowledgements</td>
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<td>5th Annual NIH Conference on the Science of Dissemination and Implementation</td>
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#### Additional Resources
- [GEM Homepage](https://www.gem-beta.org/)
- [IS Team Website](http://cancercontrol.cancer.gov/IS/resources.html)
- [Office Cancer Survivorship](http://dccps.nci.nih.gov/ocs/)
Go Sun Smart (GSS)

**The Need**

Excessive exposure to ultraviolet radiation (UV) from sunlight is both the primary and the most easily prevented cause of skin cancer. Total lifetime exposure to UV is positively associated with several types of skin cancer, including basal cell carcinoma, squamous cell carcinoma, and possibly melanoma. Intermittent and severe exposure (i.e., sunburning) may also be linked to the development of melanoma.

Although exposure to UVR in... 

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**Highlights**

- **Purpose**: Designed to promote sun safety to ski area employees (2005)
- **Program Focus**: Behavior Modification
- **Topic**: Sun Safety
- **Age**: Adults (40-65 years), Older Adults (65+ years), Young Adults (19-29 years)
- **Gender**: Female, Male
- **Race/Ethnicity**: Hispanic or Latino, White, not of Hispanic or Latino origin
- **Setting**: Workplace
- **Funded by**: NCI

**RTIPs Scores**

- **Research Integrity**: 3.8
- **Intervention Impact**: 5.0
- **Dissemination Capability**: 4.0

1.0 = low, 5.0 = high

**RE-AIM Scores**

- **Reach**: 60%
- **Effectiveness**: 100%
- **Adoption**: 50%
- **Implementation**: 80%
- **Context**: Yes

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Cancer Control P.L.A.N.E.T. Home
Research to Reality (R2R): A Virtual Community of Practice

A dialogue between practitioners and researchers on how to move evidence-based programs into practice

- Launched February, 2011 (NCI)
  - Linked to Cancer Control P.L.A.N.E.T. Step 2

- Site Features:
  - Monthly cyber-seminars
  - Discussion forums
  - Mentorship program
  - An events calendar
  - Featured partners
  - Community profiles

https://ResearchtoReality.cancer.gov
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Evidence based Recommendations & policies (Guidelines)

Implementation into Practice, Organizations, and Communities

Modified from Khoury MJ et al; Am J Epidemiol 2010; 172:517-524
• There is a pressing need for a DIFFERENT type of research — “D&I” that translates more rapidly, and is more relevant to stakeholders

• This field is still emerging, but there is agreement on key common points among different models of D&I research

• There are many opportunities for this type of research, especially among networks including the Livestrong, VA, CRN, PBRN, cancer center, CTSA and community networks
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Contact me: glasgowre@mail.nih.gov

IS Team Website: http://dccps.cancer.gov/is/
Informed, Supportive System

Family, Friend, Peer Network
Patient Citizen

Health Care System
Care Team

Successful PCP-Community Link

Informed Referrals and Support Opportunities
Patient Preferences and Status

Evolving Evidence-Based Community Program and Resources

Larger Orgs/Networks
Community Resource Program

Broader Multi-Level Context:
(intrapersonal/biological, interpersonal/family, organizational, policy, community/economic, social/environment/historical)