Using Formative Research to Successfully Tailor a Complex Health Literacy Program

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Introduction: (10 minutes)

- Canyon Ranch Institute
- Canyon Ranch Institute
  Life Enhancement Program (CRI LEP)
Our Mission

Canyon Ranch Institute catalyzes the possibility of optimal health *for all people* by translating the best practices of Canyon Ranch and our partners to help educate, inspire, and empower every person to prevent disease and embrace a life of wellness.

*Canyon Ranch Institute is a 501(c)3 non-profit public charity.*
Focus Areas

Canyon Ranch Institute strives to:

- Advance **health literacy**
- Improve **prevention**
- Honor **cultural diversity** and meet each person where they are
- Apply **integrative health** and understand that personal and emotional connections lead to positive behavior changes
- Eliminate **health disparities**
CRI LEP Sites

- south Tucson, AZ
- Milan, MO
- South Bronx, NY
- Savannah, GA
- Pittsfield, MA
- Great Barrington, MA

Starting soon:
- North Adams, MA
- Eagle County, CO
- Anchorage, AK
- San Antonio, TX
CRI Partners

Through partnerships with health care organizations, universities, companies, individuals, and non-profit organizations, we are achieving unprecedented outcomes.
## Canyon Ranch Institute partnerships – Total reach

<table>
<thead>
<tr>
<th>CRI Program Participants</th>
<th>CRI Program &amp; Policy Reach</th>
<th>Audience of Mass Media Coverage of CRI</th>
</tr>
</thead>
<tbody>
<tr>
<td>5,526 people and more than 1,000 organizations</td>
<td>319,025,975</td>
<td>11,706,930</td>
</tr>
</tbody>
</table>
CRI Programs

• CRI Life Enhancement Program
• CRI Life Enhancement Program for Teens
• CRI Life Enhancement Program for Families
• CRI Theater for Health
• CRI Healthy Community
• CRI Healthy Garden
• CRI Healthy Table
• CRI Healthy World Scholarship
Health literacy in public health: Canyon Ranch Institute Life Enhancement Program

Health Literacy: Golden rule

Engage people early and often

Integrative Health

Include their whole lives

Prevention of Chronic Disease

To achieve prevention

CANYON RANCH Institute
THE POWER & POSSIBILITY OF A HEALTHY WORLD
CRI LEP Partners

- Established health care organizations
  - Serve low-income population, who are underserved and at high risk for chronic disease
  - Connected to their community
  - Facilities: classroom, food preparation and fitness area, and relaxation space
CRI LEP Core Team

• Champion
• Core Team Lead
• Cultural and linguistic capacity
• Integrative: medicine, nutrition, exercise, behavioral health, spirituality & pharmacology
• Credentialed

• Training: At Canyon Ranch and at partners’ sites by CRI
CRI LEP Participants

• High risk for chronic disease, such as diabetes, heart disease, stroke, and cancer
• From low-income and traditionally underserved communities
  ○ Race & ethnicity
  ○ Lower education & literacy
  ○ Social determinants of health
  ○ Urban & rural
• Access and availability
CRI LEP: Seven Core Elements

1. Behavior Change
2. Integrative Health
3. Nutrition
4. Physical Activity
5. Sense of Purpose
6. Spirituality
7. Social Support and Follow-up
CRI LEP Components

• Program tailored to community
• 12 sessions - food demos, grocery store visit, exercise
• Participant assessments
• One-On-One consultations:
  1. Integrative Health
  2. Behavioral Health
  3. Nutrition
  4. Exercise
  5. Medication and Supplements
  6. Spirituality
CRI LEP Program Materials

- All participant materials are in English & Spanish.
- Also included are Power Point presentations for program sessions.
A partner’s video on the CRI LEP
CRI LEP Participants

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Average Age</th>
<th>Percent Female</th>
<th>Average Years of Education</th>
<th>Average Number of Chronic conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Across all sites</td>
<td>591</td>
<td>52.2</td>
<td>86%</td>
<td>12.4</td>
<td>2.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Percent with Annual Income Less than $15,000</th>
<th>Percent Full Time Employed</th>
<th>Percent Unemployed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Across all sites</td>
<td>41%</td>
<td>36%</td>
<td>41%</td>
</tr>
</tbody>
</table>

• Note: All are statistically significantly different between sites.
# Pre-Post change

<table>
<thead>
<tr>
<th>Health Literacy</th>
<th>PHQ-9 Depression Score if 15+ at Pre</th>
<th>Stress</th>
<th>Feel Better Able to Take Care of Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent change across all sites</td>
<td>+ 10.2%</td>
<td>- 49.7%</td>
<td>- 25.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Glasses of Water/Day</th>
<th>Soda per day</th>
<th>Days Health Limits Activities</th>
<th>Body Consciousness Prevents Exercise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent change across all sites</td>
<td>+ 20.8%</td>
<td>- 60.0%</td>
<td>- 40.1%</td>
</tr>
</tbody>
</table>
# Pre-Post change

| Percent change across all sites | Average Minutes Exercise/ Week | Strenuous Exercise Per Week | Number of Sit-ups | Weight |
|--------------------------------|
| + 48.9% | + 74.8% | + 22.0% | - 3.1% |

| Percent change across all sites | C-Reactive Protein if >1 at Pre | Unhealthy Days Per Month | Satisfaction with Life | Receive Needed Emotional Support |
|--------------------------------|
| - 24.6% | - 47.3% | + 13.4% | + 17.8% |
Reggie Franklin – participant
Cost efficient

- Using Quality Adjusted Life Year (Pre/ Post) as basis for analysis of cost effectiveness:
  - The cost of improved health status for 393 people across all sites is occurring at an average cost savings of $188,395.77.
- Range is based on range of the average cost of a QALY in the United States.
- Calculation based on using CDC’s healthy days index to predict EQ-5D scores. (Haomiao, et al. 2011)
Tailoring programs and materials: (20 minutes)

- What is tailoring? Why is it important?
- How tailoring is informed by the CRI LEP’s formative research process.
• Matching program design and materials to the realities of people’s lives.
• NOT a one-size-fits all approach.
• Involves language but also program design (e.g. days of week, time of day, etc.).
• Also involves matching to staff’s capacities and skills.
Why tailor?

• Broad range of health literacy exists in communities.
• Especially low in lower-income communities with lower levels of education.
• Tailored interventions are more effective than non-tailored (i.e. more likely to create behavior change).
How tailor?

• More than matching a reading grade level
  ○ What about people with no or very low literacy?
  ○ What about helping people improve their health literacy by practicing and using skills?
  ○ What about matching the program to the skills, expertise, and resources of the staff as well as the participants?

• Must be evidence-based – thus formative research is required.
Evidence-based is not! (Perkins, 1999)

- A set of morals
- Casual conversations
- A brainstorming session
- Continuing the status quo
- Arguments in defense of past actions
- An opinion or value
- A new idea that seems good
- Something only a Ph.D. can collect
The Role of Formative Research

• **Research** – best tool for understanding what does and does not work – and why.

• **Research** – How we learn from effective programs and improve less effective programs.

• **Formative research** – creates evidence-base for developing effective strategies, including communication channels, for influencing behavior change.
An Example – Food Deserts

- Food deserts – what is the utility of talking about the importance of eating fruits and vegetables when your audience lives in a food desert?
An Example – Food Deserts

• That would:
  ○ Disempower participants.
  ○ Let them know the program was not designed with them in mind.
  ○ Waste time and resources.

True usability is more than words at a certain reading grade level and design approach.
Another Example – Jobs

• In the CRI LEP for Teens initial pilot (ongoing in the south Bronx) we learned:
  ○ One of the strongest determinants of health and outlook on life is quality of employment for both adults and teens.
  ○ Therefore, the CRI LEP for Teens partners with Project HOPE – a workforce skills development program.
  ○ Within the first four weeks of the initial pilot, we helped one participant find employment after months of searching.
## Plain Language and Behavior Change: Process and Scope

<table>
<thead>
<tr>
<th>Category of action</th>
<th>Typical approach to plain language material development to increase understanding</th>
<th>The CRI LEP approach to tailoring the program and materials to each community to create informed behavior change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop partnership</td>
<td>• Partnership development – includes learning capacity and outlook of local partner and core personnel/leadership.</td>
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</table>

The CRI LEP approach to tailoring the program and materials to each community to create informed behavior change.
<table>
<thead>
<tr>
<th>Plain Language</th>
<th>CRI LEP</th>
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<tbody>
<tr>
<td><strong>Begin formative research and training</strong></td>
<td><strong>Secondary data sources to create a written report and Power Point presentation – focus on identifying social, economic, political, and environmental determinants of health.</strong></td>
</tr>
<tr>
<td>• Identify intended audience and define/research the key health problems or interests.</td>
<td>o E.g. CDC, DHHS, County Health Rankings, as well as regional, state, local agencies and institutions</td>
</tr>
<tr>
<td>• Tailor research protocols based on that written report for each community.</td>
<td>• Begin core team training: Introduce them to integrative approach to health at the personal level (A week at Canyon Ranch)</td>
</tr>
<tr>
<td>• Engage the intended audience determine what their needs, beliefs/values, and interests are, and their level of knowledge of the identified health topic.</td>
<td>• Conduct individual interviews and focus groups in community with:</td>
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<tr>
<td></td>
<td>o Potential participants</td>
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<td></td>
<td>o Community leaders across all sectors</td>
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<td></td>
<td>o Partner’s leadership</td>
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<td></td>
<td>o Core Team members</td>
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<tr>
<td>Summarize findings of formative research</td>
<td>Plain Language</td>
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<td>----------------------------------------</td>
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<tr>
<td>• Determine key concepts and messages based on knowledge of the audience.</td>
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<tr>
<td>Apply findings of formative research to program materials, design, and presentation</td>
<td>• Design a draft of the material.</td>
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<td></td>
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<tr>
<td>Pretest materials</td>
<td>Plain Language</td>
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</table>
| • Pretest materials with intended audience. | • Finalize training of Core Team members with a multi-day “Bridge Practicum.”
  ○ Prepare talking notes for CRI personnel that summarizes formative research and recommended actions. | |
| • Each Core Team member practices presentation(s). Encouraged to ‘own’ the materials and personalize the session. | • Capstone experience - present the sessions to potential participants. |
| • Focus groups with Core Team members and audience members. | • Focus groups with Core Team members and audience members. |

<table>
<thead>
<tr>
<th>Refine and finalize materials</th>
<th>Plain Language</th>
<th>CRI LEP</th>
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</thead>
<tbody>
<tr>
<td>• Tweak draft according to feedback from the audience.</td>
<td>• Written and verbal feedback from peers and CRI staff to Core Team members about further suggested adaptations to presentations.</td>
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<tr>
<td>Plain Language</td>
<td>CRI LEP</td>
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<tr>
<td>Recruit participants and conduct baseline evaluation – including objective health status indicators</td>
<td>• Recruit participants.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Conduct baseline evaluation of participants: Includes knowledge, attitudes, beliefs, behaviors, exercise/fitness, blood work, physical measurements.</td>
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<tr>
<td>Launch program/distribute materials</td>
<td>• Publish and distribute materials.</td>
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<tr>
<td></td>
<td>• Launch CRI LEP.</td>
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<tr>
<td>Continual process monitoring and improvement</td>
<td>• Conduct weekly interactions with Core Team.</td>
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<tr>
<td></td>
<td>Plain Language</td>
<td>CRI LEP</td>
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<tr>
<td>------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
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<tr>
<td>Evaluate effects post program</td>
<td>• Evaluate the audiences’ satisfaction and understanding.</td>
<td>• Conduct focus groups with Core Team members and with participants at each group’s graduation.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Evaluate outcomes (Post, + 3 month, + 1 year) for continuous quality improvement &amp; feedback to participants and Core Team. (Include knowledge, attitudes, beliefs, behaviors, exercise/fitness, blood work, physical measurements).</td>
</tr>
<tr>
<td>Sustainability and learning</td>
<td></td>
<td>• Outcome and process report for each group distributed to Core Team members and leadership.</td>
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<tr>
<td></td>
<td></td>
<td>• Continuous sharing of best practices across sites.</td>
</tr>
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# A few key differences

<table>
<thead>
<tr>
<th>Plain Language</th>
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</thead>
<tbody>
<tr>
<td>Dominant focus on clean design, plain language, and readability levels.</td>
<td>Main focus on supporting participants and Core Team members, to:</td>
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<tr>
<td></td>
<td>• find/access information</td>
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<tr>
<td></td>
<td>• understand that information</td>
</tr>
<tr>
<td></td>
<td>• evaluate that information in the context of their own lives</td>
</tr>
<tr>
<td></td>
<td>• communicate that larger understanding to themselves and others in their lives to create a supportive environment for change</td>
</tr>
<tr>
<td></td>
<td>• use that information in a sustained and informed process of behavior change to reach healthier outcomes.</td>
</tr>
</tbody>
</table>
A few key differences

<table>
<thead>
<tr>
<th>Plain Language</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Approach does not explicitly address tailoring a program or materials to the</td>
<td>Explicitly takes a two-sided approach by addressing challenges in both the health system</td>
</tr>
<tr>
<td>skills of health care professionals or systems who will be delivering the</td>
<td>and the public.</td>
</tr>
<tr>
<td>information.</td>
<td></td>
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</tbody>
</table>

Canyon Ranch Institute
## A few key differences

<table>
<thead>
<tr>
<th>Plain Language</th>
<th>CRI LEP</th>
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</thead>
<tbody>
<tr>
<td>Put most important message first.</td>
<td>Sometimes people are not ready for the most important message first. They, for example, may think they need to lose weight but not yet realize what is driving their weight issue, such as depression or other determinants. Sometimes they need to find a path to their true goal and that doesn’t happen in the first session of a complex health literacy intervention.</td>
</tr>
<tr>
<td>Often removes complexity.</td>
<td>Works to make complexity understandable and actionable.</td>
</tr>
</tbody>
</table>
Descriptions of formative research findings and discussion: (35 minutes)

• Given each finding, let’s discuss how you would then tailor a program and program materials to address the finding
Findings and responses

• Let’s work together to develop some tailored responses!
• How would you design a program if you learned the following about potential participants, the community, or your health care partner in that community?
What if you learned that …

- Part of the community you hoped to reach held a strong perception that the hospital system you were partnering with to provide the program was the place where people went to die.
- This often meant people delayed seeking care.
What if you learned that …

- Failure to complete physical education is among the most common reasons for failure to graduate from high school.
What if you learned that …

• In a community where health was largely seen as the lack of disease (versus a resource to live a more fulfilled life), about half the people engaged in a formative research process expressed an opinion that exercise might make a person’s body look better but doubted it would help make a person happier in life.
What if you learned that …

- Among parents of young children especially, there was a strongly held and widely shared perception that an obese child was only overweight and an overweight child was a healthy child?
What if you learned that …

• In a community:
  - Health care providers felt the community’s biggest needs were economic (e.g. jobs).
  - Community members felt the community’s biggest needs were health and wellness, including low access to health care information and treatment.
What if you learned that …

- Secondary data about a small town in a rural area indicated that drug abuse (both legal and illegal) was at a high level.
- However, in this very religious and conservative community that health concern was only mentioned very few times in a formative research process (focus groups and individual interviews) despite direct probes on the issue.
What if you learned that …

• In a community, you meet several individuals with type 2 diabetes who express a belief that, like over-the-counter medicines such as aspirin, they should take them when they don’t feel well but otherwise they don’t see a need to do so.
What if you learned that …

- In largely Latino/Hispanic community, you find that while women generally do the home cooking, their male husbands/partners often strongly influence how things are cooked – preferring a traditional cultural approach to cooking, e.g. the way my mother cooked with lard, salty flavors, and not with a lot of fruits or vegetables?
• Mental health issues are described as being “spurred by a sense of hopelessness in the situation.” Mental health was an unknown surrounded by stigma. “Because there's no magic pill I could take. With diabetes you can lose weight. High blood pressure you can change with your diet. Mental health is something that I just don't understand. So it's almost like you don't want to know you got it. You don't want nobody to say it.”
What if you learned that …

• In an urban area in the ‘stroke belt’ that runs across the southern U.S., a very common sense of fatalism was expressed about chronic disease. One said, “everything my mother has I seem to have gotten.” Another person speaking about type 2 diabetes said, “My grandfather had it, my mother had it, my brother and sister had it, my brother still has it, my sister died.”
Two strategies – based on a health literacy and narrative theory approach to behavior change: (10 minutes)

- Infusing narratives into program materials
- Simulated participant exercise
Infusing narratives of change into program materials

One linguistic tool for change: the narrative structure - stories

- All narratives involve:
  - an opening situation.
  - a transformation.
  - a closing situation.
The world’s shortest narrative?

Lucy, will you please tell me a story?

A man was born. He lived, and died.

The End
Narrative vs. Scientific truths

• Very often science-based efforts assume people are rational according to the scientific method (e.g., evidence-based medicine)

• This approach is repeatedly frustrated when people don’t ‘get it.’
Narrative truth

• The world presents us with a range of stories that we must choose between or adjust our stories to reduce conflict.
• In this sense, culture often equals stories.
• Culture can certainly be identified through stories.
“Narrative rationality”

• What makes a story acceptable – it is **understandable**.

• What helps a story make the most ‘sense’ – its **context & cohesion**.

• What best matches the stories already known – its **relevance**.
Simulated participant training for health care professionals

- Conducted as part of the Core Team training to launch the CRI LEP
- Specifically focuses on One-On-One interactions with participants
The process - 1

1. Conduct formative assessment and analysis to identify common themes and perceptions about health and well-being in the community.

2. Identify a local person with the abilities to improvise and communicate clearly – not afraid of role-playing.

3. Develop a ‘character’ for that individual and conduct training sessions in advance.
The process - 2

4. Core Team members conduct individual One-On-Sessions during the training.
   ○ Focus on: Individual communication skills/deficits and the ‘hand-off’ of information between the Core Team.

5. Provide immediate on-site verbal feedback.

6. Provide written feedback and their own video-taped session for review.
Infusing narratives into CRI LEP program materials

• Each CRI LEP has a Program Guide for participants (among other program materials.)
• That CRI LEP Participant Guide contains a number of unique narratives about people that reflect the health challenges and possible successes in each community.
• Thus, based on formative research, we craft new narratives for every community.
The process

1. Conduct formative research and analysis.
2. Craft narratives reflecting the individual, social, and culture barriers to improved health and well-being.
3. Build in successful change elements to each story.
4. Test stories with formative researchers, Core Team members, and potential participants.
Abigail’s story – She is 45 years old.
Sometimes, people think I am not from here. I think there are still folks who don’t know black people have always lived here. I went to the Conte School over on West Union in Pittsfield. I liked school a lot. When my dad was laid off, we had to move a lot. I dropped out of high school but am working on my GED now. Learning can help me be healthier, that’s why I’m in this program.

Cassandra’s story – She is 30 years old.
I love Berkshire County, but I don’t know that Berkshire County loves me back. That makes me sad. I don’t see any other choices for me. My grandfather David doesn’t agree with me. I don’t think he knows the life I face. He used to earn five times as much working in his job as what I get now from the state to live on. I keep waiting for a job like his to come around. I am not sure that will ever happen. I can get some food from the food pantries and there are some places where I can get a free lunch for my son and me. I just have to figure out how to get us there. Transportation is always difficult, especially at night when the buses stop. I named my son David after my grandfather. I think my son can live an awesome life. He has a clean slate in front of him. I’m not sure I ever did. I sure hope his life is different than mine.
Discussion of how you can tailor your programs to the communities where you work: (10 minutes)

- Your challenges?
- Your opportunities?
- Your lessons learned?
Wrap-up and final questions – 5 minutes
Thank you!!!

Help someone help themselves to better health and wellness – that is a truly rewarding experience for everyone involved.

e-mail: Andrew@canyonranchinstitute.org