Identifying Research Priorities for the National Cancer Institute’s Cancer Research Network:

Developing a Collaboratively Authored Conceptual Framework

American Evaluation Association Annual Conference, Denver, CO
November 8, 2008

Kathleen M. Quinlan, 1 Katy Hall1, Leah Tuzzio, 2 Wendy McLaughlin, 3 Ed Wagner 2, Martin Brown3, and Robin Yabroff3

1Concept Systems, Inc.
2Group Health Cooperative
3National Cancer Institute
Cancer Research Network Context

• National Cancer Institute’s (NCI) Cancer Research Network (CRN) consists of 14 integrated health systems nationwide

• Cooperative research grant that encourages the generation of new research ideas and increased involvement by other cancer researchers

• Entering its third 5-year funding cycle
Goal: develop framework of scientific priorities to guide research agenda, planning and decision-making in CRN’s 3rd funding cycle

CRN Steering Committee brainstormed a list of potential research priorities in Fall 2007

CRN sought CSI’s assistance in facilitating broad input into:

– Developing a consensus framework of the ideas generated

– prioritizing these items for action.
IDEA GENERATION: Eliciting knowledge and opinion
Brainstorming Session- Fall 2007:
• CRN Steering Committee members generated 75 statements.
• The planning group edited the statement list for clarity, split statements with multiple ideas, reviewed for relevance and representativeness.
• Planning group approved final set of 98 ideas.

STRUCTURING: Data collection to build the conceptual framework
Sorting and Rating of Ideas - March 3 - March 25, 2008:
• 276 participants were invited to rate the 98 ideas on relative Importance and Feasibility
  ▪ 121 people (44%) contributed input on the Importance rating for analysis.
  ▪ 90 people (33%) contributed input on the Feasibility rating for analysis.
• 35 people were invited to organize the 98 ideas into conceptually similar piles or themes.
  ▪ 22 people (63%) conceptually sorted the ideas for analysis.
The Participants

IDEA GENERATION: Eliciting knowledge and opinion
Brainstorming Session - Fall 2007:
• CRN Steering Committee members (18)

STRUCTURING: Data collection to build the conceptual framework
Sorting and Rating of Ideas - March 3 - March 25, 2008:
• Sorting: 35 people were invited
  • CRN Steering Committee
  • CRN Investigators and site staff
  • CRN Academic Liaison Committee

• Rating: 276 participants were invited
  • All those invited to sort
  • Cancer researchers, both CRN affiliated and not
  • NIH staff and researchers
  • Patient advocates
Communication

• Email invitations were sent from both the NCI Program Director and the CRN Principle Investigator
  • Acknowledged the invitee’s expertise in cancer research
  • Succinctly summarized the project goals
  • Clearly outlined the tasks that were being asked of the invitee
  • Gave explicit instructions for next steps

• Follow-up communications came directly from the NCI Program Director
  • Again stressed that the invitee was selected for inclusion in this process because of his/her recognized expertise in this area
  • Acknowledged demands on invitee time, and reminded him/her of the ability to complete the activities in multiple sessions, using the online process
The Participant Process: Respondent Questions

These screens contain a series of questions that will be used as part of the project analysis. This information will not be used to personally identify you. Follow the instructions to respond to each question, then select the Continue button to continue or Cancel to exit.

Which category below best describes your role in relation to the National Cancer Institute’s (NCI) Cancer Research Network (CRN)?

- CRN Investigator or Research Staff
- Member of the CRN Academic Liaison Committee
- Investigator at a CRN-affiliated Cancer Center
- NCI Staff involved directly with the CRN
- NCI Staff, not directly involved with the CRN
- Staff in another HHS agency (not NCI)
- Member of the National Cancer Advisory Board
- Member of the NCI Board of Scientific Advisors
- Patient Advocate
- Other

Continue  Cancel

Done With Preview
1. First, read through the statements in the 'Unsorted Statements' column below on the left. Note that each statement completes the unfinished project focus prompt below.  
2. Next, sort each statement into a category you create, by using your mouse to click and drag the statement from the unsorted list to the 'Your Categories' column on the right. Group the statements for how similar in meaning or theme they are to one another. You can create new categories as you go by selecting the 'Add New Category' button. Give each category a name that describes its theme or contents.

Do NOT create categories according to priority, or value, such as 'Important', or 'Hard To Do.' Do NOT create categories such as 'Miscellaneous' or 'Other' that group together dissimilar statements. Put a statement alone in its own category if it is unrelated to all the other statements. Make sure every statement is put somewhere. Do not leave any statements in the Unsorted Statements column.

People vary in how many categories they create. Usually 5 to 20 categories works well to organize this number of statements. Find Out More: 

PROJECT FOCUS PROMPT: A specific CRI research (scientific) priority should be to...

Unsorted Statements

- study patient activation as relates to decision-making about diagnosis, treatment, and screening.
- study the effect of an exercise intervention on cancer incidence.
- examine factors affecting the timeliness of referrals and coordination.
- increase participation in clinical trials.
- use natural language processing (NLP) to look at treatments.
- develop capacity to study biologic variables relevant to prognosis and treatment.
- study the effects of Medicare part d drug coverage on the use of drugs.
- compare the adherence for oral vs infusion alternatives.
- identify treatments for late-diagnosed cancers.
- develop a biospecimen repository that links data on cancer cases, tissue, and pretreatment blood with web-based data.

Your Categories

- Rename
- Delete

Add New Category

- Unnamed Category
  - count: 0

- develop methods to rapidly ascertain cancers.
The Participant Process: Rating

Importance Rating [PREVIEW]

Please rate each statement below on how important you think it is for the Cancer Research Network to address in order to fulfill its mission. Please rate each statement relative to the other ones listed so you are using the full range of the scale.

1 = relatively unimportant
2 = somewhat important
3 = important
4 = very important
5 = extremely important

PROJECT FOCUS PROMPT: A specific CRN research (scientific) priority should be to...

- Show unrated statements only
- Show all statements

<table>
<thead>
<tr>
<th>Rating</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>study patient activation as relates to decision-making about diagnosis, treatment, and screening.</td>
</tr>
<tr>
<td></td>
<td>develop methods to rapidly ascertain cancers.</td>
</tr>
<tr>
<td></td>
<td>study the effect of an exercise intervention on cancer incidence.</td>
</tr>
<tr>
<td></td>
<td>examine factors affecting the timeliness of referrals and coordination.</td>
</tr>
<tr>
<td></td>
<td>increase participation in clinical trials.</td>
</tr>
<tr>
<td></td>
<td>use natural language processing (NLP) to look at treatments.</td>
</tr>
<tr>
<td></td>
<td>develop capacity to study biologic variables relevant to prognosis and treatment.</td>
</tr>
<tr>
<td></td>
<td>study the effects of Medicare part D drug coverage on the use of drugs.</td>
</tr>
</tbody>
</table>
Participant Representation: Role

Which category below best describes your role in relation to the National Cancer Institute’s (NCI) Cancer Research Network (CRN)?

- CRN Investigator or Research Staff (63) 53%
- Investigator at a CRN-affiliated Cancer Center (16) 13%
- Member of the CRN Academic Liaison Committee (4) 4%
- Member of the NCI Board of Scientific Advisors (2) 3%
- NCI Staff involved directly with the CRN (5) 4%
- NCI Staff, not directly involved with the CRN (7) 3%
- Other (15) 6%
- Patient Advocate (3) 3%
- Staff in another HHS agency (not NCI) (5) 3%

Total N = 120
What of the following *best* describes your primary research interest or focus related to cancer?

- Causes of Cancer/Etiology (8)
- Diagnosis/Prognosis (2)
- End of Life Care (2)
- Health Disparities (11)
- Not applicable (8)
- Other (25)
- Prevention (14)
- Risk Factors (8)
- Scientific Model Systems (3)
- Screening/Early Detection (16)
- Survivorship (11)
- Treatment (12)

Total N= 120
Participant Representation: Area of Expertise

Which of the following best describes your primary area of expertise?

- Basic Biomedical Science (1)
- Behavioral Medicine/Science (16)
- Biostatistics (4)
- Clinical Research (7)
- Epidemiology (34)
- Health Services (35)
- Health Systems/Policy Research (9)
- Informatics/Programming (7)
- Not Applicable (2)
- Other (5)

Total N = 120
Participant Representation: Involvement with CRN

Which of the following best describes your knowledge of and/or involvement with the Cancer Research Network?

- **Extremely High** (Multiple years of experience or leadership within the CRN) (19)
- **High** (Major role on a CRN project, Committee, and/or Scientific Interest Group) (20)
- **Medium** (Significant participation on a CRN project, Committee, and/or Scientific Interest Group) (49)
- **Low** (Little knowledge or involvement) (29)
- **None** (3)

Total = 120
This initial map shows all the elements in relation to one another.
Each point represents one of the brainstormed ideas.

“A specific CRN research (scientific) priority should be to increase VDW data to include outpatient infusion and treatment data.” (15)
Conceptually *similar ideas are in close proximity*

- Increase VDW data to include outpatient infusion and treatment data. (15)
- Include health behavior and risk assessment data in the Virtual Data Warehouse. (46)
- Enhance Virtual Data Warehouse (VDW) to identify disease episodes. (90)

“A specific CRN research (scientific) priority should be to…”
The detailed ideas are organized into groups

..so that many concepts can be considered in a shared structure
...contains all the details and provides a conceptual framework.

© 2008 Concept Systems, Inc.
Importance & Feasibility Ratings

Please rate each statement below on how **important** you think it is for the Cancer Research Network to address in order to fulfill its mission. Please rate each statement **relative** to the other ones listed so you are using the full range of the scale.

1 = relatively unimportant
2 = somewhat important
3 = important
4 = very important
5 = extremely important

Please rate each statement below on how **feasible** it is for the Cancer Research Network to address in the next 2 - 3 years. Please rate each statement relative to the other ones listed so you are using the full range of the scale.

1 = not at all feasible
2 = somewhat feasible
3 = feasible
4 = very feasible
5 = extremely feasible
Importance vs. Feasibility (All Participants)

Importance (n=121)  Feasibility (n=90)

C. Healthcare Delivery, Quality, Costs & Outcomes
F. Data Resources & Infrastructure
A. Enhancing Cancer Communication & Decision Making
G. Building Capacity to Support Emerging Areas of Cancer Control Research
B. Psychosocial Factors & Burden of Cancer
E. Research Translation & Patterns of Screening, Treatment, & Care
D. Health Insurance Benefit Design & Patterns of Care Utilization
H. Cancer Epidemiology, Prevention, & Health Promotion

r = .67

3.59  3.59

3.08  3.08
Importance by Role (Internal vs. External)

Internal (n=88)

- C. Healthcare Delivery, Quality, Costs & Outcomes
- F. Data Resources & Infrastructure
  - A. Enhancing Cancer Communication & Decision Making
- B. Psychosocial Factors & Burden of Cancer
- G. Building Capacity to Support Emerging Areas of Cancer Control Research
- E. Research Translation & Patterns of Screening, Treatment, & Care
- H. Cancer Epidemiology, Prevention, & Health Promotion
- D. Health Insurance Benefit Design & Patterns of Care Utilization

External (n=32)

- C. Healthcare Delivery, Quality, Costs & Outcomes
- E. Research Translation & Patterns of Screening, Treatment, & Care
  - A. Enhancing Cancer Communication & Decision Making
- D. Health Insurance Benefit Design & Patterns of Care Utilization
- G. Building Capacity to Support Emerging Areas of Cancer Control Research
- F. Data Resources & Infrastructure
  - B. Psychosocial Factors & Burden of Cancer
- H. Cancer Epidemiology, Prevention, & Health Promotion

r = .72
Example of a Go-Zone: Comparing Statements on the Rating Scales

Feasibility Mean for this cluster

<table>
<thead>
<tr>
<th>Importance</th>
<th>Low Feasibility</th>
<th>High Feasibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>32</td>
<td>20</td>
</tr>
<tr>
<td>High</td>
<td>49</td>
<td>11</td>
</tr>
</tbody>
</table>

- **Low Importance Low Feasibility**: refresh the cancer counter. (32)
- **Low Importance High Feasibility**: support a lab to evaluate how therapies should be used appropriately. (49)
- **High Importance Low Feasibility**: develop a biospecimen repository that links data on cancer cases, tissue, and pretreatment bloods with risk factor data. (11)
- **High Importance High Feasibility**: examine health care utilization and delivery for cancer patients post-treatment. (20)
D. Health Insurance Benefit Design & Patterns of Care Utilization

- Study the effects of Medicare part D drug coverage on the use of drugs. (8)
- Examine impacts of insurance benefit design (traditional, HSAs) and cost sharing on cancer related services. (39)
- Investigate why people on Medicaid do worse. (58)
- Undertake studies of the impact of quality measurement and pay for performance. (81)

- Study the effects of health benefit design on use of drugs. (72)
- Study the impacts of policy differences among health plans. (44)
- Study the utilization, outcomes, and impacts of national coverage decision for EPO. (93)
RESULTS & CONTINUING WORK

• NCI published the CRN Brochure which included the 8 Research Themes
  • http://crn.cancer.gov/publications/capacity_collaboration_investigation.pdf

• CRN issued a call for pilot proposal which encouraged, although not required, applicants to select the CRN’s Research Themes that their pilot proposal covered.

• CRN developed workgroups around each Research Theme.
  • NCI staff, the CRN Steering Committee, CRN Scholars/Junior Investigators, Academic Liaison Committee, and investigators
  • Each WG met at least once via conference call to develop an action plan to operationalize the CRN’s research themes.
  • The suggestions/workplans were shared and discussed at an in-person meeting on September 19th in Rockville, MD.
  • All of the workplans have been posted on a Web portal so everyone involved in the CRN can view them.

• CRN staff are reviewing each of the workplans to identify commonalities.
Thank You...

For more information contact:
Concept Systems, Inc.
36 East State Street
Ithaca, NY 14850
www.concepts systems.com