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

Developing a Collaboratively Authored Conceptual Framework

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The HMO CRN Cancer Research Network

Funded by the National 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

Project Goals and Background

- 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.

The Project Details

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 w/ 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

Participant Characteristic Questions - Windows Internet Explorer

http://www.conceptsystemsglobal.com/question_ask.php?project=122&preview=true&list=true&sid=h5lbjcaa3djodc2cd0q3nc0b36

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Mapping Scientific Priorities

show menu | signed in as **Katy Hall** | sign out | save | cancel | home | help

Progress:

Participant Characteristic Questions [PREVIEW]

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

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The Participant Process: Sorting

Statement Sorting - Windows Internet Explorer

http://www.conceptsystemsglobal.com/statement_drag.php?project=122&preview=true&list=true&sid=h5lbjcaa3djodc2cd0q3nc0b36

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 CRN research (scientific) priority should be to...

Unsorted Statements

Display Fewer Display More

- 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 bloods with risk factor data

Your Categories Add New Category

Collapse All Expand All Alphabetize

Unnamed Category *count: 0* Rename Delete

- develop methods to rapidly ascertain cancers.

The Participant Process: Rating

Importance Rating - Windows Internet Explorer

http://www.conceptsystemsglobal.com/rating_rate.php?project=122&rating=193&preview=true&list=true&sid=h5lbjcaa3djodc2cd0q3nc0b36

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Mapping Scientific Priorities

show menu | signed in as **Katy Hall** | sign out | save | cancel | home | help

Progress:

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

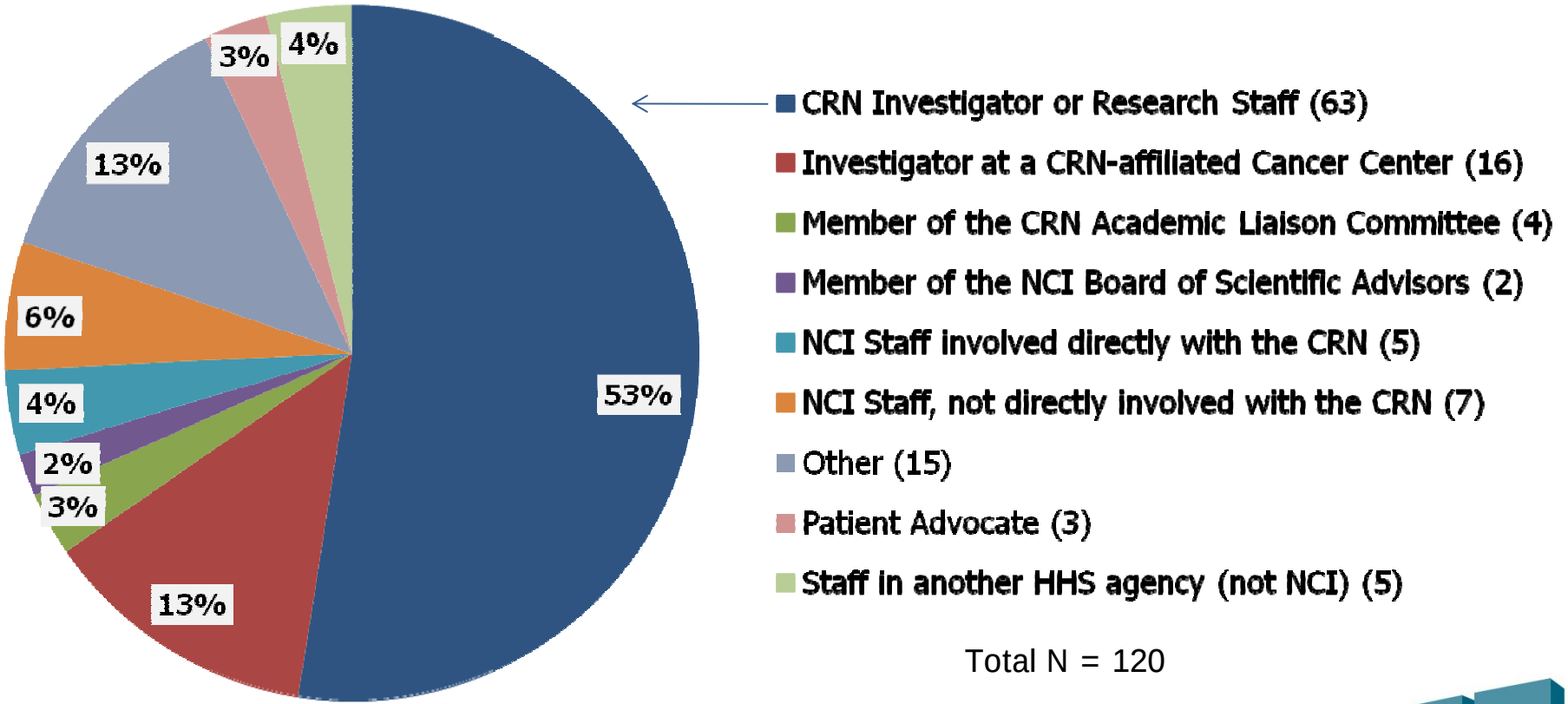
PROJECT FOCUS PROMPT: A specific CRN research (scientific) priority should be to...

○ Show unrated statements only ◉ Show all statements

Rating (*relatively unimportant* → *extremely important*)	Statement
○ 1 ○ 2 ◉ 3 ○ 4 ○ 5	study patient activation as relates to decision-making about diagnosis, treatment, and screening. [unrate]
○ 1 ○ 2 ○ 3 ◉ 4 ○ 5	develop methods to rapidly ascertain cancers. [unrate]
○ 1 ◉ 2 ○ 3 ○ 4 ○ 5	study the effect of an exercise intervention on cancer incidence. [unrate]
○ 1 ○ 2 ○ 3 ○ 4 ◉ 5	examine factors affecting the timeliness of referrals and coordination. [unrate]
○ 1 ○ 2 ○ 3 ○ 4 ○ 5	increase participation in clinical trials.
○ 1 ○ 2 ○ 3 ○ 4 ○ 5	use natural language processing (NLP) to look at treatments.
○ 1 ○ 2 ○ 3 ○ 4 ○ 5	develop capacity to study biologic variables relevant to prognosis and treatment.
○ 1 ○ 2 ○ 3 ○ 4 ○ 5	study the effects of Medicare part D drug coverage on the use of drugs.

Participant Representation: Role

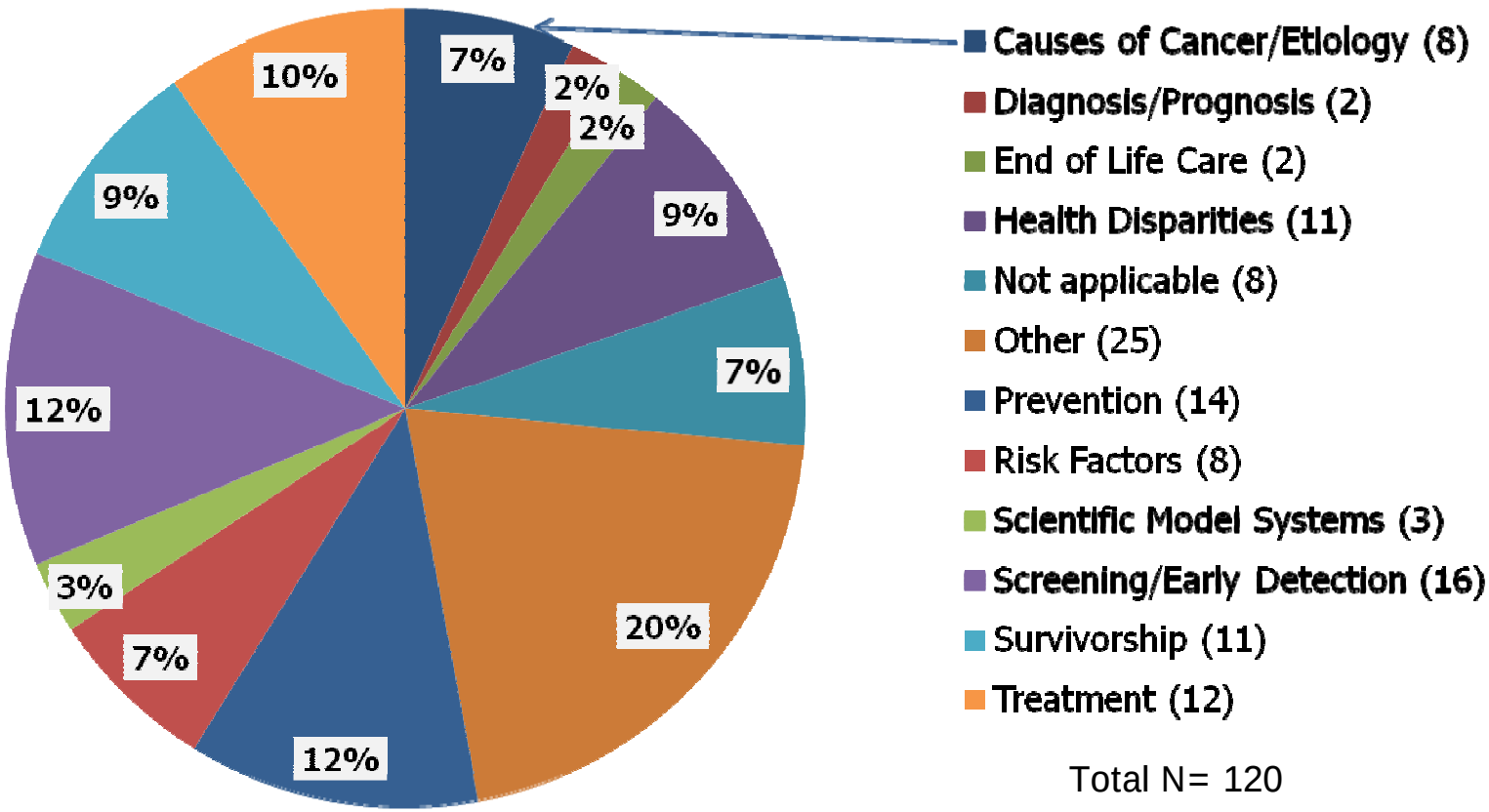
Which category below *best* describes your role in relation to the National Cancer Institute's (NCI) Cancer Research Network (CRN)?



Total N = 120

Participant Representation: Research Focus

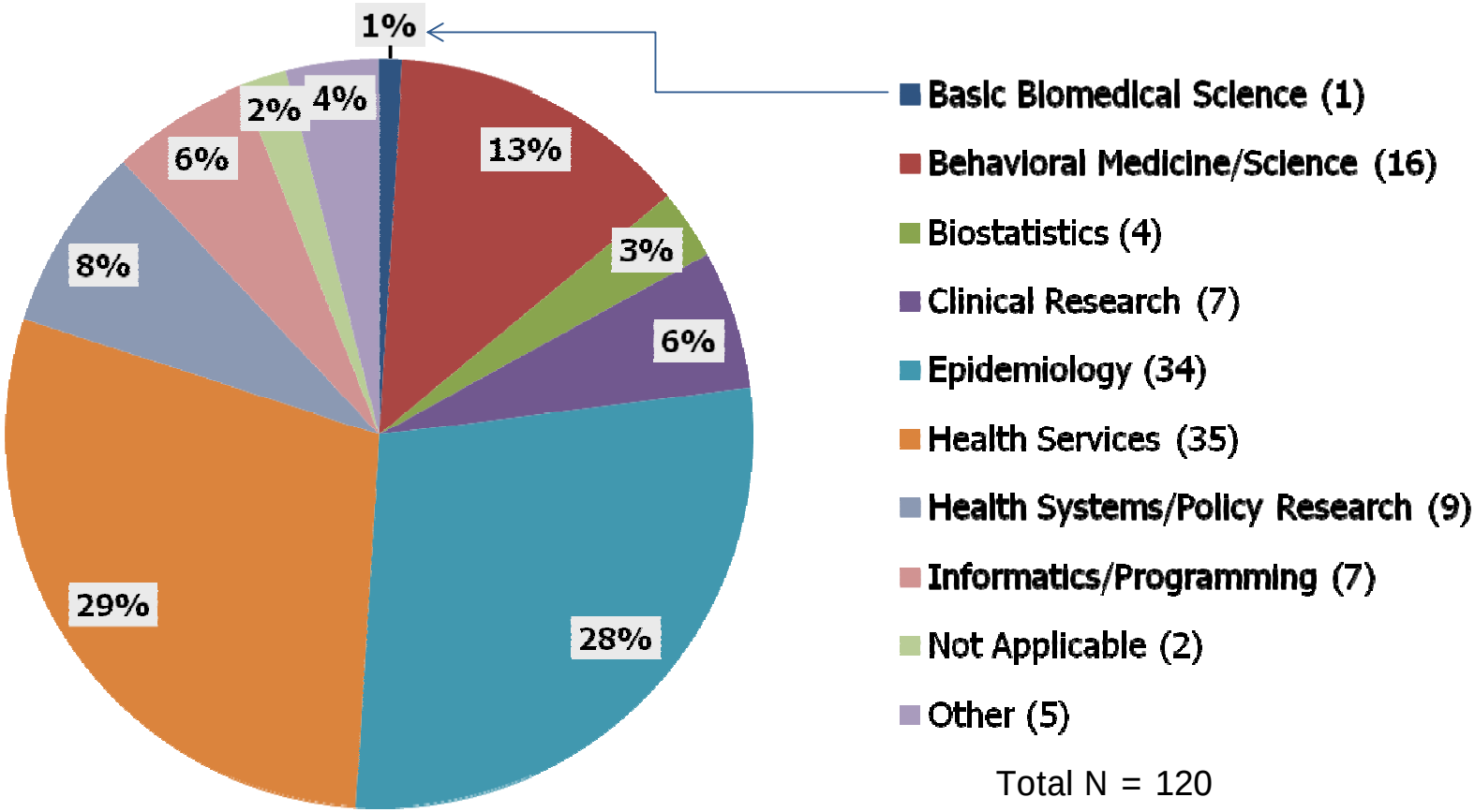
What of the following *best* describes your primary research interest or focus related to cancer?



Total N= 120

Participant Representation: Area of Expertise

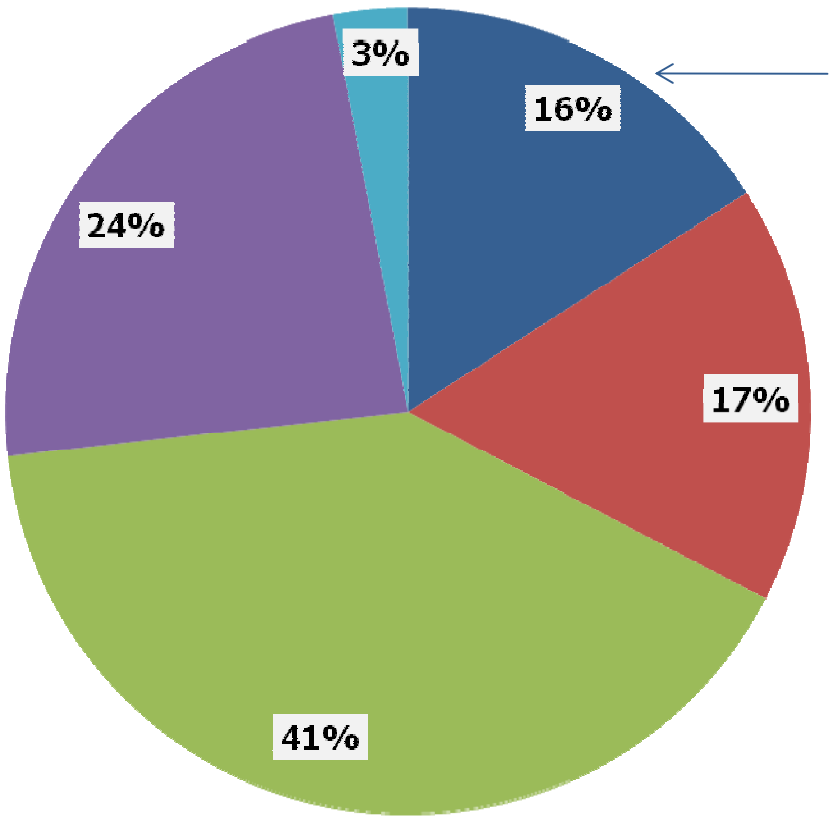
Which of the following *best* describes your primary area of expertise?



Total N = 120

Participant Representation: Involvement with CRN

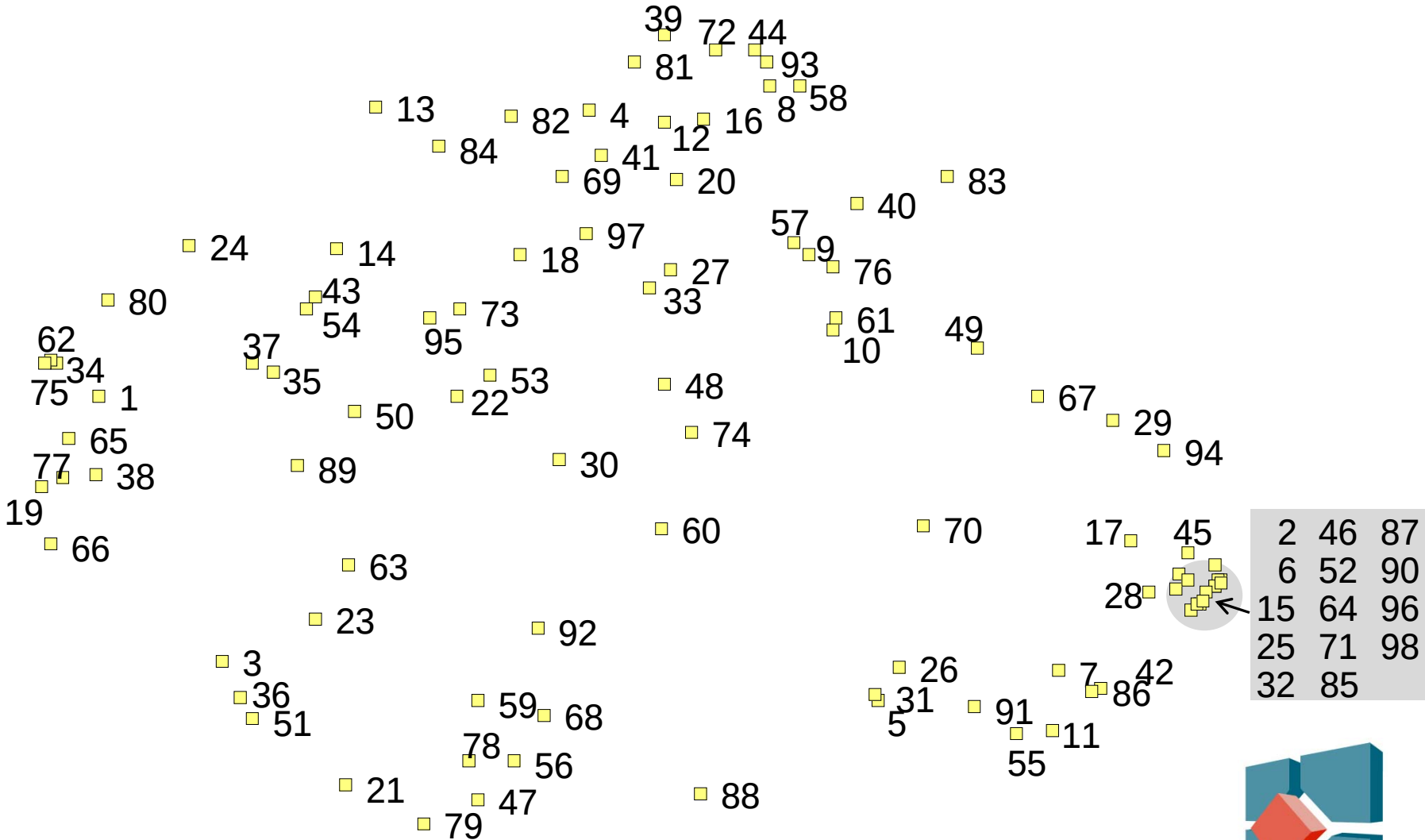
Which of the following *best* describes your knowledge of and/or involvement with the Cancer Research Network?



- 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)

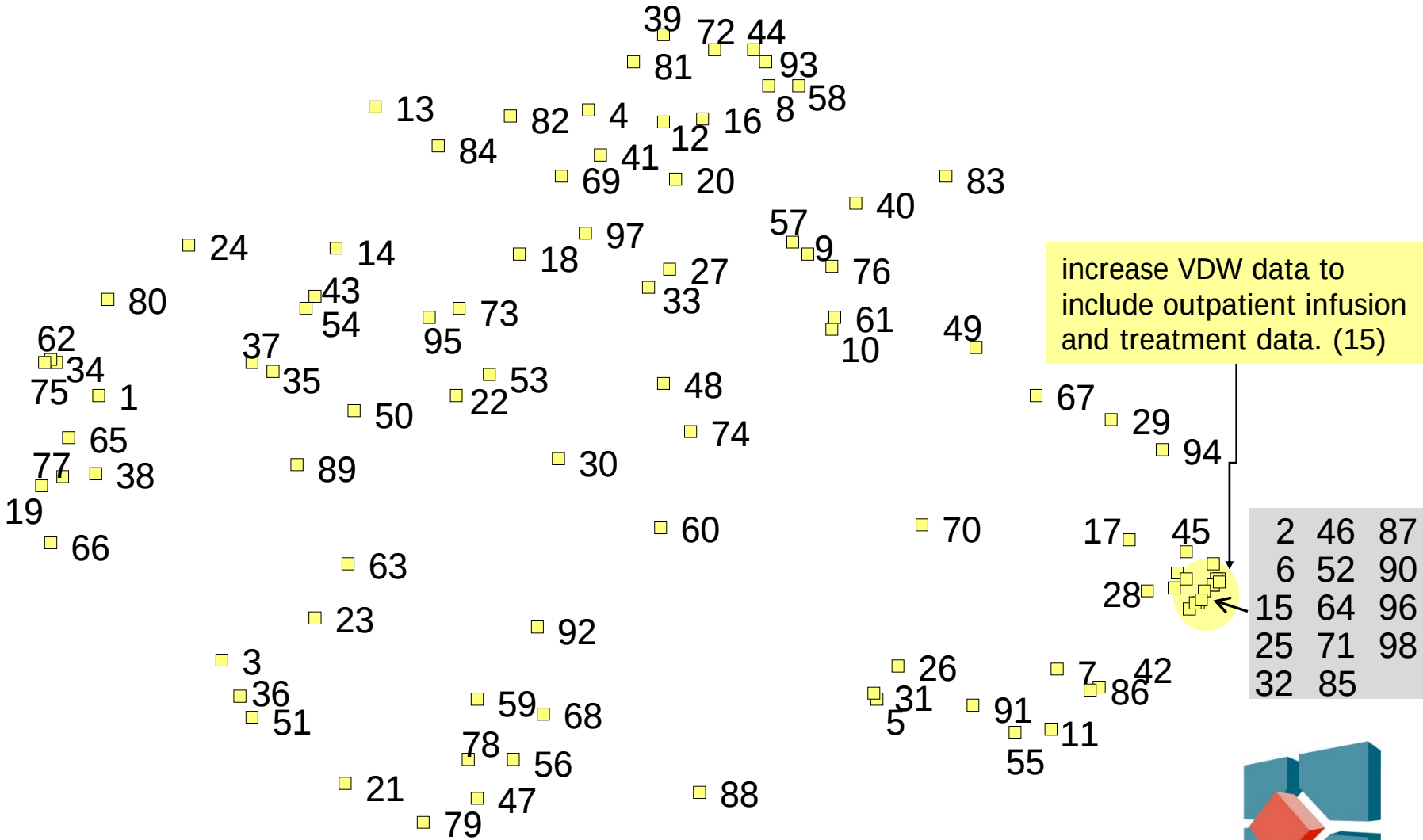
Total = 120

This initial map shows all the elements in relation to one another.



2	46	87
6	52	90
15	64	96
25	71	98
32	85	

Each point represents one of the brainstormed ideas.

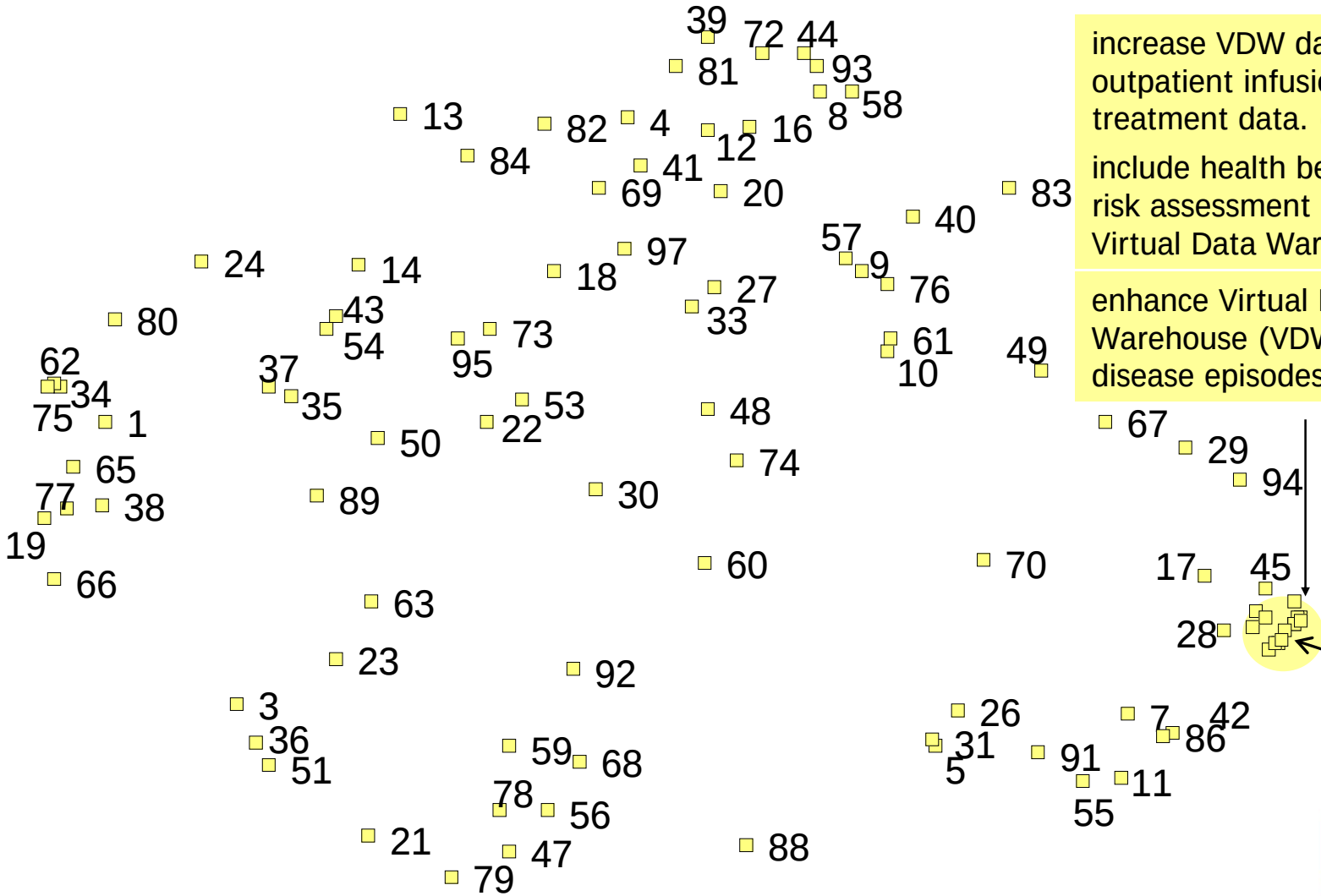


increase VDW data to include outpatient infusion and treatment data. (15)

2	46	87
6	52	90
15	64	96
25	71	98
32	85	

"A specific CRN research (scientific) priority should be to…"

Conceptually *similar ideas* are in *close proximity*



increase VDW data to include outpatient infusion and treatment data. (15)

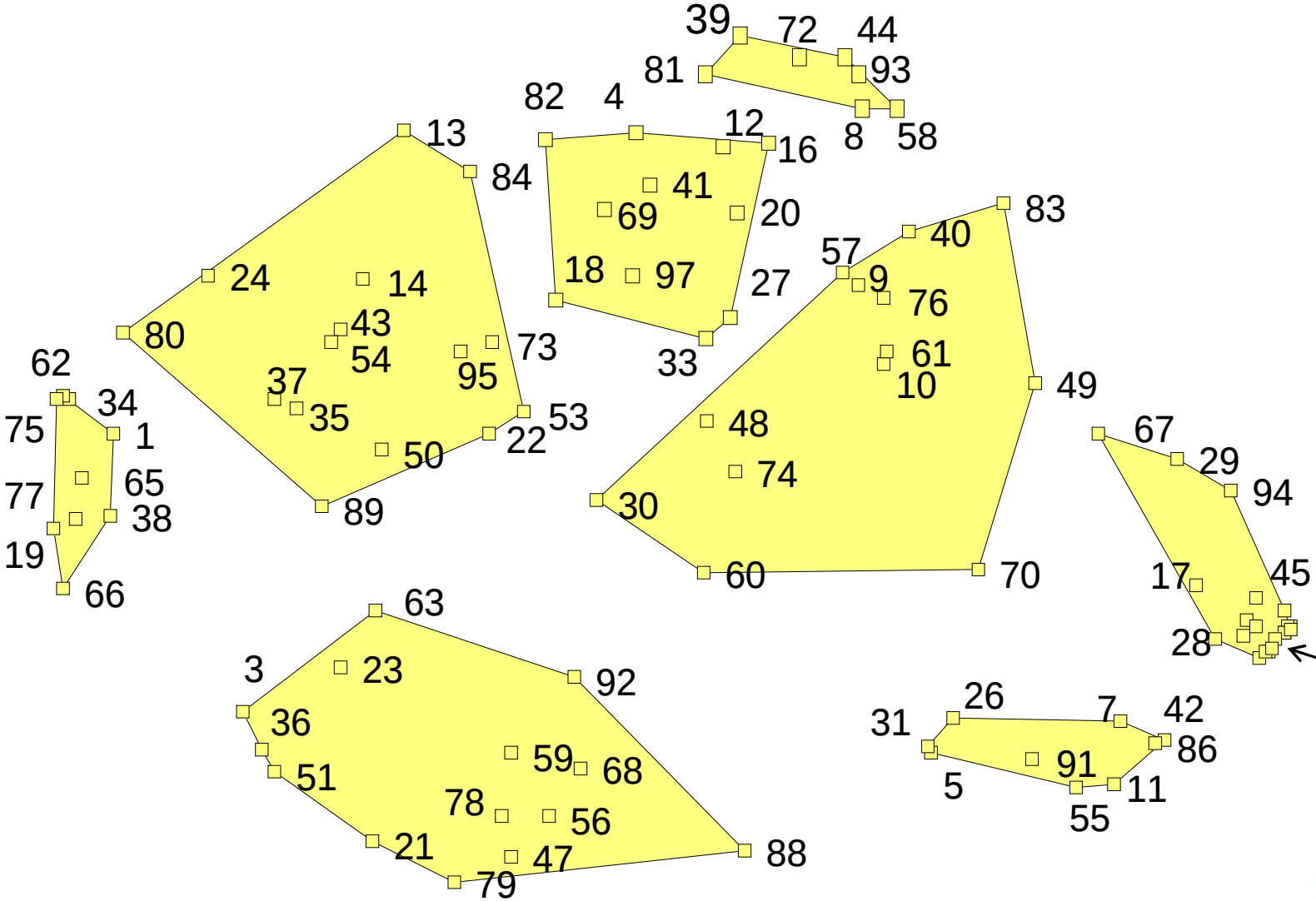
include health behavior and risk assessment data in the Virtual Data Warehouse. (46)

enhance Virtual Data Warehouse (VDW) to identify disease episodes. (90)

2	46	87
6	52	90
15	64	96
25	71	98
32	85	

"A specific CRN research (scientific) priority should be to…"

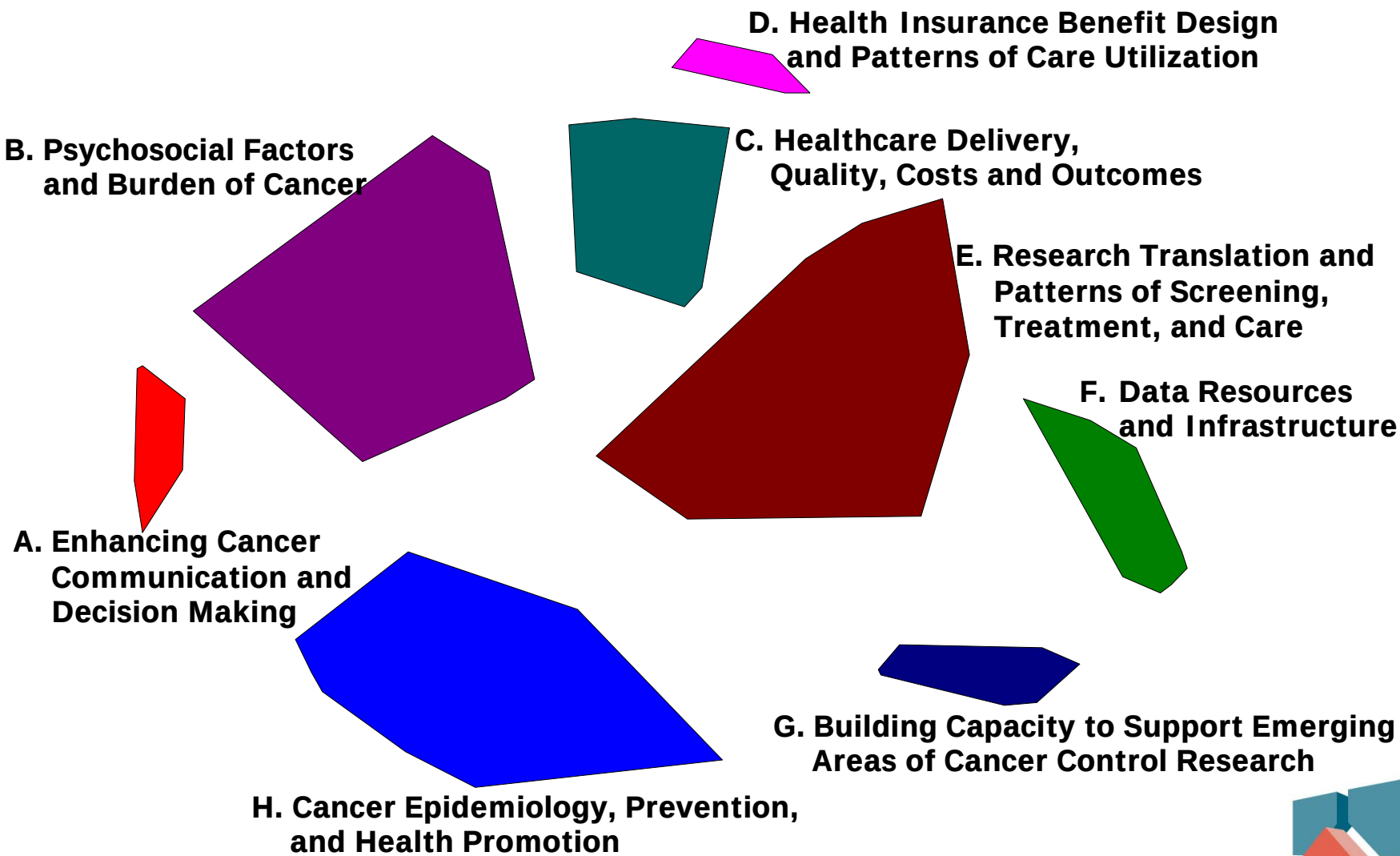
The detailed ideas are organized into groups



2	46	87
6	52	90
15	64	96
25	71	98
32	85	

...so that many concepts can be considered in a shared structure

The emerging structure



...contains all the details and provides a conceptual framework.

Importance & Feasibility Ratings

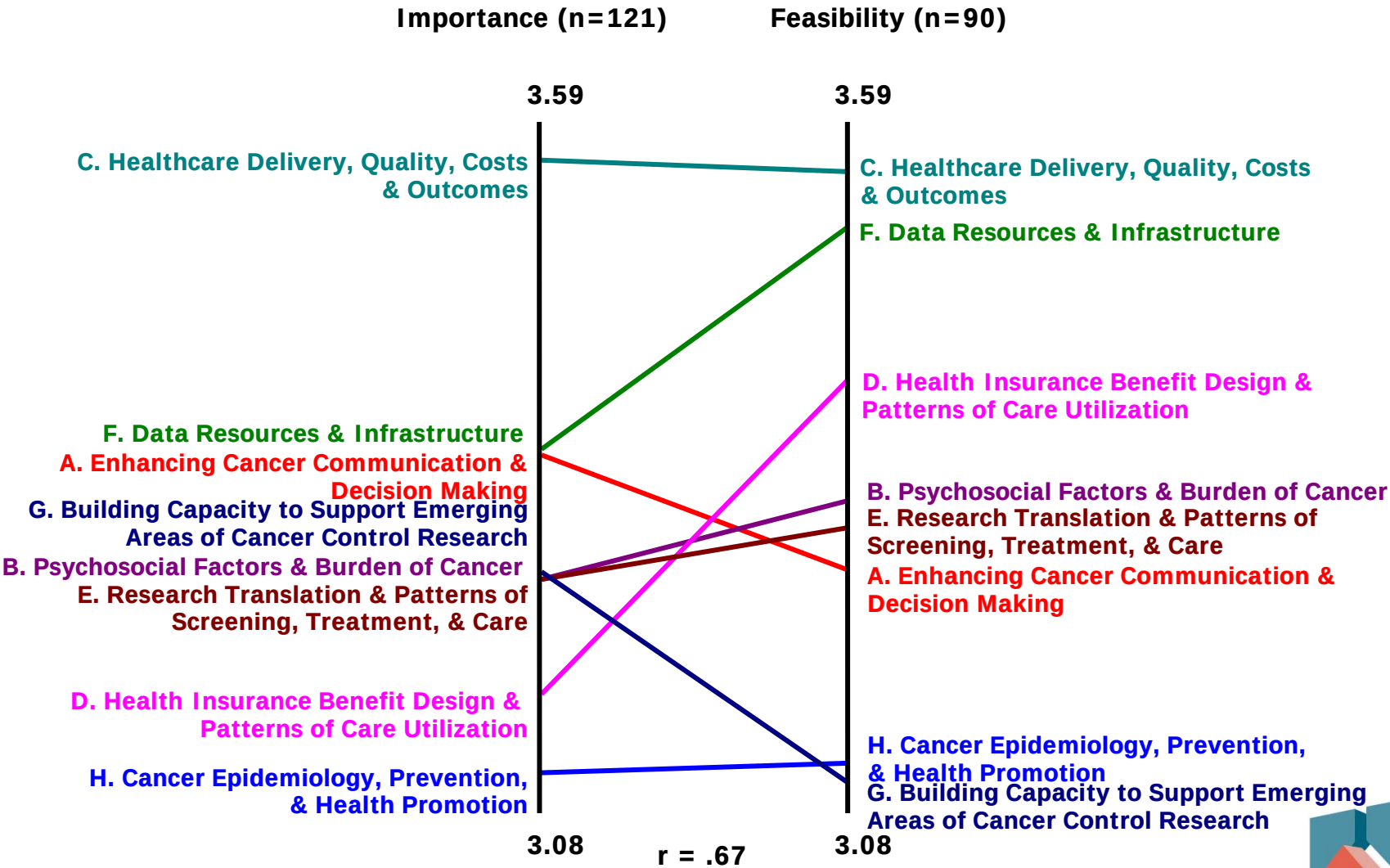
Please rate each statement below on how **important** you think it is for the Cancer Research Network to address in order to fulfill its mission. Please rate each statement *relative* to the other ones listed so you are using the full range of the scale.

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

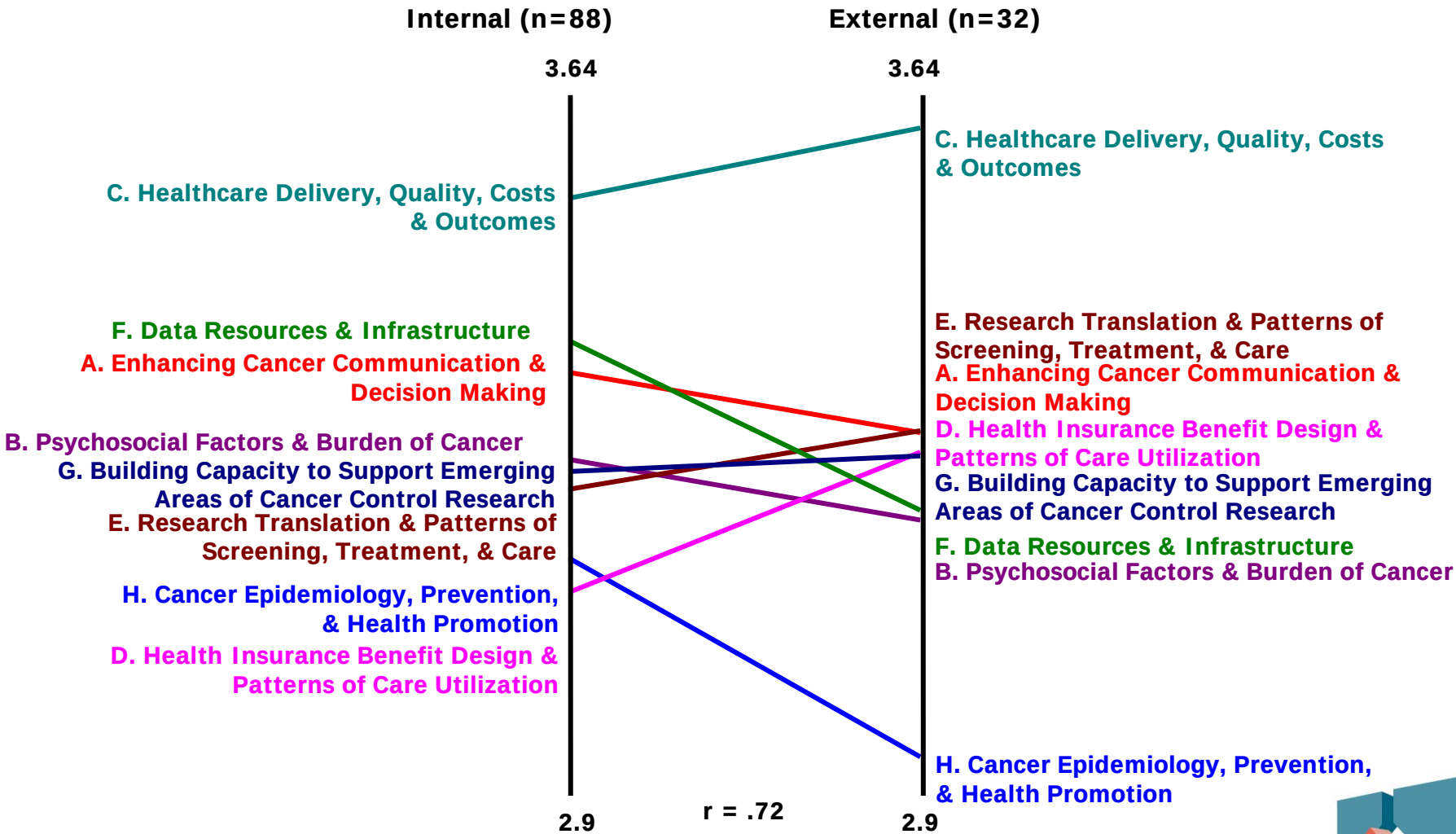
Please rate each statement below on how **feasible** it is for the Cancer Research Network to address in the next 2 - 3 years. Please rate each statement relative to the other ones listed so you are using the full range of the scale.

1 = not at all feasible
2 = somewhat feasible
3 = feasible
4 = very feasible
5 = extremely feasible

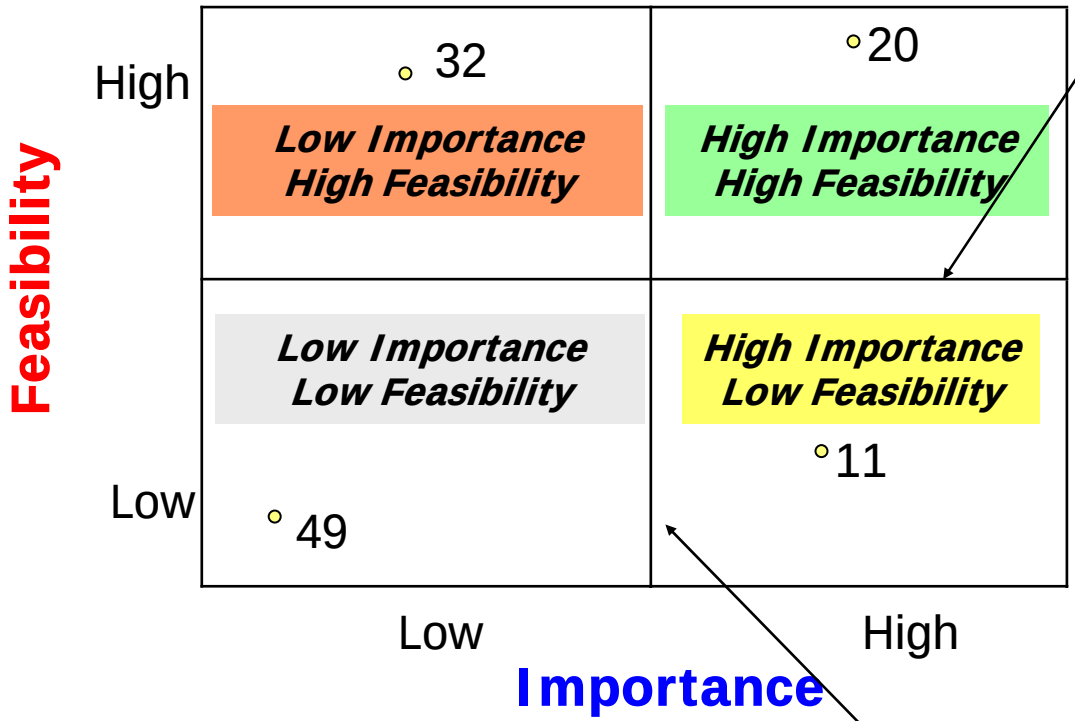
Importance vs. Feasibility (All Participants)



Importance by Role (Internal vs. External)



Example of a Go-Zone: Comparing **Statements** on the Rating Scales



Feasibility Mean for this cluster

examine health care utilization and delivery for cancer patients post-treatment. (20)

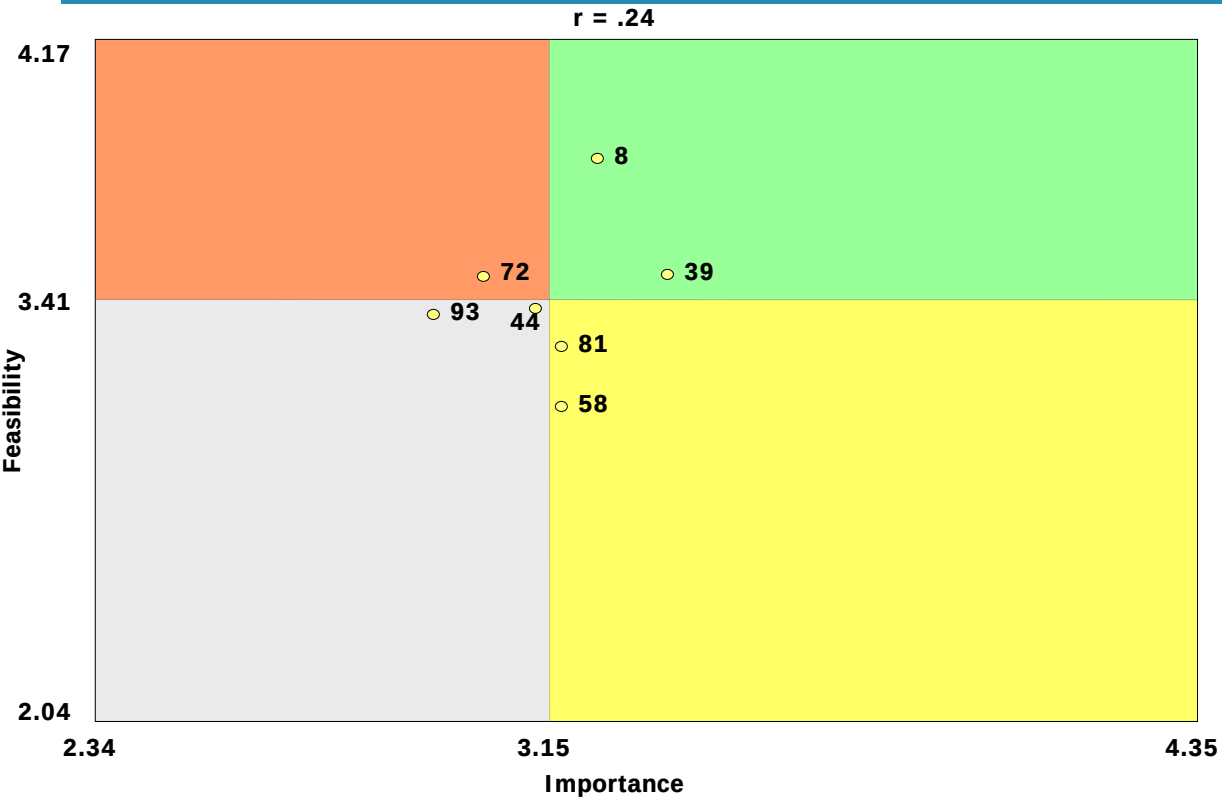
develop a biospecimen repository that links data on cancer cases, tissue, and pretreatment bloods with risk factor data. (11)

Importance Mean for this cluster

refresh the cancer counter. (32)

support a lab to evaluate how therapies should be used appropriately. (49)

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:

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