

CONCEPT SYSTEMS INC.



LOWER PREVALENCE CHRONIC CONDITIONS

CONCEPT MAPPING SUMMARY REPORT

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LOWER PREVALENCE CHRONIC CONDITIONS

BUILDING THE CONCEPTUAL FRAMEWORK: SUMMARY REPORT

EXECUTIVE SUMMARY

Through the collaborative efforts of several advocacy groups, the annual funding that the Centers for Disease Control and Prevention (CDC) receives to address epilepsy continues to increase. At the same time, there is growing interest in funding programs to address other less prevalent conditions such as multiple sclerosis, ALS, and Parkinson's Disease. As interest and funding levels increase, there is a growing expectation that CDC will fund state programs addressing epilepsy and other less prevalent conditions, but there is uncertainty about the appropriate role of state health departments in this area.

To assist state health departments and their constituents in achieving mutual awareness and understanding of the appropriate role that states may take in addressing such public health conditions, The Association of State and Territorial Chronic Disease Program Directors (CDD) established an initiative with key informants from appropriate organizations, offices, and agencies to:

- create a shared awareness and appreciation of the range of issues related to these conditions
- enable shared recognition of the relative importance and comparative feasibility of addressing such concerns through public health
- foster mutual understanding among state public health personnel, groups that provide support and advocate for less prevalent health conditions, and federal agencies that fund programs to address issues related to these conditions

In collaboration with CDD and CDC, Concept Systems Inc. asked participants to help them understand the key issues relating to the role of public health agencies in addressing lower prevalence chronic conditions. What follows is a summary of the results of that assessment project. It provides a conceptual framework which agencies in both the private and public sectors can use to understand how public health can address these conditions. While this project also included an action planning session in February 2003, specific action plans are included in a separate report created by the Chronic Disease Directors.

PROJECT DESIGN

The purpose of this project was to gather, aggregate, confirm and integrate the specific knowledge and opinions of key members of communities of interest on the topic of the role of public health in addressing lower prevalence chronic conditions. The Steering Committee identified three levels of participation to ensure that the project would benefit from appropriate involvement from individuals with experience, knowledge and commitment to the issue at hand: Steering Committee, Core Group, and Invited Group.

The Steering Committee itself acted as the client group and design team for the project. The Steering Committee consisted of representatives from the Centers for Disease Control and Prevention, Chronic Disease Directors, and state public health. The Steering Committee's major responsibilities included

- the logistics and timing of the project
- identifying participants with knowledge and experience relevant to the issue
- drafting and approving communications with participants
- planning for presentation of results and additional data collection
- assisting in the successful completion of each phase of the project.

Core participants included those on the Steering Committee, others currently involved with lower prevalence chronic conditions, and public health representatives. Core members were asked to participate in three activities: the initial brainstorming, the individual sorting, or categorizing of the subsequent set of statements, and the rating on value scales defined by the Steering Committee. These activities are described in more detail below, under Procedures.

The Invited Group members were identified by the Steering Committee as individuals with valuable knowledge and information gained from their work in the field. Invitees were asked to participate in both brainstorming and the rating of the subsequent list of statements on value scales identified by the Steering Committee.

METHODOLOGY

To accomplish the desired result, planners utilized The Concept System planning and facilitation methodology. Key components are concept mapping and action planning. Concept mapping is a mixed methods planning and evaluation approach that integrates familiar qualitative group processes (brainstorming, categorizing ideas, and assigning value ratings) with multivariate statistical analyses to help a group describe its ideas on any topic of interest and represent these ideas visually through a map.¹ The process typically requires the participants to brainstorm a set of statements relevant to the topic of interest, individually sort these statements into piles of similar ones, rate each statement on one

¹ References and articles on the Concept System can be obtained by calling 607-272-1206 or by emailing infodesk@conceptsistemas.com

or more dimensions, and interpret the maps that result from the data analyses. The analyses includes multidimensional scaling (MDS) of the sort data, hierarchical cluster analysis of the MDS coordinates to create a two dimensional XY plot of the points. The result shows the individual statements in two-dimensional (x,y) space with more similar statements located nearer each other and grouped into clusters. Additionally, the ratings provide the data to compute an average for each individual item and for each cluster of items. These rating results can then be added to the map as third dimension (height). The result is multiple maps that are then interpreted by stakeholders in a facilitated session(s). Participants are actively involved in interpreting the results to ensure that the maps are understandable and labeled in a meaningful way.

PROCEDURES

ESTABLISHING THE FOCUS

To facilitate the collection of meaningful input, the Steering Committee for the project, with guidance from Concept Systems, Inc., developed this focus prompt to which stakeholders responded:

"If relatively uncommon chronic conditions (such as epilepsy, multiple sclerosis and Parkinson's disease) are to be addressed effectively, a specific action, program or service that state public health agencies should do or facilitate is..."

IDEA GENERATION

145 stakeholders were asked to provide input on programs or services for lower prevalence chronic conditions, using the prompt above as the focus for the structured responses. Each participant was asked to generate or brainstorm approximately five to ten ideas. Recognizing that the stakeholders' locations and access to technology varied, the project enabled multiple methods for submitting ideas. Stakeholders were contacted and provided with a web address for a project-specific website on which participants could submit their ideas online. Additionally, participants could choose to submit ideas using a fax back form. Participants could also return forms by mail.

STATEMENT REDUCTION

The preliminary statement set for this project numbered 222. The Steering Committee used the following criteria to produce a final set of statements:

- Relevance to the stated focus question or within the scope of the question at hand
- Redundancy or duplication
- Clarity of meaning
- Relative appropriateness for the sorting and rating tasks to be completed

Appendix I shows the final list of ideas, which numbered 100.

STRUCTURING THE IDEAS

Following the completion of the idea generation or brainstorming phase, participants were contacted again and asked to participate in tasks to structure the information.

Sorting. In the sorting task, each individual organizes or sorts the entire database of ideas into groups or themes based on similarity of the ideas. Each member of the Core Group and Steering Committee was asked to identify themes among the ideas by completing a sorting task. Concept Systems, Inc.² provided a dedicated website for those participants to complete the task online.

Rating. For the rating task, all stakeholders who participated in the idea generation were again contacted and asked to evaluate or rate on a five point scale each of the final ideas. Participants were asked to rate along two dimensions: *Importance* and *Feasibility*. Stakeholders could complete this task using the dedicated website, or by faxing back a form sent to them.

COMPUTING THE MAPS

The Concept System³ uses multi-dimensional scaling and hierarchical cluster analysis to integrate the sorting information from each individual and develop a series of easily readable concept maps and reports. These maps show the perspective of the entire group of participants as well as sub groups. In effect, the Concept System represents the unique perspectives of a diverse group of individuals, preserves the best thinking of each individual and integrates the individual detail to construct and produce a coherent picture of the entire group.

The analysis uses the sort information to construct an NxN binary, symmetric matrix of similarities, for all sorting participants.

The total similarity matrix was analyzed using non-metric multi-dimensional scaling (MDS) analysis with a two-dimensional solution. The two-dimensional solution yields a configuration in which statements grouped together most often are located more closely in two-dimensional space than those grouped together less frequently. The x,y configuration resulting from the MDS analysis was the input for the hierarchical cluster analysis. To determine the best fitting cluster solution the analysts examined a range of possible cluster solutions suggested by the analysis, and took into account the fit of the contents within clusters as well as the specific desired uses of the results in planning and action development.

MAP INTERPRETATION

The maps and reports produced by the Concept System reflect and summarize the work of the stakeholders during the idea generation and structuring (sorting and rating) phases. The next step in the process requires interpretation and discussion by the stakeholders in this project. Two tasks were undertaken in this step. First, the resulting data were reviewed with the Steering Committee to ensure the reasonableness of the solution and name the categories, or clusters. This review also involved a

² The Concept System[®] computer software (Concept Systems, 2000) was used to perform all analyses and produce all of the maps and statistical results. Most of the data was collected over the Worldwide Web using the Concept System Global[®] software to allow for participation from any location with access to the Worldwide Web.

³ The Concept System[®] and Concept System Global[®] software are licensed through Concept Systems Incorporated, Ithaca, New York (<http://www.conceptsystems.com>).

preliminary discussion of the meaning, relevance and potential uses and implications of the results. Second, the results were presented to the Core Group at a meeting on February 17, 2003 in St. Louis, where stakeholders had the opportunity to discuss the results at length, examine how they as a group viewed and organized the ideas, review the rating, and discuss implications for action planning. A more detailed description of the results appears below.

RESULTS

RESPONSE RATE

The brainstorming activity is open to all identified stakeholders who were invited to participate in the project, about 145 people in all. Brainstorming is confidential and anonymous, thus limiting CSI's ability to identify with certainty the number of people who participated.

50 stakeholders were identified to complete sorting task. 20 completed the sorting phase of the project.

To engage a broader group of people in the rating task, all who were invited to participate in brainstorming were again contacted and asked to complete the rating task. Approximately 50 stakeholders completed the ratings.

MAPS

In concept mapping, several different maps are typically generated based on the same underlying data structure, the arrangement of the statements by MDS. The foundation for all maps is the point map. The point map shows the relation of each idea to each other idea in a two dimensional Euclidean space. Distance between points is meaningful: the closer two points are on the map, the more frequently those two ideas were sorted together by the people who took part in this project. Therefore, on the point map, points that are closer together are more similar in meaning and points that are distant are more dissimilar.

Figure 1 shows the arrangement of points for the Lower Prevalence Chronic Conditions Project. This point map can be used to illustrate the location of ideas in relation to each other. Appendix I: List of statements used in the concept mapping project contains all statements represented on this map.

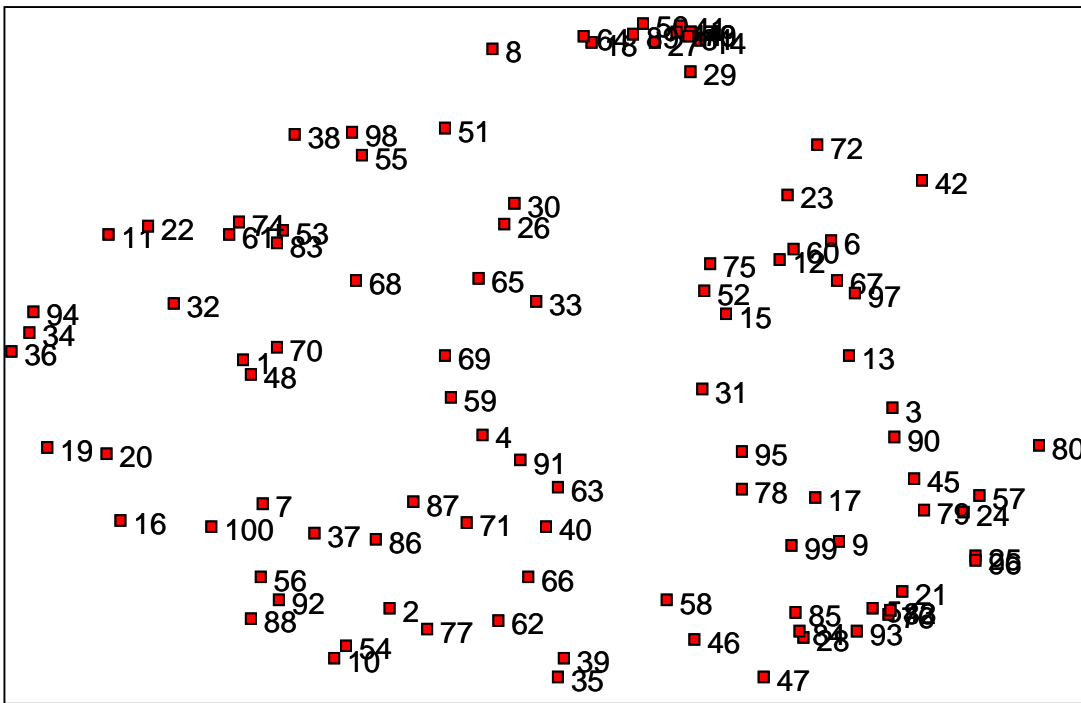


Figure 1. Point Map, indicating the array of all statements and their relationship to each other.

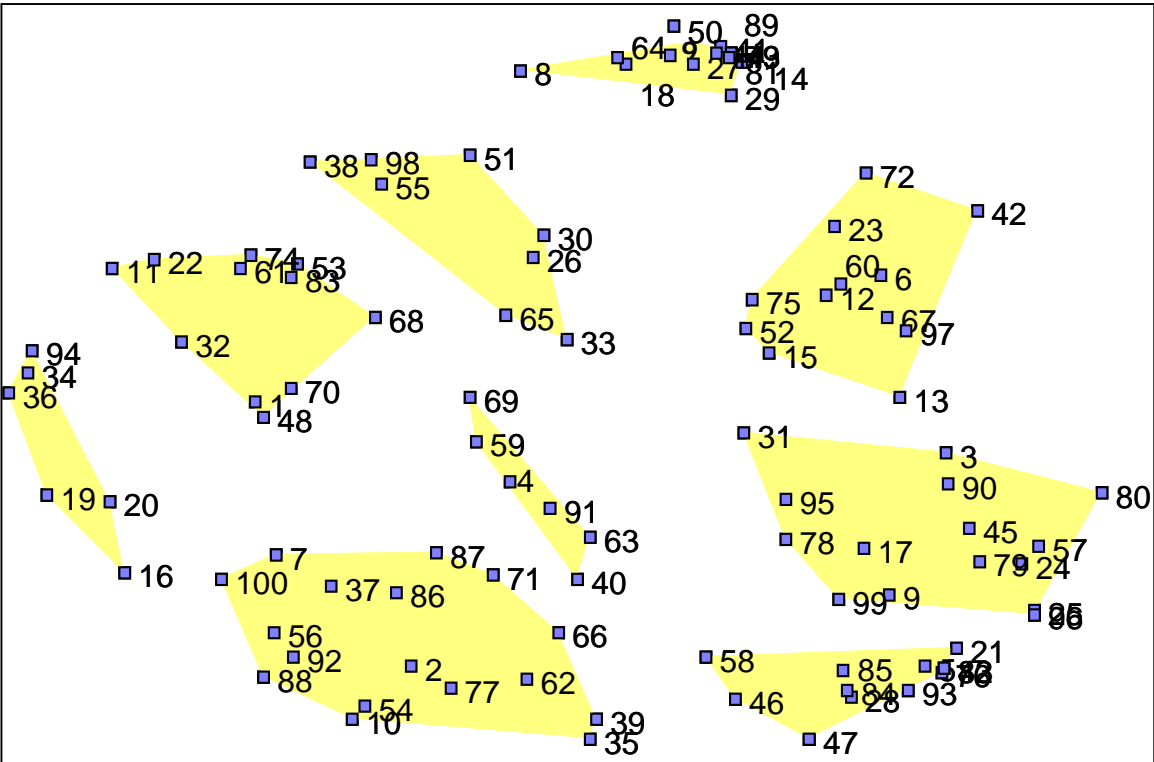


Figure 2. Point Cluster Map

While the arrangements of ideas and their relationships in the point map are interesting, the level of detail is useful primarily as a means of introducing stakeholders to the results and for laying the foundation for the additional maps and other analyses. The application of cluster analysis parses the map's space into groups, or clusters, of key ideas. In this case, the optimal solution was an eight-cluster solution (**Figure 2**). The compelling value of the cluster map graphic is to enable the recognition of a shared conceptual framework for discussing and planning for progress on a broad topic such as lower prevalence chronic conditions. Establishing agreement among constituents and key participants on the reasonableness and utility of the cluster map as a frame of reference, discussion and action is a major element in the process.

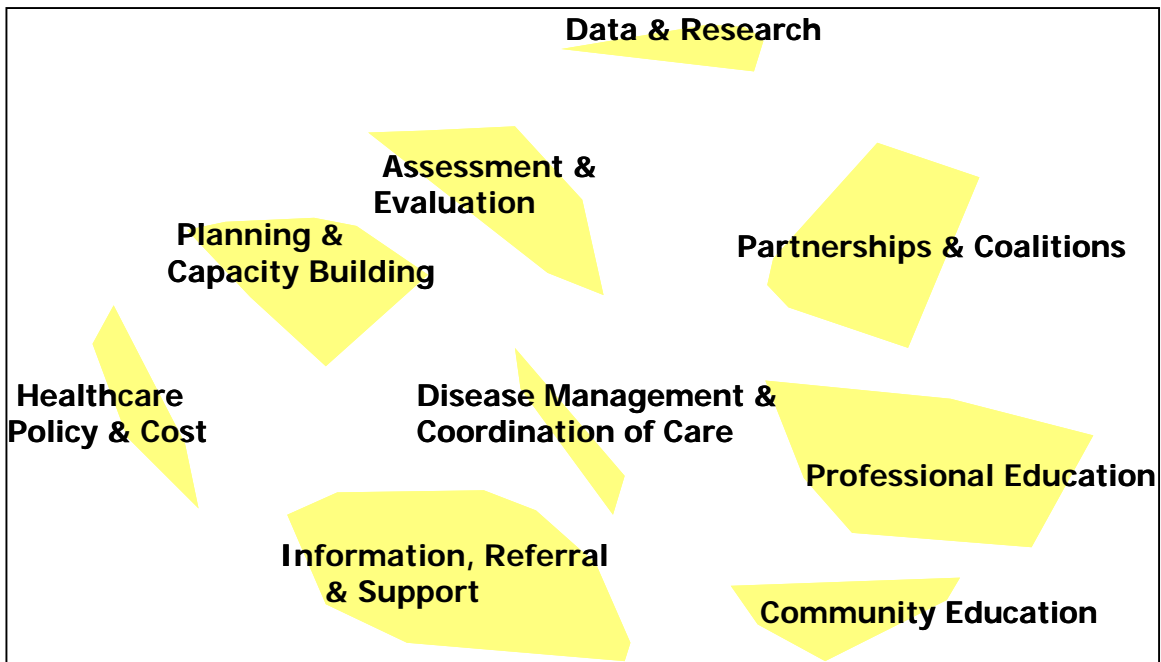


Figure 3. Concept Map. A nine-cluster concept map indicating the main topics, or concepts, that contain the 100 ideas that make up the content of the project. Small clusters like Disease Management & Coordination of Care and Healthcare Policy & Cost suggest groups of closely related ideas, and areas like Professional Education are representative of a broader, more encompassing concept.

Each of the clusters is comprised of items that, while specifically different, contribute to a common theme. An interpretive task is to determine the most appropriate label or title to express the theme in each of the clusters. While this is partly an analytical task and can be accomplished by an analyst, there is more value in engaging the stakeholders in reviewing the content and reaching consensus on the labels. There is a threefold value in this approach. First, this provides an opportunity for stakeholders to understand and internalize the deep structure of the map and, as a result, begin to consider the implications of these data. Second, the stakeholders are experts in the content and as such recognize and appreciate the nuances of meaning that may be missed by an analyst. Third, this provides stakeholders with a common framework with which to begin sharing ideas and begin the mutual construction of a shared framework.

As Figure 3 shows, this map is a nine cluster solution, with the following conceptual categories:

- Planning & Capacity Building,
- Healthcare Policy & Cost,
- Information, Referral & Support,
- Disease Management & Coordination of Care,
- Professional Education,
- Community Education,
- Partnerships & Coalitions
- Assessment & Evaluation, and
- Data & Research.

The analyses described above applied the data only from the sorting exercise; thus, no implications of relative value exist in these graphics. Value on whatever scales the project has used is represented below, in the Ratings discussion. Rather, the shape and size of the categories reflects the distribution of the points within that cluster, with large clusters typically covering more conceptual area than smaller clusters.

Appendix III shows the complete list of statements in each cluster

RATINGS

Identifying the issues is a critical first step for a needs assessment. The rating data then provides additional information to answer four questions.

- First, while all of the ideas are important, which ideas are considered most important by the key informant participants? In other words, among all of the ideas, are there a smaller number of clear priorities?
- Second, what ideas are most feasible to implement?
- Third, what is the relationship of importance and feasibility among the concepts?
- Fourth, do different priorities emerge from different groups of stakeholders?

The rating data, when coupled with the concept map data, provides the means to facilitate discussion of these important questions. To make rating data accessible and meaningful to all stakeholders, the data is represented in three types of graphs: Cluster Rating Maps, Pattern Matches, and Go-Zone Analyses.

CLUSTER RATINGS MAPS

In the cluster rating map, the greater the height dimension, the higher the average rating for the cluster. Using the specific statements as the data points, the analysis computes the average rating of each item and then the average of all items within a cluster or concept. The resulting value for each cluster is shown in the Cluster Rating Maps below (Figure 4 and 5). In the Cluster Rating Map, the greater the height dimension, the higher the average rating for the cluster. Figure 4 shows the average cluster ratings for the Importance scale, and Figure 5 shows the average ratings for the Feasibility scale.

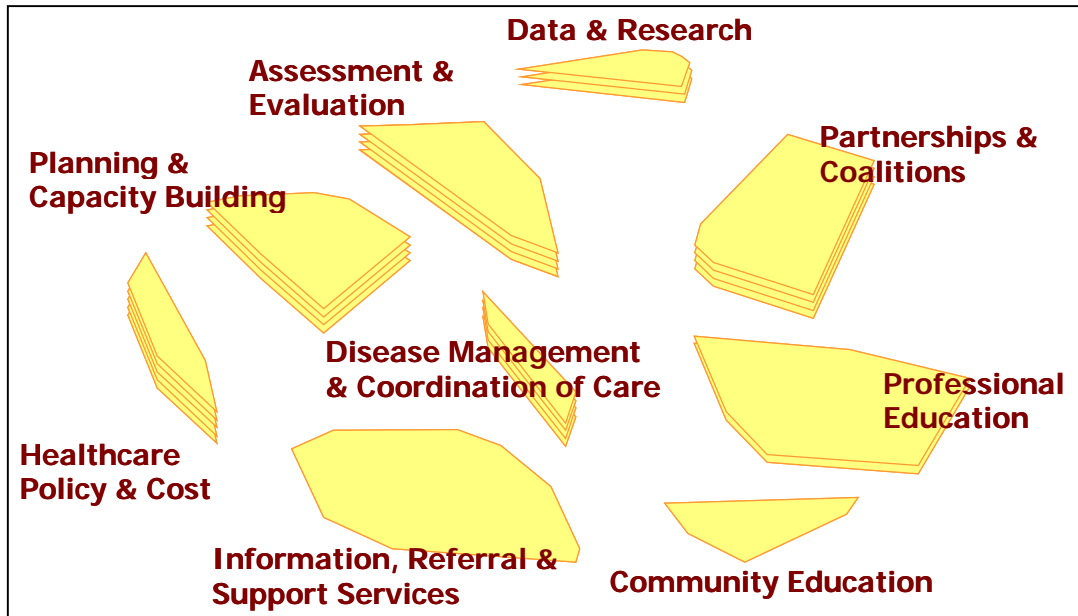


Figure 4. Cluster Rating Map, indicating the relative *importance* of the contents of each cluster. This suggests that Assessment & Evaluation and Disease Management & Coordination of Care are considered relatively more important than, for example, Information, Referral & Support Services or Community Education.

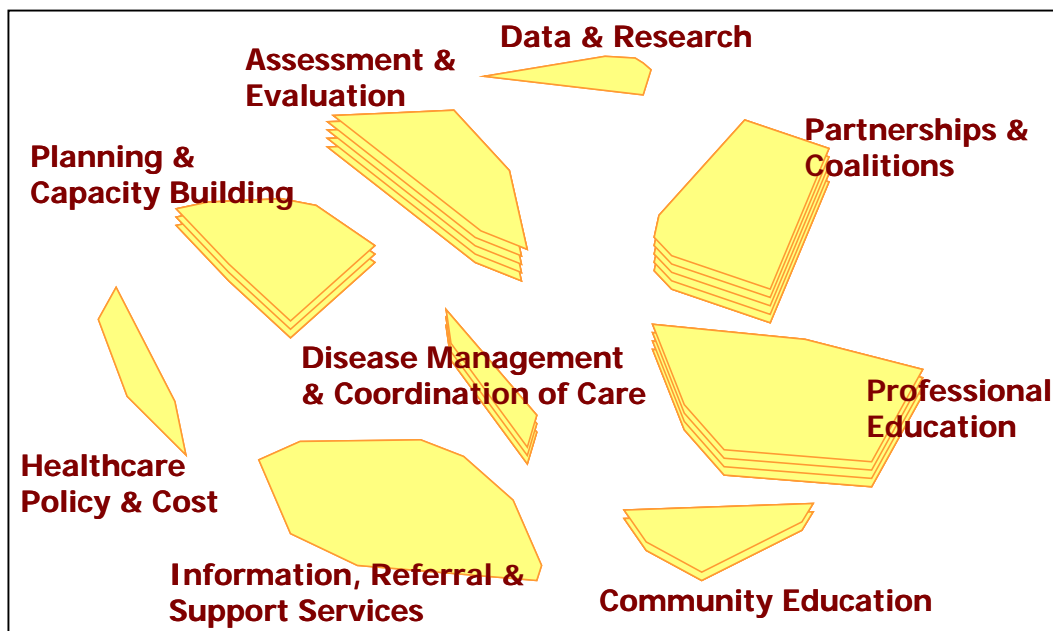


Figure 5. Feasibility Cluster Rating Map, indicating the relative *feasibility* of the contents of each cluster. Though Healthcare Policy & Cost is shows a high average importance (Figure 4), stakeholders rated it relatively low in Feasibility.

PATTERN MATCHES

A second graph enables the presentation of two values on the map contents in comparison to each other. In this analysis, each cluster is arrayed on a vertical number line for *importance*, and on another vertical number line for *feasibility*. Figure 4 and 5 show the Cluster Rating Map, for importance and feasibility, respectively; and Figure 6 shows the number lines, or Pattern Match, for these variables. To facilitate interpretation by groups of stakeholders, these number lines are joined to compare the pattern of results for importance to the pattern for potential impact; hence the term “pattern matching.”

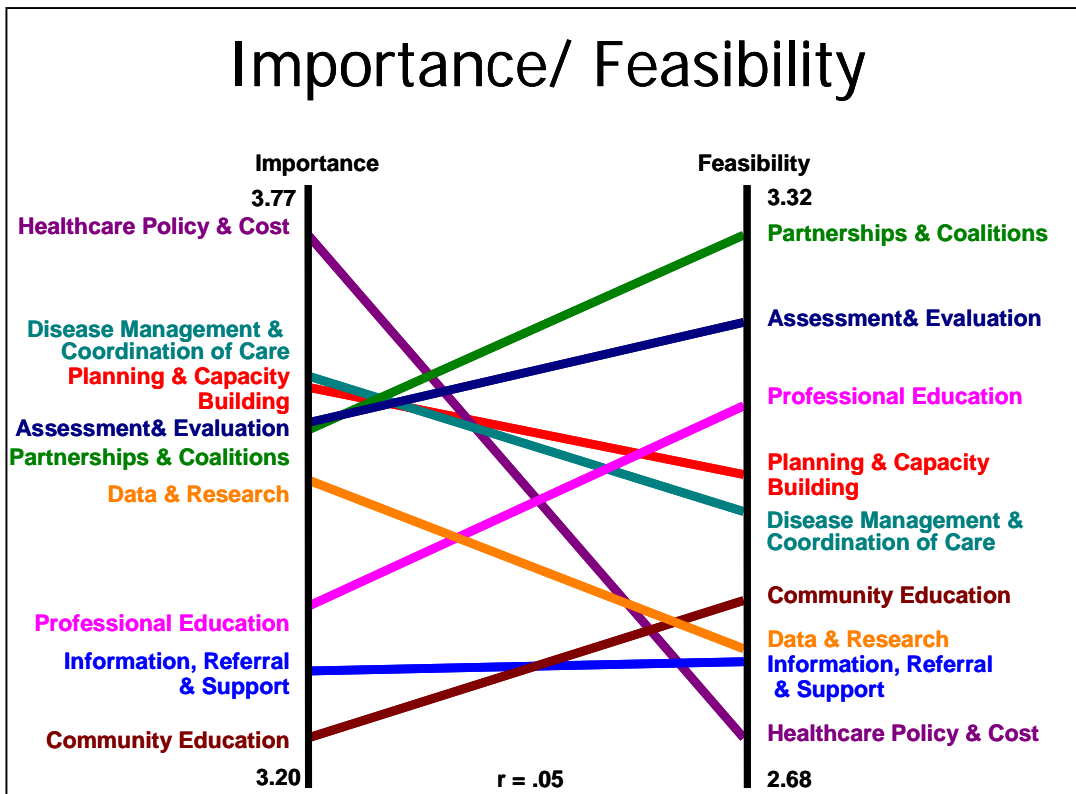


Figure 6. Importance and Feasibility Pattern Match: All Participants

Pattern matches can also compare the value ratings of two different groups. Figure 7 compares the Importance ratings of participants affiliated with the public sector with those affiliated with the private sector. According to this graph, public and private sector participants prioritize many of the issues similarly, and others quite differently. Top priorities for public sector participants are Healthcare Policy & Cost and Assessment & Evaluation. For private sector participants, it is Healthcare Policy & Cost and Planning & Capacity Building. Both groups had the same five clusters in the top five priorities. This information provided the framework for detailed discussion of the current thinking about lower prevalence issues, assisting groups to understand the positions and concerns of others.

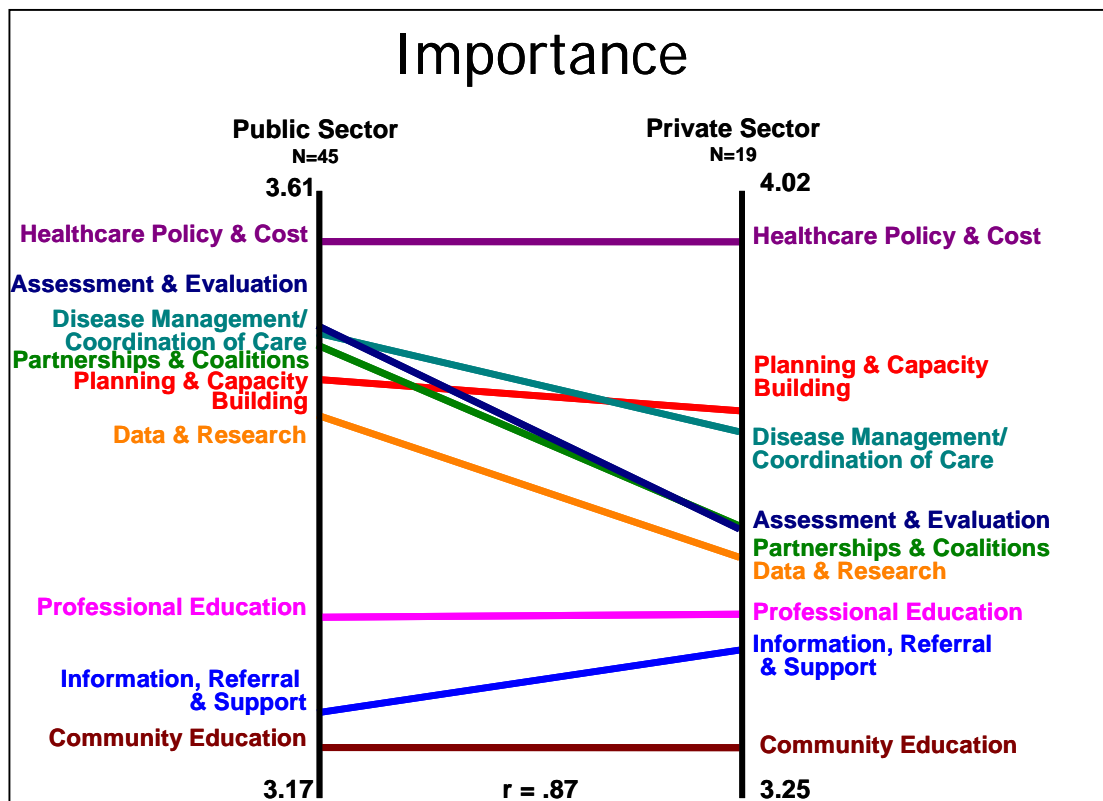


Figure 7. Public and Private Sector Importance Pattern Match

The purpose of these graphs is not to provide a specific data driven answer about actions. Rather, the point is use the data to show decision makers what their stakeholders are thinking. The goal of this presentation is to elicit and even provoke a discussion, based on evidence, of what this result means and what responses might logically emerge. The discussion can be focused on the issues that seem to need the most attention.

One final point must be made. The range on the scales is somewhat small due to the fact that the cluster mean is the mean of item scores, and the item scores are the mean values across raters. In effect, the pattern match is a mean of means and the deviation among scores is quite small. However, the results are not meant to be extrapolated from a sample to some other population. Rather, the results are intended to show what a group of selected key informants think about an issue. As such, while the dispersion may be small the fact remains that items within some clusters were systematically rated higher [or lower] than items in other clusters. This systematic bias represents information that should be noted by stakeholders.

“GO-ZONE” ITEM ANALYSES

A further graphical result derived from participant-provided data is the Go-Zone Analysis. Just as the concept map cluster levels and the pattern match enable decision makers to observe, understand and agree upon the relationship and relative value of concepts, the go-zone analysis enables stakeholders to keep the larger conceptual view in mind, while returning to the contents of each cluster to answer questions in more detail within each concept. As an example, consider the Importance/ Feasibility pattern match (figure 6) and look at the line between Importance and Feasibility for the concept of “Healthcare Policy & Cost.” If this were an area of interest and discussion it would be useful to revisit the detail for this conceptual cluster. Are there items within this concept that are both important and feasible? To examine this, a plot of all of the items that comprise this cluster is graphed along the two dimensions of Importance and Feasibility (Figure 8). A line was drawn on the vertical at the mean to divide high and low importance; and a horizontal line was drawn at the mean to divide high and low feasibility. The result is that items in the upper right quadrant have the highest mean ratings for both dimensions; that is, above the mean on importance **and** feasibility. These items might suggest issues that ought to be addressed first, given that they are considered both important and feasible. Appropriately, the items in the upper left (high feasibility and relatively low importance) and those in the lower right (high importance and relatively low feasibility) can be considered “gap” areas. These gap areas contain items for which value imbalance exists. Key informants may choose to review these areas, in conjunction with the go zone review, to enrich the discussion and planning. Certainly there are other interpretations that could be added to understand this graph. The key point is that this provides a way for all stakeholders to view the data and to then engage in assisted dialogue about implications. Go-Zone analyses comparing Importance and Feasibility for all clusters are located in Appendix II.

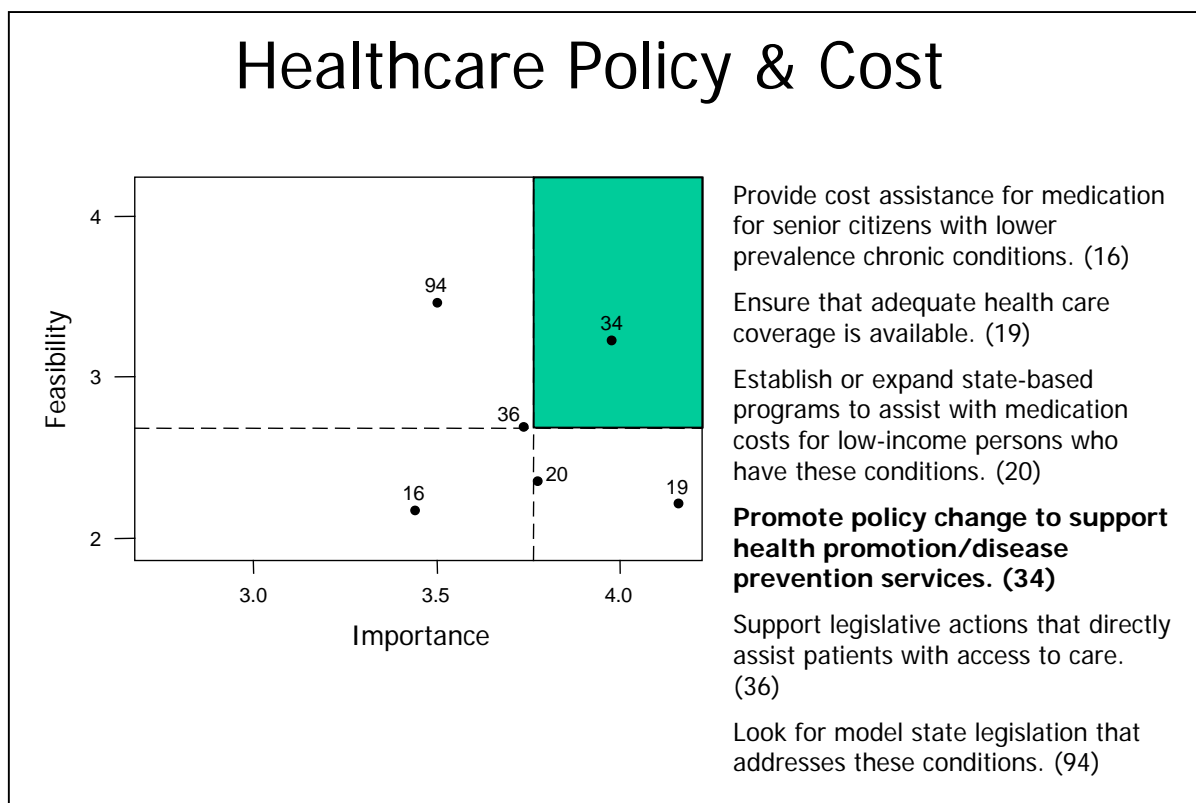


Figure 8. Sample Go-Zone Analysis

ACTION PLANNING

With the information provided through this process, core group participants were able to focus on identifying the major concerns for public health and lower prevalence chronic conditions, and what steps to take next. Participants defined action steps for each cluster or area of the concept map. These action recommendations are included in a separate report created by the Chronic Disease Directors.

CSI will add the action planning info to this report upon receipt.

CONCLUSION AND RECOMMENDATIONS

The Concept Mapping project described in this report provides a summary of what key stakeholders who work with lower prevalence chronic conditions see as the programming and dissemination priorities for public health. It provides a conceptual framework that these professionals can use to define the role of public health in addressing these conditions. This is new territory for public health, which has not yet been involved in providing programming or dissemination about these conditions. This conceptual framework allows public health planners to move forward in this endeavor equipped with input from public health professionals as well as those who are already involved in programming for lower prevalence chronic conditions. This information will help reduce duplication of services and facilitate collaboration among agencies that already work with lower prevalence chronic conditions.

To continue the work summarized in this report, core group participants may wish to review the high level action planning report provided by Chronic Disease Directors, and follow up with another meeting to fine tune specific action plans, prioritize the action steps and establish timelines for those actions.

APPENDICES

Appendix I: List of statements used in the concept mapping project

#	Statement
1	Fund demonstration projects to define effective health promotion interventions for people with these conditions.
2	Provide support for appropriate management in school settings.
3	Help disseminate care guidelines and best practices for each condition to providers and managed care organizations.
4	Address broader impact issues such as disability and pain management instead of a disease specific approach.
5	Establish community-based communication campaigns designed to increase knowledge and decrease stigma around these disorders.
6	Partner with voluntary organizations, business, the media & community special interest organizations to explore mutual interests & agendas.
7	Assess/catalog available resources for family members of persons with specific conditions.
8	Initiate a study of factors that impede access to care.
9	Engage high-profile, well respected individuals with these chronic conditions, to provide personal stories.
10	Provide support for patients adherence to appropriate treatment regimes.
11	Create a comprehensive strategic plan for these conditions, to guide local efforts.
12	Establish partnerships with health systems to implement specific evidence based actions.
13	Determine if there is a local affiliate for this condition.
14	Develop a common assessment tool to provide baseline data and reflect potential changes over time.
15	Include specific constituencies in quality of life and disability prevention efforts.
16	Provide cost assistance for medication for senior citizens with lower prevalence chronic conditions.
17	Run a regularly updated clearinghouse that keeps and supports information on these diseases.
18	Conduct or support state-based research on the impact of chronic conditions on health resources.
19	Ensure that adequate health care coverage is available.
20	Establish or expand state-based programs to assist with medication costs for low-income persons who have these conditions.
21	Provide public education around relative impact/burden of a given condition.
22	Develop a strategic state plan with input from affected individuals.
23	Collaborate internally with other state health department programs when appropriate (such as chronic disease & environmental health for MS).
24	Educate public health staff to understand such conditions and their interactions with other diseases/ conditions.
25	Educate LPD providers about the need for looking broadly at prevention, not just costly medical management.
26	Convene interested partners to examine magnitude of the problem and develop strategies for addressing priorities.
27	Conduct special surveys to assess prevalence, self care practices, and barriers to care.

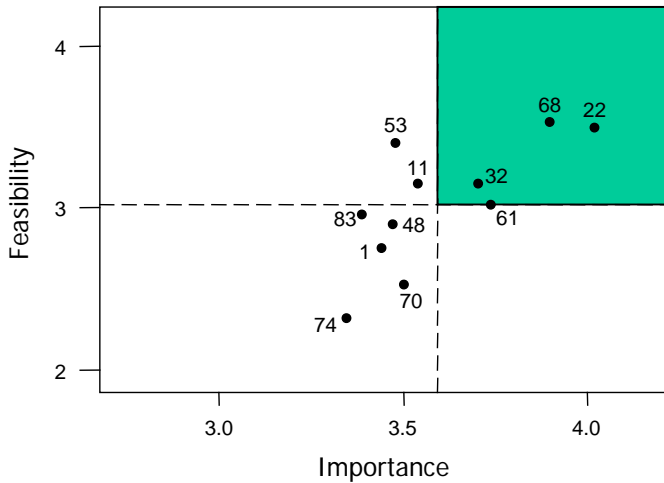
#	Statement
28	Train school staff to recognize early symptoms of the diseases.
29	Build capacity to assess and monitor disease burden/needs in population (eg, survey prevalence, disability, access to care).
30	Assess the current level and types of actions of relevant advocacy/interest groups.
31	Focus on the preventive aspects, where known, to assist in integrating with other existing programs.
32	Use systems change approaches that are not limited to a particular disease or condition.
33	Serve as a facilitator to bring organizations together in order to develop plans to address these conditions.
34	Promote policy change to support health promotion/disease prevention services.
35	Use technology (i.e. telemedicine) to reach individuals with these diseases in more rural communities.
36	Support legislative actions that directly assist patients with access to care.
37	Support and promote existing centers of expert care.
38	Determine state health department capacity and interest in addressing such conditions.
39	Provide information on healthcare resources (home health agencies, etc.)
40	Identify and disseminate proven chronic disease self-management programs.
41	Add questions to the state BRFSS to obtain information about prevalence of epilepsy in the population.
42	Assess provider knowledge of treatment and care of patients.
43	Educate community by using available, relevant channels.
44	Implement a pilot project to develop baseline prevalence data.
45	Serve as a conduit for distribution of educational materials to local health departments.
46	Educate individuals with these diseases about the aid/support that exists.
47	Ensure that medical staff who treat epilepsy are trained to deliver quality care.
48	Integrate efforts towards addressing these conditions into existing state-funded programs (cardiovascular health, Meals on Wheels, etc.)
49	Implement a surveillance system that can assess the prevalence of these disorders in the community.
50	Investigate public concerns of disease clustering (eg, special studies of incidence and etiology).
51	Evaluate programs to identify effective strategies for prevention and control.
52	Conduct focus groups or interviews with people who have these conditions, to inform the work of health professionals.
53	Convene disease key informants to identify common issues resolvable via public policy & program solutions.
54	Assure access to early diagnosis & treatment.
55	Explore avenues for translating research into practice.
56	Provide access to existing community services for meals and home care.
57	Put information on the condition on the state public health website.
58	Develop and disseminate educational materials on safe and effective physical activity for affected individuals.
59	Assure collaboration with vocational rehabilitation and other social services as resources for people with disabilities.
60	Create a coalition of health agencies to focus on common issues of lower prevalence chronic conditions.
61	Create statewide plans which are inclusive of these disorders.
62	Promote access to health promotion/disease prevention services.
63	Create a comprehensive chronic disease program providing education on the importance of early detection and treatment/self-mgmt.

#	Statement
64	Do etiologic studies for geographic, environmental, occupational, prenatal, or infectious patterns.
65	Assess local environment for people with mobility problems. (sidewalks, curbs, bus stop access).
66	Develop resources to be used for information and referral purposes as a service to residents of the State.
67	Identify partner organizations concerned with this condition.
68	Use lessons learned from other health issues for which programs have been built.
69	Create collaborative initiatives which provide coordinated and comprehensive care.
70	Work with other government agencies to ensure that people don't fall through the cracks (e.g. social security).
71	Maintain referral resources to organizations better equipped to address each condition.
72	Establish standardized case definitions.
73	Maintain chronic disease registries to gather incidence and prevalence data, which inform research and clinical efforts.
74	Build comprehensive capacity to address low prevalence chronic conditions that cause disability.
75	Create awareness among decision makers and the public of the tremendous individual cost of these conditions.
76	Work to educate media on risk factors.
77	Provide patient/family referrals to grassroots organizations.
78	Encourage existing illness-specific advocacy groups to provide relevant public information.
79	Provide information on prevention and control on the worldwide web with links to reliable on-line resources materials.
80	Provide educational forums for public health professionals.
81	Compile existing data to develop a sense of the burden of the disease or conditions.
82	Educate the public about these diseases/conditions.
83	Determine if other chronic disease activities and resources can be applied to programs addressing these disorders.
84	Train local staff regarding the disease, diagnosis, and treatment options.
85	Educate employers to help people with these conditions to stay employed.
86	Provide health promotion programs to bring people with these conditions to their highest level of functioning.
87	Promote injury prevention and intervention services among persons with lower prevalence chronic diseases.
88	Provide reliable and reasonably priced transportation services for persons who cannot drive.
89	Institute reporting of all cases and deaths resulting from these conditions.
90	Promote public understanding and acceptance of these conditions through partnerships with community organizations.
91	Identify and promote best practices related to diagnosis, treatment, and management of these diseases.
92	Provide services, strategies or technology for home modification.
93	Educate public health about how to address burden of disease issues in the media.
94	Look for model state legislation that addresses these conditions.
95	Provide technical assistance to advocacy groups concerning sources of effective interventions.
96	Educate EMS and injury program providers about what they need to know to help treat people with these conditions/ diseases.
97	Collaborate with disease-related agencies, e.g., The Epilepsy Foundation, The MS Society, The Parkinson Foundation, and other non-profit agencies.
98	Determine whether any effective public health programs or policies exist to address the disorder and its prevention.
99	Ensure that private providers have culturally appropriate information about social services for their patients.
100	Support health and mental health for caregivers.

APPENDIX II: GO-ZONE ANALYSES

The next pages show Go-Zone reports for each cluster. The ideas in bold indicate those within the cluster that are located in the Go-Zone; that is, both important and feasible. These ideas were used as the foundation for the action planning discussion at the February meeting. .

Planning & Capacity Building



Fund demonstration projects to define effective health promotion interventions for people with these conditions. (1)

Create a comprehensive strategic plan for these conditions, to guide local efforts. (11)

Develop a strategic state plan with input from affected individuals. (22)

Use systems change approaches that are not limited to a particular disease or condition. (32)

Integrate efforts towards addressing these conditions into existing state-funded programs (cardiovascular health, Meals on Wheels, etc.) (48)

Convene disease key informants to identify common issues resolvable via public policy & program solutions. (53)

Create statewide plans which are inclusive of these disorders. (61)

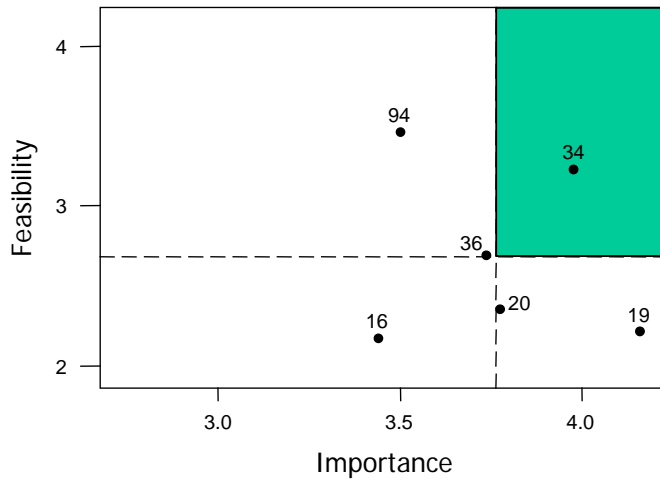
Use lessons learned from other health issues for which programs have been built. (68)

Work with other government agencies to ensure that people don't fall through the cracks (e.g. social security). (70)

Build comprehensive capacity to address low prevalence chronic conditions that cause disability. (74)

Determine if other chronic disease activities and resources can be applied to programs addressing these disorders. (83)

Healthcare Policy & Cost



Provide cost assistance for medication for senior citizens with lower prevalence chronic conditions. (16)

Ensure that adequate health care coverage is available. (19)

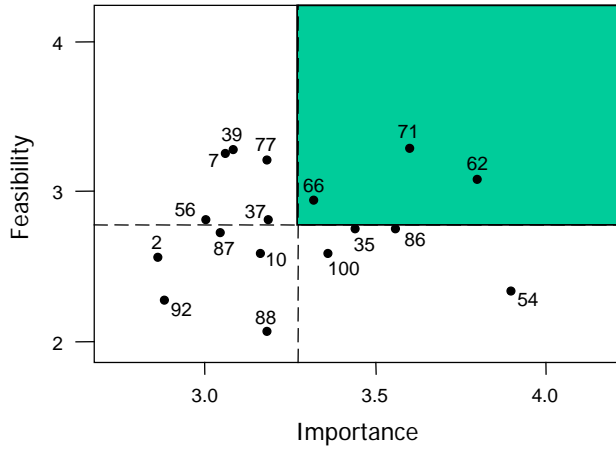
Establish or expand state-based programs to assist with medication costs for low-income persons who have these conditions. (20)

Promote policy change to support health promotion/disease prevention services. (34)

Support legislative actions that directly assist patients with access to care. (36)

Look for model state legislation that addresses these conditions. (94)

Information, Referral & Support



Provide health promotion programs to bring people with these conditions to their highest level of functioning. (86)

Promote injury prevention and intervention services among persons with lower prevalence chronic diseases. (87)

Provide services, strategies or technology for home modification. (92)

Provide reliable and reasonably priced transportation services for persons who cannot drive. (88)

Support health and mental health for caregivers. (100)

Provide support for appropriate management in school settings. (2)

Assess/catalog available resources for family members of persons with specific conditions. (7)

Provide support for patients adherence to appropriate treatment regimes. (10)

Use technology (i.e. telemedicine) to reach individuals with these diseases in more rural communities. (35)

Support and promote existing centers of expert care. (37)

Provide information on healthcare resources (home health agencies, etc.) (39)

Assure access to early diagnosis & treatment. (54)

Provide access to existing community services for meals and home care. (56)

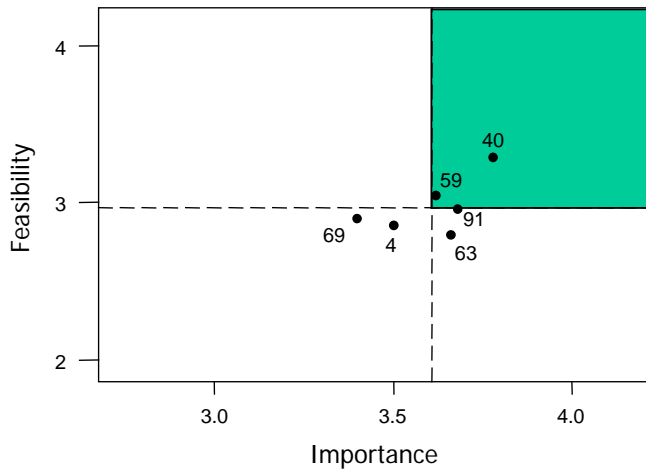
Promote access to health promotion/disease prevention services. (62)

Develop resources to be used for information and referral purposes as a service to residents of the State. (66)

Maintain referral resources to organizations better equipped to address each condition. (71)

Provide patient/family referrals to grassroots organizations. (77)

Disease Management/Coordination of Care



Address broader impact issues such as disability and pain management instead of a disease specific approach. (4)

Identify and disseminate proven chronic disease self-management programs. (40)

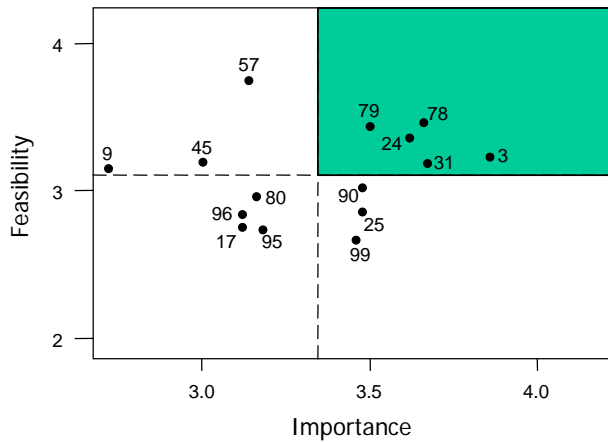
Assure collaboration with vocational rehabilitation and other social services as resources for people with disabilities. (59)

Create a comprehensive chronic disease program providing education on the importance of early detection and treatment/self-mgmt. (63)

Create collaborative initiatives which provide coordinated and comprehensive care. (69)

Identify and promote best practices related to diagnosis, treatment, and management of these diseases. (91)

Professional Education



- Provide educational forums for public health professionals. (80)
- Promote public understanding and acceptance of these conditions through partnerships with community organizations. (90)
- Provide technical assistance to advocacy groups concerning sources of effective interventions. (95)
- Educate EMS and injury program providers about what they need to know to help treat people with these conditions/diseases. (96)
- Ensure that private providers have culturally appropriate information about social services for their patients. (99)

Help disseminate care guidelines and best practices for each condition to providers and managed care organizations. (3)

Engage high-profile, well respected individuals with these chronic conditions, to provide personal stories. (9)

Run a regularly updated clearinghouse that keeps and supports information on these diseases. (17)

Educate public health staff to understand such conditions and their interactions with other diseases/conditions. (24)

Educate LPD providers about the need for looking broadly at prevention, not just costly medical management. (25)

Focus on the preventive aspects, where known, to assist in integrating with other existing programs. (31)

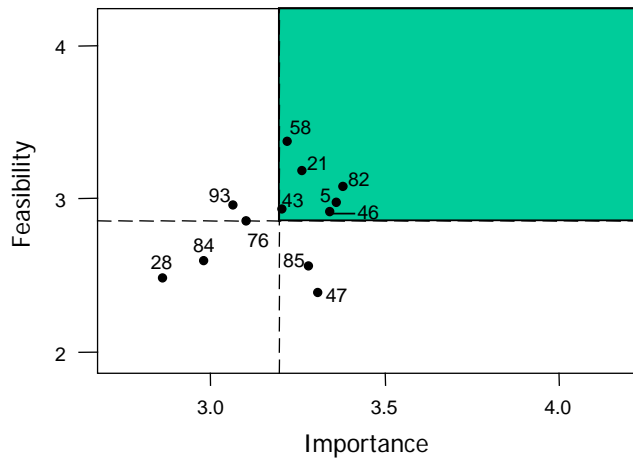
Serve as a conduit for distribution of educational materials to local health departments. (45)

Put information on the condition on the state public health website. (57)

Encourage existing illness-specific advocacy groups to provide relevant public information. (78)

Provide information on prevention and control on the worldwide web with links to reliable on-line resource materials. (79)

Community Education



Establish community-based communication campaigns designed to increase knowledge and decrease stigma around these disorders. (5)

Provide public education around relative impact/burden of a given condition. (21)

Train school staff to recognize early symptoms of the diseases. (28)

Educate community by using available, relevant channels. (43)

Educate individuals with these diseases about the aid/support that exists. (46)

Ensure that medical staff who treat epilepsy are trained to deliver quality care. (47)

Educate the public about these diseases/conditions. (82)

Train local staff regarding the disease, diagnosis, and treatment options. (84)

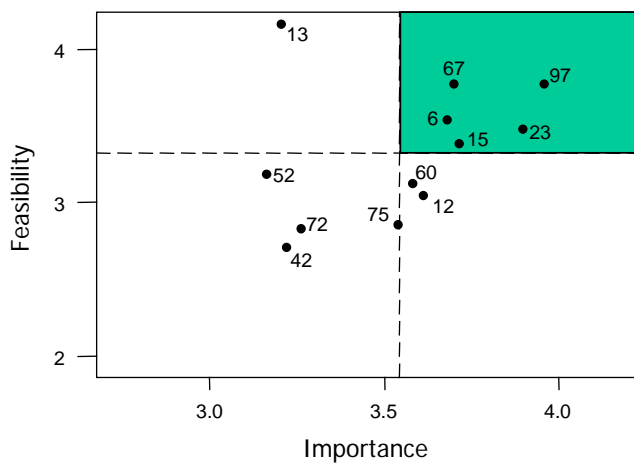
Educate employers to help people with these conditions to stay employed. (85)

Educate public health about how to address burden of disease issues in the media. (93)

Develop and disseminate educational materials on safe and effective physical activity for affected individuals. (58)

Work to educate media on risk factors. (76)

Partnerships and Coalitions



Identify partner organizations concerned with this condition. (67)

Establish standardized case definitions. (72)

Create awareness among decision makers and the public of the tremendous individual cost of these conditions. (75)

Collaborate with disease-related agencies, e.g., The Epilepsy Foundation, The MS Society, The Parkinson Foundation, and other non-profit agencies. (97)

Partner with voluntary organizations, business, the media & community special interest organizations to explore mutual interests & agendas. (6)

Establish partnerships with health systems to implement specific evidence based actions. (12)

Determine if there is a local affiliate for this condition. (13)

Include specific constituencies in quality of life and disability prevention efforts. (15)

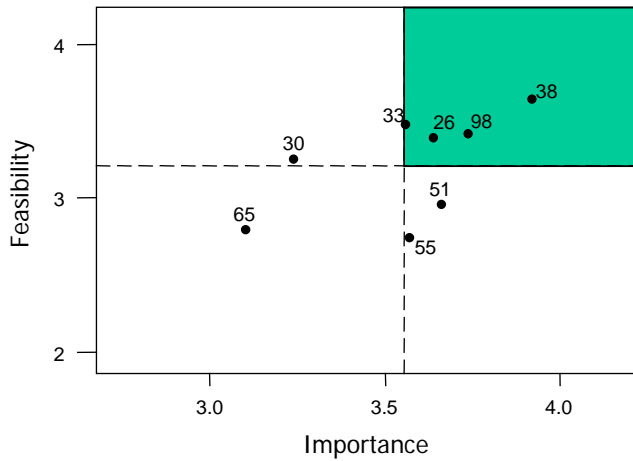
Collaborate internally with other state health department programs when appropriate (such as chronic disease & environmental health for MS). (23)

Assess provider knowledge of treatment and care of patients. (42)

Conduct focus groups or interviews with people who have these conditions, to inform the work of health professionals. (52)

Create a coalition of health agencies to focus on common issues of lower prevalence chronic conditions. (60)

Assessment and Evaluation



Convene interested partners to examine magnitude of the problem and develop strategies for addressing priorities. (26)

Assess the current level and types of actions of relevant advocacy/interest groups. (30)

Serve as a facilitator to bring organizations together in order to develop plans to address these conditions. (33)

Determine state health department capacity and interest in addressing such conditions. (38)

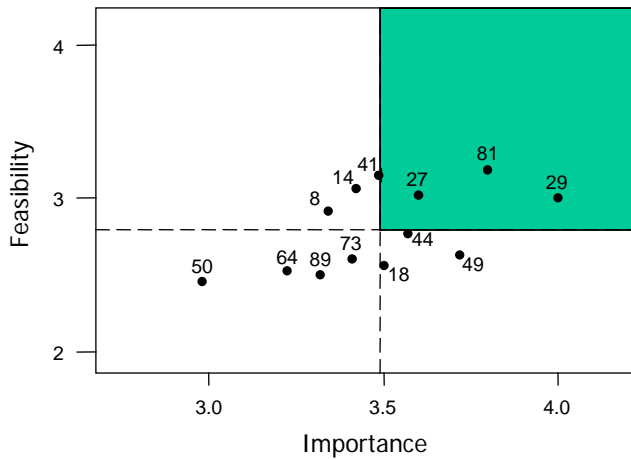
Explore avenues for translating research into practice. (55)

Assess local environment for people with mobility problems. (sidewalks, curbs, bus stop access). (65)

Determine whether any effective public health programs or policies exist to address the disorder and its prevention. (98)

Evaluate programs to identify effective strategies for prevention and control. (51)

Data and Research



Do etiologic studies for geographic, environmental, occupational, prenatal, or infectious patterns. (64)

Maintain chronic disease registries to gather incidence and prevalence data, which inform research and clinical efforts. (73)

Institute reporting of all cases and deaths resulting from these conditions. (89)

Compile existing data to develop a sense of the burden of the disease or conditions. (81)

Initiate a study of factors that impede access to care. (8)

Develop a common assessment tool to provide baseline data and reflect potential changes over time. (14)

Conduct or support state-based research on the impact of chronic conditions on health resources. (18)

Conduct special surveys to assess prevalence, self care practices, and barriers to care. (27)

Build capacity to assess and monitor disease burden/needs in population (eg, survey prevalence, disability, access to care). (29)

Add questions to the state BRFSS to obtain information about prevalence of epilepsy in the population. (41)

Implement a pilot project to develop baseline prevalence data. (44)

Implement a surveillance system that can assess the prevalence of these disorders in the community. (49)

Investigate public concerns of disease clustering (eg, special studies of incidence and etiology). (50)

Appendix III: List of Statements by Cluster

PLANNING AND CAPACITY BUILDING

- Develop a strategic state plan with input from affected individuals. (22)
- Use lessons learned from other health issues for which programs have been built. (68)
- Create statewide plans which are inclusive of these disorders. (61)
- Use systems change approaches that are not limited to a particular disease or condition. (32)
- Create a comprehensive strategic plan for these conditions, to guide local efforts. (11)
- Work with other government agencies to ensure that people don't fall through the cracks (e.g. social security). (70)
- Convene disease key informants to identify common issues resolvable via public policy & program solutions. (53)
- Integrate efforts towards addressing these conditions into existing state-funded programs (cardiovascular health, Meals on Wheels, etc.) (48)
- Fund demonstration projects to define effective health promotion interventions for people with these conditions. (1)
- Determine if other chronic disease activities and resources can be applied to programs addressing these disorders. (83)
- Build comprehensive capacity to address low prevalence chronic conditions that cause disability. (74)

HEALTHCARE POLICY AND COST

- Ensure that adequate health care coverage is available. (19)
- Promote policy change to support health promotion/disease prevention services. (34)
- Establish or expand state-based programs to assist with medication costs for low-income persons who have these conditions. (20)
- Support legislative actions that directly assist patients with access to care. (36)
- Look for model state legislation that addresses these conditions. (94)
- Provide cost assistance for medication for senior citizens with lower prevalence chronic conditions. (16)

INFORMATION, REFERRAL AND SUPPORT

- Assure access to early diagnosis & treatment. (54)
- Promote access to health promotion/disease prevention services. (62)
- Maintain referral resources to organizations better equipped to address each condition. (71)
- Provide health promotion programs to bring people with these conditions to their highest level of functioning. (86)
- Use technology (i.e. telemedicine) to reach individuals with these diseases in more rural communities. (35)
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- Provide services, strategies or technology for home modification. (92)
- Provide support for appropriate management in school settings. (2)

DISEASE MANAGEMENT/ COORDINATION OF CARE

- Identify and disseminate proven chronic disease self-management programs. (40)
- Identify and promote best practices related to diagnosis, treatment, and management of these diseases. (91)
- Create a comprehensive chronic disease program providing education on the importance of early detection and treatment/self-mgmt. (63)
- Assure collaboration with vocational rehabilitation and other social services as resources for people with disabilities. (59)
- Address broader impact issues such as disability and pain management instead of a disease specific approach. (4)
- Create collaborative initiatives which provide coordinated and comprehensive care. (69)

PROFESSIONAL EDUCATION

- Help disseminate care guidelines and best practices for each condition to providers and managed care organizations. (3)
- Focus on the preventive aspects, where known, to assist in integrating with other existing programs. (31)
- Encourage existing illness-specific advocacy groups to provide relevant public information. (78)
- Educate public health staff to understand such conditions and their interactions with other diseases/ conditions. (24)
- Provide information on prevention and control on the worldwide web with links to reliable on-line resources materials. (79)
- Promote public understanding and acceptance of these conditions through partnerships with community organizations. (90)
- Educate LPD providers about the need for looking broadly at prevention, not just costly medical management. (25)
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- Run a regularly updated clearinghouse that keeps and supports information on these diseases. (17)
- Educate EMS and injury program providers about what they need to know to help treat people with these conditions/ diseases. (96)
- Serve as a conduit for distribution of educational materials to local health departments. (45)
- Engage high-profile, well respected individuals with these chronic conditions, to provide personal stories. (9)

COMMUNITY EDUCATION

- Educate the public about these diseases/conditions. (82)
- Establish community-based communication campaigns designed to increase knowledge and decrease stigma around these disorders. (5)
- Educate individuals with these diseases about the aid/support that exists. (46)
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- Educate public health about how to address burden of disease issues in the media. (93)
- Train local staff regarding the disease, diagnosis, and treatment options. (84)
- Train school staff to recognize early symptoms of the diseases. (28)

PARTNERSHIPS AND COALITIONS

Collaborate with disease-related agencies, e.g., The Epilepsy Foundation, The MS Society, The Parkinson Foundation, and other non-profit agencies. (97)

Collaborate internally with other state health department programs when appropriate (such as chronic disease & environmental health for MS). (23)

Include specific constituencies in quality of life and disability prevention efforts. (15)

Identify partner organizations concerned with this condition. (67)

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Conduct focus groups or interviews with people who have these conditions, to inform the work of health professionals. (52)

ASSESSMENT AND EVALUATION

Determine state health department capacity and interest in addressing such conditions. (38)

Determine whether any effective public health programs or policies exist to address the disorder and its prevention. (98)

Evaluate programs to identify effective strategies for prevention and control. (51)

Convene interested partners to examine magnitude of the problem and develop strategies for addressing priorities. (26)

Explore avenues for translating research into practice. (55)

Serve as a facilitator to bring organizations together in order to develop plans to address these conditions. (33)

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Assess local environment for people with mobility problems. (sidewalks, curbs, bus stop access). (65)

DATA AND RESEARCH

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